

THE PENNSYLVANIA STATE UNIVERSITY
SCHREYER HONORS COLLEGE

DEPARTMENT OF COMMUNICATION SCIENCES AND DISORDERS

PERSPECTIVES OF PARENTS OF EARLY ELEMENTARY CHILDREN ON THE
EXPERIENCE OF PARENTING A CHILD WITH AUTISM SPECTRUM DISORDER

MEREDITH KATHERINE KRAS
SPRING 2013

A thesis
submitted in partial fulfillment
of the requirements
for a baccalaureate degree
in Communication Sciences and Disorders
with honors in Communication Sciences and Disorders

Reviewed and approved* by the following:

Kathryn Drager
Associate Professor of Communication Sciences and Disorders
Thesis Supervisor

Carol A. Miller
Associate Professor of Communication Sciences and Disorders
Honors Advisor

* Signatures are on file in the Schreyer Honors College.

ABSTRACT

Multiple studies have been conducted regarding autism spectrum disorders (ASD) and the individuals with ASD themselves. Studies have also been conducted that focus on specific aspects of family life for those families of individuals with ASD, including coping strategies and family dynamics. However, there is little research that encompasses all the aspects involved in parenting a child with ASD, including how parents perceive and handle raising a child with ASD and the positives and negatives of this experience. The current study was conducted using a qualitative online focus group design that allowed for the examination of the benefits, challenges, supports and needs of parenting an early-elementary school child with ASD. This study included ten parents from across the United States who participated in weekly discussion board posts and comments in regards to certain questions about their parenting experience. The parent participants in this study acknowledged many common themes such as the future, parental friendships, anxiety, classroom issues, medications, and sleep.

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ACKNOWLEDGEMENTS

I would like to extend my thanks and appreciation to the following people, without whom the completion of this thesis would not have been possible. I am extremely grateful to Dr. Kathryn Drager, my thesis advisor, for her continued guidance and assistance throughout my involvement in this research and my writing process. Without her extensive knowledge of autism and her interest in researching this topic further, this thesis would not have been possible. Working with her has been an incredible and unique opportunity.

I would like to thank Dr. Carol Miller, my honors advisor, for her constant support and involvement. Without her encouragement and supervision as an advisor, I would have been lost. I greatly appreciate her assistance in reviewing my thesis.

I am also grateful to Dr. Erinn Finke. As the other chief researcher involved in this project, I am thankful for your acceptance, input, and guidance during my immersion in this project.

In addition, I am appreciative of all the other undergraduates, graduate students, and doctoral candidates that have also been involved in this research and assisted in the completion of this thesis, including Lauren Frey, Laura Dengler Richardson, Megan Tobin, and Nimisha Muttiah.

Finally, I am eternally grateful to my family and friends for all of their encouragement, support, and love throughout my time as an undergraduate at Penn State. Without them, all that I have accomplished thus far in my academic career would not have been possible.

Literature Review

Autism

Autism is defined as a developmental disability of varying degrees that usually emerges during infancy and impacts an individual's ability to communicate and interact with others (Autism Society of America, 2013). Autism and autism spectrum disorder (ASD) are broad terms for a spectrum of complex and pervasive developmental disorders including autistic disorder, Rett syndrome, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome. This spectrum of disorders known as autism are typically "characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors" and "associated with intellectual disability, difficulties in motor coordination and attention and physical health issues such as sleep and gastrointestinal disturbances" (Autism Speaks, 2013, What is Autism section).

Even though all children on the autism spectrum are unique, they do tend to display common characteristics such as social issues, patterned and repetitive behavior, specified interests, self-injurious behavior, and anxiety (Glazzard & Overall, 2012). Individuals on the autism spectrum also have difficulty with theory of mind, or the understanding of someone else's thoughts and feelings (Glazzard & Overall, 2012). There is also a possibility for children with ASD to present with epilepsy as well as skin and food allergies (Glazzard & Overall, 2012). Since autism and ASD is a spectrum disorder, individuals with autism have a wide range of abilities and skills. Some excel in

music and academics and “about 40 percent have average to above average intellectual abilities”, while other individuals with autism are significantly disabled and unable to care for themselves (Autism Speaks, 2013, What does it mean to be “on the spectrum” section).

According to the Centers for Disease Control and Prevention, autism diagnoses have risen to 1 in every 88 births in the United States and almost 1 in 54 boys (Autism Speaks, 2013). Statistics on autism provided by federal research suggest an annual increase in autism diagnoses of 10 to 17 percent. “Over 2 million individuals and tens of millions worldwide” are affected by ASD (Autism Speaks, 2013, How common is Autism section). The increase in the number of children diagnosed on the autism spectrum can be attributed to multiple factors such as administrative changes for special education, comorbidity of autism signs and symptoms with other common disorders and disabilities, outside pressure on parents to test their children, and local resources and information about autism. All of these factors may have contributed to the increase in prevalence of ASD (Levy, Mandell, & Shultz, 2009).

Causes

Although research in recent years is providing more answers to the question of what causes autism, there is still not one single answer – mainly because there is not one single type of autism. Research has cited rare gene mutations as one cause and some of these gene mutations may be capable of causing autism on their own. Another cause refers to a group of environmental, or non-genetic, risk factors such as “advanced parental age at time of conception (both mom and dad), maternal illness during pregnancy and certain difficulties during birth, particularly those involving periods of

oxygen deprivation to the baby's brain" that, when combined with possible genetic risks, increase the likelihood of autism (Autism Speaks, 2013, What causes Autism section). Levy, Mandell, and Shultz (2009) believe that, while ASD is influenced by the interaction of multiple risk factors, genetic factors play a very large role in the cause of ASD. These authors note, "the relative risk of a second child having this diagnosis is 20–50 times higher than the population base rate" (Levy, Mandell, & Shultz, 2009, p. 1632). As for any type of disease or disorder, there is also some evidence that premature birth and low birth weight can increase the risk of ASD (Centers for Disease Control and Prevention, 2012). However, the most prevalent idea behind the cause of autism is "a combination of autism risk genes and environmental factors influencing early brain development" (Autism Speaks, 2013, What causes Autism section).

Signs and Symptoms

Autism is a spectrum disorder, which means there is great variation in when signs and symptoms appear, the severity of these symptoms, and how these symptoms are actually portrayed (Centers for Disease Control and Prevention, 2012). A child with autism may display some important signs such as repetitive language and/or motor activities, lack or delay of spoken language development, difficulties making eye contact, little or no interest in peer relationships, lack of play in any form, and fixation or persistent interest in certain objects (Autism Society of America, 2013).

In general, there are three areas of development that ASD impacts: socialization, communication, and behavior (Levy, Mandell, & Shultz, 2009). Some of the more exact signs and symptoms, within these three developmental areas, include a lack of response to their name by 12 months, delayed speech and language skills, repetition of words or

phrases, inability to deal with change of routine or activity, obsessive interests, unusual sensory reactions, and repetitive body movements (Centers for Disease Control and Prevention, 2012). Specific social impairment issues include difficulty in engaging in daily social interactions, lack of listening to and looking at peers and other individuals within their community, failure to point or share activities with others, and unusual responses to peers and other individuals' emotions such as anger, distress, or affection (National Institute of Mental Health, 2011). According to National Institute of Mental Health (2011) research, children with ASD lack the ability to interpret tone of voice, gestures, facial expressions, and other nonverbal communication such as smiles and winks. On the other hand, typically developing individuals can have difficulties interpreting the body language of individuals with ASD. Because individuals with ASD are unable to interpret body language in others, their own body language, this again includes tone of voice, facial expressions, body movements, and gestures, usually does not match up with the information they are attempting to share (National Institute of Mental Health, 2011).

Children with ASD characteristically do not meet all the developmental milestones in the same way that typically developing children do. Therefore, children with ASD may or may not: be slow or unable to respond to their own name or other forms of attention getting, be slow or unable to use gestures, have delayed language skills, coo and babble for some time and then withdraw, use only single words or repeated phrases to communicate, lack generativity in communication, constantly repeat heard words and phrases, and employ the use of words that are different or unique to the child (National Institute of Mental Health, 2011). The most obvious communication issue

is a child's difficulty being understood, through difficulty expressing wants and needs, due to lack of useful and meaningful language, and struggles with the turn-taking of conversations. Repetitive actions, abnormal behaviors, and extremely focused interests are also characteristic of children with ASD. From these repetitive and stereotyped behaviors comes a reliance on routines and schedules and any changes to these daily routines, activities, and environments create extreme distress and behavior issues (National Institute of Mental Health, 2011).

Although the characteristics of ASD systematically appear before the age of three and remain with an individual throughout their life, there are a few different ways the signs and symptoms of ASD can present themselves. The signs and symptoms of ASD can appear during the first few months of a child's life, they can appear between the ages of two and three, or a child can develop normally until about 18 to 24 months and then decline significantly. Parents are almost always the first to realize their children are not following the typical developmental patterns for social and communication skills. These atypical behaviors usually become more obvious when parents compare children of similar ages (National Institute of Mental Health, 2011).

Diagnosis

According to Luther, Canham, and Cureton (2005), autism diagnoses are increasing at a rate of 10-15% each year, which makes autism "the fastest growing diagnosed developmental disability" (p. 40). There are usually two stages to the diagnosis of ASD. The first stage, which is done for all children, consists of developmental screenings at a child's pediatrician. For toddlers and preschools, these ASD screening instruments can include the Checklist of Autism in Toddlers (CHAT), the Modified

Checklist for Autism in Toddlers (M-CHAT), the Screening Tool for Autism in Two-Year-Olds (STAT), the Social Communication Questionnaire (SCQ), and the Communication and Symbolic Behavior Scales (CSBS). For older children, mild ASD and Asperger syndrome screening instruments can include the Autism Spectrum Screening Questionnaire (ASSQ), the Australian Scale for Asperger's Syndrome (ASAS), and the Childhood Asperger Syndrome Test (CAST). All of these screening instruments involve parent answered questions about their child's signs and symptoms, doctor observations of the child's signs and symptoms, or a combination of both (National Institute of Mental Health, 2011).

If a child does not pass one of these developmental screenings during a check-up and a child is deemed at risk for an ASD, that child is usually referred for further assessment. This is the second stage, a more complete evaluation by a multi-disciplinary team, including a speech language pathologist, occupational therapist, physical therapist, special educator, social worker, and psychologist, which may conclude with a diagnosis of autism or other pervasive developmental disorder.

This comprehensive assessment typically includes the use of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* or *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10)* diagnostic criteria in a standardized evaluation along with case history information such as medical history, completed questionnaires, behavior descriptions, and expressed parent concerns and observations. Two of the most commonly used standardized evaluations for determining an ASD are the autism diagnostic observation schedule (ADOS) and the revised autism diagnostic interview (ADI-R) (Levy, Mandell, & Shultz,

2009). Levy, Mandell, and Shultz (2009) describe the ADOS as “a semistructured standardised assessment for social behaviour, communication, and imaginative play” (p. 1629).

School Based Intervention

After early intervention, a child’s family and educational system, such as school, are the two prominent groups involved in the provision of intervention for ASD. The first step when a child with ASD enters school is to have a professional evaluation conducted. This can be organized by contacting the child’s classroom teacher, school psychologist and/or social worker, or the support staff team in general. This team of professionals, consisting of a speech language pathologist, school psychologist, reading specialist, social worker, and other professionals, will carry out an evaluation using multiple tools and tests (National Institute of Mental Health, 2011). Once the evaluation is complete, the child and their family have many available options. Depending upon the child’s specific needs, they can be placed in a special education classroom full or part time, in a school specifically for children with more severe disabilities, or in a regular education classroom with specific supports for the child such as a resource room or a personal care aide (Levy, Mandell, & Shultz, 2009). These special education services and the creation of an individualized education plan (IEP) are available through the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973 (National Institute of Mental Health, 2011).

Intervention is usually a multi-faceted approach that includes “specialised educational curricula, developmental therapies, behaviourally based treatments, and intensive parent training in the home, community, or school setting” (Levy, Mandell, &

Shultz, 2009, p. 1634). Intervention targets core deficits in the areas of socialization, communication, and behavior, with behavior and related developmental differences being most important due to their overt nature. The purpose of intervention is to “improve functional status of the individual through acquisition of skills in core deficit areas, and decrease effects of comorbid conditions” (Levy, Mandell, & Shultz, 2009, p. 1634).

The child’s family, as stated above, is also essential to a more positive outcome for a child with ASD. Parents trained in specific interventions are able to help their children thrive more in the home and community because generalization and maintenance are able to occur across settings. Because of the encouraging results of more parent involvement in intervention, it is clear that parents of children with ASD are “important collaborators at all stages – from assessment through to goal development and treatment delivery” (Levy, Mandell, & Shultz, 2009, p. 1634).

However, when it comes to professionals, such as teachers and other school personnel, parents are very concerned with those individuals truly getting to know their children and tailoring instruction to meet their needs. Parents are also concerned with the training these professionals receive about ASD as well as teaching and behavior strategies. Parents would like to see more education and knowledge about ASD presented to peers of their children, so their children with ASD can be more accepted by their peers and invited to engage in friendships and social interactions (Bevan-Brown, 2010).

Parents and Caregivers

Along with the stresses of school-based interventions, parents and caregivers of children with autism are dealing with many other issues and difficult situations due to their children’s disorder. Altieri and Kluge (2008) state that a child on the autism

spectrum, no matter the level of severity, “presents unique challenges and stressors for the family because of the ambiguity of diagnosis, the severity and duration of the disorder, and problems with the child’s lack of adherence to social norms” (p. 83). Therefore, parents and family members are required to make changes to the family dynamic to support their children and cope and function adequately from day to day (Altiere & Kluge, 2008). While parents and family members work to change many aspects of life to accommodate their children, these parents of children with ASD still seem to experience many negative and stressful outcomes due to their children’s disorder. These include lack of sleep and fatigue, strained family and peer relationships, feeling unqualified as a parent, and possible psychiatric issues (Glazzard & Overall, 2012). Furthermore, these parents are also struggling to deal with other issues including the family dynamic revolving around their uniquely disabled children, the loss of a “normal” life for their families, very few moments of happiness and family togetherness, inadequate child care for both the autistic child and his/her siblings, and lack or loss of leisure activities (Luther, Canham, & Cureton, 2005).

Luther, Canham, and Cureton (2005) also mention that “parents of children with autism are frustrated with the scarcity of professionals trained to work with their children in specialized programs” (p. 40). Many parents, according to Altieri and Kluge (2008), cite a lack of support groups, school issues, unaware and uneducated doctors and clinicians, and searching endlessly for services as activities that cause them stress. These parents also mentioned public and community knowledge about autism and how they still feel unknown, unseen, and underserved despite the growing media coverage of autism (Altiere & Kluge, 2008). Related to parents’ feelings of being unknown, unseen, and

underserved, parents also worry and become stressed about their children's social connections and acceptance within the community. According to Bevan-Brown (2010), parents emphasize the importance of their children having friends, being included in both daily routines and special occasions, receiving acceptance and kindness from peers, and feeling comfortable at school and in the community. Because children with ASD may not experience these important social aspects of life, parents become stressed and fearful about the future of their children (Bevan-Brown, 2010).

Another large factor contributing to all this stress, that parents mentioned across studies, is a lack of financial aid and access to care; parents oftentimes find it difficult to gain assistance from state and federal programs due to the uniqueness of their children's diagnosis (Glazzard & Overall, 2012). Research shows that this rapidly growing disorder known as autism also comes with the steep national price tag of \$90 billion annually, putting increased strain on federal education resources and, more importantly, on these children's families (Luther, Canham, & Cureton, 2005).

It has been found that the impact of autism on a family and the family's dynamic differs significantly from the impact of other disorders that occur in childhood. Studies show that families with children with autism "experience more stress, depression and anxiety" (Altiere & Kluge, 2008, p. 85). Because of this, most parents engage in a wide range of coping strategies to deal with this stress "including relying on family and support groups, excluding themselves from social situations and relying on the health care service or on their faith or religion" (Glazzard & Overall, 2012, p. 39). Parents of children with ASD also seem to employ changes in lifestyle and thought processes including placing more importance on parenting than career goals, caring less about what

other people think of their children with ASD, and having more understanding about the uncertainty that comes with autism, their children's future, and the rest of their life as parents to successfully cope with their children's disorder (Luther, Canham, & Cureton, 2005).

Altiere and Kluge (2008) found that a vital part of a family's ability to cope with a diagnosis of autism and function effectively is social support, such as that from family and friends. Similarly, Luther, Canham, and Cureton (2005) cited reframing, best described as the ability to change your outlook on stressful situations and experiences, social support, and parent support groups as highly ranked coping strategies among parents of children with ASD. Yet, most parents of children with autism, because of the extreme amount of support and commitment their children demand, are usually unable to interact with others and benefit from the aforementioned social support (Altiere & Kluge, 2008).

Despite this challenge, Luther, Canham, and Cureton (2005) discuss a collection of protective factors, at many different levels, that can help families cope with the stress of children with ASD and the changes in family dynamic. These protective factors include positive self-worth and self-esteem (personal level), the ability for the family to communicate and solve problems (family level), and receiving support from religious and cultural groups as well as professional support groups (community level).

Bronfenbrenner's Ecological Theory

The protective factors mentioned by Luther, Canham, and Cureton (2005), share a structure similar to Bronfenbrenner's bio-ecological model of development; Bronfenbrenner's bio-ecological model consists of five systems, microsystem,

mesosystem, exosystem, macrosystem, and chronosystem, that interact and change based on the individual in the microsystem and the life they live (Swick & Williams, 2006).

Swick and Williams (2006) state that the microsystem consists “of the child’s most immediate environment (physically, socially, and psychologically)” (p. 372). With regards to children, families are a large part of the microsystem because they lead by example; the child learns many things by watching their immediate family and remembers these interactions throughout their life.

Exosystems are created through our close connections with our families. As humans, we are drawn to emotions and feelings before physical connections. Therefore, we create these close connections within families and consequently become a part of our family members experiences vicariously and feel the impact of these experiences, both good and bad, even if we are not present physically. Because of their unique nature, exosystems are a large source of stress to families. Family members need to understand the impact exosystems have on their individual members, whether or not an individual is an active part of that exosystem physically. Professionals need to encourage practices that support family connections and attention to exosystems (Swick & Williams, 2006).

The macrosystem consists of the larger “cultural beliefs, societal values, political trends, and ‘community happenings’ ” in which we as humans live (Swick & Williams, 2006, p. 372). These beliefs, values, and trends influence all aspects of our development because they shape our view of others and the world. More generally, macrosystems connect and keep together many different parts of our lives; these overarching beliefs, values, and trends provide structure for individuals and families. Mesosystems are primarily responsible for creating connections beyond dyads, which are relationships,

communication situations, or connections involving two individuals. Mesosystems connect the multiple systems of children, parents, and families to create stronger relationships between individuals and expanding circles of relationships. More simply, mesosystems create communities and connections that young children can readily see and parents can turn to in times of need.

Chronosystems refer to the historical context and circumstances that surround every dynamic of family life. This outer system describes the pattern of important life events across the lifespan and how these events occur within each system and impact individuals. Most obviously, chronosystems include important socio-historical circumstances such as wars, genocide, and natural disasters. However, these “historical” issues can also refer to previous patterns of relationships and connections in families, or anything that can explain or impact currently existing family dynamics (Swick & Williams, 2006). Bronfenbrenner’s bio-ecological model is useful to understanding and aiding families dealing with stress, like these families with children on the autism spectrum, “because it is inclusive of all of the systems in which families are enmeshed and because it reflects the dynamic nature of actual family relations” (Swick & Williams, 2006, p. 371).

Focus Groups

Qualitative researchers conduct interviews to gain information from individuals. More specifically, interviews are used to understand and make sense of an individual’s world by gathering descriptions of that world in the individual’s own words. The central goal of an interview is to understand how the individual thinks and feels (Bogdan & Biklen, 2007). Group interviews are another way to understand the thoughts and feelings

of individuals, because they stimulate discussion between a group of people about specific issues (Bogdan & Biklen, 2007). In very basic terms, Kitzinger (1995) defines group interviews, better known as focus groups, as a “form of group interview that capitalises on communication between research participants in order to generate data” (p. 299). Focus groups are usually comprised of a group facilitator and anywhere from seven to ten individuals. Focus groups are most productive when the topic in question is broad and the purpose of the focus group is to encourage discussion from a wide range of perspectives (Bogdan & Biklen, 2007).

This method of qualitative research invites and supports participants’ collaboration and discussion about questions and ideas presented to the focus group; members of the focus group are encouraged to interact with one another through questions and comments. A focus group is especially useful for understanding not only a specific group of people’s opinions about and familiarity with a topic but also the how and why behind their thinking. A basic tenet of this method of research is that group discussion allows for more exploration and clarification of ideas better than one-on-one interviews (Kitzinger, 1995).

Focus groups allow participants to direct the conversation by pursuing issues that are important to them. Directing the conversation and outcome of the focus group is also done through everyday and casual forms of communication that occur in a group setting, such as “jokes, anecdotes, teasing, and arguing” (Kitzinger, 1995, p. 299). Through these unique forms of communication, focus groups also shed light on cultural values, group norms, and minority opinions. Focus groups, and the subsequent interactions of their participants, also allow for understanding of attitudes and priorities of participants,

analysis of experiences common to all participants, comprehension of group explanations of knowledge, and expression of criticism and taboo topics (Kitzinger, 1995).

In order to gain useful qualitative data from focus groups, it is important to consider the role the group facilitator plays in a focus group. It is also important to consider the following: choosing a topic that will produce multiple responses and opinions, developing a strategy to stress confidentiality and value of responses to participants, creating diverse group dynamics, and planning a sequence that, from introductions to final thoughts, facilitates group discussion (Bogdan & Biklen, 2007).

Purpose

Although many studies on autism and ASD have used face-to-face focus groups, few studies on autism and ASD have been conducted with an online focus group design. Further, while these other studies have looked into more specific issues involved in parenting a child with ASD, such as coping strategies, stressors to families, and family dynamics, no study has been implemented to gain a complete picture of parenting a child with ASD.

Therefore, based on the formerly mentioned research, this study strived to look at the experiences of parents of early elementary aged children with ASD from a more comprehensive approach. This study investigated what was going on in these families' lives at the time, their constant struggles, and their hopes and dreams. This study used Bronfenbrenner's bio-ecological model of development as its theoretical framework in order to look at how different systems interact in a family with ASD. The current study attempted to answer the following research question: what are the experiences of parents raising early elementary school children with ASD?

Method

Research Design

As stated in the previous chapter, focus groups traditionally involve a small number of participants and a moderator who is central to the participants' discussion and keeps the conversation on track (Reid & Reid, 2005). Furthermore, the purpose of focus groups according to Reid and Reid (2005) is to "obtain in-depth understanding of participants' perspectives and opinions" (p. 132). The focus group methodology was selected for several reasons, which include but are not limited to the following. Focus groups allow for the exploration of new knowledge regarding a specific topic of interest as well as create a "flow of input and interaction related to the topics that the group is centered around", in this case new understanding concerning the perspectives of parents raising children with ASD (Reid & Reid, 2005, p. 132). This new knowledge is gained through questioning and interactions of participants, the essential aspect of the focus group methodology (Deggs, Grover, & Kacirek, 2010).

Focus groups also establish how participants create points of view about common and exceptional issues, such as how parents of children with ASD perceive their children and their life experiences. According to Deggs, Grover, and Kacirek (2010), individuals do not form points of view in a vacuum but rather use the ideas and opinions of others around them to clarify and formulate their own. Additionally, focus groups allow participants to share beliefs, emotions, and opinions that may not be explicitly gained using other methods. Kitzinger (1995) reinforces this by arguing that because of the

nature of everyday communication and its unique ability to enlighten us to an individual's knowledge and opinion, focus groups tap into knowledge that would most likely be overlooked in more conventional research methods.

However, the research for this study was conducted by nontraditional means through a qualitative online focus group design. Instead of requiring participants to meet and converse face-to-face each week at a prearranged time and place, the focus groups used in this study were conducted online. Because of the nature of focus groups, online or otherwise, discussion between participants was the main source of data for this study. Online focus groups were specifically selected for unique reasons, most of which, but not all, are discussed here. While online focus groups are cost effective and invite more efficient collection of qualitative data, one of the most important factors involved in the selection of the online focus group methodology is the lack of time restrictions (Deggs, Grover, & Kacirek, 2010). An online focus group allows participants the flexibility to communicate on their own time and in their own space. The schedules of parents of children with ASD are extremely busy and chaotic and do not have the flexibility for weekly face-to-face discussions. Yet, an online focus group gives these parents the freedom to respond to questions and post comments at whatever time and location is convenient for them.

Along with reduced time and location constraints, Reid and Reid (2005) mention improved group participation and overall increased communication and information transfer, mainly because participants are not forced to wait to respond. The ability of participants to make a statement without waiting for another member of the group to complete their response creates more equality of participation and more discussion by

and large (Reid & Reid, 2005). The fact that participants, and their children with ASD they were discussing, were anonymous while posting and commenting in the online focus group also produced more honest and uninhibited posts and comments. The pseudonyms participants create for themselves and their children allowed for more self-disclosure and disinhibited communication throughout the online focus group (Reid & Reid, 2005).

Finally, since this study was aimed at understanding the parents' perspective about their children with ASD, it was appropriate to obtain opinions and points of view from parents across the United States and online focus groups allowed for that collaboration and discussion to occur.

Participants

Participants were chosen based on the following criteria: the individual was a parent of a child diagnosed with ASD, had access to a computer with an internet connection and was available for the length of the discussion group, eight weeks, and was a resident of the United States. Recruitment requests and materials, including details about the project, additional questions and answers related to the project, and flyers, all of which are included in Appendix A, were forwarded to many different individuals and groups. This recruitment information, sent by email, was passed on to American Speech and Hearing Association (ASHA) members, including speech-language pathologists and audiologists throughout the United States, online support groups for parents of children with ASD, such as those on Facebook, Yahoo, and Google, and moderators of support groups through Autism Speaks and Autism Society of America. Any and all interested participants were sent consent forms and demographic questionnaires, either through

email or postal mail, and upon the return of these consent forms and demographic questionnaires, participants were added to the study.

After reading through the consent forms and demographic questionnaires, participants were placed in one of six focus groups based on the age of their children with ASD. Group one included parents of preschool aged children who had most likely been diagnosed with ASD recently, group two included parents of children with ASD in early elementary school from Kindergarten to second grade, group three included parents of children with ASD in the secondary elementary grades three to five, group four included parents of children with ASD in middle school, or grades six to eight, group five included parents of individuals with ASD in high school, or grades nine to twelve, and group six included parents of adults with ASD. These six groups, first diagnosed, early elementary, secondary elementary, middle school, high school, and adulthood, were organized according to the age and stage in the lifespan that the children with ASD, and therefore the parents of the children with ASD, were currently experiencing. The focus groups were organized this way in order to provide parents with peers and companions to allow for better discussion of common issues.

The remainder of this thesis will focus on group two of the study, the online focus group for parents of children with ASD in early elementary school. Specifically for this group, there were ten parents that volunteered to participate in the study. All ten participants were mothers of children diagnosed with ASD, ranging in age from four to eight years old. The majority of the participants' children were male, in Kindergarten, and had received the diagnosis of Autistic Disorder. More information regarding the

participants of group two can be found below, in Table 1. (Please note: All names in the table are pseudonyms.)

Table 1

Participant Demographics

Participants	Miranda	Christina	Samantha	Jen	Dana	Elizabeth	Melanie	Lindsay	Alexis	Josie
Child's Age ⁱ	5	5	6	6	6	8	6	8	4	6
Child's Grade	K	K	K	K	K	1	1	2	K (Cyber School)	K
Child's Diagnosis	Autistic Disorder	Autistic Disorder	Asperger Syndrome	Autistic Disorder	Autistic Disorder	PDD-NOS ⁱⁱ	PDD-NOS	PDD-NOS	PDD-NOS	Autistic Disorder
Child's Gender	M	F	M	M	M	M	M	M	M	F
State	CA	CO	PA	PA	IL	MI	TX	MD	PA	OR

ⁱ The age included in this table was the child's age at the time of recruitment

ⁱⁱ Pervasive developmental disorder not otherwise specified (PDD-NOS)

Materials

Wikispaces, an online, password protected discussion board website, was used by participants during the eight weeks of online focus group discussion. Participants were able to read questions presented by the moderator and post answers to these questions. Participants were also encouraged to read and comment on responses posted by fellow participants in the discussion group to generate dialogue and information sharing. A separate Wikispaces page was created for each of the six focus groups involved in the study and each individual page was password protected to keep all information discussed during the study confidential.

The questions, developed by the researchers, were created based on a literature review concentrating on the views of parents of children with ASD, the transitions these children go through from the perspective of the parents, and needed/lacking support services. The finalized six questions focused on a wide range of issues including pressing concerns, successes, hopes and dreams, the parenting experience, and lifelong struggles

and victories. The questions, along with the general introduction and final thought questions, were created to enhance and encourage communication between participants, and were therefore open-ended. These six questions were presented to all six online focus groups, since they were not specific to any one age group.

Before being finalized these questions were given to two parents of children with ASD for clarity and confirmation that the topics contained in the questions were appropriate. The questions were also presented to the research group to further confirm that they were understandable, meaningful, and relevant. The final questions used for the online focus groups can be found in Appendix B of this document.

Procedure

Once each participant gave informed consent, the participants received an invitation to join the Wikispaces page for their specific online focus group discussion; this invitation included information about creating a Wikispaces account and connecting to the online focus group. After the participants created accounts, they were given instructions explaining how to perform certain tasks on the Wikispaces discussion page such as creating a new post, reading a post, and responding to a post. During the first week, participants were asked to post short introductions, that included information about themselves, their children with ASD, and any other relevant information, and reply to one other participant's introduction to confirm that they understood how to use Wikispaces.

From this point forward, questions were posted for discussion on a weekly basis and participants were encouraged to visit the discussion group at least once a week to respond to the posted question and to comment on responses posted by fellow participants. This occurred each week for the eight weeks the online focus group was

administered, this eight-week time frame included the introductory posts, the six focus group questions, and the final thoughts posts. While a new question was posted to the group each week, participants still had access to previous questions and were able to create a new post or comment on a post whenever they saw fit.

There was a moderator assigned to the online focus group who was required to post these questions as well as confirm that each participant was contributing to the discussion through the creation of a new post and comment each week. The moderator also encouraged dialogue concerning the weekly question through mid-week summaries and broad prompts, changes to the focus of the discussion, and requests for further explanation of posts and comments if necessary. Refer to Appendix C for the complete moderator guide.

Data Analysis

Upon completion of the online focus group, every discussion post and comment was saved from Wikispaces to a word-processing document using Microsoft Word. All discussion posts and comments were then placed in a Microsoft Word table that organized all posts and comments. These posts and comments were subsequently given number codes based on the question the post responded to and whether the post was original or a comment on another post. This table also included the username each participant used to login to the Wikispaces page and the number of words included in the post or comment. From the table, the data was then separated into thought units, which are the smallest written statements, typically a sentence at least, that still have meaning and are able to stand alone.

Once all of the posts and comments had been separated into thought units, the data were coded using the broad codes that were created based on Bronfenbrenner's Ecological Theory. The four broad codes created from this theory, that begin at the microsystem and build up to the macrosystem level, included: (1) the individual child with ASD (microsystem level), (2) their nuclear family (microsystem level), (3) schools and the school system (exosystem level), and (4) society, such as people in the community and extended family members (macrosystem level).

Reliability

Because this coding system was based on an individual's opinion and subjective view of a thought unit, reliability within the coding system had to be determined. This was done by the author and another honors student in the Department of Communication Sciences and Disorders. First, both individuals coded the same two pages from the data set, compared the codes selected for these two pages, and calculated the number of reliable codes using the simple inter-rater reliability formula: $\text{agreement} / (\text{agreements plus disagreements}) * 100$. Using this formula reliability should not be lower than 90%. Yet, if it was, both individuals first discussed the disagreement concerning the codes and then moved on to code another two pages. Later, after becoming proficient with the coding system and remaining at 90%, 20% of the full data set was coded by both individuals, excluding as many previously agreed upon codes as possible. This resulted in an 87% reliability, which verified a high degree of reliability for this data set.

Results

Throughout the eight weeks of this online focus group, including the introductory posts, six focus group questions, and the final thoughts posts, the ten participants involved in the early elementary (K-2) focus group wrote 24,369 words in 150 posts and comments. The 150 posts and comments were broken down into about 700 thought units. Most importantly, of these ten participants, almost all remained active through posts and comments during the entire duration of the focus group.

As previously mentioned, the thought units included as the results are discussed using the four broad codes designed from Bronfenbrenner's Ecological Theory: the individual child with ASD, the nuclear family, school and the school system, and society. Each of these four broad codes, or themes, has multiple subthemes, or important issues highlighted by the parents within that broad code. Both the broad themes and subthemes are presented in Table 2 on the following page.

Throughout this section, the themes and the subthemes will be presented together and supported by direct quotations from the participants. These statements are copied exactly as they were written by the participants, which may include spelling and grammatical errors. Information in participants' statements such as names and places of residence are excluded to ensure confidentiality. To further ensure confidentiality and anonymity, participants will be referred to using the pseudonyms created in Table 1.

Table 2

Summary of Coding

Themes	Subthemes
The Individual Child with ASD	Strengths Lifelong Struggles Anxiety Emotional Struggles Friendships & Social Interactions The Future
The Nuclear Family	Therapies Medications Aftermath of ASD Diagnosis Knowledge Gained Advocacy Acceptance of Diagnosis Family Relationships Parental Issues Finances The Future
School	Academic Successes Homeschooling Classroom Issues Access to Services School Support
Society	Extended Family and Friends Outside Agencies Judgment Lack of Understanding

The Individual Child with ASD

Among issues concerning parents regarding their children with ASD, the most prominent were: the strengths and lifelong struggles of their children with ASD, anxiety, emotional struggles, friendships and social interactions, and the future of their children with ASD. All of these subthemes were discussed by at least three out of the ten parent participants in this online focus group.

Strengths

Many of these parents cited a love of reading and storytelling, their sense of self, curiosity about the world, and academic skill as strengths of their children. One participant, Samantha, shared the unique strengths she saw in her child with ASD in her post:

His intelligence of wanting to learn how things relate to one another. His interest for Science, Geography and Music. The awesome relationship he has with his younger brother, who also has ASD. How when he is afraid to do something, we can talk about it and make him feel better to go through the motions of it and then he is ready to actually do it. How he accepts the fact that he has ASD and is all right with that and knows what to do in situations that he can't handle.

Another participant, Lindsay, put the strengths of her child with ASD into much simpler terms: “The positive is his loving heart, his memory, how far he has come and how hard he works. The little things he truly smells the roses!”

Lifelong Struggles

Most of the statements about lifelong struggles appeared when parents were asked to discuss both positive and negative aspects of ASD that they felt would never go away.

The responses, not unexpectedly, usually began with the negative aspects, or the struggles these parents believed would be with their children with ASD for the rest of their lives. These lifelong struggles included constant protection, lack of basic self-help skills, and social skill deficits. Alexis summarized all of these struggles in her post:

Now the negatives are he probably will never be able to complete toilet training, bathe himself, or understand why he has to put toys away when he's done with them. He likely will never go to a traditional brick and mortar public school because he learns best in the cyber school one to one interaction. He may never understand the cues for social interaction properly or "stranger danger".

Similarly, Josie confirmed many of these lifelong struggles in her post:

Like many of you, it seems, I fear she'll never catch on to seemingly simple actions like wiping herself effectively, spitting out her toothpaste, or blowing her nose. That she'll never tune in to the "basic niceties" of conversational exchanges, or learn to deliver her ideas in ways that don't alienate children who might otherwise want to be her friend. That she won't learn to track on her surroundings better in order to keep herself safe, so I'll have to accompany her everywhere.

Anxiety

One of the major issues discussed, throughout the eight weeks of this online focus group, was anxiety and the challenges associated with it. These challenges included overstimulation, as a cause of anxiety, and self-regulation and coping strategies, as a means to manage anxiety both before and after anxiety inducing experiences. While a few parents discussed positive experiences dealing with anxiety and coping strategies,

most parents used the focus group as an outlet to converse about the negative experiences and distress that anxiety caused for them and their children with ASD.

One positive statement concerning anxiety came from Lindsay. After discussing thoughts about her son when they first received his ASD diagnosis, she stated: “Now he has come very far we still have stressful days with anxiety but his future is very bright!!” Samantha commented with a positive anxiety statement, in response to another participant’s post about a positive and anxiety free summer camp experience: “I know when my son feels comfortable in his environment away from home, he does extremely well and his self esteem soars while his anxiety goes way down.”

However, most of the posts regarding anxiety were very disheartening and negative, such as this other blog post from Samantha:

Even things that he used to like doing (Rock Climbing for example) he stopped doing, because his anxiety became too great and it was a struggle to get him to go. However, once he is there, he would have a blast, it's just getting him out of his comfort zone that's the tricky part. He gets so upset that he would lock himself in the bathroom, dry heave, foam at the mouth, hysterically cry, bang his head into my chest or my husband's if we are just holding him while talking calmly to him or worst yet go after his brother.

Elizabeth also shared this statement about how much of a struggle her son’s anxiety truly was with the group:

My son prefers to stay at home as well. He is fine if the outside location is in his comfort zone like school, OT, doctor, etc. However, he does not want to go

anywhere new. He hates crowds and noise and will not stand or sit next to someone he does not know – even in church.

Josie was another participant that shared feelings of distress and sadness concerning her child's anxiety:

Yes--the anxiety is such a huge issue for us. It breaks my heart to see my daughter struggle so hard with her anxieties. It's so important to us that she feel her own uniqueness as a set of gifts first and foremost, but so much worries her.

Emotional Struggles

Along with anxiety, these parents brought up their children's struggles with other emotional issues. Some of these emotional struggles included screaming, tantrums, emotional outbursts, and general frustration. Again, while there were some positive and neutral comments concerning these emotional struggles, most of the posts involved negative statements.

The participant known as Melanie divulged this positive statement with regards to her son's emotional outbursts: "He is doing really well keeping his rage under control and if we can find a way to keep him from saying everything that pops into his head life will be perfect." In conjunction with this, Josie remarked on both the positives and negatives of her daughter's emotional struggles in this statement:

Still, even though she's working hard at regulating her emotional responses/anxiety with each new thing, it's not as if the change is encountered and then moved past--it builds up, really drains her inner resources, and eventually she has to let the stress and frustration out. On a good day, she's able to hold out through the changes and just take lots of time to be alone to read and tell stories

with her paper dolls, with no outright meltdown. Other days, even if it seems like she's been holding her own like a pro, a shrieking hurricane of frustration and exhaustion is unleashed.

As far as the negative statements go, both Alexis and Dana had simple yet effective comments concerning their children's emotional difficulties. Alexis while discussing an outside agency, stated that: "Since they started, he has been encouraged to defy me, eat things that do not agree with his system, and alter his behavior to be worse than it was before they began." Dana shared that: "My son is only 6, but he is very tall for his age and looks much older. He is not violent (right now), but he has had outbursts that have the potential to hurt others."

Friendships and Social Interactions

Another aspect of their children with ASD that many of these parents discussed was their difficulty making friendships and having encouraging social interactions. Because one of the key components of ASD is lack of social skills, this was an issue discussed by almost all participants. Particularly, the participants discussed their children's variability when interacting with peers, their ability to alienate others with their actions, and their differences in understanding the social world they live in.

Josie had this to say with regards to her child's difficulties with friends and social interactions: "It's so hard to see Bird inadvertently alienating her young friends because she doesn't show her feelings the same way, or gets frustrated when the way they play doesn't match what she thought was going to happen, etc., etc." Another participant, Lindsay, stated bluntly: "Socially It is still difficult to make friends. Kids can be so cruel." Melanie shared her son's inability to connect socially and the problems that may

ensure: “I have to say that my biggest worry, with my little Froggie is that his inability to understand social cues and to read others emotions will get him hurt or into trouble.”

The Future

The future, specifically focusing on the children with ASD, was a topic these parents felt was important to discuss at one time or another. With this specific focus, most parents concentrated on the future independence and capability of their children and how their ASD may affect that goal. While the parents who discussed the future independence of their children with ASD mainly spoke in hypothetical terms, one parent, Josie, made a statement that referred more directly to her child’s current functioning level and the impact that was having and possibly would have on her independence in the future:

I try really hard not to think too much about the future--some days it seems like Bird is blossoming so much that she'll make her way towards independence, and other days I find it hard to feel that way. Autism isn't just a spectrum of experiences across children--Bird has her own spectrum of her life trajectory, where she falls on the spectrum from year to year, from week to week, day to day, even from the beginning of the day to the end of the day . . .

As mentioned, all other parents who commented about future independence for their children with ASD spoke from a hopeful perspective. Dana shared her hopes for her child with ASD by stating that: “I hope he can grow up to live independently and have a life and job that he enjoys and be able to pay his own bills and take care of himself. I hope that he can have at least one good friend, perhaps more, to enjoy life with.”

Christina also commented about her daughter’s possible independence in the future with

her statement: “For the future all I want for her is to be happy and be able to live a full life. I don't want her to be sheltered because of her disabilities like I feel she is now.”

Another participant, Lindsay, contributed to the discussion by stating that: “I want him to be happy and healthy. I want him to be able to make friends and go to College fall in love and live on his own someday.”

The Nuclear Family

With regards to the family and its function with a child with ASD, some of the most pressing topics of discussion were: therapies, medications, the aftermath of the ASD diagnosis, the knowledge gained as parents of children with ASD, advocacy for their children with ASD, the acceptance of the ASD diagnosis, family relationships, parental issues, finances, and the future of their families and children with ASD. All of the subthemes for this broad code were discussed by at least three out of the ten participants of the online focus group.

Therapies

Since the parents involved in this online focus group were parents of children with ASD in Kindergarten to second grade, many of them were experimenting with multiple different therapies. During their time involved in this online focus group, the participants discussed their experiences with homeopathic remedies, speech therapy, occupational therapy, physical therapy, and Defeat Autism Now (DAN) doctors and protocols. Based on the posts and comments, responses were split evenly between the supports and positive aspects and the barriers and negative outcomes of therapies. Josie discussed her and her daughter's positive experience with homeopathic therapy in her statement:

Still, she's really been managing these changes pretty well on a change-by-change basis if we prepare her for what to expect in advance. At the risk of being labeled a "crunchy granola" type, we've found that homeopathy has been really helpful in helping her anxiety on a general basis.

Melanie also mentioned the support she, her family, and her child with ASD have gained from speech and occupational therapy through her remarks:

I would say that the most successful thing we have done for our little froggie was Speech and occupational therapy. We began these therapies based on the symptoms of developmental delay that he exhibited early on, we at this time had no formal diagnosis other than Speech delay. Through therapy he was able to communicate and function more appropriately and this was a huge leap for him and our family. Being able to perform normal daily functions and being able to communicate with others helped him to have less frustration and with help eventually all rage fits stopped and now tantrums and screeching are not a constant occurrence in our home.

Nevertheless, barriers and struggles with therapies were still common to the discussion of therapies. Although Alexis mentioned some positives in her statement, she did not see great improvements overall: "He is getting so much help through therapies, but still can't manage to do daily self-care tasks such as toilet-training and bathing. Now, lately, even eating solid food has been a struggle." Lindsay made comparable observations regarding the DAN protocols they had implemented for their child with ASD: "The DAN protocol has worked some. We have a huge yeast issue we chronically fight. It has not helped that

much with his anxiety sometimes it has made it much worse we had to stop certain supplements.”

Medications

Another serious concern of the parents involved in this focus group was the idea of medicating their children with ASD, either for behavior or anxiety difficulties. These parents contemplated whether to medicate their children or not and considered many different factors when deciding on this issue. One parent, Elizabeth, discussed this inner turmoil in her post about medication:

I really struggled with this since I never wanted to medicate him. In my mind, medication means that I am trying to "fix" him and I have never wanted to believe that he is broken. On the other hand, what if I could help him by giving him a medication and I failed to do that?

As for the benefits provided by medications, these parents cited reduced emotional outbursts, such as tantrums and violent behaviors, and better focus for school and other daily activities. Elizabeth contributed another post concerning these positives, her child, and his medication situation: “We just started my son on an anti-anxiety med. I was not thrilled to medicate him, but I do have to admit that I can already see a difference.” An additional positive comment with regards to medications and the outcomes of them came from Samantha:

We have seen a major difference in him since he has been on the medications. Before the medications, he would throw, hit, attack his brother, less focus in school, anxiety through the roof and not handle things at all. Now that he is on the medication, he finished the school year without being absent hardly, he was

mostly in regular Kindergarten, he was less violent, his anxiety went way down, he stayed focus, slept better on his own and seemed to come out of his timid shell more.

Other participants spoke about the negative outcomes of medications that consist of unwanted behaviors, taste changes, outbursts, and other side effects. A participant that focused on this issue of unwanted side effects was Melanie:

We even tried behavior meds at this time, which of course I was always against because I just don't think he needs them, but I knew if I didn't ever try them then I couldn't be certain I was right of course the side effects were awful and it was so not worth it but at least we don't ever have to go down that road again and he doesn't seem to remember any of it.

Aftermath of ASD Diagnosis

This subtheme proved interesting because almost all the parents had a different reaction and experience upon receiving their children's ASD diagnosis. Some parents felt they needed to do everything to attempt to fix their children, others became extremely depressed about the diagnosis of ASD, and others in spite of everything felt relieved and unchanged by this information. Illustrating one of these opinions was Lindsay's statement:

When we first received his PDD-NOS diagnosis I was on a mission to start every therapy to help him out there. I just wanted him to talk and I wanted to reach him. It was very stressful at the same time it felt good to have a diagnosis and be able to start on his long journey. It was a day and a step at a time.

In the same way, Dana posted about her desire to connect with and help her son:

When we first suspected that my son had autism spectrum disorder, I thrust myself into researching the different interventions, and essentially expected that I had some window of time in which I could "fix" him. As he has grown into a little boy, I still feel inclined to want to fix things, but my expectations are evolving into the realization that this is a slow, steady process of adaptation and acceptance for everyone involved.

A different perspective on the outcome of receiving the ASD diagnosis came from Samantha in her post regarding her fears and worries:

At first my heart sank to the floor and all I could think about was my husband's friend who has Aspergers and only thinks of himself and uses people to get what he wants. Once that thought passed, I kept thinking of all the people I had to contact that the Developmental Pediatrician gave me and running the numbers of how much it is going to cost in my head. Of course, price is no subject, I say out loud, but in my head I'm thinking how are we going to afford all of this since my husband is the only one working?

Another perspective on this experience was that of Melanie and her unaffected response to the ASD diagnosis:

I can't honestly say that the diagnosis changed anything for us or that I really had any expectations. My son was a delayed talker & walker and we took steps to help him. The diagnosis/label was only a tool needed to get him services within the school system.

Knowledge Gained

Somewhat related to the subtheme of the aftermath of the ASD diagnosis, is this subtheme of knowledge gained so far as a parent of a child with ASD. Again, parents had mixed responses. From feeling able to now help other parents through the diagnosis, to looking at their children as complete individuals regardless of the diagnosis, these parents' views about their knowledge gained was varied. Samantha shared her transformation as a parent of a child with ASD in this post:

Secondly, I remember how clueless I was in the beginning on everything from who to see down to getting MA and now people are coming to me asking for help on who to see for diagnosis or how to get MA and I just love helping a fellow parent, because if I can help them avoid the run around we experienced than I will, because it was not fun and a waste of valuable time.

Dana also shared her outlook on her knowledge as a parent of a child with ASD. Although different, it is still similar in the sense that she was now looking at the larger picture for her child with ASD: "I not only just think of his needs, but I am more interested in what he enjoys, what makes him happy, and what we can do to enjoy things together. It doesn't have to be therapeutic all the time."

Advocacy

Especially for this group of participants, parents of children with ASD just entering school, advocacy was an unbelievably important topic of discussion. These parents not only discussed advocating for their children in the school setting, which will be focused on more in the third broad code, school, but also talked about ways to

advocate for their children with ASD with other parents, authority figures, and in the community.

Statements illustrating advocacy and its importance were found in posts by Christina and Josie. Christina stated: “Although I have no good advice to give you in your situation, stay strong and keep fighting. You are the best advocate for your child as you know him best.” and Josie shared that: “We just need to be advocates for not only their needs, but for a world that sees their needs as being as valid as anyone else's.”

Alexis also shared her views on advocacy and how this relates to parenting:

To say that the parents of special needs children are stronger attached to their kids is no lie. However, it is only with our support that they will succeed, so we must in ourselves be special and do a better job of parenting than the average parent. We are their advocates, their support system, their world...and as such must be stronger, more supportive, and more loving than those parents that are not faced daily with the challenges their needs pose.

Acceptance of Diagnosis

Given that the participants were still new to the idea of ASD and the ASD diagnosis, this topic of accepting the diagnosis as a parent or caregiver was one that was conversed about often in this online focus group. Josie shared her preconceptions and realizations post-diagnosis in this comment:

I'm not sure what expectations I had. Even pre-diagnosis I sort of knew what we were dealing with. At the same time, my daughter "didn't fit" so many criteria for autism exactly. So, I guess with the diagnosis I finally shed some of my residual

"expectations" (not exactly the right word here) that some of the challenges Bird was facing might just be things she'd grow out of.

Dana made an additional comment, regarding the acceptance of her son's diagnosis and how she was coming to terms with specific issues related to his ASD:

I'm trying to come to terms with the realization that this isn't going away, or getting significantly better any time soon. It's getting better, to be sure, but it's a long, long road and there are no quick fixes. I guess I'm having trouble looking at my son's autism as a part of who he is. I thought and still do think of it as something that should be remedied. Quirks, stimming, no problem. I can certainly live with and even embrace them. But some behaviors and the impulsivity and regulation issues that are a big part of his autism do need to be addressed and if they aren't, his freedom and his ability to realize any hopes or dreams will be severely limited. That's what keeps me up at night.

Family Relationships

There were many family related concerns mentioned throughout the duration of this online focus group including the family members' relationship with the child with ASD, sibling relationships, dividing time between children, and husband and wife struggles and issues. These parents also discussed general family dynamic concerns, such as balancing work and all the therapies and appointments of their children with ASD.

Despite most of the comments concerning family relationships being negative, Josie was able to find a way to turn these family issues around and look at them from an optimistic perspective:

But it's a gift, too, because you can't take anything for granted. There's rarely that simple kiss-the-boo-boo-and-make-it-better situation that seems so commonplace in other families. But really solving something together as a family, growing that way--well, we get maybe more of those moments than others.

While this positive outlook on the difficulties of family relationships was very important, almost all other participants made comments regarding the barriers and roadblocks to cohesive family dynamics. Lindsay shared: "He loves when I can sit next to him. It's just so hard when I have another one to watch." Elizabeth also shared her issues with possibly juggling work and her child with ASD in this post:

I am currently staying at home, but am considering returning to work in the fall. Not sure how I will manage that with all the therapies and doctor appointments, but I feel like it might be nice to have something for myself again.

The most complete comment on the topic of family relationships and its struggles came from Dana. The first part of this lengthy post discussed Dana's concerns for her daughter and how everything related to ASD had influenced her:

How all of this is impacting my daughter. The draining of our resources really makes this family no fun to be in, I'm sure. And her behavior is often quite challenging. She craves attention and just can't ever seem to get enough of it.

In the second part of this post, Dana brought up her marriage and the effect ASD had on her marriage and husband and wife relationship:

My marriage - the most precious thing in the world to me right now. He talks me in off the ledge and helps me keep my sense of humor when things just get too

overwhelming. But what toll does an autism diagnosis have on many marriages?

That's often on my mind as well.

Parental Issues

This focus group dealt with many parental stressors and struggles, including lack of friendships and social life and criticisms of parenting styles and choices. With regards to criticisms of parenting styles, one example of this came from a post by Elizabeth that stated: "You could be as strict as someone wanted you to be and it would not change the fact that your child has an ASD and it would not change how he responds to certain situations." Similarly, Christina shared her opinion of this struggle with parenting styles and choices:

I unfortunately do not rely on anyone else but myself anymore no matter how good it sounds. Even programs/events tailored for my daughter. All of our children's needs will be different and we are the only ones that can accommodate appropriately. I hate to sound this way but living in survival mode for 5 1/2 yrs will do that to you. On the bright side it has made me appreciate life more because I am not worrying about what others are thinking/saying/attempting to accommodate anymore.

In spite of all these posts and comments relaying difficult and stressful situations concerning parenting these children with ASD, Samantha was able to make a positive and constructive suggestion for all parents involved in this focus group: "Don't forget you. You still exist and that is a big problem we all face, we forget ourselves and put everyone in front and then we are left empty. Take care of you first and foremost."

Along with the aforementioned parental struggles, these participants had a lot of unresolved emotional issues they were dealing with, such as anxiety, stress, helplessness, and loneliness, on a daily basis. One display of this hopelessness appeared in Melanie's comment: "You just never know what is around the corner when other people have a say in your child's fate." Elizabeth described comparable emotional struggles in her post:

I always wanted to stay home, but the past 4 years have been difficult. I am immersed in my child's life. I have a few friends, but they are mainly friends I had before my son was born. I'm just lonely and often overwhelmed.

The participant Samantha, in spite of her encouraging reflection earlier, also mentioned emotional barriers to truly being happy as a parent of a child with ASD:

I never pictured myself in the place where I am now, I truly feel dead inside and constantly on auto pilot. Half the time on don't know which end is up and my life is basically the kids, my husband, the cats, the house and maybe me. It's a sad existence.

Finances

Even though the issue of finances seems straightforward, these participants brought to light many financial barriers that directly impact their families and children with ASD. On top of the worries about the expensive nature of ASD treatments and where all the money was going to come from, these parents also discussed how job loss caused a schedule change for their children, the financial output for little to no emotional or behavioral changes in their children, and the wonder about whether retirement will ever be an option for these parents. Alexis shared the financial struggles in her life and the life of her child with ASD in this post:

Our boy is no good with changes in routine, so it's no wonder that daddy losing his job caused a problem with his behavior either. Now I'm afraid a little about what will happen when my husband finally does get a new job, since our son has come to be comfortable with daddy being home.

Lindsay also mentioned the issue of finances in her comment stating: “The hard part is finding the money we have used savings, and credit cards. In my state Insurance does not pay for any Autism treatments.” She expanded on that statement further in this post:

But it is so extremely expensive not only the Dr.visits but all the blood, stool and urine , tests and I hate putting him through that. Then all the money on supplements which half the time don't work. As parents we are trying to help our children the best we can. I will do everything I can to try to help him but it is a huge financial strain.

Dana continued to elaborate on finances and the impact it had on her family:

MONEY! How much less of it we have ever since we discovered our boy wasn't developing on track - many interventions are still not covered. And they are very expensive. And they do not guarantee any results, of course, you just do it until you recognize that it's not working and try something else. And will we ever be able to retire?

The Future

On top of the worries of the future solely for their children with ASD, the participants in this online focus group were also very concerned about the future of their family when the time comes that they are no longer able to be active parents for their children. With this in mind, these parents referenced writing a will, assigning

guardianship, and future financial planning to ensure money for their children with ASD. Specific to their children with ASD, these parents worried about how those caring for their children in the future will see their child, either as someone to support or someone to fix, and how their children with ASD will adapt in the world without them.

The participants also discussed how they could, in each of their families, help their children with ASD gain that independence and success in the future that they discussed previously in the first broad code, the individual child with ASD. With regards to the future, parents went further and focused on the ideas of happiness, growth, learning, and other typical parent concerns. Christina shared many of these worries and concerns for the future in her post:

I recently had major surgery and I couldn't help but worry about this very thing. I had all of her activities and paperwork in order, etc just in case. I am a very thorough person anyway but to think someone else would have to start over with her is frightening. After all, it's taken me 3 1/2 years to take a few baby steps with my husband.

Josie also disclosed these fears and concerns regarding the future of her family and child with ASD in this comment:

And the process of putting together a will, guardianship paperwork, and even financial planning for the future makes me feel anxious, and sometimes like I'm not showing enough faith. And, of course, the actual finances issue, with everything else we're paying for, is a whole separate issue.

Alexis was another participant who voiced concerns about the future of her son with ASD in her post:

Will he realize he has to eat, bathe, and go to the bathroom after mommy is no longer around to help him remember? Will there be someone to take my place with enough courage to actually help him, since he can become violent?

School

Since these parents were just becoming acquainted with the school environment, particular to their children with ASD, there was a great deal of discussion regarding this new experience. Specifically, the issues regarding school and the school system these parents discussed were: academic successes, homeschooling, classroom issues, access to services, and school support. Each subtheme included in this broad theme was brought up by at least three out of the ten participants in this online focus group.

Academic Successes

Many of the participants in this online focus group noticed great improvements in academic abilities in their children with ASD. Most of these participants attributed these advances to the school and school personnel, such as teachers and support staff, including speech language pathologists, reading specialists, and social workers. These improvements and successes were seen in multiple academic areas such as communication, writing, and spelling. Samantha mentioned these academic successes and more in her post:

It was amazing to watch the transformation of where he was in the beginning of the school year and how he hated going to where he got the help from OT and Speech (I had to fight for that) and it all clicked and came together to where he is now reading whole stories and enjoying writing sentences without moan or sigh. It is truly amazing.

Lindsay also noted extreme changes to her child with ASD after the school year had ended:

Well my son is nine and has come along way. At the start of school this year he was still not able to read and Speech was around a four or five year old. This year we started a new school and all the extra time we have put in he is now reading!!! His Teacher and Speech Teacher can't believe the progress he has made.

Homeschooling

Contemplated by all participants was the option of homeschooling their children with ASD. Almost all participants weighed in on this debate, since there are so many possible outcomes for children with ASD depending on the educational choices made by the parents. Through many posts and comments back and forth, participants argued for or against homeschooling and issues related to this, including the benefits of different school settings, barriers to homeschooling, additional stress placed on parents who homeschool, and possible alternatives to public school and homeschooling. An important post concerning homeschooling and the reasons for choosing it came from Alexis:

We've decided to home school him through a cyber charter school to allow him to focus on his academic education instead of the distractions posed in a classroom environment. We already tried doing the early intervention thing through DART. When they decided to transition him to sending him to a classroom, it nearly killed him! Not a mistake I'm likely to repeat any time soon.

Josie also discussed her choice of schooling for her child with ASD and how it worked for her family in this post:

Trust yourself and your choices for your child--I know as a half-homeschool/half-public school parent that it's hard to find people who can accept that a child, maybe especially an autistic child, can flourish in a home environment. School has so many sets of stimulus and so many unknowns!

Another participant, Christina, mentioned her thoughts about homeschooling and why the decision was so difficult to make in the following comment: "I thought about homeschool but I have such a hard time getting her to focus at home. BUT when she's at school ALL her anxieties/SPD are held in and she explodes at home."

Classroom Issues

This group of participants, again because they were just becoming immersed in the school environment for children with ASD, conversed about multiple different classroom issues related to their children with ASD. Placement decisions and issues, schedule changes, lack of decent service delivery, and behavior problems in the classroom were all mentioned as important classroom issues by these parents. Melanie posted about these classroom tribulations during the online focus group:

My little Frog also got placed in a regular classroom for Pre-K and that was a disaster, but a phrase from my Grandpa kept playing in my head "Just play their silly little game". So in order to get along I let them do things their way for a few months,

Josie also wrote about a specific incidence of schedule changes in the classroom and school being an issue for her daughter with ASD: "School ended for Bird on Friday, and this last week was so difficult for her--half days, a "field day," assemblies to hold still for, classrooms being stripped bare and emptied. You know, about a million things different

every day.” In addition, Alexis mentioned a particular experience with classroom issues for her child with ASD:

The BSC actually went to the school and is going to make sure they are doing what his best for my son, because they are just doing the bare minimum and it's not enough, but I can't afford a private school nor what my oldest away from his peers for he needs that for the social skills.

A different participant, Samantha, made a general comment about classroom and school struggles in this post:

When they are comparing my son to a dollar bill or the fact that they just looked at his numbers and didn't take into account his Anxiety at all and put him in a Kindergarten classroom with 16 other kids and telling me that is the smallest classroom environment.

Access to Services

Related to the classroom issues explained and quoted above, was the problem of access to services in school and the school system. The participants pointed out that gaining access to services in school, such as personal aides, daily therapies, and special education classrooms, was extremely difficult for many parents of children with ASD.

Samantha voiced her frustration about her child's rights to services in this post:

However, though he is only going to be in the regular classroom for only 2.75 hours, he is not going to have a TSS/one on one help. The school won't allow it. All through out Kindergarten, at every IEP meeting, I requested that he has one and they just denied the request. At one point I was told that there was just not enough room in the classroom for another person (mind you the classroom at 17

kids). This year there are going to be 24 kids he is going to deal with for 2.75 hours. I know it is going to be too much for him.

Christina was another participant who had some choice words to say about the school and their inability to provide any form of supportive services to her child with ASD:

I thought we would actually get the help we needed with the state, boy was I WRONG. It basically boils down to this: since my daughter doesn't feel comfortable enough to lash out at a student or teacher she doesn't get services at school and to them she doesn't have a disability. She tested average academically (a lot of ASD's do!) and they kicked her off her IEP, REALLY?!

School Support

The overarching problem behind access to services and classroom issues was the lack of school support for parents of children with ASD. The participants in this online focus group referred to the deficits in school support as a means to express their struggles with services and the classroom. When participants discussed barriers to school support, they concentrated on the lack of understanding from school, little assistance for them, as parents, and their children with ASD, and the constant fighting with the school so their children could be successful. Elizabeth cited this lack of assistance from the school with this comment: “What ends up happening is that I try to do everything at school events on my own (unless my husband is able to take off work) and then I look standoffish and unfriendly.” The participant Melanie also mentioned how she dealt with the scarcity of school support in the following post:

I'm kind of the Momma pitbull around the school now, I have stood up to them and questioned every action, made demands and held firm, attended every

meeting, and yes a couple times lost my cool but just as with raising a strong willed child for every battle you lose you have three more to fight and the school is no different.

Josie was another participant that voiced an opinion about the difficulty in gaining support from schools and other professionals in this statement:

How to get schools, and even therapists, to understand that my goal isn't just to make sure she can "tough things out" for longer and longer periods of time, or, for that matter, that my goal isn't to teach her that she has to "pass" for a "typical" child. That the goal is to give her tools to help her work with her challenges, and guidance to use her gifts to support this and inspire her self confidence!

One other post pertaining to school support was written by Samantha:

When the school does events that he can't handle, he tells me (he is very aware of what he can deal with and what he can't) and I let his teachers (he is in full day Kindergarten, the AM is with Autism Support and PM is with Regular class) know and they either let him hang out with them or he stays home with me that day. Since he has been home 36 days this year, I have to either get a note from his Psychiatrist to be excused from the event or I have to face the truant officer and be charged a \$300 fine. Public School system is so understanding to my son's ASD and especially his Anxiety disorder.

Society

As for society and the community in which the child with ASD, and consequently that child's family, lives and interacts, there were more generalized issues including: extended family and friends, outside agencies, judgment, and lack of understanding. Each

subtheme presented here was discussed by at least three out of the ten participants in the online focus group.

Extended Family and Friends

The primary topic of concern for the participants in this online focus group, with regards to society and the community, was extended family and friends. These participants spoke about their friends' inability to recognize how different their children are, to make sense of their children's ASD, and their lack of knowledge about how to positively assist their children with ASD. Josie shared these concerns about family and friends with this comment: "I can relate--even some of the most "well-meaning" of some of our friends don't really get what support looks like for an autistic child." Josie continued this thought in a later post that stated:

I really agree--sometimes I get exasperated when family, friends, etc. suggest, meaning to be helpful, when they see an opportunity for me to "correct that behavior" or "push Bird a little more out of her comfort zone there," etc.

Lindsay agreed with these extended family and friends troubles in her comment:

I agree. Sometimes family can be the hardest to really understand. Some of your friend don't truly understand also. When they are sorting what sport or activities their child can excel in and we are at the very basic level with our children.

Elizabeth also made a comment about problems relating to extended family and friends:

"I wish all of our families could understand our kids and make plans that accommodate them."

Outside Agencies

Participants involved in this focus group made a point to discuss the outside agencies they had found to assist them with their children with ASD. These children require a great deal of attention and focus, and because this can be quite draining for parents and caregivers, many of the participants turned to outside caregiving agencies for assistance. Although these agencies can be very helpful, they can also cause problems and create more stress for the families and children with ASD. Samantha shared both a positive and negative point of view about the outside agency she was currently employing to assist with her child with ASD. One of her positive statements regarding outside agencies was seen in this post:

Life in our house isn't easy as you can imagine, especially with my oldest having such high anxiety. However, it is getting a tad easier with the help of our Wrap Around team, whom helps him out at our house once a week to twice a week.

While one of her more distressing comments was read in this post:

The Wrap around team I have are doing their best to help us, but at the end of their shift, they get to go home and I am the one who still has to deal with the pains of my 6 year old dealing with the fact he no longer has Kindergarten and fears he will no longer see his best friend, though I keep telling him that I am talking to his mother trying to come up with a date we can get them together.

Alexis also commented about the outside agency she utilized throughout the online focus group. One of her discouraging statements concerning family based services was seen in the following post:

Our son receives Family Based Services, which are not pleasing to me to say the least! The team that comes to the house admitted they were turning me in to Childline...for bruises on his face, which I did Not give him. He even admitted that he got them on the one side from a doorknob he ran into and the other from a fight with another kid at church! So why did they say I put them there?!?

Judgment

Condescending opinions and judgment was one of the biggest obstacles, when discussing society and the community, mentioned by the participants in this focus group. These parents were very distressed and angry about the judgmental barriers imposed by their peers in the community. Elizabeth shared this frustration relating to judgment from peers in this comment: "It is hard to make friends when your child is unique. You can see judgement on the faces of others and they often don't understand the situation to begin with". Samantha provided a similar statement concerning the opinions of others in this post: "I just love when people who have no clue about what our children are going through have the nerve to open their mouths on our parenting skills as if we are just sitting back doing absolutely nothing."

Lack of Understanding

Although knowledge related to ASD is becoming more commonplace in the community, there are still many people that are unaware of everything this disorder involves and many of the participants in this focus group expressed concerns about this. Most participants made statements regarding their frustration and anger about people not fully understanding everything that they had to do for their children with ASD and all the support and comfort that they needed as parents. Alexis, nevertheless, was able to make

the following statement that showed some tolerance for others lack of understanding:

“Although I admit, it is hard for people that do not have a special child to have any clue as to how best to help.”

However, most participants did not feel likewise, an example being Christina when she wrote this: “No matter how many times people tell me they get it, they don't. Its like a going through a death, don't tell me you know how I feel unless you have truly been through my situation.” Josie also discussed how she was looking for more understanding upon first receiving her child's ASD diagnosis: “It was a difficult time--I found it especially difficult dealing with others' lack of understanding or ability to be supportive in the ways we needed.” Samantha also confirmed these hopes for more understanding and concern from the community in this comment: “It breaks my heart, because Munchkin is so loving, sweet and smart and I just wish we had/got more understanding than we do from people in our community, even in our own family.”

Discussion

This final section conveys the results, or the data collected from the focus group posts and comments, in a more general sense. This section informs readers of each of the four broad codes, or themes, again, which include the individual child with ASD, the nuclear family, school and the school system, and society. Within the context of these four broad themes, the prominence of the subthemes is communicated and discussed. More importantly, the importance of these subthemes is considered in relation to implications for practice in the realm of speech language pathology and the more general area of Communication Sciences and Disorders.

This section also concludes with remarks about the limitations of the current study and considerations for future research in the area of parent perspectives of children with ASD. While there were many great insights gained from this study, there are many considerations that must be made when interpreting the results and still a great deal that can be improved upon. Possible changes, improvements, and areas of study for future research will also be conveyed.

The Individual Child with ASD

Of the topics presented in the results for this broad theme, the subtheme most prominently discussed by participants was their children's lifelong struggles. Brought up by eight out of ten participants, this group felt that the pitfalls and negatives aspects of their children's ASD were extremely important and overwhelming. These participants were quite focused on all the abilities and skills their children currently lacked and were

very concerned that they would never improve. The participants mentioned their tremendous concern that their children with ASD would struggle constantly and have difficulty throughout their life because of these skills they lacked and the barriers their ASD diagnosis imposed on them.

These parents felt that the anxiety their children with ASD experienced was also a central topic in the life of their child currently, as it was mentioned by six out of ten participants in the online focus group. These parents believed that anxiety, and the problems ensuing from it, were very significant in their children's life. Furthermore, the parents discussed how it changed their children into individuals who were constantly fearful and worried, intently focused and often perseverated on the anxiety causing issues, and homebodies. Because of these changes in their children caused by anxiety, the participants noted that their children found it difficult to participate in everyday and "normal" activities. These parents also cited locations and activities as causes for their children's anxiety, such as school.

The future and the worries of the future for their children with ASD were also referenced by six out of ten participants. The participants discussed their concern about the independence and capability of their children in the future, mainly because of the possibility that they might no longer be with their children. These parents wondered throughout the eight weeks of the online focus group about whether their children would ever become independent and free from at least some of the lifelong difficulties associated with ASD.

Friendships and social interactions, while expressed by only five out of ten participants, was an issue central to the online focus group. The participants discussed

their children's lack of ability to socially connect with peers and others on a daily basis. Participants brought up the ability of their children's extreme behaviors, opinions, obsessions, and anxieties to alienate potential friends and peers. Because this online focus group was conducted during the summer months, when these children with ASD did not have school, participants shared their children's fears and anxiety regarding never seeing their school friends again. Differences in social interactions and friendships when homeschooling children with ASD were also disclosed by participants.

Despite the fact that only four out of ten parents discussed emotional struggles, many of the emotional problems revealed by the parents were very extreme. These emotional struggles included tantrums, screaming, self-injurious behaviors, and vomiting. Along with the extreme nature of these emotional struggles, parents also discussed how these emotional problems were debilitating for their children with ASD. Parents referenced that many of these emotional outbursts stemmed from anxiety problems, behavior difficulties, or both. Most importantly, since these emotional struggles caused so much turmoil in their children's life, parents worried about how to help their children handle these outbursts, work through them when they occur, and prevent them in the future.

It was clear throughout this online focus group that the strengths of their children with ASD was not at the forefront of these parents minds currently, especially because only four out of the ten parents mentioned their children's strengths. Many parents found it difficult to see through all the problems at this age, mainly because this age group's diagnosis was still recent. This diagnosis and all the ideas it conjured up, created a significant barrier to identifying strengths. However, some parents found strengths in the

little things their children with ASD did, such as their laughter, honest answers, happiness at times, and their strong family relationships, as well as the big things, such as success in school and the community.

Clinical Implications

Many clinical approaches and decisions, for speech language pathologists and other professionals, can be inferred from the information gained in this first broad theme. Because the children of the parents in this group were still very young, and based on the information the participants provided throughout the eight weeks, they will most likely be interacting with many different professionals. All professionals need to remind these parents that children can change over time and remaining more open and positive will help make that happen. Focusing on the possible lifelong struggles of their children with ASD will certainly not improve the situation for anyone. Similarly, when thinking about the future of the children with ASD, speech language pathologists can support parents in using the future as a means to set goals. This future goal setting will also help speech language pathologists structure their service provision to help the child with ASD meet these goals and one day possibly become independent and self-sufficient.

With regards to anxiety and emotional struggles, speech language pathologists and other professionals can provide the child with ASD with a great deal of structure, through schedules in many forms, so the child has an understanding of what, when, and why activities and events are happening (National Institute of Mental Health, 2011). Professionals can also assist parents in providing this same structure in the home in hopes of reducing anxiety and emotional outbursts. Speech language pathologists and other

professionals should also remember to refer parents to trusted professionals to help remedy these problems that are beyond their scope of practice.

While it is well known that speech language pathologists provide instruction in social skills, they and other professionals can support positive social interactions and friendships in other ways too. Speech language pathologists, especially those in the schools, can facilitate friendships and social interactions throughout the school day. Professionals should also remind parents that friendships and social interactions are difficult for typically developing children and that everyone needs some assistance and guidance when learning how to interact with others.

The Nuclear Family

Parental issues, noted by seven out of ten participants in the online focus group, were evidently the most pressing concern of these parents, probably because of all the different aspects this subtheme encompassed. Lack of social life, parenting styles, and every pleasant and unpleasant emotion these parents experienced were all included under this umbrella of parental issues. Most importantly, this subtheme contained an array of different barriers and areas in need of support in the family lives of these children with ASD. These various barriers and weak areas were all present in the lives of these families of children with ASD, and therefore built on each other, intensified, and created extreme strain and stress.

Within this subtheme, parents discussed the difficulty with making time for themselves and keeping in mind that they matter too; these parents were constantly working so hard for their children and families that they forgot to take time out of their day for themselves and consequently became burnt out and exhausted very quickly. The

participants were also struggling with the sadness and frustration of witnessing their children with ASD constantly inundated with obstacles. The loss of any social and enjoyable activities was also mentioned as a barrier to parents in this subtheme. A significant topic of conversation that these parents brought up, which fell under the subtheme of parental issues, included the comparison of worries and fears to those of parents of typically developing children. Most of the parents of children with ASD noted that their concerns were more closely linked to basic functioning and day-to-day activities, while their peers, parents of typically developing children, were more focused on the far away worries of college and future career goals. In the vein of parental issues, participants also wrote about common family struggles, such as financial difficulties, fear of the future, ignorance and lack of support from family members, and for all intents and purposes parenting alone because their spouses were constantly working to support their families, that became exacerbated in their families due to their children with ASD.

In addition to all the concerns stated by participants above, parental emotions were also incorporated into this subtheme. Because participants often felt they had the least amount of authority in the decision making process regarding their children with ASD, most participants felt a great deal of helplessness; many of the participants believed that other professionals and the school system had more power than they did as parents based on the laws and regulations regarding special education and ASD. Feeling overwhelmed and alone, in the sense that these parents were dealing with their children's ASD constantly, did not have anyone to turn to, were continuously just going through the motions everyday, and a belief that they were living a depressing and monotonous existence, were other emotions stated by the participants.

During the time that this online focus group was conducted, participants articulated that they felt more stressed and anxious than at other times throughout the year. This amplified stress and anxiety stemmed from the immense change in schedule, from the school schedule to the summer schedule, for their children with ASD. On top of having less time for themselves, which these participants usually had during the school day, the participants noted more emotional outbursts from their children with ASD, increased variability in their children's behaviors, and impatience with themselves, the parents, due to more time spent with their children and their challenging behaviors. Throughout the school year and the summer, the participants stressed that they were always relying on themselves to make it through the day because their spouses were working. Overall, parents emphasized that they were constantly on an emotional rollercoaster and always worrying, about their families, finances, future, and children with ASD.

Medications, and the difference in opinion of whether to medicate or not, was discussed by six out of the ten participants in the online focus group. Participants, if they chose to medicate their children with ASD, explained their reasoning behind this choice including extreme signs of ADHD, rage and other serious behaviors, anxiety, daydreaming, and sleep problems. If participants were not medicating their children with ASD, many of these behavior concerns were reasons they were contemplating medicating. Participants went on to list the types of medications they were using with their child, along with specific examples, including anti-psychotics, behavioral medications, and anti-anxiety medications such as Zoloft and Celexa.

However, the critical discourse points in terms of medication included the side effects and the pros and cons of medicating. Many participants were concerned that using medications would corroborate an opinion or outlook of “fixing” their children and not having confidence that their children could improve these troubling behaviors on their own. Other participants took this concern and elaborated on it by considering both sides of the medication debate. From not wanting to hurt or upset their children with ASD by using medication, to wondering and needing to know if medications actually work, in spite of their fears, participants discussed all this and more when talking over the possibility of medications. Participants who had been reluctant to medicate their children with ASD before becoming involved in this online focus group mentioned the benefits and positive outcomes they were currently seeing because they chose to medicate. Parents cited better focus in the classroom and with their families and less emotional and behavioral outbursts as some of the advantages to medication. Other participants mentioned the possibility of using medications in the future, as a way for their children with ASD to calm down, focus, and gain coping skills. These participants hoped that this strategy would allow their children with ASD to gain coping skills while on medication and hopefully still be capable of implementing those skills while no longer on medication.

The subtheme of strained family relationships was brought to light by five out of the ten participants. The participants in this online focus group, as parents of children with ASD, were struggling to care for multiple children. Especially with one child having special needs and requiring additional attention and focus, many participants felt that they as a parent were shortchanging their other children. More generally, their children with

ASD needed so much attention and energy that other family members were shortchanged as well, including extended family, friends, pets, and the parents themselves.

This group of participants also mentioned multiple times that their marriages were greatly impacted by their children's ASD diagnosis and behaviors. Interestingly, all participants who mentioned their marriages discussed how much stronger they became upon receiving their child's diagnosis. This strength originated from parents needing to work together to truly be on the same page for their children with ASD and their families, engaging in more family first activities to connect all members of their families, and problem solving together as families.

Reactions and actions of parents after receiving their children's ASD diagnosis were also discussed by five out of ten participants. Most parents attempted to do everything for their children as soon as possible and operated on the mentality that this was a problem to be fixed. Participants mentioned spending countless hours researching any and all therapies, medications, and doctors that might have helped their children. It was stated that this mentality emanated from the parents' desire to connect with their children who had not been connecting with them. Fear and worry were two common reactions to the diagnosis, specifically fear of how to handle this now and possibly in the future. Other participants cited feelings of relief to finally have an answer regarding their children's unique behaviors as well as unchanged opinions concerning their children and the diagnosis. It seems that for some, the reactions and actions upon receiving the ASD diagnosis were supportive and helpful to understanding their children and for others they were barriers.

Once more, the future was an area of intense thought for the participants of this online focus group. Commented on by five out of ten participants, the future was a topic that created sizeable barriers and roadblocks for these parents of children with ASD. Many participants shared the sentiments of other friends and parents of children with ASD who were not members of this online focus group, and held onto these firmly, that their children's ASD would improve with age. While seeing this light at the end of the tunnel may take more time than expected by these parents, many were hopeful that this comment and positive thought was in fact true.

Furthermore, in preparation for the future, participants organized all relevant documents and paperwork regarding their children, including will and guardianship information, financial statements, and Individualized Education Plan (IEP) documents, in the event that something were to happen in the near future. Although this is in no way a bad idea, it caused fear and anxiety for many participants because they were forced to think about who would look after their children if they could no longer do it, and they found they had no good choices in mind. Many participants, because they were female, noted even their husbands had difficulty handling their children with ASD. Participants also mentioned that extended family members lack much of the understanding that they as parents have gained and do not always fully understand how to take care of and help their children with ASD. The participants' principal apprehension for the future was whether their children's possible caregivers would truly assist their children in developing into an independent and functioning adult or just attempt to fix them and rid them of this diagnosis of ASD.

Although just four out of ten participants wrote about their experiences with therapies, a multitude of them were tested out including homeopathy and flower remedies, speech, occupational therapy, physical therapy, Defeat Autism Now (DAN) protocols and doctors, Applied Behavior Analysis (ABA), The Play Project, gluten free and casein free diets, Verbal Behavior Therapy, Cognitive Behavioral Therapy, and Floortime. After listing out the therapies they had evaluated and experienced with their children with ASD, participants discussed why they chose these therapies. Some reasons included developmental delays, desire for more communication, anxiety, and emotional outbursts. These parents also posted comments and statements sharing with others whether they believed these therapies were effective or not. These sentiments were very mixed; while some believed the therapies were barriers to their children and families' functioning and only created more tribulations, others saw therapies as great supports that were actually improving their children's behaviors and mood. The problem with these statements was that whether they were discussing medication, therapies, or other forms of intervention, participants believed that, in that moment, the intervention they were discussing was the key to success. Participants did not make the correlation that all the medications, therapies, and other interventions may be connecting and helping their children collectively.

Participants also commented on the positive and supportive aspects of knowledge gained as parents of children with ASD. Those involved in this online focus group felt that because they had learned who to contact, what to say, and generally how to avoid all the circuitous phone calls and meetings to acquire services for their children, they were now confident enough in their knowledge and understanding to assist other parents who

were just becoming acquainted with ASD. In addition, participants noted that they knew that this diagnosis was not a handicap or crutch for all parts of life and that their children with ASD could excel in specific areas, subjects, and life events. Through the knowledge they have gained since their children's diagnosis, these parents were able to think about their whole child, rather than just the ASD diagnosis. By and large, these parents had acquired an understanding that this road of ASD, this journey, will never really end and that even though things will always keep changing and require work, everything is worth it.

Related to this knowledge gained as parents, was their comprehension and acceptance of their children's ASD diagnosis. The four participants, out of the ten, who reflected on this all discussed how the willingness to believe this was actually happening did not occur overnight. The acceptance of participants' friends and extended families took even longer and many of them, extended families, friends, and parents included, were still coming to terms with this diagnosis and what it actually meant. Accepting their children's diagnosis was a barrier for many of these parents in that they were constantly working to remind themselves that their children's diagnosis was not going away anytime soon, their children would probably never one day wake up "normal", and this diagnosis was now a part of their children and made their children who they were. Most parents noted that even though acceptance became better as time went on, the process of accepting something this life changing would always be a barrier and never complete.

Advocating for their children with ASD and the choices they made as families was an issue of great importance to the four out of ten participants who discussed it. In describing many different interactions, with teachers and administrators, family and

friends, neighbors, and strangers, participants expressed a unified adamant attitude toward these individuals in regards to their decisions for their children and families. Participants felt that it was necessary to advocate for the fact that they, as parents and caregivers, knew exactly what their children needed more so than anyone else in their life. Advocacy also encompassed working for the validity and recognition that their children with ASD deserve; these parents believed that their children deserved to be seen, heard, and treated as individuals that matter.

Nevertheless, with advocacy comes a sacrifice of one's own life and needs and these parents discussed the intense focus they had on the lives of their children with ASD. Educating themselves and becoming knowledgeable was another aspect of advocating for these children that participants mentioned. Participants noted that their taking action to advocate for their children with ASD was prompted by their desire for them to succeed and become independent. Since their children could not advocate for this on their own right now, the parents stepped in to support and assist them.

The family financial situation and the associated fears and concerns were directly stated by only three out of the ten participants. This number may be lower because participants referred to financial concerns in some posts and comments but did not explicitly mention them in others. Of those participants that did, financial strain and struggle was a significant stressor for families. Participants voiced the stressful nature of job loss and the toll it took on their families; parents became stressed and wondered where money would come from and children with ASD became stressed because it created a change in routine.

Running out of money in the near future or currently having no money to spend, due to everyday expenses and the expenses of an ASD diagnosis, was another significant financial issue. The overwhelming financial strain on these parents related to the lack of insurance and federal coverage for ASD treatments and interventions. Moreover, these extreme financial struggles caused parents to question what they were actually paying for with respect to medications, therapies, interventions, and doctors. Participants argued that not every treatment or therapy worked and some choices were a waste of time and money.

Clinical Implications

Based on the information gathered from this second broad code, many innovative clinical practices can be implemented by speech language pathologists and other professionals to include the needs of these children with ASD and their families. When focusing on therapies, medications, and general ASD knowledge, it is important to help educate parents more about these areas. Referring parents to specialized physicians, who can explain possible side effects and outcomes of medication, is a constructive way to help parents gain knowledge about medications and other interventions. Speech language pathologists and other professionals should also direct parents to recommended and highly regarded sources to gain knowledge about ASD, such as Autism Speaks, Autism Society of America, and other trusted websites, journals, magazines, and professionals. It is important that parents gain knowledge that is professionally supported and accurate.

Taking into consideration advocacy and these families, as a speech language pathologist it is important to advocate for the children with ASD as well as make choices and suggest ideas that are believed to be important for the children and their families. In

this vein, it is imperative to take into account the parents' belief that they have fewer rights than professionals in determining choices for their children with ASD. Because this belief is not accurate, speech language pathologists and other professionals need to assist parents, remind them that their feelings, opinions, and beliefs about their children are most important, and support parent and caregiver decisions.

While a lot of clinical and practical suggestions to assist parents and families have been discussed, there is not much that can be done as a speech language pathologist for many of the other prominent family issues mentioned, including the acceptance of the ASD diagnosis, family relationships, parental issues, finances, worries and fears about the future, and the aftermath of the ASD diagnosis. It is important to remember that, as a speech language pathologist, it is perfectly acceptable to refer parents and caregivers to other colleagues and professionals for whom these issues are within their scope of practice. As a speech language pathologist, it is important to remain within the scope of practice for the field while also involving the parents and easing any parental stressors. Suggesting support groups and other online resources, babysitter contacts, and information about respite care services are all ways to provide assistance to parents with family difficulties within the scope of practice.

School

With the school setting being such a new environment for these parents and children with ASD, it was no great surprise that classroom issues comprised the most significant subtheme. Discussed by six out of ten participants, parents had quite a lot to say about teachers and the classroom setting. For these participants, teachers had a serious absence of knowledge about the children's diagnosis and how to accurately help

them in the classroom. Participants also believed that teachers and other administrative professionals in the school were not considering their children's struggles and difficulties in the classroom when making placement choices. Along with this lack of consideration during placement decisions, parents felt that teachers and school staff were inconsiderate when it came to schedule changes. The participants, as parents of children with ASD, understood very well what an erratic schedule could do to their children. Yet, even though they had told the school and the school said they understood, these parents still felt the scheduling needs of their children were falling on deaf ears. The only real support these parents seemed to have, and not on a regular basis, was that from outside agencies that these parents employed. A few participants noted that their outside agencies were fighting to get services and classroom changes for their families and children with ASD in the school. In spite of that, the general message from these parents was that they were frustrated with teachers and schools for not doing enough for their children with ASD and with the fact that the public school setting was the only school option they could afford.

Equally as exasperating, and generally similar, were the participants' struggles with school support. Five out of ten participants felt that the school was not providing enough support to their families and children with ASD. This lack of support was illustrated in the participants' constant fighting for school-based services and the ability to get their children one service but not all the others that were necessary as well. These parents believed that the school and administration only chose to provide their children with ASD with the bare minimum with regards to accommodations and services. The participants in this online focus group overwhelmingly agreed that they wished the school could realize, hopefully in the near future, that their children with ASD were more than

one of the many students the school was teaching and providing an education to. Clearly, the classrooms and schools in general created extreme barriers and impediments for these parents that would not be going away anytime soon.

Another interconnected issue for these participants was the barrier and subtheme of access to services. Written about by four out of ten participants, participants cited the school not supporting or being willing to provide services, such as a personal one-to-one aide, to their children with ASD. Participants felt that when they made progress in one area, such as classroom placement, schools would not make any more accommodations in other areas, including personal aide services. Because of this constant give and take with regards to service access, parents felt that their children did not have the opportunity to use all possible services available to them in the school setting. These parents argued that because typically developing children were given access to all available school services, children with ASD should be afforded the same rights and have the availability of aides, special education, and any other interventions throughout the day.

Participants also noted the additional state barriers to services, on top of the local school difficulties. The assumption of these parents was that, because the schools and the state were not aware of all that ASD entails and were not privy to every problem behavior that these children exhibit, these administrators and other professionals with more authority did not believe that these children required all the services that were available to help them succeed. All of these access barriers, classroom struggles, and school support issues created a great deal of frustration and resentment in these parents, caregivers, and families involved in this online focus group.

With all of these dilemmas related to the public school environment, it is no shock that the topic of homeschooling was another prominent subtheme. Mentioned by four out of ten participants, this topic had both barriers and supports depending on the point of the view of the participant. The participants who commented on homeschooling employed a number of different options including a cyber charter school and a half homeschool and half public school design. These participants cited too many barriers and struggles with teachers and schools, too much commotion and distraction, too many unknowns, and their children's lack of focus in the school environment as some of the many reasons for removing their children from the traditional school setting.

Participants who were contemplating homeschooling discussed their own personal parental anxieties, along with problematic behaviors of their children, as main reasons to keep their children in the public school setting. Their children's inability to focus at home, the extreme stress and pressure homeschooling places on parents, and a lack of knowledge regarding educating their children were all some of the disadvantages to homeschooling for these parents. Many parents still educating their children through traditional schooling also noted the social and emotional interactions their children with ASD gain from a typical school schedule that would not be available through homeschooling. Nevertheless, these parents considered their children's severe anxiety and behavioral problems at school and the flexibility of creating a school schedule that would fit their children's attention span and ability levels more accurately as encouraging reasons to choosing homeschooling.

Similarly to the strengths of these children with ASD, discussed in the first broad code, participants did not have too many academic successes to share with the online

focus group. The three out of ten participants that did find successes, both big and small, posted remarkable transformations in their children with ASD. It was noted that these parents were very quick to thank the school and therapies within school, as well as any other outside therapies. This small window into how parents felt upon seeing improvements, showed that their opinions and feelings about the school environment changed once their children began to experience success. However, parents did not disregard all of the fighting and pushing they did to ensure that their children did become successful through the school. Interestingly, other participants did not take the time to thank or mention help from any therapies or services in their posts. Participants may have still had resentment toward schools and administration and felt that it was not fair to give credit to the school when the parents put in all time and effort to help make those improvements happen.

Two other, slightly less significant subthemes that should be addressed here are teachers and Individualized Education Plans (IEPs). Both subthemes were discussed by only two participants and were portrayed as barriers to positive functioning of families and children with ASD in the school setting. With regards to teachers, participants felt they were under qualified and did not understand their children with ASD. Because teachers only spent part of the day with these children, even with the understanding that it was most of the day, parents believed it did not give teachers a complete and comprehensive picture of their children. As for IEPs, participants struggled with the school considering their child to be overly smart and therefore not in need of an IEP. While these parents accepted the fact that their children with ASD were able to pass academic tests, they were very aware of the social, emotional, and functional deficits

their children had that required an IEP and goals. However, because their children with ASD were able to control themselves during the school day, and then meltdown and become a completely different child at home, these children and families received no IEP services from the school.

Clinical Implications

Especially for those speech language pathologists and other professionals who work in the schools, the insights gained from this third broad theme will be particularly valuable when implementing novel clinical practices in the school setting. As a speech language pathologist and other school professional, it is important to help create a comfortable and secure school environment because for many of these parents this is their first parenting experience in the schools. Furthermore, it will be important to let parents know that they are always welcome to come ask questions and share concerns; it is vital to establish a contact person these parents can turn to for assistance.

Educating and providing information about children with ASD to teachers, administrators, and other professionals within the school is another fundamental role a speech language pathologist can fulfill. They can offer fellow professionals trusted websites, books, other paperwork, and even offer personal insights regarding specific students with ASD. However, while offering to be a resource and to provide help to others, they must be sure to do so in a considerate, approachable, and friendly manner.

In this vein, it will be important to provide support for these children and families and act as a liaison between them and the school. The input, support, and advocacy of the school speech language pathologist may help to provide more school support for children with ASD. When advocating for these families and children with ASD, speech language

pathologists should be sure to provide parents, as well as teachers and administrators, with evidence, including research and other evidence based practices, and reasoning to back up suggestions and choices. It is imperative to explain why specific interventions or accommodations are necessary and why they have worked for children with ASD, which is provided clearly in research and other evidence based documents. Data collection of problem behaviors over time as well as detailed background knowledge of the family and child with ASD will also provide more concrete evidence to teachers and administrators within the school, especially those who may not be aware of all the same problem behaviors and emotional outbursts that a speech language pathologist sees on a daily basis outside the classroom.

Society

Extended family and friends, discussed by six out of the ten participants and making it the most prominent subtheme, turned out to be one of the biggest barriers for the participants of this online focus group. While friends and extended family should be a support for these families and individuals, they were actually a barrier and an area in need of support. Consequently, the participants expressed intense frustration and anger towards this group of individuals, mainly because they felt that extended family, friends, and community members had no idea what it actually took to be parents of children with ASD and that it was not at all comparable to raising typically developing children. This frustration also originated from other parents' complaints regarding what was viewed as overly simple problems with their typical children along with these parents' attempts to sympathize with little understanding of what the lives of parents of children with ASD were like. The participants stated that they had learned to just let go of the struggles with

these extended family members and friends and instead chose to be matter of fact and shared with these individuals that their children have a disability known as ASD.

In conjunction with the aforementioned frustration and anger, participants also felt alienated and judged by fellow parents and peers because of their children's ASD. Moreover, four out of the ten participants stated that these individuals had wrongly judged them because they really did not understand that parenting children with ASD was entirely dissimilar from parenting typical children. The participants believed that their peers perceived them as lazy and as bad parents, based on the small amount of parenting they witnessed. Participants also cited specific incidents where peers and parents of typical children had suggested a stricter parenting style with their children, signifying that this would solve all the problems of ASD. Sentiments regarding these incidents included feeling hurt, undermined, and altogether angry with those condescending parents who were very unaware of the situation at hand.

Along with the perception that their parental peers and other community members were constantly judging them based on their parenting skills, the participants also referred to these others' lack of understanding as a barrier to better family functioning in society. The three out of ten participants who brought up this lack of understanding also mentioned their lost trust in these peers, community members, and extended family and friends. The participants expressed that if these individuals were not going to attempt to understand their families and children with ASD and constantly judge them, then they did not deserve to be trusted.

Participants also feared that this lack of understanding of ASD in the community and society would lead to problems in the future including altercations with other

individuals, protective custody, and even jail time, especially when these parents were no longer able to care for their children. In addition to the lack of community and society understanding, participants even noted lack of understanding from some outside agencies, such as children, youth, and family services, with regards to the parenting styles and behavioral difficulties of children with ASD.

The final subtheme within society, outside agencies, had both supports and barriers, again based on the each individual participant's point of view. Of the three participants, out of ten, who commented on outside agencies they employed, some supports included providing assistance to and facilitating activities for their families, an apparent understanding of the children, families, and all their needs, and their ability to provide respite just by being present and recognizing what the parents were dealing with on a daily basis. Some barriers included that these individuals were able to experience breaks from the children with ASD, unlike the parents, they felt it necessary to report false abuse and neglect to authorities, a lack of cooperation and willingness to work with the families, and a strong disconnect between individuals and families. From the evidence provided by participants, experiences with outside agencies truly depended on the agency and the individuals employed by that agency.

Clinical Implications

From broad code four, many considerations can be made with regards to the knowledge imparted on extended family members, friends, peers, and general community members of these families and children with ASD by speech language pathologists and other professionals. The most important suggestion that can be made from this broad code is the need for education of extended family members, friends, other parents,

community members and even outside agency members. Providing pamphlets and other forms of information, whatever that may be, to these individuals will truly help to bridge the gap that these parents of children with ASD feel. Speech language pathologists can help parents and caregivers research outside agencies, by speaking with employees and other parents that have employed them in the past or currently; experiences similar to those discussed by participants in this study are perfect examples of why parents do not choose to ask for outside help. All in all, professionals can attempt to educate all involved in the life of these children with ASD, in hopes that the knowledge will help improve the outlook of many of the prominent issues when dealing with society.

Limitations of the Current Study

Even though this online focus group was completed successfully and many insights were gained, there are still many limitations present in the results and overall study. This online focus group began with ten participants, yet only eight participants were active by the final week. This means that the same small group of people made many of the statements referenced in the results and discussion. If all parents had remained active, different topics of discussion may have become more prominent than others, changing the results. As stated, this online focus group only involved parents of children in Kindergarten to second grade. In order to fully understand the results and get a complete and accurate picture of parenting issues throughout the lifespan, all groups' responses would need to be compared and analyzed. Finally, this being an online focus group, the participants were not as varied as hoped. With regards to the age, gender, and specific diagnosis on the ASD spectrum, most of the children were extremely similar.

Directions for Future Research

Future research should be conducted based on the areas discussed most by these parents. Research should investigate extended family and friends to determine how these individuals perceive a child with ASD, what they actually know about ASD, and whether or not they do actually judge parents of children with ASD based on the parenting decisions and actions they witness. Investigations should also be completed that explore classroom issues and school support to gain knowledge regarding how well schools incorporate students with ASD in classrooms and the school environment, whether or not schools are actually open to decisions and suggestions made by parents, and teachers and their knowledge and experience teaching children with ASD. Future studies might also focus on examining the lifelong struggles of children with ASD and how many of the problem behaviors and academic deficits identified when they are first diagnosed stay with them all the way to adulthood, what kind of strategies were implemented to improve the outcomes of children with ASD, and what might the variables be to help children improve these behaviors and deficits before reaching adulthood.

Appendix A

Recruitment Materials: Messages and Flyers
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Hello!

My name is Meredith Kras and I am an undergraduate Communication Sciences and Disorders major at Penn State. I am a member of a research group with Kathryn Drager and Erinn Finke who are professors in the Department of Communication Sciences and Disorders at Penn State.

We hope that you can help us with some exciting research. We would like to learn about the experience of being a parent of a child with autism spectrum disorder (ASD). We recognize that parents have many different experiences, and we are interested in learning about how having a child on the autism spectrum affects how they parent their child.

We are inviting parents of children with an ASD to join an online discussion group. We want to learn about the experiences of those parents and how they compare to parents in similar situations. We would like to learn about the issues that parents feel are unique and specific to having a child with an ASD. We plan to share what we learn with each participant and other parents of children with an ASD.

If you could help us by sharing this research information with the members of your local Autism Society chapter we would really appreciate it; sharing this information will help us get our research up and running. Please email us back if you are willing to

share this with your chapter and include an estimate of how many people will be receiving this information.

If you have any questions, please feel free to contact either Erinn Finke at enh109@psu.edu or at (814) 867-4340, or Kathryn Drager at kdd5@psu.edu or at (814) 863-6247 with your questions.

Here is some additional information about our research:

What do we want to do?

We are inviting parents of children with an ASD to join an online discussion group. We want to learn about the experiences of those parents and how they compare to parents in similar situations. We would like to learn about the issues that parents feel are unique and specific to having a child with an ASD. We plan to share what we learn with each participant and other parents of children with an ASD.

Who will participate in the discussions?

People who want to participate must:

- Be a parent of a child with an ASD
- Have access to the Internet at least weekly
- Be able to commit approximately 1 hour to the discussion group at your convenience for 8 weeks

How will participants be involved in the discussions?

Participants in this project will be asked to take part in a group “discussion”. This discussion will take place at a website on the Internet, where individuals will be able to type and post comments, and read the comments of the other participants.

How can parents get more information about the project? We are asking for your assistance in identifying potential participants for this project. In order to provide parents

with an opportunity to make a confidential decision about this project, nominations can be handled in one of two ways: a) please contact the parent, describe the project, and ask the parent for permission for you to send their name to us (so that we may contact them with additional information and discuss informed consent procedures), or b) please contact the parent, describe the project, and ask the parent to contact us directly.

Erinn Finke, Kathryn Drager

308 Ford Building, Penn State University, University Park, PA, USA 16802.

E-Mail: enh109@psu.edu

Phone: (814) 867-4340

E-mail: kdd5@psu.edu

Phone:(814)-863-6249

*This Project has been reviewed and approved by the Institutional Review Board for the Protection of Human Subjects at The Pennsylvania State University. All procedures will be explained fully, and informed consent will be received from all participants before any research activities begin.



Do you or does someone you know have a child with an Autism Spectrum Disorder?

Would you like to interact with parents in similar situations?

Do you want to participate in new, exciting research about your experiences as a parent?

If you answered yes to any of these questions, feel free to contact us!

Erinn Finke and Kathryn Drager

308 Ford Building, Penn State University

University Park, PA 16802

Email: enh109@psu.edu or kdd5@psu.edu

Phone: (814)867-4340 or (814)863-6249

Appendix B

Questions for the Online Focus Group	
Week	Question
Introduction	Introductory Posts
	1. Describe what's going on right now in your life as it relates to parenting a child with an ASD.
	2. Of the issues you described, which would you consider to be the issues that weigh on you the most? What are the things that you worry about the most right now?
	3. What successes have you experienced recently, as a parent of a child with ASD?
	4. How do you feel having a child with ASD is making your experience as a parent different at this point in your life than it would otherwise have been?
	5. What aspects of being a parent of a child with ASD seem like they will never go away (positive and negative)?
	6. What are your hopes and dreams for your child?
Final	Final thoughts:
	If there was one (or a few) thing(s) you wish everyone could “magically” understand about your life right now, what would they be?

Appendix C

Moderator Guide

- Locate numbered emails and contact scripts (1-5) on Angel in the “Participant Contact Folder.”
DATE: _____
- Send the e-mail, “1 Email before sending consent form” to the participants individually. Attach the informed consent form to the e-mail.
DATE: _____
- Put two copies of the informed consent form as well as the letter, “2 consent form cover letter” in the mail with a postage paid envelope for the participants.
DATE: _____
- After you have received all the signed informed consent forms (or enough to run a group, > 6) from the participants, it is time to invite the participants to join the wiki. First send each participant email 3, “3 email before sending Wiki invite.” Be sure to fill in the correct date in bold at the bottom of the email for the deadline (one week from the date the email is sent). Immediately following this, complete the next step.
- On the wiki site, click on “Manage wiki -> Invite people.” Type the participant’s e-mail address into the “Send to” message box. Delete the text in the “Your Message” message box, and replace it with the text from the script, “4 Wiki Invitation Message Script.” Click send.
DATE: _____
- If a participant has not returned the informed consent form two weeks following mailing them, follow up with the participant.
DATE: _____
- Send each participant the e-mail, “5 Introduction Instructions E-mail groups 1-3” or “5 Introduction Instructions E-mail groups 4-6”, depending on which group they are in. Be sure to fill in the correct date in bold (one week from the date the e-mail is sent). Attach “wiki instructions” to this e-mail.
DATE: _____

Week One

Day 1: Post the first question:

Describe what’s going on right now in your life as it relates to parenting a child with ASD.

Check in on the discussion at least once.

Day 2: Check in on the discussion at least once. Redirect discussion to relevant topics as needed.

Day 3: If there are participants who have not responded to the discussion topic, post a broad prompt to the group: “Please make sure you respond to the topic and to other participants’ posts.”

Day 4: Check in on the discussion at least once. Post a brief summary of the ongoing discussion and request feedback. For example, “Some of the common themes you seem to be discussing are _____. Is that correct? What do you think about _____?”

Day 5: Provide a focused prompt to participants who haven’t responded through private e-mail: “Please make sure you respond to the current discussion topic.”

Day 6: Check in on the discussion at least once. Redirect discussion to relevant topics as needed.

Day 7: Check in on the discussion at least once. Request clarification of responses as needed. Thank all participants for their contributions thus far.

Week Two

Day 1: Post the second question:

What successes have you experienced, as a parent of a child with ASD, recently?

Check in on the discussion at least once.

Day 2: Check in on the discussion at least once. Redirect discussion to relevant topics as needed.

Day 3: If there are participants who have not responded to the discussion topic, post a broad prompt to the group: “Please make sure you respond to the topic and other participants’ posts.”

Day 4: Check in on the discussion at least once. Post a brief summary of the ongoing discussion and request feedback. For example, “Some of the common themes you seem to be discussing are _____. Is that correct? What do you think about _____?”

Day 5: Provide a focused prompt to participants who haven’t responded through private e-mail: “We appreciate your contributions to the discussion thus far. Please make sure you respond to the current discussion topic.”

Day 6: Check in on the discussion at least once. Redirect discussion to relevant topics as needed.

Day 7: Check in on the discussion at least once. Request clarification of responses as needed. Thank all participants for their contributions thus far.

Week Three

Day 1: Post the third question:

What are the issues that weigh on you the most right now, that you worry about the most?

Check in on the discussion at least once.

Day 2: Check in on the discussion at least once. Redirect discussion to relevant topics as needed.

Day 3: If there are participants who have not responded to the discussion topic, post a broad prompt to the group: “Please make sure you respond to the topic and other participants’ posts.”

Day 4: Check in on the discussion at least once. Post a brief summary of the ongoing discussion and request feedback. For example, “Some of the common themes you seem to be discussing are _____. Is that correct? What do you think about _____?”

Day 5: Provide a focused prompt to participants who haven’t responded through private e-mail: “We appreciate your contributions to the discussion thus far. Please make sure you respond to the current discussion topic.”

Day 6: Check in on the discussion at least once. Redirect discussion to relevant topics as needed.

Day 7: Check in on the discussion at least once. Request clarification of responses as needed. Thank all participants for their contributions thus far.

Week Four

Day 1: Post the fourth question:

How do you feel having a child with ASD is making your experience as a parent different at this point in your life?

Check in on the discussion at least once.

Day 2: If there are participants who have not responded to the discussion topic, post a broad prompt to the group: “Please make sure you respond to the topic and other participants’ posts.” Redirect discussion to relevant topics as needed.

Day 3: Provide a focused prompt to participants who haven’t responded through private e-mail: “We appreciate your contributions to the discussion thus far. Please make sure you respond to the current discussion topic.” Post a brief summary of the ongoing discussion and request feedback. For example, “Some of the common themes you seem to be discussing are _____. Is that correct? What do you think about _____?”

Day 4: Check in on the discussion at least once. Request clarification of responses as needed. Thank all participants for their contributions thus far.

Day 5: Post the fifth question:

What aspects of being a parent of a child with ASD seem like they will never go away, both positive and negative aspects?

Check in on the discussion at least once.

Day 6: If there are participants who have not responded to the discussion topic, post a broad prompt to the group: “Please make sure you respond to the topic and other participants’ posts.” Redirect discussion to relevant topics as needed.

Day 7: Provide a focused prompt to participants who haven’t responded through private e-mail: “We appreciate your contributions to the discussion thus far. Please make sure you respond to the current discussion topic.” Post a brief summary of the ongoing discussion and request feedback. For example, “Some of the common themes you seem to be discussing are _____. Is that correct? What do you think about _____?”

Week Five

Day 1: Check in on the discussion at least once. Request clarification of responses as needed. Thank all participants for their contributions thus far.

Day 2: Post the sixth question:

What are the hopes and dreams for your child at this point in time?

Check in on the discussion at least once.

Day 3: If there are participants who have not responded to the discussion topic, post a broad prompt to the group: “Please make sure you respond to the topic and other participants’ posts.” Redirect discussion to relevant topics as needed.

Day 4: Provide a focused prompt to participants who haven’t responded through private e-mail: “We appreciate your contributions to the discussion thus far. Please make sure you respond to the current discussion topic.” Post a brief summary of the ongoing discussion and request feedback. For example, “Some of the common themes you seem to be discussing are _____. Is that correct? What do you think about _____?”

Day 5: Check in on the discussion at least once. Request clarification of responses as needed. Thank all participants for their contributions.

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ACADEMIC VITA

Meredith Kras
606 Middletown Avenue
New Haven, CT 06513
Phone: 203-641-0768
Email: meredithkras@gmail.com

Education

B.S., Communication Sciences and Disorders, 2013, Pennsylvania State University, State College, Pennsylvania

Honors and Awards

- Pennsylvania State University, Schreyer Honors College Acceptance, Spring 2011
- Pennsylvania State University, Dean's List, Fall 2009 to present

Association Memberships/Activities

- National NSSLHA (National Student Speech Language Hearing Association) Member
 - Fall 2011 to present
 - Member Number: 14040857
- National Student Speech Language Hearing Association Member, Pennsylvania State University Chapter
 - Fall 2009 to present
 - NSSLHA THON Chair: Fall 2011-Spring 2012
 - NSSLHA President: Fall 2012-Spring 2013
- Health and Human Development Honor Society, Pennsylvania State University
 - Fall 2010 to present

Research Interests

My general research interests in the area of Communication Sciences and Disorders include Autism Spectrum Disorders, Alternative and Augmentative Communication, and rare genetic disorders.

Research Experience

Undergraduate Honors Thesis: Perspectives of Parents of Early Elementary Children of Parenting a Child with Autism Spectrum Disorders

Spring 2011 to present

Thesis Supervisor: Dr. Kathryn Drager [email: kdd5@psu.edu] [phone: 814/863-6247]

- Purpose: To contribute to the understanding of parents' outlook and opinions about raising a child on the Autism Spectrum
- Reviewed relevant research literature
- Recruited parents and analyzed online focus group data through coding and creating themes and subthemes

Professional Presentations

2012 American Speech and Hearing Association (ASHA) Poster Presentation

Presenter/Author of Parenting a Child With Autism: Parents' Perspectives at Different Stages

Atlanta, Georgia November 14-17, 2012 Session Number: 7408 Poster Board 233

Notable Coursework

Introduction to Augmentative and Alternative Communication (AAC): Honors Option
Spring 2013

- Involved exposure to AAC programs, including EZ Keys, Minspeak and Speaking Dynamically Pro, or Boardmaker, and an AAC device, the L*E*O*
- Formal APA style report written discussing the strengths and weaknesses of each program and the device

Evidence-Based Instruction for Elementary Students with Disabilities in Reading, Math, and Writing (SPLD 403A) Honors Option

Spring 2012

- Involved observations of elementary classrooms that contained students with disabilities reading, math, and writing that may or may not be related to a developmental disability,
- Created case studies, lesson plans, and activities for future students.
- Formal APA style report written to discuss all observations and created materials.

Intervention for Students with Severe Disabilities (SPLD 411) Honors Option

Fall 2012

- Involved observations of severely disabled individuals at a school with programs specifically for more severely disabled individuals.
- Formal APA style report written to discuss observations and the connection of observations to topics and techniques discussed in class.

The Study of Language (LING 001)

Spring 2012

- Learned about the bases of language and gained a better understanding of how languages develop.

Introduction to Teaching English to English Language Learners (CI 280)

Spring 2013

- Gaining knowledge related to cultural competency as a future professional.