PARENT EXPERIENCES WITH EARLY SYMPTOMS AND DIAGNOSIS OF
CHILDREN WITH MILD AUTISM AND ASPERGER’S SYNDROME

by

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Abstract

Autism spectrum disorders include autistic disorder, Asperger’s syndrome, pervasive developmental disorder-not otherwise specified, and Rett syndrome. Currently, one out of every 88 children in the United States is diagnosed with an autism spectrum disorder. Despite the average age at diagnosis being three years, parents typically begin reporting concerns to pediatricians before their children are one year old. The purpose of this study is twofold. First, this study aims to identify the concerns that parents of children later diagnosed with autism have regarding the child's development prior to two years of age. Second, this study will attempt to identify the average age where children begin to develop characteristics of mild autism. In order to investigate these research questions, participants recruited from the Interactive Autism Network (IAN) will complete a demographics questionnaire and the First Year Inventory-Retrospective Edition. The research will include both quantitative analysis and qualitative analysis in order to get a more complete picture of the symptoms and concerns parents have, the age at which the concerning behaviors occur, the amount of time that lapses between the development of concerning behaviors and the diagnosis of autism, and the parents’ own feelings and perspectives of the referral and diagnostic process.
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CHAPTER 1. INTRODUCTION

Introduction to the Problem

On April 1, 2012, the United States Centers for Disease Control and Prevention (CDC) announced that more than 1% of children in the United States are diagnosed with an autism spectrum disorder, making the prevalence one child out of every 88. The prevalence among male children is 1 in 54 male children (CDC, 2012). Researchers speculate that the rate of actual autism spectrum disorders may be even higher than the diagnosed rate (McConachie, Couteur, & Honey, 2005). Kim, Leventhal, Koh, and colleagues (2011) screened 55,266 children between the ages of 7 and 12 years old in a South Korean community using the Autism Spectrum Screening Questionnaire. Those who were found to be likely to have an autism spectrum disorder were offered additional assessments. The results of the study found that the prevalence of autism is actually estimated to be 2.64%, or 1 in 37 children. Because the majority of the children who were found to have autism were in the mainstream school population, the researchers suggested that a similar rate of autism spectrum disorders might be found outside of South Korea, including in the United States.

There are several diagnoses that are referred to under the umbrella term autism spectrum disorders. Currently, autistic disorder, Asperger’s syndrome, pervasive developmental disorder-not otherwise specified (PPD-NOS), and Rett syndrome are classified as autism spectrum disorders (Howlin & Moorf, 1997). These disorders begin during childhood and interfere with several areas of development, including social, language, and behavior development (American Psychiatric Association, 2000).
According to McConachie and colleagues (2005), the diagnosis is made on average by three years of age.

Many children with a diagnosis of an autism spectrum disorder exhibit typical or near-typical development throughout infancy. However, these children begin to display marked characteristics of autism and atypical or regressive development as the first or second birthday approaches (Bernabei et al., 1998). In a growing number of documented cases, children may begin to show signs of autism as early as a few months of age and perhaps as early as days following birth (McConachie et al., 2005). Recent research has found that some infants demonstrated, within days or weeks, atypical behaviors such as prolonged screaming or delays in eye contact with parents (Ozonoff, Williams, & Landa, 2005).

McConachie, Couteur, and Honey (2005) stated that following a child’s diagnosis of an autistic disorder, parents reported that there were concerns with the child’s development in the months prior to the referral and developmental evaluation. In several documented cases, parents of children with autism noted that the child developed typically until approximately 12 months of age, and then clear atypical behaviors were noted (Eaves & Ho, 2004). These behaviors included the lack of appropriate eye contact, poor motor imitation, lack of joint attention, lack of pointing and shared interest, and delays in communication (Maestro et al., 2005). Shared interest and joint attention are defined as developmental milestones typically emerging between 9 and 12 months of age in which an infant begins to reference another adult and can coordinate visual attention to an event or item that an adult shows interest in (Flom & Pick, 2003). Some parents may
have reported these symptoms to a pediatrician or specialist prior to the child turning 12 months of age. However, the symptoms were most evident and distinguishable to a specialist for diagnostic purposes after the child’s first birthday (Goin & Myers, 2004).

**Background of the Study**

Current research suggests that parents of children diagnosed with autism spectrum disorders actually began reporting concerns with their child’s development to the pediatrician or other specialist during infancy (Gomez & Baird, 2005). The most frequently reported concern was the infant’s difficulty in regulatory behavior such as difficulties being comforted, colic-type behaviors, and waking up frequently during the night (Young, Brewer, & Pattison, 2003). Gomez and Baird concluded that a significantly higher proportion of infants with regulatory difficulties were later diagnosed with an autism spectrum disorder than infants who were not reported to have regulatory difficulties. Regulatory difficulties are defined as being unable to exhibit control of emotional, behavioral, and attention reactions to various stimuli (Olafsen et al., 2008). These behaviors can include quieting to the sound of a parent's voice, being able to soothe with breastfeeding or a pacifier, and being able to focus on a particular object or person in a distracting environment (Olafsen et al., 2008).

Goin-Kochel, Mackintosh, and Myers (2006) stated that the first step in the diagnosis of autism is often a referral from a physician. Following the referral from the physician, the child is often evaluated by various specialists, including psychologists, speech pathologists, and occupational therapists. Research suggests that parents often report concerns in the child’s development to pediatricians or early intervention
specialists (Midence & O’Neill, 1999). However, Siklos and Kerns (2007) speculated that the parents typically have to express concerns on multiple occasions before the pediatrician or specialist refers the child for further evaluations.

Research on autism interventions, such as applied behavior analysis, occupational therapy, social skills therapy, and speech therapy, conclude that the earlier a child with autism receives intervention, the better the child’s prognosis is (Eaves & Ho, 2004). Eaves and Ho also stated that this positive impact was even more pronounced in children with higher functioning forms of autism spectrum disorders, including Asperger’s syndrome. In addition, the earlier a child is diagnosed with autism, the earlier interventions can be started.

**Statement of the Problem**

Some researchers suggest that the average age of the child when an autism diagnosis is made is three years of age (Eaves & Ho, 2004). The practice of early diagnosis is controversial though, as other researchers have noted that some children who meet criteria for autism before the age of three no longer meet criteria by the time the children reaches school age. This factor can cause pediatricians to be hesitant about making a referral for evaluation prior to age three (McConachie et al., 2005). McConachie, Couteur, and Honey (2005) demonstrated that autism can reliably be diagnosed prior to a child’s third birthday if the symptoms are detected and reported and the referral for evaluation is made. McConachie and colleagues also indicated that parents often detect and report atypical development in children prior to the referral being made.
One problem with the current procedures in autism diagnosis and treatment is that parents appear to be able to detect symptoms of autism in infancy, yet the average age for diagnosis is three years of age. There appears to be some discrepancy between when a child is diagnosed with autism and how early a parent becomes concerned about the child’s development, what symptoms or concerns are present when the parent first becomes concerned, how early those concerns are voiced to a pediatrician or specialist, and how many times the parent expresses those concerns to the pediatrician or specialist before a referral for evaluation is made. It is essential that the gap is closed between the time where parents first begin having concerns and the time a child receives an autism diagnosis.

**Purpose of the Study**

The purpose of this study was to identify the concerns that parents of children later diagnosed with an autism spectrum disorder have regarding their child’s development prior to two years of age. In addition, the study examined parents’ experiences of the discrepancy between the time parents first become concerned with the child’s development and the time the concerns are mentioned to the pediatricians or specialists. The total length of time and parents’ experiences of the time between the parents’ first concerns and the final diagnosis was also investigated.

Better understanding the discrepancy between parents’ notice and when professionals respond could contribute to earlier diagnosis or prediction of autism. With this knowledge, practitioners could begin to ask parents during the first 12 to 24 months of the child’s life whether the parents have any concerns regarding the development of
the child. This could potentially allow counselors or other health providers to intervene at
the youngest possible age. The earlier an intervention is administered, the higher the rate
of a positive prognosis (Eaves & Ho, 2004).

Autism spectrum disorders are being diagnosed at high enough rates that many
counselors and individuals in the human services field will likely encounter either a child
with autism or a parent who has concerns about the child’s development (McConachie et
al., 2005). In addition, the results of the study may lead to further research that may
impact the age at which mental health practitioners can begin providing interventions to
children diagnosed with an autism spectrum disorder. This can be accomplished by
helping practitioners to identify potential symptoms of autism early in a child’s life.

It is anticipated that the study will advance theory by demonstrating what the
expected developmental course of autism is within the first two to three years of life,
which is a current gap in the literature. The research addresses the deviations from typical
child development and as such, will potentially advance developmental theory.

Rationale

The rationale for the study was that research shows an early diagnosis of an
autism spectrum disorder can encourage intervention at a younger age. This often results
in a better long-term prognosis (Eaves & Ho, 2004). However, current research indicates
that the average age of an autism diagnosis is three years old (McConachie et al., 2005).
By identifying what parents perceive to be potential symptoms of autism during infancy,
practitioners can begin to work towards diagnosing autism at a younger age.
A study using mixed methodology was needed in order to obtain a more complete picture of parent experiences. Quantitative methodology provides data on the frequencies and types of symptoms present, as well as the average length of time for the diagnostic process. Qualitative methodology allows parents to share their experiences in their own words, giving information that is not often allowed in quantitative studies.

The study is significant in the field of human services because many practitioners are becoming involved in the autism intervention process. Human services professionals can include behavior specialists, social workers, individual counselors, and social skills interventionists. This study may allow professionals to be able to diagnose autism at an earlier age, which directly impacts how human services professionals provide services to these clients and their families.

**Research Questions**

The study included a primary research question as well as several qualitative and quantitative sub questions.

**Primary research question**

How do parents describe their experiences of the entire process of having a child diagnosed with mild autism or Asperger’s syndrome?

**Qualitative Sub-questions**

Q1: How do parents describe the social, emotional, cognitive, and physical development of their child during the first two years of the child’s life?

Q2: How do parents describe their experiences reporting concerns to pediatricians early in the life of their child?
Q3: How do parents describe their experiences with the diagnostic process?

**Quantitative sub-questions**

Q1: What types of prenatal and neonatal complications are most prevalent in this population?

Q2: At what age did parents first begin noting concerns about their child’s social, emotional, cognitive, and physical development?

Q3: What age was the child when the parents first reported concerns to the child’s pediatrician?

Q4: How many times did the parent report concerns to the pediatrician prior to the diagnostic referral being made?

Q5: How many months was the average diagnostic process, from referral to final diagnosis?

**Significance of the Study**

Due to the increased prevalence of autism diagnosis, more practitioners in the human services field are becoming involved in the intervention process of children with autism spectrum disorders. These practitioners can include behavior specialists, social workers for the family, individual counselors, or social skills interventionists. In order for the interventions provided by human services professionals to be most successful, the child should receive the interventions as early as possible, including before age three (Eaves & Ho, 2004).

However, in order for most prescribed interventions to begin, a team of professionals that may include licensed pediatricians, psychologists, neurologists,
occupational therapists, physical therapists, and speech therapists must have previously made a formal diagnosis. While Eaves and Ho (2004) demonstrated that most interventions have the highest rate of success if begun prior to the child entering preschool, current diagnostic criteria set forth in the *Diagnostics and Statistical Manual, (4th ed TR)* and evaluation tools such as the Autism Diagnostic Observation Schedule (ADOS) are not standardized for children under 36 months old.

Autism is most often diagnosed with a series of observations and standardized tests, including the ADOS, the Childhood Autism Rating Scale (CARS), and the Autism Diagnostic Interview Revised (ADIR). However, many of the accepted standardized tests for screening and diagnosing autism spectrum disorders in children have not been standardized for use in children less than three years of age (Fenton et al., 2003). In addition to standardized tests, research has found that the American Psychiatric Association’s *Diagnostic and Statistical Manual (4th ed., TR)* may also be inadequate and inappropriate for use in detecting symptoms of autistic disorders in very young children (Eaves & Ho, 2004). Many of the accepted diagnostic criteria for autism, such as lack of appropriate peer relationships, are typically a part of development in children under age three; therefore, those criteria cannot be used to detect autism in infants and toddlers.

Despite the critiques of current diagnostic procedures, McConachie, Couteur, and Honey (2005) suggested that the average age of diagnosis of an autistic disorder can be reduced from the current age of three years old to sometime during infancy or the early toddler years. McConachie and colleagues (2005) suggested that it may be possible for clinicians to reliably diagnose autism before the child’s second birthday. Symptoms such
as atypical language development may be reliable indicators of autism in infants and toddlers (McConachie et al., 2005). In fact, in younger children, the most common reason the child is referred for further evaluation by an autism specialist is a marked delay in speech and language development (McConachie et al., 2005).

**Definition of Terms**

*Asperger’s Syndrome*— APA diagnostic code 299.80. A pervasive developmental disorder characterized by an impairment in social interaction, restricted repetitive and stereotyped behavior, interests, and activities, no clinically significant cognitive delays, and no significant delays in language development (APA, 2000)

*Autistic Spectrum Disorders (ASD)*—The category of pervasive developmental disorders including autistic disorder, Asperger’s syndrome, pervasive developmental disorder—not otherwise specified (PDD-NOS), and Rett syndrome (APA, 2000). These disorders begin during childhood and interfere with several areas of development, including social, language, and behavior development.

*Autism/Autistic Disorder*—APA diagnostic code 299.0. A pervasive developmental disorder exhibiting marked impairment in social interaction, qualitative impairments in communication, restricted repetitive and stereotyped behavior, interests, and activities, delays in social interaction, delays in functional language, and delays in symbolic and imaginative play (APA, 2000). These symptoms have an onset prior to age three.

*Joint Attention/Shared Attention/Shared Interest*— A developmental milestone typically emerging between 9 and 12 months of age in which an infant begins to
reference another adult and can coordinate visual attention to an event or item that an adult shows interest in (Flom & Pick, 2003).

*Neurotypical*-- A individual who does not have a diagnosis of an autistic spectrum disorder and has demonstrated typical cognitive and developmental growth (Behrmann et al., 2008).

*Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)*-- APA diagnostic code 299.80. A pervasive developmental disorder characterized by impairment in social interaction or presence of stereotyped behavior, interests, and activities (APA, 2000). A diagnosis of PDD-NOS indicates that the diagnostic criteria for autistic disorder is not met due to atypical symptomatology, a later age of onset, or symptoms of autistic disorder present, but not in the combination required for a diagnosis of autistic disorder.

*Regulatory Behavior*-- The aspect of infant development where the infant is able to control emotional, behavioral, and attention reactions to various stimuli (Olafsen et al., 2008). These behaviors can include quieting to the sound of a parent's voice, being able to soothe with feeding or a pacifier, and being able to focus on a particular object or person in a distracting environment (Olafsen et al., 2008).

*Rett Syndrome*-- APA diagnostic code 299.80. A pervasive developmental disorder characterized by normal prenatal development, normal head circumference at birth, and normal psychomotor development from birth to five months of age. Between 5 and 48 months of age, head growth decelerates, purposeful hand skills deteriorate, deterioration of social engagement is present, as well as an impairment in language development (APA, 2000).
Stereotypic Behavior-- Repetitive motor or vocal actions that do not have an apparent adaptive function (Gardenier, MacDonald, & Green, 2004). These behaviors can include hand flapping, moaning, body spinning, head shaking, rocking, pacing, and manipulating small objects between one's fingers.

Assumptions and Limitations

The study included several assumptions. The first assumption was that all of the parents who consented to participation in the study actually had children who were diagnosed with an autism spectrum disorder. It was also assumed by the researcher that the diagnostic procedures to obtain that diagnosis were aligned with the standard and accepted diagnostic procedures according to the American Psychological Association and thus all diagnoses in the study are valid and standardized. It was also assumed that all of the respondents were actually the caregivers of the children during infancy and can comment on the child’s early development. Finally, it was assumed that the parents were providing an honest portrayal of their memories and their recollections of their child’s development.

In addition to assumptions, there were two anticipated limitations with the study. First, all of the participants answered the survey via an internet-based questionnaire. Therefore, the only individuals who can answer the survey were those who had access to a computer, Internet connection, and a working knowledge of the English language. Second, the study required that the parent answering the survey was the parent who had daily or near-daily contact with the child from early infancy. Therefore, the results of the study might not be able to be generalized to families in which the child with autism was
adopted into the family or to families in which the parents had custody 50% or less of the child’s infancy. Finally, because there was no face-to-face contact with the respondents, the researcher could not verify that the individual responding to the survey was the same individual who was recruited as a participant.

Nature of the Study

The study utilized mixed methodology, with both qualitative and quantitative aspects. In order to investigate the research questions, participants completed multiple surveys and questionnaires, including a demographics questionnaire and the First Year Inventory—Retrospective Version. The study explored and attempted to identify common experiences among parents of children with mild forms of autism spectrum disorders. The study was in large part retrospective in nature, with the parents being asked to recall details of their child’s early development prior to the child’s formal autism diagnosis.

Organization of the Remainder of the Study

Chapter 2 will review the literature research relating to autism spectrum disorders including (a) this history of autism, (b) the symptoms of child development theories, (c) history of child development theories, (d) parental role in autism diagnosis, treatment, and (e) research methodologies when investigating autism spectrum disorders. Chapter 3 will review the methods for conducting the study and analyzing the data. Chapter 4 will provide an overview of the results. Chapter 5 will provide a discussion of the results.
CHAPTER 2: LITERATURE REVIEW

The literature review presented here investigates historical and modern literature and research relating to autism spectrum disorders. Specific areas of literature examined include: (a) this history of autism, (b) the symptoms of child development theories, (c) history of child development theories, (d) parental role in autism diagnosis, treatment, and (e) research methodologies when investigating autism spectrum disorders.

History of Autism

The history of autism spectrum disorders is long, yet the majority of the research and advances in the study of this disorder have occurred only within the past two decades (Glazer, 2003). In the early 1940's, early infantile autism was first described by Johns Hopkins University psychiatrist Leo Kanner. Kanner described these children as having difficulties interacting socially and having troubled emotional bonds with parents (Glazer, 2003). In 1943, Donald Triplett, known as Case 1, was the first individual diagnosed as having early infantile autism (Kanner, 1943). Triplett was 10 years old at the time. Shortly after Triplett was diagnosed, there were 10 other known cases diagnosed. Kanner (1965) stated that prior to Triplett’s diagnosis, there were other known cases of children with emotional disturbances similar to schizophrenia or who had autistic-like characteristics, but Triplett’s diagnosis marked the first time where children with autistic-like characteristics were given the diagnosis of autism (Kanner & Eisenberg, 1965). However, until the 1960’s, autism, or early infantile autism, was not seen as separate from schizophrenia or mental retardation (Lyons & Fitzgerald, 2007).
Triplett was described as being a typically-developing infant, with the exception of some difficulties with eating, including a lack of desire to eat (Kanner, 1943). He began to walk at 13 months old, which is within the realm of typical motor development. However, at a year old, Triplett was able to hum and sing various tunes with extreme accuracy and by two years old, he could recite Psalm 23. He also demonstrated an above-average ability to recognize names and faces, could count to 100, and could say the alphabet both forwards and backwards. He was content to be alone the majority of the time, and did not show distress when a parent left the room. This is in contrast to typical child development where many toddlers will show some degree of separation anxiety when left alone (Bernabei, Campaigni, & Levi, 1998). Triplett was observed spinning toys in unusual ways for sensory stimulation, but showed intense fear of riding tricycles (Kanner, 1943). Soon after, he began to demonstrate intense temper tantrums and an inability to associate discipline with an offending action. At age five, Triplett was institutionalized in an attempt to discern whether a different environment would influence his behavior. At age 10, Triplett still had significant delays in socialization, as well as intense inflexible interests and patterns of behavior, difficulties in sensory regulation, and limited spontaneous activity, resulting in a diagnosis of autism (Kanner, 1943).

While Kanner was developing his theories on infantile autism based on Triplett’s development, Hans Asperger was researching a similar population. In 1944, Hans Asperger took a different approach and defined similar children as "little Professors" with bizarre obsessions. Asperger worked with four males and noted a lack of empathy, social skills delays, intense interests, difficulties with gait, and one-sided communication
The condition described by Hans Asperger was later termed Asperger’s syndrome. In the scientific and psychological arenas, autism was described as being similar to schizophrenia, and was often termed "childhood schizophrenia" (Glazer, 2003). In 1981, Asperger’s syndrome was deemed a separate diagnosis than autistic disorder, although it was similar enough to be considered to be part of the autism spectrum (Wolff, 2004).

In the 1990's, the pursuit to find a cause for autism led parents and scientists to question routine childhood vaccinations (Glazer, 2003). In 1998, Andrew Wakefield, a British researcher, first suggested that the measles-mumps-rubella (MMR) vaccination was one cause for autism. In 1999, the Food and Drug Administration (FDA) recommended that the mercury-based preservative thimerosal be removed from all childhood vaccinations as a precaution (Glazer, 2003). In 2001, all routine childhood vaccines were made thimerosal free. However, during that same year, the Institute of Medicine committee rejected the causal connection between the MMR vaccination and autism (Glazer, 2003). In 2010, *The Lancet*, which published Wakefield’s original study in 1998, retracted the study after questions surfaced regarding Wakefield’s research techniques (Lancet, 2010). According to the retraction publicized by *The Lancet*, Wakefield’s original study was not approved by an ethics committee and it was alleged that the study’s data were contrived to produce a particular result (Lancet, 2010).

Despite the lack of research indicating a definitive cause for autism spectrum disorders, the United States government and the American Psychological Association determined that there was a great need for greater recognition and intervention. In 1991,
autism was first considered by the Department of Education as a disability eligible for free special education services (Glazer, 2003). Additional recognition was made in 1994 when the Diagnostic and Statistical Manual recognized the five disorders on the autism spectrum: autistic disorder, Asperger’s syndrome, Rett syndrome, PDD-NOS, and childhood disintegrative disorder (Glazer, 2003).

**Symptoms of Autism Spectrum Disorders**

Autism spectrum disorders include the diagnoses of autism, Asperger’s syndrome, pervasive developmental disorder-not otherwise specified (PPD-NOS), and Rett syndrome (Howlin & Moorf, 1997). Today, 1 in 88 children is diagnosed with autism each year (CDC, 2012). The average age of diagnosis was found to be around age three (McConachie et al., 2005). In families where one child is diagnosed with autism, there is a 5% to 10% chance of the child’s younger siblings being diagnosed with autism, which represents a 20-fold increase in the likelihood of autism in those particular families (Sumi, Taniai, Miyachi, & Tanemura, 2006).

Autistic disorder is assigned the APA diagnostic code of 299.0 and is defined as a pervasive developmental disorder exhibiting marked impairment in social interaction, qualitative impairments in communication, delays in social interaction, delays in functional use of language, and delays in symbolic and imaginative play (APA, 2000). In addition, individuals with autism will likely demonstrate repetitive and stereotypic behavior. Stereotypic behavior refers to repetitive motor or vocal actions that do not have an apparent adaptive function (Gardenier, MacDonald, & Green, 2004). These behaviors can include hand flapping, moaning, body spinning, head shaking, rocking,
pacing, and manipulating small objects between one's fingers. These symptoms have an onset prior to age three.

Asperger’s syndrome, which is APA diagnostic code 299.80, is classified as a pervasive developmental disorder characterized by impairment in social interaction, restricted repetitive and stereotyped behavior, interests, and activities, no clinically significant cognitive delays, and no significant delays in language development (APA, 2000). Due to the criterion regarding no significant delays in language development, Asperger’s disorder is typically diagnosed later than autistic disorder as children under three years old are still usually experiencing large areas of growth in language development.

Pervasive developmental disorder, not otherwise specified (PDD-NOS) is assigned the APA diagnostic code of 299.80 and is defined as a pervasive developmental disorder characterized by impairment in social interaction or presence of stereotyped behavior, interests, and activities (APA, 2000). A diagnosis of PDD-NOS indicates that the diagnostic criteria for autistic disorder is not met due to atypical symptom presentation, a later age of onset, or symptoms of autistic disorder present, but not in the combination required for a diagnosis of autistic disorder.

Rett syndrome, also assigned the APA diagnostic code of 299.80, is classified as a pervasive developmental disorder characterized by normal prenatal development, normal head circumference at birth, and normal psychomotor development from birth to five months of age. Between 5 and 48 months of age, head growth decelerates, purposeful hand skills deteriorate, deterioration of social engagement is present, as is impaired
language development (APA, 2000). This is the only autism spectrum disorder that requires changes in physical growth and development for diagnosis. Rett syndrome also shows a different development pattern as children diagnosed with Rett syndrome exhibited typical social, emotional, and physical development until school age rather than regressing in infancy or during the toddler years.

Autism spectrum disorders typically involve a triad of symptoms. This triad includes (a) impairments in social interaction, (b) impairments in either or both verbal and nonverbal communication, and (c) restricted, repetitive, and stereotyped patterns of behavior, activities, and interests (Woods & Wetherby, 2003). Many children develop typically throughout infancy but then begin to display marked characteristics of autism as the child’s first or second birthday approaches (Bernabei et al., 1998). However, in a growing number of cases, children may begin exhibiting signs of autism as early as a few months of age and perhaps earlier. Some infants begin showing odd behaviors such as prolonged screaming or delays in eye contact with parents at a very young age (Ozonoff et al., 2005).

Mercer and Glenn (2004) found that children with autism and developmental delays often tended to have a pain response that is atypical as compared with children who are typically developing. Mercer and Glenn observed young infants as the infants received routine vaccinations. The researchers noted that infants with autism or developmental delays showed lowered response to pain, fewer grimaces, and less crying in response to the vaccination needle. Mercer and Glenn (2004) noted that decreased pain
expression could be the result of sensory processing deficits that often occur with autism spectrum disorders.

Wimpory, Hobson, Mark, Williams, and Nash (2000) interviewed 10 parents who had preschool-aged children with autism and 10 parents with preschool-aged children without autism. Using the Detection of Autism by Infant Sociability Interview (DAISI), the respondents answered questions regarding the presence or absence of 19 social engagement characteristics during the child's first 24 months of life. Wimpory and colleagues found that the parents of children with autism reported marked deficits in person-to-person engagement.

Woods and Wetherby (2003) argued that communication might be one of the most important of the autism spectrum disorder symptoms. The range of communication deficits among children on the autism spectrum can impact the ability of the children to interact socially, even with intervention (Fecteau, Mottron, Berthiaume, & Burack, 2003; Moony, Grey, & Tonge, 2006). Nonverbal children who are not able to develop alternate forms of communication, such as sign language or picture communication, will likely have a more difficult time in forming and maintaining appropriate social interactions while children with autism who have some form of communication can use that to learn to initiate and maintain social interactions. Woods and Wetherby (2003) also stated that if fluent speech can develop before age five, it generally indicates a more positive prognostic indicator of IQ, adaptive skills, and academic achievement. In addition, severe communication impairments can be a source of stress for families and caregivers who are unable to find a way to communicate with the children.
While communication difficulties are one of the main symptoms of autism spectrum disorders, the degree to which an individual on the autism spectrum is affected by communication deficits varies from person to person. A significant predictor of language development appears to be the presence of joint attention (Woods & Wetherby, 2003). Joint attention is defined as (a) the orienting and attending to another individual in a social partnership, (b) the shifting of gaze between people and objects that are involved in the interaction, (c) the sharing of either affect or emotions with the other person, (d) following the gaze and point of the social partner, and (e) being able to share experiences by drawing the partner's attention to objects or events (Woods & Wetherby, 2003). Language development was more likely to occur in children that had some level of joint attention, even at the gestural level than with children who had no joint attention.

In addition to joint attention, language deficits also appear to impair a child’s ability to properly utilize objects in the environment. Williams (2003) found that children who are diagnosed with autism tend to have difficulties not only relating to other people, but also in using objects. Williams argues that people play a major role in one's understanding of objects. In particular, parents often introduce objects and their proper use to infants. In many individuals with autism, there are marked deficits in the ability to use receptive and expressive language to understand situations. Therefore, communication and language deficits might lead to the child misinterpreting the use of objects. Because children with autism are not always able to understand the appropriate use of objects, functional play with toys, exploration of various objects, and using objects
for personal care is often markedly different from how those objects would be used in neuro-typical children (Williams, 2003).

In addition to differences in the use of objects, individuals with autism spectrum disorders also appear to focus on human faces in a different way than neuro-typical individuals tend to focus on human faces. Langdell (1978) determined that individuals with autism appear to focus on the lower half of the face to identify familiar people whereas most typically developing individuals will focus on the eyes and upper half of the face when identifying familiar people. Hobson, Ouston, and Lee confirmed the results (1988). Hobson and colleagues (1988) studied adolescents with autism. The participants were asked to identify emotions in faces portrayed on pictures. In the pictures where the mouth region was obstructed, the participants had difficulty identifying the emotions portrayed. This could help to explain why lack of eye contact is a prominent feature of autism spectrum disorders.

While much is known about the symptoms of autism, new research is being conducted in order to determine what factors might predict the development of autism spectrum disorders. Merin, Young, Ozonoff, and Rogers (2007) conducted research with the younger siblings of both typically developing children and of children with autism. Younger siblings of children with autism are considered to be high risk for the development of autism, as they have a 5% to 10% risk of being diagnosed with autism, compared to the 1 in 166 risk of the general public (Sumi et al., 2006). All of the infants were presented with the Still Face episode, in which the child's mother interacts with the child, then displays an expressionless face, and then continues to interact with the child
(Merin, Young, Ozonoff, & Rogers, 2006). In 11 out of 55 participants, the infants demonstrated significant diminished gaze to the mother's eyes and instead focused on the mouth region of the mother. Ten out of the 11 children who showed this focus on the mother had an older sibling who had been diagnosed with autism.

Wetherby and colleagues (2004) analyzed videotapes of 54 children who were selected from a pool of 3,026 children. Of the 54 children, 18 were diagnosed with an autism spectrum disorder, 18 were diagnosed with a non-ASD-related developmental delay, and 18 were typically developing children. Using the Communication and Symbolic Behavior Scales Developmental Profile, a sample of the children's behaviors were videotaped. An analysis of the videotapes identified nine behaviors that differentiated children in the ASD group from both the developmental delay group and the typically developing group. These behaviors included lack of appropriate gaze, lack of warm, joyful expressions with gaze, lack of sharing enjoyment or interest, lack of response to name, lack of coordination of gaze, facial expression, gesture, and sound, lack of showing, unusual prosody, repetitive movements or posturing of body and limbs, and repetitive movements with objects (Wetherby et al., 2004). In addition, four other behaviors were determined to differentiate the ASD group from the typically developing group, but not the developmental delay group. These behaviors included lack or response to contextual cues, lack of pointing, lack of vocalizations with consonants, and lack of play with a variety of toys (Wetherby et al., 2004). Ziatas, Durkin, and Pratt (1998) compared children with autism to those with specific language impairments and normal development by having the children complete tasks evaluating false beliefs, belief term
comprehension, and expression tasks. Ziatas and colleagues found that the children with autism performed significantly worse in all three tasks than children in language impaired and normal groups.

In addition to Wetherby and colleagues (2004), as well as Ziatas and colleagues (1998), Baron-Cohen, Baldwin, and Crowson (1997) also attempted to determine risk factors that might predict the development of autism spectrum disorders. Baron-Cohen, Baldwin, and Crowson (1997) used the Checklist for Autism in Toddlers (CHAT) on approximately 16,000 children. Of those 16,000 children, 19 children were identified at 18 months of being at higher risk for an autism diagnosis. Those 19 children were later diagnosed with autism. Each of those children experienced the following symptoms: (a) lack of protodeclarative pointing, (b) lack of pretend play, and (c) lack of gaze monitoring. At a follow-up of those 16,000 children at age 7 years, 94 children were diagnosed with autism. Baron-Cohen's research demonstrated that the current knowledge of symptoms of autism in toddlers is accurate at predicting the children who will be diagnosed with autism if they possess those characteristics. However, the current knowledge misses almost 60% of children who are later diagnosed with autism (Wetherby, et al., 2004).

There is no current known cure for autism, even though a wide variety of therapeutic interventions exist to target symptoms (Levy, Mandell, & Schultz, 2009). However, the autism spectrum includes a variety of severity, and a sizeable number of individuals who have a diagnosis of PDD-NOS, Asperger’s syndrome, or mild-moderate autistic syndrome are able to either progress enough to lose their diagnosis or live
independently and productively as adults (Helt, Kelley, & Kinsbourne, 2009). A significant number of individuals who gain verbal ability prior to age five, who have an IQ over 50, and who are not diagnosed as severely affected are able to decrease the severity of symptoms with age, although core deficits in social skills and communication often remain to some degree (Rapin & Tuchman, 2008). The prognosis often improves if the individual possesses some type of marketable skill that can be developed and utilized in an academic and employment setting (Helt et al., 2009).

In 2008, the rate of autism spectrum diagnosis was reported to be 1 in 166 children (Caronna, Milunsky, & Tager-Flusburg, 2008). A year later this statistic was broken down and reported that 1 in 500 children were diagnosed with autism, 0.6 in 1000 children were diagnosed with Asperger’s syndrome, and 1 in 270 children were diagnosed with pervasive developmental disorder-not otherwise specified (PDD-NOS) (Fombonne, 2009). This indicated a major increase in diagnoses from less than 1 in 1000 children being diagnosed in 1996 to 6 in 1000 children being diagnosed in 2007 (Caronna et al., 2008). On April 1, 2011, the Centers for Disease Control and Prevention (CDC) announced that 1% of children in the United States are diagnosed with an autism spectrum disorder, with a prevalence of 1 child in 110. The prevalence among male children was 1 in 70 male children (CDC, 2011). However, these statistics don’t account for increased awareness, more refined diagnostic tools, children who meet criteria for autism but don’t receive a formal diagnosis, and under-reporting. The true rate of autism diagnosis is not yet known, nor is it known how many individuals would have been diagnosed in 1996 if the standards set in 2007 had been applied (Fombonne, 2009).
Child Development Theories

Autism spectrum disorders are classified as developmental disabilities, and thus examining early concerns regarding development should occur within the context of what is considered to be appropriate childhood development. Speech and language, social, emotional, and cognitive development are all essential areas of examination in research regarding early symptoms of autism spectrum disorders (Woods & Wetherby, 2003). Many of the early symptoms of autism, such as lack of eye contact and difficulties being comforted, may also have a basis in the attachment processes of the infant and child.

Developmental theories refer to the set of theoretical approaches that define the accepted and typical path of human development (Blanc, Adrien, Roux, & Barthelemy, 2005). In addition, deviations from these typical developmental trajectories often signify a clinically significant event warranting further investigation. In order for typical and appropriate development to occur in any human, certain milestones must be met at various chronological ages.

Jean Piaget. According to Piaget, child development occurs in four stages: sensorimotor, preoperational, concrete operational, and formal operational (Piaget, 1953). The sensorimotor stage is of primary importance in the research on autism. The sensorimotor stage refers to children age birth to two years of age. During this stage, children are egocentric and work through various tasks in order to develop reflexes, reactions, curiosity, object permanence, and internalization (Piaget, 1953).

Within the sensorimotor stage, there are several sub-stages that infants move through. The first is the simple reflex stage, where infants engage in simple reflexes to
survive (Piaget, 1953). Some of these reflexes include rooting, suckling, and startle. The reflexes don't necessarily correlate with the action presented to the infant. For example, infants will root whenever anything touches his or her cheek, regardless of whether that object is a breast or bottle for eating, or if it is just a finger.

After the first month of life, the infant begins coordinating actions and consequences in the primary circular reaction phase (Piaget, 1953). In this phase, an infant will attempt to reproduce something that might have occurred accidentally. For example, if the infant accidentally puts her thumb in her mouth and begins sucking, she might later try to reproduce that accidental action due to the pleasurable consequence the action had (Piaget, 1953).

Around the middle of the first year of life, the infant enters the secondary circular reaction phase, where the infant begins to identify actions with consequences outside of him or herself (Piaget, 1953). In this phase, an infant might shake a rattle in response to the noise it makes or smile at a parent in order to receive a positive reaction from the parent. Children with autism can sometimes be stuck in this phase when spinning objects or mouthing them in order to receive the sensory pleasures that occur.

Towards the end of the first year of life, the infant begins to act intentionally (Piaget, 1953). The infant might act in order to receive something; for example, scooting across the floor to reach a desired toy. The child also begins to develop a sense of object permanence, or the knowledge that an object not in sight still exists (Piaget, 1953).

From a year old through 18 months of age, the infant moves through the tertiary circular reaction stage (Piaget, 1962). During this stage, the infant will attempt to use the
same object multiple ways in order to elicit different responses. For example, the toddler might use a pot to carry toys in, and then turn the pot over and use it as a drum.

The final stage in the sensorimotor stage is the early representational thought stage (Inhelder & Piaget, 1962). In this stage, children begin to think symbolically through rudimentary pretend play. A child in this stage might use a toy block as a telephone or wear a blanket as a hat. This stage is often difficult for children with autism, who often do not have the capabilities to see the world through symbols instead of concrete objects (Williams, 2003). Pretend play is often difficult for the autistic children, whom often see an object and only identify the literal meaning of the object instead of associating any symbolic meaning to the object.

The second major stage in Piaget's developmental theory is the preoperational stage (Piaget, 1962). During this stage, children are consumed with magical thinking and pretend play. In addition, children begin to refine motor skills. Children at the beginning of this stage are often quite egocentric, but move away from egocentrism towards the end of the stage.

The third major stage in Piaget's developmental theory is the concrete operational stage, which occurs from ages 7 through 12 (Piaget & Inhelder, 1962). In this stage, children are very concrete thinkers and are developing rudimentary logical thinking abilities. In this stage, children often require aids in order to refine their logical thinking. This correlates with the Montessori theory of development, which depends on the use of carefully designed manipulatives in order to teach a child to think logically about the
world around them (Montessori, 1949). Children at this stage are not egocentric and are developing the ability to be empathetic towards others and see others’ points of view.

The final stage in Piaget's developmental theory is the formal operational stage (Inhelder & Piaget, 1958). During this stage, children are able to think abstractly and logically without the use of concrete aids. Children are not egocentric and begin to show a concern about the world around them.

When a child is unable to successfully move through a particular stage, Piagetian developmental theory states that it is difficult to progress to a new stage. Thus, children with autism who are not able to master those Piaget-based tasks before age two may remain in the egocentric phase where exploration leads to the development of repetitive reactions instead (Lancy & Goldstein, 1982). If a six or seven-year-old child is still moving through the stages that typically developing children mastered at six to eight months of age, it becomes very difficult for the child to interact with same-age peers. In addition, it becomes very difficult for the child to progress through the stages enough to be able to form age appropriate relationships with other individuals, further damaging the child’s social, intellectual, and cognitive development (Lancy & Goldstein, 1982).

For example, in order for one to develop an awareness of self and others, one must develop the capacity to imitate others according to Piaget (1953). However, in children with autism, the ability to imitate others is often a skill that is delayed (Malvy et al., 1999). While typically developing children often learn imitation during infancy when imitating facial expressions and early language sounds, children with autism may not develop this characteristic until long after the child's first birthday. Delays in imitation
and early language sounds can lead to further delays in the child's ability to develop an awareness of self and others (Malvy et al., 1999). Furthermore, the deficit in developing an awareness of others could lead to noted symptoms of autism, including aloofness around others, poor or delayed social development, and language difficulties.

Albert Bandura. Bandura developed the social learning theory in order to describe how the learning process works (Bandura, 1986). Bandura hypothesized that individuals learn from other people through three modes: observation, imitation, and modeling (Bandura, 1977). When one observes a behavior, generally they are observing not only the behavior, but also the outcome of the behavior. Behaviors that appear to be rewarded or reinforced are then imitated in the observer. However, in typical development, Bandura believed that behaviors that were observed to result in punishment were not later imitated by the observer. This reciprocal interaction between people influences how individuals behave and respond in any given situation (Bandura, 1969).

In order to learn social behaviors, Bandura stated that individuals are required to have the capability for attention, retention, reproduction, and motivation (Bandura, 1977). Attention refers to whether an individual can orient to and attend to an action. In order to orient to and attend to an action, individuals must have the sensory capacities, including vision or hearing. If an individual is deaf or blind, the individual must be able to somehow compensate for those deficits so that he or she can attend to the behavior of others. An individual must also be able to be aroused enough to attend to the behavior. If an individual does not find a behavior exciting or arousing enough to attend to, the behavior will generally go unnoticed (Bandura, 1962).
Retention refers to the ability to remember what one attended to and code that information for future use (Bandura, 1977). Deficits in short-term working memory or long-term memory can negatively impact one's ability to retain information, and if one cannot retain information, it is difficult to then imitate and model the behavior. Once the information is retained, the individual must also be able to code the information to determine why the behavior occurred and what the result of the behavior was (Bandura, 1969).

In addition to attention and retention, individuals must also have the capability to reproduce the behavior (Bandura, 1977). If one attends to a handshake, can retain why the handshake happens, but does not have the motor capability to extend and shake a hand during a handshake, or is missing limbs, it becomes difficult for the individual to complete the social behavior unless the individual is able to compensate for the specific deficit.

Finally, one must have the motivation to imitate the behavior (Bandura, 1962). Motivation does not have to be the pure behaviorist form of reinforcer, and instead, one can have imagined incentives or just the intrinsic motivation of wanting to engage in the social act. If a social act is not motivating to the individual, the individual is not likely to engage in that social behavior (Bandura, 1962).

The social learning theory clearly illustrates the reason individuals with autism have difficulties in social situations. In the attention realm, individuals with autism may have sensory processing difficulties that lead to low arousal abilities or difficulties processing sensory information (Kranowitz, 2006). In the retention realm, individuals
with autism might have difficulty with short and long-term memory. In addition, those with autism might misinterpret and wrongly code the social behavior. If one wrongly codes the information or misunderstands the information, the ability to appropriately reproduce the action becomes compromised. If one is constantly producing the social action at the incorrect time, the individual will likely stop receiving any sort of reinforcer for engaging in that behavior, and may actually be punished for it. Difficulties in social learning can cross all domains in individuals with autism, making it difficult to engage in appropriate social interactions (Woods & Wetherby, 2003).

With many other disabilities, individuals can still engage in social learning if the ability to compensate for the deficit is there. If an individual has profound hearing loss, for example, the individual is often able to compensate for that deficit by reading lips and using sign language. However, with autism, there are likely multiple deficits across all areas of social learning, making compensating for the deficits incredibly difficult for the individual, leading to delays in social development (Woods & Wetherby, 2003).

**Developmental Theory and Autism**

Typically, developmental research involving children with autism and other disabilities focuses on the deviations from the typical path of human development (Kanner, 1943; Piaget, 1962; Lancy & Goldstein, 1982). However, Hodapp, Burack, and Zigler (1995) attempted to take the opposite approach. Instead of looking for deficits, the researchers attempted to determine what the developmental paths of children with developmental disabilities can tell professionals in the field about typical human development. Rather than focusing on research that provides relevant information for the
population consisting of individuals with developmental disabilities, taking the opposite approach can yield information that would potentially contribute the knowledge of development for both those with disabilities and those that are typically developing.

Developmental theories and frameworks when discussing autism spectrum disorders also encourage the comparison of children with autism to children of similar developmental levels (Burack et al., 2002). For example, instead of grouping all five year olds with autism into one category and comparing those children with typically developing five-year-old children for research purposes, developmental research found that it is far more relevant to divide the five-year-old children with autism into groups of similar developmental levels (Burack et al., 2002). For example, if a research study is examining the development of pragmatic language in children with autism, it is more helpful to group the children into categories of similar stages of language development, instead of grouping the children into similar age levels. Developmental theorists now agree that the typical developmental trajectory for children on the autism spectrum is not always correlated with a specific chronological age (Burack et al., 2002). Some five year olds with autism may have language skills similar to six month olds while others may be closer to four years old, and even above the chronological age in the case of Asperger’s syndrome.

Developmental theories influence the age at which autism spectrum disorders can be confidentially diagnosed. Currently, there is an established consensus in the autism field regarding core deficits that most individuals with autism experience to some degree (Sigman, Dijamco, Gratier, & Rozga, 2004). The core deficits are generally found in
individuals over two to three years old, and as a result, clinicians can be reasonably confident of a diagnosis made at this time. Glazer (2003) noted that there are particular symptoms that can be present shortly after birth that could signal an autism spectrum disorder, including lack of appropriate eye contact. However, Sigman and colleagues (2004) stated that prior to age two, the current list of core deficits are often confused with delays, resulting in clinicians being cautious to make a diagnosis prior to two or three years of age. However, Sigman and colleagues (2004) also noted that this large gap in the research and understanding of early signs of autism can also lead to difficulties in referring at-risk children for intervention at an early age.

In order attempt to make an earlier diagnosis of autism, strong research knowledge is needed for what constitutes typical infant development (Sigman et al., 2004). In addition to knowing what constitutes typical development, it is also important to determine whether potential atypical development is a delay that would be outgrown and likely occurs in only one developmental domain, or a deficit that might signal psychopathology.

Landa and Garrett-Mayer (2006) conducted research with 87 infants using the Mullen Scales of Early Learning (MSEL). The infants belonged to two groups: siblings of children with no autism diagnosis and siblings of children with autism and were thus considered to be high risk for developing autism. The children were assessed at 6, 14, and 24 months of age. In addition, at 24 months of age, the children were assessed for autism. The researchers found no difference in behaviors between either of the groups at six months of age. However, at 14 months of age, there was a significant difference in
performance on the MSEL in several domains for the infants who were later diagnosed with autism. However, there were no differences in Visual Reception and language development. At 24 months of age, the children later diagnosed with autism performed significantly worse across all domains on the MSEL. In addition, there was a significant reduction in language development between 14 months and 24 months of age (Landa & Garrett-Mayer, 2006).

Volkmar, Chawarska, and Klin (2005) argued that autism should be able to be detected in young infants because, as Kanner originally hypothesized, individuals with autism have deficits in even the most basic, early social processes. Volkmar and colleagues stated that these difficulties, which begin during infancy, can significantly impact all areas of development, including communication, socialization, and cognition. The research by Volkmar, Chawarska, and Klin are in contrast to the research of Landa and Garrett-Mayer, as Landa and Garrett-Mayer did not find any significant differences in the early infant development between those with autism and those without autism before age six months (2006). This can either be explained by discrepancies between what is considered a delay and what is within the realm of typical development, and also might be explained by the fact that some parents may attribute a symptom to autism once a child is diagnosed, even if the symptom was not related (Sigman et al., 2004).

Oppenheim and Goldsmith (2007) illustrated a novel way to utilize attachment theory in working with parents who had children on the autism spectrum. By using Bowlby's concept of bereavement, the researchers were able to assist parents in mourning the diagnosis of autism. Bowlby's concept of bereavement included mourning the loss of
a particular attachment, the loss of the attachment itself, and the resolution of the
bereavement (Oppenheim & Goldsmith, 2007). This resolution often involved moving on
to new attachments. When working with parents of autistic children, Oppenheim and
Goldsmith (2007) noted that often, parents were having a difficult time attaching to their
child due to seeing the child as merely the diagnosis of autism. Oppenheim and
Goldsmith (2007) noticed that parents who mourned following their children’s autism
diagnosis often mourned the loss of their expectations of how raising their child should
be. They mourned the loss of a perceived parent-child bond. Without appropriate
intervention, the researchers also noticed that the parents then no longer felt as attached
to their children.

Howe (2007) concluded that it was often not the child’s symptoms of the
disability that led to difficulties in attachment, but rather the interaction between the
child’s disability and the parent’s state of mind regarding the diagnosis that led to
difficulties in secure attachments. Oppenheim and Goldsmith (2007) encouraged the
parents to attempt to break the unhealthy attachment the parents had with the child’s
diagnosis, and then fully mourn the diagnosis and loss of the attachment to the autism.
Following that bereavement, parents were able to see beyond the diagnosis and develop a
healthy, secure attachment to their child rather than becoming attached to the diagnosis.

Van Ijzendoorn and colleagues (2007) studied attachment behaviors between 55
young children and their parents. There were four groups of children in the group,
including those with autism, mental retardation, delays in language development, and
typically developing children. The researchers utilized the Strange Situation procedures
to assess attachment behaviors in children. The researchers also utilized the Emotional Availability Scale to assess the parental sensitivity during periods of free play. Van Ijzendoorn and colleagues found no significant differences in the sensitivity of parents with children diagnosed with autism and that of parents with typically developing children. However, the attachment styles of the children were significantly different. In general, the more sensitive a parent was, the more securely attached the child was. However, that was not the case in the group where the children were diagnosed with autism. In that group, despite the level of sensitivity of the parent, the children showed disorganized attachment styles. However, the level of attachment disorganization correlated with the severity of the autism diagnosis, with those having a milder course of autism showing more secure attachments (Van Ijzendoorn et al., 2007).

The findings by Van Ijzendoorn and colleagues (2007) are in direct contrast to Bowlby’s attachment theory. Bowlby argued that all children would form a secure attachment if parents are sensitive to a child’s needs and respond appropriately (Bowlby, 1969). In addition, Bowlby hypothesized that disorganized attachment styles were caused by parents not responding consistently and appropriately to a child’s needs. However, Van Ijzendoorn and colleagues (2007) found that those with severe autism often developed disorganized attachment styles without regard to the sensitivity and responsiveness of the parents.

Rutgers, Bakermans-Kranenburg, Van Ijzendoorn, and Van Berckelaer-Onnes (2004) utilized the Strange Situation procedure to analyze the attachment behaviors in 140 children, including children with autism. The researchers determined that when all
severity levels of autism were taken into account, children with autism were statistically less securely attached to their parents than children without autism. However, the researchers determined that the difference was much less significant when only children with autism who had little or no cognitive impairment were analyzed. The only significant difference in attachment style appears to be among children with autism who also have a co-morbid diagnosis of mental retardation (Rutgers et al., 2004).

Rutgers, Van Ijzendoorn, Bakermans-Kranenburg, and Swinkels (2007) conducted research in which 42 Dutch clinical experts on autism and 17 international experts on autism research were asked to define attachment in children who have autism spectrum disorders. The researchers provided the experts with descriptions of attachment, descriptions of autism, and descriptions of two subtypes of autism. It was concluded that children with autism were able to show secure attachment behaviors to their parents even despite social and language deficits in the children.

Rutgers, Bakermans-Kranenburg, Van Ijzendoorn, and Van Berckelaer-Onnes (2004) conducted a meta-analysis of 16 studies on attachment in children with autism. Through the meta-analysis, it was determined that children with autism were able to form secure attachments with other individuals, including parents. The meta-analysis also illustrated that when compared with typically developing children, the level of secure attachment behaviors was lower in children with autism. However, Rutgers and colleagues (2004) noted that the differences between levels of secure attachment were present in children with lower functioning cognitive levels. In children with mild autism
and higher cognitive functioning, the levels of secure attachment were similar to those of typically developing children.

Naber and colleagues (2007) conducted research with 62 children who had autism, PDD-NOS, mental retardation, and language disorder. All of the children received diagnoses around the age of 42 months. In conducting the research, each participant underwent five weekly psychiatric examinations using standardized tests of social, emotional, and behavior analysis. Using the Strange Situation Procedure, each child underwent two separations and two reunions with the primary caregiver (Naber et al., 2007).

Unlike the meta-analysis by Rutgers and colleagues (2004) and the research by Rutgers and colleagues (2007), Naber (2007) found that the children in the atypically developing groups had a much higher rate of disorganized and insecure attachment behaviors and a much lower rate of secure attachment behaviors than did the children in the control group. Willemsen-Swinkels and colleagues (2000) found similar findings in research with 32 children diagnosed with pervasive developmental disorder-not otherwise specified, 22 children with a developmental language disorder, and 28 typically developing children. However the research by Willemsen-Swinkels and colleagues (2000) concluded that merely the presence of autistic behavior does not necessarily correlate with a disorganized attachment style as many of the children with PDD-NOS, and no other cognitive deficits or risk factors, did not have disorganized attachment behaviors. However, this research also supported the findings in the meta-analysis by
Rutgers and colleagues (2004) in that the severity of the child's autism correlated with an even higher level of disorganized attachment behaviors.

Similar research was conducted in 1997, finding that children with autism did show appropriate behaviors upon separation and reunion with parents (Dissanayake & Crossley, 1997). However, the researchers noted that the children with autism were far less consistent in the responses than were typically developing children. In addition, research has found that not only were the responses from the children with autism inconsistent, but also parents often responded to their children with autism in a different way (Doussard-Roosevelt, Joe, Bazhenova, & Porges, 2003). Doussard-Roosevelt and colleagues (2003) concluded that parents of autistic children were more likely to use less verbal cues, more physical contact, and more high-intensity behaviors during interactions than did those same parents with their non-autistic children.

According to many developmental theorists, there are certain trajectories that humans follow in the course of development, from infancy, through childhood, and into adulthood (Erikson, 1950; Piaget, 1952; Montessori, 1972). However, developmental theorists have not yet agreed on why developmental disabilities and disorders occur, especially when only one child in a family or environment is affected, even if all children in that environment share the same genetics and upbringing. Developmental theorists are now beginning to be aware of the fact that various influences, including life history, living situation, and other factors may put one at risk for atypical development (Burack et al., 2002). However, there is little explanation available as to why those changes affect
one individual in a different way than they affect other individuals living in the same or similar environments.

In addition to the potential influence of environment on the developmental trajectories, another controversy regarding the developmental theory is whether or not early developmental trajectories are actually different between typically and atypically developing children. Hodapp, Burack, and Zigler (1995) proposed the argument that there are universal sequences in development that occur, regardless of whether the child has a disability or not. These trajectories occur in almost every child, even if the chronological age of particular developmental milestones is different between typically and atypically developing children.

These developmental trajectories are most clearly noted in early developmental tasks (Hodapp et. al, 1995). For example, early language development typically involves simple cooing sounds, followed by single syllable babbling, followed by single syllable imitation, followed by repetitious two syllable babbling, followed by single words, and followed by two word combinations. In typically developing children, most of the early language development steps occur before the child reaches 18 months of age. In the theory by Hodapp and colleagues (1995), even if a child does not learn to verbally speak until adolescence or later, the same language development trajectory is followed rather than the child learning simple words without previously babbling and imitating. In contrast, typical research on developmental disabilities using a developmental approach often concludes that while similarities may occur in the completion of particular
Piagetian tasks, there are also differences in the developmental trajectories that occur if developmental milestones are delayed from typical development.

Happe, Ronald, and Plomin (2006) argue that the symptoms of autism are on a continuum, from typically developing through severely autistic. Happe and colleagues note that autistic-like characteristics can be found in the general population, as well as in the autistic population. For example, some children without autism may have difficulties joining into social groups and may prefer to play and work alone. Some children without autism may have difficulties keeping a two-way conversation going. In addition, there is no point at which one can easily determine where typical "shyness" or social difficulties end and clinical autism begin when each autistic-like characteristic is looked at in isolation. Repetitive behaviors, difficulties in communication, social difficulties, and rigidness occur in the general population to an extent.

Happe and colleagues (2006) determined that up to 10% of the population researched possesses one aspect of the autistic triad (social difficulties, communication difficulties, and rigidity), and displays the characteristic at such a high level that it is clinically significant. However, because those individuals only have one characteristic of the autistic triad, a diagnosis can't be made. The diagnosis is only made when all three areas of the triad are clinically significant, and the symptoms affect appropriate development.

**Parental Role in Autism Diagnosis, Treatment, and Research**

In retrospective accounts, it was determined that parents of children diagnosed with autism spectrum disorders often had concerns regarding the development of the
child during infancy (Woods & Wetherby, 2003). Parents are often the first ones to notice that their child is developing differently than his or her similar-aged peers. In addition, by the time the child was 18 months of age, many parents with children later diagnosed with autism expressed these concerns to a pediatrician or other physician (Woods & Wetherby, 2003).

One important experience noted by parents of children with autism is the ability to bond and attach to their child during infancy (Openheim & Goldsmith, 2007). Oppenheim and Goldsmith (2007) noted that often, parents were having a difficult time attaching to their child due to seeing the child as merely the diagnosis of autism. Howe (2007) concluded that it was often not the child’s symptoms of the disability that led to difficulties in attachment, but rather the interaction between the child’s disability and the parent’s state of mind regarding the diagnosis that led to difficulties in secure attachments. Rutgers, Van Ijzendoorn, Bakermans-Kranenburg, and Swinkels (2007) conducted research in which 42 Dutch clinical experts on autism and 17 international experts on autism research were asked to define attachment in children who have autism spectrum disorders. It was concluded that children with autism were able to show secure attachment behaviors to their parents even despite social and language deficits in the children. However, Rutgers and colleagues (2004) noted that the differences between levels of secure attachment were present in children with lower functioning cognitive levels. In children with mild autism and higher cognitive functioning, the levels of secure attachment were similar to those of typically developing children.
McConachie, Couteur, and Honey (2005) stated that following a child’s diagnosis of an autistic disorder, many parents report, in retrospect, that there were concerns with the child’s development long before the developmental evaluation occurred. In many cases, research suggests that parents report that the child developed typically until approximately 12 months of age, and then noticeable differences began to be noted (Eaves & Ho, 2004). Many parents reported concerns with lack of appropriate eye contact, poor motor imitation, lack of joint attention, lack of pointing and shared interest, and delays in communication (Maestro et al., 2005). These concerns may have been present prior to a year old, but became more evident once the child was a year old (Goin, & Myers, 2004).

More recent research indicates that many parents begin reporting concerns with their children’s development even during the child’s infancy (Young, Brewer, & Pattison, 2003). Parents typically report difficulties in regulatory behavior in infants as the primary concerns. Gomez and Baird (2005) conclude that a significantly higher portion of infants with regulatory difficulties was later diagnosed with autism than were infants who had little or no regulatory difficulties.

McConachie, Couteur, and Honey (2005) stated that following a child’s diagnosis of an autistic disorder, many parents reported that there were concerns with the child’s development in the months prior to the referral and developmental evaluation. In several documented cases, parents of autistic children noted that the child developed typically until approximately 12 months of age, and then clear atypical behaviors were noted (Eaves & Ho, 2004). The concerns most often reported by parents include the lack of
appropriate eye contact, poor motor imitation, lack of joint attention, lack of pointing and shared interest, and delays in communication (Maestro et al., 2005). Some parents may have reported these symptoms prior to the child turning 12 months of age. However, the symptoms were most evident and distinguishable after the child’s first birthday (Goin, & Myers, 2004).

Current research suggests that parents of children diagnosed with autism spectrum disorders actually began reporting concerns with their children’s development to the child’s pediatrician or other specialists even during the child’s infancy (Gomez & Baird, 2005). The most frequently reported concern was the infant’s difficulty in regulatory behavior (Young, Brewer, & Pattison, 2003). Gomez and Baird (2005) concluded that a significantly higher proportion of infants with regulatory difficulties were later diagnosed with autism than were infants who had little or no regulatory difficulties. These difficulties included problems with sleeping, difficulties being comforted, difficulties with eating, and extended crying, especially when in stimulating environments.

Goin-kochel, Mackintosh, and Myers (2006) stated that the first step in the diagnosis of autism is often a referral from a physician. This is typically followed by several evaluations from various specialists, including psychologists, speech pathologists, and occupational therapists. However, despite research suggesting parents often reported concerns in the child’s development, it is believed that parents often have to express concerns on multiple occasions before the referral for further evaluation is made (Midence & O’Neill, 1999; Siklos & Kerns, 2007).
Overall, the research on autism interventions concludes that the earlier a child with autism receives intervention, the better the child’s prognosis. Eaves and Ho (2004) stated that this positive impact is even more pronounced in children with higher functioning forms of autism spectrum disorders, including Asperger’s syndrome. In addition, the earlier a child is diagnosed with autism, the earlier interventions can be started.

Despite the accepted research regarding the success of early intervention, research also suggests that the average age of diagnosis is three years of age. However, research continues to demonstrate that autism can reliably be diagnosed prior to age three if the symptoms are detected and reported, and the referral for evaluation is made. Research also indicates that parents often can detect and report atypical development in children prior to the referral being made. The problem that exists with the current procedures in autism diagnosis and treatment is that parents appear to be able to detect symptoms of autism in infancy, yet the average age for diagnosis is three years of age. There appears to be some discrepancy between when a child is diagnosed with autism and how early a parent becomes concerned about the child’s development, what symptoms or concerns are present when the parent first becomes concerned, how early those concerns are voiced to a pediatrician or specialist, and how many times the parent expresses those concerns to the pediatrician or specialist before a referral for evaluation is made.

Practitioners in the Human Services field are often involved in the intervention process of children with autism spectrum disorders, often as behavior specialists, social workers for the family, individual counselors for the children, or as social skills
interventionists. In order for the interventions provided by Human Services professionals to be most successful, the child should receive the interventions as early as possible, including before age three (Eaves & Ho, 2004).

However, in order to begin those interventions, a formal diagnosis must have previously been made by a licensed psychologist and team of specialists. As the diagnostic system is currently set up, most interventions have the highest rate of success if begun prior to the child entering preschool, yet current diagnostic criteria and tests are not standardized for children prior to age three despite reported concerns from parents regarding the child’s development.

**Research Methodologies when Investigating Autism Spectrum Disorders**

**Content Analysis of Home Videos**

Content analysis in the form of videotapes was one of the most commonly used research designs when investigating early symptoms of autism (Sigman et al., 2004). In video analysis, researchers collect home videos from the infancy and early childhood of those children who were diagnosed with autism after two years of age. The behaviors and events in the videos were coded and categorized, and then compared with videos of neuro-typically developing children of the same age. Henry Massie used this form of research as early as 1975 by when he attempted to determine signs of psychosis in young children (Massie, 1975).

Video analysis presents several weaknesses. The first weakness was that the researchers knew the children’s diagnoses (Sigman et al., 2004). Therefore, it is possible
that some behaviors were coded as being "autistic behaviors" simply because the researchers were aware that the children were autistic.

Second, because parents were likely not aware that their children were autistic, the videos were not meant to be used in research. The events on the videotapes did not always match in content and age with other videos being analyzed (Sigman et al., 2004). One videotape might have been of a child's first birthday party where another videotape might have been of a nine month old's first Christmas. As a result, it is difficult to standardize behaviors and ages that those behaviors occur due to the fact that the videos and events were not matched for age among all research entries.

The third weakness of the video analysis research design is that the researchers cannot choose the events that will be included in the research prior to the research being conducted (Sigman et al., 2004). Because the researchers and parents do not know ahead of time which individuals will be diagnosed with autism, the researchers can only analyze videos months or years after those videos were taken once the child is actually diagnosed.

Osterling and Dawson (1994) analyzed the videotapes of the first birthdays of 11 children diagnosed with autism and 11 neuro-typically developing children. The researchers coded the videos for social, affective, joint attention, and communication behaviors. In addition, the videos were coded for symptoms of autism as defined by clinical diagnostic criteria. Osterling and Dawson (1994) determined that the lack of pointing, the lack of showing objects to others, the lack of looking at others, and the lack of responding to the child's name differentiated the autistic children from the non-autistic children after the videos were coded.
The study provided important information on the early signs of autism at one year of age. In addition, the videotapes could be matched for age and event among all study participants. However, the researchers also found the symptoms and signs noted in the autistic group to occur in three of the typically developing children as well. In addition, only seven of the 11 children in the autism group actually met the DSM-III-R criteria for autism; the other five children were either diagnosed with non-clinical methods or were strongly assumed to have autism but did not receive a formal diagnosis. Inconsistencies in diagnostic procedures and inconsistent screening of study participants for an autism diagnosis lends to difficulty in generalizing the results of the research. In addition, the videos varied in length from 3 to 29 minutes, making it difficult to determine whether parents were videotaping particular behaviors or whether the children who were displaying more autistic symptoms were not videotaped as long due to parental concerns with the behavior.

Clifford, Young, and Williamson (2007) attempted to utilize video analysis in order to determine early characteristics of autistic disorder in children. The researchers contacted 200 families from the Flinders University of South Australia, autism SA, Women's and Children's Hospital, and special needs schools in Australia. All of these families had a child diagnosed with autistic disorder, a developmental delay, or had a typically developing child that would be used as a control. Of the 200 families, 48 families consented to participation in the study and provided one or more home videos for analysis. Each video submission was a minimum of 15 minutes long and was recorded when the child was between 12 months and 24 months of age. The researchers
only allowed videos to be analyzed where the age of the children could be determined within two months at the time of the video recording.

Of the 48 families who gave consent for participation, 45 children were accepted as participants in the study (Clifford et al., 2007). The autistic disorder group consisted of 15 males. The developmental delay group consisted of nine males and six females. The typically developing group consisted of nine males and six females.

Each of the videos was coded using ten specific items that measured the frequency of social behaviors and seven items that measured the quality of social behaviors (Clifford et al., 2007). Inter-observer reliability was determined to be 80% for each of the 17 items. Frequency counts were taken throughout 25-minute periods for each video. In addition, a brief recording of an overall qualitative rating for the observed behaviors followed each five-minute observation. Clifford and colleagues (2007) determined that rather than impaired joint attention behaviors, early deficits in the autistic group involved dyadic social behaviors such as the quality of eye contact, nestling, positive affect, and social peer interest. In addition, the autistic disorder group demonstrated a lower rate of showing objects of interest to others.

Clifford and colleagues (2007) illustrated the weaknesses of the video analysis design. First, the research failed to determine the earliest symptoms and signs of autism because the earliest video submitted was of 12 months of age. One gap in current literature is the knowledge of autism signs that occur before a child's first birthday. The second weakness of the study is that there was less than a 25% response rate for contacted participants. Because 75% of the families contacted did not even respond to the
study, it is difficult to determine whether those 75% had videos that may have showed different signs than the 25% that were submitted. Third, the diagnoses of the children were known prior to the viewing of the videos, and so it is possible that behaviors were attributed to autism more often in the autistic disorder group than in the other groups, even if the behaviors occurred in the videos of the control and developmental disability groups. Finally, the researchers were not able to control for the type of videos received. Thus, not all videos may have been representative of the child's typical behaviors. In addition, the videos could not be matched for age or type of event.

**Observations of the younger siblings of autistic children**

In addition to video analysis, another popular research design entailed field observations of the siblings of known autistic children (Sigman et al., 2004). Sigman and colleagues (2004) noted that siblings of children with autism were at greater risk for being diagnosed with autism themselves. Therefore, it is reasonable to assume that when a group of siblings is observed, at least some of those siblings will eventually be diagnosed as autistic. Therefore, observations from birth can usually include early symptoms and signs of autism that might otherwise not be remembered by parents or professionals as the child grows older.

The ability to observe the children from birth and determine very early symptoms is a great advantage of this form of research (Sigman et al., 2004). Despite the benefits of sibling observation, there are still weaknesses that must be considered. First, the studies require very large sample sizes, because even in families where a child was diagnosed with autism, the prevalence of autism among siblings is still only approximately 6%
(Sigman et al., 2004). The researchers must spend considerably large amounts of time and resources observing and assessing all of the siblings in the sample for several years before learning which 6% will actually be diagnosed with autism and produce usable research results. The second major weakness in this type of research is that currently, research has not been able to consistently demonstrate what determines typical early social development and what is classified as a core deficit in early social development (Sigman et al., 2004). Without this knowledge, it is quite difficult to conceptualize a long term research project assessing for particular early signs of autism or atypical development.

Landa and Garrett-Mayer (2006) conducted research using the sibling observation technique. The researchers studied 87 infants, with half of the children being siblings of autistic children and half of the children having no autistic siblings. Using the Mullen Scales of Early Learning (MSEL), the children were assessed at 6, 14, and 24 months of age. In addition, at 24 months of age, the children were assessed for autism. The researchers found no difference in behaviors between either of the groups at six months of age. However, at 14 months of age, there was a significant difference in performance on the MSEL in several domains for the infants who were later diagnosed with autism.

The study by Landa and Garrett-Mayer (2006) was able to provide very important information regarding the early development of children with autism. However, one weakness of the study was that 87 children were studied to determine early symptoms of autism, and only 24 of those children were later diagnosed with autism. Of those 24 children, two were from the control group. Therefore, not only was half of the high-risk
group able to provide data regarding early symptoms of autism, but two children from the control group were also diagnosed with autism, potentially altering the control group results. In addition, there was no long-term follow-up, so it is not known whether any of the children would have been diagnosed with autism at age three or later. Because this research observed children almost two years before a diagnosis could be made, all of the data collection occurred with the assumption that one group was high risk for autism and the other group was low risk for autism, but the researchers did not know which children in either group would later be diagnosed. In addition, without an even longer follow-up, additional diagnosis of children could be missed.

**Parent Interviews**

In addition to sibling observations and the analysis of videotapes, interviewing parents of children with autism is a commonly utilized research method. In this design, parents are either asked to fill out questionnaires or they are asked to participate in interviews. These methods often involve determining the experiences of autism from the parents’ perspectives.

Hoppes and Harris (1990) researched the perceptions of child attachment and maternal gratification in mothers of children with autism. In order to conduct the research, Hoppes and Harris administered questionnaires to 17 mothers of children with autism and 21 mothers of children with Down syndrome. In addition, ten mothers in each group were selected for open-ended interviews in addition to completing the questionnaires. These individuals were chosen from a pool of over 100 women, indicating a response rate of almost 36%. Participants for the open interview were
selected by choosing the first ten mothers from each group to volunteer. The research design might have been inherently weak due to a low response rate for the questionnaire and the interview group being chosen simply from the first ten individuals to volunteer. It is unknown whether there were significant differences between those who chose to participate and those who did not respond in time to be chosen.

Hoppes and Harris (1990) discovered that parent perceptions of the behavior of the children were more positive the older the parents and children were and the further from the age of diagnosis the child was. Hoppes and Harris theorized that it is possible that parental answers to interviews changed over time, with more severe or negative reactions occurring immediately after diagnosis and more positive reactions occurring the further from the age of diagnosis the child was. The chance that perceptions of particular events can change over time is a weakness of relying on parental perceptions and interviews. The answers on the questionnaire or interview may not always be exactly representative of the actual course of events. However, Gomez and Baird (2005) noted that parental reports of symptoms of autism in their children’s infancy often correlated with a diagnosis of autism one to three years later.

**Summary of Research**

There are several diagnoses that are referred to under the umbrella term *autism spectrum disorders*. Currently, autistic disorder, Asperger’s syndrome, pervasive developmental disorder-not otherwise specified (PPD-NOS), and Rett syndrome are considered to be the autism spectrum disorders (Howlin & Moorf, 1997). Currently, the diagnostic rate for autism spectrum disorders is 1 in 110 children each year (CDC, 2011).
According to McConachie, Couteur, and Honey (2005), the diagnosis is made on average by three years of age.

The history of autism spectrum disorders is long, yet the majority of the research and advances in the study of this disorder have occurred only within the past two decades (Glazer, 2003). Early theorists, such as Kanner, compared autism to schizophrenia and suggested that social and attachment delays in autism were the result of the inability of parents to attach to the child. More recent research, however, indicated that social deficits in autism were not the result of parenting and that children with autism were able to show attachment behaviors, but they often demonstrated atypical social behaviors.

Current research suggests that parents of children diagnosed with autism spectrum disorders actually began reporting concerns with their children’s development to the child’s pediatrician or other specialists even during the child’s infancy (Gomez & Baird, 2005). The most frequently reported concern was the infant’s difficulty in regulatory behavior (Young, Brewer, & Pattison, 2003). Gomez and Baird (2005) concluded that a significantly higher proportion of infants with regulatory difficulties were later diagnosed with autism than were infants who had little or no regulatory difficulties. These difficulties included problems with sleeping, difficulties being comforted, difficulties with eating, and extended crying, especially when in stimulating environments. Current literature in attachment theory primarily focuses on the parent-child attachment and bonding process when the disruptions are the result of parental factors, such as mental illness or separation.
Hypotheses

Hypotheses for this study included:

H1: Parents of children with Asperger’s syndrome or mild autism will report deficits and variations in the development of their child across multiple domains, including cognitive, social, emotional, and physical development. These deficits and variations will likely correspond to many of the symptoms of autism as listed in the DSM-IV-TR for an autism spectrum disorder. However, there will also be important differences between the symptoms parents notice in their children with mild forms of autism and the symptoms presented in the DSM-IV-TR.

Null hypothesis: Parents of children with autism will not report deficits and variations in the development above what is in the typical and known range of normal for early childhood development.

H2: Parents of children with an ASD will report sharing their concerns with a pediatrician or physician during the child’s first year of life. It is hypothesized that the majority of parents will perceive their first report of concerns as being ignored, brushed off, or not leading to referrals to a diagnostic team for further evaluation.

Null hypothesis: Parents of children with an ASD will report not sharing concerns with a pediatrician or physician prior to the child having a referral for an autism diagnosis. Therefore, there will not be a significant number of parents reporting perceptions of being ignored or brushed off.

H3: Parents will report delays of a minimum of 18 months to 2 years between the time they first report their concerns to a physician before a formal diagnosis is made.
Null hypothesis: Parents will report that no delays existed between the time the first concerns were noted and a formal diagnosis was made.
CHAPTER 3. METHODOLOGY

The purpose of this study was to identify the concerns that parents of children later diagnosed with Asperger’s syndrome or mild autism have regarding their child’s development prior to two years of age. In addition, the study examined parents’ experiences of the autism diagnostic process and the length of time between when parents first become concerned with the child’s development and the final diagnosis. The total length of time and parents’ experiences of the time between the parents’ first concerns and the final diagnosis was also investigated.

Better understanding the discrepancy between parents’ notice and when professionals respond could contribute to earlier diagnosis or prediction of autism. With this knowledge, practitioners could begin to ask parents during the first 12 to 24 months of the child’s life whether the parents have any concerns regarding the development of the child. This could potentially allow counselors or other health providers to intervene at the youngest possible age. The earlier an intervention is administered, the higher the rate of a positive prognosis (Eaves & Ho, 2004).

Autism spectrum disorders are being diagnosed at high enough rates that many counselors and individuals in the Human Services field will likely encounter either a child with autism or a parent who has concerns about the child’s development (McConachie et al., 2005). In addition, the results of the study may lead to further research that may impact the age at which mental health practitioners can begin providing interventions to children diagnosed with an autism spectrum disorder. This can be accomplished by helping practitioners to identify potential symptoms of autism early in a child’s life.
It is anticipated that the study will advance theory by illustrating differences between the expected developmental course of Asperger’s syndrome and the expected developmental course of more moderate or severe forms of autism within the first two to three years of life, which is a current gap in the literature. The research addresses the deviations from typical child development and as such, will potentially advance developmental theory. In addition, it is anticipated that the study will help practitioners better support parents during the autism diagnostic process.

Participants

The CDC (2012) estimates that there are 1,000,000 children under the age of 21 with a formal autism diagnosis, with approximately a third of those meeting criteria for Asperger’s syndrome or mild autism. In order to have a 95% confidence level and an 8% confidence interval, a sample size of 100 participants was needed. All parents must have had at least one child who meets DSM-IV-TR criteria for an ASD, and a psychologist, neuro-developmental specialist, or other qualified autism specialist must have made the diagnosis. For the purposes of this study, the child must have been formally diagnosed with an autism spectrum disorder, the child must be verbal, and the child must be of average or above average intelligence. Parents of children with a related condition such as Sensory Processing Disorder, without the official autism spectrum disorder diagnosis were not included in the participants’ group from analysis.

If a parent had more than one child with a confirmed diagnosis of an ASD, the parent was asked to answer all questions according to the experience with the child who was diagnosed with an ASD first. The parents participated by completing a series of self-
administered questionnaires and assessment tools. Included in this chapter is the
identification and recruiting of participants, the instrumentation that will be used, and the
procedures for data collection and analysis.

The sample was limited to volunteers from across the United States. Using a non-
random sample of participants is advantageous because HIPAA privacy laws limit access
to medical information, making it difficult for the researcher to be able to randomly select
a sample of participants out of the population. The volunteers acknowledged that they
were willing to participate in a study regarding their experiences with autism. However,
there were limitations in using a non-random sample. The most important limitation was
that it was difficult to know whether there is a particular segment of the population that
has been excluded from participation. In addition, there was a risk that the results may
not be representative of the entire population if some groups are over-represented in the
sample and some are under-represented. No limitations on the gender, socioeconomic
status, race, or the education of the parents were made.

The most important limitation was that it is difficult to know whether there is a
particular segment of the population that has been excluded from participation. The
research design potentially contributes to an unintentional limitation due to the fact that
some populations may not have had a chance to be included due to lack of access to the
Internet or knowledge of the IAN website. This may be due to education level,
socioeconomic status, or geographic location. In addition, there is a risk that the results
may not be representative of the entire population if some groups are over-represented in
the sample and some are under-represented.
Participants were recruited using the Kennedy Krieger Institute’s Interactive Autism Network (IAN). The IAN Project gathers willing volunteers from across the country and matches them with research projects where parents who have autistic children are sought as participants. The researcher submitted a brief summary of the research along with a call for participants to the administration of IAN. Once the administrators approved the application, the administrator sent the call for participants to a sample of 100 individuals randomly selected from all eligible database members. There are currently approximately 45,000 parents who are registered participants on the IAN network (IAN, 2011). Each participant was given the direct link to the survey and informed consent page in the initial recruitment email and did not have direct contact with the researcher.

**Instruments**

A convergent parallel mixed methods design was used in the study. Both the qualitative and quantitative data was gathered concurrently. Both sets of data had equal weight. The results were merged during interpretation in order to gather a more complete view of the parent experiences.

The quantitative portion of the study involved the participants answering questions on the First Year Inventory-Retrospective Version and Howlin and Moorf’s (1997) demographics questionnaire. All questions had a yes or no answer, a multiple-choice answer, or will involve a rating on a scale. The quantitative aspect of the study provided numerical data that was compared between several subgroups in the participant population.
The qualitative portion of the study involved open-ended questions on the demographic questionnaire. Parents used their own words and wrote one or more paragraphs about their experiences, thoughts, feelings, and emotions. These answers were then coded by keywords. The qualitative aspect of the study provided insight into the parents’ experiences in their own words, rather than asking participants to choose between provided choices. This provided extra information that was missing in current research.

First Year Inventory—Retrospective Version (FYI-RV)

The First Year Inventory—Retrospective Version is a relatively new assessment instrument created by Watson, Baranek, Crais, Reznick, Dykstra, and Perryman (2007). The instrument targets parents of children who are 12 months old and are at risk for autism spectrum disorders. Watson and colleagues (2007) determined that those at the highest risk for developing an autism spectrum disorder exhibit certain characteristics even at a young age, including a reduced ability for eye contact, pretend play, and meaningful interaction. The assessment was created in response to the desire to diagnose autism at a younger age.

Watson and colleagues (2007) claimed that differences in development between children with autism and neuro-typical children could be detected as early as nine months of age. Most of the available assessment instruments are standardized for use in children older than 18 months old. Therefore, even if differences in development could be detected in children as young as 9 months of age, a formal diagnosis of autism could not be made until 18 months of age at the earliest. In addition, no available instruments allow
researchers and clinicians to accurately and reliably obtain retrospective data from parents of children suspected of having an autism spectrum disorder.

The FYI-RV is a questionnaire of 63 identifiers of autistic disorders that typically emerge prior to the 12th month of life (Watson, et al., 2007). These identifiers included unusual behaviors, the absence of typical behaviors, and typical behaviors that only occur with extensive assistance from outside individuals such as parents. Of the 63 items on the questionnaire, 46 include the response choices of never, seldom, sometimes, and often. Fourteen of the items are multiple choice questions that ask respondents to identify a behavior from a series of behaviors that their children exhibited during the first year of life. One of the 63 items requires parents to choose from a list of possible sounds to indicate which sounds their child was able to produce as an infant. Two items are open-ended questions where parents can indicate concerns about development, medical characteristics, or unusual physical attributes of the child (Watson et al., 2007).

The FYI-RV measures eight separate constructs and two domains that were determined to be important features in child development (Watson et al., 2007). The two domains include the Social-Communications domain and the Sensory-Regulation domain. The constructs in the Social-Communications domain refer to how the child interacts with others. In the Social-Communications domain, the four constructs are as follows: Social orienting and receptive communications, imitation, social affective engagement, and expressive communication.

Social orienting and receptive communications refers to the child’s ability to make eye contact with someone who is talking to him or her, the ability to turn towards
someone speaking the child’s name, and the ability to understand simple language spoken to the child (Watson et al., 2007). Imitation refers to the child’s ability to copy the actions of other people. Social affective engagement refers to the ability of the child to share in emotional experiences and to demonstrate appropriate emotions in a given situation. Expressive communication refers to the child’s ability to verbally utilize language in an age-appropriate manner (Watson et al., 2007).

**Reliability.** The FYI-RV was normed using responses from 1496 parents of 12-month-old children (Watson et al., 2007). When using cutoff scores at or above the 90th percentile in the normative sample, the sensitivity of the FYI-RV is .92 with a specificity of .78 (Watson et al., 2007). With regard to the average split-half reliability correlation of the First Year Inventory across all possible splits, the Cronbach's alpha score was .81 (Reznick, Baranek, Reavis, Watson, & Crais, 2007).

**Validity.** The First Year Inventory was determined to be a valid instrument for classifying children as being at risk or not at risk for an autism spectrum disorder (Watson et al., 2007). Watson and colleagues (2007) state that setting the score threshold at the 90th percentile produces results with a very high sensitivity level and a negative predictive value. However, the 90th percentile threshold results in a lower specificity and positive predictive value. If one uses a 98th percentile threshold, the results produce an increased specificity and positive predictive value but a lower sensitivity and lower negative predictive value.

The instrument creators noted that the optimal threshold is dependent on the clinician's purpose in using the First Year Inventory. The 98th percentile threshold was
deemed appropriate for research that seeks to identify those children with more severe manifestations of ASD. However, up to 30% of children with ASDs would not be identified at the 98th percentile threshold. Most of that 30% percent would include those with symptoms placing them at them mild to moderate end of the autism spectrum. Watson stated that using the 90th percentile threshold is more appropriate than the 98th percentile threshold if the research involves epidemiological research or large-scaled screenings that attempt to identify infants at risk for ASDs.

**Demographics Questionnaire**

Howlin and Moorf (1997) wrote and published the demographics questionnaire. The questionnaire was used to survey 1,300 parents of children with autism in the United Kingdom. Howlin and Moorf were examining parents’ experiences and satisfaction with the autism diagnostic process.

The questionnaire items include the age of the child when the parent first began having concerns, the types of concerns present, and the age of the child when the parent first sought help. In addition, the questionnaire includes items regarding the type of help the parent was offered, what type of diagnosis was made, and who made the diagnosis. Finally, participants are asked to rate their level of satisfaction with the process and the help received, state the most useful form of help offered, and state any additional information or reflections in the diagnostic process.

Some of the items on the demographics questionnaire are multiple-choice questions, with participants being asked to choose one or more answers. Some additional items ask the participants to provide a single written answer, such as an age, date, or
location. Some items allow the participants to rank an experience or satisfaction level using a scale. Finally, some test questions ask the participants to write multiple words, sentences, or paragraphs in order to describe personal feelings and experiences.

The demographics questionnaire by Howlin and Moorf (1997) does not have any available published psychometric properties, as it has not been published for public or clinical use. Instead, the tool was used as a demographics questionnaire in a study conducted by the questionnaire’s author. The authors of both questionnaires have given written consent to utilize the questionnaires in this research.

**Procedures**

Once the Capella University Institutional Review Board approved the study, the Interactive Autism Network (IAN) was contacted and the research proposal was submitted for review. After the IAN reviewed the proposal, a call for participants was emailed to the potential participants by the coordinator at the IAN Project. All calls for participants included an email address where potential participants could contact the researcher for further information regarding the study. To help ensure that participation was voluntary, all potential participants did not have direct contact with the researcher and instead the initial call for participants included a direct link to the study to complete if the individuals chose to participate.

The researcher’s survey page was located at http://www.surveymonkey.com. The Survey Monkey link first directed the participants to an informed consent form that must have been completed and submitted electronically prior to the participant gaining access to the questionnaires. Following the submission of the informed consent form, the
participants were directed to the online questionnaires. These questionnaires were versions of the standardized tests and demographics questionnaire that were entered into Survey Monkey by the researcher following written permission from each of the authors or publishers of the standardized tests used. The standardized tests were entered exactly as they appear in the paper-testing booklet, with none of the questions altered or deleted from the original version. Once the participant had electronically submitted the research materials, the participation period of the study was considered complete. As part of the electronic submission, the participant were given an email address to contact the researcher for further information or to discuss concerns, questions, or the final results if desired. The participants also had the opportunity to provide an email address in order to receive a $10 Amazon.com gift card. The email address was not linked to the survey answers and was not used to identify participants. All participants were offered a gift card whether or not they chose to complete the study.

Following the completion of the data collection procedures, the researcher checked each survey for completeness. The surveys that did not indicate that the child had a formal autism spectrum disorder diagnosis were removed from the final analysis. All remaining data was entered into Microsoft Excel for analysis. To ensure the confidentiality and privacy of the participants, no identifying information was on any of the surveys. All survey results were downloaded from Survey Monkey and stored on a removable USB drive. Following analysis of the data, the removable USB drive as locked inside of a filing cabinet in the researcher’s home office. This filing cabinet is only accessible by the researcher. The USB drive will be destroyed seven years
following the completion of the study. In addition, all data as aggregate data and did not use information personally identifying the participants.

**Data Analysis**

**Q1: How do parents describe the social, emotional, cognitive, and physical development of their child during the first year of the child’s life?** In order to examine this research question, the researcher first measured the central tendency for the following aspects of the demographics questionnaire. The researcher determined the mean gestational age of the children, as well as the standard deviation. The researcher determined the grouped frequency distribution for questions relating to the type of birth the child had and the types of symptoms noted in the child from birth to three years of age. The mean and standard deviation were determined for the age of the child when the parents first noted concerns about the child’s development.

**Q2: How do parents describe their experiences reporting concerns to pediatricians early in the life of their child?** The mean and standard deviation were determined for the age of the child when the parents first reported concerns to the child’s pediatrician and the number of times the parents reported concerns before a referral was made. The mean and standard deviation were also determined for the number of months between when the first report was made and when the referral for further evaluation was made.

In order to analyze the parents’ descriptions of their experiences in reporting their concerns, descriptions of the reporting process were coded by keyword and analyzed for existing themes. The keywords were categorized into feelings of the parent, actions and
behaviors of the parent, and actions and behaviors of the pediatrician or early intervention team. The data was reviewed for any significant deviations from these prominent themes. If deviations occurred, the researcher attempted to determine any relevant factors that might have resulted in the deviations.

**Q3: How do parents describe their experiences with the diagnostic process?**

The mean and standard deviation were determined for the number of specialists the child was referred to prior to the final diagnosis and the number of months between referral and diagnosis. The open-ended question on the demographics questionnaire regarding the parents’ feelings of the diagnostic process were coded by keyword and analyzed for themes that may have existed. The keywords were categorized into feelings of the parent, actions and behaviors of the parent, and actions and behaviors of the referral or assessment team. The data was also reviewed to see if there are any significant deviations from these themes, and if so, the researcher attempted to determine if any factors occurred that might have lead to those deviations.
CHAPTER 4: DATA COLLECTION AND ANALYSIS

Introduction

The purpose of this qualitative and quantitative mixed methods study is to investigate parent experiences with the symptoms of Asperger’s syndrome or mild autism prior to two years of age. In addition, the research studied parent experiences with the autism diagnostic process. Based on the inclusion criteria, 96 parents of children diagnosed with mild autism or Asperger’s syndrome were asked to complete a series of questionnaires about their experiences with the symptoms and diagnostic process of Asperger’s syndrome.

Chapter 4 describes the results of the mixed methodology study conducted in February 2013. The first section will describe the sample for the study, including relevant demographic characteristics. Following the description of the sample, a brief summary of the results will be included. Next, a detailed description of the results will be provided. The summary will include statistical results relevant to the quantitative research questions, as well as the descriptive data relevant to the quantitative research questions. Finally, the conclusion will summarize the results as they relate to the research questions and hypotheses.

Description of the Sample

The subjects for this study were recruited using the assistance of the research database of the Interactive Autism Network, also known as IAN. This database belongs to the Kennedy Krieger Institute and Johns Hopkins Medicine in Baltimore and is sponsored by the Autism Speaks Foundation. The purpose of the IAN Project is to
connect individuals affected by autism spectrum disorders with researchers studying the ASDs. Currently, there are 43,709 individuals registered in the database (IAN Project, 2013). These individuals are primarily parents who have children diagnosed with a form of autism. Those who are registered are able to volunteer or be recruited to participate in studies conducted by corporations, universities, and other research organizations. The IAN Project recruiting coordinator was given a Capella-approved recruiting script and participant requirements. The coordinator took a random sampling of 100 individuals in their research database that met the following criteria:

- Respondent must be between the ages of 18 and 62 years of age.
- Respondent must have a child diagnosed with an autism spectrum disorder of mild severity or Asperger’s syndrome.
- The child who was diagnosed must be able to utilize verbal speech and demonstrate an average or above average IQ score based on the child’s initial diagnostic testing or school reports.
- The respondent must be able to read and type in English.

The first recruiting email resulted in 89 participants agreeing to be part of the study. However, 13 surveys were not included in the analysis as those individuals chose not to complete the survey. Three ended the participation following providing informed consent but before beginning the study and the remaining 10 withdrew from the study after completing the demographics questionnaire but prior to completing the research questions. The IAN Project conducted a second email recruiting effort to an additional
random sampling of 10 individuals who met the criteria. Seven individuals responded to the email and completed the study.

In total, 96 participants completed the study. The researcher hoped to achieve a 95% confidence level and an 8% confidence interval. The CDC estimates that there are approximately 1,000,000 children in the United States with an autism spectrum disorder, and approximately a third of those diagnosed with an ASD meet criteria for Asperger’s syndrome or mild autism. The actual number of participants resulted in a confidence interval of 10% with a 95% confidence level.

Each participant was asked to answer the questionnaires using the data for the first child in the family to be diagnosed with an autism spectrum disorder. Of the 96 children, 83 children (86.46%) were male and 13 children (13.54%) were female. All of the children were diagnosed with an ASD prior to turning 18 years old with the respondents all listed as the primary caregiver at the time of diagnosis. Of the 96 respondents, 92 individuals (95.83%) identified herself as the biological mother, three individuals (3.13%) identified as the biological father, and one (1.04%) identified as the custodial grandparent. None of the participants identified themselves as being the adoptive parents, foster parents, or stepparents of the children.

Fifty-nine children (61.46%) were the first-born children in the family. Twenty-nine children (30.21%) were second-born children in the family. Five children (5.21%) were identified as being the third-born in the family. Finally, three children (3.13%) were the fourth-born children in the family.
The children in the study were all diagnosed with an autism spectrum disorder between the years 1980 and 2009. Two children (2.10%) were diagnosed between 1980 and 1989, 31 children (32.30%) were diagnosed between 1990 and 1999, and 63 (65.63%) were diagnosed between 2000 and 2009.

**Summary of Results**

**Q1: How do parents describe the social, emotional, cognitive, and physical development of their child during the first year of the child’s life?**

The majority of participants reported a typical gestational period with children born after a full-term pregnancy. However, a significant number of participants reported prematurity and serious complications during pregnancy, birth, or the neonatal period. Almost all of the study participants reported having significant concerns about their children’s development before the child turned two years old. Finally, when asked to rate whether their children exhibited developmental characteristics never, seldom, sometimes, or always, children diagnosed with Asperger’s syndrome or mild autism exhibited a mix of atypical and typical characteristics of child development, including characteristics of typical development that are not thought to occur frequently in children diagnosed with autism spectrum disorders.

**Q2: How do parents describe their experiences reporting concerns to pediatricians early in the life of their child?**

All 96 participants reported discussing developmental concerns with a pediatrician or developmental specialist. However, the response received by the participants varied considerably. Out of the 96 participants, 39.58% were told that there
were no problems, the child would grow out of the concerns, or to wait until the child was older to address the concerns. Out of all participants, 45.83% were referred for further evaluation after concerns were reported. Only 32% of the children received a diagnosis of an autism spectrum disorder following the initial reporting of concerns.

Q3: How do parents describe their experiences with the diagnostic process?

Participants were given the opportunity to describe the diagnostic process in their own words. When asked to discuss their own emotions of the diagnostic process, half of the participants stated feeling that pediatricians, therapists, medical professionals, or the school district dismissed their concerns or didn’t provide an adequate response to parental concerns or requests for help. One parent stated, “The whole thing made me know that no one cared about him because they just wanted him to go on hyperactivity medication even though he didn’t have hyperactivity.” Another parent said, “It felt like no one would listen to me.” A third said, “No real help here. Just pushed through the system.” Another parent stated, “I was told by the doctor that he didn’t have autism and not to worry because he made eye contact.” One parent stated, “I feel that doctors need to listen to parents when they say something isn’t right with their child. Had we been listened to, our son would have had a diagnosis much sooner than 5 ½.”

Nearly a third of participants reported negative emotions of the diagnostic process. One parent stated, “I know now that he had all the classic signs. I just wish someone had helped us. I felt like such a bad parent.” A second parent said, “It was devastating, even though I had a feeling something as major as this was wrong.” Another
parent said, “It was an overwhelming process. We were given information and then
basically told to have a nice day.”

Approximately 40% of participants reported a negative outcome with the
diagnostic process. A parent revealed, “Very little family support was given. With the
first diagnosis, we were given a pamphlet that began with ‘Autism is the most tragic of
all childhood illnesses’.” Another parent stated, “There was no help available at the time.
I had to order a book from England to educate myself on Asperger’s syndrome.” A third
parent stated, “We were told things but then set adrift with limited or no resources
available.” Another parent responded, “Finally diagnosed after two years by a child
psychiatrist. Process was grueling. Even the pediatrician alluded that I (his mom) was
contributing to my son’s behavior.”

A third of participants reported a positive outcome from the diagnostic process.
One parent said, “The behavior analyst was informative and positive after the neurologist
gave us no hope.” Another said, “The first diagnostic process was pretty easy considering
the overwhelming stress you face when dealing with words like ‘autism’ for the first
time.” A third participant stated, “The school did its own analysis and put into place an
IEP with accommodations that have sufficed.” Another participant stated, “I feel the
health providers did a very good job.”

Finally, five participants (5.20%) responded with keywords grouped into the
positive parent emotions theme when discussing the diagnostic process. One participant
said, “I was very blessed to have Dr. {Name Redacted} as a pediatrician who was
lightening fast to begin intervention.” Another stated, “The initial feeling of the process
was fear, but so relieved after getting the help my son needed.” A third stated, “It was a relief to finally have an explanation.”

**Analysis of Findings**

This study focused on answering three primary research questions. These questions include the following:

Q1: How do parents describe the social, emotional, cognitive, and physical development of their child during the first year of life?

Q2: How do parents describe their experiences reporting concerns to pediatricians early in the life of their child?

Q3: How do parents describe their experiences with the diagnostic process?

These questions were answered by the 96 participants through the use of the First Year Inventory—Retrospective Version created by Watson, Baranek, Crais, Reznick, Dykstra, and Perryman (2007), and a demographics questionnaire created by Howlin and Moorf (1997). Participants were asked to complete these questionnaires online using the website http://surveymonkey.com.

**Q1: How do parents describe the social, emotional, cognitive, and physical development of their child during the first year of the child’s life?**

Out of 96 participants, 14 (14.58%) reported that their child was born prior to 38 weeks of pregnancy. One child was born at 24 weeks (1%), one child at 29 weeks (1%), two children at 33 weeks (2.1%), three children at 35 weeks (3.1%), three children at 36 weeks (3.1%), three children at 37 weeks (3.1%), and one child born premature with no exact gestational age stated. Several parents also reported additional health
complications at birth, regardless of gestational age. Table 1 shows those medical complications that occurred at birth or during the first week of life:

Table 1: Pregnancy, Birth, & Neonatal Complications

<table>
<thead>
<tr>
<th>Medical Condition</th>
<th># of children</th>
<th>% of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABO disease</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Apnea requiring NICU</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Chiari malformation</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Fetal distress</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Fever requiring NICU</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Respiratory distress requiring resuscitation</td>
<td>3</td>
<td>3.1%</td>
</tr>
<tr>
<td>Severe jaundice</td>
<td>2</td>
<td>2.1%</td>
</tr>
<tr>
<td>Umbilical cord around neck</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Triplet birth</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Twin birth</td>
<td>2</td>
<td>2.1%</td>
</tr>
</tbody>
</table>

Nearly all of the participants reported having concerns about their child’s development. One respondent stated, “It was my first child, so I was not aware that there were other problems” when asked what age she began having concerns about her child’s development. Her child’s pediatrician first raised concerns. Table A1 describes the age of the children, in months, where the parents began having concerns about development. Of the 95 respondents that reported having concerns, the age of the child ranged from
birth through 108 months, with a median age of 18 months. The mean age is 24.19 months with the 95% confidence interval for the mean as 20.20 through 28.18. The standard deviation is 19.6 months with an average absolute deviation from the median as 11.3 months.

Respondents were asked to choose up to five characteristics of atypical development that were concerns in their own child’s development. The most frequent concern noted by the participants was a failure to relate to people in a typical way. This delayed social development was noted in 71 children (73.96%). Fifty-six participants (58.33%) listed rituals, obsessions, abnormal object attachment, and a dislike of change as a concern. A delay in starting to talk was listed as a concern by 52 participants (54.17%). Remaining concerns included a delay in gross motor milestones such as walking (22.92%), failure to develop typical pretend play (44.79%), behavior problems such as hyperactivity and tantrums (51.04%), academic concerns (10.42%), medical problems such as epilepsy (4.17%), hearing problems (10.42%), regression in speech or motor skills (5.21%), eating difficulties (1%), extreme irritability (1%), change in head circumference (1%), and elopement (2.1%). One person stated that as a first time parent, she was not aware that there were any developmental issues with her child.

Participants were asked to complete the First Year Inventory in order to gather data about the early characteristics and development of the children. Table A2 illustrates the developmental characteristics of the children during the first 12 months of life. These characteristics covered the areas of social development, sensory development, shared
attention, adaptive behavior, and communication. Deficits in each of those areas are typically required for a diagnosis of an autism spectrum disorder.

In the area of sensory development, participants were asked to rate whether their children exhibited the stated behavior during the first 12 months of life, using the scale of never, seldom, sometimes, or often. The following characteristics were included in the sensory development area as behaviors that occurred sometimes or often: being bothered by loud sounds (52%), being overly sensitive to touch (40%), perceived difficulty with hearing (49%), ignoring loud or startling sounds (33%), spitting out certain textures of foods (70%), forcefully pressing body against other people or furniture (47%), feeling loose or floppy when being picked up (31%), difficulty calming once upset (83%), and staring at bright lights for long periods of time (46%). These characteristics were considered to be representative of atypical sensory development, with neuro-typically developing children exhibiting the behaviors never or seldom.

In the area of shared attention, 58% participants rated their children as sometimes or often exhibiting shared attention by looking at an object that a parent pointed out. In addition, 50% of parents reported that their baby tried to get parent attention in order to show the parent something the baby found interesting. Both of these characteristics were considered to be characteristics of typically developing children, while deficits were considered to be characteristics of children on the autism spectrum.

In the area of social development, 69% of participants reported that their children sometimes or always turned their head when their name was called, 71% stated their child sometimes or always got excited at games such as “I’m gonna get you”, and 62%
sometimes or always looked at the parent’s face for comfort in a new or strange situation. Approximately 43% of parents reported their children looked at people who began talking even when the child was not the one being spoken to, 83% smiled when the parent looked at the baby, 32% attempted to get the parent’s attention to play peek a boo or patty cake, and 13% seemed interested in other babies of the same age. Approximately 49% stated their baby attempted to imitate the actions of the parent and 53% said their baby attempted to imitate noises and words of the parent. These social skills behaviors were thought to exist only in neuro-typically developing children. The only atypical social skill on the questionnaire asked whether the baby turned his or her head to avoid making eye contact, and 64% of parents reported that their children exhibited that behavior.

Stereotypical behavior is also considered to be a trait of children on the autism spectrum. Nearly 35% of participants reported that their baby repeatedly rocked back and forth while 82% of children got stuck doing simple activities over and over. In addition, 68% of participants stated that their child got stuck playing with a single part of a toy, such as the wheel or tag, rather than the toy as a whole, 57% of parents reported that their children sometimes or always enjoyed making objects spin over and over, and 37% stated that their children stared at their fingers while wiggling the fingers in front of their eyes.

Communication and adaptive behavior were the final two areas of the First Year Inventory. In the communications area, 38% of participants stated that their children communicated and played less at 12 months than they did earlier in development, 56%
said that their children used pointing in order to communicate desire or interest, 51% of children used gestures such as raising arms to be picked up, shaking head to indicate “no,” and waving goodbye at someone, 62% babbled by putting sounds together, and 74% of children were able to use recognizable facial expressions to communicate emotions. In the field of adaptive behavior, 56% of children were able to look up from a favorite toy when presented with a different toy, 79% were upset when asked to transition from one activity to another activity, 81% were content to play alone for an hour or more at a time, 72% had regular sleeping and waking patterns, and 70% were able to get the attention of a parent to obtain a desired object or food item.

The null hypothesis that parents of children with autism will not report deficits and variations in the development above what is in the typical and known range of normal for early childhood development was not supported. This study found several areas of concern, deficits, and variations in development reported by parents. Some variations occurred during pregnancy and delivery, while many were noticed before the child turned 12 months old. However, the data also shows several areas of development where children developed according to what was thought to be the typical path of child development, exhibiting characteristics that would otherwise exclude the child from a diagnosis of an autism spectrum disorder under the current criteria.

Q2: How do parents describe their experiences reporting concerns to pediatricians early in the life of their child?

Each participant was asked to state how old his or her child was when the participant reported concerns to a pediatrician or child development specialist. Figure 1
illustrates the child’s age in months when concerns were first reported to an expert in early childhood development.

![Graph showing the number of parents reporting concerns at different ages.](image)

**Figure 1: Child’s age when parent reported first concerns**

All 96 participants provided an answer to the question of the age of the child when concerns were first reported. The age range of the children was 0.5 months of age through 118 months of age. The mean was 36.65 months with the 95% confidence interval for the mean is 31.39 through 41.91 months. The median age was 28.0 months. The standard deviation was 26.0 months.

There was a wide range of professions chosen by parents to first discuss concerns regarding the children’s development. General practitioners were chosen by 12 participants (12.5%), pediatricians were chosen by 44 participants (45.83%), Child Find
or state Early Intervention programs were chosen by six participants (6.25%), child psychiatrists were chosen by 6 participants (6.25%), developmental pediatricians by two participants (2.08%), psychologists by eight participants (8.33%), teachers by six participants (6.25%), and social workers by five participants (5.20%). In addition, two parents choose a speech therapist (2.08%), one chose a school psychologist (1%), two chose a neurologist (2.08%) and one chose a multidisciplinary team (1%).

During the first encounter with the child development professional where parents reported concerns, participants reported one of five outcomes. A referral for further evaluation was given during this visit to 44 of the participants (45.83%), while 17 participants (17.70%) were told that their children would outgrow the concerns. The initial professional made a diagnosis during this first meeting for 14 participants (14.58%). An additional 13 parents (13.54%) were told that there were no problems or reasons for concern and eight participants (8.33%) were told to wait and return if problems continue.

Out of the 44 children given a diagnosis at that first encounter with the specialist or following the first referral, four (4.17%) were diagnosed with ADHD, one (1%) was diagnosed with an anxiety disorder, seven (7.29%) were diagnosed with Asperger’s syndrome, seven (7.29%) were diagnosed with autistic disorder, two (2.08%) with developmental delays, one (1%) with epilepsy, and three (3.13%) with mild autism. In addition, 14 (14.58%) were diagnosed with pervasive developmental disorder-not otherwise specified, two (2.08%) were diagnosed with recurrent ear infections, two (2.08%) with Sensory Processing Disorder, and one (1%) with speech and language
delays. A total of 31 (32.29%) children were diagnosed with autism at this first visit with the remainder of the children (66.67%) later being diagnosed with an autism spectrum disorder.

The null hypothesis is that parents of children with an ASD will report not sharing concerns with a pediatrician or physician prior to the child having a referral for an autism diagnosis. Therefore, there will not be a significant number of parents reporting perceptions of being ignored or brushed off. In this study, the null hypothesis was not supported. All 96 participants reported discussing developmental concerns with a pediatrician or developmental specialist. Out of the 96 participants, 39.58% were told that there were no problems, the child would grow out of the concerns, or to wait until the child was older to address the concerns.

**Q3: How do parents describe their experiences with the diagnostic process?**

Following the initial report of concerns, 76 participants reported that they were either referred to a second specialist or they sought out a second opinion following the lack of an initial diagnosis. The children ranged in age from 10 months to 132 months at the second referral. The mean age was 43.77 months, with a 95% confidence interval for the mean of 37.06 through 50.48 months. The standard deviation was 28.9 months and the median age was 35.00 months.

During this second referral, 46 children received a diagnosis. Of these 46 children, 15 were given an autism diagnosis, although one child was given an educational diagnosis of autism and not a medical diagnosis. An additional nine were given an Asperger’s syndrome diagnosis, one was given an ADD diagnosis, three were diagnosed
with developmental delays, five with mild autism, and eight with pervasive developmental disorder—not otherwise specified. Two children were diagnosed with speech and language delays and one was diagnosed with low oral-motor awareness. In addition, 16 children were referred to a third specialist, three were told that there were no problems, four were told not to worry and that the child would grow out of the concerns, and three were told to return at a later date if the problems did not improve.

Participants were given the opportunity to offer insights into whether they experienced any difficulties in obtaining a referral to another professional following the initial contact after mentioning concerns. Out of 96 parents, 75 (78.13%) did not experience difficulties or did not require an additional referral. The remaining 21 participants (21.88%) stated that they experienced some type of difficulty when attempting to obtain a referral. Four participants stated that his or her child had so many varied symptoms that it was difficult for professionals to pinpoint what specialist should be sought out. One parent stated:

It took until doctor #10 to identify there was a problem. He gave us OT and ST and a referral to a Neurologist... However, we were told there weren’t services in {City Redacted}, TX so we immediately started looking across the country for help... We moved to Virginia and they promptly completed a very thorough evaluation and started him in their preschool program, which was an outstanding program. The parent group in Texas was depressing because they were all so desperate for services that did
not exist. In Virginia, they put us with 2 therapists and a group of about 8 parents with children the same age and it was the first step to healing and sanity for me. The Texas hospital would not help defray the cost of occupational therapy and speech therapy at $110/hour for $440/week out of pocket. By the time we determined insurance wouldn’t help and the hospital wouldn’t help, we owed $8-10K and we quit therapy. It was discouraging to see others getting that service for free. In Texas, I sought out a counselor on my own; none were recommended for me.

Four parents stated that the costs of further testing and treatment were too prohibitive and insurance wouldn’t pay for testing and treatment for autism. Three parents stated that a lack of cooperation from the public school district made it difficult to obtain referrals and diagnoses. One parent stated that her doctor insisted nothing was wrong and that she was a “hypersensitive new mom” while three parents stated that the doctor refused to make a referral because the doctor believed nothing was wrong with the child. Four parents cited long waiting lists as an obstacle for referral.

The remaining participants who did not receive a diagnosis in the first two encounters ultimately received an autism spectrum disorders diagnosis during future medical or educational appointments. The range of the children’s ages in months when the final diagnosis was made for these 29 children was between 18 months and 288 months. The mean age was 71.83 months with a 95% confidence interval for the actual
mean between 50.99 and 92.66 months. The standard deviation was 54.8 months with a median age of 50 months.

Including all participants, the age of the children at time of final diagnosis ranged from 10 months to 288 months. The mean age was 50.79 months old with a 95% confidence interval for the actual mean falling between 42.86 months and 58.62 months. The standard deviation was 39.7 months and the median was 37 months.

The length of time between the age of the children when the participants first had concerns about their children’s development and the age at final diagnosis was determined for each participant. The range of each participant’s waiting time was between zero months and 216 months. The mean number of months between noted concerns and a final diagnosis was 32.08 months with a 95% confidence interval for the actual mean falling between 25.39 and 38.77 months. The standard deviation was 32.8 and the median was 24 months.

Participants were asked to describe the type of help or support they were offered by professionals during the diagnostic process. Participants were allowed to select up to five types of help, while ranking those five in order of what they felt was most useful to them. Help with preschool or school choices was ranked as the most useful and most frequent form of assistance, with 39 participants ranking this form of assistance in their top two forms of help. An explanation of the child’s problems was provided and found to be helpful with 24 participants. A statement of special educational needs, known as an IEP, was ranked within the top two for 22 participants. The next highest category was “no help offered,” which was selected by 21 participants. Speech and language therapy
was offered to 21 participants, and home visits to 19 participants. No parents in this study were offered family therapy, one was offered financial assistance, one was offered personal counseling for the parent, and 12 were offered general parenting advice.

The final part of the study asked participants to describe their feelings about the autism diagnostic process. Table A3 presents the participant’s answers in their own words, with any identifying information redacted. Table 3 also contains theme words used during the qualitative analysis. The data was coded using five themes based on several keywords extracted from the responses. The first theme, lack of response, contained the following keywords: dismissed, more information desired, lack of help, pushed through, long process, blamed, parent advocate, not thorough, lack of communication, insurance limits, and lack of support. Theme two, negative parent emotions, contained the following keywords: devastated, frustration, intuition, denial, overwhelmed, mistrust, felt like a bad parent, felt bad, hopeless, scared, isolated, and grueling. The next theme, positive parent emotions, included the following keywords: relieved, glad, blessed, grateful, and thankful. The fourth theme, positive response obtained, included the following keywords: helpful, positive experience, professional advocate, explanation provided, given information, therapies, understanding, fast process, referral made, support, reassuring, easy, validation, and thorough. The final theme, negative response obtained, included the following keywords: diagnosis uncertainty, difficulties with school, difficulties with professionals, unwanted medication, negative experience, inconsistency, and poor information.
Figure 2 illustrates the frequency of themes. Each response could have multiple themes depending on the keywords extracted, but each theme could only be used one time per response even if multiple keywords fit into the theme. There were 12 respondents who did not provide a response.

![Bar chart showing the frequency of themes in parent experiences.]

**Figure 2: Themes in parent experiences**
Figure 3 illustrates the frequency of keywords. Each response could have multiple keywords, but each keyword was only counted once per response even if the word occurred multiple times in a response.
The null hypothesis that parents will report that no delays or difficulties existed between the time the first concerns were noted and a formal diagnosis was made was not supported. While some respondents reported a short time between concerns and diagnosis, the majority of participants reported an extended wait. The average time between concerns and diagnosis was nearly three years, with some participants waiting a decade or more for a final diagnosis. When asked to discuss their own emotions of the diagnostic process, half of the participants stated feeling that pediatricians, therapists, medical professionals, or the school district dismissed their concerns or didn’t provide an adequate response to parental concerns or requests for help. Nearly a third of participants reported negative emotions ranging from their own fear and denial of the diagnosis to frustration with the diagnostic process. Approximately 40% of participants reported a negative outcome with the diagnostic process, including professionals disagreeing with each other on the diagnosis and difficulties with the school system or professionals. Nearly a third of participants reported a positive outcome, including appropriate services, support, and reassurance. Only five participants (5.20%) responded with keywords grouped into the positive parent emotions theme, including being thankful or grateful, glad, or relieved.

Summary

This study included 96 participants who reported on their children’s development from the gestational period through the second year of life. In addition, participants reported on the diagnostic process for their children who were diagnosed with Asperger’s syndrome or mild autism. The majority of participants reported a typical gestational
period with only a small number of participants reporting premature birth. However, a significant number of participants experienced complications during pregnancy, birth, or the early neonatal period. During the first two years of the children’s life, all but one participant stated that the participants had significant concerns about their children’s development. Participants also identified characteristics of their children’s development that include both atypical and typical characteristics, including those that are representative of typical development and previous research shows do not occur frequently in children diagnosed with autism spectrum disorders.

All 96 participants reported concerns regarding their children’s development with an expert in the field. Almost half were referred for further evaluation, with only a third of the total participants citing a diagnosis of an autism spectrum disorder was received following these initial concerns. The remainder of the participants’ children did not receive a diagnosis for months to years following these initial concerns.

When asked to discuss their own emotions of the diagnostic process, only a third of the participants reported positive outcomes, and only 5% used positive emotion keywords to describe their experiences. Half of the participants reported a lack of response and 40% reported negative outcomes, indicating that even those who received positive outcomes also faced negative aspects of the diagnostic process.
CHAPTER 5: DISCUSSION OF RESULTS

Introduction

Using internet-based digital copies of The First Year Inventory-Retrospective Version, created by Watson, Baranek, Crais, Reznick, Dykstra, and Perryman (2007), and a demographics questionnaire created by Howlin and Moorf (1997), 96 parents of children diagnosed with Asperger’s syndrome or mild autism answered questions about the development trajectory and concerns of their children. They were also given the opportunity to discuss the autism diagnostic process from the point of addressing concerns with a professional through the final diagnosis. Chapter 5 will provide a summary and discussion of the results of this research. In addition, this chapter will address study limitations as well as recommendations for further research.

Summary of the Results

On April 1, 2012, the United States Centers for Disease Control and Prevention (CDC) announced that 1.15% of children in the United States are diagnosed with an autism spectrum disorder, making the prevalence one child in 88. There are several diagnoses that are referred to under the umbrella term *autism spectrum disorders*. Currently, autistic disorder, Asperger’s syndrome, pervasive developmental disorder-not otherwise specified (PPD-NOS), and Rett syndrome are classified as autism spectrum disorders (Howlin & Moorf, 1997).

Several researchers have attempted to address early symptomatology of children later diagnosed with autism. Most of these studies involved children with moderate or severe autism, however, with Asperger’s syndrome and mild autism, the literature rarely
addresses these diagnoses. McConachie, Couteur, and Honey (2005) found that many parents of children with moderate or severe autism reported developmental concerns in the months prior to referral for further evaluation. According to available research, the children usually developed typically until 12 months of age, with atypical behaviors occurring after the child’s first birthday (Eaves & Ho, 2004). Maestro and colleagues (2005) indicated that many children with autism exhibited lack of eye contact, poor motor imitation, lack of joint attention, lack of pointing, lack of delayed interest, and communication delays. Young, Brewer, and Pattison (2003) found that many children with autism showed disordered regulatory behaviors during infancy, including colic and waking up frequently at night.

Baron-Cohen, Baldwin, and Crowson (1997) utilized the Checklist for Autism in Toddlers (CHAT), a screening tool still utilized by pediatricians today, in order to identify characteristics of development that might aid in the early diagnosis of autism spectrum disorders. These researchers found out that each child that was later diagnosed with autism experienced a lack of protodeclarative pointing, a lack of pretend play, and a lack of social gaze monitoring by 18 months of age. Wetherby and colleagues (2004) believed that a large number of children with autism would not be identified by the CHAT criteria.

The statement of the problem for this study was that research indicates a potential discrepancy between the current autism diagnostic procedures used to screen infants and toddlers for autism and the number of children later diagnosed with an autism spectrum disorder. In addition, research also indicates a discrepancy between the age where
parents first begin having concerns about their children’s development and the average age of an autism diagnosis. This study attempted to address both discrepancies, while contributing to the limited body of research on the developmental characteristics and diagnostic process for children who are later diagnosed with mild or higher functioning autism. Finally, this study attempted to identify themes in the emotions and experiences of parents regarding the autism diagnostic process.

The study utilized both qualitative and quantitative methodology using a demographics questionnaire and the First Year Inventory-Retrospective Version. The questionnaires were uploaded to SurveyMonkey.com and participants were recruited using the Kennedy-Krieger Institute’s Autism database, IAN Project. Participants included 96 parents of children that had been diagnosed with Asperger’s syndrome, mild autism, or mild autism. Participants completed questionnaires designed to answer the following research questions:

Q1: How do parents describe the social, emotional, cognitive, and physical development of their child during the first year of life?

Q2: How do parents describe their experiences reporting concerns to pediatricians early in the life of their child?

Q3: How do parents describe their experiences with the diagnostic process?

The majority of this study’s participants gave birth at a gestational age of between 38 and 42 weeks, although a significant number experienced pregnancy, birth, or neonatal complications. All participants except one revealed that they had significant concerns regarding the development of their children that were reported to a physician or
other expert in early childhood development. When asked to recall their children’s
development prior to 12 months of age, many participants recalled their children
exhibiting some characteristics that are found primarily in children later diagnosed with
autism and some characteristics that are currently thought not to be present in children on
the autism spectrum.

Following the initial report of concerns, nearly half of the participants were
referred for further evaluation, and a third of the total participants received an autism
diagnosis. The remainders of the participants’ children were diagnosed at a later time.
When participants were asked to describe the diagnostic process in their own words, half
of the participants reported a lack of response from the child development experts and
40% reported negative outcomes of the diagnostic process. A third reported positive
outcomes and only 5% used positive emotions to describe the diagnostic process.

**Synthesis of Findings**

**Pregnancy and Neonatal Period.** Of the 96 participants in this study, 14 stated
that they gave birth to their child prior to 38 weeks of pregnancy, with 11 (11.46%) of
those births premature and occurring prior to 37 weeks gestational age. This number falls
below the United States average number of premature births, with the March of Dimes
reporting that 12.8% of babies are born prematurely in the United States each year
(2012). Movsas and Paneth (2012) found significantly higher levels of autistic traits in
children born prior to 37 weeks gestational age. The researchers also found that normal
gestational age, which is from 37 weeks to 42 weeks, mitigated the severity of social
impairment in children who were diagnosed on the autism spectrum disorder. The rate of
prematurity in this sample fell below the current United States average, with the majority of the children being born full term. This appears to support the research of Movsas and Paneth (2012) with a lower level of prematurity being found in these participants who have children diagnosed with mild autism.

In addition, only 14% of participants reported complications during pregnancy, birth, and the early neonatal period. The highest percentage involved respiratory distress syndrome requiring resuscitation (3.1%), severe jaundice (2.1%), and twin birth (2.1%). However, the majority of participants reported healthy, full-term pregnancies and a healthy neonatal period. It does not appear that pregnancy and birth complications played a significant role in predicting the likelihood of an autism spectrum disorder diagnosis in the children of the participants.

Current literature indicates mixed results regarding birth complications and the development of autism spectrum disorders. Brimacombe, Ming, and Lamendola (2007) found that systemic problems during the mother’s pregnancy correlate with an increased risk of the child developing an autism spectrum disorder. Glasson, Bower, Petterson, de Klerk, Chaney, and Hallmayer (2004) found that the risk of an autism diagnosis increased when the infant experienced fetal distress, a caesarian birth, one minute APGAR scores of less than six, or an induced labor. However, the researchers also found that prenatal and neonatal complications occurred at a higher rate for children later diagnosed with more severe forms of autism rather than for children with mild autism or Asperger’s syndrome diagnoses.
**First Two Years of Life.** While pregnancy and the neonatal period did not appear to be a cause for concern in the majority of the participants, significant concerns arose within the two years following birth. All but one participant reported having concerns about their children’s development. The mean age was 24.19 months, or two years of age. However, that mean may be artificially high as 73 participants reported having concerns at 24 months or prior, with 53 having significant concerns at or before 18 months and 22 of those participants having significant concerns prior to the child’s first birthday. The mean age might have been inflated due to the large range of ages, with three of the participants reporting concerns beginning at or after 88 months of age.

A failure to relate to other people in a typical way was the most frequent concern listed by participants, with 73.96% indicating this as one of the top concerns they had regarding their children’s development. The next most frequent concern was the tendency to become attached to rituals, develop obsessions, become attached to objects, and an aversion to routine changes, which was reported to be a concern by 58.33% of participants. Communication delays were reported by 54.17% of participants, behavior problems and hyperactivity were reported by 51.04%, and failure to develop typical pretend play were reported by 44.79%. With the exception of failure to relate to other people, the most frequent concerns were only exhibited by approximately half of the children of the participants. This is significant as these traits are typically criteria utilized on many current autism screening tools, such as the CHAT and CARS tests. In this study, half of the children would have been excluded from diagnosis due to their ability to develop pretend play and age appropriate communication.
Rogers (2009) found that symptoms of autism could not be detected until between 12 and 24 months of age. However, Mitchell, Brian, Zwaigenbaum, Roberts, Szatmari, Smith, and Bryson (2006) stated that by 12 months of age, children who were later diagnosed with autism were significantly delayed in communication and speech development. Zwaigenbaum, Bryson, Rogers, Roberts, Brian, and Szatmari (2005) also argued that prior to 12 months of age, children who were later diagnosed with autism showed atypical eye contact as well as deficits in visual attention, orienting to the sound of his or her name, social smiling, and social interest. These children also exhibited increased passivity and decreased activity levels by six months of age, with extreme agitation and distress symptoms and object fixation by 12 months of age. These children were all later diagnosed with moderate to severe autism. The current literature does not appear to differentiate between the early symptoms of mild autism and more severe forms of ASDs. Ziatas, Durkin, and Pratt (1998) and Wetherby, Woods, Allen, and colleagues (2004) attempted to screen for autism spectrum disorders in infants and found that those with autism showed marked deficits across all areas prior to turning 12 to 24 months old. However, neither group of researchers differentiated between mild autism and severe autism, possibly helping to explain why the findings of this study do not support the findings of Ziatas and colleagues or Wetherby and colleagues.

It is not known whether the children actually had deficits in these areas of evaluation or if those deficits existed but not at a level that would have triggered parental concern. The majority of participants in this study became concerned about their children’s development when the children did not show interest in same age peers or did
not relate to parents and caregivers in a way that appeared to be typical or similar to interactions with other children. The ability to interact with others is a characteristic that changes as the child grows and matures, but can begin even from early infancy with the ability to smile, coo, or gaze at the parent. Therefore, it also seems highly likely that atypical social development might be a cause for concern early in the child’s development. These findings help to support the research of Wimpory, Hobson, Mark, Williams, and Nash (2000), who found that parents were likely to report concerns when those concerns involved person-to-person engagement.

**Developmental Traits in Mild Autism.** Bernabei, Campagni, and Levi (1998) stated that many children with autism spectrum disorders develop according to a typical trajectory until the first or second birthday when abnormal developmental characteristics begin to develop. In addition to recalling and listing concerns, participants in this study were asked to rate specific developmental traits as occurring rarely, seldom, sometimes, or often. To support previous research, it was expected that the majority of abnormal developmental characteristics would surface only after the child’s first birthday. However, almost all of the respondents reported a mixture of typical and atypical developmental traits occurring before the children’s first birthdays. In the area of sensory development, the majority of the characteristics listed on the First Year Inventory-Retrospective Version were developmental traits expected to be found primarily in children with autism spectrum disorders and other developmental delays rather than being traits associated with typical development. Therefore, it would be expected that the majority of children in this study would exhibit those sensory traits. However, only two
of the nine traits were found in the majority of children, with 83% of parents recalling that their children were difficult to calm once upset and 70% reporting that their children spit out certain textures of foods.

Approximately half of the children appeared to be bothered by loud sounds, forcefully pressed their bodies against other people or furniture, had perceived difficulties with hearing, or stared at bright lights for long periods of time. Finally, only about a third of the children were reported to be overly sensitive to touch, ignored loud or startling noises, or appeared loose or floppy while being picked up. While all of these characteristics were thought to be present in the majority of children with autism, this study suggests that many children with Asperger’s syndrome or mild autism may have a lower level of sensory concerns during the first year of life than do children of moderate or more severe autism. These findings do not support the research of Mercer and Glenn (2004) who found that children with autism were likely to have atypical pain responses and increased sensory processing deficits during infancy. However, the presence of food texture aversions and difficulty being calmed once upset appear to be frequent concerns in children later diagnosed with mild autism. These findings helps to support the findings by Ozonoff, Williams, and Landa (2005), who found that children with autism spectrum disorders typically engage in prolonged screaming and are often difficult to calm.

Shared attention, or the ability direct gaze or attention to an object, person, or experience that another individual wishes to point out or share, is an important developmental milestone, with deficits in the development of appropriate shared attention is considered to be a key symptom of autism spectrum disorders. In this study, 58% of
the children were able to look at an object that a parent pointed out. In addition, half of the children attempted to get parent attention in order to show the parent something the child found interesting. In this study, at least half of the participant’s children developed the ability to engage in age-appropriate shared attention behaviors during the first year of life. Deficits in the development of shared attention behaviors do not appear to be present in the majority of children with mild autism in this study, indicating that it may not be a reliable indicator for those on the autism spectrum who are not considered to be moderately or severely affected.

**Social Concerns.** Social development concerns are often the most significant factor in determining an autism spectrum diagnosis or the need for further evaluation (Zwaigenbaum et al., 2005). Wimpory, Hobson, Mark, Williams, and Nash (2000) found that most of the parents of children with autism interviewed in their research reported deficits in person-to-person engagement. During the majority of the child’s first year, social development occurs between the child and the adult caregivers while toward the end of the first year, there is a slight shift towards an emerging interest in same-age peers or older siblings. In this study, 69% of participants reported that their children turned their head when their name was called, 71% said their children got excited at social games such as “I’m gonna get you”, 83% smiled when looked at by the parents, and 62% of children looked at their parent’s face to be comforted in new or strange situations. These traits are generally found in children who are neurotypically developing, while notably absent in children on the autism spectrum (Zwaigenbaum et al., 2005). However, the majority of children of this study’s participants were found to exhibit these traits.
during the first year of life, contrary to the research by Zwaigenbaum and colleagues (2005). Zwaigenbaum’s sample population, as well as the majority of studied populations in the literature, refers to more moderate to severe forms of autism rather than differentiating between mild and severe forms of autism.

Approximately half of the children were able to look at people who began talking, attempt to imitate the actions of the parent, and attempt to imitate the noises and words of the parent. These traits are also often considered to be absent in children on the autism spectrum (Fecteau, Mottron, Berthiaume, & Burack, 2003; Moony, Grey, & Tonge, 2006). However, this study did not find those traits to be reliable indicators as half of the children in this study met those developmental milestones. Only 13% of children in this study appeared to be interested in other babies of the same age and 64% turned their head to avoid making eye contact with other people. Lack of interest in same-age peers, as well as the tendency to avoid making eye contact, is considered to be traits indicative of autism and in this study, these traits were found in the majority of the children (Fecteau et al., 2003).

**Stereotypical Behavior.** Stereotypic behavior includes motor and vocal actions that are repetitive without any obvious adaptive function (Gardenier, MacDonald, & Green, 2004). Stereotypical behavior, including staring at spinning objects, becoming fixated on parts of objects, repeating the same motor movements over and over again, and rocking or spinning are often considered to be important indicators of autism spectrum disorders and are often not found to a significant extent in neuro-typically developing children. In this study, only a third of the children engaged in rocking behaviors or
staring at their fingers moving in front of their eyes. However, the majority of the children would get stuck doing simple activities over and over, in addition to focusing on small parts of a toy, such as the wheel or tag, instead of playing with the whole toy. Stereotypical behavior does appear to be a trait of children diagnosed with mild autism, although it may occur to a smaller extent than it does with children who are moderately or severely affected.

**Communication Development.** Eaves and Ho (2004) found that many children with autism appeared to develop typically for the first 11 months of life, but then exhibited a regression in communication, adaptive behavior, and other skills at or around the first birthday. However, in this study, only 13% of participants reported that their children communicated or played less at 12 months than they did earlier in development, indicating that the majority of children with mild autism in this study did not exhibit a significant regression around the time of their first birthday. In addition, 70% of the children were able to use non-verbal and verbal communication to get the attention of a parent in order to obtain food or a desired object, 74% were able to use recognizable facial expressions to communicate, 62% babbled by putting sounds together, 51% could use non-verbal gestures such as waving goodbye, shaking head to indicate “no,” and raising hands to be picked up, and 56% were able to point in order to communicate desire and interest. The majority of the children in this study were able to develop age-appropriate functional verbal and non-verbal communication prior to 12 months of age. This finding does not support the findings of Woods and Wetherby (2003). Woods and
Wetherby (2003) found that communication delays are some of the most common symptoms of autism spectrum disorders are often found prior to the child’s first birthday.

The ability to develop these types of communications is commonly thought to exclude a child from a diagnosis of autism. However, this study indicates that the majority of children with mild functioning autism in this study were able to develop at least rudimentary forms of functional communication. Deficits in communication with peers or adults is not something that is evident prior to 12 months of age, which is often one of the key indicators of Asperger’s syndrome. This could possibly account for why many of the children in this study were not diagnosed until around school age, when deficits in social communication may become more apparent.

While social communication in the first year of life did not appear to be a strong indicator of mild autism, several aspects of adaptive behavior do appear to be significant. Of the 96 participants, 81% reported that their children were content to play alone for an hour or more at a time prior to 12 months of age. This is often not a typical behavior as many infants desire to be talked to, played with, or held by adults after short periods of play. In addition, 79% of parents reported that their children became extremely upset when transitioned from one activity to another. These two traits were considered to be abnormal and appear to be highly suggestive of a mild autism diagnosis.

**Reporting Developmental Concerns to Professionals.** Once concerns were reported to a pediatrician or other child development expert, participants reported one of five outcomes. Nearly 45% were given a referral for further evaluation while an additional 14% were given a diagnosis of autism or another medical condition. Of all of
these children who were referred or given a diagnosis, only 31 were diagnosed with an autism spectrum disorder, while the rest were either told there were no concerns at this evaluation or they were given diagnoses including ADHD, anxiety, developmental delays, epilepsy, ear infections, speech delays, or sensory processing disorder. However, a significant number of participants were told that their children would outgrow the concerns, that there were no problems, or to wait and come back if the concerns didn’t abide. So, after the first round of discussion and evaluations, 66% of children who eventually would be diagnosed with mild autism did not receive an autism diagnosis.

There are several reasons this may have occurred. Several children were given alternative diagnoses during the first meeting. In addition, other participants reported that their concerns were dismissed because their children exhibited some social behaviors, made eye contact, or were able to use verbal communication. This study found that many of the symptoms used to screen for autism are not present at all or to the same severity in children with more mild forms of autism, causing these children to not be referred for further evaluation.

Seeking out a second opinion following an initial diagnosis of autism or assessment is a common phenomenon. In fact, Williams, Atkins, and Soles (2009) found that 86% of the participants sought out more than one opinion. Many parents in this study sought out second or third opinions in order to have their concerns addressed. Of the 76 that sought out a second opinion, 37 were given an autism diagnosis at that time, six were given alternative diagnoses, and 16 were referred to a third specialist. In addition, three were told there were no concerns, four were told that their child would
outgrow the concerns, and three were told to return at a later date if the symptoms did not improve. Ultimately, all 96 participants received an autism diagnosis during future medical or specialist appointments, with the mean age at diagnosis being 50.79 months. According to McConachie, Couteur, and Honey (2005), the average age of an autism diagnosis is 36 months of age. This study indicates that children with mild forms of autism may receive their diagnoses at a significantly later age than do children with moderate or severe forms of autism.

The average age of diagnosis in this study was 4.25 years, indicating that many of the children who received an autism diagnosis in this study were not eligible for early intervention and preschool services to provide interventions for autism since early intervention covers ages birth to three while preschool services often cover children until approximately five years of age. Eaves and Ho (2004) found that children with higher functioning forms of autism often experienced a pronounced positive impact when given early interventions prior to entering preschool around age three, including Applied Behavior Analysis, speech therapy, social skills therapy, and occupational therapy.

**Post-Diagnosis Assistance.** Once a diagnosis was received, many participants reported that they desired assistance and information in order to assist their children. The most frequently offered form of assistance was an Individualized Educational Program, or IEP, followed by speech and language therapy and home visits. However, 21 participants indicated that they were not given any form of assistance following their child’s diagnosis. In addition, no parents were offered family therapy, one was offered assistance with financial concerns, and one was offered personal counseling. When
asked to describe their feelings about the diagnostic process, 27 participants used negative emotion words such as “devastated,” “frustrated,” “scared,” “hopeless,” “isolated,” “denial,” and “overwhelmed” to describe their feelings. This study indicates the possibility that parents going through the autism diagnostic process may benefit from family or personal counseling in order to have an avenue to work through the negative emotions surrounding the diagnostic process and resulting autism diagnosis and to receive advice and support about how to best work with their children.

**Parent Experiences with Diagnostic Process.** When discussing their own experiences of their children’s diagnostic process, 47 participants described a lack of response from medical and educational professionals. A significant number of these participants expressed that they felt dismissed by professionals who did not feel that their child met criteria for diagnosis. While this may be due in large part to the fact that individuals with mild autism do not appear to exhibit the same symptoms to the same degree as children with more severe forms of autism, it also indicates an existing need for professionals and parents to work together to address the concerns parents have in a way that reassures the parents. Many parents also indicated that they felt like they had to be an advocate for their child. Other recurring keywords in the lack of response theme include the parent feeling blamed for causing the child’s symptoms, the process being long, a lack of communication from professionals, and a lack of support and information from those involved in the diagnostic process. Child development professionals, and especially pediatricians who are often the first professionals to hear parent concerns, are looked to by the parents as being responsible for providing this support, communication,
and information and therefore, if the child development professional does not see a need for concern while the parents show significant concern about development, parents appear to perceive that as a lack of adequate response. It may be useful for professionals to have adequate up-to-date materials available to provide to parents concerned about autism or to have a member of the staff trained in the full spectrum of ASDs in order to provide information and reassurance to the parents, increasing the likelihood of positive encounters.

The final theme that encompasses negative diagnostic experiences includes a negative outcome, which was reported by 37 participants. Negative outcomes include diagnosis uncertainty, difficulties with educational or medical professionals as an inconsistent process, or poor information given. The most common response was a diagnosis uncertainty where the child was given one diagnosis with that diagnosis being changed months to years in the future. In this study, diagnosis uncertainty was not a diagnosis of autism changing to a different diagnosis and was almost always a diagnosis of ADHD, ADD, or emotional disturbance later being revised to an autism spectrum disorder. This occurrence may happen for several reasons, with one likely reason being the young age of the child. It is likely more difficult to get a firm diagnosis in a very young child, especially when symptoms are indicative of several different types of disorders. In addition, diagnosis uncertainty may occur because the children in this study who were eventually diagnosed with mild forms of autism exhibited developmental characteristics, such as eye contact, imitation, pretend play, and functional communication that are often not present in children with more moderate or severe forms
of autism. This may lead to a higher rate of autism being excluded as a potential diagnosis in these children.

The final two themes in the qualitative analysis refer to positive diagnostic experiences: positive response obtained and positive parent emotions. In discussing the diagnostic process, 31 participants used keywords that indicated positive responses received, including feeling that the professionals were helpful, reassuring, and supportive. Other keywords in this category included being given information and explanations, being referred for evaluations and therapies, a fast process, a process that was easy to understand and participate in, a thorough evaluation, and validation of parental concerns. Many participants that reported a positive response also reported a negative response. However, the positive responses dominated the narratives where both positive and negative responses occurred simultaneously. These characteristics of the diagnostic process were seen as important factors in an overall positive experience for these participants even though the diagnosis itself might have elicited negative emotions, such as fear or denial. Only five participants used positive emotion keywords, including relieved, glad, blessed, grateful, and thankful.

The overwhelming majority of participants in this study indicated some type of lack of response, negative emotion, or negative response when discussing their own feelings and emotions surrounding the diagnostic process. This may indicate a significant need in the educational, mental health, and medical professions to provide additional support and resources to parents going through the process of an autism diagnosis in children. This study found that almost no parents were offered personal or
family counseling or support outside of academic accommodations. However, this study also hints at the need for including additional familial supports and resources in order to take a more holistic family-centered approach to the diagnosis of autism in children, especially in circumstances where the children are more mildly affected and the diagnosis is less certain.

Discussion of the Conclusions

Study Findings Compared With Current Research. Much of the current research on the symptoms of autism during infancy refers to moderate or severe forms of autism, with the assumption that these findings were also true in mild forms of autism, such as Asperger’s syndrome and mild autism. Maestro and colleagues (2005) found that children with autism often exhibited behaviors such as lack of eye contact, poor motor imitation, lack of joint attention, lack of pointing and shared interest, and communication delays during the first year of life. However, this study did not support the findings of Maestro and colleagues as the majority of the children in this study, who were all diagnosed with a mild form of autism after infancy, exhibited some degree of eye contact, appropriate imitation of parental words, sounds, and actions, a significant level of joint attention, and age-appropriate verbal and non-verbal communication skills. This researcher did find that many children in the study did avoid eye contact frequently, which supports the finding in the study by Maestro and colleagues (2005). Oxonoff, Williams, and Landa (2005) also found that children with autism were more likely to exhibit prolonged screaming during infancy. This finding was supported as the current study found that many participants found their children to be difficult to comfort once
upset, with one participant reporting that her child received a diagnosis of colic after six months of daily screaming.

This study also supports the findings of Young, Brewer, and Pattison (2003), who determined that many families who have children later diagnosed with autism will report colic-type behaviors and difficulties being comforted when upset. In addition, Gomez and Baird (2005) found a significantly higher proportion of infants later diagnosed with autism exhibited regulatory difficulties during infancy. However, Olafsen and colleagues (2008) determined that most children with autism spectrum disorders would not be able to focus on a particular object or person in a distracting environment. The current study found that the majority of participants reported that their children could focus on their parent’s face in a new, distracting, or strange situation. These findings may indicate that children with mild autism still exhibit some regulatory and sensory deficits characteristic of children on the autism spectrum. However, the symptoms may not exist to the same degree as more severe forms of autism, with many of the children in this study able to demonstrate some age-appropriate regulatory behaviors and a much lower level of sensory and regulatory difficulty than what would be expected from a child on the autism spectrum.

Siklos and Kerns (2007) believed that most parents of children on the autism spectrum would have to express their concerns on multiple occasions to a pediatrician or specialist before receiving a diagnosis. Siklos and Kerns’ finding was supported with the current research, with only a third of the participants reporting that they were able to procure an autism diagnosis as a result of the initial expression of concern. The majority
of participants stated that their diagnosis was received after the second or third set of referrals, with the majority of these referrals being self-referrals rather than referrals coming directly from a pediatrician or school district. This finding indicates that parents of children with mild autism frequently have to obtain referrals without the guidance or assistance of a medical or educational professional, with a diagnosis typically being obtained following these referrals. Self-referrals without the support or knowledge of the child’s medical doctor or school district might also aid in the negative parent feelings of isolation and feeling dismissed that were reported by the participants.

According to Woods and Wetherby (2003), parents were often the first ones to notice the child developing differently than what was typical of same age peers. The current study supports the findings by Woods and Wetherby as 95 out of the 96 participants reported concerns to the pediatrician or specialist prior to having developmental concerns mentioned by the specialist. Only one participant reported having a professional mention the concerns prior to the parent noticing anything seemed atypical about the child’s development.

**Re-examining Autism Screening Tools.** This study provides an argument for re-examining the current autism screening tools available to pediatricians, preschools, and early intervention programs. Many of the participants in this study reported the existence of several developmental characteristics that were once thought to occur primarily in neuro-typically developing children while being absent or limited in children on the autism spectrum. Those characteristics that did fall within the range of what is
considered to be the symptoms of autism usually occurred at a much lower frequency than would otherwise be expected for an autism diagnosis. Some developmental characteristics seen in children with autism were pronounced in the sample population, including resistance to making eye contact, aversion to certain food textures, a disinterest in same age peers, difficulties being comforted when upset, a focus on parts of a toy rather than the whole, getting stuck performing the same action over and over, getting upset when transitioning from one task to another, and being able to play alone for an hour or more at a time before the age of 18 months. These findings are in line with the findings by Woods and Wetherby (2003) and Bernabei, Campagni, and Levi (1998). However, unlike results in previous research, children in this sample were also able to demonstrate several developmental milestones that previously would have excluded them from further evaluation when assessed with current autism screening tools. These milestones include the lack of developmental regression at 12 months of age, the ability to use non-verbal and verbal communication to obtain desired objects, the ability to use recognizable facial expressions for communication, the ability to use non-verbal gestures such as waiving, and proto-declarative pointing to communicate desire and interest. In addition, children in the sample exhibited the ability to turn their head when their names were called, demonstrating excitement at parent-child social games, looking at the parent’s face for comfort in new or strange situations, and engaging in shared attention behaviors. The discrepancy between the early childhood symptoms of Asperger’s syndrome and mild forms of autism and the current screening and diagnostic tools may be one of
the most important reasons for the delay between when a parent first notices concerns about his or her child and the child being diagnosed with a mild form of autism. Pediatricians and child development specialists often have to use screening tools designed for more severe forms of autism, which may result in many children with mild forms of autism being denied opportunities for further assessment. In turn, parents of these children appear to feel dismissed and frustrated because their concerns are not being adequately addressed in their opinion. In addition, research shows that early intervention and beginning therapies prior to the child’s third year of life is one of the most important factors in a good prognosis for children on the autism spectrum, yet the average age for children receiving the final diagnosis of mild autism in this study was 4.5 years of age, excluding these children from the benefits of early intervention. These factors indicate a strong need for human services professionals to research and design specialized screening tools for individuals with mild forms of autism. In addition, the majority of the participants in this study indicated a negative overall experience with the autism diagnostic process, indicating a need for further research into more holistic interventions and resources that take into account the families and caregivers of children on the autism spectrum.

Limitations

This study had several limitations and aspects that could be improved upon in future research. First, the sample size was only 96, instead of the intended 150. To achieve a 95% confidence level with an 8% confidence interval, 150 participants are needed to strengthen research on the United States population of individuals with
Asperger’s syndrome and mild autism. The current population of children with autism spectrum disorders is estimated to be 1,000,000, and up to a third of those individuals is thought to have Asperger’s syndrome or mild autism. This study had a confidence interval of 10%, so a lower confidence interval may allow the results to be more precise.

A second limitation is that the sample was not a random sampling of the population including every individual with children diagnosed with Asperger’s syndrome or mild autism. Only individuals registered with the IAN Foundation had an opportunity to be selected, with the selection of participants being random within this population. However, it is not known whether there are particular characteristics that made some parents register in the database while other parents choose not to register. It is possible that individuals with particularly negative or particularly positive experiences chose to register in order to be able to voice those experiences. It is possible that the IAN Project participants are representative of the entire population of parents who have children diagnosed with autism; however, it is also possible that the population represents a particular segment of more vocal parents with children diagnosed with autism, excluding other segments of the population.

The research design itself also potentially contributes to an unintentional limitation because there are some parents of children diagnosed with autism who do not have Internet access and thus were excluded from the study due to the Internet based recruiting and survey. This lack of Internet access may be due to education level, socioeconomic status, or geographic location. There is a risk that the exclusion of these individuals may mean that some groups were over-represented and some under-
represented in the sample. While the researcher asked the recruiting agency to encourage members of racial and economic minorities to participate, the sample was limited to individuals who had the Internet access to be registered members of the IAN database.

The research questions themselves may also be a limitation as participants were asked to recall characteristics of infancy in their children who had already been diagnosed with autism and were older than infancy. For some participants, there were events that happened only one to two years prior, but other participants were recalling events that happened a decade or more earlier. It is possible that some participants were not able to recall details accurately or that some recollections were overly negative or overly positive based on other contributing factors.

**Recommendations for Further Research**

There are several areas of this study that lend to further research. First, it is recommended that a similar study be replicated, using at least 150 participants in order to gain that 8% confidence interval. This might be accomplished by expanding the subject recruitment beyond the IAN Project using paper and pencil surveys and random population sampling. In doing this, future researchers will be able to confirm whether the results gained in this study are able to be generalized to the population as a whole.

A second recommendation for further research might be to follow families going through the diagnostic process and allow them to share their emotions and experiences as they happen. This might reduce recollection errors and also allow the researcher to gain a deeper insight of the experiences as they are actually happening, versus this study where the experiences may have happened from one to 20 years prior to the study. This
recommendation could mediate the limitations of this study, which relied on memory and recollections for data.

A third recommendation is to create and test an intervention where parents going through the diagnostic process are provided with an advocate that can help navigate the diagnostic process, coordinate appointments and referral recommendations, provide information, and provide support, reassurance, and family counseling. A significant number of participants reported negative outcomes and a lack of response from professionals, as well as feelings of confusion, isolation, and frustration. Future research may help determine whether providing parents with an advocate can help decrease negative outcomes and feelings and increase positive outcomes and feelings of relief, support, and understanding.

Finally, further research is needed to develop appropriate screening tools that can help screen for Asperger’s syndrome or mild autism. Many participants in this study indicated that their children exhibited developmental characteristics that otherwise excluded them from an early autism diagnosis. Children with mild autism appear to exhibit many characteristics of typical development, especially in the areas of pointing, non-verbal expressions, imitation, and eye contact. However, many of the children also exhibited communication difficulties and a lack of interest in same-age peers.

Current autism screening tools eliminate the potential for further assessment if the child displays eye contact, the ability to point, and being able to imitate caregiver sounds and expressions. Many participants reported feelings of being dismissed by pediatricians and school officials that overlooked a potential mild autism diagnosis due to the children
exhibiting characteristics, such as eye contact, pointing, and imitation that are typically not exhibited in children with more severe forms of autism. Nearly 66% of participants in this study did not receive a diagnosis until several months or years after the participants reported concerns, in large part because the children did not meet criteria for further autism screening according to available screening tools and information. Screening tools designed specifically for mild forms of autism might allow children with symptoms of mild autism to receive intervention during the toddler and preschool years.

**Conclusion**

This study utilized a retrospective qualitative and quantitative mixed methods design to study the early infancy symptoms of autism in children later diagnosed with Asperger’s syndrome or mild autism. The sample included 96 parents of children diagnosed with mild forms of autism. When asked to recall their children’s development prior to 12 months of age, most of the participants recalled their children exhibiting a mixture of developmental characteristics found in children later diagnosed with autism and some currently thought to be limited in children on the autism spectrum.

All but one participant reported concerns to the pediatrician or child development specialist prior to any professional bringing up concerns to the parent. After these initial concerns were discussed, a third of the participants stated that their children received a diagnosis of an autism spectrum disorder. The remaining 66% received diagnoses after the second, third, or later referrals. When participants were asked to describe the diagnostic process in their own words, a significant number of narratives contained keywords that described a lack of response from the developmental specialists while
nearly half also reported negative outcomes of the diagnostic process. Positive outcomes were only described in a third of the narratives, with only 5% of the participants utilizing keywords that described positive emotions.

In completing this study, the researcher hoped to give a voice to parents of children with autism who are often the biggest advocates for their children. In allowing the participants to describe their experiences with the diagnostic process in their own words, the researcher was able to gain insight into the emotions and thoughts that may not always be readily shared. This knowledge may be able to impact the field of human services by helping to encourage professionals working with children who have an autism diagnosis to take a more holistic family-centered approach rather than focusing on just the child’s needs and treatment plan. By offering support, reassurance, information, and counseling to families going through the diagnostic process, human services professionals may be able to increase the positive outcomes and positive emotions experienced by the parents of children diagnosed with mild forms of autism.

Conducting this study was a very positive experience for the researcher. As a person with extensive professional, educational, and personal experience with children on the autism spectrum, the researcher felt it was important to ask the parents about their own experiences with the diagnostic process. In doing so, the researcher gained valuable insight into the needs and desires of the parents who face a child’s autism diagnosis, and in particular, the unique needs of parents who face a child’s diagnosis of Asperger’s syndrome or mild forms of autism. This knowledge will be helpful to the researcher when working with families in order to assure that the needs of all members of the family are
addressed both immediately following diagnosis and again in the months and years afterwards.
References


Centers for Disease Control and Prevention. (2012). Prevelance of autism spectrum disorders—Autism and developmental disabilities monitoring network, 14 sites,


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Table A1: Age of Child When Parent First Began to Have Concerns About Development

<table>
<thead>
<tr>
<th>Age of child (months)</th>
<th># of children</th>
<th>% of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never had concerns</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Birth</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>3.13%</td>
</tr>
<tr>
<td>6</td>
<td>2</td>
<td>2.08%</td>
</tr>
<tr>
<td>8</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>9</td>
<td>4</td>
<td>4.17%</td>
</tr>
<tr>
<td>10</td>
<td>2</td>
<td>2.08%</td>
</tr>
<tr>
<td>11</td>
<td>4</td>
<td>4.17%</td>
</tr>
<tr>
<td>12</td>
<td>4</td>
<td>4.17%</td>
</tr>
<tr>
<td>14</td>
<td>3</td>
<td>3.13%</td>
</tr>
<tr>
<td>15</td>
<td>4</td>
<td>4.17%</td>
</tr>
<tr>
<td>16</td>
<td>2</td>
<td>2.08%</td>
</tr>
<tr>
<td>17</td>
<td>2</td>
<td>2.08%</td>
</tr>
<tr>
<td>18</td>
<td>20</td>
<td>20.83%</td>
</tr>
<tr>
<td>19</td>
<td>2</td>
<td>2.08%</td>
</tr>
<tr>
<td>20</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Age of child (months)</td>
<td># of children</td>
<td>% of children</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------</td>
<td>---------------</td>
</tr>
<tr>
<td>21</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>22</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>24</td>
<td>15</td>
<td>15.63%</td>
</tr>
<tr>
<td>26</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>28</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>30</td>
<td>4</td>
<td>4.17%</td>
</tr>
<tr>
<td>34</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>36</td>
<td>3</td>
<td>3.13%</td>
</tr>
<tr>
<td>40</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>42</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>48</td>
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<td>2.08%</td>
</tr>
<tr>
<td>60</td>
<td>2</td>
<td>2.08%</td>
</tr>
<tr>
<td>72</td>
<td>2</td>
<td>2.08%</td>
</tr>
<tr>
<td>76</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>85</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>99</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>108</td>
<td>1</td>
<td>1%</td>
</tr>
</tbody>
</table>

Table A1: Age of Child When Parent First (continued)
### Table A2: Developmental Characteristics During the First 12 Months of Life

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N</th>
<th>S</th>
<th>ST</th>
<th>O</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did baby turn when name called?</td>
<td>7.29%</td>
<td>23.96%</td>
<td>37.50%</td>
<td>31.25%</td>
</tr>
<tr>
<td>Did baby seem bothered by loud sounds?</td>
<td>10.42%</td>
<td>16.67%</td>
<td>29.17%</td>
<td>43.75%</td>
</tr>
<tr>
<td>Overly sensitive to touch?</td>
<td>36.46%</td>
<td>23.96%</td>
<td>16.67%</td>
<td>22.92%</td>
</tr>
<tr>
<td>Did baby get excited at games (“I’m gonna get you”, etc.)</td>
<td>6.25%</td>
<td>22.92%</td>
<td>41.67%</td>
<td>29.17%</td>
</tr>
<tr>
<td>Seem to have trouble hearing?</td>
<td>36.46%</td>
<td>14.58%</td>
<td>21.88%</td>
<td>27.08%</td>
</tr>
<tr>
<td>Did baby turn to avoid eye contact?</td>
<td>17.71%</td>
<td>18.75%</td>
<td>44.79%</td>
<td>18.75%</td>
</tr>
<tr>
<td>In new/strange situations, did baby look at your face for comfort?</td>
<td>12.50%</td>
<td>26.04%</td>
<td>37.50%</td>
<td>23.96%</td>
</tr>
<tr>
<td>Did baby ignore loud/startling noises?</td>
<td>50%</td>
<td>16.67%</td>
<td>22.92%</td>
<td>10.42%</td>
</tr>
<tr>
<td>Did baby spit out certain textures of foods?</td>
<td>17.71%</td>
<td>12.50%</td>
<td>20.83%</td>
<td>48.96%</td>
</tr>
<tr>
<td>When you pointed to something, did baby turn to look?</td>
<td>11.46%</td>
<td>31.25%</td>
<td>39.58%</td>
<td>17.71%</td>
</tr>
<tr>
<td>Was baby content to play alone for an hour or more at a time?</td>
<td>9.38%</td>
<td>9.38%</td>
<td>22.92%</td>
<td>58.33%</td>
</tr>
<tr>
<td>Did baby look at people who began talking even when not talking to baby?</td>
<td>8.33%</td>
<td>48.96%</td>
<td>36.46%</td>
<td>6.25%</td>
</tr>
<tr>
<td>Did baby rock body back and forth?</td>
<td>46.88%</td>
<td>18.75%</td>
<td>21.88%</td>
<td>12.50%</td>
</tr>
<tr>
<td>Did baby look up from favorite toy if you presented different toy?</td>
<td>5.21%</td>
<td>38.54%</td>
<td>44.79%</td>
<td>11.46%</td>
</tr>
<tr>
<td>Did baby get upset when switched from one activity to another?</td>
<td>6.25%</td>
<td>14.58%</td>
<td>35.42%</td>
<td>43.75%</td>
</tr>
<tr>
<td>Was it easy to understand baby’s facial expressions?</td>
<td>3.13%</td>
<td>22.92%</td>
<td>45.83%</td>
<td>28.13%</td>
</tr>
<tr>
<td>Did baby forcefully press body against people/furniture?</td>
<td>38.54%</td>
<td>14.58%</td>
<td>18.75%</td>
<td>28.13%</td>
</tr>
<tr>
<td>Did baby smile while looking at you?</td>
<td>3.13%</td>
<td>14.58%</td>
<td>43.75%</td>
<td>38.54%</td>
</tr>
<tr>
<td>Did baby try to get your attention to show you something?</td>
<td>14.58%</td>
<td>35.42%</td>
<td>36.46%</td>
<td>13.54%</td>
</tr>
<tr>
<td>Did baby get your attention to play games like peek-a-boo?</td>
<td>27.08%</td>
<td>40.63%</td>
<td>26.04%</td>
<td>6.25%</td>
</tr>
<tr>
<td>Characteristic</td>
<td>N</td>
<td>S</td>
<td>ST</td>
<td>O</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------</td>
<td>----</td>
<td>----</td>
<td>----</td>
<td>----</td>
</tr>
<tr>
<td>When baby awake and picked up, did he feel loose or floppy?</td>
<td>48.96%</td>
<td>19.79%</td>
<td>20.83%</td>
<td>10.42%</td>
</tr>
<tr>
<td>Did baby copy or imitate your sounds/noises?</td>
<td>12.50%</td>
<td>35.42%</td>
<td>37.50%</td>
<td>14.58%</td>
</tr>
<tr>
<td>Did baby copy or imitate your actions?</td>
<td>12.50%</td>
<td>35.42%</td>
<td>34.38%</td>
<td>17.71%</td>
</tr>
<tr>
<td>Was baby difficult to calm once upset?</td>
<td>6.25%</td>
<td>11.46%</td>
<td>29.17%</td>
<td>53.13%</td>
</tr>
<tr>
<td>Were baby’s sleeping/waking patterns regular?</td>
<td>17.71%</td>
<td>10.42%</td>
<td>22.92%</td>
<td>48.96%</td>
</tr>
<tr>
<td>Did baby get stuck doing simple activity over and over?</td>
<td>5.21%</td>
<td>13.54%</td>
<td>38.54%</td>
<td>42.71%</td>
</tr>
<tr>
<td>Did baby seem interested in other babies his/her age?</td>
<td>35.42%</td>
<td>51.04%</td>
<td>9.38%</td>
<td>4.17%</td>
</tr>
<tr>
<td>Did baby babble by putting sounds together?</td>
<td>11.46%</td>
<td>27.08%</td>
<td>23.96%</td>
<td>37.50%</td>
</tr>
<tr>
<td>Did baby enjoy staring at a bright light for long periods of time?</td>
<td>35.42%</td>
<td>18.75%</td>
<td>30.21%</td>
<td>15.63%</td>
</tr>
<tr>
<td>Did baby use gestures such as raising arms, shaking head, or waving?</td>
<td>17.71%</td>
<td>31.25%</td>
<td>29.17%</td>
<td>21.88%</td>
</tr>
</tbody>
</table>

When you asked where a familiar person was without pointing or showing, does baby look at person?

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N</th>
<th>S</th>
<th>ST</th>
<th>O</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did baby get stuck playing with a part of a toy (wheel, tag, etc.) instead of the whole toy?</td>
<td>11.46%</td>
<td>20.83%</td>
<td>28.13%</td>
<td>39.58%</td>
</tr>
<tr>
<td>Did baby communicate by using fingers to point?</td>
<td>16.67%</td>
<td>27.08%</td>
<td>29.17%</td>
<td>27.08%</td>
</tr>
<tr>
<td>Did you feel baby played/communicated less at 12 months than earlier in development?</td>
<td>52.08%</td>
<td>10.42%</td>
<td>26.04%</td>
<td>11.46%</td>
</tr>
<tr>
<td>Did baby enjoy making objects spin over and over?</td>
<td>28.13%</td>
<td>14.58%</td>
<td>28.13%</td>
<td>29.17%</td>
</tr>
<tr>
<td>Did baby stare at fingers while wiggling them in front of eyes?</td>
<td>41.67%</td>
<td>21.88%</td>
<td>22.92%</td>
<td>13.54%</td>
</tr>
</tbody>
</table>

N = never, S = seldom, ST = sometimes, O = often

Table A2: Developmental Characteristics During the First 12 Months of Life (continued)
### Table A3: Participant Thoughts & Feelings Regarding the Diagnostic Process

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Response</th>
<th>Keywords/Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Brushed off by school &amp; health professionals as bright child with behavior problems.</td>
<td>Dismissive, negative experience, lack of response, negative outcome obtained.</td>
</tr>
<tr>
<td>2</td>
<td>It was devastating, even though I had a feeling something as major as this was wrong with my son.</td>
<td>Devastated, intuition, negative experience, negative parent emotions.</td>
</tr>
<tr>
<td>3</td>
<td>I was initially in denial of the diagnosis, but came to see that help was really needed.</td>
<td>Denial, helpful, negative parent emotions, positive response obtained.</td>
</tr>
<tr>
<td>4</td>
<td>No response</td>
<td>n/a</td>
</tr>
<tr>
<td>5</td>
<td>The doctor believed my son had the high IQ of an Asperger child but behavior closer to a classically autistic child.</td>
<td>Diagnosis uncertainty, negative response obtained.</td>
</tr>
<tr>
<td>6</td>
<td>The process was fine in my opinion. My son was young when all this was going on. He was only 25 months old.</td>
<td>Positive experience, positive response obtained.</td>
</tr>
<tr>
<td>7</td>
<td>Should have been told of diet.</td>
<td>More information desired, negative experience, negative response obtained, lack of response.</td>
</tr>
<tr>
<td>8</td>
<td>No real help here, just pushed through the system.</td>
<td>No help, pushed through, negative experience, lack of response, negative response obtained.</td>
</tr>
<tr>
<td>9</td>
<td>Wish we had gone to see the development team earlier. I began having concerns about 10 months of age and we weren’t seen until he was almost 22 months of age. Doctors and therapists kept telling me not to worry and thought I was an over-anxious new mom.</td>
<td>Long process, dismissive, parents blamed, negative experience, lack of response, negative response obtained.</td>
</tr>
<tr>
<td>10</td>
<td>No response</td>
<td>N/s</td>
</tr>
<tr>
<td>11</td>
<td>Very thorough evaluation. Once diagnosis was given, we were given pamphlets, etc. and one referral but little or no overall direction of how to proceed.</td>
<td>Positive experience, more information desired, negative experience, positive response obtained, lack of response, negative response obtained.</td>
</tr>
</tbody>
</table>
Pediatrician and preschool teachers were not informed or educated on symptoms of mild autism/Aspergers and thought he was developmentally fine, just over attached to mom.

Special diagnostic setting with psychiatrist specializing in children 5 and younger.

The educational district did an evaluation at 19 months and told us he had delays but was normal. Then at 2 years, our new pediatrician referred us to a developmental neurologist for evaluation. After the neurologist made a diagnosis, we went back to the public education system and they re-evaluated. To get private therapy, we needed a medical diagnosis and to get early intervention we needed an educational diagnosis.

No response

I was continually told my child had colic, even after 6 months of screaming. They really should consider sensory issues and autism, especially when a child is not engaging with the parent and has unusual eye contact.

It was difficult coordinating this process with the system that failed him and the majority of the professionals we encountered were difficult to deal with. The district nurse was our strongest advocate and reached out to us after the meetings to help us navigate the process more efficiently.

The specialist we saw spoke only to my son, had him go through simple commands, physical tests, speech tests, and generally talked about his interests.

The doctor told us right away about the diagnosis. We did not understand but he explained it to us. We felt bad but wanted to know what we could do to help him until he said there was not a cure for this.

The diagnostic process was an overwhelming process. We were given all this general information and then basically told to “have a nice day.”
<table>
<thead>
<tr>
<th>Page</th>
<th>Response</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>21</td>
<td>No response</td>
<td>n/a</td>
</tr>
<tr>
<td>22</td>
<td>There was no help available at the time. Had to order a book from England to educate myself regarding the diagnosis of Asperger’s Syndrome.</td>
<td>More information desired, parent advocate, lack of response.</td>
</tr>
<tr>
<td>23</td>
<td>I found the county to be unhelpful and dismissive.</td>
<td>Lack of help, negative experience, difficulties with professionals, dismissive, lack of response, negative response obtained.</td>
</tr>
<tr>
<td>24</td>
<td>This experience has completely undermined my faith in modern medicine. I don’t really feel they are capable of doing anything helpful for my son.</td>
<td>Difficulties with professionals, negative experience, mistrust, negative response obtained, negative parent emotions.</td>
</tr>
<tr>
<td>25</td>
<td>No response</td>
<td>n/a</td>
</tr>
<tr>
<td>26</td>
<td>No response</td>
<td>n/a</td>
</tr>
<tr>
<td>27</td>
<td>I knew the diagnosis was incorrect but I had to become a strong advocate for my child. Her school wanted her to be medicated asap.</td>
<td>Parent advocate, diagnosis uncertainty, negative experience, unwanted medication, lack of response, negative response obtained.</td>
</tr>
<tr>
<td>28</td>
<td>The whole thing made me know that no one cared about him because they just wanted him to go on hyperactivity medicine even though he didn’t have hyperactivity. He was overwhelmed by all the noise and lights and everything. No one was listening to me at all.</td>
<td>Unwanted medication, negative experience, dismissed, diagnosis uncertainty, lack of response, negative response obtained.</td>
</tr>
<tr>
<td>29</td>
<td>I felt like a diagnosis would get him the help he needed and if he didn’t get it, he would be lost in the school system. If in home ABA was not offered, I think he might be in an autism class and not able to do half of what he can now. The legislators need to know that if they spend money on the kids when they are little, they possibly won’t be supporting them the rest of their life.</td>
<td>Parent advocate, therapies, lack of response, positive response obtained.</td>
</tr>
<tr>
<td>30</td>
<td>I know now that he had all the classic signs. I just wished someone had helped us. I felt like such a bad parent.</td>
<td>Dismissed, negative experience, felt like bad parent, lack of response, negative parent emotions, negative response obtained.</td>
</tr>
<tr>
<td>31</td>
<td>No response</td>
<td>n/a</td>
</tr>
</tbody>
</table>
Very frustrated with the department of education when I started the process. Felt more at ease once we received a diagnosis from our private psychologist.

It was extremely frustrating!!

I feel like if he had been diagnosed earlier when I asked them to, he might have gotten better treatment and I wouldn’t have been fighting with the school so much.

I dealt with a lot of professionals telling me different things. The pediatrician believed it was nothing, school officials believed he was ADD or autistic, other school officials believed he was just a brat. The counselor told me he thought it was PDD-NOS or autism. It is hard to get a grasp on what you need to do when nobody thinks the same thing. It is also hard to figure out who to go to for a diagnosis if the pediatrician isn’t on board with it.

Doctors need to listen to parents when they say something isn’t right. Had we been listened to, our son would have a diagnosis much sooner than 5 1/2. School wanted to give him a diagnosis of emotionally disturbed and I was against that diagnosis because I knew from all that I had read that he was on the spectrum. Children that are higher functioning are the children that fall between the cracks. Our son had 9 markers for his diagnosis. I was made to feel crazy that I thought there was something wrong with my son and had to fight all the way to his diagnosis.

Diagnosis was later changed to asperger’s. He’s very verbal and desires to be social.

I wish more was done when language concerns first noticed.

Both processes were immediately helpful in opening our eyes to the needs of our children and the urgency of being proactive in early intervention.

Devastated and confused

It confirmed my own suspicion about son.
Doctor did not explain much about the process but did explain the diagnosis. It helped tremendously to have school and pediatrician accept concerns as real.

It felt like no one would listen to me.

The diagnosis was given but the psychologist had no direction on what to do for him. At that point, I called on a parent advocacy organization to get him the help and services he needed.

No response

The behavior analyst was much more informative and positive. The neurologist gave us no hope.

No response

I felt the doctor was clear with us that she believed he had Asperger syndrome but was diagnosing him with mild autism so we would be able to get services at school. She was very helpful and understanding and spent a lot of time with us.

We saw a psychologist every 6 weeks for 3 appointments and were referred for an autism diagnosis. We were able to schedule that for one month later. We returned in 2 weeks to discuss the results.

I understand that early intervention is not allowed to make a diagnosis. However, I feel there should have been a referral at an earlier age for diagnosis. It was not until the school system raised alarm that I requested testing. The school system was planning to just treat without a diagnosis.

It took a lot of people to get the diagnosis.

The diagnostic process was not good. Pediatrician referred me to neurologist who diagnosed him with mild speech delay. He said my son wasn’t 1/10th as bad as the kids he saw and I should have been referred to a pediatric psychologist. Back then, there wasn’t a lot of good info out there.
<table>
<thead>
<tr>
<th>Page</th>
<th>Text</th>
<th>Summary</th>
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<tbody>
<tr>
<td>53</td>
<td>No response</td>
<td>n/a</td>
</tr>
<tr>
<td>54</td>
<td>We weren’t taken seriously at all. We continued through the first years of elementary school with me being called in to take her home because of her meltdowns.</td>
<td>Dismissed, difficulties with school system, negative experience, lack of response, negative response obtained.</td>
</tr>
<tr>
<td>55</td>
<td>The diagnostic process through the school system was thorough and we received a huge amount of support and help.</td>
<td>Positive experience, help, support, positive response obtained.</td>
</tr>
<tr>
<td>56</td>
<td>No response</td>
<td>n/a</td>
</tr>
<tr>
<td>57</td>
<td>The diagnostic process was frightening but providers were reassuring and helpful. They seemed eager to describe him as high functioning with a good prognosis.</td>
<td>Scared, positive experience, helpful, reassuring, negative parent emotions, positive response obtained.</td>
</tr>
<tr>
<td>58</td>
<td>Everyone agreed she had sensory issues but because she was verbal, the autism diagnosis was always given with hesitancy. She could speak wonderfully but didn’t have the correct social responses.</td>
<td>Diagnosis uncertainty, negative response obtained.</td>
</tr>
<tr>
<td>59</td>
<td>It has been frustrating. The medical system refers to the school and vice versa, with little help or remediation offered.</td>
<td>Frustration, negative experience, difficulties with professionals, difficulties with school district, more information desired, lack of help, negative parent emotions, negative response obtained, lack of response.</td>
</tr>
<tr>
<td>60</td>
<td>The diagnostic process was pretty easy considering the overwhelming stress you face when dealing with words like autism.</td>
<td>Positive experience, easy, positive response obtained.</td>
</tr>
<tr>
<td>61</td>
<td>No response</td>
<td>n/a</td>
</tr>
<tr>
<td>62</td>
<td>No response</td>
<td>n/a</td>
</tr>
<tr>
<td>63</td>
<td>I knew there was something wrong with my son very early. He wouldn’t play patty cake or peak a boo. Our doctor kept telling me he was nothing wrong—he was just a boy. He was over three and attending special needs preschool before the doctor thought there might be a problem.</td>
<td>Long process, negative experience, intuition, dismissed, lack of response, negative parent emotion, negative response obtained.</td>
</tr>
<tr>
<td>64</td>
<td>I thought that the process was hit or miss.</td>
<td>Inconsistency, negative response obtained.</td>
</tr>
</tbody>
</table>
The neurologist and developmental pediatrician were great. They validated the worries that had been dismissed by the regular pediatricians. Dismissed, validation, positive experience, lack of response, positive response obtained.

The school did its own analysis and put into place an IEP with accommodations that have sufficed. Positive experience, positive response obtained.

Seemed a little light on actual observation of my son, sort of quick and dirty. Frustration, not thorough, negative parent emotions, lack of response.

This process was extremely thorough and directed us to more helpful therapies. Helpful, thorough, positive experience, positive response obtained.

Pediatricians seemed to intentionally not want to investigate issues. Later, they played down the role of autism. They seemed to think autism was over diagnosed. Dismissed, negative experience, difficulties with professionals, lack of response, negative response obtained.

Received ADHD diagnosis at age 4 years 6 months and Asperger’s Syndrome at 6 years 6 months. Diagnosis uncertainty, long process, lack of response, negative response obtained.

It was all special educator/behavior/OT driven. Positive experience, positive response obtained.

Told by doctor he didn’t have autism and not to worry because he made eye contact. Dismissed, negative experience, lack of response, negative response obtained.

Frustrating, upsetting, confusing. Frustration, negative experience, confusion, negative parent emotions, negative response obtained.

I was very pleased with the thoroughness of the evaluation. I was very grateful we had insurance which allowed us to get these evals through a private diagnostic agency. Positive experience, thorough, positive response obtained.

I felt our doctor was unreceptive to our many pleas. Our second doctor was a godsend and immediately diagnosed PDD-NOS. Dismissed, positive experience, lack of response, positive response obtained.

I thought the process took too long. Long process, lack of response.

I feel the health providers did a very good job. Positive experience, positive response obtained.

Was unsure about the diagnosis, was in denial. Denial, negative parent emotions.
<table>
<thead>
<tr>
<th>Page</th>
<th>Text Content</th>
<th>Positive Experience, Positive Parent Emotions, Positive Response Obtained</th>
</tr>
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<tbody>
<tr>
<td>79</td>
<td>Services available in our area encouraged the diagnosis.</td>
<td></td>
</tr>
<tr>
<td>80</td>
<td>The initial feeling of the process was fear but relieved after getting help our son needed.</td>
<td>Scared, relieved, positive experience, positive parent emotions, negative parent emotions, positive response obtained.</td>
</tr>
<tr>
<td>81</td>
<td>Finally diagnosed after 2 years. Process was grueling. Even pediatrician alluded that I was contributing to my son’s behavior.</td>
<td>Long process, negative experience, frustration, grueling, dismissed, blamed, lack of response, negative parent emotions.</td>
</tr>
<tr>
<td>82</td>
<td>I was glad to have the second opinion. I was alarmed that he has a form of autism but the support services I now receive help me realize there is help for my son.</td>
<td>Glad, scared, helpful, negative parent emotions, positive parent emotions, positive response obtained.</td>
</tr>
<tr>
<td>83</td>
<td>I felt very isolated and left out of the loop most of the time via the doctors and school. Since the diagnosis, the communication level has increased.</td>
<td>Isolated, dismissed, lack of communication, negative parent emotions, lack of response.</td>
</tr>
<tr>
<td>84</td>
<td>It was very frustrating and required tons of persistence on my part. Hardly any help was offered and I found much of it on my own.</td>
<td>Frustration, parent advocacy, negative parent emotions, lack of response.</td>
</tr>
<tr>
<td>85</td>
<td>It was helpful to have diagnosis to get services through the state.</td>
<td>Helpful, positive experience, positive response obtained.</td>
</tr>
<tr>
<td>86</td>
<td>Since my daughter was verbal, my doctor would not listen to my concerns. We were given no help and few resources. I feel that if I had not been ignored, my daughter could have had early intervention and would be much better off today.</td>
<td>Dismissed, lack of help, lack of response.</td>
</tr>
<tr>
<td>87</td>
<td>Due to insurance limits, not much help was available outside of medication.</td>
<td>Unwanted medication, insurance limits, lack of help, lack of response, negative response obtained.</td>
</tr>
<tr>
<td>88</td>
<td>I was very blessed to have our pediatrician who was lightning fast to begin intervention.</td>
<td>Positive experience, blessed, helpful, positive response obtained, positive parent emotions.</td>
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<tr>
<td>Page</td>
<td>Text</td>
<td>Feelings/Details</td>
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<tr>
<td>89</td>
<td>Very little family support given. With our first diagnosis, we were</td>
<td>Lack of support, poor information, lack of response, negative response obtained.</td>
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<tr>
<td></td>
<td>given a pamphlet that began with “Autism is the most tragic of all</td>
<td></td>
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<td></td>
<td>childhood illnesses.”</td>
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<tr>
<td>90</td>
<td>It was a relief to finally have an explanation. Too many people</td>
<td>Dismissed, explanation provided, relieved, lack of response, positive parent</td>
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<td></td>
<td>said she wasn’t autistic because she was a girl and was missing</td>
<td>emotions, positive response obtained.</td>
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<td></td>
<td>classic symptoms.</td>
<td></td>
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<tr>
<td>91</td>
<td>Psychologist was very good and understood my child. She prepared</td>
<td>Positive experience, understanding, explanation provided, lack of help,</td>
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<tr>
<td></td>
<td>me for the possibility of Asperger’s so that it was not a shock.</td>
<td>difficulties with school, lack of response, positive response obtained,</td>
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<td></td>
<td>The help we received was not good, due to the time and the school.</td>
<td>negative response obtained.</td>
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<tr>
<td>92</td>
<td>It was confusing. From the time we first mentioned our concerns</td>
<td>Confusing, long process, insurance limits, lack of help, parent advocacy,</td>
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<td></td>
<td>to the time we received assessments was a long process and</td>
<td>lack of response, negative parent emotions.</td>
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<td></td>
<td>confusing. We were sent to multiple locations for different</td>
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<tr>
<td></td>
<td>assessments. We paid for therapy out of pocket because insurance</td>
<td></td>
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<td></td>
<td>would not cover it. Our pediatrician suggested waiting to see what</td>
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<td>happens instead of therapy. We have pushed all along the way to</td>
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<td>make sure he is getting the help to address his areas of need.</td>
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<tr>
<td>93</td>
<td>I was frustrated with the fact the pediatrician didn’t offer more</td>
<td>Frustration, dismissed, lack of help, negative parent emotions, lack of</td>
</tr>
<tr>
<td></td>
<td>advice/help at our first visit.</td>
<td>response.</td>
</tr>
<tr>
<td>94</td>
<td>The diagnostic process went as expected. I was not surprised by</td>
<td>Lack of help, positive experience, lack of response, positive response</td>
</tr>
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<td></td>
<td>the results, only the lack of help both in and out of the school</td>
<td>obtained.</td>
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<td>systems.</td>
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<tr>
<td>95</td>
<td>Crushed that the initial diagnosis was classic autism. Thankful</td>
<td>Devastated, helpful, thankful, grateful, positive experience, negative</td>
</tr>
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<td></td>
<td>for a school district who knew what they were doing. Grateful for</td>
<td>parent emotions, positive response obtained.</td>
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<td></td>
<td>providers who finally could give us options and answers.</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>We were told things but then set adrift with limited or no resources.</td>
<td>No help, more information desired, lack of response.</td>
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