Parental Grief, Coping Strategies, and Challenges When a Child has Autism Spectrum Disorder

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Abstract

Since 1980 the number of children in the United States diagnosed with Autism Spectrum Disorder (ASD) has been on the rise. It is currently the number one diagnosed childhood affliction (Autism Speaks, 2011). Despite the increased prevalence, awareness, and diagnostic improvements over the last 20 years much of ASD remains a mystery. There is no known cause and no cure for ASD. A two year old child, who appeared to be developing normally, fails to develop language, shows little interest in other people, engages in repetitive behaviors, and spends hours spinning the wheels of his favorite Hot Wheels™ car. Parents begin a journey into the world of autism, navigating through the diagnostic process while trying to understand why their child is no longer developing normally. Parents are faced with a myriad of questions and concerns. The stress and sense of loss they experience can be overwhelming to the strongest of individuals. This paper gives a brief history of ASD, identifies the main characteristics of ASD, identifies suspected causes, explores the sense of loss and grief parents often may experience, discusses parental stress, coping strategies, the special challenges faced while parenting a child with ASD and positive personal growth parents may experience because of the child's ASD.

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Writing this paper has been very similar, metaphorically speaking, to climbing a mountain: you know where you want to end up, but there is no clear cut path to get there. I would like to thank my advisor, Dr. Kevin Doll, for helping me plan and execute my strategy for completing this project.

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Table of Contents

Chapter I: Introduction

In 1980 the likelihood of a child in the United States being diagnosed with Autism Spectrum Disorder (ASD) was one in 10,000 (Grinker, 2007). Most recent statistics from the Center for Disease Control (CDC) predict one in 150 children will be diagnosed with ASD severe enough that it will disrupt their everyday lives (CDC, 2011). Although it has been described as an epidemic, ASD is neither contagious nor a disease.

When looking at ASD statistics it is necessary to understand the difference between prevalence and incidence. The CDC states that prevalence indicates the number of individuals within a certain population who are diagnosed with a specific disorder; incidence refers to the number of new cases of a disorder or condition that occurs over a specific period of time, usually one year. Knowing the prevalence of a disorder allows professionals to estimate the types and amount of services a specific group will require. The prevalence of ASD has risen over the last 30 years in part due to it now being recognized in the Diagnostic Statistical Manual of Mental Disorders (DSM) as a specific disorder with established criteria. Wing (2005) suggests that the rising number of children being diagnosed with ASD is due in part to the broadening of the diagnostic criteria, development and use of standardized diagnostic instruments, and an increased awareness of the disorder. A number of standardized diagnostic instruments have been developed in the last 30 years: The Child Autism Rating Scale (CARS) in 1980, the Autism Diagnostic Interview (ADI) and Autism Diagnostic Observation Schedule (ADOS) in 1989 and the Asperger’s Syndrome Screening Questionnaire (ASSQ) in 1999 (Chez, 2008).

Statement of the problem

ASD is lifelong disability that affects not only the individual but the family as well. Although society has gained knowledge related to ASD in the last 20 years, the behaviors exhibited by individuals with ASD may appear odd, threatening, and unacceptable in social situations. ASD is not diagnosed at birth leaving parents, family members and friends to believe the child will develop normally. Many parents developed concerns when their child was 18 to 24 months of age and failed to develop language skills. The child may regress socially, appearing to lose interest in the world around him. The cause of ASD remains a mystery and parents struggle to understand why their child has ASD.

Having a child with ASD can bring a number of changes to the family and the parents. Recognizing how having a child with ASD affects parent's lives and identifying positive coping strategies is necessary to understand and support those parents as they care for their child.

Purpose of the Study

The purpose of this study is to identify challenges faced by parents when their child is diagnosed with ASD. I will specifically examine research related to the difficulties parents may experience related to the diagnostic process, how parents respond and react to the diagnosis, what are the positive and negative coping strategies used by parents, and identify specific challenges parents face related to raising a child with ASD.

Assumptions of the Study

Having a child with ASD is difficult however parents will develop strategies to cope with their child's disorder and the daily challenges they face. While some parents will cope better than others, all parents will experience some degree of distress related to their child having ASD and the subsequent behaviors and health issues related to ASD.

Parents will also report positive changes in their lives related to their child having ASD.

Definition of Terms

Attention Deficit-hyperactivity Disorder (ADHD). A condition characterized by distractibility, restlessness, short attention span, impulsivity, and hyperactivity.

Ambiguous. Of doubtful or uncertain nature; difficult to comprehend, distinguish, or clarify.

Asperger's Syndrome (AS). A pervasive developmental disorder characterized by deficits in social adaptation.

Autism Spectrum Disorder (ASD). A group of developmental disabilities characterized by atypical development in socialization, communication, and behavior. It includes autism, Asperger's syndrome, and Pervasive Developmental Disorder- Not Otherwise Specified.

Diagnostic and Statistical Manual of Mental Disorders (DSM). Manual put out by the American Psychiatric Association that describes the diagnostic criteria for mental disorders and provides systematic descriptions for each. The most current is the DSM VI-TR published in 2000.

High Functioning Autism (HFA). Term used to describe children who had classic signs of autism in early childhood but as they developed, where shown to have a greater degree of intellectual ability, socialization, adaptive behavior, and communication skills than is usual in children with autism.

The International Classification of Diseases (ICD). The manual used in place of the DSM in countries other than the United States for diagnosing mental disorders.

Obsessive-compulsive Disorder (OCD). An anxiety disorder involving recurrent thoughts (obsessions) or behaviors (compulsions) that cause distress to the individual.

Pervasive Developmental Disorder (PDD). An umbrella category for a range of conditions that include symptoms such as difficulties with communication and social skills, unusual interests or habits and insistence on sameness.

Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS). A pervasive developmental disorder that includes most of the characteristics of autistic disorder but not enough to meet the specific criteria for autistic disorder.

Methodology

When searching for journal articles and books related to ASD the following keywords were used: autism, Asperger's syndrome, autism spectrum disorder, parental stress, coping skills, grief, and ambiguous loss. Journal articles were limited to those that were scholarly (peer reviewed) and published between 1980 and 2011. I focused on articles where the child had been diagnosed with ASD two to three years prior to the time of the study and children were under the age of four when diagnosed.

Data bases used were Badger Link, EBSCO host, ERIC, Science Reference Center, Medline, At Health Watch, and Health Source: Nursing/Academic Edition.

I used the More Online Catalog, part of the Indianhead Federated Library System, to locate books written by professionals relating to parenting children with ASD or the experience of raising a child with ASD.

The main professional journals used were the Journal of Intellectual Development and Disability, the Journal of Autism and Developmental Disorders, and the Journal of Intellectual Disability Research.

Books used as references were written by professionals who had advanced degrees in fields related to the study of ASD or written by parents who had a child diagnosed with ASD.

Newspaper articles were chosen according to their relevance to issues related to ASD covered in this paper.

Chapter II: Literature Review

History of Autism Spectrum Disorder

The word *autism* is derived from the Greek word *autos* meaning self. According to the Oxford English Dictionary, the term was first used and defined in the 1912 American Journal of Insanity in reference to “instances where thought is divorced both from logic and from reality” (O’Brien & Daggett, 2006, page 5). Swiss physician Eugen Bleuler used the term autism, also in 1912, to describe symptoms he observed in individuals diagnosed with schizophrenia (Grinker, 2007). According to Grinker (2007), Bleuler described these individuals as disengaged from others, isolated and self-absorbed. Bleuler used the term autism as an adjective to describe those behaviors. It wasn’t until 1943 that autism was used in reference to a specific developmental disorder (O’Brien & Daggett, 2006, Grinker, 2007).

Austrian Leo Kanner was a psychiatrist working as a professor at Johns Hopkins University in Baltimore, Maryland, when he studied the behavior in eleven children between the ages of three and nine (Grinker, 2007, Volkmar & Wiesner, 2009, O’Brien & Daggett, 2006). In 1943 Kanner published “Autistic Disturbances of Affective Contact” describing the children’s behaviors and referring to these children as having “infantile autism” (Grinker, 2007). Kanner believed that the behaviors these children presented were unique and thus required a separate diagnostic category (Grinker, 2007). The children, eight boys and three girls, demonstrated an inability to relate to people and social situations, had minimal or no verbal skills, experienced sensory over sensitivities, had an extreme need to maintain sameness or routine, and engaged in repetitive behaviors (Volkmar & Wiesner, 2009, O’Brien & Daggett, 2006).

According to Wing (2005), in 1944 Viennese pediatrician Dr. Hans Asperger described unusual behaviors he observed in four boys. Asperger identified three core problem areas in these children: (a) they exhibited delays in social understanding, social maturity and social reasoning; (b) despite having average or above average grammar and vocabulary skills, they were unable to interact with peers or take part in everyday conversations; (c) they became so focused on a topic or area of interest that it dominated their time and thoughts. Asperger also observed sensory processing problems such as over sensitivity to auditory, visual, tactile, or gustatory stimuli, difficulty with gross motor skills, and clumsiness of gait (Wing, 2005, Grinker, 2007). Asperger referred to this disorder as ‘autistic psychopathy’ (Wing, 2005).

In 1981 Dr. Lorna Wing, a British psychiatrist, published the findings of Hans Asperger’s 1943 report (Attwood, 2007). Prior to that time Asperger’s work, written in German, was not well known in English-speaking countries. Wing (2005) referred to the disorder as Asperger’s Syndrome, feeling the term ‘autistic psychopathy’ had a tendency to be confused with sociopathic which had a negative connotation.

The earliest published record of children with AS behaviors may have been an article published in 1926, written by Russian psychiatrist G.E. Ssucharewa (Wing, 2005). Ssucharewa published a paper describing behaviors she had observed in six children, all boys, very similar to those observed by Asperger. In her article, published in a German journal, Ssucharewa referred to these children as suffering from “schizoid personality disorder of childhood.” Sula Wolff discovered Ssucharewa’s work in 1995 while she was researching historic psychiatric literature. In 1996, Wolff translated Ssucharewa’s work into English.

Although autism was first observed in the early 1940’s, Grinker (2007), discusses the possibility that there were autistic children long before that. Grinker refers to books and articles published over the past 200 years that describe children who were thought to be wild or feral, had perhaps been raised by animals, or had spent many years living on their own in uninhabited areas. Four examples are: Wild Peter, found in 1724, in a forested area in Germany: Kasper Hauser, found in a wooded area in Nuremberg in 1928: Kamala and Amala: possibly sisters, found in 1920 in a forest in India. Linnaeus, the father of scientific classification, categorized these feral children as *Loco ferus* and added subtypes *mutus* (mute) and *hirsutis* (hairy). These children may have been autistic, abandoned by their parents, and although dirty and seemingly wild had actually spent a very short period of time on their own. The children had no language skills, did not tolerate physical contact, and engaged in repetitive physical movements such as rocking or hand flapping. Of the 105 cases of feral children Grinker (2002) found reported in the press or literature, 73 were boys and 32 were girls, a ratio similar to what would be expected today if one were to do a random sampling of 100 children with autism.

Frith (2003) also discusses the possibility that some of the earlier children seen as feral may have been autistic. She relates the story of Victor, the “Wild Boy of Aveyron”, discovered in the forest in France in the late 1800’s. Thought to be 12 or 13 years old when discovered, his behaviors were described as anti-social; he had no formal language or communication skills, and showed no interest in others. The only time Victor would respond to sound was when he would hear the cook preparing meals and head for the kitchen in search of food. Despite attempts to educate and socialize Victor, he remained distant, avoided human contact, and failed to develop language or communication skills.

The term High Functioning Autism (HFA) was first used in 1981 in reference to children who displayed signs of autism at an early age, but as they matured were found to have higher level cognitive skills than was first suspected, demonstrated improved social skills, and acquired acceptable communication and language skills (Attwood, 2007).

The 1980, The Diagnostic and Statistical Manual of Mental Disorders, third edition (DSM-III) identified autism as a specific disorder having five criteria: (a) onset before 30 months of age; (b) lack of responsiveness to people; (c) gross deficits in language; (d) peculiar speech patterns; and (e) absence of delusions, hallucinations, loosening of associations and incoherence. In the 1987 DSM-III-R the criteria for autistic disorder was revised: (a) impairment in reciprocal social interaction (b) impairment in verbal and nonverbal communication and in imaginative activity (c) restricted repertoire of activities and interests. The DSM-VI, published in 1994, listed the following criteria for autistic disorder: (a) qualitative impairment in social interaction; (b) qualitative impairment in communication; and (c) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. The criteria for autistic disorder remained the same the DSM-IV-TR published in 2000.

Asperger's disorder was listed as a separate disorder and included in the DSM-IV for the first time in 1994. The criteria for a diagnosis included the following:

1. Qualitative impairment in social interaction.
2. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities.
3. The disturbance causes clinically significant impairment in social, occupational or other important area of function.
4. There is no clinically significant delay in language.
5. There is no clinically significant delay in cognitive development.

The United States Department of Education first recognized autism as a legitimate code for disability in 1992 which allowed children to receive special education services specifically related to ASD.

Autism Spectrum Disorder

According to O'Brien and Daggett (2006) the criteria listed in DSM-IV-TR is used by professionals, physicians, nurse practitioners, mental health workers, etc., to determine if a child has autism spectrum disorder (ASD). The DSM is the manual used for diagnosis by professionals in the United States while in other countries The International Classification of Diseases (ICD) is the diagnostic manual used (World Health Organization, 1992). In the DSM-IV-TR the term Pervasive Developmental Disorder (PDD) is the general category under which Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder- not otherwise specified (PDD-NOS) are included. The use of ASD is considered synonymous with PDD but has been found to be less confusing and more easily understood by parents (O'Brien & Daggett, 2006). The complete diagnostic criteria for PDD and the sub-categories can be found in the DSM-IV-TR (American Psychiatric Association, 2000, pg. 69-84).

In order for a child to be diagnosed with autism, Frith (2003), states all three of the following symptoms must be observed in the child before age three.

> 1. There must be qualitative impairment in reciprocal social interactions relative to developmental level. Behavioral signs include poor use of eye gaze and of gestures; lack of personal relationships.
>
> 2. There must be a qualitative impairment in verbal and nonverbal communication relative to developmental level. Behavioral signs include delay in the acquisition of language, or lack of speech; lack of varied, spontaneous make-believe play.
>
> 3. There must be markedly restricted repertoire of activities and interests appropriate to developmental level. Behavioral signs include repetitive or stereotyped movements, such as hand flapping; interests that are abnormally intense or abnormally narrow (pg. 9).

Frith (2003) believes that although social impairment is difficult to observe in children 24 months of age or younger, normally developing children begin to exhibit a strong interest in other children beginning at two years of age. A child with autism will show interest in objects instead of other children and is likely to engage in parallel play rather than interactive play when with other children.

Attwood (2007) states that AS is identified by three core features: (a) the child lacks social understanding; (b) the child has limited ability to have reciprocal conversations; (c) the child has an intense interest in a particular subject or object. AS may also be characterized by pedantic, repetitive speech; naïve and inappropriate interaction; inability to read non-verbal communication; and poor gross motor skills. AS is primarily diagnosed in children four to eight years old, more symptomatic cases are diagnosed earlier while a milder case may not be diagnosed until much later in an individual's life.

HFA is a term used when children, once diagnosed as autistic, go on to develop language and their behaviors become less autistic in nature. The distinction between HFA and AS continues to be discussed with some professionals viewing them as being distinctly different disorders, while others consider them to be the same (Wing, 2005).

Silverman (2011) believes:

> When the intense interests of the individual become obsessive and nonfunctional, and social interaction with others is diminished to the point of little practical effectiveness, the observer may be looking at a form of autism (pg. 11).

Wing (2005) states "establishing precise criteria for any syndrome defined solely on aspects of behavior is difficult or impossible." Children on the lower end of the autism spectrum have similarities to children with profound mental retardation while children on the high end of the spectrum display behaviors very similar to children who demonstrate mildly eccentric variations of typical development" (Wing, 2005).

Children with ASD may have comorbid health and behaviors issues including attention deficit-hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), sleep disturbance, seizure disorder, gastrointestinal problems, food allergies, and sensory over-sensitivities (Jepson, 2007, Mori, Ujiie, Smith, & Howlin, 2009). The most common co-morbidity issues in children with ASD are ADHD, seizure disorder and OCD (Mori et al., 2009).

Young children with ASD often have difficulties with auditory filtering as well as tactile, smell, visual, and gustatory sensitivities (Wiggens, Robins, Bakeman, & Adamson, 2009, Volkmar & Wiesner, 2009, Attwood, 2007). There is some discussion that the auditory filtering issues may factor in as to why some children with ASD do not respond to their name (Wiggens et al., 2009). The sensory sensitivity issues affect all aspects of a child life, from the basic need for food to safety issues related to over responding to sensory stimuli.

Twachtman-Reilly, Amaral, and Zebrowski (2008) feel children with ASD are lacking the ability to filter incoming stimuli:

> Sensory modulation allows an individual to appropriately filter the multitude of sensory information that constantly bombards the nervous system. It does this by inhibiting irrelevant input and alerting the individual to relevant stimuli so that he or she is able to respond to incoming information based on the task at hand and the environmental demands. Dysfunction in one's ability to modulate sensory input can be exhibited as hyper-responsivity, hypo-responsivity, and/or fluctuating responsivity, resulting in atypical responses such as sensory seeking or sensory avoidance behaviors.

Temple Grandin, born in 1947, diagnosed as brain damaged at two and with HFA as a teenager has become an advocate and spokesperson for individuals with ASD (Grandin & Sullivan, 2008). Grandin earned a doctoral degree in animal science, is currently a professor at

Colorado State University, and has written a number of books about her experiences growing up autistic; giving us first hand information as to what it is like to have HFA. Grandin had problems related to sensory oversensitivity and recalls an episode when her mother tried to get her to wear a hat:

> My ears felt as if they were being squashed together into one giant ear. The band of the hat pressed tightly around my head. I jerked the hat off and screamed. Screaming was the only way of telling mother I didn't want to wear the hat. It hurt. It smothered my hair. I hated it. I wouldn't wear it to 'talking school' (Grandin & Scariano, 1996, pg.1).

Some children with ASD have savant syndrome. These individuals develop musical talents, mathematic skills or artistic abilities beyond what would be expected of individuals with intellectual impairment. Heaton and Wallace (2004) conclude"autism and savant skills are inextricably linked" and may be due to the child's increased sensory sensitivity in combination with obsessions and restricted interests. One in 10 children having ASD will exhibit savant talents and half of all savants are autistic (Heaton & Wallace, 2004). Frith (2002) suggests, "It is possible that savant abilities are a unique feature of autism and a sign of a different intelligence" (pg.149).

In their study of children with ASD, Xianchen, Hubbard, Fabes, and Adam (2006), found 85% of the children experienced sleep problems on a daily basis. The most commonly observed problems were bedtime resistance, insomnia, morning rise problems and unusual movements, perceptions, dreams and behaviors while falling asleep.

Individuals diagnosed with autism spectrum disorder have varied degrees of symptoms. For some individuals symptoms are so mild they may not even be aware they have the disorder, while some have symptoms and behaviors so severe they are unable to function in society and must be placed in a residential facility to protect them and their families (Naseef, 2002).

Theories Related to What is Causing ASD

With the rapid increase in the number of cases of ASD the immediate question becomes "What is causing this disorder?" "Why has my child become autistic?" We do know autism is not caused by cold and distant parents, or "refrigerator mothers" as was once proposed by Kanner who claimed these parents, particularly mothers, kept their children "neatly in a refrigerator that did not defrost" (Grinker, 2007, pg 72). Bruno Bettelheim reinforced the "refrigerator mother' theory in his 1967 book, *The Empty Fortress: Infantile Autism and the Birth of Self.* Although there is no evidence supporting the mother blaming theory, the theory has persisted for a number of years (Stace, 2010).

Scientists continue to look for possible causes of ASD. A number of studies point to the correlation between the increased commercial use of mercury and the rise in the number of individuals being diagnosed with ASD. Although there is evidence of genetic predisposition in some families researchers have been unable to isolate a specific gene or gene mutation in individuals with ASD. There is also growing evidence that individuals with ASD have specific brain anomalies that may be a factor in their developing the disorder. Scientists are also looking into the possibility that there are toxic environmental factors that may be contributing to the rise in ASD.

Mercury and ASD have been linked in a number of ways over the last 20 years (Olmstead & Blaxwell, 2008). Some theories related to mercury and ASD have been disproven, while others continue to be investigated. There is no specific mercury source recognized as causing

ASD nor is there evidence related to when the exposure to mercury may cause the most damage related to the child later developing autism.

Austin (2008) compares the symptoms of mercury poisoning with the symptoms found in children with ASD, in particular neuro-chemical irregularities, gastro-intestinal distress, immune system deregulation, and neural inflammation. Austin correlates Kanner's identification of autism in the 1940's with the increased use of mercury following WWI. Austin states:

> The science behind the autism as mercury poisoning hypothesis meets all epidemiological criteria across too many independent studies to be dismissed as coincidence. So, the hypothesis that mercury causes autism is confirmed epidemiologically.

The question then becomes where, when, and how are children being exposed to mercury?

Olmstead and Blaxwell (2010) examined data related to the increased commercial use of mercury beginning in the 1930's and the identification of autism by Leo Kanner in 1943, ten years later. In the 1930's mercury was used in disinfectants and antifungal treatments for seeds, in preservatives for lumber, in amalgam used to fill dental cavities, and as a preservative in vaccines. Of the eleven children Kanner first observed with autism, eight of the children had one or both parents who were directly exposed to mercury prior to the child's birth (Olmstead & Blaxwell, 2010).

Hertz-Picciotto, Green, Delwiche, Walker, and Pessah (2010) are involved in the Childhood Autism Risk from Genetics and the Environment (CHARGE) Study " a large and comprehensive, epidemiologic investigation designed to identify factors associated with autism that may provide clues about etiology, co morbidity, or mechanisms of susceptibility" (pg. 161). The CHARGE Study is conducted at the Medical Investigation of Neuro-developmental Disorders (M.I.N.D.) Institute at U.C. Davis in Sacramento, CA. The study follows three groups of children: (a) children with autism or ASD (b) children with Developmental Delays (DD) but not autistic and (c) children from the general population. In their study, Hertz-Picciotto et al. (2010) evaluated the level of mercury (Hg) concentration in the participant's blood. They also inquired as to the participant's consumption of fish, use of nasal sprays, and number of amalgam dental fillings, all known sources of mercury. The results showed no significant difference in the mercury concentration in the blood of autistic children when compared to the concentration levels found in the blood of the DD children and children in the general population. If mercury does play a role in causing ASD, than perhaps it is exposure during pre-natal development or very soon after the child is born that is the problem.

Mercury, used as a preservative in vaccines, has been suspected of causing ASD. The connection between vaccines and ASD came about in large part due to Dr. Andrew Wakefield (Olmstead & Blaxwell, 2010, Austin, 2008, Taylor, 2006). Wakefield published an article in *The Lancet* in 1998 stating that within 14 days of receiving the MMR vaccine eight children developed autistic like behavioral symptoms (Taylor, 2006). Although the facts in his article were proven false, the article set off a media furor related to the MMR vaccine causing ASD that still persists today. Parents whose children have ASD want to blame someone or something and the vaccine continues to stir controversy.

There are two theories related to childhood vaccinations and ASD. The first questions if the mercury used in the vaccine preservative thimerosal causes ASD while the second questions if giving a vaccine against all three diseases, mumps, measles, and rubella (MMR), before the age of 18 months may be the problem.

Lawler, Croen, Grether, and Van de Water (2004) found no link between the use of the mercury containing preservative thimerosal in vaccines and the increased rate of ASD. Despite thimerosal being eliminated from vaccines in 1999 the rate of ASD continues to rise. Lawler et al. discuss that because ASD is a relatively new disorder and the diagnostic practices are changing it is difficult to make comparisons.

Honda, Shimizu and Rutter (2005) did an extensive study in Japan looking specifically at the MMR vaccine and the rate of ASD in 31,000 children. Prior to 1993 Japanese children were required to have the MMR vaccine before 18 months of age. They discontinued the practice in 1993 and from 1993-1996 not a single child was given the MMR vaccine. From 1988 – 1993 the rate of ASD per 10,000 was 47.9 while in 1996 three years after the vaccinations had been discontinued the rate had risen to 117.2 per 10,000 leading the researchers to theorize the vaccine was not the cause of ASD.

There is evidence that there could be a genetic component related to the cause of ASD. The first study that looked at twins and ASD was carried out in 1977 by Folstein and Rutter (Frith, 2003). The study included 21 sets of twin boys, 11 identical and 10 fraternal. They found concordance for classic autism in four of the 11 identical sets of twins and none in the fraternal twins. However it should be noted that in the non-concordant pairs of identical twins some of the brothers did have milder forms of autism which became more observable as they got older (Frith, 2003). In recent studies of identical twins it was found one twin having ASD increased by 60% the likelihood the other twin would also have ASD (Rutter, 2005, O'Brien & Daggett, 2006, Szatmari, Zwaigenbaum, & Bryson, 2004, Baron-Cohen, 2004). Wing (2001) determined that although identical twins may both develop ASD, they may display markedly different types of ASD symptoms indicating that other factors may be involved along with genetics. In fraternal twins or siblings with ASD the chance of the twin or other siblings developing the disorder is only five percent higher than in the general population (O'Brien & Daggett, 2006, Szatmari et al., 2004).

Lawler et al. (2004) theorized that there may be common brain abnormalities in individuals who develop ASD. Lawler et al. (2004) refer to a study done by Kemper and Bowman in 2002 in which small and closely packed neurons in the hippocampus, amygdale, and entorhinal cortexes were found during post mortem examinations on brains of nine individuals with AS. Baron-Cohen (2004) also reported findings of increased cell density in the amygdale in post-mortem examinations of individuals with ASD. As diagnostic equipment becomes more sophisticated, researchers are hoping to get gain additional knowledge of brain functioning in individuals with ASD.

Environmental factors may also be contributing to the increase in ASD. Lawler et al. (2004) point out that the increase in the number of cases of ASD parallels the increased rate of other childhood disorders such as asthma, allergies, Type I diabetes, ADHD, and auto-immune disorders leading the authors to question if there are toxic environmental causes related to all these disorders.

To date there is no definitive answer as to what causes ASD and scientists accept that the complexities related to autism require considerably more research before they determine a cause. Parents, on the other hand, find it difficult not knowing what causes ASD and they search for an explanation as to why their seemingly normal child now has autism.

Family Systems Theory

Family systems theory views the family as an emotional unit and uses systems theory to explain the interaction between individuals in the family. In a family, each individual has a role and plays an integral part in determining how that family functions as a whole. The actions and reactions of one family member may influence other member's actions and reactions (Nichols & Schwartz, 1998).

Family members solicit approval, attention, and emotional support from members within the family unit, however Bowen, a leader in family systems theory, believed that members needed to also be able to separate their thoughts and feelings from those of other family members. He referred to this ability as 'differentiation of self' (Nichols & Schwartz, 1998). Differentiated individuals do not depend on the acceptance and approval of others but rather are confident in their own abilities and thoughts. To be differentiated did not mean that an individual did not have emotional ties with others in the family; differentiated individuals however did not allow conflict and tension between other members to influence how they felt. Bowen felt if family members were too closely connected emotionally, each time one member became anxious or upset it would have a negative effect on all the other members causing tension throughout the family system. Bowen saw families whose members were differentiated as better able adapt to and cope with stress and change that takes place within families (Nichols & Schwartz, 1998).

Families whose members were not differentiated had the tendency to become enmeshed, emotionally fused, and lacked the ability to cope with stress and change creating a chaotic family system (Nichols & Schwartz, 1998).

Altierre and Von Kluge (2009) found parents who rated themselves as enmeshed believed they were able to function positively despite their child having ASD. Parents were able to seek social support during times of high stress, felt they had a strong social support network, and reported experiencing less depression and somatic problems. The closeness of being enmeshed may actually distribute the stress throughout the family members rather than having one parent responsible for the majority of the stress and worry.

Illness, death, divorce, remarriage, etc. may threaten established relationships within the family. Family members may have to re-establish family roles, power distribution, boundaries, and rules necessary to keep the family functional and relationships within the family positive.

The Diagnostic Process

There is no identified biochemical or neurological marker that can confirm a diagnosis of ASD (Keenan, Dillenburger, Doherty, Bryne, & Gallagher, 2009, Frith, 2002, Volkmar & Weisner, 2009, O'Brien & Dagget, 2002). Diagnosing a child with ASD is a process that may take 12 to 16 months (Keenen et al., 2010). Although parents may suspect something is wrong when the child is younger than 12 months, it is usually not until the child is 18 to 24 months old that parents express concerns to their pediatrician. The number one concern expressed by parents related to the child's development is the child failing to develop language skills (Matson & Sipes, 2010, Hughes, 2002, O'Brien & Daggett, 2006).

Early diagnosis and intervention are important for the child and the parents. Although parents, in hind sight, may have noticed problems related to the child's development before 12 months, the average age at which parents bring children to the pediatrician expressing specific developmental concerns in when the child is 18-24 months of age. According to Frith (2003), the problem with diagnosing children less than 18 months of age is their behavior repertoire is limited so a behavioral diagnosis is unreliable and our current knowledge of social responsiveness in infants is inadequate. Two standardized tools were recently developed that can be used effectively with children 12 – 15 months of age: The Checklist for Autism in Toddlers (CHAT) and the Pervasive Developmental Disorder Screening Test for Toddlers (PDDST-II)

(Chez, 2008). For children 24 months and older the Childhood Autism Rating Scale (CARS), The Autism Diagnostic Interview- Revised (ADI-R), and the Autism Diagnostic Observation Schedule (ADOS) are the most commonly used screening tools (Matson & Sipes, 2010, Keenen, et al. 2009, O'Brien & Daggett, 2006). Although standardized questionnaires and tests have been developed and improved in recent years, ASD remains a challenging disorder to diagnose and relies heavily on parent's observations (Keenen et al., 2010, Volkmar & Weisner, 2009, Rutter, 2005).

Although parents take part in the diagnostic process they may still feel a loss of control and feelings of frustration, often exacerbated by when doctors take a 'wait and see' attitude. The many appointments and professionals they are involved with during the diagnostic process can be challenging. At times professionals are insensitive to parent's feelings as Hughes (2003) tells of his wife's experience with the neurologist: "Well (Mrs. Hughes), I want some further tests done, but I don't hold out any hope for this child" and followed with "Down the road, I see this child in an institution" (pg. 28).

Although early diagnosis and intervention is important, professionals do not want to over diagnose. Children do develop at different rates and it is important for professionals to be thorough when taking the child's history and the parents to be forthcoming when stating concerns. Labeling the child has having ASD should only be done when all involved feel it is the right diagnosis.

Parental Response to the Diagnosis

When a child is diagnosed with ASD the parents may experience a tremendous sense of loss. The normal child they believed they were raising is no longer a reality and parents are often at a loss as to what this means for their child and their family (Norton & Drew, 1994).

When a child dies there are symbolic rituals that help parents and family members work through their loss, but that is not the case when a child is diagnosed with ASD. Featherstone (1980) gives a comparison between the death of a child and having a child with a disability: "Although death provides a moment's respite from ordinary demands, disability generates new tasks and necessities" (pg. 234).

Kubler-Ross and Kessler (2005) identified five stages individuals may go through when faced with the death of a loved one: denial, anger, bargaining, depression, and acceptance. Studies show that not all individuals faced with a loss will go through all of the stages, nor is grief linear, following the stages in a specific order. Grief is an ongoing process. When a child is diagnosed with ASD studies show that parents manifest the same emotions as when a child dies (Penzo & Harvey, 2008). Naseef (2001) expressed it this way: "The dream of a perfect child can die a painful death" (pg. 15).

Denial may be present from the time a parent suspects their child is not developing normally until the child reaches adulthood. Denial is encouraged by well-meaning relatives who tell of Uncle Ben who didn't talk until he was five, or a friend whose child appeared to be anti-social only to blossom later into a social butterfly. Professionals also perpetuate parent's denial by stating "all children develop differently," encouraging parents to be patient, and not think the worst. While denial may be thought as a negative reaction, is can also function as a positive coping mechanism. Denial creates a buffer zone between what was and what is to be, giving parents time to adjust to the situation in bearable steps. It allows parents time to find the inner strength necessary to cope with day-to-day struggles.

Anger may follow the diagnosis of ASD: as the parent's fears are confirmed and the reality of having a child with ASD begins. Anger may be directed at friends whose children are normal, professionals who they feel should have taken their concerns more seriously, or a spouse who goes to work each day and doesn't have the responsibility of caring for the child full time. Benson and Karlof (2009) found that a parent's anger does not totally disappear but reduces in frequency and severity as parents come to terms and learn to cope with their child's ASD. Anger can be isolating, but Kubler-Ross and Kessler (2005) view it as a source of strength and an indication that the person is moving forward out of denial.

Parents may also go through a bargaining stage. They may use bargaining to get through the diagnostic process and also as new treatments and educational strategies become available: parents hold out hope that their child will improve and possibly be cured. Parents may offer, "If you let this treatment work, I promise to be a better person." Certainly looking for positive options for their child is not wrong, but at some point parents must accept the reality of the child's ASD and move forward with their lives.

It is common for parents to express feelings of depression and sadness related to their child's ASD (Pottie & Ingram, 2008, Benson & Karlof, 2008, Meadan, Halle, & Ebata, 2010). Birthdays, missed developmental milestones, and medical crisis cause parents to revisit their grief and the sadness returns (Naseef, 2001, Hughes, 2003, Featherstone, 1980, Penzo & Harvey, 2008). Grief for parents is cyclic since there is no real end, no closure, as when a child dies.

Acceptance of the child's diagnosis and the changes it brings to the family may come when parents are able to move past blame, guilt, anger, and asking "Why my child?" They are able to move forward, living with the reality of their child's ASD, working through the many challenges, and realizing that they are able to still enjoy life. They do not let the child's ASD define who they are but rather accept that the child's ASD brings many challenges and it is only one part of their life.

Boss (1999) looks at a different type of loss individuals may experience, ambiguous loss. She defines ambiguous loss as "an incomplete and uncertain loss" that may occur either when the person is physically present but psychologically absent, as in the case of an Alzheimer's patient, or when the person is psychologically present but physically absent, as in the case of a soldier missing in action or a kidnapped child (pg. 9). When a child is diagnosed with ASD, the parents face an ambiguous loss; the child is physically a part of their lives, but the child is different. Boss (1999) states, "the greater the ambiguity surrounding one's loss, the more difficult it is to master it and the greater one's depression, anxiety, and family conflict" (pg. 7). Unlike when a child dies, the loss is unclear and indeterminate causing individuals to become physically and emotionally exhausted. "Significant loss always causes mental torment, but when a parent loses a 'living' child, there is no right or capacity to grieve" (Naseef, 2001, pg. 44).

Parents sometimes waver between hope and hopelessness. Hughes (2003) gives an example of this when he states:

> Despite our belief in his bright future, his silence was the One Horrible Thing that chipped steadily away at our belief. Speech is the biggest developmental issue of all, the *sine qua non,* the quantifiable test of how the child is doing, and Walker was, at three, plainly not doing well (pg. 31).

In their work as pediatric nurses, Elder and D'Alassandro (2009) identified four phases they observed in parents whose child was diagnosed with ASD:

1. Shock and disbelief: Although parents suspected something was wrong, they were clinging to the hope that there may have been a less severe diagnosis for their child. Often parents during this stage will seek out a number of professionals and get multiple opinions before they accept the diagnosis.

2. Sad and angry: As parents come to terms with the diagnosis they express feelings of grief and implications of the diagnosis become reality.
3. Disorganization and despair: Parents during this phase express feelings that their lives are "out of control." They are overwhelmed with treatment options, appointments, and the many child service agencies with which they are now involved. Paradiz (2002) expresses similar feeling related to her child's ASD diagnosis and his starting a special education pre-school program at age three: "It was the thought of allowing so many other people to involve themselves in our lives that was difficult to face "(pg.49).
4. Re-organization: Families are able to move beyond the diagnosis and adapt to the changes in their lifestyle due to the diagnosis. Although some families still have a degree of chaos in their lives, they have successfully moved through the mourning stages. Family members are able to redefine their relationship with the child and reconstruct how they will function in the future, redefining roles and rules within the family system.

Coping Strategies Used by Parents

Just as each child with ASD is unique, so too is each parent's response to the ASD diagnosis. Parents coping strategies may be affected by a number of factors including: religious beliefs, level of education, financial status, cultural norms, and living in a rural vs. urban area.

In their 2009 study, Milshtein, Yirmiya, Oppenheim, Koren-Karie, and Levi, discovered that parents who are able to reach a stage of resolution regarding their child's ASD are able to move forward integrating their previous life with their current life. Resolved parents are able to put aside questions of causation, accept the child's abilities and limitations, and look at the benefits in the situation while still acknowledging the difficulties they face.

Milshtein et al. (2009) describe parents who are unable to reach a stage of resolution as pre-occupied with the causation, focused on the negatives, and lack the energy to move forward. Unresolved parents detach from the current experience, appear confused as to what the diagnosis means and express feelings of anger, depression, and conflict. Unresolved parents, especially mothers, feel the child's diagnosis has produces negative feelings about one's abilities as a parent, and have a negative view of their prospects for the future (Tehee, Honan, & Hevey, 2008).

Milshtein et al. (2009) observed parents falling into one of three categories: feeling oriented, action oriented, or thinking oriented. In the feeling oriented group parents found that talking about their feelings openly relieved the stress and they took comfort in the emotional support they received from friends and family. Action oriented parents were interested in finding answers and taking charge. Frith (2003) believes that because the cause of ASD remains to be determined, parents struggle to find an explanation for why their child developed the disorder. For some parents, the quest to find a cause becomes all consuming and negatively effects their ability to cope with the stress related to the child's ASD. Thinking oriented parents focused on finding more information related to working through problems; they became active in support groups, had a realistic attitude toward their child's abilities, and were strong advocates for their child. Parents reported feeling more optimistic about their child's future when they took on the role of advocate (Phelps, Hodgson, McCammon, & Lamson, 2009).

Oppenheim, Koren-Karie, Dolev, and Yirmiya (2009) found that although resolution was important in reducing parental stress, insightfulness, (the ability to view things from the child's perspective), was also an important factor. Oppenheim et al. (2009) found that mothers who were both resolved and insightful formed more secure attachment bonds with their children. The authors felt insightfulness depends “Not only on the capacity of parents to read their children’s signals, but also on the capacity of the children to signal and communicate their needs,” a difficult task for children who have ASD. Insightful mothers looked for motives behind their child’s behaviors and had confidence in their child’s abilities. They are child-focused; accept the challenges of having a child with ASD and work to establish a strong and meaningful relationship with the child.

Obrien and Daggett (2006) describe three ways parents respond emotionally when their child is diagnosed with an ASD: (a) focus on what might have been; (b) focus on what could be; (c) focus on what is. Parents who focus on what might have been emphasize the negative and blame all the child’s behaviors and problems on ASD. They have a pessimistic view of the future and feel their possibilities are limited. Parents who focus on what could be take an “I’m going to fix things” approach. They see themselves in charge and responsible for finding the best treatment and a possible cure. They spend a great deal of time talking about themselves and all the effort they put into their child. This group of parents may actually be in denial. Parents in this category are often defensive and difficult to work with. Parents who focus on what is take a positive and realistic approach to their child. They view their child as a unique individual and do not compare their child’s development with standard developmental milestones or other children. They are content with the small day-to-day improvements they observe, acknowledge there are difficulties related to a child with ASD, but are able to work through problems without becoming overwhelmed.

In their study, Twoy, Connolly, and Novak (2007) looked at three levels of resources available to families: the individual, the family unit, and the community. Individual resources include: physical and emotional health, level of education, knowledge, skills and personality traits. Family unit resources include decision making skills, ability to organize, communication skills, and the ability to resolve conflict. Community resources include family, friends, religious organizations, educational and healthcare facilities. The authors noted that parents who utilized informal social support during times of increased family stress reported higher quality relationships between siblings and the child with ASD. Reframing or redefining events to make them more manageable was also a positive coping tool used by parents.

Parents, especially mothers, may have to re-evaluate career goals due to their child having ASD. Parents found that by placing less emphasis on career and more emphasis on parenting and family they had a greater ability to enjoy life and felt less stress related to parenting a child with ASD (Tunali & Powers, 2002).

Bayat (2007) determined that families who demonstrated resilience had a greater ability to cope with their child's ASD. Resilience is the capacity to endure adversity while becoming stronger and more resourceful as a result. Bayat identified three key factors contributing to a family's resiliency: (a) an ability to understand the problem; (b) acknowledging their strengths and having an ability to look at the positives in the situation; (c) having a strong belief system. Bayat (2007) found resilient families were flexible, were able to rebound despite difficult challenges, were able to access outside resources when problematic situations became overwhelming and communicated openly. It took, on average, two years from the time of initial diagnosis of the child's ASD until a family felt they had adjusted to the demands and changes related to parenting the child.

Mancil, Boyd, and Bedesem, (2009), Altiere and Von Kluge, (2009), Twoy, Connolly, and Novak (2007), Pottie and Ingram (2008) found that parents of children with ASD who have a strong social support network demonstrated a greater ability to cope and adapt to new and challenging situations. Parents who were involved in support groups, had a strong sense of faith and spirituality, and a supportive extended family rated felt better able to cope and also reported having a higher degree of satisfaction with their lives.

Altiere and Von Kluge (2009) determined that families who rated themselves as enmeshed were more likely to use positive coping strategies, adjust to new situations, viewing the child's ASD as less life-changing. The closeness, increased involvement, and protective nature of enmeshed families had a positive effect on the family's ability to function as a unit. This conflicts with the Family Systems Theory which proposes that families whose members have a high degree of differentiation of self are better able to function effectively (Nichols & Schwartz, 1998). Altiere and Von Kluge (2009) also found disengaged families had a higher level of anxiety, less adaptability, and lacked the ability to work together during times of increased stress. The rigid role expectations in disengaged families may cause a greater burden to be placed on the mother with regards to caring for the child and running the household. They also found families that rated themselves as chaotic had undefined roles, lacked rules, and indicated a high degree of stress related to conflict within the family which increased when the child was diagnosed with ASD. These findings may indicate that extreme levels of cohesion are not always a negative factor in how a family functions (Altiere & Von Kluge, 2009).

Mothers, in families that rated themselves as enmeshed, were more likely to seek social support in times of crisis, perceived a strong social support network, were less likely to be depressed and experienced less somatic problems (Altiere & Von Kluge, 2009). Fathers, however, perceived a reduction in the amount of social support they received; believing they lost friends because friends could not comprehend the nature of their child's disorder; felt uncomfortable when the child would exhibit unusual behaviors: or the father was not always available to spend time with friends due to responsibilities of caring for the child.

In their study, Pottie and Ingram (2008) identified coping responses that affected daily mood in parents of children with ASD. Parents who utilized social support, positive reframing, emotional regulation, and compromise coping skills reported having a positive daily mood, less stress, and fewer feelings of depression. Parents who chose blaming, worrying, and withdrawal as coping strategies reported a negative outlook, higher levels of daily stress, and increased feelings of depression and sadness. Problem-focused coping was found to both positively and negatively affect daily mood. This may be due in part because many of the challenges parents face related to their child's ASD are not able to be changed.

Parents who use task-oriented coping reported less stress then parents who use emotion-oriented coping (Lyons, Leon, Phelps, & Dunleavy, 2010). Task-oriented coping is problem focused, taking action by using both behavioral and cognitive strategies to alleviate stress. In emotion-oriented coping, individuals attempt to control their emotional responses to the stress. Parents using emotion-oriented coping reported more parent and family problems then parents using task-oriented coping. Lyons et al. determined that the "strongest and most consistent predictor of stress" for parents was the severity of the child's ASD.

Gray (2006) analyzed the coping strategies used by parents of children with ASD over the course of 10 years identifying if and how coping strategies had changed. In his most recent study he found that parents were using fewer but more effective coping strategies. He theorized this may be due to an increased awareness about ASD in the general population and a resulting increase in tolerance for the child’s behaviors. Two strategies remained consistent, the use of social support and a strong religious faith.

Challenges When Parenting a Child with ASD

Parents consistently stated that social support was crucial to coping with their child’s ASD. Ironically, social support is often lost due to the behaviors exhibited by a child. Society’s intolerance combined with the parent’s feelings of being judged as poor parents often caused parents to withdraw from activities outside the home.

Parents of children with ASD face many challenges. Unlike children with Down’s syndrome or cerebral palsy, children with ASD often look normal and subsequently people expect the child to behave accordingly (Gray, 2002). Parents identify four characteristics related to the child’s ASD that make parenting particularly challenging**:**

1. The child’s unpredictable, inappropriate and destructive behaviors.
2. The child’s need for sameness and routine.
3. Difficulties relating to the child’s ability to process sensory stimuli.
4. The child’s inability to communicate and lack of emotional bonding.

A child’s behaviors related to having ASD can cause the greatest amount of anxiety and distress for parents. When the child’s behaviors are unacceptable to friends and extended family members parents feel inadequate and feel they are judged to be poor parents. Mancil, Boyd, and Bedsem (2009) found parents stated isolating themselves was often easier than always having to explain or defend their child’s behavior. Gray (2002) noted that even grandparents and extended family members were often critical of the child and questioned the parent’s child raising skills. Parents felt that their parenting skills were being judged inadequate when their child had temper tantrums, was disruptive, or exhibited aggressive behaviors when out in the community (Wing, 2001).

Judy Barron (Barron & Barron, 2002) wrote: “I had a child I was embarrassed to take places …doing things that humiliated me and made me feel like a total failure as a mother” (pg. 165).

As the child’s father I found, “Apologizing to everybody, even paid professionals, for his behavior had become a reflex” (Hughes, 2003, pg. 119).

Stillman (2005) believes parents are faced with the difficult task of deciding whether the child’s behavior is a result of ASD or simply being naughty? Stillman believes parents must ask themselves two questions regarding their child’s behavior: Does the child have a good reason for what he did? and Given his skills and limitations was he doing the best he knew how? As the child got older, parents felt the child’s behaviors were less tolerated by others when in social situations (Gray, 2006). Parents reported feeling stigmatized due to their child’s behavior.

Since parents reported social support to be an important part of helping them cope with their child’s ASD the loss of that support is especially difficult. Losing friends and not being invited to attend social events is a common occurrence for parents whose child has ASD (Altiere & Von Kluge, 2009, Tehee, Honan, & Hevy, 2009).

Compared to normal children or children with other disabilities, children with ASD are 70% less likely to attend church services with their families (Lee, Harrington, Louie, & Newshaffer, 2008). An article in the St. Paul Pioneer Press, August 14, 2008, reported that a Minnesota judge upheld a restraining order barring a 13 year old autistic boy from attending church services (Kolpack, 2008). The priest claimed the boy spit, made loud noises, and nearly ran over parishioners as he ran out of the church after services. The mother claimed the congregation’s claims against the boy were exaggerated (Kolpack, 2008). In their study, Altiere and Von Klug (2009), found parents reported receiving “dirty looks” from congregation members when their child would misbehave and two families were asked to not bring the child to services. Since a number of studies found faith-based support an important aspect of coping, losing the chance to attend church services could take away an important coping strategy for those parents.

Because ASD children often prefer sameness, predictable routines and are most comfortable when things are familiar, parents are often limited in regards to outings and attending social functions (Stillman, 2005, Brill, 2001, O’Brien & Dagget, 2006). Because of this need for sameness, parenting a child with ASD can dominate family life and hold the family hostage in their home. When parents’ lose the opportunity for social interactions and social support they become emotionally exhausted and depressed (Lecavalier, Leone, & Wittig, 2006). Before the family can leave for an outing, even something as simple as going to the grocery store, it may be necessary to prepare the child well-ahead of time. If the child has a TV show he watches every day as part of his routine, parents have to plan accordingly. A child with ASD may require that you take the same route to get to a store, school, or friends or relatives home, and while this may not seem like a real difficult behavior to work around, something as simple as a detour for road construction, may cause the child great distress. Having a child throwing a tantrum in the back seat of a car, while the parent is trying to drive, is a stress producing situation. Impromptu trips can prove very difficult for a child with ASD and the parents.

Finding childcare for a child with ASD can be challenging. The more severe the behaviors the child exhibits, the less likely the parents are to find someone willing to take on the childcare challenge (Stillman, 2005). Parents, particularly mothers, may be unable to return to work because childcare centers refuse to take the child. Although facilities may not have a specific policy in regards to ASD children, they will want to meet the child and observe him in the day care setting before agreeing to allow the child to attend. Generally childcare facilities are privately owned so unlike schools, they don't have to take all children. For parents, locating a babysitter willing to stay with the child, even for just an evening, can be difficult.

Children with ASD often have limited attention spans and are easily frustrated when things don't go the way they want (Lecavalier & Wiltz, 2006, Volkmar & Wiesner, 2009). Having to wait in a checkout line, waiting to swing at the playground, wanting a toy another child has may lead to a temper tantrum and hours of screaming. Once a child with ASD becomes agitated and upset, calming the child down can be a lengthy process (Volkmar & Wiesner, 2009, Wing, 2001, Hughes, 2003, O'Brien & Dagget, 2006).

Children with ASD may develop sensory processing issues (Volkmar & Wiesner, 2009, Atwood, 2007, Brill, 2001). Certain sounds, smells, sights, tastes, and touch may be upsetting to the child.

Mealtime challenges are common (Twachtman-Reilly, Amaral, & Zebrowski, 2008). The research agrees that the predominant problem related to feeding disorders in children with ASD is sensory sensitivities. A child may not like the mouth feel of certain food, may not eat food that is a certain color, will only eat food that is certain temperature, or will only eat food that is a certain color. Although parents report feeling frustrated when a child will only eat a limited number of foods, studies show that the child seldom becomes malnourished (Davis & Carter, 2008).

There are theories that children with ASD may do better if they avoid certain foods, such as dairy products, gluten, food additives, or certain meats (Jepson, 2007). A restrictive diet adds another responsibility on the parent, having to check labels, finding foods the child will eat, while providing food the rest of the family will enjoy. A restricted diet also limits a family's ability to eat at restaurants, have dinner at a friend's home, or attend social gatherings.

Children with ASD may have auditory sensitivities. Whereas some sounds may be soothing to the child, the same song played over and over, others may cause the child distress. We live in a noisy society. Cars with loud stereo systems, fire engines with sirens blaring, thunder, low flying airplanes are all a daily part of life, but for a child with ASD and his parents it can be problematic. If a child chooses to cover his ears with his hands in response to a noise the situation is benign. However, if the child chooses to take off running on a busy street the issue becomes dangerous (Stillman, 2005, Hughes, 2003). Parents of children with ASD must be ever vigilant, anticipating, what the child may or may not do in the current situation.

Fleming's article in the St. Paul Pioneer Press, July 7th, 2010, titled "No More Scary Movies" reports on the partnership between the Autism Society and AMC Entertainment and their Sensory Friendly Films program. The program was started in 2007 when the mother of a child with ASD called her AMC theater explaining some of the problems related to attending movies with a child with ASD: auditory sensitivity, diet restrictions, and fear of the dark. The Sensory Friendly Films are now offered at 110 theaters around the country. These special movie viewings, offered twice a month, are specifically for children with autism and other disabilities. The lights are left on, no previews are shown, the sound is lowered, and families can bring their own snacks. For many families this is the first opportunity for all members of the family to attend a movie together, something most families take for granted. It is also a positive sign that awareness of ASD is increasing and businesses are taking a positive approach toward working to increase the child and the family's access to everyday activities.

The combination of problems with communication and emotional expression in children with ASD is difficult for parents to understand (Gray, 2006). Children with ASD are often unresponsive, avoid physical contact, and reject parent's attempts to be affectionate (Brill, 2001, Norton & Drew, 1994, Altiere & Von Kluge, 2009). Many children with ASD do not want to be touched, held, hugged, nor do they respond to their parent's presence or absence (Volkmar & Wiesner, 2009, Frith, 2003).

In their case study, Krausz and Meszaros (2005) found the mother was greatly affected by her son's indifference toward her. It is especially hard for parents when children appear to have no emotional attachment, recognition or fondness for the parent.

Linda, the mother, stated:

> But I think for me the worst part was that he got to the stage where he didn't care if I came or if I went and when I would go to work in the morning my mom would be holding him and saying 'Wave good-bye to your mommy' and he wouldn't wave, he wouldn't look, he'd just be looking around. And when I would come home and say, "Hi Philip, mommy's home", he would look up and look away, he wouldn't care.

Grandin (1996) writes:

> I was six months old when my mother noticed I was no longer cuddly and that I stiffened when she held me. When I was a few months older Mother tried to gather me in her arms, I clawed at her like a trapped animal. She has said she didn't understand my behavior and felt hurt by my actions (pg. 15).

A study by Davis and Carter (2008) focused specifically on parents of toddlers newly diagnosed with ASD and examined which of the child's symptoms related to ASD parents consider the most stressful. They found that deficits in social reciprocity and communication combined with repetitive and stereotypic behaviors were the major sources of stress for the parents. Of the mothers surveyed, 39% reported stress in the clinically significant range related to parent-child relationship. Among fathers, 25% reported clinically significant scores related to stress in the difficult child domain while 28% had significant stress related to parent-child relationship issues. In relation to the child's dysfunctional interaction skills 40% of parents, mothers and fathers, reported significant stress.

Davis and Carter (2008) noted that 33% of mothers in the study reported a significant degree of anxiety and depression related to their child's diagnosis while 17% of fathers reported feelings of anxiety and depression. In Milshtein et al. (2009) fathers did not feel their child's ASD diagnosis had a negative effect on their life overall but did report a great deal of stress related to the child's behaviors when they were out in public. They felt the child's inappropriate behaviors brought negative attention to the family. Because mothers are often responsible for and highly involved in the daily care of their child they reported high levels of stress related to the child's self-regulations skills, problems related to eating, sleeping, and emotion regulation (David & Carter, 2008). Atypical behaviors in the child were not predictors of stress in mothers.

Due to the high prevalence rate of medical issues in children with ASD a visit to a medical clinic or a stay in the hospital, is a strong possibility (Jepson, 2007, Paradiz, 2002, Volkmar & Wiesner, 2009). Although this can be an unpleasant experience for any child, it can be extremely distressing for a child with ASD.

When a child with ASD has to undergo diagnostic tests as an outpatient or is required to spend time a hospital, it stretches the coping capabilities of the child, the family, and even the medical staff. The hospital can be a place of sensory overload and the child's need for routine and sameness is stretched to the limits. It is especially important for the nurses and staff caring for the child that they be aware of the unique challenges related to the child to make the experience as positive and non-threatening as possible (Scarpinato, Bradley, Kurbjun, Bateman, Holtzer, & Ely, 2010). Depending on the level of impairment in social interaction and communication understanding what the child is experiencing may be difficult for nurses to assess. It is critical that parents and caregivers work closely with hospital staff to make the situation as non-threatening as possible for the child.

Scarpinato et al. (2010) identified the following eight areas that need to be addressed to insure that the child's well-being and safety are insured during a hospital stay. However, all of these guidelines are helpful and transfer to many other situations the child and his parents may encounter where individuals who will be working with the child need to be made aware of the child's specific needs and limitations:

1. Be an active participant in planning and caring for the child. As the child's parent you know the child and what strategies work best to help the child alleviate stress.
2. During any assessment ask questions and express any concerns you may have related to your child's specific areas of deficit. Tell those working with your child what works and doesn't work when your child is stressed.
3. Identify the child's strengths and weakness to aid in understanding and recognizing how your child may perceive the current situation.
4. Make sure the physical environment surrounding your child is safe. Express any safety issues of concern to the staff.
5. Identify how best to communicate with your child.
6. Identify your child's sensory issues and how best to work through or around them.

7. Identify behaviors that indicate your child is becoming emotionally overwhelmed and what strategies or interventions work best to calm the child.
8. It is important that those working with your child are aware of any dietary concerns related to meal time.

According to Scarpinato et al. (2010) assessment must be continuous and those individuals working with the child need to be mindful of the child's unique characteristics. This can't be achieved without active participation on the part of the parent.

Children with ASD often have problems related to sleeping and bedtime (Xianchen et al., 2006). Common sleep issues include bedtime resistance, sleeping for short periods of time followed by hours of staying awake, difficulty falling asleep, and trouble waking up in the morning. When a child with ASD has sleep problems it can be exhausting and overwhelming for the parents (Paradiz, 2002, Hughes, 2002, Naseef, 2001).

Although having a child with ASD can be overwhelming, by increasing awareness in others of the child's strengths, needs, and limitations can increase the chance that experiences in the community will be positive.

Treatments

Initial response to any diagnoses of any disease or disorder may be: "What do I need to do to fix it?" "How can I make this better?" Parents of a child with ASD struggle with what treatment or behavior program will be most beneficial to their child. To date there is no cure for ASD and although there are many treatments being tested none have proven to be effective with all children having ASD.

To go into all the treatments, tested and untested, that claim to be the answer would be another research paper. It is important, however, to mention that parents are faced with tough decisions related to how best to proceed with their child. Since the cause of ASD remains unknown, parents are especially vulnerable to treatments that claim high success rates, without any real research to back the claim. Parents want to do what is best and will most improve their child's quality of life, so sifting through all the treatment options is one more difficult task they face.

Positives Related to Parenting a Child with ASD

Although having a child with ASD has many negative aspects, parents do indicate there are a number of positive changes in their lives as a result of having a child with ASD.

Many parents report it has strengthened their faith and improved their spiritual self (Bayat, 2007). They find that they have an inner strength that allows them to go forward and work through the problems related to having a child with ASD. They are able to overlook many of the smaller problems in life and look at the bigger picture.

Parents find that they are more compassionate and have more empathy toward others. They have an increased level of tolerance and acceptance of individuals who are different. Parents believe they are better individuals, more aware of the difficulties other face, and more willing to help when others are facing difficult times.

Having a child with ASD strengthened relationships between spouses. Working together on their child's behalf had positive rewards and parents felt an increased emotional bond with their spouse.

Parents found new and understanding friends through their involvement in support and advocacy groups. Parents gained confidence in their abilities, not only when working on behave of their child, but also in other areas of their life.

Naseef (2001) states, “The knowledge and wisdom that I acquired through losing my dream of a typical child are helping me be all that I can” (pg. 11).

Chapter III: Discussion

As the most frequently diagnosed childhood affliction, ASD remains a mystery. There are no known causes and no cures. There are no identified genetic markers for ASD, but there appears to be a genetic link based on studies of identical twins. Without knowing the cause, parents are prone to feelings of guilt and blame, wondering if it was something they did or didn't do that led to their child's ASD.

Although parenting a child with ASD is challenging, parents have developed ways to cope and move forward.

Limitations of the Study

There is a multitude of research that has taken place since 2000 related to ASD. Finding information was easy: deciding which data to use was more difficult.

The small size of the sample group was a limitation for a number of studies reviewed including Benson and Karloff (2009), Tehee, Honan, and Hevy (2009), Davis and Carter, (2008), Pottie & Ingram (2008), and Altiere and Von Kluge, (2009).

A number of authors indicated a lack of ethnic diversity among those participating in their study group (Twoy, Connolly, & Novak, 2007, Benson & Karlof, 2009, Davis & Carter, 2008, Pottie & Ingram 2008).

Tehee, Honan, and Hevy (2009), David and Carter (2008), Altiere and Von Kluge (2009), believe parents who participated in their studies were already proactive, since they were recruited through support or advocacy groups, educational facilities, or other professional agency related their child's ASD. These parents already had social support systems in place so theoretically their stress levels would be lower than parents who were more isolated.

Lacavalier, Croen, and Wiltz (2006) had the largest and most heterogeneous sample but felt a limitation to their study was not accounting for the diagnostic specificity of the children.

In a number of studies the participants were well educated, white, middle class individuals living in urban areas (Pottie & Ingram, 2008, Benson & Karlof, 2009, Altiere & Von Kluge, 2009). Bayat (2007) reported 48% of the participants in his study had college degrees while in the study by Mancil, Boyd, and Bedersem (2009) 35% of participants were college graduates.

In his longitudinal study, Gray (2006) found that parent's used fewer coping strategies in his current study then in the previous study, ten years earlier. However, he was not able to determine what caused this change. He speculated it could have been that the child's behaviors improved as the child matured or it could relate to the parents having access to appropriate services.

Studies that reported a poor response rate theorized that parents whose children exhibited more severe ASD symptoms may have been too busy and not have had time to respond (Lacavalier, Croen, & Wiltz, 2006).

The size of the family, number of individuals living in the household, age and number of siblings, birth order of the child with ASD and how long it had been since the child was diagnosed were not addressed in any of the studies.

Conclusion

Having a child with ASD is a life altering. It can change how parents identify themselves, determine where and when they are able to go places, affect their friendships, change their social life, and affect career decisions. It alters relationships with partners or spouses and affects siblings.

Every parent reacts differently to their child's diagnosis of ASD. All parents go through an "adjustment" period where they are unsure of exactly what their child having ASD indicates for the child's and their future. They begin a journey into unknown territory. Some parents are able to quickly navigate through the difficulties resulting from their child having ASD while others struggle for years before coming to terms with the child's diagnosis and subsequent life changes. Bayat (2007) found for parents in his study it took an average of two years to come to terms with the diagnosis and the difficulties related to parenting the child. Parents must strike a balance between doing what is best for their child while also creating a sense of normalcy for others in the family.

Parents are faced with an ambiguous loss when a child is diagnosed with ASD. There is no closure and each day brings new challenges for parents. Boss (1999), says it well when she states: "Ambiguous loss is the most devastating because it remains unclear, indeterminate" (pg. 5). When his son was diagnosed with ASD Naseef (2001) wrote: "The dreams for a healthy child evaporate and the real child cannot live up to the original expectations" (pg. 17). After his son was diagnosed with ASD Hughes (2003) stated: "The word autism blew away all his qualities, vaporized the mystery, and turned him into something simple" (pg. 81). Parents need to be allowed to grieve. Whether they pass through all the stages identified by Kubler-Ross or only a few, their grief needs to be acknowledged, for it is very real: to minimize or trivialize it would be doing the parents a great disservice.

Discussion:

. How parents cope with the diagnosis and emotional issues varies, but consistently parents report a strong social support network is a necessary part of being able to cope (Gray, 2006, Altiere & Von Kluge, 2009,). Benson and Karlof (2009) found that 'perceived support,' believing the support will be there if and when you need it, is an important factor in positive coping.

A strong spiritual belief system was also consistently reported by parents to be a necessary part of being able to cope (Gray, 2006). Some parents reported they had strong ties to their belief system prior to the child's ASD which then became stronger; other parents sought solace in a belief system after their child was diagnosed as a means to help them cope with the difficulties they were experiencing related to their child's ASD.

Negative coping through withdrawal, escape, blaming, and feeling helpless were used more by mothers then fathers (Pottie & Ingram, 2008). Fathers reported that it was difficult for them to maintain personal friendships and felt this led to their feeling depressed (Teehee, Honan, & Hevy, 2009). However it should also be noted that fathers did not view the child's ASD as being as life changing as mothers did (Milshtein et al., 2009).

The severity of the child's symptoms did not appear to increase the level of stress parents experienced (Milshtein et al., 2009). However Naseef (2001), Hughes (2003), and Barron and Barron (2002) felt judged by others when their child would not conform to what others perceived as normal behavior. Judy Barron (Barron & Barron, 2002) felt when her child would misbehave in public people were judging her ability as a parent when she reveals "The look in everyone's eyes …that silently asked, Why do you allow your child to act like that" (pg. 36)?

As awareness of ASD increases, hopefully society will take a more compassionate look at the child and the parents, be more accepting and willing to accommodate, and not so quick to judge the parents by the child's behaviors.

Recommendations:

Whether educators, medical professionals, family therapists, or the cashier at Target, at some point in time we will have an encounter with an individual who has ASD. It may be the little boy down the block, who toe walks, flaps his hands when he gets excited, and always walks on the same side of the sidewalk. It could be the teenager who appears to have no friends, dresses a bit bizarre, but can fix any of your small appliances with no problem. It could be the older lady at church, who never makes eye contact, always sits in the same church pew, and rarely speaks to any other parishioners.

Research needs to continue on finding out what is causing the incidence of ASD to continue to rise. Although there is no solid link between mercury and ASD, there certainly seems to be a connection.

Tolerance of those who are different goes a long way in improving the quality of life for those individuals. We need to make individuals with ASD and their families feel welcome and accepted, not judged and looked down on. We need to make sure that the social support, families of children with ASD find so critical, is always there for them.

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