

Perspectives of Parents Who Have a Child Diagnosed with an Autism Spectrum Disorder

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Abstract

The purpose of this study was to understand the experiences and perceptions of parents having a child diagnosed with an autism spectrum disorder (ASD). Interviews with 12 parents were audio-recorded and subsequently analyzed to reveal the following themes: (a) Diagnosis of an autism spectrum disorder was not confirmed until years and/or several doctor visits after parents identified concerns. (b) Because they were given little guidance by medical professionals, parents took the initiative to educate themselves about their child's disorder and optional therapies. (c) Lack of daycare options and the cost of interventions were stressors for these families. (d) Parents were torn between their child with an ASD and other family members and friends. (e) Anxiety about the future was prevalent. (f) Parents felt judged by others when with their child in public. (g) Many parents felt that vaccinations may have played a role in their child's ASD.

Perspectives of Parents Who Have a Child Diagnosed with an Autism Spectrum Disorder

The study that will be described was conducted by the first author for her dissertation research at a university in the upper Midwest. Her interest in exploring the experiences and perceptions held by parents having a child diagnosed with an autism spectrum disorder stemmed from her extensive work as a teacher in this field for nearly a decade. The second author served as her dissertation advisor, assisting in the selection of the qualitative research design chosen for the study as well as with the subsequent data analysis. Before introducing the conceptual framework on which the study was based, a brief literature review on autism spectrum disorders in terms of definitions, causation, and parental experiences is provided.

Literature Review

The American Psychiatric Association (2000) defines autism spectrum disorders (ASD) as pervasive developmental disorders characterized by impairments in social interaction, restricted and/or repetitive behaviors, and receptive and/or expressive communication. The following five disorders are included on the autism spectrum: Autism, Asperger's Syndrome, Childhood Disintegrative Disorder, Pervasive Developmental Disorder-Not Otherwise Specified, and Rett Syndrome. Currently, the Center for Disease Control (2011) estimates "that between 1 in 80 and 1 in 240 with an average of 1 in 110 children in the United States have an ASD" (¶ 1), with boys four to five times more likely than girls to have ASD.

To date, researchers have not identified a definite cause of ASD. However, they have identified many factors that are associated with an increased risk of developing the disorders. These include being an identical twin of a person with ASD, being a sibling of a person with ASD, being diagnosed with an identifiable genetic disorder including, but not limited to, fragile X, Down syndrome, or tuberous sclerosis, having an intellectual disability, and being nonverbal or developing language normally and then losing those skills (Center for Disease Control, 2011, ¶ 6-11).

In the literature, it is noted that the rapid increase in the prevalence of ASD may occur for a number of reasons. In part, the expansion of the diagnostic criteria described in the DSM-IV_TR for ASD must be factored in. In addition, the awareness and knowledge related to ASD among healthcare and education providers has increased; this, in turn, has resulted in children being more accurately diagnosed (Aspy & Grossman, 2008).

In addition to the expansion of the definition of ASD and increased knowledge of professionals, some experts and parents of these children believe that other causes have stoked the increase in prevalence of ASD. These causes include mercury poisoning, vaccination preservatives, and virus contents (Aspy and Grossman, 2008). At this time, there is not any research to support this controversial theory of causation.

Many studies have been conducted involving parents of children with disabilities and how these may impact stress levels. One such example is a comparison study conducted by Rao and Beidel (2009) of parents with children diagnosed with high functioning autism to parents of typically developing children. They concluded that the parents of children with high functioning autism experience higher levels of stress related to parenting than those of typically developing children. Having taught typically developing children prior to and following her work with children having ASD, the first author noted higher stress levels among parents of children with ASD as well.

Renty and Roeyers (2005) surveyed 244 parents who had children with an ASD regarding their experiences with the diagnostic process, education, and support received. In addition, 15 of these parents provided supplemental interviews. The primary findings from the study include the following: Parents reported having difficulties throughout the diagnostic process, with the instruction provided to their child, as well as the availability of autism-specific services. Again, the first author has heard from the parents of the children having ASD on her caseload that they have experienced similar difficulties. It seemed appropriate to design a study that would provide further understanding of their experiences.

Conceptual Framework

Two theories guided the development of interview questions for the parents involved in the study. The first was John Rolland's theory of chronic illness, and the second was Elizabeth Kubler-Ross's theory of coping with death.

Rolland (1994) has described three phases families transition through when an immediate family member is diagnosed with a chronic illness: the crisis phase, the chronic phase, and the terminal

phase. The crisis phase begins with initial signs and symptoms of illness and closes with the diagnosis of the illness. The chronic phase involves family members attempting to adjust to this diagnosis by finding a new “normal” way of living, while they are surrounded by abnormal conditions. Finally, the terminal phase begins when the family member diagnosed with the illness dies. After death, the other members of the family exhibit symptoms of grief and mourning. In the first author’s experience, the crisis and chronic phase of chronic illness described by Rolland aligns well with what she has experienced working with families having children diagnosed with ASD.

Kubler-Ross (1969) described the grief process a family member traverses when coping with the death of a loved one and can be extended to include families coping with the disability of a family member. According to Bowe (2004), parents are often in shock and enter a period of denial upon learning of the diagnosis of a disability, which is then followed by anger. Next, it is common for parents to bargain with God and think, “If you cure my child, I promise to . . .” (p.11). After progressing through the bargaining stage, the parents may fall into a state of depression that is hopefully followed by acceptance of the disability.

Rolland’s theory of chronic illness and Kubler-Ross’s theory related to death both guided the development of interview questions for parents of children with ASD. For example, one question asked these parents to reflect on when their child first displayed signs of having an autism spectrum disorder. Another asked that they describe the process through which their child was diagnosed with ASD. Finally, parents were asked to reflect on effective and ineffective interventions that had been utilized with their children.

Methodology

Purpose of the Study

The purpose of this study was to understand the experiences and perceptions parents of a child with ASD have had. It was hoped that this understanding might provide parents of a child newly diagnosed with an autism spectrum disorder a better experience.

Qualitative Design of the Research

A phenomenological design was chosen to conduct the study. According to Creswell (2007), a phenomenological design is appropriate when a researcher’s goal is to describe the lived experiences that all participants in a particular study have in common. More specifically, Moustakas’ procedures, as outlined by Creswell (2007), guided this study. These procedures included determining the importance of understanding the common phenomenon of parenting a child diagnosed as having an autism spectrum disorder, investigating the lived experiences of these parents through in-depth interviews, and asking open-ended questions about this phenomenon.

Participant Selection

Only parents who had a child diagnosed with ASD were asked to participate in this study. Letters of invitation were sent to the presidents of three support groups for parents of children with ASD, special education case managers for children with ASD, and directly to parents of children with ASD. Finally, by attending support group meetings for one of the parent support groups, additional contacts were made. At these meetings, the study was described and a voluntary sign-up sheet was made available; this allowed interested parents to be contacted. Those parents previously interviewed were also asked to recommend other parents who may be interested in sharing their stories. The selection process described resulted in interviews with 12 parents of children diagnosed with an autism spectrum disorder, including Autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), or Asperger's Syndrome, from four different geographical locations within a pre-designated state in the Midwest.

Throughout the study, protection of privacy and of human subjects was assured. This was accomplished by informing participants of the purpose of the study, giving permission to the participants to withdraw at any time, asking the participants to give written consent using pseudonyms during the interview transcription process, altering identifying information, and locking recorded interviews in a file cabinet separate from the list of interviews.

Instruments

Open-ended parent interview questions, a site observation form, an interview transcription form, and a formulated meaning form were utilized during this study. These materials were chosen to record interview data and to later analyze that data.

An open-ended parent interview was used to collect the data for this study. The interview began with asking the parents to converse about their diagnosed child. As the interview progressed, they were asked to reflect on when they first questioned their child's development, the diagnostic process, the interventions they utilized with their child, their experiences with healthcare professionals, support systems they had in place, and advice they would give to a family with a newly diagnosed child. They were also asked to examine 14 word cards (i.e., success, anxious/worried, touched/moved, angry, guilt, important to me, torn between, sad, trust/rapport, strong conviction or belief, happy, lost, frustrated, and surprised) and comment on the cards that had specific meaning to them. The purpose of the word cards was to assist the parents in engaging in deeper examination and reflection of their experience as a parent of a child diagnosed with ASD.

The site observation form was utilized to write observation field notes. The interview transcription form was used for transcription of all conducted interviews. Lastly, a formulated meaning form was developed to organize the meaningful statements of the interviewees and used as a means to guide the member checking and peer examination processes.

Procedures

Observations.

Observing, while taking detailed field notes, is one component of qualitative research methods. Throughout the observation portion of this study, the first author was a participant observer in one support group for parents having children with ASD. The president of this support group became the gatekeeper and negotiated access for the first author to attend four monthly meetings of this group. While observing at the site meetings, it was possible for her to interact with possible research participants. The goal was to “make the strange familiar and the familiar strange” (Glesne, 2006, p. 51), while attempting to formulate generalizations about this particular social situation. At the first meeting, she was introduced to the group by the president and was given time to address the group about her educational background and experiences working with children diagnosed with ASD, her interest in understanding the experiences of the parents, and, ultimately, the goals of the study. As the monthly meetings progressed, the parents appeared increasingly comfortable with her presence, as evidenced by their social interactions and the professional advice they sought on a regular basis. Topics of conversation included possible strategies for difficult behaviors their children were displaying, information on possible interventions, and useful resources for parents. By becoming a recurring visitor to this support group for parents of children with ASD, it was possible to develop the rapport necessary to identify others interested.

Interviewing Process.

Participants were invited to participate in one to three recorded interviews with follow-up interviews scheduled when additional time or clarification of content was needed. All interviews occurred in the parents' homes, except for two that occurred in a school within the school district the child attended. Each interview was approximately 90 to 120 minutes in length. Written permission was obtained at the time of the interview to audio record the interviews for transcription and analysis at a later time. The interview questions were used as a guide to help the interview stay on track, but these questions remained flexible with new questions emerging based on the participants' responses and/or the need for the clarification and deeper insight into their experiences. Potential interview questions were formulated to gain insight into the phenomenon and included the following:

1. Tell me about your child starting with the beginning.
2. Looking back, please reflect on when your child first displayed signs of having an autism spectrum disorder.
3. Describe the process of how your child became diagnosed with an autism spectrum disorder.
4. With regard to healthcare services (doctoring, dentist, optometrist, etc.), what have your experiences entailed?
5. Reflect on the effective and ineffective interventions that have been utilized with your child.
6. The interviewees were shown word cards (success, anxious/worried, touched/moved, angry, guilt, important to me, torn between, sad, trust/rapport, strong conviction or belief,

happy, lost, frustrated, and surprised) and asked to reflect on what came to mind with regard to their child with autism spectrum disorders and any experiences they have had.

7. Describe the types of support systems that are in place for you.
8. What advice would you give to a parent who has a child recently diagnosed with an autism spectrum disorder?
9. Please take some time to tell me anything else you would like to share with me that you have not had the chance to do so already.

During the interview, field notes were taken to record relevant information and other insights gained during the interview process.

The purpose of the study was shared with the participants and the opening statement, “Tell me about your child starting with the beginning,” invited the parents to begin sharing their story, while allowing the other questions to emerge. While listening to an interview, new questions were generated based on the participant’s response, the need for further clarification, and the insight gained during the process. At the final interview, the participants were given permission to provide additional information in writing, and two did so.

Participant Description

Twelve parents of children diagnosed with an autism spectrum disorder, including Autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), or Asperger’s Syndrome, from four different geographical locations within a pre-designated state in the Midwest were ultimately selected and interviewed. Provided in the section that follows is an overview of each participant’s experience. All participant names are pseudonyms.

Anne.

Anne is the mother of a kindergarten child, Brandon, diagnosed with autism. Brandon’s diagnosis changed periodically between Pervasive Developmental Disorder-Not Otherwise Specified and autism beginning at the age of two and one half years. The diagnosis he was given was dependent on the specialist conducting the assessment. Anne was forced to quit her job due to the inability to find daycare for Brandon and became a stay-home mom. Anne spent much of her time educating herself about ASD and has become a leader for a support group for parents.

Beth.

Beth is the mother of a pre-school child, Cory, diagnosed with autism. She had many delays in her search for answers with regard to Cory’s behavior and was told to “wait and see” and that he was fine. Beth was given very little guidance from the medical community and became a self-learner. She spent 10 years earning her four-year degree and then was forced to quit her job due to the lack of appropriate daycare for Cory. Beth has become a leader for a support group for parents.

Dave and Lisa.

Dave and Lisa are the parents of Evan, a middle school boy, who lives full-time in a residential school placement facility. As his parents, they searched for answers for years and finally opted to go out of state to find a doctor who could help them. Lisa, much like Beth and Anne, was

forced to quit her job due to the inability to find daycare for Evan. Dave and Lisa enrolled Evan in a school specializing in full-time education for children with special needs after many years of trying to meet his needs on their own. Dave currently holds a leadership position in a support group for parents in their community.

Jason and Karen.

Jason and Karen are parents of Hunter, a middle school boy diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified. Hunter was diagnosed at the age of three. Upon learning of the diagnosis, Jason and Karen were in the room with the doctor while Hunter screamed and screamed. The doctor put his hands in the air and said to them, "I don't know what on earth you are going to do with this kid." With the lack of guidance given to them from the medical community, Jason and Karen relied on Internet searches for information and interventions. They became part of a core group of parents who pushed for educational programming specific to children with autism in their school district.

Cindy.

Cindy is the mother of Landon, a elementary school boy diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified. Cindy was employed as a nurse for many years and currently works in the field of early intervention. She often referred to Landon as her "little rainman" prior to his diagnosis. Cindy was not given any direction from the medical community upon learning of the diagnosis and has taken it upon herself to bring Landon to a Defeat Autism Now (DAN) doctor out of state. DAN doctors specialize in the treatment of children with autism. Cindy has helped create a non-profit organization dedicating the funding raised to the treatment of children with autism and for financial support to parents.

Genna.

Genna is the mother of Jonah, a kindergarten boy diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified at the age of three. Jonah has extreme meltdowns that typically last 45 minutes to an hour, making it difficult for her to take him on community outings. Genna currently works at Jonah's preschool and is increasing her knowledge in the area of autism by taking online courses. The computer became her best friend as she searched for answers for her child. Genna has also helped create a non-profit organization specializing in the treatment of children with autism and funding support options for families of these children.

Sean and Tonya.

Sean and Tonya are the parents of Tommy, a middle school boy diagnosed with Asperger's Syndrome in the 3rd grade. As parents they questioned his development at age three, as he was engaging in many repetitive actions. Tommy was previously diagnosed with Obsessive Compulsive Disorder, Attention Deficit Disorders, and sensory integration problems. Tonya, a speech pathologist, was working with children on the autism spectrum and began to question Tommy's diagnosis. Sean and Tonya brought Tommy to see a psychologist and the diagnosis of Asperger's Syndrome was confirmed. Sean feels they have an easier situation than most parents who have a child diagnosed with ASD because of Tonya's expertise; had they been left to struggle through possible intervention paths on their own and feel that, without, they would have had a much more difficult situation on their hands.

Dennis and Sandy.

Dennis and Sandy are the parents of Max, a recent high school graduate diagnosed with Asperger's Syndrome. Even though Dennis and Sandy questioned Max's development at the age of three, they did not get an accurate diagnosis for him until he was in the 11th grade. Prior to his diagnosis of Asperger's Syndrome, Max was on an Individualized Education Plan for a learning disability in the areas of reading and math. After watching a news report on ASD, they asked for an evaluation. Max received the diagnosis of Asperger's Syndrome shortly thereafter; both parents feel lost with this new diagnosis. They realize that Max has many social disadvantages and worry about his future now that he is entering the adulthood.

Rigor and Trustworthiness

Having an extensive background knowledge of autism spectrum disorders, as well as the struggles that the parents with whom the first author has worked have, it was extremely important to ensure that researcher bias was addressed. The validity of research refers to the degree to which the data collected from the study are accurate (Glesne, 2006). According to Maxwell (2005), "internal generalizability refers to the generalizability of a conclusion *within* the setting or group studied, while external generalizability refers to its generalizability beyond that group or setting" (p. 115). Although it was impossible to assure that threats to validity in this phenomenological study were not present, the following steps were utilized to strengthen the credibility of the conclusions drawn:

1. "Triangulation – use of multiple data-collection methods, multiple sources, multiple investigators, and/or multiple theoretical perspectives" (Glesne, 2006, p. 37). For this study, observations, interviews, and member checking were used.
2. Member checking – "sharing interview transcripts, analytical thoughts, and/or drafts of the final report with research participants" (Glesne, 2006, p. 38) to be sure the participants' ideas are being represented accurately.
3. Peer examination – the process of "asking colleagues to comment on the findings as they emerge" (Merriam, 1998, p. 205). This was utilized to combat researcher bias. Three experts in the field, a child psychologist specializing in ASD, a teacher specializing in the education of children with ASD, and a special education coordinator involved in the origination of an ASD education program, were consulted throughout this study. While conducting interviews and analyzing the data, these professionals were consulted by telephone and e-mail. In addition, all three professionals were sent copies of the data analysis forms as well as the information displayed in Table 1: Data Analysis. At this time, they were asked to read through the information and render their opinions; all three professionals submitted their opinions in writing. When further clarification was needed, it was gathered through telephone or e-mail contact.
4. Saturation of data – Interviews were conducted until saturation of data had been reached. Saturation of data can be defined as the point at which no new information or themes are observed in the data (Glesne, 2006).

5. “Rich, thick description – writing that allows the reader to enter the research context” (Glesne, 2006, p. 38). While the interviews were being audio recorded, the first author took copious notes related to her observations during the interview.

Data Collection and Analysis

“The main categorizing strategy in qualitative research is coding” (Maxwell, 2005, p. 96). In qualitative research, the goal of coding is not to count things, but to “fracture” . . . the data and rearrange them into categories that facilitate comparison between things in the same category and that aid in the development of theoretical concepts. (Maxwell, 2005, p. 96)

After the participants were interviewed, the following steps were employed to “provide an understanding of the common experiences of the participants” (Creswell, 2007, p. 61). First, the interviews were transcribed and then examined for “‘significant statements’ [or] sentences that provide[d] an understanding of how the participants experienced the phenomenon” (p. 61). Next, clusters of meaning were developed into themes. These “significant statements” and themes were then used to create the formulated meaning of the participants’ experiences. Finally, the formulated meaning statements were compiled to write a composite description that captured the essence of the participants’ experience in hopes that the reader would walk away with an understanding of what it would feel like to walk in the shoes of a parent who has a child diagnosed with an autism spectrum disorder. Reflection on these formulated meanings led to an assertion. The codes, categories, and formulated meanings are summarized in Table 1: Data Analysis.

Table 1. Data Analysis.

Codes	Categories/Themes	Formulated Meanings	Assertion
Warning sign Questioned development Early indicator Lost milestones Diagnosis	Early Signs and Diagnostic Struggles → →	Eight out of 12 parents interviewed identified specific concerns about their child’s development between the ages of 12 and 18 months. Four out of 12 parents were seeing signs by the age of three years. Despite these early concerns, the diagnosis of an autism spectrum disorder was not confirmed until years and/or doctor visits later.	Parents who have a child diagnosed with an autism spectrum disorder are constantly faced with barriers and complications while raising their child. Many of these complications are chronic, in that they continue throughout numerous everyday experiences and are the direct result of raising a child on the autism spectrum while continually searching for answers. The complexity of this experience persists throughout periods of crisis.
No knowledge Self-learner Self-advocate No guidance No plan for treatment	Lack of Guidance From Medical Professionals → →	Eleven out of 12 parents interviewed felt lost after their child was given the diagnosis of having an autism spectrum disorder. They felt they were given very little guidance from the medical community, after receiving their child’s diagnosis, with regard to helping their child. In addition, these parents felt they were not made aware of therapy options for their child. Therefore, these parents took the initiative to educate themselves about their child’s disorder and optional therapies.	
“Lost” job Daycare issues Treatment expense	Limited Daycare Options and Financial Stressors → →	Four out of 12 parents interviewed believed they had limited options for daycare. They struggled finding and keeping childcare. They had to quit their jobs in order to care for their child with an autism spectrum disorder. All of the families interviewed were also financially responsible for many of the interventions utilized. Both of these became financial stressors for the families.	

Table 1 (cont.)

Codes	Categories/Themes	Formulated Meanings	Assertion
Family stress Lack of support	Torn Between → →	Six out of 12 parents interviewed expressed feelings of being torn between their child with the autism spectrum disorder, as well as other family members and friends.	
Anxious Worried Important to me Questioning future	Concerns for the Future → →	Ten out of 12 parents interviewed expressed feelings of concern for what the future will hold for their child. They are anxious and worried about the unknown.	
Judged by others Invisibility of autism Spectrum disorders Public struggles	Judgment of Others → →	Five out of 12 parents interviewed expressed feelings of being judged by the public due to the fact their child may look “normal” but does not behave that way. Their child may have a meltdown in a public place and the stares of strangers are difficult for these parents to bear. Their child may also engage in abnormal behaviors, which, in turn, lead to stares.	
Vaccinations Food allergies Innate sensitivities Illness – never healthy	Parent Perceptions of Vaccinations → →	Seven out of 12 parents interviewed felt that vaccinations may have played some role in causing their child’s autism. They felt that this may be due to an innate sensitivity their child had, timing of the vaccinations, or multiple doses given at the same time.	

Findings

Theme One – Early Signs and Diagnostic Struggles

Eight out of 12 parents interviewed identified specific concerns about their child's development between the ages of 12 and 18 months. Four out of 12 parents were seeing signs by the age of three years. Despite these early concerns, the diagnosis of an autism spectrum disorder was not confirmed until years and/or several doctor visits later.

Six of the families or eight of the parents interviewed have children diagnosed with autism or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Of these parents, all had concerns about their child's development between the ages of 12 and 18 months. Two of the families or four of the parents interviewed have children diagnosed with Asperger's Syndrome. These parents discussed concerns with development at the age of three. All of the parents interviewed brought their concerns to medical doctors. However, the diagnosis of ASD was not confirmed for these families until years and/or doctor visits later. Anne described when she first noticed concerns with Brandon's development.

Brandon was meeting his milestones at 12 months. It was at 15 months when Right Track came in and we were seeing things that made them come back in a month or two for another evaluation and he was not passing these. We started to be concerned, because he wasn't making the evaluations.

Anne later portrayed her feelings about the diagnosis.

I think a doctor should have done it, saw the red flags. I think that when I took Brandon in to his appointments, they should have noticed it. I think that missing autism is like missing a train wreck. I think somebody should have said, "Looks like your child has autism." I would have hated them, but I think that is their job. I think they should have told me that. Absolutely.

Beth also described concerns with Cory's development, both at 12 and 18 months of age.

A little after 12 months of age Cory started having a lot of night awakenings where he would get up and also didn't want to be rocked anymore, he would fight it. He started waking a lot at night and arching his back, really stiff like a back. He also had constant diarrhea. He was sick a lot, which I blame a lot of his misery on. He would imitate, crawl, he would walk, sit up. He did everything textbook fashion, but he didn't talk a lot. At about 18 months, my husband and I wondered what was wrong here. We noticed something wasn't quite right. We would pull him in the wagon in the spring and he wouldn't even look at anything, he just had this glazed over look on his face. My mother-in-law even said that he wouldn't look at her when she would say his name and we thought it was due to the ear infections, maybe a hearing loss, you know. But then, that summer we hired a high school kid to come and watch the kids so I wouldn't have to take everyone out in the morning and that was when he started banging his head, bad. He

was very miserable; he did not talk or coo at all. He would bang his head on the floor and the door and then on the wall when I would leave in the morning.

When Beth brought her concerns to the doctor she had difficulties, as well.

I made an appointment with a local physician and he said he was fine. I said, "He is not playing. He's banging his head on the floor, and he won't talk." The doctor said he was fine that everyone had been talking for him. I was like, "Okay." I left saying, "That is not right." So, I went to a bigger city to find a pediatrician who knew everything about autism, supposedly. We walked in and Cory banged his head on the floor and then went to sit in the corner. And then, the doctor said, "He is not autistic. He is fine." He said that he was banging his head because he was frustrated because he couldn't talk.

Beth continued depicting her frustration.

I think the medical community was definitely a failure. Definitely. I was disappointed with the first two pediatricians. If I would have been one of those mothers who would have been relieved at the fact that they said he was fine, I probably would not have seen another doctor until I really had to. However, I needed to keep searching for that answer.

Dave described concerns with Evan's development.

Evan developed normally throughout his first year. He crawled on time, did all the normal things that he was supposed to do. He was really a fun kid – a little clingy to mom, but a fun kid. At about a year and maybe a few months, we noticed that he wasn't talking. He wasn't saying mom or dad or any of these sorts of things and it was very hard to direct him. You couldn't tell him anything. He had his own mind on how he was going to do things. He wouldn't listen. He was very noncompliant. The speaking was the biggest thing. In terms of having an autism disorder, at about a year we noticed he was not talking. We didn't think autism at that time, but looking back that would have been one of the first signs that we saw . . . even younger than that, had we known all the signs, we would have questioned his clinginess and his clinginess to mom and his noncompliance. He also loved to swing. This would have been a sign to us now.

Lisa added to Dave's concerns.

I think it was about 18 months that I really noticed. He just didn't play like the other kids on the playground. He had this fascination with watching wheels turn on cars.

Dave and Lisa brought their concerns to their doctor many times. After seeing a news program on autism, they brought their concerns back to their doctor. The lack of direction and of a diagnosis from their own doctor led them to seek a specialist in a bigger city.

We went back to the doctor and I told the doctor that I felt bad about diagnosing my child

off of the TV and I certainly didn't want to do that, but I said, "Could our child have autism?" I said that I saw this show on 20/20 and Evan acted just like that. He took his glasses off and put them on the table and set his pen down and then he looked at us and said, "Dave, one thing we know for sure is that your son does not have autism." Then he kind of mumbled about autism being the word this week, because he already had two other parents in this week thinking their sons had autism. We felt kind of small and wished we hadn't said anything, and out the door we went. We were very, very disappointed with the local medical system here. We just struggled with it.

Dave continued explaining their experience with a specialist in a bigger city.

The doctor down there didn't state that his diagnosis was autism, but he went over the findings and how each person that reviewed Evan said the same things. Then he pulled those things off and put them into another chart/calculator, and it came up with a more than average possibility that this child has autism. Then he said, "I am not saying your child has autism, but I think it is something we should be focusing on as we move forward." In the back of my mind, I went back to this TV show that I saw and thought that I had seen some of these things and it made sense to me.

Tonya described when she first questioned Tommy's development.

I want to say it was around age three that I started noticing things. He was doing a lot of repetitive actions and wanted to do the same thing over and over. Just because I am a speech pathologist I noticed it more than my husband and was clued into it. I would mention it to my friends and they would be like, "No, Tonya, you are looking too much into this." He was finally given his actual diagnosis of Asperger's when he would have been going into 2nd grade.

Tonya explained the diagnostic process, as well.

Tommy was seeing our family physician for "attention," but I had a gut feeling he had Asperger's Syndrome. We requested some testing be done at school due to some language concerns, as well as attention concerns. He was diagnosed with ADHD (Attention Deficit Hyper-Activity Disorder), OCD (Obsessive Compulsive Disorder), sensory integration, and language delays. Still in my gut I felt it was Asperger's. Finally, when going into 2nd grade he still had those repetitive behaviors and he still did some very different things. We knew he was attention deficit, and OCD, and had some sensory integration problems. Even though he had all of these things, something just didn't seem quite right. So, then we took him to another doctor to see if it might be Asperger's. At that point I was reading a lot more and dealing with a lot of kids in the school system with Asperger's. The psychologist that we took him to confirmed the diagnosis of Asperger's.

Sandy also had concerns about her son's development around the age of three.

When he was very young, around three years old, he didn't like the feel of grass on his

bare feet. He was very sensitive to touch and loud noises. He didn't like to eat anything too cold or frozen, like popsicles and ice cream. We had him in tball and I remember that his hands flapped when he ran. Also, when he got interested in something it was to the point of obsession. Max did not receive the diagnosis of Asperger's Syndrome until he was a junior in high school, when his parents questioned his learning disability and OCD diagnosis and asked for further evaluations.

Three professionals in the field were asked to review the formulated meaning statements generated from the interviewee's meaningful statements. When asked to reflect upon the early signs and diagnostic struggles that these parents had encountered and described, the school psychologist stated that she partially agreed with the findings.

I agree that many parents of children with autism spectrum disorder have concerns about their child's development before the age of two or three. I disagree with the statement that diagnosis is not confirmed until years later, because this is specific to individual children and the severity of their autism spectrum disorder and is vague. Children with Asperger's Syndrome are usually not identified until well into elementary school, but many children with more severe autism are identified before kindergarten.

It seems the school psychologist misinterpreted the findings, because her statement "Children with Asperger's Syndrome are usually not identified until well into elementary school, but many children with more severe autism are identified before kindergarten" ultimately agrees with the formulated meaning. The parents in this study who have children with autism and PDD-NOS expressed concerns regarding their child's development between the ages of 12 and 18 months. Even if these children are receiving a diagnosis prior to kindergarten, it is years and several doctor visits after the parents' initial concern. In addition, the parents of children with Asperger's Syndrome expressed concern regarding their child's development around the age of three. If these children are not diagnosed until well into elementary school, again this is years and doctor visits after the parents' initial concern. Therefore, the formulated meaning is actually in agreement with the school psychologist's opinion.

Another expert in the field described her thoughts when asked to reflect upon the diagnostic process.

I would agree that there is a frustration among many parents of kids on the autism spectrum that their concerns weren't taken seriously early on when reported to the family physician. With the importance of early intervention for kids on the autism spectrum, valuable time can be lost.

In summary, the parents interviewed in this study who brought concerns to their doctors between the ages of 12 and 18 months finally received the diagnosis prior to kindergarten, but many doctor visits later and approximately three years after their initial concerns. Therefore, despite the diagnosis happening prior to kindergarten, there was a significant period of time between their expression of concern and actual diagnosis. Max was not officially diagnosed until he was a junior in high school and Tommy did not

receive an accurate diagnosis until he was in 2nd grade. This delay in diagnosis meant lost time for appropriate interventions, resulting in parents and educational professionals playing catch-up. According to Taylor et al. (2009), children who receive interventions specific to ASD by the age of three show greater improvements than children who do not receive these interventions until after the age of five.

Theme Two – Lack of Guidance from Medical Professionals

Eleven out of 12 parents interviewed felt lost after their child was given the diagnosis of having an autism spectrum disorder; they were given very little guidance from the medical community, after receiving their child's diagnosis, with regard to helping their child. In addition, these parents felt they were not made aware of therapy options for their child. Therefore, these parents took the initiative to educate themselves about their child's disorder and optional therapies.

Anne reflected on her feelings of being lost after receiving Brandon's diagnosis.

I cannot believe that we saw so many people and nobody gave us any real direction. No real direction at all. I kept hearing about specific therapies, like floortime and ABA [applied behavior analysis] and other things. I thought it was odd that no one was really pushing any of them on us, but I was starting to hear about kids that did really well with some of these. I remember that even though the doctor agreed with the diagnosis of autism, he told us that it was a lifelong disability, that symptoms progress, this isn't something he grows out of, he will get worse, and speech may not happen. Practically in the same sentence that he told us this was a lifelong disability, he also didn't need to see him for another year and didn't give us any direction. These [autism spectrum disorders] are one of the most common childhood disorders right now: 1 in 150 kids, let's be generous and say 1 in 250 kids or 1 in 500 kids. I should not feel alone. I should not feel lost. I should not wonder what we do next. I should be given more guidance.

Karen recalled her frustration with the lack of direction given to them upon receiving Hunter's diagnosis.

After the three hours of testing, Hunter had to sit in a room with a doctor and it was pretty bad. He screamed and screamed and screamed. He cried and cried and cried. At this point the doctor just put up his hands and said, "I don't know what on earth you are going to do with this kid." And that was kind of his diagnosis: He has autism and cannot imagine what we were going to do. So, that was kind of hard. Tears were rolling down my face and Hunter was screaming, and he just said that he didn't know what we were going to do. I said that he was the one that was supposed to tell me what to do and was not given one answer, not a single one. No direction whatsoever. We just left there devastated. I didn't know what we would do. Then, after that we read tons of things on the Internet about autism. We got our autism degree on the Internet.

Karen continued.

Probably the best explanation I have heard about it is that if your kid has cancer they say you need to do this, this, this, and this, and there is a set plan. There is just no one stop set plan for autism and you just don't know where to begin or what to do. I think the biggest thing that we did was to not give up and to do as much as we can.

Justin added to Karen's feelings.

It is sad that there are not enough people around that are knowledgeable about autism therapies. There are no avenues to take when trying to find where to go from here. Even if they would say that there are many different therapies and give information on them . . . that would help. You would think that the hospital or somewhere there would be information on therapies. Nobody really did.

Cindy also educated herself on autism therapies.

From the diagnosis we were not given any real direction, just told that behavior modification and therapy were what was needed, but nothing beyond that, such as what to pursue and when. They made it sound pretty hopeless. I started doing my own research. We don't see a psychologist and psychiatrist, because we would go to the appointments and they would ask me what we were doing. I felt like they should be telling me what I should be doing, not the other way around. As it turned out I would tell them what we were doing, where we were going, and I just thought it was stupid. Therefore, the computer was my best friend after the diagnosis.

Tonya stated that it was very difficult not having any answers after the diagnosis and that she had to rely on her knowledge, as a speech language pathologist, and self-education to help Tommy. She also had to use this knowledge to educate others who worked with him.

I feel that a lot of what has happened for Tommy has been a result of the research that I have done, as a parent. The things that we have asked for, and the services put in place have been things that I have asked for. Again, the school system has been great, but there are still so many people who don't know or aren't educated about Asperger's or the autism spectrum.

When asked to reflect upon the lack of support given to these parents from the medical field, the special education coordinator stated:

I would say that the medical community, in general the family doctors, could use more training in the area of autism. I would hope that the majority of psychologists/psychiatrists would have more guidance for parents. I would say, however, that in my experience, the parents that I have worked with have had to learn much on their own.

Another expert in the field of autism described her views regarding parent support and education from the medical community.

I feel these statements vary based on different experiences of individual families and the needs of children. I feel that parents of children with autism spectrum disorders feel lost and parents may mourn after receiving the diagnosis. I agree that some parents may receive little guidance from the medical community and in some areas of the country it is difficult for parents to even get a confirmed diagnosis from medical professionals, which prevents children from getting proper treatment and special education services. I agree that parents are often not made aware of therapy options or parenting styles that would benefit their family. Some parents are able to educate themselves about this disorder and therapies but, unfortunately, if parents are uneducated or uninformed themselves, this is not likely to happen.

To summarize this last theme, the parents interviewed in this study were given very little information after receiving the diagnosis with regard to where to go next or what interventions were proven to be effective for children on the autism spectrum. Therefore, many parents took the initiative to educate themselves. Unfortunately, most often they relied on the Internet. While there is a vast amount of information on the Internet regarding autism and possible interventions, it is also difficult to decipher which interventions are research-based and proven and which interventions are the newest hoaxes. Therefore, having the guidance of professionals in the field is essential to ensuring that effective interventions are utilized.

Theme Three – Limited Daycare Options and Financial Stressors

Four out of 12 parents interviewed believed they had limited options for daycare and struggled finding and keeping childcare. They felt they had to quit their jobs in order to care for their child with an autism spectrum disorder. All of the families interviewed were also financially responsible for many of the interventions utilized. Both of these factors became financial stressors for the families.

Anne described her frustration with limited daycare.

I lost my job. Most people would view it as I quit my job to stay home with my kids. (Crying) I really lost my job. There was nobody to take care of him. It is easier to say that I quit my job to stay home with my kids and that I am lucky to do so, but that is not factual. That is not factual.

Beth also had to quit her job to stay home due to the lack of daycare available to her. She stated:

It took me 10 years to get my four-year degree and then I ended up quitting my job to stay home. It is very lonely, and it is something that people who have experienced it can really only talk about.

Dave and Lisa also had to make a choice regarding one parent quitting a job to stay home with Evan. In their case, it was Lisa.

It is tough because usually both parents are working and trying to find a fit for a child with special needs. It gets to be a load. We had Evan in daycare when Lisa went back to work. All of a sudden we got a call from the daycare center saying that they didn't really know if Evan was the right fit for childcare. Basically, he got kicked out of daycare and I have heard that from other parents, as well. We had no choice. One parent needed to quit working. In our case it was Lisa. I am sure in most cases it is the mom who ends up quitting work to take care of the child. I can tell you about several families where the mom has quit her career to stay home for this same reason.

The lack of one parent's income may become a financial stressor for the family. In addition, the parents expressed that they are financially responsible for many of the therapies they choose for their child. Beth shared her feelings of anger at the lack of financial support for her child's therapies:

I get angry because the medical field and insurance companies in our state will not help me. They will not pay for anything. I would say financially it is a huge struggle when you are trying to help your child. Nobody wants to be accountable for any of it.

Upon hearing that many of the parents interviewed felt they had limited options for daycare, that they struggled finding childcare, and some had to quit their jobs in order to care for their child with special needs, the special education coordinator stated: This is very true and very stressful for parents.

The school psychologist agreed with this, as well.

I agree that there are little options for daycare for families of children with autism (as well as many other disabilities). I agree that some parents do quit their jobs in order to care for their child, depending on the severity of their child's needs and other family support.

In summary, finding childcare for children with ASD can be challenging. The parents interviewed in this study were often forced to make a decision regarding one parent quitting his or her job and staying home. Also, many of the therapy options, including applied behavior analysis, are expensive and the responsibility of the parents rather than their insurance companies. The lack of one parent's income and the added financial responsibility for therapies can become a hardship for many of these families.

Theme Four – Torn Between Child with ASD and Others

Six out of 12 parents interviewed expressed feelings of being torn between their child with the ASD, as well as other family members and friends. Dave described his feelings of being torn between Evan and his other family members and their friends. We are torn between our own lives at home, our work, and whether we should be with Evan more or with relatives. That is probably the biggest thing. Some weekends we would like to go home and visit Lisa's mom and dad or Lisa's brothers and sisters, but we

feel we need to see Evan every weekend. We are torn a little bit that way or sometimes we would like to see friends. That tears us a little bit, but we are making it work.

Cindy has three other children that she has to care for in addition to Landon. She has difficulty dividing herself between them and is constantly torn between them and Landon, along with time for her husband. She expressed the stress of this and the guilt she feels.

I think I get torn between how to get Landon better and my other three kids. I have talked about this to other parents, too. I know that he needs me the most, so I justify that in my mind. I want to perfectly divide myself up between my husband and my other kids and my job and myself. However, I think that guilt component would still be there.

Beth has many feelings of guilt associated with the amount of time she spends with Cory and her other children, as well as not being able to do things as a family.

There is that guilt with the other children. My life is consumed with autism and their lives are consumed by autism. Also, the fact that mom and dad cannot go everywhere with them, that we usually have to split up is not fair to them. There are all sorts of things that we want to do as a family that we can't. It is way too hard to bring Cory. We cannot go out to eat as a family. This is hard on everyone.

Karen has a daughter who is older than their son Hunter and feels badly that so much of their time and energy is focused on Hunter's therapy.

I think about his older sister, because we are so focused on all of Hunter's therapy. We are still trying to help her, but feeling like we don't give her enough time. She tells us that we don't give her enough attention, that it is always her brother. I often feel torn between the two of them and trying to give them enough time each.

The experts were asked to reflect upon the idea that some of the parents interviewed feel torn between their child with autism and their other family members. The school psychologist agreed with this.

They are torn between their child with autism and their other typically developing children who may not get as much attention because of the needs of the child with autism. In addition, they may feel separated from extended family members who do not want to spend time with their family, may feel uncomfortable around them, may be overly judgmental or blame the parents of the child with autism.

The special education coordinator agreed, as well.

This is also very true. The child on the autism spectrum consumes a lot of time, money, energy, effort, and emotional reserves. Many times the impact on the family unit is impacted greatly.

In summary, the parents interviewed for this study had a difficult time dividing their time among their other children, family members, and friends. When spending their time and energy on their child with autism, they had feelings of guilt regarding their other children. When focusing their time on their children without an ASD and other family members and friends, they experienced feelings of guilt because they were not spending this time on improving their child's disorder. These parents experienced this sense of being torn between the child with ASD and others important to them on a constant basis and struggled with finding a balance.

Theme Five – Concerns for the Future

Ten out of 12 parents interviewed expressed feelings of concern for what the future will hold for their child. They are anxious and worried about the unknown. Cindy exemplified this concern.

I worry about his future and if something would happen to me, what would happen to him. I am kind of the instigator for all of this.

Dave expressed his concern about Evan's future, as well.

Every day Lisa and I wonder about Evan's adult life – and if we think too much about it, we can make ourselves literally sick. We just have to concentrate on today. However, we never know what is going to be the future with Evan. He will teach us and we will figure it out as we go along. We are anxious and we are worried a lot, certainly there is not a day that goes by that there isn't a prayer or two said for Evan. Of course, my dad and mom have both passed away now and we certainly want for them to watch over him. We worry about his future and would like to make it as trouble free and as easy for him as possible.

Beth described her worries.

I am anxious and worried about Cory's future. I don't know what else to say there. I want him to be able to have a friend and I don't care if he knows his social studies, to be honest. More importantly, I want him to have a friend so that is what we will be working on in the next couple of years. I want him just to continue to get better.

Anne expressed her hope for Brandon to become independent enough to live on his own away from home.

It is important to me that Brandon moves away from me at some point. I really don't want him to live with me forever. That is my goal. When people ask how we do this, my answer is, "I do it because I want him to move away someday." You assume that that is going to happen with your kids. It might not happen here, but I really want it to. I mean that in the bad ways and in the good ways. I do mean that I really do want him to move away someday. I want him to go away. (Laughing) I know that doesn't sound nice, but I don't want to have to raise children until I'm 80. I would like them to live by themselves.

I would really like my kids to grow up and move away at some point. That is important to me. I don't know if that will happen with Brandon.

Sandy had many questions about what the future will hold for Max.

We just want Max to have a better future or more normal future. We just don't know where to go from here. Do we enroll him in college? I don't even know. Is he going to be able to get a job? I don't know. Is he going to qualify for disability services? How do we know?

Tonya worried about Tommy's future due to the cruelty of other children.

Socially things are so scary in this world right now. He can be taken advantage of so easily because he trusts everyone. Anyone could lead him to do anything and he would do it and he wouldn't think about it, even if he might think it is wrong. That is very scary for us. Kids are very cruel. As kids get older we see it more often. We try to teach him that he cannot do things that are wrong. I tell him, "Please don't do things that are wrong." It could happen – something could ruin his life, because he is a very trustworthy person.

The special education coordinator who was asked to review the themes has many years of experience working with families who have a child diagnosed with ASD. She has also accumulated many years working with families who have children diagnosed with other disabilities. She speculated about the concerns these families have for their child's future.

I think any parent with a child with a disability has a fear and worry as to whether or not their child can lead a productive and fulfilling life. This fear looms large.

Another expert in the field agreed with the special education coordinator, stating that this fear could be generalized to all parents who have a child with a disability. She also felt that parents of children with Asperger's Syndrome might not have this same fear. However, all parents who were interviewed in this particular study who have a child with Asperger's Syndrome expressed a concern for their child's future. In addition, in the first author's experiences working with parents of children with Asperger's Syndrome, she has heard them express concerns regarding their child's future. Although their concerns may be different from the concerns parents who have a child diagnosed with autism have, they are concerns, nonetheless.

To summarize this theme, the parents interviewed in this study were anxious and worried about the unknown or future for their child. These concerns varied from having real friendships to having the ability to live and work independently. There were also concerns about what would happen to their child after they, the parents, die.

Theme Six – Judgment of Others

Five out of 12 parents interviewed expressed the feelings of being judged by the public due to the fact their child may look “normal” but does not behave that way. Their child may have a meltdown in a public place and the stares of strangers are difficult for these parents to bear. Their child may also engage in abnormal behaviors which, in turn, lead to stares.

Genna described the uncomfortable feelings she has when she goes out in public with Jonah.

It is so hard because I think people look at me like I can't control my kid, but if they only knew. I want to tell everyone, but I would never be able to leave the store. Do I put a shirt on him every day when we go to Wal-Mart that says, "I don't misbehave. I can't help it, I am autistic."? People look at me like I cannot control my kid, but I don't owe them an explanation anyway. But it is hard because they look at me like that.

Tonya explained the frustration she has with the lack of knowledge the general public has regarding ASD.

I just think our public, in general, doesn't have the knowledge about this population. Some people are so quick to judge and don't want to look beyond what is normal in their world. Just because a child looks normal doesn't mean they are normal. Like Tommy, he looks normal, but he has these goofy behaviors, and there are many times that we have been looked at and I think, "He is our son, and we are doggone proud of him." They don't know what he is going through. He may want something or there may be a schedule change. Sometimes he can handle it and other times he may melt down. However, we may be at a store or a restaurant and he may start crying and people will stare because here is this big kid crying.

Karen and Jason described an outing that Hunter and his after-school therapist took to a local pizza restaurant. While waiting for their pizza to arrive, the therapist was conversing with Hunter and he was engaging in some abnormal behaviors, such as blowing bubbles with his spit and repeating things from favorite television shows. Another table of customers asked the therapist to leave with Hunter, because they felt that his behavior was inappropriate. Karen stated that this sort of thing is very common when they go on outings and wishes that there were something she could do. She also stated that the stares from others are very uncomfortable.

One expert in the field had the opportunity to assist parents with community outings early in her work with the autism population. She described her thoughts regarding the judgment the parents of these children feel, along with the anxiety of taking their child with them to do simple errands.

I strongly agree with the statement that the parents of children with autism feel judged by others because their child looks "normal." In addition, I feel that sometimes the parents

themselves may get angry with their own children for the same reason and may not understand that their child does not choose to behave in an autistic way. For parents of children with autism going in public causes great anxiety, even running routine errands such as shopping or eating out.

Another expert supported this.

This is absolutely true. I have heard quite a few sad stories about times when people who didn't know the "whole story" judged these kids and their parents inappropriately and harshly.

In summary, autism has been described as an "invisible disorder" in that these children typically look "normal." Due to the "normal" look of these children, people, who do not understand ASD, often wrongfully judge these families and children by expecting them to act and behave as a typically developing child would behave. The judgmental stares and comments made it difficult for parents interviewed in this study to take their children out in public.

Theme Seven – Parent Perceptions of Vaccinations

Seven out of 12 parents interviewed felt that vaccinations may have played some role in causing their child's ASD. They felt that this might be due to an innate sensitivity their child had, timing of the vaccinations, or multiple doses given at the same time. After looking at the interview affect cards and picking up the "strong conviction or belief" card, Anne discussed her views about vaccinations.

I strongly believe that immunizations are a problem. It took me a long time to say that out loud. I had to be very sure of that. I know that most people think that is just insane to think that vaccines that save lives can harm our kids. I don't think we should not vaccinate our kids, but I do think there is a smarter way instead of treating all kids the same, as if they all weigh the same, as though nothing could ever go wrong. I believe that vaccines are about pharmaceuticals making money. I blame food allergies and vaccinations for Brandon's autism – those two things combined. I don't know what came first, the chicken or the egg, but he just was not able to tolerate his immunizations like most kids can, probably due to the make-up of his body previous to the vaccinations.

Beth also discussed a similar conviction.

I would say a strong conviction or belief is that vaccines have something to do with autism – Cory's autism. In fact, there wasn't really a period when he was really healthy. Even if he was healthy for a week, he probably shouldn't have been given five vaccines at a time if he was still struggling. If I were to go back now, I surely would have done it differently. I would have vaccinated later and split them up instead of doing combination vaccines or any of that. It seems like once he got five in one day it just tipped him over the edge. There is a lot of controversy out there. You just don't know if your child might have that immune disorder that might tip them over the edge. Cory did get a flu vaccine,

which nobody else in my house has ever gotten. He got it at 12 months along with three other shots at that time. After that he got really sick, really, really, really □sick – asthma, bronchitis, always on medicine. He didn't sleep ever. He wasn't that get up in the middle of the night and giggle or talk to himself kind of kid autistic child, he was up crying a lot and did not feel good and couldn't breathe.

Justin described his feelings about vaccinations, as well.

I don't think autism is probably caused by vaccinations but, I do think it is the overall cause of that coming into their system, a person who cannot handle it, probably accelerates that a little bit. I am not so sure that he would be any different any other way. It is just that, it seems like a lot of things became more pronounced at that time or if it was just his age or his vaccine.

Karen added to Justin's thoughts.

I think that vaccines should not be a one size fits all sort of thing, especially for kids who are sick or behind, maybe they should spread them out so they don't get such a big jolt of them all at once. We never did give Hunter his third MMR shot; I don't know, it was just at that time he was doing so much better that we just wanted to revert back to what he had been. Who knows if that is the right call or not, we will never know, but, I don't know. I think it is genetic, but I also think that there is something environmental that is making it happen, too. I don't know. That is the time that all these kids seem to change, so it really makes you wonder if there isn't some sort of connection, but I think it is inborn, too.

Cindy also discussed her belief about the role vaccinations play in causing autism disorders.

I always ask myself about what if I wouldn't have given Landon the flu shot when he was sick or given him vaccines when he was ill or if I should have spread them out. I think that for some kids vaccinations can definitely cause their autism. I believe that it was the vaccines that spiral them down into this world. I think that for some kids it can be part of it. I think there is definitely a genetic component, too. I think that we need to do our homework a little bit better before loading these kids up with vaccines. I think that we can spread vaccines out; that they don't need to be given nine at once. I do believe that they can wait until the age of two to vaccinate and that some kids probably shouldn't be vaccinated at all. However, I don't think it should be up to the parents to decide. I think that mainstream medicine needs to get in touch with that. I don't know when that is going to happen. I think it deserves to be researched, but it hasn't so far. I don't think that full load of vaccines caused Landon's autism. I think the vaccines that he got when he was so sick maybe pushed him over, but I think he was already somewhat there. He just wasn't as deep. That is how I feel. I am not antivaccine, but I am anti-crap in our vaccines. I think that we really need to look at the specific contents. It is not just the thimerisol, it is also the aluminum and lead that don't need to be there.

Dave described his view of vaccinations.

The “experts” are telling us there is not a link between autism and vaccinations. If someone finds a link, certainly I would be one of the first to have Evan tested to see if there is a causal relationship. Certainly there was no indication of Evan having any disability until around 12-18 months, so to say I believe there is no link wouldn’t be exactly correct either, but we can’t change what has happened.

When asked to reflect upon the idea that vaccinations may play a role in the cause of ASD, all experts asked did not feel comfortable drawing conclusions on this topic and did not feel they had spoken about this topic to many of the parents to give adequate thoughts. One expert stated:

I agree with this statement in that some individuals and families do believe that vaccinations may have played a role in causing autism, but there are also many families who do not believe this to be true. It is my understanding that the preservative used in some vaccinations is in question in addition to the innate sensitivity, timing, and dosage. I personally do not believe that the research is conclusive enough one way or the other to take a stance on this issue.

To summarize this theme, several parents interviewed felt that vaccinations may have played some role in causing their child’s autism. They felt that this might have been due to an innate sensitivity their child had, the timing of the vaccinations, or multiple doses given at the same time.

Limitations

The purpose of this study was to understand the experiences and perceptions parents of a child with an ASD have had that may provide parents of a child newly diagnosed with an autism spectrum disorder a better experience. Participants in the study were parents of male children diagnosed with an ASD, including Autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), or Asperger’s Syndrome, who were selected for interviews from four different geographical locations within a pre-designated state in the Midwest. The majority of these parents attended regularly scheduled support group meetings in their communities, which may have led to the possibility of groupthink. Groupthink refers to the idea that the members of the support group have cohesive ideas rather than independent thoughts. The geographic location, lack of parent participants of female children, and the possibility of groupthink, result in parents’ experiences not being representative to all parents with children diagnosed on the autism spectrum.

Conclusions

Parents interviewed in this study felt constantly faced with barriers and complications while raising their child. One of the first barriers originated with the realization that their

child was not developing typically and continued throughout the diagnostic process, which often spanned a long period of time and/or numerous doctor visits. This continued as parents were given very little guidance from the medical community about how to proceed with therapy options, resulting in the parents becoming self-educated. The complications continued as parents became overwhelmed by the amount of information they encountered in their search for answers and were faced with making decisions for how to help their child.

The parents in this study also felt constantly scrutinized by outsiders, making it difficult for them to engage in many community activities as a family. Many of these complications were chronic, in that they continued throughout numerous everyday experiences and were the direct result of raising a child on the autism spectrum while continually searching for answers. The complexity of decisions persisted throughout periods of crisis, such as preparing for transitions, both big and small.

Recommendations

Recommendations for Medical Professionals

Parents of children with an autism spectrum disorder are often left with many questions and few answers upon learning of their child's disability. Participants in this study felt lost and were given very little guidance from the medical professionals regarding what steps to take or interventions to pursue to improve their child's level of functioning. Therefore, these parents became self-educated on the topic of ASD primarily through information provided to them via the Internet. Once a diagnosis of ASD is confirmed, it is the responsibility of the medical community to provide parents with information regarding research based interventions and therapies for children with ASD. This practice would give parents a starting point for helping their child. Furthermore, medical professionals should provide the parents with information regarding where to go for additional help, guidance, and services that would assist them in getting interventions in place for their child as soon as possible after receiving the diagnosis.

Recommendations for Research

Continued research is needed regarding the experiences and perspectives of parents who have children with ASD. As stated in the limitations, the geographic location, lack of parent participants of female children, and the possibility of groupthink, result in parents' experiences not being representative of all parents with a child diagnosed on the autism spectrum. Conducting research studies involving parents of children with a single, specific autism spectrum disorder, children of similar age groups, and parents of female children would result in richer, more vivid experiences that may be generalized across a multitude of situations.

Closing Statement

Raising a child with an autism spectrum disorder, as well as any disability, is challenging. The provision of support, guidance, and information to the parents of these children is not only essential to ensure that these children receive proven interventions in their

programming, but it also empowers the parents with knowledge at the beginning of their journey and ultimately throughout.

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