THE PENNSYLVANIA STATE UNIVERSITY
SCHREYER HONORS COLLEGE

DEPARTMENT OF COMMUNICATION SCIENCES AND DISORDERS

PERSPECTIVES OF PARENTS OF PRESCHOOL CHILDREN ON THE EXPERIENCE OF
PARENTING A CHILD WITH ASD

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Spring 2012

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

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Acknowledgements

I would like to acknowledge and extend my gratitude to the following people who have made the completion of this thesis possible: Erinn Finke, for her assistance and guidance. Carol Miller, for her assistance and role as an advisor. Kathryn D.R. Drager, for her assistance and her role as a thesis advisor. Most especially to my family and friends, without which none of this would have been possible.

Abstract

Many studies have been done on autism spectrum disorders (ASD) and the effects that they have not only on the children affected by them, but also the families of those children. While these studies offer a unique insight into the stressors that parents of children with ASD face, they fail to encompass the entire experience, both the positive and negative aspects, of raising that child. This study utilized a qualitative research design to explore the benefits and challenges of raising a preschool-aged child with an ASD. Eight parents from around the United States participated in an online focus group. Each week, participants responded to a question about a specific part of their experience as a parent. In addition to responding to the question, the parents were asked to respond to at least one comment made by another parent. Parents identified the following themes in their responses: concerns for the child, concerns for self, school, extended family, siblings, the community, money, and the future.

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CHAPTER 1

Literature Review

Autism

Autism spectrum disorders (ASD) are a group of developmental disabilities that are characterized by significant social, communication and behavioral challenges (Centers for Disease Control and Prevention, 2011). The term "spectrum" refers to the wide range of skills, symptoms and the level of impairment that the individual with ASD can have. The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-Text Revision* (DSM-IV-TR) lists guidelines in order to diagnose ASD and it currently lists five disorders, typically referred to as pervasive developmental disorders (PDD). These disorders include: autistic disorder, Asperger's disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), Rett's disorder and childhood disintegrative disorder (CDD) (National Institute of Mental Health, 2011).

According to the Center for Disease Control, more people than ever are being diagnosed with ASD, due to more people having ASD, better efforts to diagnose and a broader definition of ASD. Today, it is estimated that 1 in every 88 children in the United States has an ASD (Center for Disease Control and Prevention, 2011). Autism occurs in all social, racial and ethnic groups, impacting millions of people around the world (Autism Speaks, 2011). While Autism affects everyone, 1 in every 70 males has ASD, a risk four to five times higher than females (National Institute of Mental Health, 2011). Although boys are at a higher risk of having ASD than girls, girls are thought to manifest a more severe form of the disorder (Autism Speaks, 2011). At least 1 to 1.5 million Americans are living with an ASD and this number is growing by 10-17% each year, making ASD the fastest-growing developmental disability (Autism Society of America, 2012). Twenty-four thousand of the four million babies born each year will eventually be

diagnosed with ASD, meaning more children will be diagnosed with ASD this year than with AIDS, diabetes and cancer combined (Autism Speaks, 2011).

Signs and Symptoms

Due to the fact that autism is a spectrum disorder, there are several signs and symptoms that vary depending on the individual. These symptoms can also be seen in children without autism or in children with other disabilities, so each symptom on its own is not typically considered to be a sign of autism (Greenspan, 2006). These signs and symptoms can be classified into three categories: socialization, communication and restricted, stereotyped and repetitive patterns of behavior (Levy, Mandell, & Schultz, 2009). The socialization symptoms include: delayed peer interactions, little initiation of interactions, little or no social reciprocity, lack of social judgment and no interest in sharing enjoyment or interests. The communication symptoms include: delay in verbal language, expressive language impairment, delayed imaginative as well as social imitative play, and stereotyped, repetitive or idiosyncratic language. Language and communication deficits often persist into adulthood, causing some with ASD to remain nonverbal (Tuchman, 2003). Restricted, stereotyped and repetitive patterns of behavior include: restricted interests in topics, adherence to routines, stereotyped, repetitive motor mannerisms and fascination with parts of items and unusual visual exploration (Levy, Mandell, & Schultz, 2009).

The most important thing that a parent or caregiver can do for their child is be aware of developmental milestones and also typical behaviors of autism (Autism Speaks, 2011). Several articles targeted toward parents have listed more specific symptoms that they can observe if they believe their child may have an ASD. The "red flags" listed include: not making eye contact, not having an interest in peers, preferring to play alone, rocking back and forth, repetitive hand flapping, delayed language development, intense temper tantrums or inability to deal with

changes in routine (Eden, 2010). Many parents may minimize the symptoms of autism, thinking that their children may get to the developmental level of their peers. However, research has shown that an earlier diagnosis may result in a better prognosis for the child (National Institute of Mental Health, 2011).

Diagnosis

Diagnosing autism is difficult because there is no medical test. Therefore, the doctors must examine the child's development and behaviors. ASDs can be detected before the child is 18 months old and typically occur before the child is two years old. However, some individuals are not diagnosed until much later in life (Center for Disease Control and Prevention, 2011).

ASD diagnosis is a two-stage process consisting of general development screening during well-child checkups and, if the child is referred, a thorough evaluation by a team of doctors and other health professionals (National Institute of Mental Health, 2011). In some areas, there may also be universal autism-specific screening at high-risk ages, such as 18 months, 24 months and 30 months (Levy, Mandell, & Schultz, 2009). Because there is no specific test to diagnose autism, several different approaches are used in order to reach a diagnosis. These approaches can involve the child's parents, a pediatrician, a psychologist, speech language pathologist and occupational therapist (Eden, 2010).

From birth to around 36 months of age, children are screened for developmental milestones during routine doctor's visits. These developmental tests are short and make sure that the child is learning basic skills when they should. The doctor may also ask the parents questions about the child at home or even talk to and play with the child to see how the child talks and behaves (Center for Disease Control and Prevention, 2011). If these screenings, or the child's parents, bring up a concern, the doctor can refer the child to a specialist who can do further

testing (Autism Speaks, 2011). There are several different tests available, and sometimes one is selected based on the age of the child. The most common tests used for toddlers and preschoolers include: Checklist of Autism in Toddlers (CHAT), Modified Checklist for Autism in Toddlers (M-CHAT), Screening Tool for Autism in Two-Year-Olds (STAT), Social Communication Questionnaire (SCQ), and the Communication and Symbolic Behavior Scales (CSBS). The screening tools used for older children include: Autism Spectrum Screening Questionnaire (ASSQ), Australian Scale for Asperger's Syndrome (ASAS), and Childhood Asperger Syndrome Test (CAST) (National Institute of Mental Health, 2011).

Often times, autism co-occurs with another disorder such as: deficit-hyperactivity disorder, depression, anxiety, seizures, sleep disruption, sensory differences, gastro esophageal reflux, or intellectual delays (Levy, Mandell, & Schultz, 2009). Because autism typically co-occurs with other disorders, additional tests may be done (Autism Society of America, 2012). Examples include: brain imaging, gene tests, problem-solving tests, or language testing. It is also recommended that children with any delayed development receive a hearing test and are screened for lead poisoning (National Institute of Mental Health, 2011).

Causes

There is no known cause for autism, but research is being done in hopes of finding one (Eden, 2010). Scientists currently believe that both genes and environment play a role in the development of autism (National Institute of Mental Health, 2011). There is strong evidence supporting a neurological basis of autism, and evidence from twin and family studies have shown that the rate of autism in siblings of autistic individuals is about 2.2% and the sibling recurrence rate for all PDDs is 5-6% (Parr, 2008). Parents and siblings can show mild manifestations of autism, including delayed language, social development, few close friendships

and a perfectionist personality, further supporting a genetic cause of autism (Levy, Mandell, & Schultz, 2009). However, despite a great deal of research, the causes of autism are still unclear and a mystery (Eden, 2010).

Early Intervention

For children with developmental disabilities, early intervention programs have been found to be quite effective in reducing symptoms and behaviors (Baker & Feinfield, 2008). It is estimated that early diagnosis and treatment can reduce the cost of lifelong care by 2/3 (Autism Society of America, 2012). Early intervention helps children from birth to three years of age learn important skills such as walking, talking and interacting with others (Center for Disease Control and Prevention, 2011). It serves to enhance development, minimize potential of delay and need for special education services, and enhance the capacity of the family as caregivers (Baker & Feinfield, 2008). To further involve and educate the family, some early intervention programs involve the therapist coming directly to the child's house to train parents and allow parents to lead therapy sessions while supervised by a professional (Autism Speaks, 2011).

A specific type of therapy used for children in early intervention programs is Early Intensive Behavioral Intervention (EIBI). This is a type of Applied Behavior Analysis (ABA) targeted toward children younger than five, the majority of them being younger than three. ABA is widely used among professionals and in schools and encourages positive behaviors while discouraging negative behaviors in order to improve various skills (Center for Disease Control and Prevention, 2011).

Although therapy differs depending on the child, there are common traits among successful early intervention programs. These traits include: 25 hours of therapy per week; sessions led by highly trained therapists or teachers; having specific and defined learning

objectives; regular evaluation of the child's progress; focus on core areas affected by autism; opportunities for the child to interact with typically developing peers; respect for the needs of the child and family; and the involvement of a multidisciplinary team (Autism Speaks, 2011).

Parenting

Autism is a disorder that affects not only the child's whole life, but the family's as well, especially because the disorder is lifelong (Bevan-Brown, 2010). Parents of children with autism experience a higher amount of stress and are more susceptible to negative outcomes when compared to parents of typically developing children and parents of children with other disabilities (Bowers, Burbine, Dunn, & Tantleff, 2001). Parents also report feeling less competent, increased marital problems, and less family adaptability (Bowers, Burbine, Dunn, & Tantleff, 2001). These stressors are likely due to the unique challenges of raising a child with autism such as the ambiguity of diagnosis, severity, duration of the disorder, and the child's failure to adhere to social norms (Altiere & von Kluge, 2008).

Financial woes are also a cause of stress to families. It has been estimated that raising a child with a disability costs three times the cost of raising a nondisabled child. These costs include difficulties maintaining employment and difficulty paying for child care along with intangible costs such as lost leisure time and less time available for other children in the family (Canham & Cureton, 2005).

Support in any form has been found to be beneficial to families affected by these stressors. Mothers who found social support to be more readily available reported fewer stress-related problems and less anxiety (Bowers, Burbine, Dunn, & Tantleff, 2001). However, not every family responds to social support. One study found that families may withdraw from, or not have the time for, social activities. Families with a child with an ASD were less likely to

engage in social activities or recreational activities (Altiere & von Kluge, 2008). Such families may have used other ways to cope with their stressors, some of the more prevalent ones being: placing more importance on the role of a parent, rather than on a career; viewing the opinions of others about the child's behavior as less important; and a higher tolerance for uncertainty of their child's future (Canham & Cureton, 2005).

Bronfenbrenner's Ecological Theory

In *The Ecology of Human Development: Experiments by Nature and Design,* Urie Bronfenbrenner summarized the interrelationship of different processes as they guide life-span development. In this theory, an individual is placed in the middle of a large system or "ecosystem" comprised of smaller systems that include the: microsystem (the child's family, peers, classroom), exosystem (the child's community, school, health agencies) and macrosystem (political systems, economics, culture) (Darling, 2007). This approach emphasizes systems within systems and the relationship between systems to show how the systems affect the individual. For example, in order to understand the individual child with an ASD, it is important to understand settings such as the child's classroom, culture and family, to name a few. The ecological systems theory also promotes the effectiveness of changing an outlying system in order to achieve a balance between the individual and his/her surroundings (Bronfenbrenner, 1975).

Focus Groups

In a study done by Bevan-Brown in 2010, a questionnaire was given to parents of children with ASD to accumulate their thoughts and opinions about raising a child with an ASD. The questionnaire sought to figure out what parents believed should be included in a DVD about ASD. One-hundred thirty-seven parents responded to 10 questions ranging from questions about

family awareness to the community in general. The most common pieces of knowledge that parents wanted to be included in the DVD included: ASD is not an illness that can be cured; children with ASD think and act differently; people need to accept differences; children with ASD and their families need to be included; children with ASD need to be treated with dignity and respect (Bevan-Brown, 2010).

Thus far, few studies have examined the direct input of parents raising a preschool-aged child with an ASD and their perspectives on both the positive and negative aspects of this unique parenting information. The current investigation sought to answer the following research question: what are the experiences of parents raising a preschool-aged child with ASD?

CHAPTER 2

Method

Research Design

The methodology used by the study was a qualitative online focus group. Online focus

groups were chosen because they allow participants to interact in a different way than they could

face to face. They are a form of communication that rely on the interaction between participants

as a form of data. Online focus groups were chosen for several reasons, including but not limited

to the following. Due to the fact that it was online, it allowed the participants to communicate on

their own personal schedule, only requiring that they log in once a week. Additionally, in

previous studies, parents of children with developmental disabilities have found it helpful to use

the internet as a form of support. According to Reid and Reid (2005), focus groups are efficient

and effective because they promote "flow of input and interaction related to the topics that the

group is centered around" (p. 135). Studies conducted through the internet also do not have the

time constraints of in person studies. Therefore, the participants are able to post thoughts and

opinions according to their own schedules, which is typically hectic for a parent of a child with a

developmental disability.

Along with lacking time constraints, online studies promote equality of participation,

disinhibited communication, group interaction, and self-disclosure (Reid & Reid, 2005).Also, the

identity of the participant can be anonymous, eliciting more honest responses than in a face-to-

face interaction (Reid & Reid, 2005). Reid and Reid also state that online focus groups allow

participants to respond without having to wait for someone else to stop talking, which prompts

more responses in a lesser amount of time. Lastly, it allowed for participation from parents from

across the United States. Therefore, using the internet was the most appropriate choice for this particular study.

Participants

The participants met three criteria: (a) being a parent of a child with an autism spectrum disorder (ASD), (b) living in the United States, (c) having access to the internet. The recruitment messages and materials were sent to several different places, including online groups for parents of children with an ASD, speech-language pathologists throughout the United States, and members of ASHA (American Speech-Language Hearing Association). Any interested participants were sent consent forms and demographic questionnaires and were added to the study once they were returned.

Depending on the age of their child, the participants were added to one of six groups. The groups were determined based on the age of the child. Group one was comprised of the parents of preschool aged children, group two was comprised of the parents of early elementary school children in Kindergarten through 2nd grade, group three was comprised of the parents of later elementary school children in grades 3-5, group four was comprised of the parents of middle school children, group five was comprised of the parents of high school students, and group six was comprised of the parents of adults with ASD. The separation by age allowed parents to communicate with parents of children of a similar age in each focus group.

The current investigation will focus exclusively on group one (parents of preschool aged children). In this particular group, there were eight participants. For more information on participants, refer to Table 1. (Note: pseudonyms are used in place of real names.)

Table 1

Participant Demographics

Participants	Melanie	Theresa	Amanda	Josie	Betsy	Jen	Lindsay	Elizabeth
Child's Age	2	3	5	4	5	5	5	3
Child's Gender	M	M	M	M	M	M	F	F
State	PA	OK	AL	OH	MA	CA	PA	WA

Materials

To conduct this study, an online WikiSpace was used. A WikiSpace is an online site with its own address. WikiSpaces allow for text-based discussions on any topic. The participants were able to read focus group questions and posts written by other participants and respond with their own ideas and comments. There was a separate WikiSpace created for each group of the study and each WikiSpace was password protected in order to prevent any user not approved by or included in the study to read anything discussed in the focus group.

Questions were developed to facilitate discussion in the focus group. The six questions formulated were open-ended, allowing the participants to answer to the extent desired. The questions were also not specific to any age, therefore they could be used for all of the focus groups. The questions were meant to ask about a broad range of topics such as hopes, successes, and challenges while also trying to identify common themes among the parents that they could communicate about in the group. See Appendix A for the questions that were used for the online focus-group.

Procedures

After the participants completed their demographic questionnaire and informed consent and returned them via e-mail or mail, an e-mail was sent to them with specific instructions on how to create a pseudonym and how to log into their designated WikiSpace.

A moderator was put in charge of each group to post the new questions every week and also to ensure that each participant was writing both a new response to the question and a reply to another participant's post each week. To start, the moderator posted an introductory question that allowed each participant to describe him/herself, his/her child and anything else that each participant believed would be pertinent to the group. After a week of the introductory question being open, a new question was posted to prompt more responses from the group. This occurred each week for the eight weeks that the study occurred (the introductions, six focus group questions, and a "final thoughts" wrap up week). Even though new questions were posted each week, participants were still able to return to older questions and either create a new post or respond to an already existing post. See Appendix B for the moderator guide.

Data Analysis

The data was transferred from the WikiSpace to a Microsoft Word document. It was then arranged into a table, separated by post. Information was added into the table including: (a) what question the post was responding to, (b) if it was a new post or a response to another participant's post, (c) the pseudonym of the participant who posted and (d) the number of words in the post. After the data was transferred successfully to Microsoft Word, each post was broken up into "thought units", which are the smallest amounts of information that expressed a complete thought or idea.

Once the thought units were completely formed, each thought unit was coded for themes developed using Bronfenbrenner's Ecological Theory as an example. Based on Bronfenbrenner's Theory, coding was developed to find common themes among the thought units. These codes were: (a) the individual child with ASD, (b) the nuclear family, (c) schools and the school system/education, and (d) society, including extended family members.

Reliability

In order to ensure that the coding was reliable, a small portion of the data (two pages) was coded by the author and another honors student in the Department of Communication Sciences and Disorders. The codes by the two researchers were compared, using the formula agreement/ (agreements plus disagreements) * 100. If reliability was lower than 90%, the two researchers negotiated agreement, and then coded an additional two pages. Final reliability was calculated for 20% of the full data set, resulting in 87%, indicating a high degree of reliability for the data.

CHAPTER 3

Results

During the eight-week period of the online focus group, the participants posted 190 comments, totaling 30,330 words, to the six topic questions along with the prompts for the introduction and final remarks.

The results of the focus group are presented in the four coding themes that were derived from the data (Table 2). The main themes include: the individual child with ASD, the nuclear family, schools and the school system/education, and society, including people in public as well as extended family. Each of these themes were broken into subthemes. The main themes and subthemes will be presented, along with quotes representing the data collected. Each quote is presented in its original form, including any spelling and grammatical errors, excluding any personal information (e.g. child's name, city of residence, etc.).

Table 2

Summary of Coding Themes and Subthemes

Themes	Subthemes
The individual child with ASD	Communication
	Peer interaction
	Potty training
	Tantrums
	Sleeping
	Future
The nuclear family	Sibling relationships
	Dividing time
	Discipline
	Appreciating small successes
School	Resources
	Training of professionals
	Success of the child in the classroom
	Teachers
	Therapy length
	Therapy cost
Society	Babysitters
	Perception of the general public

The Individual Child with ASD

All of the participants reported having concerns about their child with ASD. Several subthemes emerged from these concerns, including: communication skills, interaction with peers, potty training, tantrums, trouble sleeping, and the future.

Communication Skills

All of the parents discussed the problems their children were currently having with communication, along with the ways their children were able to communicate. Difficulties were discussed by several parents as highlighted in a response by Melanie: "He understands a lot more words than he can communicate through either through verbal or sign communication, so it can be frustrating for him sometimes." These struggles were also illustrated in a response by Theresa: "His major issues are communication-related, primarily echolalia, jargon, and a lack of age-appropriate functional speech."

Interaction with Peers

Along with communication issues in general, many parents talked about the problems their children were having when interacting with peers. Amanda stated, "He did have a hard time with trying to figure out the other kids and he also had a hard time with how loud and unpredictable they could be."

Some of the children with ASD had more serious problems in communicating with peers. Josie stated: "I am most concerned about how my child interacts with other children his age and his speech. He does play around other children but not really with them, unless he is pushing them down or hitting."

Potty Training

Five of the parents mentioned struggling when potty training their child with ASD. Struggles and successes were mentioned, as illustrated by Theresa:

…Today was the first time he ever told us he needed to go. He just stood up and said "Jason potty" and went into the bathroom. I about peed my pants I was so happy. it's all been very random trying to make ot [*sic*] "click" for him. If you would have asked me two days ago, I would have told you we were making no progress.

Tantrums

Four of the parents mentioned their children with ASD having tantrums frequently and how they as parents felt about the tantrums. These feelings were illustrated by Betsy:

…My son has always tantrumed, but he is now getting big enough that (1)it is more difficult physically to contain the situation and (2)it is more noticeable to onlookers when we are out in public. I try very hard to let it roll off my back when people stare at us as my son throws himself on the floor or starts hitting me and pulling my hair, but the truth is, it bothers me.

Trouble Sleeping

Six of the parents noted sleep issues that their children with ASD were experiencing currently or had experienced in the past. Josie illustrated these ideas when she said: "His hyperactiveness keeps him from being able to fall asleep or stay a sleep. This causes problems for him and also makes him agitated[*sic*]"

The Future

Along with mentioning concerns for issues in present times, all of the eight parents talked about concepts and situations their children with ASD may face in the future. Amanda summed up the ideas of the parents when she said:

>…I really don't like to think about future worries and things that I cannot control. From the very first day that I realized my son was different my brain has played through all the what-ifs and most of them just make me sad. Not that I am in denial about what the future could hold for him, I just like to focus on current concrete issues and what we can do about them now in order to make his future better.

However, Jen felt differently about the future when she said:

>…When my son was diagnosed with Asperger's my mind immediately went to the future and instead of thinking that I could raise him like everyone else raises their children and then when he got to be eighteen he would move out and get a job or go to college like other children, I started thinking that he might need long term care. I started thinking that he might never "grow up" in the sense that he might never be fully independent and that he might never be able to live on his own and might never go to college or get married and have children of his own.

The Nuclear Family

The participants reported questions or concerns regarding the nuclear family, including themselves as parents of the children with ASD and also any siblings of the children with ASD. Several subthemes emerged from the data including: relationships between the child with ASD and siblings, dividing time between children, discipline, and appreciating the small successes.

Relationships between the child with ASD and siblings

Three of the parents mentioned relationships between their children, the child with ASD and any typically developing children. This was illustrated by Jen: "One thing that we are truly blessed with is that the two boys adore each other. All our younger guy wants to do is play with his older brother. And older brother is very patient and kind to his younger brother."

Other parents described how the relationship was not bad, but was not the same as a relationship between typically developing siblings. Theresa stated: "He doesn't interact with him much, but when he does it's sweet. He's never been mean to him. The only thing that bothers him is that now baby brother is old enough to start grabbing things and putting them in his mouth, and Jason gets annoyed when he grabs at him."

Discipline

Five of the parents mentioned struggling when it came to deciding how to discipline their children with ASD. Lindsay said:

… We have been dealing with alot of issues lately with my daughter scratching and swatting at us. At first, I think I was being a little too nice- perhaps not firm enough in dealing with it. Then, one of our therapists asked me how I would have dealt with it had my typical daughter done something like that. I stated that I would firmly tell her that this is not acceptable, it is painful, and put her in some sort of down time, and take something away that she likes if it happened again. the therapist then asked me why I didn't try that with my daughter- I couldn't answer her- probably, because, I again didn't think she would understand that.

Appreciating the small successes

All eight of the parents mentioned the importance of focusing on the small successes as ways of coping with the struggles. Amanda stated:

… I am also able to be proud of things that he has learned that come naturally to other kids but for him are a real struggle, like pedaling a tricycle or telling me that he needs to go potty. I also think that because some things are such a challenge for him that every little step he takes towards learning those things feels like a large accomplishment.

On the other hand, the same parent also believed that it was important to also focus on the bigger picture, rather than only the small details. Amanda stated:

… Celebrating all those tiny (but huge) accomplishments actually makes it harder for me to see the bigger picture. For instance, I hung on every letter he wrote, every snip he took with his scissors, and every step he took on the stairs while he was in occupational therapy and then the day came when they told me that he had learned everything he needed to know for his age and he graduated out of therapy and I was blown away. I was focusing on all the little struggles and victories that I forgot to step back and focus on the bigger picture.

Schools and the school system/education

All of the participants reported having concerns about the school system, therapy and education. Several subthemes emerged from the data including: resources, training of professionals, success of the child with ASD in the classroom, teacher expectations, length of therapy sessions, and the costs of therapy.

Resources

Five of the parents expressed concerns about the lack of resources available in schools for their children with ASD. Theresa stated: "As much information as there is out there on autism/asperger's, you'd think the schools would all be up to date, but some are ignorant about autism and the laws they have to follow."

Betsy agreed when she stated: "When he turned three we found that our district was woefully prepared to meet his needs. We engaged in a legal back and forth until they agreed to fund a private placement for him."

Training of professionals

Along with problems with resources in general, six of the parents discussed how unprepared the majority of professionals in the schools were and how more training is necessary. This was illustrated by Jen: "the schools do need better trained professionals. The cynic in me also feels like they are turning a blind eye to some of the red flags - to avoid being on the hook to providing care."

Jen also discussed the lack of understanding by professionals when she stated:

… At my first IEP, the school district speech therapist raved about my son in her report and discussed how advanced his speech and language was. She said: "when talking to him, he used a sentence that was 43 words long!" I said that may have been the case, but those words were meaningless to him - it's basically music/rhythm to his ears. She was to [sic] busy counting words to recognize that there was little comprehension behind them.

Success of the child with ASD in the classroom

Three of the parents expressed concerns when it came to how their children would do in the classroom. This was illustrated by Melanie: "At first, he was observing more than participating, but now, since he is now familiar with the routines (circle time, activity time, outdoor time, snack time), he participates with just a little prompting."

Teachers

Five of the parents discussed the importance of having a good teacher and the way the teacher impacted their children's achievements in the classroom. Amanda stated: "His teachers did help to ease some of my anxiety about leaving him though because they really made me feel like they wanted to understand him and protect him."

However, several parents also discussed how it was sometimes difficult for their children to understand what the teacher's expectations were. As illustrated by Amanda: "I worry that he will have trouble in school even though he is very smart because he will have trouble understanding what the teachers want from him."

Length of therapy sessions

Six of the parents were concerned about the toll that long therapy sessions would have on their children. As illustrated by Jen: "I am concerned over the hours the 1:1 has been scheduled - 2 days a week, his 1:1 goes until 6:15pm. This makes an 11 hour day for him."

Melanie also expressed concerns when she stated "I feel conflicted sometimes about the hours my own son spends with therapy and the fact that he doesn't get to play outside and just enjoy being a kid. I know that the whole point of early intervention is to target children at their peak of developmental learning, but sometimes, it does seem like a lot for Noah to take in."

Costs of therapy

Three of the parents expressed concerns about paying for the therapy their children required. They agreed that it was hard to refuse to pay for services due to the progress their children were making. This was highlighted by Elizabeth: "My daughter just progressed after ABA, but we are paying it private and it very difficult for us."

Amanda expressed similar frustrations when she stated: "There are so many services that the school doesn't provide, and paying for those services is not easy even with insurance. The co-pays start to add up so quickly."

Society

All of the participants reported having concerns about society, including people in public and extended family members. Several subthemes emerged from the data including: babysitters, and how other people perceive the child with ASD.

Babysitters

One of the main concerns of six parents when it came to society was about leaving their children with other people. Amanda stated: "I honestly think that part of the reason that I feel extra anxiety leaving my son is because developmentally he is younger than his age. I just always have this feeling that he needs me."

Some parents only felt comfortable leaving their children with an extended family member. This was illustrated by Melanie:

> …I work three days a week and I leave him with a grandmother who comes to my house. She has been with me since he was born, and before we knew he had any developmental issues. They are very close and she understands his sign language, so I feel comfortable with leaving him in her hands. She comes and babysits for a night when my husband and

I need to take a break and get away for a few hours, so I feel fortunate that I haven't yet

needed to find a different sitter for him. I don't know what I will do if she every decides

not to work anymore, I guess I will have to cross that bridge when it gets here.

Jen shared similar concerns: "He has had severe stranger anxiety since birth and I had only been

able to have his grandparents and our babysitter (he's worked for us since he was 6

months)watch him."

How other people perceive the child with ASD

Although autism is becoming a topic that more people are familiar with, five of the

parents worried about what people in society would think about their children. Betsy highlighted

how she felt when she stated: "Sometimes I wish I could dress him in a t-shrit [*sic*] that said, "I

have autism; I am not a brat. Please don't judge me or my mommy.""

Several of the parents expressed being embarrassed, such as Josie: "It is so embarrassing

[*sic*] in public. My husband and I dont [*sic*] know what to do, we were told by his psychologist to

ignore it. Its [*sic*] very hard to do that....especially in a public setting when everyone is starring

[*sic*] at you or your child."

Amanda said: "I worry about what strangers think about him and the way he talks

because it does sound so scripted still and he can't hold a real conversation no matter how hard

he tries."

CHAPTER 4

Discussion

The study used an online focus group methodology that explored the experiences of eight parents of preschool-aged children with ASD as part of a larger body of research studying the experiences of parents of children with ASD at different stages in the life cycle. Several themes merged from the data based on the parental reports of preschool-aged children with ASD: the individual child with ASD, the nuclear family, schools and the school system/education, and society, including people in public as well as extended family members.

The Individual Child with ASD

The parents expressed several concerns for the challenges their children were currently facing and would face throughout their lives. The parents mainly focused on the challenges their children were having with communication. Some of the children signed, some were verbal, while others were non-verbal. If they were verbal, their speech was often unintelligible or characterized by echolalia, jargon, or not appropriate for their age. While the parents felt as if their children were making progress in communication, they also felt like they, as parents were the only ones able to understand their children, which caused them to worry about how their children would survive in school and in society.

Aside from having communication problems in general, the parents also had worries about how their children with ASD interacted with their typically developing peers. The answers varied, but majority of them had witnessed negative interactions between the two. Some of the parents thought that their children simply had no interest in their peers, whereas other parents believed their children simply did not understand their typically developing peers. A few parents

noted that their children with violent toward their peers. Overall, they were dissatisfied with the interactions.

The participants were also concerned about toilet training. Four of them were currently potty training their children and experiencing many difficulties and few successes. Most of them noted that progress was slow and inconsistent. Because their children were non-verbal, they were not able to inform the parents of when they needed to use the bathroom, which was the main frustration of the parents. While only four of them were working on potty training, the remaining participants provided words of encouragement saying that all of their hard work would pay off eventually and that their children would be potty trained.

The parents also discussed the frequent tantrums their children with ASD had. They mentioned that their children had thrown tantrums for a long time, but some of them were concerned that the tantrums weren't going away as their children were getting older. A majority of them were also embarrassed in public when their children threw tantrums and there was nothing the parents could do to make them stop. The parents also noted that the tantrums typically only occurred in new settings or pubic settings and struggled with the decision of exposing their children to new environments or keeping them at home to avoid trouble behaviors and tantrums.

Along with tantrums, many of the parents noted that their children were having trouble sleeping. Those who were not experiencing this problem currently shared their experiences of what their children had gone through. Some parents thought the lack of sleep was due to hyperactivity, while others thought it was due to naps during the day. A few parents were giving their children Melatonin to help them sleep and noted that this was helping the children sleep through the night. Other strategies parents used included: less naps during the day, playing with

their children if they woke up during the night, or doing nothing and hoping the children would grow out of it and eventually sleep through the night on their own.

All of the parents also worried about the futures of their children with ASD. The main concern was, "What will happen to my child when I'm gone?" The parents thought they were the only ones who knew their children and how to care for them, along with being the only ones their children were comfortable with and trusted. They also worried about little things such as driving, school, jobs, etc. Many of the parents felt as if there was too much going on in the present to worry about the future while some parents accepted what the future was going to bring and felt confident in their abilities to manage everything. However, some parents expressed that they were in denial about their child's diagnosis and were not currently worrying about the future.

Based on the concerns expressed by the parent participants, it is recommended that more social support groups be put in place to give them a place to express their concerns and also read the advice from others who have been through the same experiences. Many parents expressed that this focus group helped them significantly when deciding what to do with their children, along with helping them feel as if they were not alone and that someone else understood what they were going through.

The Nuclear Family

The parents also expressed concerns within their family, including relationships between their children, discipline and appreciating the small successes. Several of the parents had a child with ASD along with one or more typically developing children. They expressed being worried that their children would not have a good relationship, but were pleasantly surprised that their children were good friends and loved each other. However, even though the relationship was

positive, many parents believed that it differed from the relationship between two typically developing siblings. They believed that this difference resulted from one of the hallmark symptoms of ASD, trouble forming relationships. The parents also found it challenging dividing time between their children with ASD and their typically developing children and feared their typically developing children would suffer because their children with ASD required more time and attention.

The parents also discussed their uncertainties about how to discipline their children with ASD. They struggled finding the balance between being too nice and being too harsh on the child. Several parents found it beneficial to discipline their children with ASD the same way they would discipline their typically developing children. However, they feared that their children with ASD may not understand what was happening and that the discipline would not stop the behavior due to the lack of understanding.

While the parents noted the struggles associated with raising children with ASD, they also recognized the importance of celebrating the small successes, rather than always looking at the big picture. The parents felt as if everything their children accomplished was worth celebrating because things that may come naturally to other children are often difficult to children with ASD, such as pedaling a tricycle or communicating the need to go to the bathroom. However, some parents disagreed with this and believed it was more important to look at the big picture because it is easy to get engrossed in the little details and forget to look back at everything the children with ASD have accomplished in the long run.

This data shows that parents of preschool-aged children with ASD share some of the worries and expectations that parents of typically developing children face, but they may be slightly different because of ASD.

Schools and the School System/Education

The parents expressed their concerns and frustrations with the schools/education/therapy. Their main concerns included: resources, training of professionals, success of the children with ASD in the classroom, teachers, length of therapy sessions, and costs of therapy.

All of the parents were worried when it came to educating their children with ASD. Generally, they felt that information was readily available on ASD, but that educators and administrators were ignoring this information. They often found school districts unable to meet the needs of their children with ASD and several of them ended up in legal battles with the school districts in order to obtain the necessary services for their children.

Along with lack of resources in general, several parents noted that professionals were not adequately trained to diagnose and treat their children. Some of them even felt as if the professionals were ignoring the red flags of ASD to avoid having to go through all of the steps to reach a diagnosis and treatment plan. The parents expressed their frustrations with the general lack of knowledge about ASD and how the professionals seemed unwilling to help in most situations.

While they felt that districts and administrators were unprepared, the parents also feared for their children in the classroom setting. Children with ASD can have difficulties adjusting to new settings, and these difficulties were what parents feared the most. However, most agreed that, after some time, the children adjusted to the routines and were able to function successfully in the classroom. A large part of this success was dependent on the teacher in that classroom.

Several parents expressed the importance of having good teachers for children with ASD. Not only did the teachers help the children succeed in the classroom, they also helped the parents feel more comfortable leaving their children at school every day. They stressed how important it

was to have teachers who were genuinely interested in taking care of the children and doing everything in their power to make sure the children transitioned well in school. However, some parents felt that it was difficult for the children to understand exactly what the teachers expected and that more communication needs to occur.

While parents felt that therapy helped their children immensely, they also thought that therapy sessions were too long and were taking a toll on the children. Some children had an eleven-hour day when they had to go to therapy after school, which the parents felt was too overwhelming for them. These therapy sessions also hindered the children from participating in activities that most children do such as playing outside or coloring.

While therapy is lengthy, it is also expensive, and several parents worried about having to pay for the services necessary for their children. Many parents noted that they fought hard to get services, so it was difficult to turn down anything they were offered. However, several of them had to cut down on hours at work because of their children's needs, so they were making less money to begin with. When adding in therapy costs, parents commented that they didn't know how they were going to afford it.

Based on the concerns expressed by the participants regarding the school system, it would be beneficial to conduct further research on the general availability of services, how professionals are trained in school districts, and how much therapy is necessary for children to make progress while also giving them time to do typical child-like activities.

Society

The parent participants expressed a few concerns about society in general, including people in public as well as extended family members. These concerns included: babysitters and how the general public perceived their children.

Several parents discussed how they were uncomfortable leaving their children with anyone because it may make their children uneasy and they were worried about how the children would react. However, some of them were able to have extended family members such as grandparents babysit the children when it was necessary and the children did quite well. A few of the parents were able to have strangers babysit their children, but they were very afraid of doing this because many people in the general public are not educated about ASD.

All of the parents expressed their frustrations with the general public's perception of their children and of children with disabilities in general. Several of their children threw tantrums in public, and the parents were embarrassed because ASD is not something that can be seen, the children look like typically developing children. A few parents wished that they could have their children wear shirts saying they had an ASD so people in public would stop staring and understand that the children had a developmental disability. On the other hand, some parents stopped caring about what other people thought and found that they were happier when they did not let the perceptions of others affect them.

Based on the data from the parent participants about society, further research should be done on how educated the general public is about ASD due to the fact that is a developmental disorder that is becoming more prevalent each year.

Limitations and Directions for Future Research

There are limitations of this study to keep in mind when interpreting the results. There were only eight participants involved in the focus groups and all of these parents had preschool-aged children with ASD. Given these factors, it may be hard to compare these findings to parents of all parents of children or adults with ASD.

Future research should explore what support groups are available to parents of newly diagnosed or preschool-aged children with ASD. If there are currently several different types of groups available, more research should be done to find ways to make them more widely known and accessible to parents. Also, further research should explore the resources available in the school system for preschool-aged children with ASD. Additionally, research should be done to identify the knowledge of ASD in the general public and how this can be improved. Lastly, research should compare the experiences of parents of preschool-aged children with ASD to parents of children with ASD throughout the life course and also parents of typically developing children.

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Appendix A

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 B

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 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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