

THE IMPACT OF CHILD SYMPTOM SEVERITY AND STRESS ON SCHOOL  
SATISFACTION AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM  
DISORDERS

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## ABSTRACT

### THE IMPACT OF CHILD SYMPTOM SEVERITY AND STRESS ON SCHOOL SATISFACTION AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

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Autism Spectrum Disorders (ASD) consist of a continuum of disorders that are increasing in prevalence (Centers for Disease Control and Prevention, 2012). This study used the variables of parenting stress and autism symptom severity to try to predict parent satisfaction with their child's classroom and educational team. Participants in this study were 97 parents/guardians of children with ASD who completed a series of surveys including: a demographics form, a scale to measure autism severity, a parenting stress scale, and a survey measuring the parent's satisfaction with their child's classroom and education team. In this study, autism symptom severity and parent stress when combined were not significant predictors of parent satisfaction with their child's classroom or his or her education team. There was a small correlation between parent stress and parent satisfaction with their child's classroom. It is possible that this study was limited by the low scores on the autism symptom severity measure, suggesting that either the tool did not adequately measure autism symptom severity or the sample included parents of children who had less severe presentation of autism than in other studies. The study supported a link between autism symptom severity and parent stress. Consideration of

different aspects of the education of a child with an ASD is needed in order to improve the education of one of the most rapidly growing disability groups in schools.

## CHAPTER ONE: LITERATURE REVIEW

### **Definition of Autism Spectrum Disorders**

Autism Spectrum Disorder (ASD) refers to a continuum of disorders including the previous diagnoses of Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS). According to the American Psychiatric Association (2013), Autism Spectrum Disorders are categorized under the broader area of Neurodevelopmental Disorders. The current version of the *Diagnostic and Statistical Manual of Mental Disorders* (5<sup>th</sup> ed.; *DSM-5*; American Psychiatric Association, 2013) states that ASDs are characterized by impairment in the following areas of development: social communication/social interaction and restricted, repetitive patterns of behavior, interests, or activities. Table 1 lists the criteria for meeting a diagnosis of Autism Spectrum Disorder according to the *DSM-5*. Individuals with ASD often have an additional diagnosis of intellectual disability, and they may display behavioral symptoms such as hyperactivity, impulsivity, aggressiveness, self-injurious behaviors, and temper tantrums (Wilkinson, 2010). The term Autism Spectrum Disorder is now recognized as the most appropriate term for this constellation of behaviors.

According to the American Psychiatric Association deficits in the following three areas of social communication and social interaction must be present in order to receive a diagnosis of ASD: (1) Deficits in social-emotional reciprocity; (2) Deficits in nonverbal communicative behaviors; and (3) Deficits in developing, maintaining, and understanding relationships (American Psychiatric Association, 2013). The criteria also mandate that there is a pattern of restricted or repetitive behaviors, interests or activities evidenced by



at least two of the following symptoms: (1) Stereotyped or repetitive motor movements, use of objects or speech; (2) Insistence on sameness/Inflexible adherence to routines or ritualized patterns of behavior; (3) Highly restricted, fixated interests that are abnormal in intensity or focus; or (4) Hyper- or hyporeactivity to sensory input or unusual sensory interests (American Psychiatric Association, 2013).

Table 1

DSM-5 Characteristics of Autism Spectrum Disorders

<b>Social Communication and Interaction (Must have all)</b>	<b>Restricted or repetitive patterns of behavior, interests, or activities (Must have 2)</b>
Deficits in social-emotional reciprocity	Stereotyped or repetitive motor movements, use of objects, or speech
Deficits in nonverbal communicative behaviors used for social interaction	Insistence on sameness, inflexible adherence to routines or ritualized verbal or nonverbal behavior
Deficits in developing, maintaining, and understanding relationships	Highly restricted, fixated interests that are abnormal in intensity or focus
	Hyper- or hyporeactivity to sensory input or unusual sensory interest

In the areas of social communication/interaction and restrictive/repetitive behaviors a level of severity is now assigned. There are three levels given in the two diagnostic areas. These levels include: Level 3: “Requiring very substantial support”; Level 2: “Requiring substantial support”; Level 1: “Requiring support” (American Psychiatric Association, 2013). See Table 2 for a description of the characteristics for each level. There is international and cross-disciplinary agreement on the characteristics that make an ASD diagnosis (Wilkinson, 2010).

Table 2

## DSM-5 Severity Levels

<b>Severity Level</b>	<b>Social Communication and Interaction</b>	<b>Restricted and Repetitive Behaviors</b>
3 - "Requiring very substantial support"	Severe deficits in social communication skills (verbal and nonverbal).	Inflexible behaviors with extreme difficulties coping with change. These behaviors must impact functioning must be present across settings.
2 - "Requiring substantial support"	Marked deficits in social communication (verbal and nonverbal).	Inflexibility of behavior and difficulty coping with change. Marked distress by changes.
1 - "Requiring support"	Deficits in social communication causing impairments when no supports are in place.	Inflexibility of behavior that hampers independence causing difficulties in one or more contexts.

A diagnosis of ASD also requires that symptoms be present in early childhood, and that the impairments must be observed across settings. Lastly, there is a rule out clause stating that these symptoms must not be better explained by an intellectual disability or a global developmental delay (American Psychiatric Association, 2013).

Prior to the usage of the *DSM-5*, Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) were considered separate disorders falling under the category of Pervasive Developmental Disorders (American Psychiatric Association, 2000). The diagnosis of Autistic Disorder, Asperger's Disorder, and PDDNOS was included in the previous iteration of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* and many individuals still have this label as a psychological disorder. For this reason, these disorders will still be discussed briefly in this paper, though in the current nomenclature it is subsumed by the Autism Spectrum Disorders categorization (American Psychiatric

Association, 2013). The clinical diagnosis of Autistic Disorder included qualitative deficits in social interaction, communication, and restrictive/repetitive patterns of behaviors, interests or activities (American Psychological Association, 2000). Asperger's Disorder affected similar areas of the child's functioning and development as Autistic Disorder (American Psychological Association, 2000). The clinical description of Asperger's Disorder included impairment in social reciprocity and restricted or repetitive patterns of behavior, interests or activities. Unlike the previous diagnosis of Autistic Disorder, Asperger's did not include cognitive impairment or a history of delayed language development (American Psychiatric Association, 2000), though children with Asperger's may demonstrate some difficulties related with pragmatic language. Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) was also included in the *DSM-IV* and individuals continue to have this disorder, even though it is not present in the *DSM-5* (American Psychiatric Association, 2013). PDDNOS was used frequently and was often considered the diagnosis of exclusion (Wilkinson, 2010). Children with PDDNOS have impairments in at least two of the three symptom categories of Autistic Disorder without meeting the criteria for any other ASD (Wilkinson, 2010).

The pattern of uneven development that exists in ASD is on a continuum that varies in severity of symptoms, age of onset, and association with other childhood disorders. ASD is a life-long condition that has implications for education and social development (Wilkinson, 2010). ASD represents one of the fastest growing disability categories in the world (Centers for disease Control and Prevention, 2012).

## **Prevalence of Autism Spectrum Disorders**

While the prevalence rate of ASDs has clearly increased in the last few decades there is mixed evidence regarding the current prevalence rate (American Psychiatric Association, 2000; Centers for Disease Control and Prevention, 2012; Wilkinson, 2010). Autism Spectrum Disorders are estimated to affect about 1 in every 88 children in the United States (Centers for Disease Control and Prevention, 2012). Boys are three to four times more likely to be identified on the autism spectrum than girls (Wilkinson, 2010), and boys are ten times more likely to be referred for evaluation for an autism spectrum disorder than girls (Attwood, 2006). Between the years 1994 and 2006, the number of students with ASD receiving special education services under IDEA grew more than 900 percent. (US Department of Education, 2006). Autism and autism-related disorders are no longer rare, and all school professionals will encounter students with ASD in their schools. Therefore, it is important to consider the most common issues in the education of students with ASD. As the number of children diagnosed with autism increases, teachers and other educational professionals are faced with struggles to educate this growing population. The dramatic increase of ASDs can be explained by better recognition, changes in diagnostic criteria, and increased availability of services (Wilkinson, 2010).

## **Autism Spectrum Disorder Severity**

The impairments in autism spectrum disorders exist on a continuum that varies in severity of symptoms (Wilkinson, 2010). The “triad of impairments” that define ASDs include deficits in communication, social interactions, and behaviors/interests (Wilkinson, 2010). Children with ASD demonstrate the three core features mentioned above with variability in the severity of symptomology. Symptom severity refers to the

magnitude in which the symptoms of ASD are expressed and the degree to which they interfere with typical development (Konstantareas & Homatidis, 2006). The symptom expression falls onto a continuum and will range from children with marked impairments to children with higher cognitive and linguistic abilities. The continuum can consist of children with varying intellectual functioning ranging from individuals with intellectual disabilities to those with extremely high intelligence.

### **Education of Individuals with Autism Spectrum Disorders**

Research supports the benefits of early identification and early and intensive intervention for young children with ASD (National Research Council, 2001). Early intervention services for individuals with ASD are governed by the Individuals with Disabilities Education Improvement Act, 2004 (Wilkinson, 2010). ASDs can be diagnosed in children as young as two years-old (Wilkinson, 2010). IDEA mandates that children with autism are entitled to early intervention services and special education. Federal grants are provided to states for early intervention services addressing the individual needs of diagnosed children.

There is a push to identify children with ASD at a very early age in order to prevent or mitigate the symptoms of the ASD from manifesting. Best-practices suggest that children diagnosed with ASD ages 2 through 5 should receive intensive, long-term early intervention for many hours per week (Corsello, 2005). Early detection and intervention for individuals with ASD is currently the most effective strategy for improving functioning. Parent involvement in early intervention is linked to more progress for young children diagnosed with ASD than when early intervention efforts fail to adequately involve parents (Wallace & Rogers, 2010). Programs that include parent

coaching with a focus on parental responsiveness and sensitivity to their children's cues resulted in the most efficacious interventions for individuals with developmental disabilities (Wallace & Rogers, 2010). An emphasis has been placed on early detection, early intervention, and strong parent involvement in the treatment of children with ASD. The trend of early detection of ASDs leads to increased family involvement at a very young age.

**Special Education Classification for Individuals with ASDs.** The Individuals with Disabilities Education Act (IDEA) provides categories of disabilities to determine eligibility for special education services. IDEA, like the *DSM-5* is a categorical system; the child either meets criteria or does not. For an ASD diagnosis, IDEA overlaps with the *DSM-5* with regard to the presentation of the primary characteristics of autism spectrum disorders. The main difference between the IDEA definition and the *DSM-5* definition is that IDEA does not require the child to have the symptoms in early childhood (Wilkinson, 2010). Both the IDEA and the *DSM-5* definitions of autism require that the child's educational performance is negatively impacted. Since all spectrum disorders are characterized by functional impairments it is rare that a child with ASD will not need special education services (National Research Council, 2001).

Federal law in the United States entitles all students with disabilities to a free and appropriate public education (FAPE) (Individuals with Disabilities Education Act, 2004). Through IDEA a child identified as needing special education is given an individualized education plan which identifies the services a student needs (Wilkinson, 2010). The IEP for an individual with ASD should reflect an understanding and awareness of the challenges presented by the disorder. Goals for a child with ASD commonly reflect the

“triad of impairments” discussed above (Wilkinson, 2010). The IEP should also include appropriate instructional modifications as well as related services such as counseling, speech/language therapy, occupational therapy, physical therapy and transportation needs.

Current legislation through the 2004 Individuals with Disabilities Education Improvement Act, requires that all educators implement evidence-based educational programs. However, the interventions and treatments being used with children with ASD often do not have empirical evidence supporting their effectiveness (Hess, Morrier, Heflin, & Ivy, 2008).

**Educational Interventions for Students with ASDs.** The most effective treatment for autism is a comprehensive and intensive program that includes educational interventions, developmental therapies, and behavior management. It is generally agreed by professionals that intensive programs combined with early identification can lead to improvement in a child’s functioning (Wilkinson, 2010). Addressing autism in the classroom should include an individualized approach that targets deficits of the disorder in areas such as: communication, social interaction, sensory issues, and academic difficulties.

There are several methodologies for interventions for individuals with autism. Debates exist regarding which treatments are the most effective for children with ASD, but there is a movement towards combining elements of different approaches (Wilkinson, 2010). Best practices require an individualized approach for addressing the core deficits in students with an ASD, a focus on long-term outcomes, and consideration of the needs and developmental level of the child.

Educators are faced with several challenges when teaching individuals with autism. The ambiguity in identifying best practices that generalize across children with ASDs make it very difficult for educators and parents to know the best way to educate children with ASD and to comply with federal legislation. There is no clear program to follow that works for everyone since ASD includes a multitude of symptoms. Because of the unique social and communication difficulties that are present in individuals with autism, special services are often required when educating this population (National Research Council, 2001). Most students with social-communication disabilities receive their education in general education classrooms with teachers who have limited experience and training in working with children with special needs (Myles & Simpson, 2002). Providing effective supports and interventions for children on the autism spectrum in the general education setting can be very difficult for this reason.

An evaluation of 37 interventions and treatments for children with autism in the general education and self-contained classrooms indicated five categories of common interventions and treatments (Simpson et al., 2004). These categories of common ASD treatments included the areas of interpersonal relationships, skills-based, cognitive, physiological/biological/neurological, and miscellaneous. Of these 37 treatments only 10.8% were considered scientifically-based. This suggests that students with autism may not be receiving evidence-based interventions that are mandated by law.

Similarly, researchers studied interventions for individuals with ASD in early intervention programs (Stahmer, Collings & Palinkas, 2005). Most educators reported a desire to implement evidence-based interventions, but indicated that these interventions were often not being used. All educators included in the study felt that they lacked



adequate training for working with individuals with ASD. This examination of common practices used when working with individuals with ASD suggests that teachers may not have the resources needed to appropriately work with this population. As the prevalence rate of students with ASD increases it is important for educators working with individuals with ASD to have knowledge of and access to scientifically-based treatments.

The knowledge base in autism spectrum disorders is changing so rapidly that it is a challenge to stay current with the latest evaluation and treatment methods (Wilkinson, 2010). Unfortunately, there continues to be controversial and unsupported techniques used in the schools for individuals with autism (Hess et al. 2008; Simpson et al., 2004; Stahmer et al., 2005). In a study examining strategies used in the education of children with ASD, researchers found that fewer than 10% of the strategies used with students with ASD in general education and special education classrooms in Georgia Public Schools were constructed from scientifically-based practice (Hess et al., 2008). These findings suggest a disconnect between best practices and reported educational practices. Because of these challenges with educating individuals with autism it is critical that educators receive ongoing education and training opportunities. Most of the children with autism are educated within the public school system, and often times in general education classrooms. More effort is needed to ensure that teachers are knowledgeable regarding evidence-based practices for working with students with ASD.

The autism spectrum includes impairments in social interaction, communication, and restricted/stereotyped patterns of behaviors and interests. There are a wide variety of these attributes observed in individuals with autism. The symptoms observed in children can be very different depending on how ASD presents itself in each child. In addition to

the resources provided in school settings, parents play an important role in the intervention process. It is important to consider the characteristics of families with children with an ASD.

### **Families of Individuals with Autism Spectrum Disorders**

**Genetic Link in Individuals with Autism.** Although there has been a considerable amount of research on ASD, the etiology of the disorder is unknown. The most consistently supported link to ASD is the interaction of multiple genes (Kozlowski, Matson, & Worley, 2012). Twin studies found that identical twins are much more likely than fraternal twins to share an autism diagnosis (Bailey et al., 1995). In these studies, the concordance rate for identical twins ranged from 36%-91%, while the concordance rate for fraternal twins ranged from 0%-19% (Bailey et al., 1995; Kozlowski et al., 2012). The higher prevalence of ASD concordance in identical twins supports the idea that ASDs are a result of the interaction of multiple genes rather than a single gene.

**Family Characteristics of Individuals with Autism.** While there is a clear genetic link in ASD, there are not any specific characteristics that define families of children diagnosed with ASD. There is no evidence that ASDs affect individuals of different races/ethnicities, socioeconomic statuses, parental ages, or geographical locations differently (CDC, 2006). The Centers for Disease Control and Prevention highlights a need to increase research to identify risk factors associated with ASDs. While ASDs do not affect racial groups or families with varying degrees of education differently, Caucasian children with well-educated parents are more likely to receive an ASD diagnosis at a younger age than non-white children with parents without higher education (Mandell et al., 2009). This suggests that there may be a difference in

identification for early intervention services based on race and socioeconomic status, but the overall prevalence rate for diagnosis across the lifespan does not differ. The only risk factors for ASDs that are clearly supported by research include being male and having a genetic history of ASD in the family (CDC, 2006).

Raising a child with ASD can present significant challenges to families. Specifically, mothers of children with ASD are more likely to have poorer psychological well-being when compared to parents of children without disabilities (Abbeduto et al., 2004). Mothers of children with ASD might also have high levels of depression and anger due to parenting a child with ASD (Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). Parents of children with ASD typically report higher levels of parenting stress when compared to parents of typically developing children (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005). Research suggests that parents that employ problem-solving coping are able to decrease their levels of stress, while emotional coping leads to more stress and pessimism in parents (Lyons, Leon, Phelps, & Dunleavy, 2010; Smith et al., 2008). Problem-solving coping is aimed at reducing or eliminating the source of stress, while emotional coping is a focus on managing the emotions that accompany stress (Lazarus & Folkman, 1984). In addition to coping strategies, family support, spousal support, and community support have also been linked to decreased stress and better functioning in families of children with ASD (Tehee, Honan, & Hevey, 2008; White & Hastings, 2004). There are numerous stressors that affect parents raising children with ASD. A possible stressor to families of individuals with autism includes accessing appropriate services and education for their child. Parent involvement in their

child's education as well as knowledge of available services for their child appears to predict overall satisfaction with their child's education (Renty & Roeyers, 2005).

### **Parental Stress and Autism Spectrum Disorders**

In the field of psychology stress has consistently been viewed as a stimulus or response to a situation (Selye, 1973). Definitions that view stress as a stimulus focus on events in the environment that produce stress, such as having a child with a disability (Lazarus & Folkman, 1984). By taking this approach, it is assumed that certain situations are stressful, but it does not allow for individual differences. Another definition of stress suggests that a state of stress is defined as how the person reacts to certain stimuli (Lazarus & Folkman, 1984). For example, if a child with a disability had an outburst, stress would be the response to that occurrence. Both of these definitions view stress in terms of a response to a stressful stimulus.

Other definitions of stress emphasize the relationship between the person and the environment, accounting for personal characteristics and the nature of environmental events (Cohen & Edwards, 1989). For example, a person who views driving during a storm as too emotionally tough views him/herself to be in danger; however, others might not appraise this same situation as stressful. Lazarus and Folkman (1984) describe stress as "a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources" (p. 21). This definition takes into account the reciprocal relationship of the parent and the child with a disability and how each individual affects the other (Hastings, 2002). Within this definition of stress, children's problems associated with autism lead to stress in parents, and parents under stress have parenting behaviors that interact with these behavior problems.

Evidence exists demonstrating that when children with developmental disabilities partake in problem behaviors, parents report more stress and more psychiatric problems (Hastings, 2002). Childhood developmental disabilities may give rise to a complex network of stressors (Randall & Parker, 1999). Parenting a child with a disability can produce great stress and imbalance in a family. Research shows that family stressors associated with non-normative family dynamics, such as a disability of a child, can place high demands on parents (Beresford, 1994). This theoretical background would suggest that a parent of a child with autism would have primary stressors due to the challenges of raising a child with autism, which affect him or her through all areas of his or her life.

Levels of parenting stress in parents of individuals with Autism Spectrum Disorders have been consistently high in studies (Robbins, Dunlap, & Plienis, 1994; Tobing & Glenwick, 2006). Researchers identified several factors that contribute to the stress of parents of children with autism (Sharpley, Bitsika, & Efremidis, 1997). These factors included a concern over the permanency of the condition, poor acceptance of autistic behaviors by society, and the very low levels of social support received by parents. Research suggests that the stressors of parenting a child with autism emanates from factors directly related to the child's disability (Hastings, 2002). These factors associated with the disability include socially deviant behavior, ritualistic behavior, and deficits with language use.

Parents of individuals with autism also report higher levels of parenting stress when compared to parents of typically developing children (Baker-Ericzen et al., 2005). In a study investigating parental stress of children with High Functioning Autism (HFA), the stress levels of parents of children with HFA were compared to the stress levels of

individuals with a child with no psychopathology (Rao & Beidel, 2009). Children with high functioning autism have IQs in the average range but still display other autism symptoms. The HFA group and the control group were matched on ethnicity, income, gender, and cognitive ability. This study found that parents of children with HFA were more stressed than the parents of children with no psychopathology (Rao & Beidel, 2009). While this finding is not surprising, it is an important step towards viewing the different clinical profiles that are present in Autism Spectrum Disorders.

There is also evidence that parents of children with autism have higher levels of stress than parents of children with other disabilities (Hastings, Kovshoff, Ward, Degli-Espinosa, & Remington, 2005). Research suggests that when compared to parents of children with Down syndrome, parents of children with ASD have higher levels of parenting stress (Hastings et al., 2005).

**Level of Parenting Stress and Severity of ASD.** Stress among parents of children with ASD is strongly and positively related to the child's autism severity (Konstantareas & Papageorgiou, 2006; Lyons et al., 2010; Moh & Magiati 2012). This relationship suggests that as the level of autism severity increases, the level of stress also increases. Researchers examined the effect of child temperament, symptom severity, verbal ability and level of functioning on maternal stress in 47 Greek mothers of children with autism spectrum disorder (Konstantareas & Papageorgiou, 2006). Researchers found that the severity of autism, rather than the child's overall functioning, predicted maternal stress. In a different examination of the role of autism severity and parental coping strategies, the child's autism severity was the strongest and most consistent predictor of level of stress (Lyons et al., 2010).

A study from Singapore examining factors associated with parent stress during the diagnosis of children with ASD gives insight into the relationship between parent stress and ASD severity (Moh & Magiati 2012). Lower levels of stress were associated with lower severity of the child's ASD symptoms as well as higher parental satisfaction with the diagnostic process. This relationship suggests that parents of children with more severe autism symptoms might not only be more stressed, but also have lower levels of satisfaction with their child's experiences. These findings indicate that a child's autism severity plays a significant role in the amount of stress in parents of children with autism.

Some debate exists regarding the source of the stress for parents of children with ASD. Some argue that parents of children with ASD are more stressed because of the behavior problems that are common in individuals with ASD (Hastings et al., 2005). In one study, individuals who demonstrated ritualistic behaviors were associated with maternal stress even when controlling for their child's externalizing behaviors (Lecavelier, Leone, & Wiltz, 2006). In a study examining predictors and moderators of stress for individuals on the autism spectrum, researchers found a positive relationship between children's functional impairment and parenting stress (Tobing & Glenwick, 2006).

Other research has suggested that the behavior problems associated with ASD predict maternal stress rather than the severity of the autism symptom (Hastings et al., 2005). It is possible that parental stress is more associated with behavior problems than any other characteristic measured (Lecavelier et al., 2006). Some research indicates that stress is more pronounced when children with autism have problematic behavior.

Because autism symptomology is so diverse it is difficult to understand where the parental stress originates. It is unclear whether it is the core symptoms of autism or the associated behavioral problems that contribute to the high levels of parental stress (Lyons et al., 2010). It is clear that level of severity is related to parenting stress in families of individuals with ASD (Konstantareas & Papageorgiou, 2006; Lyons et al., 2010; Moh & Magiati, 2012).

### **Parent Satisfaction with Child's Educational Experience**

Examining parent satisfaction with their child's schooling can be important for understanding the source of parent-school conflicts. By understanding the views about education from a parent's view, professionals working with individuals with disabilities will be able to provide better services and supports that meet the parent's needs. Differences between parent expectations and parent experiences with services result in a specified level of satisfaction (Wood et al., 2009). Expectations are formed through a complex combination of prior experiences and factors specific to an individual (Ruiz-Moral et al., 2007). Parents create expectations in certain situations based on their past experiences in similar situations and their own personal characteristics (organization, control, values, etc). When considering parents' satisfaction with their child's education several areas should be considered. The Offices of Special Education Programs identified five areas of satisfaction that are important to parents (Newman, 2005).

**Parent Satisfaction with Special Education.** The Office of Special Education Programs (OSEP) completed two national longitudinal studies regarding parent satisfaction with their children's education (Blackorby et al., 2004; Newman et al., 2011). Children and youth who received special education were involved in this study. Parents



were asked about their satisfaction with their children's education, services, teachers, and schools, as well as with the efforts by schools to keep them informed of their children's performance.

One of these studies was The Special Education Elementary Longitudinal Study (SEELS, 2000-2006), which had a nationally representative sample of more than 11,000 students receiving special education. These students were in at least first grade and receiving special education services during the 1999-2000 school year. The sample included children ages 6 through 13 at the time the data first were collected, in 2000. The second study was the National Longitudinal Transition Study-2 (NLTS2, 2001-2011), which was similar to SEELS. It consisted of youth who were ages 13-17 and receiving special education when selected for the study. Information from SEELS and NLTS2 represented youth with disabilities as a group, as well as youth in each of the federal special education disability categories. Both studies were conducted by the same group (SRI International) for The Office of Special Education Programs. The longitudinal studies found that approximately 90% of parents with children with special needs ages 6-13 were at least somewhat satisfied with all aspects of their child's education. For children ages 13-17 the percent of parents who were somewhat satisfied with their child's education dropped to 86%. These percentages suggest that parents of children with disabilities were mostly satisfied with their child's school; however, a sizable number of parents were at least somewhat dissatisfied as well. Approximately 10% of parents were dissatisfied or somewhat dissatisfied with some aspect of their 6-13 year-old child's overall education, and about 14% of parents with children ages 13-17 were dissatisfied or somewhat dissatisfied with their child's overall education. This suggests that parents of

older children in special education were less satisfied than younger children in special education. Research by Spann, Kohler, and Soenksen (2003) also supported this finding that older children's parents felt that schools were doing little to meet their child's most pressing needs.

OSEP also compared parents of students with disabilities to parents of students in the general population (Newman, 2005). They found that parents of children without disabilities are 8-11% more likely to be very satisfied with their child's schools and teachers than parents of children with disabilities.

Parents of children with special needs have different experiences with their child's education when compared to parents of typically developing children. In an in-depth examination of the views of parents of children with different disabilities, parents reported that 44% of the time schools were doing little or nothing to address their child's most pressing needs (Spann, Kohler, & Soenksen, 2003). These findings suggest that parents of children with disabilities experience difficulties with their child's education. However, this study utilized a small sample size and did not provide information about the type of disability or severity. This study provided insight into parents' experiences with the education of their child with a disability and it supported OSEP's findings that parents of children with disabilities struggle with their child's educational services.

**Parent Satisfaction with Education and ASDs.** The Office of Special Education Programs's (OSEP) examination of parental satisfaction with the education of their child with a disability gave insight into parents of children with autism spectrum disorders (Blackorby et al., 2004; Newman et al., 2011). An examination of the different disability groups showed that parents of students with emotional disturbances were

consistently more dissatisfied than any other special education group. In this group 78% of parents with children ages 6-13 and 71% of parents with children ages 13-17 were at least somewhat satisfied with their child's schooling. Following parents of students with emotional disturbances were parents of children with other health impairments, traumatic brain injuries, and autism spectrum disorders. From the sample of children diagnosed with other health impairments, 80% of parents with children ages 6-13 and 73% of parents with children ages 13-17 were at least somewhat satisfied with their child's school. The sample of parents of children with traumatic brain injuries showed that 81% of parents with children ages 6-13 and 73% of parents with children ages 13-17 were at least somewhat satisfied with their child's school. The sample of parents of children with autism spectrum disorders found that 83% of parents with children ages 6-13 and 79% of children ages 13-17 were at least somewhat satisfied with their child's school. These groups of parents were considerably less satisfied in all areas of their child's schooling including: overall satisfaction, services, schools, teachers, and communication with the school. This suggests that parents of children with ASD are among the least satisfied parents regarding their child's education. Several studies have attempted to look more in depth at the specific areas of education in which parents of children with ASD are the least satisfied.

Because of the unique experience of raising children with autism spectrum disorder it is important to consider areas of education that are problematic for individuals with ASD. Understanding the complexity of the autism spectrum and the stress that it puts on families is important when considering a parent's view of their child's education. Several descriptive studies have been completed examining parent's satisfaction with the

education of their child with ASD (Kohler, 1999; Renty & Roeyers, 2005; Renty & Roeyers, 2006; Tissot & Evans, 2006; Whitaker, 2007). Descriptive studies have been used to identify factors associated with variations in the level of parental satisfaction with the education provided for children with ASD. These studies examining parents of children with ASD have found that parents report experiencing difficulties with the diagnostic process (Moh & Magiati, 2012; Renty & Roeyers, 2005), the educational setting (Renty & Roeyers, 2005), and accessibility of appropriate services for the child (Kohler, 1999; Renty & Roeyers, 2005).

While OSEP's evaluation of parent satisfaction with the education of their child with disabilities found that parents of children with ASD were among the least satisfied with their child's education, some research suggests that parents of children with autism have similar experiences with education as parents of children with other disabilities (Parsons, Lewis, & Ellins, 2009; Starr, Foy, Cramer, & Singh, 2006). Other research provides evidence that parents of children with autism have different perceptions of their child's education than parents of children with other disabilities (Bitterman, Daley, Misra, Carlson, & Markowitz, 2008; Kasari, Freeman, Bauminger, & Alkin, 1999; Siklos & Kerns, 2006).

The views of parents of children with ASD and those of children with Down syndrome were compared on questions relating to their child's educational placement (inclusion, mainstream or specialized classes) (Kasari et al., 1999). Within this study there was no difference in parents' levels of satisfaction regarding their children's education between the two groups with approximately 40% of each group who were dissatisfied with their child's current placement. The differences in parents' perceptions

of educational services were discussed. Over 50% of parents with ASD favored specialized services addressing their child's ASD, while parents of children with Down syndrome preferred inclusive settings. Parents of children with ASD were more likely than parents of children with Down syndrome to request teachers to have specialized teaching and knowledge about their child's disability (Kasari et al., 1999). This suggests that while the desires of parents of individuals on the autism spectrum are different than the desires of parents of children with other disabilities, the groups may have few differences in their level of satisfaction with their child's schooling.

Some research examined educational services for children ASD and other disabilities under IDEA, and focused on parent satisfaction with these services (Bitterman et al., 2008) Researchers contrasted children with ASD to children who had other disabilities by examining the services received by preschoolers with disabilities and parents' satisfaction with these services. The severity of the child's behavior was examined through a measure of adaptive skills. Researchers found that children with ASD received more services even when controlling for severity of the disability. Children with ASD spent more time in special education settings than children with other disabilities when controlling for severity of the disability. Significantly more parents of children with ASD felt their children did not spend enough time with typically developing peers and that their child needed more of the services they were currently receiving when compared to parents of children with other disabilities. A comparison of parents' perceptions of the needs of their children with ASD and of children with Down Syndrome found that parents of children with ASD reported a greater need for therapies as well as more professionals who are knowledgeable about the disability (Siklos &

Kerns, 2006). While parents of children with ASD were less satisfied in particular areas of their child's education, the overall satisfaction of parents of children with ASD was similar to the overall satisfaction of parents of children with Down syndrome. Other studies have found few differences in parent satisfaction with the school system based on their child's disability (Siklos & Kerns, 2006; Starr et al., 2006). Researchers considered specific aspects of children's educational services in Canada and compared the views of parents of children with ASD, Down syndrome, and learning disabilities (Starr et al., 2006). The sample consisted of 144 parents whose children had ASD, 45 parents whose children had an LD, and 20 parents of children with Down syndrome. When controlling for age of the child with a disability there were few differences among the groups, with just over 30% of the entire sample who were dissatisfied with their child's overall education. The most common need indicated by parents of children in all three groups was more training in how to effectively teach children with their specific needs. This study suggests that there may not be much difference between parents of children with ASD and parents of children with other disabilities in their satisfaction with their child's education.

In another study, the views of parents of children with ASD were compared to the views of parents of children with other disabilities in regards to their experiences with their child's education (Parsons, et al., 2009). Participants were recruited (n=125) through websites that served individuals with disabilities. The comparison group of other disabilities ranged from learning disabilities, speech and language disabilities, and emotional disturbances. Researchers considered parent satisfaction in five themes of educational concerns: (1) Independence and autonomy, (2) Experience of

accessible/inaccessible educational environments, (3) Attitudes and behaviors, (4) Knowledge and assertion of rights, and (5) Ambition and aspirations. Researchers found that parents of children with and without ASD were more alike than different. The only area where there was a clear difference was that parents of individuals with ASD were more likely to be dissatisfied with their ability to choose the educational setting that was best for their child than parents of children with other disabilities.

Kohler (1999) conducted a study designed to examine the services received by 3-9 year-olds with autism and pervasive developmental disabilities. Researchers conducted telephone interviews with 25 families examining types of services received, the accessibility of these services, the family involvement, general satisfaction, and concerns in families of individuals with autism. Researchers found that 50% of the parents reported that the services their child was receiving were either ineffective or unrelated to their child's most important needs. This study revealed that on average, families received 6.4 different services for an average of 37 hours of service per week. Because of the discontinuity of services, parents of children with autism interacted with, on average, 7.7 different professionals and almost 5 different agencies. Of these services, 64% of parents indicated that at least one service was ineffective. Some of the most common complaints unrelated to services included communication with parents and difficulties with the diagnostic process. While this study had a small sample size (n=25), it brought up issues related to parental satisfaction with the schooling of their children with autism.

In an attempt to describe factors associated with the variations in the level of parental satisfaction with the education for children with ASD, researchers mailed a questionnaire to individuals involved in a parent organization for ASD (Renty &

Roeyers, 2006). These questionnaires were followed-up with a semi-structured interview to understand the problems that parents faced with their child's education in greater depth. The questionnaire in this study covered information about satisfaction with the diagnostic process, the accessibility of ASD-specific services, education, and autism-specific knowledge of teachers. Within this examination, parents were generally satisfied with the quality of education and support that their child received; however, satisfaction scores were higher in parents whose children were educated in separate schools rather than in inclusion-based schools.

Overall, Renty and Roeyers (2006) found that higher satisfaction ratings within parents of individuals with autism were related to a lower age of diagnosis, higher levels of parental involvement in school, and more information following the diagnosis. Parents of children with ASD but without an intellectual disability had the most difficult time finding appropriate services to meet their child's needs. This might be because typically children with ASD without intellectual disabilities are served in general education classrooms where teachers might not be familiar with ASD.

Descriptive studies have also been useful in identifying areas in which parents of children with ASD are most satisfied. In these studies, many parents reported being satisfied with the quality of autism-specific support (Renty & Roeyers, 2005) and the overall quality of education (Renty & Roeyers, 2005; Whitaker, 2007).

Whitaker (2007) examined parents of children with an ASD and compared those who were satisfied with the parents who were dissatisfied with their child's education. Within the sample of parents of children with ASD, 40% of parents were not satisfied with their child's education. Parents with children in mainstream settings were more



likely to be dissatisfied with their child's education than parents whose children were in special schools. Another big difference in individuals who were dissatisfied versus those who were satisfied with their child's overall schooling was the extent to which the teacher understood the student with ASD. Parents who were satisfied with their child's education rated themselves to have "high" levels of home-school communication, while dissatisfied parents were more likely to rate the home-school communication as "low".

Renty and Roeyers (2005) looked at specific predictors of overall satisfaction, and found that parents of children with ASD who were most satisfied were involved in their child's education and had knowledge of available services for their child. This suggests that parent involvement might play a large role in parent's satisfaction with their child's education.

These descriptive studies help to highlight areas in which parents of children with ASD are dissatisfied with their child's education (Kohler, 1999; Renty & Roeyers, 2005; Renty & Roeyers, 2006; Whitaker, 2007). The studies above also give insight into parents of children with ASD who are satisfied with particular aspects of their child's education.

To this date the current research has mostly focused on parent's perception towards the inclusion of children with autism (Kasari et al. 1999), educator's knowledge about autism (Siklos & Kerns, 2006; Starr, Foy, & Cramer, 2001), appropriateness of the setting (Starr et al., 2006), or the parent's involvement in their child's education (Renty & Roeyers 2005). There has been very little emphasis in the research on parental satisfaction with the educational techniques used for their child with autism. Since there is an emphasis on using research-based teaching strategies for individuals with autism (Wilkinson, 2010), it would be useful to gather information regarding parents perceptions

and satisfaction with teaching strategies and classroom environment. Additionally, researchers have failed to control for level of ASD severity when looking at parents' satisfaction with education.

## CHAPTER TWO: PURPOSE OF STUDY

The number of children diagnosed with an Autism Spectrum Disorder (ASD) has increased dramatically over the last few decades (Centers for Disease Control and Prevention, 2012). Because of this increase, understanding the diverse experiences of parents of children with ASD is important. Identifying areas of their child's education that parents are most dissatisfied with could help educators to better understand parents of children on the autism spectrum.

Parenting a child with ASD is very stressful and challenging. Parents of children with ASD report higher levels of stress when compared to parents of typically developing children (Baker-Ericzen et al., 2005; Erguner-Teckinalp & Akkok, 2004), and when compared to parents of children with other disabilities (Perry, Harris, & Minnes, 2005; Weiss, 2002).

Autism Spectrum Disorder consists of a continuum of disorders that are exhibited in some people more severely than in others. The severity of ASD symptoms is a predictor of parental stress (Bromley, Hare, Davison, & Emerson, 2004; Hastings, 2002; Konstantareas & Papageorgiou, 2006; Lyons et al., 2010).

There have been several studies on parent's satisfaction with their child with autism's education. Some of these studies looking at parent's educational satisfaction have been descriptive (Kohler, 1999; Renty & Roeyers, 2006; Whitaker, 2007), while others have considered statistical differences in parent satisfaction between disabilities (Parsons et al., 2009; Starr et al., 2006). Some have found areas in which parents of children with autism were not satisfied with their child's education (Bitterman et al.,

2008; Kohler, 1999; Renty & Roeyers, 2006; Whitaker, 2007), while others have found that parents of children with autism were primarily satisfied with their child's education (Parsons et al., 2009; Starr et al., 2006). There is very little information in the literature regarding the differences in parent's educational satisfaction based on severity of autism and parental stress.

The purpose of this study is to examine the degree to which autism severity and parental stress can predict parent's satisfaction with their child's classroom environment and education team. There are large differences in symptom presentation and severity for individuals on the autism spectrum, and these differences should be considered when examining parent's satisfaction with schooling. Because there is an established relationship between autism symptom severity and parental stress, I hypothesize that parent stress and autism severity, when combined, will be a significant predictor of parent satisfaction with their child's classroom environment and with the educational professionals who work with their child. When controlling for stress, I hypothesize that autism severity will still be a significant predictor of parent's satisfaction with the classroom as well as a significant predictor of the parent's satisfaction with the education team.

## CHAPTER THREE: METHOD

### **Participants**

Participants in this study consisted of 97 parents or guardians that had children attending a summer camp in central North Carolina designed for children on the autism spectrum. Since the camp serves only residents of the state, the participants all resided in North Carolina. Demographic information about the sample will be summarized in the next several paragraphs.

There were some male raters ( $n = 8, 8.2\%$ ), but the majority of the raters were female ( $n = 89, 91.8\%$ ). Most of the raters were biological mothers ( $n = 85, 87.6\%$ ). Other raters included biological fathers ( $n = 5, 5.2\%$ ), adoptive mothers ( $n = 4, 4.1\%$ ), adoptive fathers ( $n = 1, 1.0\%$ ), and legal guardians ( $n = 1, 1.0\%$ ). One rater did not provide information about his/her relationship to the child.

A majority of the raters were married or living with a partner ( $n = 81, 83.5\%$ ), some were single/never married ( $n = 3, 3.1\%$ ), some were divorced/separated-not married ( $n = 12, 12.4\%$ ), and one rater was widowed-not re-married ( $n = 1, 1.0\%$ ). Information about the rater's level of schooling indicated that raters had completed high school/some college ( $n = 14, 14.5\%$ ), Associates/Bachelor's/some graduate school ( $n = 51, 52.6\%$ ), and graduate degree ( $n = 32, 33\%$ ).

Demographic information was collected on the students as well. Ethnic composition of the sample was predominately Caucasian ( $n = 73, 75.3\%$ ) and African American ( $n = 15, 15.5\%$ ). The rest of the participants were either Hispanic/Latino ( $n = 4, 4.1\%$ ), Asian ( $n = 2, 2.1\%$ ), or multi-racial ( $n = 3, 3.1\%$ ). The sample of children was

made up of more males ( $n = 76$ , 78.4%) than females ( $n = 20$ , 20.6%). The average age of the children was 11.9, and the average age in which the children were diagnosed with an Autism Spectrum Disorder was 4.7 years.

Information was collected on the experiences of the students at school. The sample of students received services in a variety of school settings. The majority of the sample was in a self-contained public school setting ( $n=45$ , 46.4%). The sample also included students from public schools in a combination of general education and resource classrooms ( $n=20$ , 20.6%), and in public schools fulltime in the general education classroom ( $n=8$ , 8.2%). The remainder of the students attended a private school setting ( $n=4$ , 4.1%), were homeschooled ( $n=2$ , 2.1%), attended some other setting not specified ( $n=8$ , 8.2%), or did not answer the question ( $n=2$ , 2.1%).

The students from this study represented many different grades including: pre-kindergarten/kindergarten, ( $n=6$ , 6.2%), first grade ( $n=14$ , 14.4%), second grade ( $n=6$ , 6.2%), third grade ( $n=8$ , 8.2%), fourth grade ( $n=7$ , 7.2%), fifth grade ( $n=9$ , 9.3%), sixth grade ( $n=4$ , 4.1%), seventh grade ( $n=9$ , 9.3%), eighth grade ( $n=9$ , 9.3%), and high-school grades ( $n=19$ , 19.6%), and a few did not respond ( $n=6$ , 6.2%).

These students received a variety of services at school including: speech therapy ( $n=62$ , 63.9%), occupational therapy ( $n=44$ , 45.4%), social skills training ( $n=29$ , 29.9%), applied behavior analysis ( $n=9$ , 9.3%), physical therapy ( $n=3$ , 3.1%), and other services ( $n=6$ , 6.2%). Along with school services, many of these students received services privately, including: social skills training social skills training ( $n=37$ , 38.1%), speech therapy ( $n=25$ , 25.8%), occupational therapy ( $n=25$ , 25.8%), applied behavior analysis ( $n=16$ , 16.5%), physical therapy ( $n=7$ , 7.3%), and other services ( $n=25$ , 25.8%).

## Materials

The instruments used to collect the data for this research were in questionnaire format. Participants completed a demographics form, a scale to measure autism severity, a parenting stress scale, and a survey measuring the parent's satisfaction with their child's schooling.

**Demographics Questionnaire.** A demographic questionnaire (see Appendix A) was used to collect information about parents and their child. The questions about the parent included: relationship to the child, gender, ethnicity, educational level, employment status, income level, and relationship status. Questions about the child included: age, grade, number of siblings, age at diagnosis, placement in the school setting, and the type of services the child receives at home and at school.

**Social Communication Questionnaire.** The *Social Communication Questionnaire (SCQ)* (Rutter, Bailey, & Lord, 2003) is a 40-item parent rating scale that was used to assess the child's autism severity. The *SCQ* is a scale in which parents endorse symptoms of autism in the form of yes/no questions. Total scores on the *SCQ* range from 0 to 39, with scores towards 39 being the most severe ASD presentation. The questionnaire is based on the Autism Diagnostic Interview-Revised (Lord, Rutter, & Le Couteur, 1994). This instrument was normed using a sample of individuals (n=200) between the ages 4 and 32. This sample included 160 individuals with a Pervasive Developmental Disorder and 40 individuals without a Pervasive Developmental Disorder.

The *SCQ* is shown to have sensitivity (proportion of true positives identified by the *SCQ*) as well as specificity (proportion of true negatives accurately identified by the screener). The Cronbach's alpha for sensitivity and specificity are 0.85 and 0.75

respectively. Factor analysis suggested a 4-factor solution: Social Interaction, Communication, Abnormal Language, and Stereotyped Behavior. The Cronbach's alpha of the Total Score was .90 and the coefficients ranged from .67 (Stereotyped Behavior) to .91 (Social Interaction) for the four factors. The SCQ domain totals correlated with their corresponding ADI-R subscales, with coefficients ranging from .55 to .59. This suggests that the *Social Communication Questionnaire* has convergent validity with the Autism Diagnostic Interview-Revised (Lord et al, 1994). (For a sample of questions see Appendix B.)

**Family Stress and Coping Questionnaire - Autism.** The *Family Stress and Coping Questionnaire* (FSCQ-A) (Tehee, Honan, & Hevey, 2009) was adapted from the Family Stress and Coping Interview (Nachshen, Woodford, & Minnes, 2003). It assesses parents' perceived stress in 19 areas of raising a child. These areas include those often affected (e.g., acquiring respite care, explaining their child's disorder to friends/family /community) when raising a child with autism. It is a 26 item self-report survey that uses a 4-point Likert scale ranging from 0 (Not Stressful) to 3 (Extremely Stressful), as well as an open-ended question asking the parents to list their top 3 sources of stress. The range of scores is 0 to 78. On the FSCQ-A higher scores suggest higher levels of parenting stress, while lower scores suggest lower levels of parenting stress. Good internal consistency was found for the FSCQ-A (Cronbach's alpha = 0.72) (Tehee et al., 2009). The FSCQ-A was highly correlated with the *Perceived Stress Scale-10* with a Spearman's  $\rho = .68$ , suggesting that it is a good measure of parent stress (Tehee et al., 2009). The sample for this study had good internal consistency with a Cronbach's alpha = .904 (See Appendix C).



### **The Parent Education Perception and Satisfaction Survey: Autism Spectrum**

**Disorders.** The PEPSS-ASD (see Appendix D) was developed through a study of best teaching practices for individuals with autism (Starr et al., 2001). The areas examined in the parent satisfaction survey include: classroom environment and educational team. The areas of interest in this survey are parent's satisfaction with their child with autism's classroom and education team. The survey includes 30 Likert scale items on the Classroom Satisfaction Scale and 25 Likert scale items on the Education Team Satisfaction Scale. Likert items are scored on a scale of 1 (Strongly Agree) to 4 (Strongly Disagree). There is also a U (Unable to Comment) option for each question. Some items are "negatively" worded throughout the survey to minimize the possibility of patterned responding. Scores on the Classroom Environment Scale range from 22 to 88, and scores on the Educational Team Scale range from 21 to 84. Scores on the two scales are considered separately. Scores are determined by finding the mean scale score and multiplying it by the number of items that can be scored within that particular scale. On this scale there are also items to determine if certain educational practices are important to parents. If a parent "Strongly Agrees" or "Mostly Agrees" that these practices are not important then that item is not scored; therefore it does not contribute to the overall satisfaction score. High scores suggest that parents are satisfied, while low scores suggest that parents are dissatisfied with that aspect of their child's education. The reliability analysis of the Likert scale items on the Classroom Environment and Education Team scales of the PEPSS-ASD have good internal reliability with Cronbach's alphas of .94 and .88, respectively. In this study similar internal reliabilities were found with

Cronbach's alphas of .92 on the Classroom Environment scale and .82 on the Education Team scale.

### **Procedure**

While waiting to register their child for summer camp the researcher explained the purpose of the study to the parents, and informed parents that the participation was voluntary. Parents were asked to complete an informed consent (see Appendix E), and then parents were asked to complete a series of surveys. Parents completed the demographic form first, and the order of remainder of the surveys was counterbalanced in the packets to prevent order effects. Most participants opted to take the survey home, fill it out, and then return it when they came to pick up their camper at the end of the week. The camp serves about 250 children and adolescents with autism each summer, and 97 parents participated.

### **Results**

In order to determine the relationship between independent variables (autism symptom severity and stress) and the dependent variables (parent satisfaction with the classroom environment and parent satisfaction with the educational team), statistical analyses were run through Statistical Package for the Social Sciences (SPSS). Analyses were run to determine whether level of autism severity and parenting stress could be used to predict parent satisfaction with their child's classroom environment and education team. Other correlational analyses were run, which will be discussed below.

**Descriptive Statistics.** It is important to look at the sample statistics on each of the instruments used in this study to examine the range of scores provided by the participants. The sample shows that there is some variability in the scores obtained on the

two measures of parent satisfaction. This suggests that we did not merely have a sample of satisfied parents. The parent satisfaction with the classroom environment had a wide range of scores, and the mean was 62.6 ( $SD=17.1$ ). Similarly, the parent satisfaction of the educational team had a wide range of scores, and a mean of 52.6 ( $SD=12.5$ ).

The stress scores measured by the FSCQ-A ( $M=39.45$ ,  $SD=12.71$ ) show that the sample had overall low levels of stress. The sample had a large range of autism symptom severity scores, measured by SCQ ( $M=17.58$ ,  $SD=6.4$ ), but there were not a lot of raters in the bottom or top of the range. Most of the raters were clustered in the middle of the range of scores on the SCQ, suggesting that we have a limited variability of severity scores. Some studies have suggested using a cutoff score of 15 on the SCQ as an indication of further investigation for ASDs. This sample mean was barely above this threshold.

**Hypothesis Testing.** Because of the established relationship between autism symptom severity and parental stress, it was hypothesized that parent stress (as measured by the *Family Stress and Coping Questionnaire - A*) and autism severity (as measured by the *Social Communication Questionnaire*) when combined would be a significant predictor of parent satisfaction with their child's classroom environment and the education team working with their child (as measured by *The Parent Education Perception and Satisfaction Survey: Autism Spectrum Disorders*). High scores on parent stress and high scores on autism severity would be related to low scores on parent satisfaction with the classroom environment and low scores on parent satisfaction with educational professionals. When controlling for stress, it was hypothesized that autism

severity would still be a significant predictor of parent satisfaction with the classroom as well as a significant predictor of parent satisfaction with the child's education team.

Hypothesis testing revealed no significant relationship between autism severity (*SCQ*) and parent satisfaction with their child's education team (*PEPSSedu*), Pearson's  $r = -.082$ ,  $p = .441$ . There was also no significant relationship between autism severity (*SCQ*) and parent satisfaction with their child's classroom (*PEPSSclass*), Pearson's  $r = .019$ ,  $p = .861$ . No relationship was found between parental stress and parent satisfaction with their child's education team (*PEPSSedu*), Pearson's  $r = -.160$ ,  $p = .133$ . There was a small correlation between parental stress and parent satisfaction with their child's classroom (*PEPSSclass*), Pearson's  $r = -.225$ ,  $p = .032$ . This correlation suggests that as stress increased, parent satisfaction with their child's classroom environment decreased.

There was a strong positive correlation between parent satisfaction with their child's education team (*PEPSSclass*) and parent satisfaction with their child's classroom (*PEPSSclass*), Pearson's  $r = .702$ ,  $p < .001$ . This suggests that parents who are dissatisfied with their child's educational team are also typically dissatisfied with their child's classroom environment as well.

**Exploratory Analyses.** Autism symptom severity was not related to parent satisfaction with their child with autism's educational team or classroom environment. Parent stress was not related to parent satisfaction with the educational team, and there was a small relationship between parent stress and the parent's satisfaction with the classroom environment. Because of these outcomes, other variables were considered that might be related to parent satisfaction with their child with autism's educational team and classroom environment.

***Demographic Variables as Correlates of Parent Satisfaction with Education.***

Some of the demographic variables were examined to determine if any characteristics specific to the child or family were related to parent's satisfaction with their child with autism's education team and/or classroom environment. The age of the child did not correlate with parent satisfaction with the education team, Pearson's  $r = -.10$ ,  $p = .929$ , or with parent satisfaction with the classroom environment, Pearson's  $r = -.085$ ,  $p = .422$ . Similarly, the age of the diagnosis of autism did not correlate with parent satisfaction with their child's education team or classroom environment, Pearson's  $r = -.086$ ,  $p = .419$  and Pearson's  $r = -.107$ ,  $p = .308$ , respectively. The number of services that the student received at school was not a significant variable for differentiating parent satisfaction with the education team,  $F(4,85) = .985$ ,  $p = .420$ , or parent satisfaction with the classroom environment,  $F(4,85) = .357$ ,  $p = .839$ . The number of services the student received at home was not a significant variable for differentiating parent satisfaction with the education team,  $F(7,82) = .350$ ,  $p = .928$  or the classroom environment,  $F(7, 82) = .160$ ,  $p = .922$ . Examining the child's placement at school also did not differentiate parent satisfaction with their child's education team,  $F(6,84) = .809$ ,  $p = .566$ , or the classroom environment,  $F(7,83) = 1.070$ ,  $p = .390$ . The household income was also not a significant variable differentiating parent satisfaction with their child's education team,  $F(4,84) = .350$ ,  $p = .843$ , or the classroom environment,  $F(4,84) = 2.061$ ,  $p = .093$ .

The rater's employment status was a significant variable that differentiated parent satisfaction with the education team,  $F(1,89) = 7.252$ ,  $p = .008$ , and the classroom environment,  $F(1,90) = 4.857$ ,  $p = .030$ . Raters who were employed were more likely to be satisfied with their child's education team ( $M = 54.71$ ,  $SD = 11.41$ ) and their child's

classroom environment ( $M = 65.22, SD = 16.65$ ) than those who were not employed ( $M = 47.17, SD = 13.62; M = 56.94, SD = 16.99$ ).

***Correlates with Parent Stress.*** Correlational analysis revealed a moderate, significant relationship between parent-rated severity on the demographic questionnaire and autism symptom severity measured by the *SCQ* was moderately significant, Pearson's  $r = .374, p < .001$ . Parent stress was negatively correlated with the age of the child (Pearson's  $r = -.274, p = .007$ ) and the age of the child's diagnosis (Pearson's  $r = -.225, p = .028$ ). This suggests that as children's age increases parents level of stress decreases. Also as the age in which children are diagnosed with autism spectrum disorders increases the stress of parent decreases.

There was a small to moderate correlation between parent stress as measured by the *FSCQ-A* and autism symptom severity as measured by the *SCQ*, Pearson's  $r = .238, p = .021$ . A linear regression was conducted finding that autism symptom severity and the age of the child accounted for 14.2% of the variance in stress scores,  $F(2,91) = 7.53, p = .001$ .

## CHAPTER FOUR: DISCUSSION

Research suggests that there is controversy regarding the appropriateness of educational techniques used with individuals with ASDs (Hess et al. 2008; Simpson et al., 2007; Stahmer et al., 2005). In this study, the sample of parents had high levels of access to services both in school and outside of school. One way to examine the education of individuals with an ASD is by looking at parent satisfaction with the education of their child with autism, as this study aimed to do.

The Office of Special Education Program's (OSEP) examination of parent satisfaction with education showed that parents of children with autism have high levels of parent dissatisfaction when compared to parents of children with other special needs (Blackorby et al., 2004; Newman et al., 2011). Parents of children with autism were less satisfied in areas of their child's education including: overall satisfaction, services, schools, teachers, and communication with the school. This gives evidence that parents of children with an ASD are less satisfied with their child's education when compared to parents of children with other disabilities. Based on previous research, parents of children with ASDs appear to not be satisfied with their child with autism's education; however, it is not clear what predicts parent satisfaction. Some research suggests that it is the availability of appropriate services and the degree of parent involvement (Kohler, 1999; Parsons, et al., 2009; Renty & Roeyers, 2005; Renty & Roeyers, 2006; Whitaker, 2007). Predictors of parent satisfaction with their child with autism's education need to be better explored in research.

Renty and Roeyers (2005) looked at specific predictors of overall satisfaction, and found that parents of children with ASD who were most satisfied were involved in their child's education and had knowledge of available services for their child. Renty and Roeyers (2006) found that higher satisfaction ratings by parents of individuals with autism were related to a younger age of diagnosis, parental involvement in school, and more information following the diagnosis. Parents of children with ASD that did not have a comorbid intellectual disability had the most difficult time finding appropriate services to meet their child's needs. In another study, parents with children in mainstream settings were more likely to be dissatisfied with their child's education than parents whose children were in special schools (Whitaker, 2007).

In the current study, the parent satisfaction with the classroom environment had wide range of scores, showing that there was variability in the parent satisfaction scores. The current study; however, did not support a relationship between autism symptom severity and parent satisfaction with education. It is possible that no relationship exists because the scores on autism severity were particularly low. The severity scores may be low because individuals who are willing to bring their child on the autism spectrum to a sleep-away summer camp have lower levels of ASD severity. Parents who have children with more severe presentations of autism might feel uncomfortable letting their child stay away from home for a week. The low levels of symptom severity could be because the parents who filled out the questionnaires obtained successful interventions for their child with autism. By obtaining these high levels of interventions they could have lessened their child's symptoms of ASD. Lastly, and most likely, parents who bring their children to camp may have more access to available resources. By having better access to



resources, their children on the autism spectrum may have lower levels of symptom presentation when compared to children who do not have access to these resources. If parents know about the state-wide autism camp, and are able to spend the time getting their child enrolled for the camp and transported to the camp, it is likely that these same parents are able to advocate for and obtain resources for their children.

There is considerable research suggesting that parents of children with ASDs are likely to have high levels of stress (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005) and poorer psychological well-being (Abbeduto et al., 2004; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). Higher levels of stress have been found in parents of children with an ASD when compared to parents of typically developing children (Baker-Ericzen et al., 2005; Rao & Beidel, 2009). There is also evidence that parents of children with an ASD have higher levels of stress than parents of children with other disabilities (Hastings et al., 2005).

The sample of parents in this study had low levels of stress of the *Family Stress and Coping Questionnaire – Autism*. Low levels of stress in this sample may be because of the sample demographics. This sample of parents had high socio-economic status, high levels of education, and high levels of services for their child both within and outside of school. For these reasons, this study has lower levels of stress than other parents of children with autism spectrum disorders.

Evidence indicates that parent stress is strongly and positively related to the child's autism severity (Konstantareas & Papageorgiou, 2006; Lyons et al., 2010; Moh & Magiati 2012). This relationship indicates that as the level of autism severity increases, the level of stress also increases. There is debate about whether this is because of the

increased behavioral concerns in individuals with more severe autism presentation or the higher levels of autism symptoms. Some research suggests that when controlling for level of functioning, autism symptom severity still predicts stress (Konstantareas & Papageorgiou, 2006; Lyons et al., 2010). Other research has suggested that it is the behavior problems associated with higher severity of autism symptoms that actually predict parents stress (Hastings et al., 2005; Lecavelier et al., 2006). While it is not clear in the research whether it is truly autism symptom severity or the severity of behavioral problems that predicts it is clear that parents of children with autism have high levels of stress compared to parents of typically developing children (Baker-Ericzen et al., 2005; Rao & Beidel, 2009) and parents of children with other disabilities (Hastings, 2005). Therefore, it would be expected that at a camp serving children on the autism spectrum that parents would report high levels of stress that is predicted by autism symptom severity.

The current study supported this relationship between autism symptom severity and stress with a small to moderate positive correlation between these two variables. As child autism severity increased, parent stress increased. In this study, parent stress was negatively correlated with the age of the child and the age of the child's diagnosis. This suggests that as children's age increases parents level of stress decreases. Also as the age in which children are diagnosed with autism spectrum disorders increases the stress of parent may decrease.

In a study examining the diagnostic process, lower levels of stress were associated with lower severity of the child's ASD symptoms as well as higher parental satisfaction in a study from Singapore (Moh & Magiati 2012). This study provided evidence that

parents of children with more severe autism symptoms might not only be more stressed, but also have lower levels of satisfaction with their child's experiences.

Because of difficulties associated with autism symptom severity, which lead to higher levels of stress, it was predicted that high levels of parent stress and high levels of autism symptom severity would lead to lower levels of parents satisfaction with their child with autism's education. The purpose of this study was to examine the relationship between autism symptom severity, parent stress, and parent satisfaction with their child with autism's education. The results of this study did not support this hypothesis: autism symptom severity and parent stress were not significant predictors of parent satisfaction with their child's education team and parent satisfaction with their child's classroom environment. It is possible that the sample that was chosen did not have enough variability in stress and autism symptom severity scores, which is why significant results were not found.

Correlations suggest that parents who are employed may have higher levels of satisfaction with their child's education team and classroom environment. This might be because employed parents have more knowledge about the education system, and are better able to help their children receive the services that they needed. It is also possible that employed parents have better resources and therefore live in areas in which the schools have more resources. It should be noted that on the questionnaire the only options were employed and not employed. There was no differentiation between being unemployed or not employed by choice.

### **Limitations and Implications for Future Research**

There are several limitations that should be noted in this study. The measure of stress may not have been sensitive enough to adequately represent the variability of stress and severity in the sample. It is possible that the parents who were the most stressed may not have filled out and returned the questionnaire. This would have limited the variability of stress in the responders.

Similarly, it is possible that the measure of symptom severity was not sensitive enough to adequately measure the variability of ASD severity in the sample. The tool that was used to measure symptom severity is designed for use in screening for the presence of autism in an individual. Since it uses a yes/no question format it might not have picked up on the differences in the severity of symptoms for individuals with autism. Autism symptom severity is a difficult construct to define because of the many different aspects of autism spectrum disorders that might be elevated for some individuals but not for others with autism. Behavior problems that are often associated with autism sometimes might be more responsible for parent's satisfaction with their child's education. In the future it would be useful to develop measures that measure autism symptom severity separate from behavior problems, and to consider parent stress while looking at these two variables.

The camp that was used to collect data was a convenience sample that was limited to North Carolina residents. It is possible that individuals who have access to this camp may be more likely to advocate for their child's needs, and therefore be more satisfied with their child's education. Although the camp attempts to serve individuals all over North Carolina, the majority of campers come from the central part of the state where

there are a lot of universities and possibly more services. Over 85% of the sample for this study had an Associate's degree or higher, with a large percentage who completed advanced degrees. Therefore, participants in this study had many protective factors including: higher levels of education, high levels of SES, high levels of support (married/living with a partner), and access to services, which protect them from many psychological stressors. These factors also make advocating for their children at school and accessing appropriate services at school easier. Future research considering parent satisfaction with their child with autism's education should consider families with broader SES since poverty is a general risk factor for stress.

The parent satisfaction measure might not be sensitive enough to identify parents who are the least satisfied with their child's education. An updated tool to measure parent satisfaction with their child's education specific to the autism population is needed. Because teaching individuals with ASDs requires such specific training, it is important to have parent satisfaction measures that reflect the best practices for teaching students with ASDs. Another area of research could be to consider parent employment status and its relationship to parent satisfaction with their child with autism's education.

## **Conclusion**

With the number of children with ASD being served in schools continuing to increase, it is important to know how to best serve these children and their families within the school setting. Due to the mixed results in the literature regarding parents of children with an ASD's satisfaction with their child's schooling it is important to continue to consider variables that help parents of children with ASDs successfully navigate the public schools. This study measured the variables of autism symptom severity (measured

by *SCQ*) and parent stress (measured by *FSCQ-A*) and their relationship to parent satisfaction with their child's education team and classroom environment (measured by *PEPPS-ASD*). Although there were no significant predictors of parent satisfaction identified in this study, autism symptom severity and age were predictors of parent stress. It also suggested other variables that could be considered when examining parent satisfaction with their child's education, including parent employment and socio-economic status. By considering different aspects of a child with an ASD's education it will help to improve the education of one of the quickest growing disability groups. It may be especially important to work with parents of young children with severe autism symptoms who have lower levels of education and SES. This population has a high risk of psychological stressors and often lower levels of access to services and lower levels of support. Because participants in this study had overall low levels of stress, it supports the importance of having these protective factors.

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## APPENDICES

**Appendix A: Demographic Questionnaire**

1. What year were you born?

19 \_\_\_\_ \_\_\_\_

2. What is your gender?

Male

Female

3. Which racial group best describes you?

American Indian or Alaskan Native – Specify \_\_\_\_\_

Asian – Specify \_\_\_\_\_ (e.g., Chinese, Korean, Indian)

Black or African American

Hispanic or Latino/a – Specify \_\_\_\_\_ (e.g. Mexican, Cuban)

Native Hawaiian or Pacific Islander

White or Caucasian

Other – Specify \_\_\_\_\_

More than one race – Specify \_\_\_\_\_

4. What is the highest grade in school that you completed?

Some high school

Completed high school or GED

Vocational, technical, trade, or business school beyond the high school level

Some college, but no degree

Associate degree

Bachelor's degree

Some graduate school

Master's degree

Doctorate degree

5. Are you currently employed?

Yes

No

6. In which county in NC do you live? : \_\_\_\_\_

7. What is your marital status?

Married or living with partner

Single- never married

Divorced- not remarried



Widowed- not remarried

The following questions are about your child with an autism spectrum disorder. If more than one of your children has an autism spectrum disorder, please answer these questions for the child whose name comes first alphabetically.

**8. What is your relationship to your child?**

- Biological mother
- Biological father
- Adoptive mother
- Adoptive father
- Legal guardian—Specify \_\_\_\_\_

**9. What is your child's date of birth? :** \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
 Month / Day / Year

**11. What is your child's gender?**

- Male
- Female

**12. Does your child live with you \_\_\_\_\_?**

- Full time
- Part time
- None of the time

**13. Which racial group best describes your child? Please circle all that apply.**

- American Indian or Alaskan Native – Specify \_\_\_\_\_
- Asian – Specify \_\_\_\_\_ (e.g., Chinese, Korean, Indian)
- Black or African American
- Hispanic or Latino/a – Specify \_\_\_\_\_ (e.g. Mexican, Cuban)
- Native Hawaiian or Pacific Islander
- White or Caucasian
- Other – Specify \_\_\_\_\_
- More than one race – Specify \_\_\_\_\_

**14. What diagnosis has your child received?**

- Autistic Disorder
- Asperger Syndrome or Asperger's Disorder
- Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

**15. Who diagnosed your child?**

- Physician/ Medical doctor
- Psychologist

- Educational professional- Specify\_\_\_\_\_
- Other- Specify\_\_\_\_\_

**16.** How old was your child when he or she received a diagnosis: \_\_\_\_\_

**17.** Does your child have any comorbid diagnoses?

Yes: Please list any comorbid diagnoses

\_\_\_\_\_

No

**18.** What school does your child currently attend? \_\_\_\_\_

**19.** What is your child's placement in school?

- Public school- regular education classroom (mainstreamed)
- Public school- special education classroom
- Public school- a mixture of regular and special education classes
- Private school- regular education classroom
- Private school- special education classroom
- Private school- a mixture of regular and special education classes
- Home school
- Other- Specify\_\_\_\_\_

**20.** What grade is your child currently in? : \_\_\_\_\_

**21.** What interventions has your child received in the past year or your child is currently receiving? Please indicate all that apply?

- Applied Behavior Analysis (ABA) therapy
  - Speech therapy
  - Occupational therapy
  - Physical therapy
  - Social skills intervention
  - Other- please list any not mentioned above
- \_\_\_\_\_

**22.** What is your annual household income:

- Less than \$35,000
- \$35,000-\$49,999
- \$50,000-\$74,999
- \$75,000 or above
- Prefer not to respond

**23.** Do you receive additional financial coverage or funding for your child's needs and services? Please select

all that apply:

Private health insurance

Medicaid only

Medicaid Waiver

Other- Specify \_\_\_\_\_

**Appendix B: Social Communication Questionnaire (SCQ) Sample Items**

1. Is he/she now able to talk using short phrases or sentences?

YES

NO

2. Do you have a to and fro “conversation” with her/him that involves taking turns or building on what you have said?

YES

NO

3. Does she/he ever use odd phrases or say the same thing over and over in almost exactly the same way (either phrases that she/he hears other people use or ones that she/he makes up?)

YES

NO

## Appendix C: Family Stress and Coping Questionnaire (FSCQ-A)

### **Part II: Stress & Coping**

*Please read each statement and rate the level of stress you experience or have experienced in the past in relation to caring for a son/daughter with an Autistic Spectrum Disorder (ASD) by circling the appropriate response.*

**1. The diagnosis of your son/daughter as having ASD.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**2. The possible causes of your son/daughter's disability.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**3. Explaining your son/daughter's disability to family.**

*If not applicable please tick box*

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**4. Explaining your son/daughter's disability to friends.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**5. Explaining your son/daughter's disability to people in the community.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**6. Interacting with family members.**

*If not applicable please tick box*

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**7. Interacting with friends.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**8. Interacting with people in the community.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**9. Dealing with doctors or other health professionals regarding your son/daughter.**

*If not applicable please tick box*

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**10. Dealing with your son/daughter's therapy providers.***If not applicable please tick box* 

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**11. Dealing with your son/daughter's teachers.***If not applicable please tick box* 

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**12. Dealing with the education system.***If not applicable please tick box* 

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**13. Creating and/or finding opportunities for your son/daughter to make friends and participate in activities.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**14. Deciding the best level of integration for your son/daughter.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**15. Meeting the needs of your other children.***If not applicable please tick box* 

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**16. Meeting your own personal needs.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**17. Meeting the needs of your spouse.***If not applicable please tick box* 

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**18. Maintaining satisfying personal friendships.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**19. Dealing with your son/daughter's sexuality.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**20. Thinking about present/future work placements or employment for your son/daughter.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**21. Thinking about present/future long-term accommodation for your son/daughter.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**22. Planning wills, trusts and/or guardianships for your son/daughter.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**23. Planning emotional and social support for your son/daughter.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**24. Planning assistance with care. *If not applicable please tick box***

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**25. Attaining respite care. *If not applicable please tick box***

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

**26. Dealing with finance issues.**

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

***Please list the top 3 issues that cause you the most stress when caring for your son/daughter at present:***

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

**Appendix D: The Parent Education Perception and Satisfaction Survey: Autism Spectrum Disorders (PEPSS-ASD)**

For the following statements, please circle the best answer from the following:

- Strongly Agree ..... SA
- Mostly Agree ..... MA
- Mostly Disagree ..... MD
- Strongly Disagree ..... SD
- Unable to Comment.... U

**Please base your answers on the class placement your child has just finished.**

**My Child's Classroom**

1. The classroom layout made it easy for my child to locate areas for working and free time activities

SA                      MA                      MD                      SD                      U

2. Visual aids (e.g., pictures, written words) were used to supplement classroom instructions.

SA                      MA                      MD                      SD                      U

- 3. I feel that the use of visual aids is important for my child.**

**SA                      MA                      MD                      SD                      U**

4. My child's daily classroom routine was predictable.

SA                      MA                      MD                      SD                      U

- 5. I feel that a predictable routine is important for my child**

**SA                      MA                      MD                      SD                      U**

6. My child's classroom was a calm environment.



SA MA MD SD U

7. A class schedule was clearly visible in the classroom.

SA MA MD SD U

**8. I feel that having a visible timetable in the classroom is important for my child.**

**SA MA MD SD U**

9. My child was provided with an individual visual schedule (e.g., either in pictures or in words depending on my child's needs).

SA MA MD SD U

**10. I feel that my child needs an individual visual schedule.**

**SA MA MD SD U**

11. My child's work area was cluttered.

SA MA MD SD U

12. My child was adequately prepared for changes in classroom routines.

SA MA MD SD U

**13. I feel that my child needs to be prepared for changes in classroom routines.**

**SA MA MD SD U**

14. I am confident that my child understood what was required of him/her in the classroom.

SA MA MD SD U

15. My child learned appropriate life skills at school appropriate to his/her level this past year.

SA MA MD SD U

16. My child did not progress as well as s/he could have because of the classroom environment.

SA MA MD SD U

17. My child spent too much time in “time-out” or outside of the learning environment.

SA MA MD SD U

18. My child’s teacher regularly documented my child’s performance in writing in addition to report cards.

SA MA MD SD U

**19. I do not feel that documentation in addition to report cards is important.**

**SA MA MD SD U**

20. My child’s aide/assistant assumed primary responsibility for organizing and running my child’s program rather than the teacher.

SA MA MD SD U

21. My child’s teacher assumed primary responsibility for organizing and running my child’s program rather than the assistant.

SA MA MD SD U

22. My child’s aide/assistant was more knowledgeable about my child’s needs than the teacher.

SA MA MD SD U

23. My child’s teacher actively set up opportunities for peer interactions.

SA MA MD SD U

**24. I felt that my child's teacher needed to actively set up opportunities for peer interactions for my child.**

SA MA MD SD U

25. My child's teacher structured free time and recess for my child.

SA MA MD SD U

26. My child's teacher used positive methods when teaching (e.g., praise, rewards).

SA MA MD SD U

27. When my child displayed challenging behavior the **teacher** was usually able to determine its cause.

SA MA MD SD U

28. My child was included in most classroom activities.

SA MA MD SD U

29. I felt welcome to observe my child in the classroom.

SA MA MD SD U

**30. I feel that being able to observe my child in the classroom is helpful.**

SA MA MD SD U

31. Has your child ever been suspended from school because of his/her behavior?

Yes

No

32. Was your child suspended from school this past year because of his/her behavior?

Yes

No

32a. If you answered “yes” for either 31 or 32 please provide details of the situation and how it was resolved.

### **My Child’s Education Team**

Now I would like to ask about your perceptions and feelings about your child’s education team. An education team is a group (e.g., parent, teacher, assistant, psychologist, occupational therapist) that meets regularly to discuss a child’s progress or problems at school or address any questions that any of these members may have.

33. Did your child have an education team that assisted in making decisions regarding your child’s education this past year?

1. NO → 33a. (If no) Please explain why.

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2. YES → 33b. (If yes) Please indicate, by circling the letter of all that apply, who made up your child’s team.

- a. PARENT
- b. TEACHER
- c. TEACHER ASSISTANT
- d. PRINCIPAL
- e. ASSISTANT PRINCIPAL
- f. PSYCHOLOGIST
- g. SPEECH PATHOLOGIST
- h. OCCUPATIONAL THERAPIST
- i. SPECIAL EDUCATION CONSULTANT
- j. OTHER (please specify) \_\_\_\_\_

3. Team meetings were regularly scheduled throughout the school year.

SA                      MA                      MD                      SD                      U

**4. I believe that my child needs a good education team.**

- |   | SA | MA | MD | SD | U |
|---|----|----|----|----|---|
| 5. I thought that my child's education team was effective this past year.                 |    |    |    |    |   |
|   | SA | MA | MD | SD | U |
| 6. My child's education team did not meet as frequently as I would have liked.            |    |    |    |    |   |
|   | SA | MA | MD | SD | U |
| 7. I felt the team understood my child's needs.   |    |    |    |    |   |
|   | SA | MA | MD | SD | U |
| 8. I felt uncomfortable when talking with team members.                                   |    |    |    |    |   |
|   | SA | MA | MD | SD | U |
| 9. School personnel made me feel responsible for my child's difficult behavior.           |    |    |    |    |   |
|   | SA | MA | MD | SD | U |
| 10. I am confident that the team did what is best for my child.                           |    |    |    |    |   |
|   | SA | MA | MD | SD | U |
| 11. I often found it difficult to understand the words used by school personnel.          |    |    |    |    |   |
|   | SA | MA | MD | SD | U |
| 12. I felt school personnel did not listen to my comments, suggestions and concerns.      |    |    |    |    |   |
|   | SA | MA | MD | SD | U |
| 13. School personnel relied on me as the "autism expert."                                 |    |    |    |    |   |
|   | SA | MA | MD | SD | U |
| <b>14. I believe that school personnel should rely on parents to be "autism experts."</b> |    |    |    |    |   |

**SA MA MD SD U**

15. I felt that the school personnel that worked with my child this past year were knowledgeable about autism.

SA MA MD SD U

16. I felt that school personnel were willing to learn about autism.

SA MA MD SD U

17. School personnel communicated what my child did **well** in addition to problems that arose.

SA MA MD SD U

18. I met informally with my child's teacher on a frequent (e.g., daily, weekly) basis.

SA MA MD SD U

19. I met with school personnel only when there was a problem.

SA MA MD SD U

20. The primary communication between the teacher and myself was through a daily communication book.

SA MA MD SD U

**21. I do not feel that the use of a daily communication book is necessary for my child.**

**SA MA MD SD U**

22. I felt I was viewed more as an opponent than a partner in my child's education.

SA MA MD SD U

23. My child has a **written** Individual Education Plan (IEP).

SA            MA            MD            SD            U

**24. I feel that a written Individual Education Plan is important for my child.**

**SA            MA            MD            SD            U**

## **Appendix E: Informed Consent Form**

### **The Impact of Child Symptom Severity and Stress on School Satisfaction among Parents of Children with Autism Spectrum Disorders**

#### **What is the purpose of this research?**

The purpose of this research project is to examine parent's perceptions of their child with autism's education in North Carolina. This study will examine how characteristics like parent stress and autism symptom severity contribute to parent's satisfaction with their child's education.

#### **What will be expected of me?**

As a participant in this study you will be expected to complete a questionnaire including demographic information, a measure of stress, a rating scale measuring ASD symptom severity, and a measure of parent satisfaction with their child's education.

#### **How long with the research take?**

The questionnaire will take between 30 and 40 minutes to complete.

#### **How will you use my information?**

Responses on this survey will remain anonymous. After consenting to partake in the research, participants will be given a questionnaire with an identification number listed on it. The names collected on this consent form will not be connected with respondents' questionnaires. When participants turn in their completed questionnaire they will place it in a box at the exit, so that researchers will not connect questionnaires with individual participants. The data will be summarized for the whole group, so individual data will not be considered.

#### **Can I withdraw from the study if I decide to?**

Participation in this study is voluntary. Even if you decide to participate in the study you can stop at any time during the survey. If you choose to do so, you have the right to refuse the use of your data in the study. If you withdraw from the study or do not participate there will be no negative consequences.

#### **Is there any harm that I might experience from taking part in the study?**

There are no foreseeable risks to participating in this study.

#### **How will I benefit from taking part in the research?**

The only benefits to participation in this research will be an ability to express your satisfaction or dissatisfaction with your child with ASD's educational experiences. By gaining understanding of parents of children with ASD and their experiences with schools this research could help to add knowledge to areas in which schools can improve in serving children with an ASD.

#### **Who should I contact if I have questions or concerns about the research?**



Contact me Erica Nesbit at 919-619-4903 (elnesbit@email.wcu.edu). You can also contact Dr. Boan-Lenzo, faculty director of the project, at 828-227-3369 (or cboan@email.wcu.edu). If you have concerns about your treatment as a participant in this study, contact the chair of WCU's Institutional Review Board through the office of Research Administration at WCU (828-227-7212).

I understand what is expected of me if I participate in this study. My signature shows that I agree to participate and am at least 18 years old.

Participant Name \_\_\_\_\_

Date \_\_\_\_\_

Participant Signature \_\_\_\_\_

Researcher Signature \_\_\_\_\_