# EDUCATIONAL PLACEMENT AND SERVICE PREFERENCES OF PARENTS OF STUDENTS WITH AUTISM SPECTRUM DISORDERS

# DISSERTATION

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by

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## EDUCATIONAL PLACEMENT AND SERVICE PREFERENCES OF PARENTS OF

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#### Abstract

# EDUCATIONAL PLACEMENT AND SERVICE PREFERENCES OF PARENTS OF STUDENTS WITH AUTISM SPECTRUM DISORDERS

The purpose of this descriptive study was to investigate the type of educational placement and services preferred by parents of students with Autism Spectrum Disorders (ASD). Participants (N= 187) included 122 parents of children with Autism, 30 parents of students with Asperger Syndrome and 35 parents of students with Pervasive Developmental Disorders-Not Otherwise Specified (PDD-NOS). Respondents, who represented different regions of the country, completed an online survey including questions pertaining to educational placement and services as well as satisfaction with their child's education. The majority preferred the full-time general education classroom; however, a significantly higher proportion of parents whose offspring were already in a full-time general education classroom preferred this type of placement. Parents desired their children to receive more special education services than they were actually receiving, particularly language therapy, social skills training, assistive technology, sensory integration, and transitional services. No significant differences were found among parents of children with Autism, Asperger Syndrome, and PDD-NOS on their total satisfaction with the education of their child and with transitional services. Parents did not differ on their satisfaction with transitional services based on their education; however, parents with a doctoral or professional degree were significantly more satisfied about their child's education, placement, and services than parents with a bachelor's degree. Satisfaction with the child's education was negatively correlated with the age of the child, suggesting that as the child becomes older, parents become more disenchanted with the services and education received. Parents of students with ASD who lived in the

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Northeast were significantly more satisfied with their child's education, placement, and services than parents who lived in the Southeast.

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Dedication

This research study is dedicated to all the parents of children with ASD.

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#### **CHAPTER I**

# THE PROBLEM

#### **Autism Spectrum Disorders**

In recent years, researchers and educators in the field of special education and related areas have been inundated with new information about Autism Spectrum Disorders (ASD). The continuous need of parents, educators, researchers, and society in general to comprehend in-depth and acquire more knowledge concerning children with ASD reflects the rapidly increasing rates of this relatively new diagnosis. In the last two decades, the number of children with ASD has increased at a faster rate than the number of children in other disability categories (Allen, Decker, & Robins, 2008). According to the Center for Disease Control (CDC) and Prevention (2012), the rate of children with ASD has increased from 1 in 150 children in 2008 to 1 in 88 in 2012.

According to the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV) (American Psychiatric Association, 2000), ASD include Autism, Asperger syndrome, Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS), Rett Syndrome, and Childhood Disintegrative Disorder. Children with ASD constitute a heterogeneous group, whose intellectual, social, and behavioral abilities may fall within a very wide range (very high functioning to very low functioning). Children with ASD exhibit difficulties in the domains of social interaction, communication, and play and imagination; they may also exhibit a limited variety of behaviors or interests (Klin, McPartland, & Volkmar, 2005).

Autism, which is one of the conditions under the umbrella of ASD, is categorized by insufficiencies in three domains: social relatedness, communication or language, and

atypical behaviors or patterns (Allen et al., 2008). At the mild end of ASD is Asperger syndrome. Asperger syndrome is characterized by impairments in the social area; however, children with Asperger syndrome do not have general language delays and most have average to above average intelligence (Heward, 2009). Present-day diagnostic practices identify people with Asperger as meeting similar conditions as those with highfunctioning autism (Baron-Cohen et al., 2005). Children who display difficulties in social relatedness and one of the other two previously mentioned domains (communication and atypical behavior or patterns), but do not meet the qualifications for other ASD diagnoses, would meet the criteria for Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). Children with Rett syndrome (mostly girls) and Childhood Disintegrative Disorder may exhibit difficulties in several of the ASD domains, but also may demonstrate intellectual disabilities and a deficiency in functional skills (Allen et al., 2008).

ASD is a fairly new concept in the field of special education. Our understanding of the condition and its definition have changed drastically just within the past four decades (Magnusson & Saemundsen, 2001). Well into the 1970's, autism was referred to as a psychosis, and was often associated with childhood schizophrenia; however, this idea is not in vogue at the present time (Rutter, 2000). Today, there still remains an incredible amount of misinformation regarding ASD, amongst educators, researchers, and parents of children with ASD (Rapin, 2005).

As the DSM-IV explains, one of the characteristics of ASD is early onset, by the age of three. The heterogeneity of features in ASD may partially explain why the symptoms are not easily recognized until two or more years after the first signs appear

(Filipek et al., 2000; Perry, 2004). In recent years, the term ASD has progressed to incorporate these heterogeneous symptoms, recognizing the individuality of people with ASD (Tincani, Travers, & Boutot, 2009).

One concept utilized today in the study of children with ASD, is *neurodiversity*. The term neurodiversity has developed to counter the notion that people with ASD are essentially flawed (Fenton & Krahn, 2007). The movement towards neurodiversity challenges the medical approach of defining ASD as pathology and questions social institutions that may categorize people with ASD according to a hierarchy of 'neurotypical persons' (Tincani et al., 2009). Neurodiversity encourages understanding the strengths and the predilections of people with ASD, which allows them to navigate the environment around them (Tincani et al., 2009). Similar to neurodiversity, strength-based assessment (SBA) is an additional development in the study and understanding of people with ASD. SBA is a substitute for the deficit-based understanding of ASD, and supports the neurodiversity viewpoint (Cosden, Koegel, Koegel, Greenwell, & Klein, 2006). SBA pursues to highlight the positive attributes of individuals with ASD and integrate those attributes into probable support strategies utilized in the education of students with ASD (Tincani et al., 2009).

### **Placement and Services**

Due to the rapid increase in the number of children diagnosed with ASD and the 1990 reauthorization of Individuals with Disabilities Act (IDEA), that was enacted to meet the educational needs of students with disabilities, children with ASD have been incrementally enrolling in our public and private schools for the past few decades. The educational placement and services provided to students with ASD may vary based upon

the individual needs of the child. Academic, behavioral, and functional services can be provided to a student with ASD in the special education classroom setting or in the general education classroom, otherwise known as the inclusive setting. According to IDEA Regulations (34 C.F.R. § 300.550(b)(2)), students in special education can only be removed to separate classes or schools when the nature or severity of their disabilities is such that they cannot receive an appropriate education in a general education classroom with supplementary aids and services. These direct services include, but are not limited to: speech/language therapy, behavioral support services, academic support services, communication services, employment support services, and post/school adult living services (Dymond, Gilson, & Myran, 2007). Because the number of students with ASD educated in the inclusive classroom has increased within the last decades (Humphrey, 2008), today nearly all services for these students are provided within the general education classroom (Heward, 2009). Related services such as occupational therapy, physical therapy, applied behavioral analysis, assistive technology, and counseling can also be provided in the general education setting or in the special education classroom (Dymond et al., 2007).

Some studies have investigated the impact that different educational placements and services can have on students with ASD (Humphrey, 2008; Jones & Frederickson, 2010). Due to the increase in the placement of students with disabilities in the general education classroom setting, researchers have specifically examined the effects of inclusion on students with ASD (Humphrey, 2008). Eldar, Talmor, and Wolf-Zukerman (2010) studied the successes and difficulties of students with ASD who were fully included in the general education classroom. They found that those students

demonstrated higher levels of social collaboration, obtained more social support, had an assortment of social networking, and had more progressive personal educational goals than students with ASD placed in special education classrooms (self-contained classrooms).

However, Eldar et al. (2010) reported that students with ASD experienced difficulties in the areas of behavior, social, cognitive, and speech/communication in the general education classroom. Comparable findings were found in a study involving the social inclusion of students with ASD attending mainstream schools. Jones and Frederickson (2010) discovered that students with ASD attending mainstream schools were considerably less accepted by their peers and had substantially higher social rejection than the comparison group of students without ASD. In addition, students with ASD in those schools demonstrated lower levels of appropriate social behaviors and higher levels of emotional difficulties. These negative encounters experienced by students with ASD cannot only be discouraging for the child, but also disheartening for the parents of students with ASD (Eldar et al., 2010). It is essential that school districts and parents work together and collaborate to promote positive experiences for students with ASD. Eldar et al. (2010) suggest that teachers and parents should be aware of the social benefits of inclusion. They also emphasize the need for all staff members to be sufficiently prepared to educate students with ASD prior to their educational placement, as well as the need for and importance of the continuous cooperation among parents and staff.

For students with disabilities at the age of 14 or older, transitional services are provided according to the student's Individualized Educational Plan (IEP), which

prescribes the appropriate placement and services in order to prepare each student for life after high school. IDEA defines transitional services as a synchronized set of activities for a child with a disability that focuses on improving academic and functional achievement to enable a child's movement from school to post-school activities (i.e., post-secondary education, vocational education, integrated employment, adult education, adult services, independent living, or community participation). Transitional services are based on the individual needs of a child with a disability while taking into consideration the student's strengths, preferences, and interests. These services must include instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and if needed, procurement of daily living skills and functional vocational evaluation (P.L. 108-446, 20 USC 1401, Sec. 602[34]).

### **Parental Preferences**

How parents perceive the educational placement of their children in more inclusive or less inclusive settings and the service options provided is vital to the social and academic development of their children (Dymond et al., 2007). Negative preferences (e.g., dissatisfaction with the quality, quantity, accessibility, and availability of services and placement) may hinder the relationship between the school and the parent, which in turn could create adverse effects on students with ASD. Lynch and Irvine (2009) reported on a study conducted by Kasari, Freeman, Bauminger, and Alkin (1999), who examined the perspectives of parents of children with ASD about inclusion. In that study, parents stated that the communication between home and school was intermittent and often occurred due to a negative experience involving the student. Research indicates that children with ASD make easy targets for bullies and are often considered

by teachers as a challenge to educate (Humphrey, 2008). These difficulties that children with ASD face in an inclusive setting are felt by parents, possibly resulting in negative attitudes or perceptions about inclusion. Moreover, negative preferences or attitudes exhibited by parents have been shown to be correlated to students' performances (Xitao & Michael, 2001).

Positive preferences (e.g., satisfaction with school placement and educational programs for students with ASD) not only can help create an effective relationship between school and home, but may allow the development of an encouraging learning environment (Dymond et al., 2007). Studies have found that positive parental attitudes result in higher levels of academic success for a student with or without a disability across all cultures and societies (Kordi & Baharudin, 2010). McDonall, Cavenaugh, and Giesen (2012) reported results from the nationally representative Special Education Elementary Longitudinal Study, which indicated that positive parental attitudes and parent involvement at school correlated with higher mathematic achievement in students with disabilities.

Some studies have shown the general dissatisfaction of parents of children with ASD toward placement and services offered to their children, specifically older students with ASD in inclusive classroom settings (Kasari et al., 1999; Lynch & Irvine, 2009). As children with ASD grow older, parents may become less satisfied with the educational services because it may become more obvious that their children's needs are not being met appropriately (Kasari et al., 1999). This may be related to the limited or insufficient knowledge available about ASD, due to the relatively new development of this disability area. While some studies show a positive parental outlook about the quality of life for

adults with ASD (Billstedt, Gillberg, & Gillberg, 2011), other studies reveal a negative parental outlook regarding the quality of life for adults with ASD (Howlin, Goode, Hutton, & Rutter, 2004).

However, in general, studies about parental satisfaction in the area of adults with ASD are scarce, since this is a relatively new diagnosis. One way to increase the satisfaction of parents of future adults with ASD is to intervene early in their children's education to improve their outcomes in adulthood. Listening to parents' opinions at an early stage in their children's lives could help to prevent future dissatisfaction among parents of persons with ASD. According to IDEA, schools must collaborate with parents in the planning and implementation of placement and related services. Parents' contribution and wishes must be included in determining Individualized Education Plan (IEP) goals, related-services, and placement decisions (Heward, 2009).

Taking into account the parental preferences of older children with ASD and the growing concern over unsuccessful young adults with disabilities in the worksite and community living, Congress authorized funding for secondary education and transitional services for children with disabilities when IDEA was amended in 1990 (Heward, 2009; Yell, 2006). The law passed by Congress as well as parental concerns both helped to develop transition models to support students with disabilities in their adjustment to adult life. The 1990 and 1997 amendments to IDEA reflect these transition changes (Halpern, 1985; Will, 1986). According to Halpern (1985), the main transitional goal for students with disabilities is for them to live independently, to the fullest extent possible, in their own community.

The transitional goal proposed by researchers is similar to the transitional goals of parents of children with disabilities (Turnbull, Turnbull, Erwin, & Soodak, 2006). Rehfeldt, Clark, and Lee (2012) conducted a study comparing the satisfaction of two groups of parents (control and experimental) regarding the IEP or Individualized Transition Plan (ITP) process. Participants in the experimental group utilized the transition-planning inventory (TPI) along with a structured IEP meeting process. Parents in the experimental group had higher ratings of satisfaction toward the implementation of their child's transitional IEP than parents in the control group. The results offer further validation to the hypothesis that when parents participate during their child's transitional assessment, planning, and IEP meeting, parents are more likely to be satisfied with the overall outcomes, resulting in positive attitudes (Martin, Marshall, & Sale, 2004; Martin, et al. 2006; Rehfeldt, Clark, & Lee, 2012)

Many studies show that adults with ASD may not adapt so well to society (Sperry, 2005). Billstedt et al. (2011) found that adults with ASD were dependent on the support of their parents, while Camarena and Sarigiani (2009) emphasized postsecondary training for this population. Given the increase in the knowledge available about ASD in recent years, parents may be able to assume the role of effective advocates for their children, including giving their opinion about the most reasonable and appropriate placement and services for their children (Stoner et al., 2005). Dymond, Gilson, and Myran (2007) summarized the thoughts and beliefs of many parents of children with disabilities that one specific placement or service is not applicable to all children with ASD.

Parental advocacy has increased within the last few decades due to the increase in the diagnoses of children with ASD and the increase in parental knowledge pertaining to this condition (Dymond et al., 2007). Although some studies have found that parents of preschoolers with autism prefer inclusion (Bailey & Winton, 1987), others have shown that parents of older children with ASD are less approving of inclusion (Lovitt & Cushing, 1999). Again, this could be related to the fact that limited information and opportunities were available in previous years (Kasari et al., 1999). Parents of children with ASD request the best types of educational placement and services that can be provided to their children (Klin, McPartland, & Volkmar, 2005).

In the study conducted by Kasari et al. (1999), the parental preferences of children with autism were compared to the parental preferences of students with Down syndrome. The ages of both groups ranged from two to eighteen. Less than half of the parents of children with autism implied that inclusion was not an effective setting because their child required more specialized instruction, which could be provided through a continuum of services. Contrary to this finding, the authors indicated that over half of the parents of children with Down syndrome preferred inclusion because they felt their children benefitted socially within the inclusion setting.

As expected, parents of students with high functioning ASD prefer the inclusive classroom environment because it meets the needs of their children (Garrick-Duhaney & Salend, 2000; Kasari et al., 1999). The preferences of many parents of students with ASD are similar to the parental preferences concerning children with learning disabilities (LD) (Nugent, 2007). Although some parents of students with LD expressed their satisfaction with their child spending part of the day in a special education classroom and

the other part of the day in a general education classroom (Nugent, 2007; Hishinuma & Nishimura, 2000), other parents prefer to fully include their children with LD into the general education classroom (Bennett, Deluca, & Bruns, 1997; Salend & Garrick-Duhaney, 1999).

Parents are vocalizing that changes need to occur within the special education field. Parents of children with ASD expressed the need for quality services, for trained teachers to work with students with ASD, for increased funding, and for the creation of suitable placements and services (Dymond et al., 2007). However, when parents are confronted with decisions regarding the placement of their children in an inclusive or non-inclusive classroom, they may become anxious thinking that the future of their children with ASD may be too challenging (Marcus, Kunce, & Schopler, 2005).

The battle parents and their children face between full inclusion and part time inclusion is correlated with the Least Restrictive Environment (LRE) mandate of the special education law, the Individuals with Disabilities Education Act (IDEA), originally Public Law 94-142. According to the LRE principle, each state must guarantee that children with disabilities are educated with non-disabled peers to the maximum degree appropriate (Mandlawitz, 2005; IDEA Regulations, 34 C.F.R. § 300.550(b)(1)). Any removal of a child with disabilities from the general education environment should occur only if education in a general class cannot be achieved adequately due to the severity of the disability (Mandlawitz, 2005). The LRE principle ensures that students are taught in the environment that is appropriate for their needs; therefore, school districts are to ensure that there is a continuum of alternative placements such as general classes, resource rooms, special classes, special schools, homebound instruction and placement in

hospitals/institutions (Yell, 2006). This creates much controversy among parents and schools as to what is considered the most appropriate placement/services for an individual child with ASD (Mandlawitz, 1999). The law also requires providing appropriate services to all students with disabilities, including students with ASD.

#### **Theoretical Framework**

This study will be conducted using the theoretical framework derived from the *personal construct theory* or personal constructivism. Personal construct theory was developed by George Kelly in 1955. He proposed that people systematize their experiences by developing personal constructs (Raskin, 2002). Cunningham and Davis (1985) explored this theory and applied it to parents' cognitive interpretation of their children's disability. The personal constructs are used to predict and envisage how society and others might act, and how people make their own meaning based on the events that occur in their lives. A benefit of the personal construct theory is that it allows parents to be seen as individuals with their own viewpoints and preferences (Case, 2000). This approach permits school professionals to accept or at least understand the realism of parents' interpretations of their children's disability.

Similar to the scientific method, the ordinary individual within the personal constructivism framework behaves comparable to a scientist. An individual develops interpretations of his/her reality the same way scientists develop theories (Boeree, 2006). Individuals advance their understanding of reality contingent upon their experiences parallel to how scientists regulate theories to correlate with facts. Case (2000) analyzed several personal constructivism studies regarding parents of students with disabilities. Parents encounter different reactions to their children's disability because they bring

diverse interpretations to the situation (Cunningham & Davis, 1985). Particular experiences facilitate parents' interpretations and adjusting to a disability is contingent on the parents' situation at the time (Case, 2000).

Incorporating George Kelly's personal construct theory, this study will focus on parental personal constructs of their children with ASD. Their preferences of education placement and services could be related to their own interpretations of the disability, based on previous experiences of themselves and experiences involving their children.

#### Rationale

Research has shown that the parental preferences of students with ASD may vary according to the child's characteristics or where the child may benefit most among the different placement options, including inclusion and the continuum of services (Handleman, Harris, & Martins, 2005). Parents' variations may also be a function of the child's specific type of ASD, which include Autism, Asperger syndrome, Rett syndrome, Childhood Disintegrative Disorder, and PDD-NOS (Lynch & Irvine, 2009). Parents who prefer a self-contained special education classroom environment may do so because they believe their child's specific type of disability may not benefit from an inclusive setting (Palmer, Fuller, Arora, & Nelson, 2001). A parent's preference and perception of his/her child's education is an essential factor when determining the appropriate educational placement and services for a student with ASD.

Historically, parents have been an important force in influencing policy as it relates to the educational placement and services provided to students with disabilities (Mandlawitz, 2005; Stoner & Angell, 2006). Parents have brought attention to the legal issues related to the education of children with disabilities by questioning placement

decisions based upon a prescribed program, rather than the individual needs of a child (Blackmon v. Springfield R-XII School District, 1998; Portland Early Intervention/Early Childhood Special Education Program, 1999; Windsor C-1 School District, 1998).

Parents involved in cases such as these create a strong force that can indirectly affect the lives of students with ASD; thus, it is important to know what their opinions are regarding placement and services, particularly since ASD is a relatively new category in special education.

#### **Purpose of the Study**

Minimal research has been conducted that specifically focuses on the different ASD classifications and parental preferences regarding educational placement and services. The purpose of this study was to investigate the type of educational placement and services preferred by parents of students with ASD. Thus, the researcher assessed what parents think about the placement and services their children with ASD presently receive. Parents disclosed their preferences toward the educational placement of their child (i.e., full inclusion, pull-out/resource services, or full-time special education classrooms) in addition to the current placement of their child. Parents communicated their preferences and satisfaction concerning an array of special education and related services, and also indicated how well the school prepares their child for the future.

Throughout the past several decades, we know that many changes have occurred in the education of children with disabilities. Many of these changes have transpired over the years due to the persistent advocacy of parents (Stoner et al., 2005). An increasing number of research studies suggest that parental involvement not only influences the changes reflected in the laws, but it also has a positive influence on their children's

learning and accomplishments in school (Eccles & Harold, 1993; Koegel, Koegel, & Schreibman, 1991; Newmann & Wehlage, 1995). Changes in the lives of children with ASD will occur if their parents are involved in the educational process, including sharing their opinions and perspectives.

# **Research Questions**

The following research questions guided this study:

- 1. What are the educational placement preferences of parents of students with ASD?
- 2. What are the educational service preferences of parents of students with ASD?
- 3. How do parental preferences differ based on their children's specific ASD subtype (i.e., Autism, Asperger syndrome, Rett syndrome, Childhood Disintegrative Disorder, or PDD-NOS)?
- 4. What are parents' perceptions about the effectiveness of schools in preparing students with ASD for adulthood?

## **Definition of Terms**

*Asperger Syndrome*- Developmental disorder categorized by normal cognitive and language development with impairments in all social areas, repetitive and stereotyped behaviors, fixation with abnormal activities, arcane speech patterns, and motor ineptness (Attwood, 2006; Klin, McPartland, & Volkmar, 2005).

*Autism*- A pervasive developmental disorder characterized by three defining features with onset before age three; impairment of social interaction, impairment of communication, and restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (Autism Society of America, 2011; Heward, 2009).

*Autism Society of America (ASA)*- Organization that provides sources information regarding autism by increasing public awareness about autism and advocating for appropriate services for individuals with autism (Autism Society of America, 2011). *Autism Spectrum Disorder (ASD)*- Group of five developmental disorders that share similar core difficulties in social relationships, communication, and formulaic behaviors; differentiated from one another primarily by the age of onset and severity of various symptoms; includes autism, Asperger Syndrome, Rett Syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (Autism Research Institute, 2012; Heward, 2009).

*Centers for Disease Control and Prevention (CDC)*- Organization that provides information and tools people and communities need to protect their health using health promotion, prevention of disease, injury and disability, and preparedness for new heath threats (Centers for Disease Control and Prevention, 2012).

*Childhood Disintegrative Disorder*- Similar to autism behavioral characteristics, but does not begin until after age two and sometimes not until age ten; medical problems are common (Heward, 2009).

*Continuum of Services*- A variety of placement and instructional options for children with disabilities, placement include and not limited to general education classroom, special education classroom, special schools, residential facilities, and hospital or homebound placements (Handleman, Harris, & Martins, 2005).

*Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*- Used to diagnosed autism spectrum disorders, manual was published by the American Psychiatric Association and covers all mental health disorders for both children and adults (Klin, Sauliner, Tsatsanis, & Volkmar, 2005).

*IEP*- Individualized Education Plan; written document required by the Individuals with Disabilities Education Act (P.L. 94-142) for every child with a disability (Heward, 2009). *ITP*-Individualized Transition Plan; specifies desired post school outcomes for students 16 or older in the areas of employment, postsecondary education, residential, and recreation/leisure along with instructional programming and supports (Heward, 2009). *Inclusion*- Education of students with disabilities in general education classrooms (Handleman, Harris, & Martins, 2005).

*Least Restrictive Environment*- Mandated by the Individuals with Disabilities Education Act (IDEA), education setting that closely similar to a regular school program and also meets the child's special educational needs (Mandlawitz, 2005).

*Pervasive Developmental Disorder; Not Otherwise Specified (PDD-NOS)*- Children who meet some but not all of the criteria for autism are frequently diagnosed as having PDD-NOS (Volkmar & Klin, 2005; Wing, 2005).

*Rett Syndrome*- Neurodevelopmental disorder during childhood characterized by normal early development followed by loss of decisive use of the hands, typical hand movements, slowed brain and head growth, gait abnormalities, seizures, and intellectual disabilities; affects females almost exclusively (Heward, 2009; Volkmar & Klin, 2005; Wing, 2005).

*Transition*- An organized set of activities for a child with a disability designed to enable the child's advancement from school to post school activities including; postsecondary education, vocational education, employment, independent living, or community participation (Heward, 2009; Sperry, 2005; Sullivan, 2005).

#### **CHAPTER II**

# LITERATURE REVIEW

# **Historical Trends in ASD**

# **Clinical History**

There have been numerous efforts to precisely define Autism Spectrum Disorders (ASD) and/or related conditions (Wing, 2005). As early as the 1800's, documented records revealed persons with behaviors similar to the characteristics of individuals with ASD (Frith, 1989; Houston & Frith, 2000; Lane, 1977; Wing, 1997). Henry Maudsley (1867) was one of the first to create a classification system for people with comparable characteristics to ASD. Maudsley categorized children with strange and/or distraught behavior into groups under the label "insane." Researchers suggest there are indications within Maudsley's theory that some of the children he studied had ASD, especially those in his subcategory identified as "instinctive insanity" (Wing, 2005).

In the early 1900's to the 1950's, many authors struggled to define disorders among children referred to as having psychoses (Wing, 2005). Even within this era, researchers were trying to discover the reasons that children lost their language, social skills, and other skills after normal development, within the first four years (De Santics, 1908; Hulse, 1954). These realizations and observations eventually led to more studies in the area of autism and related disabilities.

Kanner (1943) created the label 'early infantile autism' from clear depictions of children with abnormal patterns of behavior. Kanner noticed through his observations that these children exhibited behaviors such as: social remoteness and indifference to other people, wordlessness and echolalia (repetitive speech), anxiety toward change, obsession with particular objects, and at times high cognitive capabilities (Wing, 2005). Similarly, Hans Asperger (1944) observed children with comparable behavior patterns and developed the term 'autistic psychopathy', which was often interchanged with 'childhood schizophrenia' by other authors (Bender, 1947; Despert, 1938). Asperger reported observing particular traits among children, such as: inappropriate social interactions, a narrow span of interests, inadequate expressive language, insignificant motor coordination, and a lack of common sense; he revealed that the children documented coincided with the descriptions of children with high-functioning autism (Asperger, 1944; Wing, 2005).

By the 1960's, researchers were beginning to take a more scientific/clinical approach toward childhood psychoses (Wing, 2005). One of the first researchers to investigate the age of onset for children exhibiting these characteristics was Kolvin (1971). Kolvin discovered a significant difference between the early and late onset of characteristics exhibited by the groups studied. These differences included variations among their cognitive ability, genetic factors, and social factors (Kolvin, 1971). Those characteristics exhibited at an early age correlated to Kanner's observations of early infantile autism. Individuals who exhibited characteristics at a later age had similar features and family histories comparable to that of schizophrenia in adults (Wing, 2005). The study conducted by Kolvin was prominent in the move toward using the term 'autism' for those experiencing autistic characteristics at an early age, and away from the idea of childhood schizophrenia (Wing, 2005). Finally, the 1960's provided additional research regarding the characteristics described by Kanner and Asperger such as social remoteness and echolalia (Lotter, 1966).

Soon to follow, Wing and Gould (1979) stumbled upon how the individual qualities found in autistic disorders were established and dispersed amongst the population of children under the age of fifteen who participated in their study. More specifically than Kanner's observations, Wing and Gould discovered that deficiencies in socialization could be observed in the following types of behavior: remoteness and unresponsiveness to others, inert acceptance of others, and peculiar approaches to others (Wing, 2005). Wing and Gould (1979) also found that these children experienced difficulties in social interaction, communication, and imagination, which occurred simultaneously and was associated with other repetitive behaviors. Most importantly, all these features could occur in an extensive range of manifestations, of which those individuals in Kanner's study manifested in a small proportion. The importance of this study is that it brought about the idea of the autism spectrum of disorders.

The 1980's and beyond brought about a more distinct definition of ASD. The research conducted by Rapin and Allen (1983) alluded to the fact that disorders in the semantic (comprehension/word meaning) and pragmatic (communication strategies) properties of language could also occur outside the boundaries of autism, but within the realms of a developmental disorder. The close relationship between semantic difficulties, pragmatic difficulties, and autism was later stressed by Lister-Brook and Bowler (1992). Bishop (2000) found that semantic and pragmatic language difficulties in children occur within the boundaries of developmental disorders and language disorders, confirming early research conducted by Rapin and Allen (1983) and Lister-Brook and Bowler (1992).

Since the 1980's, the prevalence of autism spectrum disorders has increased radically. Due to this increase, researchers, educators, and policy makers have been in search for more effective assessments and interventions (Tincani et al., 2009). As the definition of ASD became more precise and more efficient diagnoses were established, research was developed to guarantee that students will be provided high-quality services that will produce positive academic outcomes as well as a high quality of life (Tincani et al., 2009).

#### **Educational History**

The Individuals with Disabilities Education Act (IDEA), began initially as the Education for All Handicapped Act (EHA) in 1975. With its amendments in 1986, 1990, 1997 and 2004, IDEA has enabled eligible children with disabilities from birth to age 22 to receive special education and related services (Mandalwitz, 2005). The U.S. Department of Education has defined the six main principles of IDEA as: the delivery of a free and appropriate public education, a fair and comprehensive psychological evaluation, the planning and implementation of an individualized education plan, placement within the least restrictive environment, the participation of parents and students in the IEP process, and the provision/enforcement of procedural safeguards (U.S. Department of Education *Annual Report to Congress*, 1998).

Functional and procedural issues soar when examining educational debates involving students with autism spectrum disorders. One of the main issues in most ASD special education cases is the claimed failure of schools to provide free and appropriate public education (FAPE) (*Amanda v. Clark County School District,* 2001; *DiBuo v. Board of Ed. of Worcester County,* 2002; *Gadsby v. Grasmick,* 1997; *Wagner v. Board of* 

*Ed. of Montgomery County*, 2002). Many of these FAPE related legal issues involve the schools' failure to evaluate/assess all areas of a suspected disability, or incorrectly making eligibility or placement decisions based upon the prearranged program rather than the child's individual needs and characteristics.

Another important legal debate regarding students with ASD involves the educational placement of these students. Many court cases involve the debate over different placement options, such as appropriate placement within the public school, placement at a private or public school, placement in special schools for students with disabilities, or placement at a residential facility (*Gwinnett County School System*, 1999; *S.C. v. Deptford Township Board of Education*, 2003). In relation to these court cases affecting students with ASD, within the last decade, about 42% of all students served under the ASD category of IDEA were educated outside the general education classroom for over 60% of the school day (U.S. Department of Education, 2008).

Since LRE refers explicitly to the individual needs of the child, inclusion into a full-time general education classroom may be controversial, causing debates amongst parents and educators concerning the best placement option for the child. Several parents support full inclusion regardless of the severity of ASD, while other parents wish for the child to be in a setting with more intensive instruction or supports (Mandlawitz, 2005). Some court decisions have considered the benefits of inclusion for children with ASD and the associated benefits to the surrounding non-ASD children, the anticipated success in meeting the child's LRE needs, and the necessary accommodations to allow success in the general education classroom (*Beth B. v. Van Clay, 2001; Deptford Township Sch.* 

Dist. v. H. B., 2002; L. B. and J. B. v. Nebo Sch. Dist., 2002, Letter to Anonymous, 2000; M. A. v. Voorhees Township Bd. Of Educ., 2002).

#### **Incidence and Prevalence**

The prevalence of ASD has increased significantly within the last decade. In March of 2012, the Center for Disease Control and Prevention (CDC, 2012) released their prevalence report, indicating that the ASD diagnosis rate has risen from 1 in 110 children to 1 in 88 children. The CDC (2012) also indicated a 289.5% increase in diagnosis from 1997 to 2008. It is estimated that 1.5 million Americans are living with a disorder within the autism spectrum. The ratio reported by the CDC is translated to mean that of every four million children born each year, 36,500 will be identified with ASD (Autism Society of America, 2011). Researchers are still unable to pinpoint as to why the prevalence and incidence of ASD have increased so dramatically within the past decade. A study on the prevalence of ASD in children, conducted by Rice (2009), revealed that in 2006, on average, approximately 1% or one child in every 110 was classified as having ASD, supporting the prevalence report released by the CDC in 2011.

ASD is generally reported to occur across all racial, ethnic, and socioeconomic groups. However, ASD has been described to be disproportionally underrepresented among African-American and Hispanic groups due to a delay in identification (Tincani et al., 2009). In addition, the CDC and Autism Society of America (2011) report that 1 in 70 boys are diagnosed with ASD and boys are four to five times more likely than girls to develop ASD characteristics. Although different theories regarding the prevalence difference between genders exist, some researchers explored the ASD prevalence in boys and discovered it was related to fetal testosterone that affects the areas of behavior and

cognition (Baron-Cohen et al., 2011). Other researchers explain how the prevalence among males may be attributable to the improved identification process or to an increased risk for males that is not yet known (CDC, 2011; Rice, 2009).

The average age of diagnosis is 4.5 to 5.5 chronological years, but over 50% of children currently diagnosed with ASD have been reported to have developmental delays before the age of three (CDC, 2011). Rice (2009) stated that the average prevalence of children with ASD identified among children aged 8 years increased by 57% from 2002 to 2006. Chakrabarti and Fombonne (2005) conducted a study that investigated the diagnostic rate of children with pervasive developmental disorders (PDD) ranging from age 4 to 6. Out of the 10,903 children screened, the rate of PDD was higher than reported 15 years ago. The prevalence of ASD in children is also increasing across other nations. For example, in Israel, researchers have also seen an increase in children diagnosed with ASD and investigated the factors related to successes and failures of inclusion (Eldar et al., 2010). Smeeth et al. (2004) analyzed the rates of pervasive developmental disorder (PDD) and ASD diagnosis over a 13-year time frame. Both ASD and PDD diagnoses increased within the measured timeframe; the increase is attributed partially to better diagnostic practices and improved acknowledgment of the condition (Eldar et. al, 2010; Smeeth et al., 2004).

Genes may be one risk factor associated in the development of ASD characteristics, and about 10% of children with ASD may have an identifiable genetic, neurological, or metabolic disorder (CDC, 2011). A study conducted by Boyle, Van Naarden Braun, and Yeargin-Allsopp (2005) found that among identical twins, if one child has ASD, then the other twin will be affected 60-96% of the time. Scientists are also
still investigating a link to prescription drugs (thalidomide and valproic acid) taken during pregnancy and childhood vaccines (Thimerosal) as a possible cause for ASD (CDCP, 2011). Stehr-Green, Tull, Stellfeld, Mortenson, and Simpson (2003) examined whether Thimerosal-containing vaccines found in childhood vaccines was associated with ASD. Over a ten year time frame, they compared the prevalence/incidence of autism within the United States, Sweden, and Denmark with the average exposures to Thimerosal-containing vaccines. When analyzing the prevailing data, the authors of this study found that increased exposure to Thimerosal-containing vaccines was not responsible for the increase in rates of autism.

Some researchers are attributing the practices used for diagnosing ASD as a considerable cause for the rapid increase of the prevalence of ASD (King & Bearman, 2009). These authors utilized empirical data to find that most individuals obtained their ASD diagnosis due to the changes in ASD assessment over a 13-year time frame. Researchers continue to express the need for more research in this area. Frith (2004) explains how the prevalence increase in Asperger syndrome has brought about a need to raise awareness and educate others. Taking all these possible explanations for the increase in ASD diagnosis into consideration, it is crucial that further research about the nature, cause(s), and best treatment practices be conducted.

## **Classification System and ASD Type**

Physicians and researchers have come to a mutual understanding on the validity of ASD as a diagnostic category, although they have modified its definition over time (Rutter, 1996). Two major diagnostic and classification systems exist, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) and the International Classification of Diseases (ICD-10). Clinicians and school psychologists most commonly utilize the DSM-IV, which categorizes ASD as including the following conditions: Autism, Rett syndrome, Childhood Disintegrative Disorder, Asperger syndrome, and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS).

For the diagnosis of autism, a child must exhibit six characteristics, including at least two characteristics related to social abnormalities, one related to communication difficulties, and one related to lack in age appropriate interests or activities (Volkmar & Klin, 2005). The presence of these characteristics must have been prior to the age of three as demonstrated by a delay in social interaction, language as used in social interactions, and symbolic play. Social interaction can appear as impaired nonverbal behaviors, failure to create peer relationships, absence of shared enjoyment, or absence of social-emotional interchange. The characterizations displayed in the DSM-IV are similar to those behaviors found in many research studies that focused on this population of children (Cohen, 1980; Rutter, 1978; Siegel, Vukicevic, Elliot, & Kraemer, 1989).

Rett syndrome and Childhood Disintegrative Disorder are both progressive neurological disorders indicated by behavioral and developmental deterioration beginning between 5 and 30 months of age (Amir et al., 1999). At this age, the growth of the baby's head slows and decisive hand movements are replaced with stereotypic hand movements, gradual gait unsteadiness is observed, and severe cognitive and language impairments are exhibited. Rett syndrome typically affects girls and seizures are common (Heward, 2009). The importance of including Rett syndrome under the ASD spectrum is because of the similar social withdrawal traits exhibited during a child's early development (Volkmar & Klin, 2005).

According to Heward (2009), Childhood Disintegrative Disorder shares many behavioral characteristics with ASD, but does not usually appear until after the age of two and sometimes not until a child turns 10. Medical problems often occur and the projection for considerable improvement is usually low. The justification for including Childhood Disintegrative Disorder is not only because it involves the decline of behavioral and developmental skills, but also due to the search for a gene connected to the disorder (Volkmar & Klin, 2005).

According to the DSM-IV, individuals with Asperger syndrome demonstrate similar characteristics to individuals with autism; however, individuals with Asperger syndrome usually develop fair communication and language skills and their intellectual range usually falls between mild and normal limits, and sometimes even above the normal limits (Volkmar & Klin, 2005). Several researchers have identified a set of characteristics typically exhibited by individuals with Asperger syndrome: perseverating behaviors, passionate interest in a particular subject, preoccupation with one own's interest, clumsiness, difficulties with nonverbal behaviors, following routines, rote memory, invading others' personal space, speech/language impairments, misjudging others' feelings, extensive vocabulary, and perfectionism (Attwood, 2006; Barnhill, 2007; Myles & Simpson, 2001; Ritvo, 2006; Safran, 2001; Simpson, 2007; Winter-Messiers et al., 2007). Some studies have shown that many children with Asperger syndrome also meet the diagnostic criteria for autism (Howlin, 2003; Tryon, Mayes, Rhodes, & Waldo, 2006). This finding confirms Wing's (1998) argument that Asperger syndrome and high-functioning autism are not separate conditions (Heward, 2009).

The DSM-IV classifies a child with Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) if the child exhibits problems with social interaction and communication or limited interests. These are children who have met some, but not all of the qualitative or quantitative criteria for ASD according to the DSM-IV (Heward, 2009). Heward also explains that the boundaries for PDD-NOS are not well defined, but many of the characteristics are similar to Asperger syndrome with difficulties in socialization and a normal to above normal intellectual ability.

There are several benefits related to the classification of children with ASD. These classifications occur for the essential purpose of enhancing communication among researchers, physicians, and educators (Rutter, 2002). In order to achieve reliability and validity among findings, researchers utilize the classification system of ASD to share knowledge and conduct further research. Classifications assist physicians and educators to determine treatments and establish effective evaluation of interventions for individuals with ASD (Cantwell, 1996). Based on the research regarding the classification of ASD, there is a general agreement that ASD are developmental in nature, that ASD represent the behavioral symptoms of the underling functioning of the central nervous system, and that continued educational and behavioral interventions are useful for treatment (Klin, Sauliner, Tsatsanis, & Volkmar, 2005; National Research Council, 2001). As previously mentioned, researchers are constantly changing the definition of ASD and a new proposed definition (DSM-V) is scheduled to be released in the spring of 2013. The major difference of the proposed DSM-V will focus on the severity levels of children with ASD (Autism Research Institute, 2012).

# ASD in Adulthood

Taking into consideration the current debates and issues discussed regarding the prevalence and classification of ASD, educators and researchers are often skeptical about how individuals with ASD function during adulthood. In the United States, there are roughly 25 agencies that voluntarily deliver services specifically to adults with ASD (Sullivan, 2005). The current number of adults living with ASD is unknown due to insufficient data or studies related to the prevalence of adults with ASD (CDC, 2012; Sullivan, 2007). Researchers can only project the prevalence of adults with ASD by utilizing the counts collected from children with ASD. According to the National Association of Residential Providers for Adults with Autism and the Census Bureau population predictions, there will be approximately 1,495,264 adults with autism by the year 2014 (Sullivan, 2007). However, a study conducted by the California Department of Developmental Studies (2003) revealed that 1 in 320 adults had a developmental disorder. Using this ratio, researchers predicted that 603,125 adults nationwide had a developmental disorder (Sullivan, 2005); however, no information was given about the exact number of adults with ASD.

Billstedt, Gillberg, and Gillberg (2011) conducted a study that analyzed the quality of life of adults who were diagnosed with ASD in their childhood. Out of 120 adults with ASD, they found that the majority continued to depend on the support of their parents or caregivers in adulthood, which suggests that there is a need for improvements in the areas of employment and the development of meaningful activities for adults with ASD. Many of the parents requested a need for a 'lifelong' school for adults with ASD (Billstedt et al., 2011). Other studies have shown that not only students with ASD exhibit

problems after completing high school, but students with major cognitive limitations, severe physical impairments, sensory difficulties, behavioral disabilities, and mild disabilities encounter significant challenges in every phase of adult life (Johnson, Mallard, & Lancaster, 2007; Tymchuk, Lakin, & Luckasson, 2001).

IDEA requires that schools provide information on the IEP discussing how a student with a disability will transition from school to adult life. The requirement to include transitional services in the IEP was added to IDEA in 1990 and 2004 for students of the age at 16 (20 U.S.C. § 1401 (a)(19)). The reason for including transition services in the IEP is to provide a longer-range perspective into the IEP process; to help students make a meaningful transition from the school setting to a post-school setting, which possibly entails further education, employment, or independent living; and to enable students to better reach their potential as adults (Ray, 2002; Tucker & Goldstein, 1992).

Individualized Transition Plans (ITP) include appropriate measureable postsecondary goals based upon age appropriate transition assessments related to training, education, and employment; transition services needed to assist the student in achieving established goals; and beginning no later than one year before the student reaches the age of majority under state law, a statement that the student has been informed of his/her rights and that those rights will transfer to the student on reaching the age of majority (P.L. 108-446, 20 USC 1401, Sec.614 [d][1][A][8]). The purpose of the transition planning is to guarantee that all students with disabilities are prepared for the adult life that they desire, not confining a student into a life plan (Horvath, 2006). However, common mistakes made by schools when addressing the transition of a student who is 16 or older, occur in the areas of: not including the mandated transition

participants at the IEP meeting; not notifying the parent about the role of transitional planning; and not creating a transition plan that involves a coordinated set of activities to assist the student to meet his or her post-school goals (Lake, 2002).

Camarena and Sarigiani (2009) researched the postsecondary aspirations of parents of children with ASD. They discovered that postsecondary training is a reasonable path for expanding personal growth as well as educational possibilities. If pursuing postsecondary opportunities is not an option, the path could emphasize more intensively the vocational needs and support toward independence for some children with ASD. Parents of children with ASD felt that schools should provide more training towards a vocational or postsecondary school track in order for their children to become more independent (Camarena & Sarigiani, 2009).

## Parents of Children with Disabilities: Involvement and Preferences

Parent participation through shared decision-making is one of the six basic principles of IDEA. Approximately twenty years of research has confirmed that the education of children with disabilities can be made more effective by solidifying the role of parents and guaranteeing that families of such children have meaningful opportunities to participate in the education of their children at school and at home (U.S.C.601[c][5][B]). Many researchers have examined the attitudes and perceptions of parents of children with disabilities toward special education placement and services. Some parents desire and advocate for an inclusive placement, while other parents may prefer a separate placement (Grove & Fisher, 1999).

Elkins, van Kraayenoord, and Jobling (2003) examined the attitudes of parents toward the inclusion of their children with special needs in the general education

classroom. The parents of children with disabilities were surveyed at random from one hundred different preschools, 150 primary schools, and 150 secondary schools. Disabilities of students included intellectual disabilities, physical disabilities, visual/hearing impairments, ASD, speech/language impairments, learning disabilities, and traumatic brain injury. Even though many of the parents reported that they approved of inclusion and others would prefer inclusion if additional services were provided, some believed their child would benefit from a more secluded environment (Elkins et al., 2003).

We know that the trend to include students with disabilities into the general education classroom has acquired wide support from educators and researchers (Gartner & Lipsky, 1987; Stainback & Stainback, 1992, 1996). The trend toward inclusion of children with disabilities introduces matters concerning effectiveness, applicability, readiness, and acceptance by parents (Elzein, 2009). Nonetheless, do parents share the same beliefs as our educators and researchers? Some studies have revealed that parents do wish for the inclusion of their children with disabilities (Davern, 1999; Yssel, Engelbrecht, Oswald, Eloff, & Swart, 2007). Even for those who exhibited hesitation toward inclusion, some parents have expressed that they would be more in favor of inclusion if adequate in-service education regarding inclusion was provided to the general education instructors (Elkins et al., 2003).

A qualitative study conducted by Davern (1999) explored the attitudes of parents of children with disabilities toward inclusive schools in order to inform and provide recommendations for teacher preparation programs. Interviews were gathered from 21 parents of children with ASD, speech/language impairments, learning disabilities,

intellectual disabilities, developmentally delayed, physical impairments, or emotional difficulties. In spite of the many insufficiencies observed between schools, parents were satisfied with the fact that their children were part of a general education class and would not consider a change of placement into a special class/school. However, many of these parents also desired more active roles in their child's education and felt parent-professional relationships brought about many challenges (Davern, 1999).

Similarly, Elzein (2009) conducted a case study of two elementary schools that adopted and implemented the policy of inclusion. Data were collected through an interview process from fifteen parents of children with disabilities, including ADHD, Down syndrome, physical impairments, deaf and hard of hearing, emotional disabilities, language impairments, and learning difficulties. Elzein (2009) discovered that parents expressed positive attitudes toward the possible outcomes of inclusion such as academic improvement and social adjustment.

The previously mentioned studies describe the need for improved communication between parents of students with disabilities and special educators/staff. Through a collaborative effort among the Education Service Center Region IX, the Texas Education Agency, and the Parent Coordination Network (2006), parents in Texas were surveyed about their attitudes and perceptions of the special education services their children received. Data collected from 434 surveys indicated an overall satisfaction with special education placement and services. Nonetheless, one pertinent concern of parents involved the lack of communication between parents and the special education staff. In addition, parents requested more frequent notification of academic and social progress from teachers and the school.

In order to analyze the preferences and perspectives of parents of children with disabilities, the definition of quality inclusion needs to be clarified. Buysse, Skinner, and Grant (2001) investigated the perspectives of parents toward effective inclusive classrooms for children with disabilities. Collecting data from 19 different schools, they conducted 92 interviews from parents of children with physical impairments, speech/language delays, sensory impairments, developmental delays, or behavior problems. Parents described the importance of having qualified personnel, a well-planned classroom environment, and developmentally suitable practices that influence the program's quality for students with disabilities. Parents also mentioned the need for related services or therapies, adaptations to the classroom environment, and maintenance of small staff-child ratios, as being essential components to inclusive settings (Buysse et al., 2001).

The research findings discussed express the desire and need for the involvement of parents of children with disabilities. The questions, however, is how much do parents essentially involve themselves in their child's education? Zhang, Wehmeyer, and Chen (2005) examined parent engagement in fostering the self-determination of students with disabilities. Surveys were administered to 203 parents of students with emotional/behavioral disabilities, learning disabilities, and intellectual disabilities. Results indicated that parents of students with disabilities engaged in self-determination and nurturing behaviors on a more consistent basis than do parents of students without disabilities. Learning about and knowing of the behaviors and attitudes of families of children with disabilities can allow prospective teachers in pre-service education

programs to begin to better understand and appreciate parents' views (Zhang, Wehmeyer, & Chen, 2005).

# Parents of Children with ASD: Involvement and Preferences

Parental involvement of children with ASD is critical for the development and education of their children. Even though parents may not have the professional experience or objectivity to value the degree to which their children do or do not adapt to standardized expectations, the information parents can offer to educators, psychologists, and researchers is vital (Lord, Rutter, & Le Couteur, 1994). Despite the laws that have been enacted to assist children with ASD, evidence suggests that the interaction between school and home is often disjointed and inadequately assimilated (Stoner et al., 2005). Misperceptions, frustration, and anxiety amongst parents or educators often affect the value of service delivery and potential well-being of those students with ASD (Lake & Billingsley, 2000).

Recent studies have investigated the involvement and perceptions of parents of children with ASD regarding their children's special education services. Spann, Kohler, and Soenksen (2003) discovered several important realities pertaining to this topic. Based on parent surveys, the majority of the children with ASD spent part of their school day in the general education classroom while receiving one or two special education services. Families stated that they communicated on a regular basis with the school, and most of the parents felt they were fairly knowledgeable regarding their child's IEP.

However, more important is that parents of children with ASD have acknowledged many urgent needs for their children and they reported that the schools were not doing enough to address their priorities (Spann et al., 2003). This was mostly

observed from parents of older students with ASD. Interestingly, Spann et al. noted that parents were surprised by the questions brought about from the investigators due to the fact that they had never been asked how they felt about their children's special education services before.

Parents (usually mothers) take on the role of the negotiator, the monitor, the supporter, and the advocate (Stoner & Angell, 2006). The involvement of parents of children with ASD and the related stressors occur in phases. Such phases include the difficulty of obtaining a diagnosis for a child with ASD; the gathering of information regarding ASD following the diagnosis; the transition between early intervention to special education; the struggle or demand for services while developing trust for schools; the need for recurrent and honest communication; the dispositions of teachers; and finally, the stages of building trust with all special education school personnel (Stoner et al., 2005).

The amount of time parents devote to being involved in the education of their children with ASD, may impact their views and perceptions regarding the quality of life of their children (Connor, 2000; Jordan, 2005). Brewin, Renwick, and Schormans (2008) investigated parental perspectives concerning the quality of services within the school environment for children with ASD. Parents expressed that their children with ASD were in need of support and correct educational placement, but these needs were often ignored by the general population and the educational system. Parents also conveyed a need to provide social skills training as an additional service for children with ASD (Brewin, Renwick, & Schormans, 2008).

So how do parents of children with ASD feel about the educational placement and special education services of their children? Several research have shown that most parents of children with ASD desire a continuum of services (part-time inclusion, part-time special education classroom) and those parents who prefer full inclusion are usually parents of younger children with ASD (Kasari et al., 1999; Lynch & Irvine, 2009). Comparably, parents of children with ASD in a special education classroom are less content with their child's current placement and services, and yearn for more services or full inclusion than do parents of children in early intervention or general education programs (Kasari et al., 1999).

Hence, the special education debate between inclusion or a continuum of services continues among researchers, educators, and parents. Researchers argue that if a systematic change is to occur that guarantees all children with ASD the essential supports to maximize their academic success, there must be unification between the ASD community and the inclusion reform movement (Andrews & Lupart, 2000). Humphrey (2008) discusses numerous evidence-based strategies that are considered the beginning stages for effective placement of students with ASD. According to this author, schools and educators need to challenge stereotypes, support peer understanding, teach social skills that may not be understood by students with ASD, adapt academic curriculum, and alter conversational language useful not only between the teacher and the student, but between the child and his/her parent.

Other researchers and parent advocates provide studies that support the need for educational professionals to keep an open communication between home and school, provide effective interventions, and deliver services that meet the individual needs of the

child (Stoner et al., 2005). Educators and parents of children with ASD have a mutual goal, to provide the best education possible for children with ASD. In order to attain this goal, educators and parents must understand each other's perspectives (Stoner et al., 2005).

The parental involvement of children with ASD is vital to the support system of children with ASD. Parents who participate (as required by IDEA) in the educational planning of their children with ASD must acquire special knowledge about different kinds of related services, understand how to participate effectively during IEP meetings, and be consistent in presenting their concerns and wishes pertaining to learning goals, placement options, and career development for their children (Lindstrom, Doren, Metheny, Johnson, & Zane, 2007; Luker & Lucker, 2007; Stoner & Angell, 2006; Wright & Wright, 2006).

Benson, Karlof, and Siperstein (2008) researched maternal involvement in the education of children with ASD. Their study involved surveys and interviews from mothers and teachers of 95 students receiving services for ASD in a public school setting. Using regression analysis, the authors found that parental involvement at home and school was greatly influenced by the degree to which school staff vigorously encouraged, assisted, and provided opportunities for parent involvement.

Most recently, research concerning the importance of paternal involvement has been developed. Flippin and Crais (2011) studied the need for more efficient father involvement in early autism intervention. Analyzing empirical data, they noted that the stress level and coping differences between mothers and fathers may suggest that directly involving fathers in their child's intervention may help alleviate some of the pressure

mothers' experience. Sequentially, this may have an overall positive effect on the entire family (Flippin & Crais, 2011).

## **Personal Construct Theory**

George Kelly developed the personal construct theory in 1955. Kelly proposed that every person is a scientist who develops his/her own hypotheses or expectations about the world based on his/her own scheme or constructs (Jablonski & Lester, 2008). Contingent upon the experience that a person had with a specific construct (e.g., a disability) a person utilizes the construct, alters it, or gets rid of the construct. Therefore, personal constructs can change based upon personal experiences (Crockett, 1982).

Several personal construct theorists apply the term 'development' interchangeably to represent changes over the life span of almost all people (Sigel & Holmgren, 1983). Kelly (1995) believed that this change or development takes place through a process involving the following stages: alternating the meaning of constructs, experiencing anxiety as a result of our inability to interpret what we experienced, confirming the evidence from our experiences while making predictions, and releasing and constricting constructs to produce new ideas (Viney, 1992). Figure 1 depicts the stages involved in the personal construct theory process (Kelly, 1955; Viney, 1992).



Procter (2001) describes the personal construct psychology (PCP) model of autism, which is derived from a wide variation of research findings and literature, including writings from adults with autism. Practicing the PCP approach in a family or group setting is likely to assist other members in the enhancement of their understanding of the characteristics of people with autism, which in-turn allows for new constructs to be developed (Procter, 2001). Kelly (1955) proposes that a person's processes are psychologically directed by the way in which he/she anticipates events. This emphasizes the fact that most people with a disability are individuals to be respected, given rights, and a choice (Procter, 2001). Similarly, parents of children with ASD are knowledgeable of these rights and anticipate the events that should occur within the school setting.

Kelly (1955) explains that people differ from each other in their construction of events. Every person is exceptional, and every person with autism is exceptional. Parents of students with ASD will interpret their children's experiences differently when compared to other parents with or without a disability, resulting in varying anxiety levels. Procter (2001) emphasizes within the personal construct theory that failure to acknowledge that another person has a different point of view or another set of emotions and experiences will have a significant and overwhelming consequence that infuses every aspect of a person's life. This is often how conflicts between school and home develop.

For a group of people to remain together over a prolonged period of time, each person must make a choice within the boundaries of his/her construct system to preserve a common construction of interactions in the group (Kelly, 1955; Procter, 2001). As previously discussed, students with ASD have difficulty understanding that experiences vary from one person to another (Powell, 2000). Parents' understanding of this

disadvantage can help to create meaning from their personal experiences and child's experiences, to make predictions from confirmations of those experiences, and to allow for new ideas to be developed. The new ideas may alter attitudes and parents may apply these newly constructed ideas to help advocate for the education of their children.

Using the idea of the personal construct theory, Case (2000) analyzed the efficiency of service delivery, needs, and issues of children with disabilities from the parents' perspectives. Case discovered parental dissatisfaction with professionals and service providers during and after the diagnosis of their child's disability. Case continued to discuss the need for parental involvement as vital to the development of a justifiable parent-professional relationship. Parents should be educated and inspired by professionals to help them not only develop an effective partnership, but also to help them develop new positive personal constructs (Case, 2000). According to research results conducted by Dale (1996), researchers and educators in general have a tendency to focus on negative parent reactions at the price of acknowledging positive parent reactions to help decrease discrimination toward people with disabilities (Dale, 1996).

# **CHAPTER III**

# METHODOLOGY

# **Research Design**

This study employed a survey research design, utilizing a cross-sectional survey by which data were gathered from parents of children with Autism Spectrum Disorders (ASD). Survey research assists in determining and reporting the status of a group of participants at a single point in time (Gay, Mills, & Airasian, 2012). Survey research design was selected for two reasons. First, cross-sectional designs are valuable for providing a glimpse of the current attitudes and beliefs within a population (Gay et al., 2012). Second, survey research has the advantage of permitting the researcher to accumulate data from a large number of people at one time.

# Variables

There are several independent variables that were expected to be related to the dependent variables in this study. The dependent variables were the types of educational placement and services preferences of parents of children with ASD. The current educational placement of a student with ASD (independent variable) may be related to the educational placement preferences or perceptions (dependent variable) of their parents. Similarly, the current special education services a student with ASD receives (independent variable) may be related to the special education services preferences or perceptions (dependent variable) may be related to the special education services preferences or perceptions (dependent variable) may be related to the special education services preferences or perceptions (dependent variable) of their parents. Finally, the independent variables identified as the specific type of ASD (i.e., Autism, Asperger syndrome, Rett syndrome, PDD-NOS, or Childhood Disintegrative Disorder), age of child, age of diagnosis, parent educational level, and region of residence may also be associated with both educational placement and educational services parental preferences.

# Sample

Participants in this study were members of several online Yahoo support groups titled Denise's List, Asalv, AsaPhilly, Autism-Georgia, Dayton United Against Autism, Families with ASD, Mosaic-List, NIDS, Texas-Autism-Advocacy, Autism-Michigan, IPADD Unite, Autism-Florida, and asdNMore. These yahoo groups are specifically developed for parents of children with different types of ASD. Members join these online groups on a voluntary basis. Parents in these Yahoo support groups (social network) communicate with one another by logging into or receiving email from the above titled values. Once they are logged on or receive email from the value group, they are able to share issues, concerns, or information regarding ASD. Parents are also able to share photos, files, links, and keep up with all the latest resources and research available for children with ASD through posts and emails. These yahoo groups combined include about 5,000 active members of parents of children with ASD across the United States. Parents who chose to complete this study's survey participated on a voluntary basis. A total of 187 parents of children with ASD participated in this study from across 17 different states, representing the Southeast, Northeast, Midwest, and West regions of the United States.

# Instrumentation

Participants were asked to voluntarily fill out an online survey consisting of questions pertaining to the educational placement of their children as well as the educational services provided. The first part of the survey included descriptive questions about the child, including type of ASD diagnosis, age the child was first diagnosed, educational placement, and services received at school. The second part of the survey

assessed the type of educational placement and services that parents would like their child to receive. The third part of the survey included items that assess parents' agreement with statements evaluating their child's placement, services, preparation for adulthood, and transition; their child's happiness and improvement; the IEPs; prospects of adult success; and staff support. This section utilized a Likert scale format with responses ranging from strongly disagree (1) to strongly agree (5).

Data regarding parents' preferences and perceptions were collected through the use of the above-mentioned survey created by the researcher (Appendix A). The researcher utilized the Survey Monkey website to assist in collecting data anonymously. The survey is modeled and is based on empirical studies about parental concerns toward the educational placement and services of children with disabilities (Dymond et al., 2007; Elkins et al., 2003; Kasari et al., 1999). A few questions (e.g., happiness) included in the survey were based on parents' suggestions by phone interviews conducted between the researcher and four parents of children with ASD, who did not participate in the study. These parents were asked what type of questions they feel should be on a survey pertaining to the educational placement and services of children with ASD.

## Procedures

To help establish the content validity of the survey developed for this study, six parents of students with disabilities (who did not participate in the study) completed the survey as part of a pilot study to assist in determining the clarity of the questions, the survey flow, the sensitivity of the questions, and the length of time needed to complete the survey. Based on this pilot study, it was determined that the average time to complete the survey was approximately fifteen minutes. Parents indicated that all questions were

easy to understand and were appropriate. One parent in particular specified during a phone interview that, "The survey was simple to fill out and I felt that I was able to express my opinions sufficiently."

Members of the Yahoo support groups who chose to participate did so anonymously. The researcher worked collaboratively with thirteen Yahoo group coordinators (i.e., the gatekeepers) who showed interest in the study. Some of the group coordinators are parents of children with ASD. Members of the Yahoo groups received an introductory email from the coordinators (see Appendix B) that contained the cover letter and the link to the survey instrument. The cover letter introduced the study (see Appendix C), described the components of the survey, explained the use of the Survey Monkey website, and provided contact information. By completing the survey, the parents indicated their agreement to participate. Toward the end of the recruiting period and with verbal gatekeeper permission, the researcher posted reminders in the area designated for posting on the Yahoo group websites on a daily basis, which continued for approximately a month (see Appendix D). By using the posting forum on each website, the researcher was not able to see participant emails, keeping parent involvement anonymous. These daily posts reminded members to complete the survey, if they desired to do so. The reminder message included a phrase for parents to disregard the content of the post if they have already responded. A final message was posted to the Yahoo group members a week later to remind them of the closing date for collecting the survey (see Appendix E). The Survey Monkey website forwarded all the completed surveys to the researcher continuing to keep participant emails and identities anonymous. After the

researcher received the responses directly from the Survey Monkey website, she analyzed the data utilizing the PASW statistical data program.

Participants were notified through the cover letter that they would not obtain any direct benefit by participating in the study; however, by volunteering to participate, they could assist in understanding the topic of education regarding children with ASD. Participants were informed in the cover letter that completion of the survey would result in the opportunity to enter their email address into a drawing for one \$25 gift card to Amazon.com. Participants were prompted by Survey Monkey for their permission to enter their email address for the drawing. Through partnership with ePrize, survey monkey randomly drew one email to determine the winner. The winner was informed via email with a bar code containing a notification letter for the participant to claim the award. Survey Monkey did not reveal to the researcher the identities or emails of those participants who chose to enter the drawing.

## **Research Questions**

The following research questions guided this study:

- 1. What are the educational placement preferences of parents of students with ASD?
- 2. What are the educational service preferences of parents of students with ASD?
- 3. How do parental preferences differ based on their children's specific ASD subtype (i.e., Autism, Asperger syndrome, Rett syndrome, Childhood Disintegrative Disorder, or PDD-NOS)?
- 4. What are parents' perceptions about the effectiveness of schools in preparing students with ASD for adulthood?

# **Statistical Methods**

Frequencies were utilized to present most of the responses to the survey. A chisquare analysis was conducted to assess the current educational placement of children with ASD as it relates to parents' preferred educational placement. Another chi-square analysis was generated to find if ASD diagnosis and current educational placement were independent from one another. One-way Analyses of Variance (ANOVAs) were carried out to assess differences in total satisfaction and preferred services according to ASD type, and to analyze parental differences in satisfaction about transition and total satisfaction based on educational degree. ANOVAs were also generated to analyze differences on the Likert scale questions based on educational placement, services, and geographic location. Lastly, Pearson Product-Moment Correlations were utilized to find associations between parents' total satisfaction, total transitional satisfaction, total services, age of the child, and parents' service preferences.

#### **CHAPTER IV**

# RESULTS

# **Internal Consistency**

As a measure of internal consistency, a Chronbach's alpha was calculated for this sample on the survey used in the study. The reliability coefficient was  $\alpha$ =.94, indicating a high internal consistency of the survey.

## **Demographic Characteristics**

Frequency distributions were utilized for the demographic variables of the sample. These frequencies represent the number of occurrences and valid percentages for each variable. As observed in Table 1, more boys (n = 148, 79.1%) were diagnosed with ASD than girls (n = 38, 20.3%). The age of persons with ASD ranged from 2 to 38 (M = 11, SD = 41.0). About 20 (11.2%) were 2-5 years old, 95 (52.9%) were 6-13 years of age (elementary and middle school), 62 (34.4%) were 14-20 years old (high school and posthigh school), and very few (n = 3, 1.8%) were 29 years or older. Most parents were mothers (n=164, 91.1%) and had received a Bachelor's (n = 67, 35.8%) or Master's degree (n = 46, 24.9%) as their highest degrees earned. Moreover, 126 (66.6%) had a bachelor's degree or higher, indicating the relatively high achievement of this group.

# Table 1

# Demographic Characteristics

Characteristic	n	%	
Child's Gender			
Male	148	79.1	
Female	38	20.3	
Child's Age			
2-5	20	11.2	
6-13	95	52.9	
14-20	62	34.4	
29-38	3	1.8	
Parent relationship to child			
Mother	164	91.1	
Father	13	7.2	
Other	3	1.7	
Parent highest degree			
Doctorate Degree	13	7.0	
Masters Degree	46	24.9	
Bachelors Degree	67	35.8	
Associate Degree	30	16.2	
High School Diploma	26	13.9	
GED	3	1.6	
Child's diagnosis			
Autism	122	65.1	
Asperger	30	16.1	
PDD-NOS	35	18.8	
Age of diagnosis			
Age 1-2	81	44.0	
Age 3-4	63	34.2	

Age 5-	6	16	8.7
Age 64	-	24	13.0
State of reside	nce		
Southe	ast	53	29.3
Northe	ast	37	20.4
West		37	19.8
Midwe	st	54	29.8

Note: Some numbers may not add to the total number of participants (n = 187) due to missing data.

Since some parents selected more than one category as their child's condition, for meaningful analyses a dominant rule was created to assign persons who had more than one condition to one category only. If parents indicated that their child had a diagnosis of Autism, Asperger, and PDD-NOS (n = 12), Asperger syndrome was selected as the dominant category, since in most cases Asperger is the more salient of these three diagnoses. Similarly, if parents indicated that their child had a diagnosis of Autism, PDD-NOS, and Rett Syndrome (n = 15), Autism was selected as the dominant category. One person was not sure of the diagnosis of their child; thus, the child was categorized in the Autism group. The final distribution of diagnoses is described in Table 1, indicating that the majority of the sample (n = 122, 65.1%) had children with Autism.

As discussed previously in Chapter II, according to the DSM-IV, children predominantly exhibit ASD characteristics and tendencies by the age of 3. Parents were asked to identify the age their child was diagnosed with ASD. Almost half of the children (n = 81, 44%) were diagnosed between the ages of 1 and 2.

Parents were also requested to indicate the state they lived in. For meaningful analyses, the states were divided into four regions of the United States. Representing the

Southeast were the states of Florida, Arkansas, Texas, Kentucky, and Georgia. States representing the Northeast included New York, Pennsylvania, Connecticut, and New Jersey. The West included the states of Colorado, Idaho, and New Mexico. Lastly, the Midwest included the states of Michigan, Ohio, Wisconsin, Illinois, and Iowa. Table 1 indicates that parents were almost equally distributed in the four regions of the United States.

# **Research Questions Analyses**

One of the questions of this study investigated the educational placement preferences of parents of children with ASD. The specific research question was: What are the educational placement preferences of parents of students with ASD? However, first, parents were requested to indicate their child's current educational placement, as reported in Table 2. Placement was defined as five different categories, full time in a general education classroom (inclusion), part-time in a special education classroom, fulltime in a special education classroom, special school for students with diverse disabilities, and special school for students with ASD. For meaningful analyses, parents who indicated their child's placement occurred at a special school for students with diverse disabilities (n = 8) were collapsed with those who indicated that their child was placed in a special school for students with ASD (n = 17). As indicated in Table 2, 52 (30.6%) students were currently placed in full time general education classrooms or inclusive classrooms and 51 (30.0%) were placed part-time in a special education classroom, while 42 (24.7%) were placed in a part-time special education classroom and 25 (14.7%) were currently placed in a special school for students with ASD.

# Table 2

# Child's Educational Placement

Placement	n	%
Full-time in a general education classroom (inclusion)	52	30.6
Part-time in a special education classroom	51	30.0
Full-time in a special education classroom	42	24.7
Special school for students with ASD	25	14.7

As observed in Table 3, almost half of the parents (n = 81, 46.6%) preferred to place their children in a full-time general education classroom. In addition, 36 (20.7%) parents preferred their children to be in a part-time special education classroom, and 39 (22.4%) parents wished their children to be placed in a special school for students with ASD. Only18 (10.3%) parents preferred their children to be in a full-time special education classroom. (Consistent with the question assessing current educational placement, if a parent indicated preference of a special school for students with diverse disabilities, the response was collapsed with preferring a special school for students with ASD.)

# Table 3

# Preferred Educational Placement

Placement	n	%
Full-time in a general education classroom (inclusion)	81	46.6
Part-time in a special education classroom	36	20.7
Full-time in a special education classroom	18	10.3
Special school for students with ASD	39	22.4

As discussed previously, Table 2 revealed that many persons with ASD in this study (n = 52, 30.6%) were (or have been) placed in a full-time general education classroom (inclusion) and parents correspondingly preferred (n=81, 46.6) their children to be placed also in a full-time general education classroom, as revealed in Table 3. This study sought to determine if there was a difference based on the child's ASD diagnosis on parental preferences of educational placement. Specifically, the question asked: How do parental preferences differ based on the child's specific ASD subtype (i.e., Autism, Asperger syndrome, Rett syndrome, Childhood Disintegrative Disorder, or PDD-NOS)? This question was analyzed separately for educational placement and for educational services. Since the diagnoses were collapsed into three main groups (Autism, Asperger, and PDD-NOS), only three conditions were included in all the analyses. When analyzing educational placement preference by type of diagnosis, the majority of children with Asperger syndrome (n = 16, 66.7%) preferred their children to be in a full-time

general education classroom; this was also true, but to a lesser degree, for parents of children with PDD-NOS (n=18, 54.5%) and Autism (n = 46, 40.7%), as reported in Table 4. A chi-square analysis was conducted to indicate whether preferred placement was independent from diagnosis. Results showed that there were no significant differences (p = .220), indicating that the three main groups in this study did not differ in their preferred educational placement.

Table 4

ASD Diagnosis	Full-Time General Cla	Part-Time ss Special Class	Full-Time Special Class	Special School for ASD	
	n %	n %	n %	n %	
Autism	46 40.7	24 21.2	14 12.4	29 25.7	
Asperger	16 66.7	4 16.7	1 4.2	3 12.5	
PDD-NOS	18 54.5	8 24.2	3 9.1	4 12.1	

Preferred Educational Placement by Diagnosis

Table 5 presents the frequencies and proportions of parents who preferred a type of school placement given the current educational placement of their offspring. This analysis was conducted regardless of diagnosis. A chi-square analysis was generated to find out if current educational placement and preferred educational placement were independent from one another. A significant difference was found between current educational placement and preferred educational placement,  $x^2_{(7)}$ =125.84, *p*<.001.

Parents who had students in a full-time general education classroom had a significantly

higher preference for this type of placement (n=45, 86.5%).

Table 5

Current Educational Placement and Preferred Educational Placement

	Preferred Placement								
Current Placement	Full-T Gener	Full-Time General Class		Part-Time Special Class		Full-Time Special Class		Special School	
	n	%	n	%	n	%	n	%	
Full-time in general education classroom	45	86.5	2	3.8	0	0	5	9.6	
Part-time in a special education classroom	16	32.7	23	46.9	0	0	10	20.4	
Full-time in a special education classroom	6	15.4	10	25.6	17	43.6	6	15.4	
Special school for students with ASD	9	37.5	0	0	1	4.2	14	58.3	

Another question asked: What are the preferred educational services of parents of students with ASD? But first, parents were asked to specify which types of special education services their children with ASD currently receives. Parents were to check all that apply from a list of the following services: applied behavior analysis (ABA), speech, language, social skills, occupational therapy, physical therapy, behavioral management (not ABA), assistive technology, counseling, sensory, communication, early intervention, and transition. Inferential analyses to compare current and preferred educational services

could not be conducted due to the non-independence of observations, since parents could select as many services as they wanted.

As noted in Table 6, approximately 67.9% (n = 127) of the students received speech services and nearly 55.6% (n = 104) of the students received occupational therapy. The preferred services were speech (n = 120, 64.2%), social skills training (n =149, 79.7%), occupational therapy (n = 111, 59.4%), sensory integration (n = 95, 50.8%), and communication training (n = 104, 55.6%). Figure 2 illustrates the current and preferred special education services for selected services. The eight services selected were those that showed the highest differences between receiving and preferring a specific educational service and those services exhibiting a high desire regardless of how many services currently received. Table 6 and Figure 2 indicate that, overall, for each service there was a higher desire to receive that service compared to the actual percentage of students who were receiving it, which is consistent with other analyses described in the next section.

Table 6

	Current		Preferred		
Service	n	%	n	%	
ABA	30	16.0	88	47.1	
Speech	127	67.9	120	64.2	
Language	40	21.4	91	48.7	
Social skills	81	43.3	149	79.7	

# Current and Preferred Educational Services

Occupational Therapy	104	55.6	111	59.4
Physical Therapy	30	16.0	36	19.3
Behavioral mgmt.	41	21.9	66	35.3
Assistive Technology	28	15.0	65	34.8
Counseling	21	11.2	55	29.4
Sensory integration	20	10.7	95	50.8
Communication training	22	11.8	104	55.6
Early intervention	8	4.3	12	6.4
Transition services	26	13.9	68	36.4

Note: Percentages add to more than 100, since parents could check all that apply.



Satisfaction with the child's education, placement, and services was also investigated in this study. Parents completed a Likert scale ranging from strongly disagree to strongly agree on items regarding, services, placement, child's interest in school, child's academic and behavioral progress, knowledge of professionals, teacher strategies, class size, collaboration, acceptance by students without disabilities, transitional services, and IEP meetings. The last three items (i.e., school provides adequate transitional services, school assists families to plan for their child's post school employment, and school prepares their children with ASD to be an independent adult) of the Likert scale were answered by parents of students who were 14 years old or older, since they focused on current transitional issues. Means and standard deviations for each item in the scale (from 1 to 5) are reported in Table 7. The issues that showed higher parental satisfaction were: attendance at IEP meetings (M=4.82, SD=.608), desire for more services (M=3.97, SD=1.011), the child likes school (M=383, SD=1.205), and awareness of services available (M=3.81, SD=1.017). Results showed that when parents were requested to provide their satisfaction about transitional services (for children over the age of 14 only), parents specified lower satisfaction ratings toward the ability of schools to provide adequate transitional services (M=2.88, SD=1.08) for their children with ASD, assisting families to plan for their child's post school employment/college (M=2.79, SD=1.14), or preparing their children with ASD to be an independent adult (M=2.72, SD=1.18).
### Satisfaction with Education, Placement, and Services

Preference	n	Mean	SD
Services are sufficient	182	2.88	1.301
Placement is appropriate	185	3.69	1.155
Child likes school	184	3.83	1.205
Teacher knowledgeable about ASD	184	3.59	1.336
Teacher uses good strategies	182	3.59	1.248
Other professionals are knowledgeable	182	3.75	1.052
Child should be in a smaller class	184	3.11	1.334
Child improving academically	182	3.55	1.187
Child should be in non-ASD majority of day	184	3.35	1.371
Child improving socially	183	3.26	1.165
Child improving behaviorally	184	3.44	1.144
Should receive more services	184	3.97	1.011
Aware of services	185	3.81	1.017
Staff collaborates	181	3.64	1.130
Child is happy	185	3.69	1.155

Placement is conducive to learning	180	3.54	1.169
Accepted by students	184	3.16	1.107
Effectively preparing for future	184	3.02	1.178
Satisfied with IEP meetings	180	3.20	1.244
Attend most IEP	182	4.82	.608
Child will succeed in his/her job	185	3.15	1.135
Child will adapt to society	184	2.84	1.089
Advocate of child's rights	181	4.66	.581
Provides adequate transitional services	112	2.88	1.080
School assists to plan post-school	97	2.79	1.136
Preparing to be independent adult	96	2.72	1.176

Parents were asked on a Likert scale from strongly agree to strongly disagree whether they felt their child should receive more services than he/she currently receives and whether they felt the services their children received were sufficient. A total score for number of services was created by adding up all the current services that parents indicated their children were receiving. Pearson *r* correlations were conducted to assess if there was a relationship between Total Number of Services, parent desire for more services, and whether services were sufficient. Total Number of Services was positively correlated with parental desire for more services, r = .220, p < .05; both variables shared about 4% of their variance. Total Number of Services was also positively correlated with the sufficiency of current services, r = .201, p < .05; both variables shared about 4% of their variance. These positive relationships suggest that parents whose children were receiving more services still desired to receive even more services although, at the same time, they felt the services received were sufficient. The finding that parents desire to receive more services aligns with Figure 2 that compares current services to preferred services.

Adding up all the scores in the Likert scale, excluding the last three questions that were designed for students over the age of 14, created a total score and a new variable, Total Satisfaction. Total Satisfaction refers to parents' overall satisfaction with the child's education, services, and placement. Pearson *r* correlations were also conducted to determine the relationship between Total Number of Services and Total Satisfaction. Total Number of Services was positively correlated with Total Satisfaction, r = .266, p<.001; both variables shared about 4% of their variance. This positive relationship indicates that parents whose children received more services, showed a higher degree of satisfaction.

An ANOVA was conducted to assess whether parents differed on their Total Satisfaction and Total Number of Services based on their child's primary condition. Means and standard deviations for Total Satisfaction and Total Number of Services by condition are reported in Table 8. Results indicated that no significant differences existed by condition on parents' Total Satisfaction,  $F_{(2, 148)} = .463$ , p > .05, or on Total Number of Services,  $F_{(2,138)}=2.219$ , p > .05.

ASD Diagnosis	М	SD
	Total Sat	isfaction
Autism	79.45	15.52
Asperger	79.67	16.63
PDD-NOS	82.43	11.44
	Total Number	r of Services
Autism	3.26	1.93
Asperger	2.47	1.74
PDD-NOS	3.11	1.59

### Parental Total Satisfaction and Total Number of Services by Diagnosis

This study also investigated parental perceptions about transitional services. Specifically, the research question asked: What are parents' perceptions about the effectiveness of schools in preparing students with ASD for adulthood? Three questions on the Likert survey inquired about parental satisfaction with special education transitional services for children over the age of 14. A total score was created by adding up the three scores that addressed satisfaction with special education transitional services. An ANOVA was conducted to assess whether parents differed in their satisfaction of transitional services based on their child's primary condition. Means and standard deviations for Total Transitional Satisfaction by condition are reported in Table 9. Results indicated that no significant differences existed by condition on parents' Transitional Satisfaction,  $F_{(2, 87)} = .421$ , p > .05. Similarly, Pearson *r* correlations were conducted to indicate if there was a relationship between Total Transitional Satisfaction and Total Number of Services. However, there was no significant relationship found between Total Number of Services and Total Transitional Satisfaction, r = .198, p > .05. Table 9

Diagnosis	М	SD
Autism	8.40	3.16
Asperger	7.88	3.32
PDD-NOS	8.89	2.98

Parental Transitional Satisfaction by Diagnosis

#### **Additional Analyses**

To further investigate the overall parental satisfaction with education, services, placement, and transitional satisfaction, one-way ANOVAs were generated to assess whether parents differed in their Total Satisfaction and Transitional Satisfaction based on parents' highest level of degree completed. Means and standard deviations for Total and Transitional Satisfaction by parents' highest degree are reported in Table 10. Results indicated that no significant differences existed, based on parent highest degree, on parent Transitional Satisfaction,  $F_{(2, 86)} = .525$ , p > .05; however, there was a significant difference by parent highest degree on Total Satisfaction,  $F_{(2, 147)} = 4.248$ , p < .05, as shown in Table 11. Tukey post-hoc tests indicated that parents with a doctorate or professional degree were more satisfied than parents with a bachelor's degree.

Variable	Degree	n	М	SD
Total Transi	ition			
	Doctorate	27	8.19	3.10
	Master's	44	8.73	3.09
	Bachelor's	18	7.89	3.53
Total Satisfa	action			
	Doctorate	46	83.89	11.72
	Master's	79	80.37	14.57
	Bachelor's	25	73.40	18.38

### Total Transition and Total Satisfaction by Highest Degree

### Table 11

ANOVA: Total Transition and Total Satisfaction by Highest Degree

	SS	df	MS	F	р
Total Transition					
Between groups	10.66	2	5.33	.525	.593
Within groups	872.58	86	10.14		
Total Satisfaction					
Between groups	1783.86	2	891.93	4.248	.016
Within groups	30862.81	147	209.95		

A Pearson r correlation was conducted to assess if there was a relationship between parents' Total Satisfaction and the age of their children with ASD. Total Satisfaction was found to be negatively correlated with the age of children with ASD, r = -.211, p < .05; both variables shared about 4% of their variance. This result suggests that as the child becomes older, parents become less satisfied with educational services. It should be noted that no relationship was found between Total Transitional service satisfaction and the age of children with ASD, r = -.154, p > .05.

In one of the questions, parents were requested to specify the age that their children were diagnosed with ASD. Means and standard deviations for age of diagnosis, Total Satisfaction, and Total Transition by preference of small class are reported in Table 12. ANOVAs were conducted to assess whether the age of diagnosis was related to small class preference, to Total Satisfaction, and to Total Transition satisfaction. Results indicated that there was a significant difference based on age of diagnosis on parental preference of small class size for their child,  $F_{(3, 177)} = 4.61$ , p < .05, as indicated in Table 13. Post-hoc tests (Tukey) indicated that parents of children who were diagnosed with ASD at the earliest age (1 to 2) had a higher preference for their children being in a smaller class compared to parents whose children were diagnosed at the age of 5 to 6. However, no significant differences by age of diagnosis were found on parent Total Satisfaction,  $F_{(3,145)} = .346$ , p > .05, and on Total Transition,  $F_{(3,860)} = 1.34$ , p > .05.

	Preference for Smaller Class			
Age of Diagnosis	п	М	SD	
Age 1-2	80	3.11	1.34	
Age 3-4	61	3.03	1.22	
Age 5-6	16	2.13	1.31	
Age 6+	24	2.29	1.30	
	Te	otal Satisfaction		
Age 1-2	66	81.3	13.5	
Age 3-4	51	79.5	13.4	
Age 5-6	13	78.2	19.7	
Age 6+	19	78.5	17.9	
		otal Transition		
Age 1-2	37	7.68	2.90	
Age 3-4	26	9.08	2.48	
Age 5-6	9	9.33	4.12	
Age 6+	18	8.44	3.77	

## Smaller Class, Total Transition, and Total Satisfaction by Age of Diagnosis

	SS	df	MS	F	р	
I feel my child should be in a smaller class.						
Between groups	23.160	3	7.720	4.607	.004	
Within groups	296.630	177	1.676			

ANOVA: Age of Diagnosis and Parent Preference of Small Class

Finally, to further address the research questions regarding parental preferences of educational placement and services, an ANOVA was generated to assess whether parents differed on their preferences of educational placement and services based on the region where they reside. (Only those items that showed significant differences by region are reported in the following tables, as well as the Total Satisfaction scores.) Among the list of items, parents were asked whether their child likes to go to school, whether other professionals are knowledgeable about ASD, whether their child is happy at school, whether the educational placement of the child is conducive to learning, and whether their child is accepted by students without disabilities. Means and standard deviations for the above individual items, as well as the Total Satisfaction scores by region of residence, are reported in Table 14.

# Parent Preferences and Region of Residence

Preference	n	М	SD
My child likes to go to school.			
Southeast	51	3.33	1.41
Northeast	37	4.35	0.79
West	37	3.62	1.23
Midwest	54	4.09	1.03
Other professionals who provide services to my child are knowledgeable about ASD.	) 2		
Southeast	51	3.73	1.06
Northeast	36	4.19	0.82
West	36	3.53	1.25
Midwest	53	3.64	0.94
I think my child is happ at school.	у		
Southeast	51	3.47	1.25
Northeast	37	4.03	0.87
West	37	3.35	1.27
Midwest	54	3.96	1.01
The educational placem of my child is conducive to learning.	ent e		

	Southeast	48	3.23	1.24
	Northeast	36	4.00	0.86
	West	37	3.51	1.35
	Midwest	53	3.58	1.05
My chi student	ld is accepted by ts without disabilities.			
	Southeast	51	2.84	1.08
	Northeast	37	3.51	1.07
	West	36	3.03	1.21
	Midwest	54	3.30	1.02
Total S	atisfaction			
	Southeast	42	76.6	16.2
	Northeast	30	85.8	12.6
	West	30	77.6	17.9
	Midwest	46	81.3	11.9

Results indicated that there were significant differences by region of residency on all the above-mentioned items. Parents differed on their perceptions that their children like to go to school based on the region,  $F_{(3,175)} = 7.001$ , p < .001; on the agreement that other professionals who provide services to their children are knowledgeable about ASD,  $F_{(3,172)} = 3.022$ , p < .05; on the belief that their children are happy at school,  $F_{(3,175)} =$ 3.975, p < .05; and on the perception that the educational placement is conducive to learning,  $F_{(3,170)} = 3.169$ , p < .05. The ANOVA results are shown in Table 15. Post hoc tests (Tukey) indicated that parents in the Northeast and West felt more positively that their children liked to go to school than those in the Southeast and Midwest. Parents in the Northeast felt more positive that professionals who provide services to their children were knowledgeable about ASD, their children were happy at school, and the educational placements of their children were conducive to learning when compared to the three other regions. Tukey results indicated that parents in the Southeast differed significantly from the other three regions in that they felt that their children were less accepted by students without disabilities,  $F_{(3,174)} = 3.231$ , p < .05.

Based on the findings of these individual items, a one-way ANOVA was conducted to determine the differences in Total Satisfaction between parents in the four regions of the United States. Table 15 indicates that there was a significant difference on Total Satisfaction based on the region,  $F_{(3,144)} = 2.694$ , p < .05. Post hoc tests (Tukey) indicated that parents in the Northeast were significantly more satisfied than those living in the Southeast region of the country. Finally, an ANOVA was conducted to assess whether the number of services children receive differed amongst the regions. However, no significant differences were found on Total Number of Services by region,  $F_{(3,177)} =$ .559, p > .05.

#### Table 15

	SS	df	MS	F	р	
Child likes to go to school						
Between Groups	27.967	3	9.302	7.001	.000	
Within Groups	233.006	175	1.331			

ANOVA: Likert Scale Items and Total Satisfaction by Region

Other professionals who
provide services

Between Groups	9.538	3	3.179	3.022	.031
Within Groups	180.957	172	1.052		
My child is happy at school					
Between Groups	14.857	3	4.952	3.975	.009
Within Groups	218.037	175	1.246		
Educational placement is conducive to learning					
Between Groups	12.335	3	4.112	3.169	.026
Within Groups	220.590	175	1.298		
My child is accepted by students without disabilities					
Between Groups	11.376	3	3.792	3.231	.024
Within Groups	204.220	174	1.174		
Total Satisfaction					
Between Groups	1721.320	3	573.773	2.694	.048
Within Groups	30669.97	144	212.986		

#### **CHAPTER V**

### DISCUSSION

### **Summary of Findings**

The purpose of this study was to investigate the educational placement and service preferences of parents of children with ASD. Thus, two of the research questions specifically explored both the educational placement preferences and the educational service preferences. The findings concerning educational placement revealed that there was an association between current educational placement of students with ASD and parental desire of a similar educational placement. Parents who had children in a full-time general education classroom had a significantly higher preference for this type of placement. Many parents surveyed preferred that their children be placed in general education or in an inclusive classroom, and many of their children were indeed fully included. These findings are consistent with the research conducted by Karasi et al. (1999). His research presents the notion that parents of children with autism chose the general education classroom for both academic and non-academic interactions. The finding that so many students with ASD are fully included supports the inclusion reform movement of including students with disabilities into the general education classroom (Andrews & Lupart, 2000), of which parents seem to be satisfied with.

This study also sought to assess parental preferences of special education services. This was investigated in four areas of the survey: parents were specifically asked to specify the current services their children were receiving, whether their children should receive more services, whether they felt services were sufficient, and finally to indicate which services they desired for their children. Results indicated that parents preferred

that their children receive more services, particularly language services, social skills, assistive technology, sensory integration, communication training, and transitional services. Two of the desired services were also those that most of the children with ASD were already receiving - speech services and occupational therapy. In other words, although students were receiving these specific services, parents still desired more similar educational services. Parents whose children received more services had a higher degree of satisfaction and felt those services were sufficient as reported in the Pearson correlations conducted in this study. This result may seem contradictory, but as children receive more services, parents become more aware of the services available to them; thus, although they may be more satisfied, parents may still be willing to receive additional services. A specific survey question regarding awareness of services indicated that parents are aware of all services accessible to their children. Therefore, they feel that the services their children receive are sufficient, but still desire even more educational services.

Consistent with the findings in this study, the research study conducted by Dymond et al. (2007) discovered that parents requested more services for their students with ASD. Dymond et al. (2007) also found that parents wanted more services in the areas of language, social skills training, and transitional services. Lynch and Irvine (2009) also discuss how parents of children with ASD emphasize the need for the increase of ASD-specific services to benefit their children's needs. Resembling the other studies mentioned, this research study also signified the desire for more ASD-specific services such as social skills training, sensory integration, and assistive technology.

The next question this study examined was how parental preferences differed based upon their children's specific ASD subtype (i.e., Autism, Asperger syndrome, Rett syndrome, Childhood Disintegrative Disorder, or Pervasive Developmental Disorder-NOS). Results specified that there were no differences between parents' preferred educational placements and services by ASD type. However, contrary to the researcher's expectations, only three groups of ASD persons composed this study. There were not enough parents of children with more specific ASD diagnoses (i.e., Rett syndrome and Childhood Disintegrative Disorder) to be represented in this study. It is possible that if parents of children with more severe levels of Autism would have been part of this study, then significant differences on preferred education placements among ASD diagnoses may have occurred. Non-significant differences among parents of children with Autism, with Asperger syndrome, and with PDD-NOS, were also noted in some additional analyses in this study. Results showed that parents of children with different ASD conditions did not differ with regard to their overall satisfaction of educational services and the amount of services received.

Could the non-significant results between ASD diagnoses be related to the differences and current issues with the definition of ASD? The new proposed *Diagnostic and Statistical Manual-Fifth Edition* (DSM-V) is scheduled to be released in the spring of 2013. According to the Autism Research Institute (2012), the new DSM-V is projected to remove the diagnosis of Asperger syndrome, PDD-NOS, Rett syndrome, and Childhood Disintegrative Disorder. The new definition is intended to focus on the severity level of Autism Spectrum Disorders based upon support needed, due to challenges with social communication, restricted interests, and repetitive behaviors

(Autism Research Institute, 2012). If this study had occurred after the implementation of the DSM-V, then differences on parental preferences between ASD diagnoses may have emerged. Since the DSM-V will focus more on severity levels, it could be a possibility that the preferences of parents of children with varying ASD severity levels will differ regarding the placement of their children, resulting in significant differences.

The final question of this study inspected parental perceptions about the effectiveness of schools in preparing their children for adulthood. As discussed in chapter four, three particular questions addressed the issue regarding preparation for adulthood. Consistent with other results, no significant differences were found on parental satisfaction of transitional services, based on their child's primary condition. However, as discussed in the previous section, parents indicated a desire for more transitional services when comparing current transitional services and preferred transitional services. Considering this study did not specifically inquire about postsecondary goals, it could be possible that parents desired more transitional services to assist students with their post-secondary goals. Even though a study conducted by Camarena and Sarigiani (2009) disclosed the idea that parents of children with ASD have concerns about the readiness provided by schools toward postsecondary plans, one needs to take into consideration the fact that the study sample size was of only 21 families and only parents of children with high-functioning ASD were interviewed. Few research studies have been conducted regarding parental satisfaction of transitional services, but as society becomes cognizant of the increasing ASD prevalence in adulthood, more studies may arise as parental concerns increase.

This study did reveal a significant relationship between parents' total satisfaction with their children's education and parents' educational levels. It was found that parents who obtained a bachelor's degree were less satisfied with their children's education than parents who obtained a doctorate degree or professional degree. Limited research has been conducted in the area of special education parental satisfaction, parental preferences, and parental education levels to provide explanations, but theories for this significant result are expressed in the discussion section of this study.

In the additional analyses conducted in this study, it was found that parents of children with ASD diagnosed at the early age of 1-2 years had a higher preference for their children to be in smaller classes when compared to all other age groups. It could be assumed that parents of children diagnosed at the early age of 1-2 years desired smaller classes because they have had more time to understand the needs of their children, feeling that those needs could only be met in a smaller classroom setting. However, total satisfaction was not related with the age of diagnosis.

Nonetheless, the age of the child at the time of the study was negatively correlated with overall satisfaction, indicating that parents of younger children were more satisfied than parents of older children. To confirm these correlations, parents of children 14 years and older showed less satisfaction when specifically asked about transitional services and preparation for adulthood. Montes, Halterman, and Magyar (2009) conducted a similar study on parent preferences of children with ASD. Similar to this study, they found that parents of older children with ASD were less satisfied with their children's education and services than parents of younger children with ASD.

As discussed in the previous section, this study disclosed the fact that parents of older children are less satisfied with their child's education than parents of younger children. Other studies have revealed corresponding results by relating dissatisfaction toward special education and services by parents of older children with ASD (Karasi et al., 1999; Lynch & Irvine, 2009). Are parents becoming dissatisfied with placement and services over time?

Is it possible that parents have high hopes or expectations for educational placement and services when their children are younger and when schools fail to meet their high expectations; parents end up developing negative attitudes? As children with ASD grow older, parents may become less satisfied and disenchanted with the educational services because it may become more obvious that their children's needs are not being met appropriately (Kasari et al., 1999). The personal construct theory discussed in chapter two may help explain why parents become less satisfied as their children become older. Parents may be developing their own personal constructs based upon the negative experiences that their children encounter over time in school and therefore develop more negative preferences or attitudes toward educational placements and services. Parents of younger children who have not experienced many issues with services and have not had the opportunity to develop their own personal constructs may have more positive attitudes and preferences, including higher expectations and hope. Parents of older children may have more priorities to attend to with their children as their needs change and they expect more out of the educational system (Starr & Foy, 2012).

One of the most interesting findings in this study involved the four regions of the United States. When comparing parental satisfaction with their children's education

based on region of residence, results revealed that parents in the Northeast were significantly more satisfied with services than those in the Southeast region of the country. Theories regarding these results are discussed in the next section.

### **Interpretation of Findings**

It is evident from this research study and other studies previously mentioned (Lynch & Irvine, 2009; Dymond et al., 2007; Karasi et al., 1999), that parents of children with ASD desire more special education services. So why are these extra services not accessible to students with ASD? Unfortunately, more often than not, special education budgets are cut on a yearly basis, possibly preventing more ASD services to be offered. Budget cuts often lead to a shortage in special education teachers and/or related service providers. West and Hardman (2012) describe the critical shortage of special education teachers and suggest that federal funding should assist in alleviating the budget problem. Overall, they explain how this is an underlying issue in all areas of education and often school districts are limited as to which areas of education they are able to support financially.

On a positive note, this study exposed the concept that parents of children with ASD are, overall, satisfied with their current educational placement and do not desire a change in their placement. This could be attributed to the inclusion reform movement over the past few decades. Lynch and Irvine (2009) explain in their research that the trend in the ASD community is parallel with the inclusive education reform movement by utilizing best practices (inclusion) as an educational model. Even though the debate amongst researchers between a continuum of services and inclusion still exists, parents seem to be satisfied with their current educational placement.

Research suggests that students with ASD and other disabilities are encountering difficulties after graduation and parents are concerned about the future of their offspring in adulthood (Billstedt et al., 2011; Camarena & Sarigiani, 2009; Johnson et al., 2007; Tymchuk, et al., 2001). This study discovered that parents of children with ASD over the age of 14 seemed to be dissatisfied with their current education. Moreover, as previously explained, parents of younger children showed more satisfaction overall with the services schools provide than parents of older children. This may be a result that their children have not entered adulthood and parents are not able to witness if their children are struggling independently as adults. Camarena and Sarigiani (2009) discovered that parents of children with ASD felt that schools should provide more training toward a vocational or postsecondary school track in order for the children to become more independent, which may need to occur in a different educational placement setting.

Parents did indicate a yearning for more transitional services in this research study, which denotes a growing concern and need for adult preparation considering the influx of ASD diagnosis over the past decade. As discussed in Chapter Two, the prevalence of ASD has increased significantly and these students will be transitioning into adulthood during the next decade. Sullivan (2005) discussed the fact that there are only 25 agencies that voluntarily provide services specifically for adults with ASD. Parents are possibly now becoming more aware that the prevalence of ASD is surpassing the amount of services available to adults with ASD, giving reason for the growing concern and desire for more services prior to adulthood.

Very little research has been conducted on parental preferences amid the different ASD diagnoses. Considering the participants in this study were all members of a support

group, this may be a factor as to why there were no significant differences among the ASD subgroups. It might be assumed that parents of children with ASD have a large enough support group online or within their community when compared to parents of children with other disabilities. Support groups allow parents to educate themselves regarding ASD by communicating with other parents and utilizing the resources offered to them through an online support group. Therefore, they are able to advocate for their children, resulting in higher satisfaction. Perhaps, this is another reason why satisfaction did not vary significantly among ASD subtypes.

Parental education level and parents' satisfaction were significantly interrelated in this study. It could be possible that parents with a higher degree are more conscious or educated regarding the educational placements and services available to their children. Due to their higher educational level, they may have acquired research skills and are able to access research studies on ASD or resources for their children more effectively than those with a lower educational level. Many of these parents take the advocacy role and learn more about available educational opportunities by researching them (Stoner & Angell, 2006). So therefore, they are more satisfied with their children's placement because such placements are actually the placements for which they advocated.

Finally, this study revealed that parents of students with ASD in the Northeast of the United States are inclined to be more satisfied with the educational placement and services than parents in the Southeast. Not much research has been conducted on the comparison of parental preferences across regions of the United States. It is possible that more services for students with ASD or teacher professional development are being provided in the Northeast; however, this study did not indicate that any one particular

region was receiving more services than another. It may also be a possibility that more support groups are available in the Northeast for parents of children with ASD compared with parents in the Southeast. In-depth comparative studies should be conducted about the differences that exist in the provision of special education services across the country as well as ASD support groups available to parents. To further elaborate about this issue, Henderson (2011) reported that states in the Northeast offer content-specific summer trainings to general education teachers, which focus on how to assist and provide accommodations to students with disabilities in the classroom. As mentioned previously, the Northeast may also provide more family support than what might be offered in the Southeast. Research shows that some of the states in the Northeast do provide intensive behavioral interventions to families of children with ASD (Henderson, 2011). This combination of both educator professional development in the area of educational services and behavioral interventions for families of children with ASD may allocate more positive experiences for students. Again, consistent with the personal construct theory, parents may develop optimistic personal constructs on the basis of these experiences resulting in more satisfaction of services.

#### Limitations

This study did experience some limitations. These limitations may significantly impact the generalizations of the results of this study. The limitations of this study were as follows:

 The participants of this study were all members of particular Yahoo groups and may not be an accurate representation of all parents of children with ASD throughout the United States. If more members checked their email or logged onto the online support group, there may have been more participants. An attempt was made by the researcher to provide daily-posted reminders to complete the survey for those members who may not have logged onto the Yahoo support group within an extended period of time, but participants notified the researcher that postings were too abundant and the researcher reduced the amount of postings to once a week.

- The data for this study came from online parent support groups for families of children with ASD, and their views may differ from families who are not members of similar online support groups.
- 3. Self-reported parental preferences were represented in this research. It is unknown whether these self-reports truly reflect what may be occurring in the school districts. Even though parents and schools are encouraged to collaborate with one another, it is improbable that parents are completely aware of everything that transpires in the classroom.
- 4. Since few parents indicated a diagnosis of Rett syndrome or Childhood Disintegrative Disorder, parental satisfaction amongst all ASD subtypes was difficult to assess. This study included the most prevalent ASD conditions (i.e., Autism, Asperger syndrome, and Pervasive Developmental Disorders-NOS), without being able to assess the investigated issues with less prevalent groups (i.e., Rett syndrome and Childhood Disintegrative Disorder).

### **Recommendations for Future Research**

We know that the number of children identified with ASD continues to grow rapidly across the United States and as educators we try to make sure that these students are not only educated in the correct educational settings where they can learn to their fullest potential, but that they are receiving the services they need to become independent citizens of our society. Findings from this study propose numerous questions for future research that should be understood at the local, state, and federal levels.

More research needs to be conducted on parental preferences in the four regions of the United States. Why are parents in the Northeast more satisfied than those in other regions? Specific variables need to be investigated, such as precise services provided to students with ASD, types of supports provided to families of students with ASD, socioeconomic status, and parent educational levels. If researchers can discover what enables parents from a specific region to be more satisfied with different placements and services, than maybe these discoveries could be implemented in other regions in the United States.

Further research needs to be conducted involving parents educational and services preference variables and the effect those preferences may have on the academic and social performance of children with ASD. Countless research studies have been completed on parents' perceptions and the effect those perceptions have on academic and social progress of children with diverse disabilities (Fan & Chen, 2001; McDonnall, Cavenaugh, & Giesen, 2012), but few studies have been completed that specifically address children with ASD. As described in Chapter Two, students with ASD learn and socialize in vastly different ways and their parents may have different perceptions, preferences, or attitudes when compared to parents of children with other disabilities. The educational placement and services provided to students with ASD has improved immensely in the past few decades (Rapin, 2005), however, this research study

demonstrates the vital need for school districts to continue to improve the educational placement and services they provide to students with ASD.

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# Appendix A

## **Survey Instrument**

# Educational Placement and Service Preferences by Parents of Children with ASD Inventory

1.	Child's Gender: Male Female
2.	Child's Age:
3.	Your relationship to the child:
4.	Your highest degree: Doctorate or Professional Degree Masters degree Bachelors degree Associate degree High school diploma GED
5.	Your Gender: Male Female
6.	In which state do you live?
7.	Child's Diagnosis ( <i>check all that apply</i> ): Autism Asperger's Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) Rett's Syndrome Childhood Disintegrative Disorder Not sure Other:

- 8. When was your child first diagnosed with the above condition (*select only one*)?
  - At birth Age 1-2 Age 3-4 Age 5-6 Age 6+

- 9. Child's Educational Placement:
  - \_\_\_\_\_ Full time in a general education classroom (inclusion)
  - \_\_\_\_\_ Part-time in a special education classroom
  - \_\_\_\_\_ Full-time in a special education classroom
  - \_\_\_\_\_ Special school for students with diverse disabilities
  - \_\_\_\_\_ Special school for students with Autism Spectrum Disorders

\_\_\_\_ Other:\_\_\_\_\_

(*Explain*)

- 10. What services does your child currently receive at school? (check all that apply):
  - \_\_\_\_\_ Applied Behavior Analysis (ABA)
  - \_\_\_\_\_ Speech therapy
  - \_\_\_\_\_ Language therapy
  - \_\_\_\_\_ Social skills training
  - \_\_\_\_ Occupational therapy
  - \_\_\_\_\_ Physical therapy
  - \_\_\_\_\_ Behavioral management (not ABA)
  - \_\_\_\_\_ Assistive technology
  - \_\_\_\_ Counseling
  - \_\_\_\_Sensory integration therapy
  - \_\_\_\_Communication training
  - \_\_\_\_Early intervention
  - \_\_\_\_Transition services

\_\_\_\_ Other:\_\_\_\_\_

(*Explain*)

# **Regardless of your child's current placement and services, please indicate your preferences for the following two questions (questions 10 and 11).**

- 11. I would like my child to be in...(*please select one*):
  - \_\_\_\_\_ Full time in a general education classroom (inclusion)
  - \_\_\_\_\_ Part-time in a special education classroom
  - \_\_\_\_\_ Full-time in a special education classroom
  - \_\_\_\_\_ Special school for students with diverse disabilities
  - \_\_\_\_\_ Special school for students with Autism Spectrum Disorders
  - \_\_\_\_ Other:\_\_\_\_\_

#### (Explain)

- 12. I would like my child to receive the following services at school (*check all that apply*):
  - \_\_\_\_\_ Applied Behavior Analysis (ABA)
  - \_\_\_\_\_ Speech therapy
  - \_\_\_\_ Language therapy
  - \_\_\_\_\_ Social skills training
  - \_\_\_\_ Occupational therapy
  - \_\_\_\_\_ Physical therapy
  - \_\_\_\_\_ Behavioral management (not ABA)

- \_\_\_\_\_ Assistive technology
- \_\_\_\_ Counseling

\_\_\_\_\_Sensory integration therapy

- \_\_\_\_Communication training
- \_\_\_\_Early intervention
- \_\_\_\_\_Transition services
- \_\_\_\_ Other: Explain\_\_\_\_\_

On a scale from 1 to 5, indicate your agreement with each one of the following items. Indicate your selection by placing an 'x' in the box.

SD	Ď	Ν	Α	SA
Strongly	Disagree	Neutral	Agree	Strongly
Disagree	-		-	Agree
1	2	3	4	5

	SD 1	D 2	N 3	A 4	SA 5
13. The services that my child receives at school are sufficient.					
14. My child's current placement is appropriate.					
15. My child likes to go to school.					
16. My child's teacher is knowledgeable about ASD.					
17. My child's teacher uses good strategies to teach students with ASD.					
18. Other professionals who provide services to my child are knowledgeable about ASD.					
19. I feel that my child should be in a smaller class.					
20. I see that my child is improving academically.					
21. My child should be in classes with non-ASD students the majority of the day.					
22. I see that my child is improving socially.					
23. I see that my child is improving behaviorally.					
24. My child should receive more services than he/she currently receives.					
25. I am aware of the services that my child could receive based on his/her needs.					
26. The staff at my child's school collaborates effectively with me.					
27. I think that my child is happy at school.					
28. The educational placement of my child is conducive to learning.					

29. My child is accepted by students without disabilities.		
30. My child's school is effectively preparing my child for		
his/her future.		
31. I am satisfied with the IEP meetings at my child's school		
32. I attend most (or all) IEP meetings.		
33. I think that my child will succeed in his/her job when		
he/she grows up.		
34. I think that my child will adapt well to society as an adult.		
35. I am an active advocate of my child's rights.		
If your child is 14 years old or older, please answer		
numbers 36 through 38.		
36. The school provides adequate transitional services.		
37. The school is assisting us to plan for my child's post-		
school employment or college.		
38. The school is preparing my child to be an independent		
odult		
adun.		

## Appendix B

## **Introduction email**

Dear Yahoo group members,

Lisa Tritschler, a doctoral candidate at Barry University is researching the educational placement and service preferences by parents of children with Autism Spectrum Disorder (ASD). While substantial research has been conducted regarding the parental preferences of children with disabilities, limited research has focused on the parental preferences of children with ASD. Your voluntary participation in this study is vital in the continuing research of children with ASD. Attached you will find the cover letter explaining more information regarding your participation in this study.

Please follow the link below to direct you to the survey. The survey should take no longer than 15 minutes to complete. We thank you in advance for your time.

https://www.surveymonkey.com/s/Q6ZMXPX

#### Appendix C

#### **Cover Letter**

Dear Research Participant:

Your participation in a research project is requested. The title of the study is Educational Placement and Service Preferences of Parents of Students with Autism Spectrum Disorders (ASD). The research is being conducted by Lisa Tritschler, a doctoral student in the Education Department at Barry University, and is seeking information that will be useful in the field of special education. The aims of the research are to investigate the type of educational placement and services preferred by parents of students with ASD. In accordance with these aims, the following procedure will be used: A questionnaire called the Educational Placement and Service Preferences by Parents of Children with ASD Inventory, which follows this letter, will be completed by parents of students with ASD. I anticipate the number of participants to be 300.

If you decide to participate in this research, you will be asked to do the following: Answer the questions on the parental survey by following the link to the Survey Monkey. The questionnaire is estimated to take no more than 15 minutes to complete.

Your consent to be a research participant is strictly voluntary and should you decline to participate or should you choose to drop out at any time during the study, there will be no adverse effects. Upon completion of the survey, Survey Monkey will ask your permission to enter your email address into a drawing for one \$25 gift card to Amazon.com. Your email will remain anonymous to the researcher if you choose to participate in the drawing.

There are no risks involved in your participation of this study. The following procedures will be used to minimize these risks: You can skip any questions you do not want to answer. There are no direct benefits to you for participating in this study; however, your participation will contribute to research in the area of autism and special education. All data collected will be destroyed after five years (2016).

As a research participant, information you provide is anonymous, that is, no names or other identifiers will be collected. SurveyMonkey.com allows researchers to suppress the delivery of IP addresses during the downloading of data, and in this study no IP address will be delivered to the researcher. However, SurveyMonkey.com does collect IP addresses for its own purposes. If you have concerns about this, you should review the privacy policy of SurveyMonkey.com before you begin.

By completing and submitting this electronic survey you are acknowledging that you are at least 18-years-old and that you voluntarily agree to participate in the study.

If you have any questions or concerns regarding the study or your participation in the study, you may contact me, Lisa Tritschler, by phone at (954) 993-8170 or by email at lisa.tritschler@mymail.barry.edu. You may also contact the Institutional Review Board point of contact, Barbara Cook, by phone at (305) 899-3020 or by email at bcook@mail.barry.edu.

Thank you for your participation. Sincerely, Lisa Tritschler

## Appendix D

## **Reminder Post**

Dear Yahoo group members,

This is a reminder to complete the survey from a research study conducted by Lisa Tritschler, a doctoral candidate at Barry University. Attached you will find the cover letter explaining more information regarding your participation in this study. If you have already completed the survey, please disregard this email.

Please follow the link below to direct you to the survey. The survey should take no longer than 15 minutes to complete. We thank you in advance for your time.

https://www.surveymonkey.com/s/Q6ZMXPX

## Appendix E

## **Final Post**

Dear Yahoo group members,

This is a reminder to complete the survey for a research study by May 31, 2012. Attached you will find the cover letter explaining more information regarding your participation in this study. If you have already completed the survey, please disregard this email.

Please follow the link below to direct you to the survey. The survey should take no longer than 15 minutes to complete. We thank you in advance for your time.

https://www.surveymonkey.com/s/Q6ZMXPX