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# THE CHANGING FACE OF AUTISM SPECTRUM DISORDER: A COMPREHENSIVE LOOK AT THE HISTORY, LEGISLATION, AND SCHOOL-BASED INTERVENTIONS OF ASD

A thesis submitted to Regis College The Honors Program in partial fulfillment of the requirements for Graduation with Honors

by

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## Introduction

In the summer of 2008, fresh out of high school, I volunteered to teach a swimming lesson specifically for children with disabilities, and despite a lot of trying moments, ended up having a blast with the kids. Because of this experience, I offered my services the following summer to help out a co-worker with a swimming lesson for twin girls who had both been diagnosed with autistic disorder. The first few lessons with the girls were spent herding them away from the deep end, and helping them become comfortable in the water by practicing basic skills such as front floats, back floats, blowing bubbles, and kicking. During these lessons the girls rarely spoke and often had difficulties following verbal directions, but they were always willing to try anything my co-worker or I demonstrated to them. The twins spent the following school year working closely with a therapist specializing in autism. The improvements the girls showed the next summer was amazing. By referring to a representation of the day's lesson in pictures, they were able to follow the order of the lesson and participate in most of the group activities and games, a feat I would have thought impossible less than a year before.

By the end of that summer one twin was able to submerge herself underwater and retrieve a diving stick, and the other twin had practically mastered the front crawl stroke. I attribute the improvement in the twins' swimming skills to the behavioral therapies they had received consistently over the past school year, and the simple changes made to the swimming lessons to accommodate their learning disabilities. One of the most effective strategies we used was drawing out the order of activities on a white board the twins could easily reference during any point in the lesson.

Working with the twins at the pool motivated me to find out more about autism, so I seized the opportunity to shadow a speech-pathologist as she worked on language development with preschool aged children who had been diagnosed with autism. Watching the kids in the classroom setting was an eye-opening experience. Seeing the behaviors of the kids with autism and being able to compare those to the behaviors of the children with typical development helped me to see what autism was, and how it affects growth and development. Another benefit of the shadowing experience was being able to observe the behavioral intervention strategies I had read about in action. When playtime was winding down, the teacher came over and showed the child the schedule and a card with a picture of food, and proceeded to tell her it was going to be time to put the toys away soon and start snack time. The child nodded and began picking up her toys. Later, the teacher told me the transition from free play to snack time had been a difficult time in the day for the student, but the use of visual schedules and pictures had made the switch much easier.

The topic of autism is often splashed across the front page of newspapers or the headlines of nightly news reports along with new theories about possible treatments, cures, and causes. These reports seem to generate mass public interest despite a lack of scientific evidence. Autism is a subject that has gained a lot of attention in the past few

years. Recently, there has been much buzz in the media about the changes in the diagnostic criteria for autism, and how these changes will affect the lives of individuals with autism. The definition of autism is currently undergoing revisions for the publication of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders which is expected to be out in 2013. The American Psychiatric Association, which is responsible for the authorization of the DSM-V, is attempting to merge the pervasive development disorders of autistic disorder, Asperger's syndrome, and PDD-NOS, into one term, Autism Spectrum Disorder (ASD). With the changing language of autism spectrum disorders, the diagnostic tools used to identify this order will also have to be evaluated to determine their diagnostic utility under the new definitions. Ideally, the new definitions will make it easier for clinicians and physicians to determine whether an individual has ASD or not using already established practices, but the validity of these diagnostic methods combined with the new definitions remains to be seen.

As we learn more about Autism Spectrum Disorders, the definition becomes more precise, which often means that less people will qualify for diagnosis of the disorder. One concern for individuals with high functioning autism, or individuals previously diagnosed with Asperger's syndrome, is their eligibility to qualify for special education or additional services that serve to help them cope with their disorder and achieve their full potential. The potential for these children to no longer qualify for the special services provided by public schools is very real and imminent. If they no longer qualify for special education or other services because they are not considered to have an ASD their ability to learn will be greatly inhibited. My thesis explores the process of receiving

special education and additional services for children with ASD, how effective ASD strategies are implemented in the classroom, and how these important processes could change in coming years.

## **History of Autism Spectrum Disorders**

Although autism has most likely been present in our society for centuries, the disorder was not recognized in a clinical setting until the 1940's. Dr. Leo Kanner was one of the first researchers to systematically study children who exhibited delays in communication skills and normal social interaction, and he was also one of the first to use the term "autism" to articulate the unique behaviors exhibited by these individuals (Volkmar & Klin, 2005). Dr. Kanner's clinical observations paved the way for present autism research by providing reliable and scientific accounts of the characteristics of autism. Dr. Kanner's (1943) original study, titled "Autistic disturbances of affective contact", was based on eleven children who showed delayed communication and social skills; the results were based on collected data and the latest child development theories of 1943.

Dr. Kanner described the study's subjects as being born without the desire for normal interpersonal communication. Kanner used the term autism to define the "selfcontained quality of children born without the biological pre-conditions for psychologically metabolizing the social world." (Kanner, 1943). Kanner's research and descriptions of his subjects played an important role in initializing the distinguishment of autistic behaviors from other psychological disorders such as childhood schizophrenia. Eugen Bleuler (1951) also used the term autism to describe self-centered thinking observed in schizophrenic patients. Before Kanner's work with the disorder autism was considered to be another form of childhood schizophrenia (Pennington, 2009). Now, it is known that autism is completely separate from childhood schizophrenia.

From his study in 1943, Kanner witnessed and described many behaviors that are still used today to recognize an autism diagnosis. These behaviors include social failure, resistance to change, and communication delays (Kanner, 1943). In Dr. Kanner's study, three of the children were deaf, a few were mute, others exhibited echolalia, and some experienced difficulties using the first person and the pronoun "T" in conversation. Other participants in the study were most comfortable referring to themselves in the third person. Dr. Kanner also reported that some children in the study showed atypical responses to inanimate objects and their environment, such as changes in sound or altered routines, yet had little to no response to parental interaction (Kanner, 1943).

Dr. Kanner initiated an important paradigm shift in the understanding of autism, although some of the conclusions from his original study have been discredited in more recent years. For example Dr. Kanner reported observing problems in the parent-child relationships of the children that were in his original study (Kanner, 1943). Because of these observations, the misconception that certain psychological factors associated with parenting techniques, especially "refrigerator mothers", play a significant role in the development of autism was prevalent until it was dispelled in the 1960's (Volkmar & Klin, 2005). This early postulation of autism has since placed a sense of blame on parents of children with autism, even though it has long since been disproven. Dr. Kanner also concluded from his research that autism was not related to other medical

disorders, and children with autism were not "feebleminded"; they all possessed "good cognitive potentialities" (Kanner, 1943). Today, it is accepted that individuals with autism exhibit a broad range of IQ scores, and can exhibit strengths and weaknesses in different areas of academic achievement (Irwin, MacSween, & Kerns, 2011). A recent study done by Catherine Jones and colleagues (Jones et al., 2009) found that approximately seven out of ten adolescents with autism showed an area of significant strength or weakness in at least one area of reading, writing, reading comprehension, or mathematical skills not consistent with the expected achievement based on their IQ scores.

According to the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV-TR; American Psychiatric Association, 2000), autism is classified as a pervasive developmental disorder (PDD), along with Rett's disorder, childhood disintegrative disorder (CDD), Asperger's disorder and PDD not otherwise specified (PDD-NOS). All of these disorders involve a deficiency in three areas to some extent, and may occur at different points in development: social interaction, communication, and an unusual array of behaviors, interests, and activities (Pennington, 2009, p. 111). The diagnostic criteria for these five disorders are very similar in many aspects, but the differences constitute the need for clarification among the diagnoses. Distinctions between the disorders are important for communication purposes in the medical field, receiving educational services, and research (Volkmar & Klin, 2005). The official guidelines for diagnosis of the disorders that are outlined in the DSM-IV are based on

observation of a child's development and behavioral history. However, treatment programs should be based on an individual's needs, not their clinical diagnosis.

## **Pervasive Developmental Disorder Diagnoses**

# **Autistic Disorder**

Autistic disorder (AD) is a complicated disorder with many facets. It is characterized by deficits in communication and social skills (Pennington, 2009, pg. 109). Drs. Stanley Greenspan and Serena Wieder, authors of Engaging Autism, describe autism as a "dynamic" disorder, always changing (Greenspan & Wieder, 2006, pg. 4). The Handbook of Autism and Pervasive Developmental Disorders outlines early signs of autism; some are recognizable in infancy and others can only be seen as development progresses. Early indicators of autism include poor muscle tone as babies, odd reflexes including visual rooting reflex, and atypical response to human interaction (Fombonne, 2005). Early signs of autism can also include the tendency to put things in their mouth more often than other babies, being happy to be left alone, poor response to own name, and a preference to not be touched (Chawarska & Volkmar, 2005; Fombonne, 2005). Dawson and colleagues (Dawson, Osterling, Meltzoff, & Kuhl, 2000) also found avoidance of eye contact, focus on the mouth of the speaker, and reduced motor and babbling imitation as early precursors of childhood autism. For the official DSM-IV definition of autistic disorder see the Appendix.

Some parents begin to notice characteristics of autism within the first year of life, but concerns become more apparent when speech is delayed in their children, or they

have difficulties forming relationships with their peers. After one year of age, signs of autism expand to include poor play or pretending skills, reduced motor imitation, making odd sounds, and reduced inclination to show objects or share interests with other people (Chawarska & Volkmar, 2005). As children with autism grow and develop they continue to show limited social interest, poor interaction with peers, difficulty sharing affection, reduced verbal and nonverbal communication, and may develop stereotyped behaviors, such as repetitive motion, and hyper/hypo sensitivity to stimuli (Joseph, Tager-Flusberg, & Lord, 2002). Children with autism also frequently develop an attachment to atypical objects, which may be hard and rigid rather than typical stuffed animals, or it may be a connection to a specific type of item, such as a magazine instead of a specific object (Volkmar et al., 1994). Autism affects three to five times more males than females, but females with autism are more likely to have an intellectual disability (Volkmar & Klin, 2005).

# Asperger's Syndrome

Hans Asperger was a medical student studying at the University of Vienna during World War II in 1944 (Klin, McPartland, & Volkmar, 2005). Asperger was especially interested in boys who had difficulties forming relationships and relating to peers in social situations. In his original study in 1944, Asperger characterized the boys in his study as "little professors" to describe their idiosyncratic behaviors (Asperger, 1944). Asperger described the boys as possessing typical language, communication, and cognitive abilities, but had unusual interests (Asperger, 1944; Klin, McPartland, &

Volkmar, 2005). For example, one boy in Asperger's study knew all of the train and bus schedules going out of Vienna. These types of unusual interests are termed "circumscribed interests" (Klin, McPartland, & Volkmar, 2005); they are interests that interfere with gaining skills in other aspects of a child's life, drawing the distinction between an odd personality trait and a disorder (Klin, Danovitch, Merz, & Volkmar, 2007). The topics of circumscribed interests can vary from person to person but they typically dominate social exchanges in persons diagnosed with Asperger syndrome (Klin, McPartland, & Volkmar, 2005).

Asperger also observed impaired nonverbal communication, conduct problems, clumsiness, and awkward motor skills in the boys of his study (Asperger, 1944). Asperger noted that several of the study subjects had family members, especially fathers, with similar problems and social deficiencies. Even though Asperger did not know of Kanner's work on autism because of the war, he also used the term autistic childhood personality disorder in his description of the observed behaviors (Asperger, 1944). Asperger used a German term "Autistichen Psychopathen" that is best translated as autistic personality disorder to describe the behavioral problems the boys of his study presented; today it is known as Asperger's syndrome or Asperger's disorder (Asperger, 1944; Klin, McPartland, & Volkmar, 2005).

Asperger's disorder is currently defined by the following criteria: display of social interaction problems as those of autism, unaffected early language and cognitive function, problems not recognized right away, and having a passionate and distracting

interest (American Psychiatric Association, 2000; Volkmar & Klin, 2005). In addition to these defining characteristics, the term Non-verbal Learning Disorder (NLD) which is defined by strengths in areas such as auditory perception, verbal memory skills, and verbal output, and weaknesses in areas such as tactile perception, visual-spatial skills, and nonverbal problem solving skills, is often seen in individuals diagnosed with Asperger's disorder, although it is not part of the clinical diagnostic criterion of Asperger disorder. This type of learning disorder has been associated with children exhibiting severe impairments in socialization skills. NLDs are frequently seen in individuals diagnosed with Asperger's disorder and PDD-NOS, but not common in individuals with autism (Gunter, Ghaziuddin, & Ellis, 2002; Klin, McPartland, & Volkmar, 2005). Interestingly, Asperger's disorder is more common in males than females (Volkmar & Klin, 2005).

# **Rett's Disorder**

Rett's disorder was included in the classification of Pervasive Development Disorders because of the repetitive hand motions and atypical behavioral patterns similar to autism, but is distinguished by the disorder's unique developmental trajectory. Rett's disorder was first depicted by the Austrian physician Andreas Rett in 1966 (Van Acker, Loncola, & Van Acker, 2005). Rett (1966) described the set of girls he studied as appearing normal at birth, and showing normal development for the first few months of life, but then sometime during the first year of life, their developmental skills began to digress (Rett, 1966). Rett also observed that the subjects began to lose control of hand motions and exhibited hand-wringing behaviors. The time when children with Rett's

disorder begin to lose developmental skills is known as "developmental stagnation" (Van Acker, Loncola, & Van Acker, 2005). Rett's disorder occurs primarily in females, and is characterized by a digression in motor, language, and social skills after the first five to thirty months of the child's life. It is a progressive neurological disease, and causes a deceleration in brain growth and development (Pennington, 2009, p. 111; Van Acker, Loncola, & Van Acker, 2005).

Since Andreas Rett's first observations in 1966, other characterizations of Rett's disorder have been identified. It has been observed that children with Rett's disorder show a loss of interest in people when they approach preschool age, which has caused confusion in the past with the differences between autism and Rett's disorder, but these autism-like behaviors usually abate with time (Van Acker, Loncola, & Van Acker, 2005). The following symptoms have been added to the list characterizing Rett's disorder: unusual hand-wringing motions, respitory symptoms such as breath-holding and air swallowing, seizure disorders, frequent scoliosis and walking problems, severe mental retardation in early adulthood (Van Acker, Loncola, & Van Acker, 2005).

As with other pervasive developmental disorders, research has been done in the last few years in an attempt to identify the cause of Rett's disorder. One such study succeeded at isolating a gene that may be responsible for cases of Rett's disorder. The gene identified is the MECP2 gene on an X chromosome, and is characterized as an Xlinked dominant disease (Amir, Van der Veyver, Wan, Tran, Francke, & Zoghbi, 1999). Rett's disorder was once thought to only affect girls, but there have been documented

cases of boys with the disorder, although these are extremely rare because male fetuses with this disorder rarely survive (Van Acker, Loncola, & Van Acker, 2005).

#### **Childhood Disintegrative Disorder**

Similar to Rett's disorder, childhood disintegrative disorder also features a period of normal development followed by a period of severe regression in development at which point children can develop autistic-like symptoms. However the stage of regression occurs at a later point in development in comparison to Rett's disorder. Childhood disintegrative disorder (CDD) was first officially characterized by Theodore Heller in Vienna in 1908. Heller studied a group of children that had normal development for the first few years of their life, and then entered a striking phase where skills regressed, and did not return (Volkmar, Koenig, & State, 2005). Heller (1908) originally used the term *dementia infantilis* to describe this disorder (Heller, 1908). The cause of childhood disintegrative disorder is largely unknown, but, similar to Rett's disorder, also results in the digression of motor, language, and social skills after a period of normal development that lasts anywhere from two to ten years (Pennington, 2009, p. 111).

Children who are diagnosed with CDD usually spend the first three to five years of their lives developing normally. They exhibit normal language advancement, typical social skill development, and bowel control (Volkmar, Koenig, & State, 2005). This period of normal progression is followed by either a sudden or steady loss of skills. The regression in skills is always seen by the age of ten. Children with CDD begin exhibiting

behaviors that are similar to autism such as repetitive motion, motor mannerisms, and a lack of interest in people and environment. The digression of skills usually results in severe cognitive delays, and is frequently accompanied by seizure disorders. Childhood disintegrative disorder is rare, and there is a range of estimates concerning the exact rate of the disease, but it is estimated to be approximately one hundred times less common than autism. Gender also plays a small role in the occurrence of CDD as it is more common in males (Volkmar & Klin, 2005). The exact cause of CDD and the resulting loss of developmental skills is unknown at this point (Volkmar, Koenig, & State, 2005).

# Pervasive Development Disorder Not Otherwise Specified

The catch-all in the category of pervasive development disorders is also the last leg of the autism spectrum, pervasive development disorder not otherwise specified (PDD-NOS). People diagnosed with PDD-NOS present some aspects of the previously discussed pervasive developmental disorders but do not meet the criteria for diagnosis. PDD-NOS is hard to define or identify because it can encompass a range of symptoms and severities. PDD-NOS is characterized by problems in social aspects and either language, communication, or play skills (Towbin, 2005). In order to be diagnosed with PDD-NOS, more than one deficit must be present; a single symptom is not sufficient for a diagnosis. PDD-NOS is more common than strictly defined autism, partly because it encompasses a broader range of symptoms (Towbin, 2005). There is no significant difference in the male to female ratio for PDD-NOS (Volkmar & Klin, 2005).

#### **Causes of Autism Spectrum Disorders**

There has been much speculation about the causes of autism spectrum disorder ever since Kanner's observations of the disorder in the 1940's. In the 1970's, research began to suggest that the cause of autism was brain-based and involved genetics (Rutter, 2005). The evidence for suggesting that autism spectrum disorder is linked to genetics has been found in studies of high rates of coincidence in identical twins (e.g., Bailey, Le Couteur, Gottesman, Bolton, Simonoff, & Yuzda, 1995), and research focusing on an increased risk for autism in siblings of children with autism (e.g., Folstein & Rutter, 1977). In one study of identical twins, the concordance rate of autism was sixty percent when a strict definition of autism was used, and ninety percent when a more broad definition of autism was used (Fombonne, 2005). In a survey done by Bonora and colleagues (2006), four percent of children with autism had siblings that were also diagnosed with autism, which is extremely high when compared to the rate of the general population which is between 0.1 and 0.16 percent (Bonora, Lamb, Barnby, Bailey, & Monaco, 2006).

The exact genetic causes of autism is not known, but research suggests autism spectrum disorder induced by the interaction of as many as fifteen or more different genes, indicating it is a polygenetic disorder (Santangelo & Tsatsanis, 2005). In recent years, the researchers heading the International Molecular Genetic Study of Autism have identified a strong linkage between autism and a locus on chromosome 7q (International Molecular Genetic Study of Autism Locus Consortium, 1998). Other studies have also

suggested there are possible connections between the loci on chromosomes 1q, 2q, 3q, 15q, 16p, 17q, and 19q (Durand et al., 2007; Lamb et al., 2002; Volker & Lopata, 2008). In an attempt to link affected genes and autism, the Autism Genome Project Consortium studied the genes of 1200 families of children with autism, and specifically analyzed copy number variations, which include deletions, insertions, or duplications of nucleic acids in the DNA sequences. From this data, researchers discovered evidence supporting linkage on the loci of chromosomes, 2q, and 7q to autism, and also gathered data that suggest the involvement of chromosome 11p (Abramson et al., 2007).

Because the heritability of autism spectrum disorder is not 100%, environmental factors must also play a role in the cause of ASD. It was once believed that pregnancy complications, pre-natal infections, and vaccinations caused autism spectrum disorder but those factors have all since been disproven (Volkmar & Klin, 2005). Although there are plenty of myths out there about the environmental causes of autism spectrum disorder, none have convinced the science community of its validity. One recent study shows a correlation between traffic emissions and babies born with autism spectrum disorder, but more research is needed to draw more definite conclusions (Delwiche et al., 2011). Other studies have linked autism spectrum disorder to exposure to certain chemicals such as thalidomide, misoprostol, valproic acid, and organophosphate insecticides (Landrigan, 2010). In order to determine if any of these chemicals really do contribute to the cause of autism spectrum disorders, more research is needed.

Surveys of the population over the past few decades have revealed an increase in the rates of autism spectrum disorder. Currently, the Center for Disease Control estimates the prevalence of autism spectrum disorders to be approximately one in 110 in the United States, which is a huge increase compared to one in 150 in 1997, and one in 10,000 in the 1980's (Center for Disease Control, ASD Data and Statistics, 2007). The increasing rates of autism are likely due to a number of factors. The first credited reason for the increase in autism prevalence is improved awareness and education of both the medical community and the public about autism thanks to people like Temple Grandin who have made their struggles about living with autism and contributed to public awareness (Volkmar & Klin, 2005). Children who were previously labeled as "mentally retarded" or just socially "odd" are now recognized as meeting criteria for an autism spectrum disorder.

Another possible reason for the increase in autism diagnoses is due to a push from parents to get an autism diagnosis, since some people believe it is easier to guarantee access to special education and additional services when their child has been labeled with this prominent disorder compared to other intellectual disability labels; this is referred to as "diagnostic substitution" (Fleisher & Zames, 2001). In addition to these diagnostic reasons, the incidence of autism spectrum disorders does appear to truly be increasing in the general population although the reason for this is unknown (Volker & Lopata, 2008). Because of the raped rate of increase, it appears that some environmental influences are contributing to the increased incidence, but much more research is needed to determine

the exact environmental influences affecting the expression of the genes connected to ASD.

# **Diagnosing Autism**

There are many well-established methods available for the identification of childhood autism spectrum disorder. The instruments used to identify the presence of autism work by outlining guidelines for diagnosis based on observation of symptoms described by the DSM-IV-TR and interviews of the student and parents. The identification and classification of autism spectrum disorder is important in order for children to receive special education services early on. For the purposes of this paper, four of the fundamental instruments for identifying autism spectrum disorder are described.

## **Childhood Autism Rating Scale**

The first diagnostic tool designed to identify children with autism was developed by Shopler and Reichler in 1971. Their method was termed the Childhood Autism Rating Scale (CARS) and it consisted of the following items: relating to people, imitative behavior, emotional response, body response, listening response, perceptive response, fear or anxiety, verbal communication, non-verbal communication, activity level, level and consistency of intellective relations, and general impressions (Shopler & Reichler, 1971). The examiner scores each item from one to four with one referencing ageappropriate behavior and four indicating abnormal behavior. Individual scores for each item are equally weighted, and added together for a total score. A total score draws distinctions between considerations of autistic, moderately autistic, and severely autistic

(Shopler & Reichler, 1971). When performed in a clinical setting, studies have reported the reliability of CARS to be 94% (Shopler, Reichler, & Renner, 1988). CARS is considered to be reliable for distinguishing between subjects with autism and subjects without autism, can distinguish between autism disorder and other pervasive development disorders, and can be used to assess adults and adolescents with autism. In many situations, CARS is still used by parents to make early distinctions between normal and abnormal behavior, and can encourage them to seek further medical consultation (Worley & Matson, 2011).

## **Autism Behavior Checklist**

Another early diagnostic tool used to identify autism was the Autism Behavior Checklist (ABC). The ABC was designed to be given by a teacher or primary caregiver and evaluated by a professional clinician. The Autism Behavior Checklist describes typical behaviors of autism and assesses the presence of these behaviors in a subject. It examines five symptom areas: sensory, relating, body and object use, language, and social and self-help. The checklist consists of fifty-seven items which are scored on a scale of one to four based on the presence of the behavior in question (Krug, Arick, & Almond, 1978). It takes approximately twenty minutes to complete the evaluation, and is recommended for use with children aged three through school-aged. (Worley & Matson, 2011) The checklist was developed by Krug, Arick, and Almond (1980) who found the consistency of the Autism Behavior Checklist to be approximately 94%. Other studies have found the reliability of the checklist to be closer to a 78% diagnosis rate (Volkmar, Cicchetti, Dykens, Sparrow, Lekman, & Cohen, 1988).

More recently, the Autism Behavior Checklist is considered to be accurate in distinguishing between subjects with Autism Spectrum Disorder and those without Autism Spectrum Disorder, but is not recommended for use with children younger than three years. (Worley & Matson, 2011) It is used to identify individuals with autistic disorder only, not Asperger disorder or PDD-NOS. A study by Rellini, Tortolani, Trillo, Carbone, and Montecchi (2004) compared the clinical utility of CARS, ABC, and the definitions provided by the DSM-IV. In this study, CARS was able to identify one hundred percent of cases of Autistic Disorder, while ABC identified only fifty-four percent in a sample of sixty-five children ages two to eleven. In addition, the authors found that ABC was less accurate than CARS at identifying cases of mild to moderate autism, as the Autism Behavior Checklist reported a larger number of false positives. CARS was also found to be better at distinguishing between autism and other developmental disorders than the ABC (Rellini et al., 2004).

# Autism Diagnostic Interview-Revised

Another relied upon method for the diagnosis of autism is the Autism Diagnostic Interview-Revised (ADI-R) which is a parent interview that examines past and current symptoms of autism. According to Lord, Rutter, and LeCouteur (1994), rather than being based on a single observation period, the ADI-R takes into account the observations of parents over time and in different settings. Similar to ABC and CARS, the ADI-R also

takes into account repetitive behaviors, which is consistent with the DSM-IV diagnosis. The ADI-R evaluates areas of communication and language, reciprocation of social interaction, and repetitive and restricted behavior; the interview is usually completed within two hours (Lord, Rutter, & LeCouteur, 1994). Authors Worley and Matson (2011) explain that the Autism Diagnostic Interview-Revised is based off of the original Autism Diagnostic Interview, but modified to be relevant for children under the age of five, and to better distinguish between autism and intellectual disabilities (p. 218). The ADI-R covers a total of ninety-three items, and assesses delays in the areas of social interaction, verbal and nonverbal communication, repetitive interests and behaviors, and age of onset (Worley & Matson, 2011, p. 219). The reliability of the ADI-R was examined in a study done by Tomanik, Pearson, Loveland, Lane, and Shaw (2007), and it was found that seventy percent of children were correctly identified as having autism when evaluated with the ADI-R. However, when combined with the Autism Diagnostic Observation Schedule, outlined below, the diagnostic accuracy increased to ninety percent (Tomanik, Pearson, Loveland, Lane, & Shaw, 2007).

#### Autism Diagnostic Observational Schedule

Today, the Autism Diagnostic Observational Schedule (ADOS) is regarded as a choice instrument for identifying autism. Lord et al. (1989) describe ADOS as an observation of behaviors that are known to be linked with the social and communication delays of autism. An important facet in the completion of ADOS is the examiner, whose role is that of both participant and observer, which is accomplished by providing context and social presence for the tasks to be completed by the subject (Lord et al., 1989). ADOS is designed for individuals aged six through adult, and the tasks to be completed are tailored to the individual's abilities. The observational schedule consists of eight tasks: construction task, unstructured presentation of toys, drawing, demonstration, poster task, book task, conversation, and socioemotional questions (Lord et al., 1989). In regards to the diagnostic utility of ADOS, the reliability is well-established. Lord and colleagues (2000) found ADOS to be effective in identifying those with autism from those without autism, but was less effective at distinguishing autism from Asperger's disorder (Lord et al., 2000). Another study found that ADOS showed 100% specificity when differentiating between children with autism and children diagnosed with a receptive language disorder (Noterdaeme, Sitter, Mildenberger, & Amorosa, 2000).

# **ADOS Evaluation Shadowing Experience**

In my observation and shadowing experience, I had the opportunity to sit-in on an ADOS evaluation for a middle school aged boy who had recently transferred public schools to a district in Colorado. The evaluation of the child was done in the presence of the school's psychologist, the Special Education Coordinator for the district, a speech pathologist, and me. The school psychologist acted as the examiner during the evaluation. The first task presented in the ADOS evaluation was the construction task. The evaluation packet provided checklists for different possibilities of the scenarios including asking for more pieces for construction, and a rating of how easily the puzzle was completed by the student. The next task required the subject to make up a play based

on an assortment of toys and objects. The evaluation packet asked observers to judge the sequence of action beyond the obvious intent of the pieces. The observers were also asked to evaluate the reciprocity of play of the subject with the examiner. In this particular evaluation, the student was not interested in playing with the examiner, and preferred to just answer her questions concisely. There were several other tasks that asked the subjects to make up narrations to pictures and cartoons and to demonstrate basic hygiene steps (aka brushing teeth, washing face). The main point of these tasks was to determine how well the subject uses verbal and non-verbal communication, interacts with others, and interprets social situations.

The next set of tasks was more focused on drawing out conversation between the subject and the examiner. When asked about his daily interests, the student verbalized that he enjoyed many activities typical of children his age such as playing outdoors, swimming, and expressed a desire to try new activities such as ice hockey. The examiner also asked him questions about his emotions, and how he feels in different situations. The student expressed anxiety about being late to school and having to get a hall pass to go to class. He was able to identify situations that made him angry, including when defenseless people get picked on. The student also articulated that he felt sad when cats or dogs die; it made him feel pain in his heart.

After being asked about emotions and his response to situations, the subject was given a break in which to play with an assortment of objects left on the table including a writing utensil, paper, legos, and little animals. The observers watched how he occupied

himself with free time and how he responded to the withdrawal of the examiner from the interaction. This time also gave him the opportunity for unstructured conversation where he brought up a question that had previously been asked, and wanted to change his answer. The question had been about annoying behaviors, and the student wanted to admit that he might sometimes annoy people, but he doesn't do it on purpose. After the break, there were a few more tasks to get through. The subject was asked about the concepts of friendship, marriage, and loneliness. The last task was for the student to create a story with objects. The examiner completed the task first by pulling random objects out of a bag and creating a story line with them. After she completed the task, the student was asked to do the same.

Once all the tasks of the evaluation had been completed, the student was allowed to go back to class. The observers then gathered to discuss their observations from the evaluation. The observers noted that the student had made eye contact with each of the observers by the end of the evaluation session. The catch phrases the student used were also commented upon. The observers concluded that the student showed no echolalia, exhibited meticulous speech, but had little intonation and spoke in a mainly monotone voice. The observers agreed that the student required a lot of probing when asked to report on events, offered up little extra information, and was reluctant to ask the examiner about their thoughts or opinions on matters. It was also noticed that the student used minimal conventional gestures or facial expressions besides smiling. Of most interest to the observers was the fact that the student did not share any emotion with his stories or with the examiner, and he did not inquire about the examiner's stories or experiences; he

only asked about objects. The student also showed mild anxiety. According to the Autism Diagnostic Observational Schedule evaluation, this student was found to be on the autistic spectrum.

## Disability and Special Education Laws as They Relate to ASD

The protection of the rights of individuals with developmental disorders began with the passing of laws guaranteeing the civil rights of all people. The first legislation passed to ensure the civil rights of individuals with disabilities in the United States was the Vocational Rehabilitation Act of 1973, specifically Section 504 of that law which aimed to protect all people with disabilities from discrimination in programs that receive federal funding (Gerhardt & Holmes, 2005). In Section 504 the term "disability" is defined as an impairment that significantly limits one or more major life activities such as seeing, hearing, walking, or learning (Guthrie, 2006). This legislation was also significant in bringing attention to the need for transitional services for individuals with disabilities (Wehman, 1991).

In 1990 the Americans with Disabilities Act (ADA) was passed which effectively inherited the definition of disability given by Section 504 of the Vocational Rehabilitation Act of 1973, and is the broadest piece legislature passed to protect individuals with disabilities from discrimination at any age (Gerhardt & Holmes, 2005). The Americans with Disabilities Act applies to both the public and private sectors including employment, libraries, governments, restaurants, hotels, and transportation systems (Fleischer & Zames, 2001). ADA aims at addressing communication barriers, and is designed to level the playing field of life for individuals with disabilities and prevent discrimination (Gerhardt & Holmes, 2005). The legislation protecting the civil rights of people with disabilities brought attention to discriminations present in the public school systems that were inhibiting the ability of students with disabilities to learn or attend public school. Since the recognition of learning disorders in children by education professionals, many steps have been taken to ensure these children receive services that act to enhance their ability to learn in a typical school setting. Before 1975, the majority of children with disabilities were institutionalized and removed from their families and society. Less than twenty percent of children with disabilities were educated in public schools at this time (Mandlawitz, 2005). Children with autism were excluded from the public school system for the most part because in the late sixties and seventies, the popular practice in public school districts was to separate special education classes and autism classes from the general classroom population (Olley, 2005). Sadly, most children with autism were institutionalized where they were taught basic skills that helped them to learn to live in the institutional setting (Mandlawitz, 2005).

# **Education for All Handicapped Children Act**

In 1975, Congress passed the Education for All Handicapped Children Act, which required schools to take responsibility for providing public education and special education services to children with disabilities. States had to meet the conditions of the act in order to receive educational funding from the federal government (Sternberg & Grigorenko, 1999, p. 23). In 1986, the Education for All Handicapped Children Act was amended to include services for infants and young children (Turnbull, 2005). The Education for All Handicapped Children Act stipulated that special education services be administered in the "least restrictive environment" possible (Sternberg & Grigorenko, 1999, p. 23). The wording of the term least restrictive environment is crucial to the implementation of special education laws because it ensures that each individual is helped in the setting that is most comfortable, and therefore most conducive to learning, for them.

The passing of the Education for All Handicapped Children Act initiated a shift in the accountability of the education of children with learning disorders. Before the Education for All Handicapped Children Act was passed, if students with disabilities were going to be sent to special schools it was the responsibility of the family of that student to foot the high cost of these outside programs. After the act was passed, this responsibility was transferred to public school districts. The mandate to provide quality special education services by public schools was further incentivized by making it a requirement for the eligibility of federal educational funding (Sternberg & Grigorenko, 1999).

#### **Individuals with Disabilities Education Act**

The Education for All Handicapped Children Act was amended in 1997 to become the Individuals with Disabilities Education Act, or IDEA. IDEA applies to eligible children from the time they are born until twenty-one years of age, and warrants the right to special education services and related services (Mandlawitz, 2005). The law pertains to early education, school-based education, and transitional services (Volkmar & Klin, 2005). IDEA advocated the need for transitional services for post-high school education or vocational opportunities as well as services received while enrolled in K-12 education (Smith, 2005). The Education for All Handicapped Children Act was amended in order to address problems that were frequently encountered when trying to formulate and execute appropriate education plans for children with disabilities. The items addressed in the changes included suitable discipline methods for students with disabilities, parent participation, and the role of typical classroom teachers. IDEA also mandated a system of assessment to measure progress for students with disabilities (Smith, 2005).

The Individuals with Disabilities Education Act was reaccredited in 2004 and officially renamed the Individuals with Disabilities Education Improvement Act. The reauthorization of IDEA was done partly to ensure that the mandates described under the act were not contradictory with other federal education laws (Smith, 2005). The amendment included more strategies for resolving disagreements between parents and education providers, and dictated the implementation of evidence-based practices. Evidence-based practices require education administrators to rely on data that has been gathered to evaluate the effectiveness of learning and teaching processes, rather than emotional response or personal experience (Smith, 2005).

There are thirteen categories of disability specified under IDEA, including autism and developmental delays (IDEA, 20 U.S.C., 1400(8)). The category of developmental delays was added so that local educational agencies could provide services to children with developmental delays without an explicit label of a disability (Mandlawitz, 2005). In the IDEA regulations, autism is defined as a "developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, which adversely affects a child's educational performance" (IDEA, 20 U.S.C., 1400(8)). The category that a child with a disability qualifies for services under IDEA does not determine the services the child may receive (Mandlawitz, 2005). The services provided to children under IDEA must be determined on a case-by-case basis to address the individual needs of each child to facilitate their learning in the most effective way. Under IDEA, children who have been classified as having a disability will receive special education and related services to meet their needs (IDEA, 20 U.S.C., 1400(8)).

# **Principles of IDEA**

The Individuals with Disabilities Education Improvement Act is based around a multitude of principles that the U.S. Department of Education has determined to be the most important issues concerning the education of children with disabilities. The main principles are: free and appropriate public education, nondiscriminatory evaluation, least restrictive environment, and parent and family rights.

# FAPE

The first principle the law mandates is that children with special education needs receive a "free and appropriate public education" (FAPE) with emphasis on the word appropriate (Mandlawitz, 2005). With the passing of the Education for All Handicapped Children Act in 1975, Congress defined FAPE as "special education and related services

that have been provided at public expense and free of charge, have met the standards of the state educational authority, include an appropriate preschool, elementary, or secondary school in the state, and are provided as outlined by the child's education plan" (IDEA, 20 U.S.C., 1400(8); Yell, Katsiyannis, Drasgow, & Herbst, 2003).

**The Costs of Providing a Free and Appropriate Public Education.** The concept that students have a right to access free and appropriate public education has played a large role in the financing of special education services in public school districts. This principle of IDEA protects families from having to pay out-of-pocket for special education services for students with disabilities in the educational setting (Turnbull, 2005). If a school district is unable to provide appropriate educational services within their school system for students with disabilities, the district is responsible for paying for the services elsewhere. FAPE requires schools to provide special education through specialized instruction, related services, and supplementary aids, the specifics of which are usually outlined in the student's Individual Education Program (Turnbull, Wilcox, & Stowe, 2002).

During the 1999-2000 school year, the United States expended \$50 billion on special education support services and an additional \$27.3 billion on regular education for disabled students, totaling over \$77 billion. Special education support costs accounted for 12.4 percent of the \$404 billion total spending on elementary and secondary education. For students with disabilities overall, the average per-pupil spending cost is \$12,639, with \$8,080 being spent on special education services

(Education of Children with Autism, Jan. 2005). According to the Special Education Expenditure Project (SEEP) the estimated cost per child with autism was \$18,790 in the 1999-2000 school year, which was higher than the \$12,500 average cost of educating students with other disabilities, and almost three times the \$6,556 cost for the typical education of a student without a disability (Education of Children with Autism, Jan. 2005). Without federal, state, and local funding, it is unlikely that students with disabilities would be able to access appropriate and effective educational services.

#### **Nondiscriminatory Evaluation**

As a part of a free and appropriate public education, IDEA also stipulates that an appropriate, nondiscriminatory evaluation must be done by a qualified professional in order to determine the eligibility of the student under IDEA and the student's individual educational needs. Nondiscriminatory evaluation requires that more than one test be used to determine the occurrence of a disability, and that all areas of a suspected disability are considered. It is the responsibility of school personnel to confirm the presence of one or more disability outlined in IDEA, and to determine whether the student requires special education services as a result of that disability (Turnbull, Wilcox, & Stowe, 2002; Yell, Katsiyannis, Drasgow, & Herbst, 2003). The provision of free and appropriate public education is achieved through the "child find" system set up by each state. The child find system is a set of procedures that is in charge of alerting the public to the services that are available for children with disabilities, dispensing printed materials of services,

conducting screenings, and anything else that is needed to make certain students with disabilities are identified (Kamens, 2004).

Individual Education Programs. IDEA mandates the formulation of an Individualized Education Program (IEP) for each child eligible for services (IDEA, 20 U.S.C., 1400(8)). The prescribed educational services for children with disabilities are mapped out in individual education programs (IEPs) which are developed by IEP planning teams. When drafting an IEP, it takes a team of individuals who have the interest of the child with the disability in mind, and the knowledge to help them achieve. This team typically includes the parents of the child, a general classroom teacher, a special education teacher, an individual qualified to interpret the results of an evaluation, and any other individuals invited by the parents or the school (Mandlawitz, 2005). Once a special education plan has been made based on observation and previous knowledge of the student, it is then implemented and followed, and later evaluated in order to track the effectiveness of the program. IEP's are important for tracking the child's education path including their current standing, outlining educational goals for the future, and the plan to make these goals attainable (Mandlawitz, 2005). The IEP includes the special education services and related services the child needs to receive in order to reach their educational goals. The list of services covered under IDEA is extensive and includes such things as speechlanguage pathology, audiology services, psychological services, occupational and physical therapy, counseling and social work services, art therapy, and parent counseling and training. IEPs also include goals for after high school, and details the services needed to meet those goals as well (Mandlawitz, 2005).

# **Least Restrictive Environment**

As mentioned earlier, the education acts of the United States have stipulated that students be educated in a least restrictive environment (LRE). This means that students should be educated in an environment that is most analogous to that of their typical peers, and provides them with the opportunity to succeed when combined with required supports and services (Yell, Katsiyannis, Drasgow, & Herbst, 2003). Typically, the least restrictive environment is in the general classroom setting, but, IDEA never uses the term "inclusion", most likely because there is some controversy among professionals about the effectiveness of inclusion for all students with disabilities (Turnbull, Wilcox, & Stowe, 2002). Other least restrictive environments for children with disabilities can include separate special education classrooms, separate schools, pullout for special education for a small part of the day, and many others. The decision of placement is left to the IEP planning team, who should make decisions about an individual's classroom placement based on their individual abilities and learning styles (Yell, Katsiyannis, Drasgow, & Herbst, 2003).

The interest in inclusion has stemmed from an ineffective special education system in the United States. Leaving the general classroom to receive specialized instruction has been suggested to disrupt students and lead to a fragmented and disconnected school day (Frattura & Capper, 2006). The ineffectiveness of special education was reflected in the 22% high school dropout rate for students with a documented learning disability versus the 9% high school dropout rate for students in the

general population (National Organization on Disability, 2000). A study on students with learning disorders found that those who participated in inclusive programs earned higher grades, scored better on standardized tests, and had less behavioral problems reported than their counterparts who attended pullout special education programs (Rea, McLaughlin, & Walther-Thomas, 2002). The concept of mainstreaming or inclusion for children with autism is one that has been debated in the field for many years. Many arguments have been made for and against inclusion in mainstream classrooms.

Current special education laws that require children to be educated in the most "least restrictive environment" have contributed to an increase in the availability of inclusion programs. The least restrictive environment mandate requires that students with disabilities receive the highest possible amount of their education in a general classroom setting when appropriate, or in an environment where the student is not separated from nondisabled peers (Yell, Katsiyannis, Drasgow, & Herbst, 2003). As a result of the Education for All Handicapped Children Act, the tendency for public schools to pull kids with special education needs out of the regular classrooms for the majority of their time at school began to be eliminated (Turnbull, 2005). One benefit children with autism receive by being in a classroom with children without diagnosed learning disorders is peer modeling. Children with typical development can serve as valuable models for social skills and language for their peers with autism; this benefit has been improved when peers receive training to be effective models (Handleman, Harris, & Martins, 2005). Inclusion strategies do not only benefit students with autism, but their peers as well. One study showed improved language skills in children with autism and without

autism in an integrated classroom, as well as an increase in IQ for the students with autism (Harris, Handleman, Gordon, Kristoff, & Fuentes, 1991).

Another unexpected result also began to take shape with this legislation: children with severe physical, emotional and learning disabilities were placed in general classrooms which forced teachers, who often did not have appropriate training to deal with students with disabilities, to allocate more time and effort to those children, and resulted in a loss to the other students in the class (Sternberg & Grigorenko, 1999, pgs. 24-25).

### **Parent and Family Rights**

The last important principle of IDEA is the rights of parents and families to confidentiality. This principle requires that documentation be kept of any person who accesses student records. Parents also have the right to see and obtain all records made of their student, and to challenge anything they do not deem as accurate. Also according to this principle, any record of a student with a disability must be destroyed within a reasonable period of time once the records are no longer needed (Yell, Drasgow, & Lowrey, 2005). In order to protect confidentiality, procedural safeguards are put in place. This ensures that any decision made involving children with disabilities is done with parent participation and in accordance with specified procedures. The inclusion of parents in the decision making processes for their children is also crucial. In order for a child to be assessed for a disability, their parent must give written consent; similarly, parents must be invited to any meetings where their child will be discussed, and they

must give permission for their child to begin receiving special education services (Turnbull, Wilcox, & Stowe, 2002). If there are disagreements between parents and education personnel, an impartial hearing may be requested in order to come to an agreement.

### **Educational Program Models for Children with Autism**

In recent years, the responsibility of adapting and implementing an intervention strategy has been handed to the public school systems and their affiliated earlyintervention agencies. Under special education laws, practices must be research-based, and provide appropriate services for all students with autism. Because most intervention strategies are implemented as early as possible, many kids with Autism Spectrum Disorder have been receiving services to aid their development for years before they enter school, but this paper will only be discussing school-based interventions. The National Research Council reported in 2001 that effective school-based intervention programs should facilitate and address the following needs of children with autism: expressive language, receptive language, spontaneous language, pre-academic concepts, functional routines, play and social interaction, and instructional strategy (National Research Council, 2001).

There are a vast number of treatment strategies available for children with autism, and although the effectiveness of some programs are questionable, the most respected and current intervention approaches have documented substantial gains in verbal skills, accelerated developmental rates, and a general decrease in symptoms of autism (Rogers & Vismara, 2008). It is often difficult to find legitimate empirical research when dealing with autism spectrum disorder because of popular but ineffective fads, and ethical concerns that stem from attempting to create accurate control groups with which to compare intervention strategies against (Tuzikow & Holburn, 2011). Often in the media, intervention strategies with no medical base and no credible data claim to have found a "cure" for autism, but are quickly discredited by the science community. Some popular fads that have claimed to alleviate symptoms of ASD include gluten-free diets, casein-free diets, and secretin (Tuzikow & Holburn, 2011).

Today, many of the current and respected intervention programs for children with autism spectrum disorder have been inspired by the work of Dr. Ivan Lovaas, a psychology professor at UCLA, and his contributions to The Young Autism Project. Dr. Lovaas established that young people with autism could make significant improvements in cognitive and language skills by receiving intensive behavioral therapy forty hours per week over an extended period of time. (Lovaas, 1987) Lovaas's method has branched and been adapted to many programs and is associated with many names including Discrete Trial Training (DTT), Intensive Behavior Intervention (IBI), Applied Behavior Analysis (ABA), and Early and Intensive Behavioral Intervention (EIBI). All are based on teaching specific, adaptable skills until they are grasped (Lovaas, 1987).

# **Methods of Applied Behavioral Analysis**

Applied behavior analysis (ABA) methodology is widely used as an instructional base for intervention programs. The ABA model is based on observing and modifying behaviors through a child's environment. The most effective ABA programs provide consistent, resolute feedback and immediate amendment of a child's conduct (Ryan et al., 2011). The overall process of applied behavior analysis begins with performing an initial evaluation of the child's behavior. Next, a behavioral intervention is chosen based on the child's specific learning needs. During the behavioral intervention, data is collected and changes in the intervention are made based upon that data which reflects the child's typical behaviors and needs. The effect of the intervention on the targeted behavior is later evaluated, and any necessary changes are made before proceeding forward with the next target behavior (Arick et al., 2005).

**Discrete Trial Training.** One common behavioral intervention for children with ASD based on the foundations of ABA is Discrete Trial Training (DTT). In Discreet Trial Training, skills are taught in a sequential and logical order with new skills being built off of previously mastered skills. DTT involves one-on-one instruction with a trained professional. Large concepts are broken down into separate and specific parts for easier learning and comprehension. Discrete Trial Training is recommended for children age's two to six, and has been shown to increase levels of cognitive skills, language skills, adaptive skills, and compliance skills (Lovaas, 1987; Ryan et al., 2011). Many studies have demonstrated significant improvement in the previously mentioned skills when students with autism participated in ABA and DTT interventions (Howard, Sparkman, Cohen, Green, & Sanislaw, 2005; Lovaas, 1987).

Instructional sessions are made up of discrete, or separate, trials which are composed of a four-step sequence. The first step of the sequence is instructional cue, given by the teacher or instructor to the student, which is then followed by the child's response. For example, the instructor might say, "Look at me" in an attempt to have the child with ASD make eye contact. After the child responds by either making eye contact or not making eye contact, the teacher provides a consequence, depending on the fulfillment of the task or not. One form of consequence is a positive reinforcer, which is usually some sort of verbal praise or physical reward, and is given immediately after the desired behavior has been performed. If the desired behavior is not performed the first time, the instructor might repeat the cue in a firm voice and model the behavior for the child; the instructor may even guide the child's face to make eye contact, if only for a second. The cue would then be repeated. Finally, there is a pause to signal to the student the end of one set and the beginning of another (Arick et al., 2005; Smith, 2001).

Early and Intensive Behavioral Intervention. There are many other intervention strategies that have been based on the principles of applied behavior analysis, and have improvement in atypical adaptive behaviors and other symptoms of autism spectrum disorders. One ABA-based intervention known as the Early and Intensive Behavioral Intervention (EIBI) has yielded substantial improvement in adaptive behaviors in preschool and kindergarten aged children who have been diagnosed with autism (Eikeseth, Klintwall, Jahr, & Karlsson, 2012). Intensive Behavioral Intervention (IBI) is another program for young children with autism that focuses on the principles of ABA. In a study done by Flanagan, Perry, and Freeman (2012) the group of children who received IBI showed less severe symptoms of autism, improved adaptive behavior, and higher cognitive skills compared to a waitlist comparison group. This study also showed greater increases for children who started the intervention at a younger age than those who started at a later age (Flanagan, Perry, & Freeman, 2012).

# **Intervention Methods Utilizing Inclusion**

**LEAP.** A proponent of early intervention and inclusion, the Learning Experience: An Alternative Program for Preschoolers and Parents (LEAP) was developed by Strain and colleagues at the University of Colorado at Denver (Strain, Danko, & Lowry, 1998). Students with a range of developmental needs are enrolled in the same classroom from the beginning of the program. The LEAP program includes activities that promote social involvement, and comprise of early childhood activities and behavioral programming (Handleman, Harris, & Martins, 2005). LEAP provides training for normally developing peers to promote social interactions between them and children with autism by implementing the following tactics: getting friends' attention, sharing, organizing play, and giving compliments. While LEAP provides materials for teachers such as curriculum guides, check lists, teaching methods, and play activities, its implementation and, ultimately, its effectiveness depends on the competency of the staff, which is why it is important for teachers to be properly trained in the intervention strategy (Strain, Danko, & Lowry, 1998).

**TEACCH.** Another respected intervention strategy based on inclusion is TEACCH. The Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) in North Carolina is responsible for the state-wide provision of special education services for children with autism. It includes a full range of resources ranging from full inclusion to highly specialized programming, and enables the state of North Carolina to provide free and appropriate education in the least restrictive environment for

all children with autism. Although TEACCH provides a full range of services, it focuses on classroom structured teaching and skill enhancement for children with autism (Marcus, Schopler, & Lord, 2001). The classroom structure provided by TEACCH focuses on visual stimulation rather than auditory stimulation, reducing problem behaviors, and increasing independent function and adaptation. TEACCH consists of four main components: physical organization, schedules, individual work systems, and task organization (Marcus, Schopler, & Lord, 2001).

Physical organization incorporates elements such as structured boundaries between activity areas, specific transition areas, and physical manipulation of desks to promote attention or visual processing (Skokut, Robinson, Openden, & Jimerson, 2008). TEACCH also advocates the use of physical schedules for students with autism, to physical and visually outline their tasks and expectations for the day. The TEACCH model aims to improve and develop skills of children with autism by providing strategies such as giving clear verbal directions, offering timely prompts, and proposing external motivating reinforcements (Marcus, Schopler, & Lord, 2001). Evaluation of the TEACCH method has shown the model to be effective for children with low-functioning autism (Hume & Odom, 2007) and special education classrooms; however, it's applicability to the typical public school inclusive classroom needs more research (Skokut, Robinson, Openden, & Jimerson, 2008).

**The Denver Model.** In 1981 Sally Rogers started the Denver Model at the University of Colorado Health Sciences Center. This intervention aims at targeting the deficits of key

skills as a result of autism including imitation, emotion sharing, theory of mind, and social perception through the use of play, the fostering of interpersonal relationships, and activities to promote communication (Rogers & Pennington, 1991). In order to fulfill the curriculum goals of the Denver Model, behavioral instruction techniques and structured teaching strategies are used throughout the school districts. The Denver Model has shown to improve cognitive function, motor activities, and social relatedness in its students with autism after seven months of treatment (Rogers & Lewis, 1989).

#### **Issues with Implementation**

In order for any intervention strategy to be effective, it needs to be implemented correctly. More important than ever in our changing education system is the continual training and education of educators. In order for students with autism to be successful in the general classroom, general classroom teachers must know how to best adapt their teaching strategies to effectively address the class as a whole. Many times, the goals of intervention strategies are not met because of the lack of education provided to school administrators and teachers to understand the needs of children with autism and other learning disorders (Kantavong & Sivabaedya, 2010). Some strategies for teachers emphasize classroom organization including visually accessible schedules, and helping students to keep their school lives in order. Using visual cues is another effective strategy for teachers. One study demonstrated a decreased lag time between teacher instruction and a student with autism's response time when visual cues were used versus no visual cues (Dettmer, Simpson, Myles, & Ganz, 2000). Other strategies for teachers

of students with autism include being aware of sensory issues, providing social models and supports, and developing a behavioral plan outlining classroom expectations (Friedlander, 2008). By providing current training and additional support for general classroom teachers, intervention strategies that have shown to aid in the learning process for students with disabilities can be properly implemented.

#### The Changing Face of Autism Spectrum Disorder

In the past sixty years there has been a lot of confusion differentiating between autistic disorder, Asperger's syndrome, and PDD-NOS. Asperger's syndrome was once commonly thought of as autism for people with a higher intelligence, and as being the equivalent of PDD-NOS (Volkmar & Klin, 2005). The DSM-IV-TR primarily draws the imaginary line between individuals with autistic disorder and Asperger's syndrome based on the conservation of language and cognitive abilities in the first four years of life. The verbal delays characteristic of autistic disorder are excluded in the criteria for Asperger's syndrome. Also, the DSM-IV-TR requires the presence of a greater number of overall symptoms for autistic disorder versus Asperger's syndrome. And finally, the DSM-IV-TR stipulates that symptoms be present before the age of three for autistic disorder, but does not put age constraints on the manifestation of symptoms for individuals with Asperger's syndrome (APA, 2000; Klin, McPartland, & Volkmar, 2005).

The Diagnostic and Statistical Manual of Mental Disorders is revised every few years to keep up with current research and discoveries, and to improve the medical practicality of the definitions. This allows clinicians to be able to communicate better, target effective interventions, and differentiate disorders from non-disorders to improve treatment and avoid high rates of false positives (First, 2010). The proposed changes for the DSM-V, as of January 2011, include the removal of approximately fifty disorders from the classification guide by integrating them with pre-existing specific or NOS

categories, or by eliminating them altogether. The American Psychiatric Association, which is responsible for the publication of the DSM-V, is planning to merge the pervasive development disorders of autistic disorder, Asperger's syndrome, and PDD-NOS, into one term, the Autism Spectrum Disorder (ASD). The proposal also includes the addition of a severity rating scale, from Level 1 to Level 3, to quantify the degree of an individual's clinical presentation. These revisions and additions would serve to eliminate the often "clinically misleading" terms, and to stream-line the diagnostic processes (www.dsm5.org).

Dr. James C. McPartland, assistant professor at Yale University, told New York Times readers that the revisions to the definition of autism have been proposed in an attempt to move towards a classification system that is more consistent with the known biology of the disorder (McPartland, NYT Interview, 2012). He says evidence for this can be seen in maintaining the definition of Rhett's syndrome as stated in the DSM-IV because of its known genetic origin. For individuals suspected of having ASD, delays in social skills and communication skills will become considered as one set of symptoms, instead of being considered separately as in the DSM-IV (www.dsm5.org). For the entire official proposed change to the Autism Spectrum definition in the DSM-V, see the Appendix.

The American Psychiatric Association's (APA) website outlines the anticipated changes in the newest version of the DSM, and provides a few reasons for the merger of the previously separate PDD diagnoses. The first reason for the proposed revision is that the current distinctions between the pervasive developmental disorders have been unclear and changeable over the past years because the old definitions are more focused on the severity and intellectual levels of individuals rather than the features of the disorders. The APA states that autism is characterized by a collective set of behaviors, so it is better to have a single diagnostic category that can be adapted to fit individuals through their specific symptoms and features. Also, the classification of many different looking disorders into one spectrum more accurately reveals current knowledge of pathology (www.dsm5.org).

Another reason for the change in definition is that language delays are not unique to autistic disorder, nor do they occur in every case of autism (www.dsm5.org). The APA says that the subdomains of the new DSM-V definition encompass a large range of ages and verbal levels which serves to increase the sensitivity of the definition across all levels of severity, whereas the DSM-IV definitions included a lot of criteria to address the same symptom at different severity levels. The last reason the APA gives for changing the definition of autism and other pervasive developmental disorders is because Autism Spectrum Disorder is a neurodevelopmental disorder, so it must be present in early childhood, but it may not be detected until later due to the nature of minimal social demands and parental support before reaching school age. The DSM-IV definitions stipulate that an individual had to have symptoms present before the age of three to be diagnosed with autistic disorder, but does not include an age stipulation for Asperger's syndrome or PDD-NOS.

Critics of the proposed changes to the DSM express concern with the comprehensiveness of the new definition, the diagnostic utility, and the effect the new definition will have on the availability of special education services for children. Authors Wing, Gould, and Gillberg (2011) state the proposed revisions for the DSM-V ignore classic characteristics of autism. The first characteristic is a lack of "social imagination" which they argue is one of the most disabling symptoms of autism, and therefore essential to address for intervention purposes (Wing, Gould, & Gillberg, 2011). It is interesting to note that there is no mention of "impairment in social imagination" in the DSM-IV either, but the authors suggest it should be added to the DSM-V definition. Another symptom of autism they feel the DSM-V leaves out is reduced and enhanced responses to sensory input. Although these types of atypical responses are not exclusive to autism, it is a persistent system that has been documented throughout the lives of people with autism (Billstedt, Gillberg, & Gillberg, 2007; Wing, Gould & Gillberg, 2011). The proposed DSM-V revisions state that symptoms of ASD should be recognized in early childhood; Wing, Gould, and Gillberg (2011) argue that only an experienced observer is able to recognize early signs of autism based on the symptoms and sub-categories outlined by the DSM-V. In order to increase the diagnostic utility and encourage early recognition of symptoms, early signs of autism should be included to encourage early intervention (Wing, Gould, & Gillberg, 2011).

Another concern about the changing definition of ASD comes from the Asperger's community. Many members of this community are wary about being labeled as having Autism Spectrum Disorder rather than Asperger's Syndrome because of the

higher severity of symptoms associated with the term autism. Many people also affiliate the term "autism" with socially-withdrawn behaviors, lower functioning, and a preference to be alone, which is not characteristic of all people with ASD's. The social stigma that has been attached to autism is a concern expressed by many people with Asperger's Syndrome based on the hastiness of other people to judge a person by a label (Hamilton, 2010).

The last concern professionals have with the proposed changes to the definition of Autism Spectrum Disorder in the DSM-V is the eligibility of children with less severe symptoms of autism to qualify for the definition of ASD. The concern is that these children will not receive an ASD diagnosis and therefore will not be eligible to receive special education services, even if they exhibit symptoms that interfere with their learning processes. An analysis done by Dr. Fred Volkmar, director of the Yale Child Study Center, along with Dr. Brian Reichow and Dr. James McPartland, also from Yale, assessed 372 children and adults who had previously been diagnosed with classic autistic disorder, Asperger's syndrome, or PDD-NOS, and compared the symptoms of these individuals to the new definition proposed in the DSM-V. Preliminary findings showed that approximately twenty-five percent of those diagnosed with autistic disorder in 1993 would not be diagnosed with ASD under the new definition. Seventy-five percent of those diagnosed with Asperger's syndrome would not be diagnosed with ASD, and eighty-five percent of those diagnosed with PDD-NOS would not be diagnosed with ASD under the new revisions. Overall, only forty-five percent of those assessed would be diagnosed with Autism Spectrum Disorder under the new definition (Carey & Harmon,

2012). Although the study has not been published yet, it is projected to be available in spring 2012.

Dr. James C. McPartland, told New York Times readers that in order to compensate for the changing definition, a new disorder is being added to the DSM-V known as social communication disorder. This disorder addresses impairments in the application of verbal and nonverbal communication for social purposes (www.dsm5.org). Dr. McPartland says that social communication disorder can be used as an alternate diagnosis for those who no longer meet the ASD diagnosis under the new definition, but still exhibit communication and social delays (McPartland, 2012). In other words, this category has been added to "catch" those who may not fully qualify for the ASD diagnosis, but still exhibit abnormal social and communication skills. The implications for services and eligibility for those diagnosed with social communication disorder are still unclear.

The study done by Dr. Volkmar and colleagues raises a lot of questions and has caused a lot of stress for people in the autism community. The implications for the new definition are mostly unclear at this point, and not a lot of research studies or projections for the future of this community have been published thus far. One major concern to think about for the future is the eligibility of students to receive special education services, despite their medical diagnosis or lack of one. For students who do not qualify for an ASD diagnosis, but exhibit some characteristics of the disorder that impact their ability to learn, their ability to receive special education services hangs in the balance.

The worst case scenario for children who no longer qualify for an ASD diagnosis could greatly impact their ability to learn in the public school system. Without an ASD diagnosis these kids might get lost in the public education system, and would be excluded from receiving special education services. This would put more stress on general classroom teachers and aides. Plus, these students would not receive the highly structured learning environment that studies have shown they need to succeed academically. These children could potentially no longer receive special education or additional services under IDEA, and would be held to the same academic standards as their peers with typical development. When held to these standards, there is a very real possibility that they could fail without proper support and instruction. When these students begin to show delays in the skills required for their grade levels on standardized tests, I think the legislative and medical communities will be forced to take notice and reevaluate the education services these children are receiving. The time between the students failing in school and the attention and action of government officials to the problem could take years. The implications of this scenario are endless. The children who require but do not receive special education services will struggle more, which will cause them to do poorly in school, which will lead to poor job availability, which could lead to endless problems for society.

However, this scenario is quite extreme, and legislative experts have provided safe-guards in the laws to prevent situations like this from happening as medical knowledge changes and evolves. It is important to keep in mind that a medical diagnosis is not the only factor in determining the distribution of special education services. The

cognitive and social abilities of children are also factored in to the eligibility of receiving services. Children who no longer qualify for an ASD diagnosis, but show characteristics of the disorder that interfere with their ability to learn and therefore warrant special education or additional services, will most likely continue to receive the services they require by being absorbed by other categories specified under IDEA. Some examples of these categories children could be absorbed into are developmental delays, intellectual delays, and emotional disturbances.

Another option for children who no longer qualify for an ASD diagnosis is the qualification for a different diagnosis such as social-communication disorder. If the proposed changes to the DSM-V are published, the addition of social-communication disorder will most likely recognized by legislators and educators and be added to the categories of disability covered under IDEA. If this happens, social-communication disorder would be covered the same as any other category of disability, and students would be assessed by the proper professionals and receive the education services they require to succeed.

Although the changing definition of autism has gained a lot of media attention and caused a lot of stress for some people, precautions and safe-guards have been formulated to minimize the impact on children in schools. Children who require special education services, regardless of the quantity or severity of their ASD symptoms, will more than likely go on receiving the special education and additional services needed to meet their educational and future goals. It is important for students with all forms of

ASD to receive services under IDEA; one aspect of services that serves to help students enter the world beyond school is transitional services. For students with less severe language and cognitive delays, but significant social delays, the transitional services that help to find jobs and work with other people are extremely important and their benefit should not be discounted. Children with ASD may be able to make it through the academic setting without additional supports, but could potentially fail in the social setting of the work force.

Receiving special education and additional services is extremely important for the growth and development of children with Autism Spectrum Disorder in order for these children to reach their full potential. As our biological and medical knowledge of this disorder expands and develops, our legislation that regulates the distribution of services must as well. In order to ensure that all children with symptoms of ASD receive the special education services they need, the wording of the legislature needs to be clear so there is no dispute as to which disorders warrant special education services, and which do not. The wording of the laws should keep up with appropriate medical terminology. In this case, the term "autism" should be changed to "Autism Spectrum Disorder", and social communication disorder should also be added to the categories of disabilities specified under the Individuals with Disabilities Education Act. Additionally, all other new or changed definitions of mental disorders in the DSM-V should be guaranteed special education services, if needed, under federal legislation. It is important that these changes happen at the legislative level because schools are powerless to help these students without the legal means to do so.

One of the most important plans of action to ensure that all children with Autism Spectrum Disorder receive the best educational services possible is to make sure the services they are receiving are most conducive to their learning. This will require more research in the field of ASD and special education methods. Many steps have been taken in past years to recognize and bring attention to ASD, but there is still a lot of information that is unknown. Further research into treatment methods will help to bring about a consensus on the best way to address symptoms in individuals with ASD, based on specific needs.

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# Appendix

# **DSM-IV** Autistic Disorder:

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
  - (1) qualitative impairment in social interaction, as manifested by at least two of the following:
    - (a) marked impairment in the use of multiple nonverbal behaviors such as eye-toeye gaze, facial expression, body postures, and gestures to regulate social interaction
    - (b) failure to develop peer relationships appropriate to developmental level
    - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
    - (d) lack of social or emotional reciprocity
  - (2) qualitative impairments in communication as manifested by at least one of the following:
    - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
    - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
    - (c) stereotyped and repetitive use of language or idiosyncratic language
    - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
  - (3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
    - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
    - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
    - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)
    - (d) persistent preoccupation with parts of objects

- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

# **DSM-V** Autism Spectrum Disorder:

Must meet criteria A, B, C, and D:

- A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:
  - 1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction,
  - 2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.
  - 3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people
- B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:
  - 1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).
  - 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
  - 3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
  - 4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse

response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).

- C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)
- D. Symptoms together limit and impair everyday functioning.