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# Under the Umbrella: Redefining the Spectrum of Autism

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Under the Umbrella: Redefining the Spectrum of Autism

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Abstract  
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Under the Umbrella: Redefining the Spectrum of Autism

This research examines the scope of how autism spectrum disorders (ASD) have changed over the history of special education. From Dr. Leo Kanner's initial study in 1943 to the present-day DSM-5, the diagnostic criteria for an accurate identification of autism in children has been extremely varied, resulting in an increased prevalence rate and confusion as to what actually constitutes ASD. A major discovery by Wing and Gould in 1979 brought to the forefront the concept of a spectrum of disorders within the autism category. Leading to an over-diagnosis of children requiring related services and supports in schools and at home, also examined is the response to the American Psychological Association (APA) removal of the spectrum in the latest Diagnostic and Statistical Manual Fifth Edition (DSM-5) manual.

This paper explores the field of autism study including the assessments used to determine a diagnosis, suggestions for evidence-based interventions and strategies with proven success, and how the changes in the DSM-5 have impacted the community of children and families with autism. An explanation for meeting the needs of the whole child, not just their label or stigmatized disability category under IDEA, is also investigated to assist teachers in making accurate and appropriate accommodations for children with autism spectrum disorders in their classrooms.

*Keywords:* autism, Asperger syndrome, spectrum, prevalence, diagnostic criteria, Diagnostic Statistical Manual of Mental Disorders fifth edition (DSM-5), intervention, accommodations

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## Rationale

The population of children on the autism spectrum has increased dramatically over the past several years. According to the Centers for Disease Control and Prevention (CDC, 2016), 1 in 68 children are diagnosed with autism spectrum disorder, which has increased 30% from 1 in 88 in 2012 (Centers for Disease Control and Prevention [CDC], 2016). It would seem that researchers, schools, and parents would have a thorough, complete understanding of what this disability classification is, yet that is not the case. After revising the Diagnostic and Statistical Manual of Mental Disorders from its fourth edition (DSM-IV-TR) to its fifth edition (DSM-5), society has seen steady increases in diagnoses, shifting or disappearing labels, and a changing definition of what autism is. It is a fundamental responsibility of a teacher to understand all of the variations of her class members. This definition change presents a challenge for teachers seeking support for students with autism.

As the DSM-5 takes its foothold in society, there is a growing sense of discontentment with its new description of autism (Frances, 2012). Previously, autism has been referred to as deficits in socialization, communication, and repetitive, restricted behaviors. Children with autism have a reputation for being antisocial, rigid, and having specific, obsessive interests. Tager-Flusberg, Paul, and Lord (2005) note that children and adolescents with autism tend to struggle with pragmatics, citing issues with turn-taking, listening to others' wants and needs, following polite etiquette, and making irrelevant comments in conversation. Children with ASD don't make eye contact, are exceptionally smart yet don't understand sarcasm, prefer to be alone, don't like change...this list could go on extensively. Many children with autism want to build relationships and

communicate with others, they just lack the skills needed to do so. According to Catherine Lord (2010), the new DSM-5 changes the definition of autism, instead describing deficits in two areas, reciprocal social communication and restricted, repetitive interests and behaviors. The revisions to the DSM also alter the makeup of members in this classification. Gone are the subcategories of autism, such as Asperger syndrome, Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS), Rett syndrome, and Childhood Disintegrative Disorder (CDD). Now, all children and adults are categorized under one heading, Autism. There is an added leveling system of severity, as well as an additional diagnosis, Social (Pragmatic) Communication Disorder (SCD), included to compensate for individuals who have the social deficits of autism but lack the restricted, repetitive behaviors necessary for a formal ASD diagnosis. This substantial change has many in the autism community, especially those previously classified under the subcategories of autism, worried that their access to specific services might change and/or disappear because they no longer meet the diagnostic criteria. In a study conducted by Smith, Reichow, and Volkmar (2015), on the effects of the criteria under the DSM-5, the researchers found that, "...The new criteria will make it more difficult for high-functioning individuals to be diagnosed at an early age and receive the intensity of services that is most likely to result in an optimal outcome," (p. 2549). In addition, those in the Asperger community feel as if they have lost part of their identities now that the terminology has changed. Matthew Vaillancourt (2015) stated the following:

I was living with Asperger's. Until, suddenly, I wasn't. I didn't exist anymore...Imagine that you've been a Christian all your life and then some

‘specialists’ come along and rewrite the Bible so you’re not a Christian any longer. That’s what it feels like to be me.

Imagine families who have come to terms with and even celebrated a diagnosis that likely caused joy, confusion, tears, amazement, emotional stress, and challenges, to name a few, just to have that identity stripped away from their child. These children did not just disappear, so where did their community go?

Teachers need to be trained in identifying characteristics, how to assess and teach students with ASD, and determine which interventions and accommodations will be necessary to allow the child to be a successful member of the classroom community. Their “quirks,” or differences that set them apart from other children make them special, yet complex for teachers without the proper experience to accommodate and educate. I want to learn more about this special group of children, such as helping them acclimate to classroom settings, building social relationships, and shaping them into successful members of society; however, in the classrooms I have worked in, I have come across few children with autism. My first experience came during a student teaching semester, when I met a 3<sup>rd</sup> grader named Andy<sup>1</sup>.

Andy was in an inclusive classroom at a public school in Westchester County, NY. He had Asperger syndrome, a label the DSM-5 has removed in its recent update. Upon meeting this child, I could see atypical characteristics for his age [8]. The way he interacted with others, rather, the way he interacted next to others, was striking. He was brilliant, wanting to answer every question the teacher posed in class. When not called on to allow for others to have a chance, it seemed as if he would jump out of his skin in

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<sup>1</sup> Name changed for anonymity

anger for not being acknowledged for knowing the right answer. Andy *loved* to talk about his passions, though did not seem to notice that his peers didn't show much interest in what he was talking about. He frustrated easily, especially when he did not get his way. He had a need to know, "why," which reared its head during one of my whole-group lessons. "*Why* do we need to find the area of this shape? *Why* do we need to find the area of this shape a second time [again]? *Why* do I need to keep doing this same activity when I have already understood its purpose and I've answered correctly?" This last question threw me – he was right. Maybe it was the blunt, matter-of-fact statement I would have expected from a child twice his age that surprised me when it came out of this eight-year-old's mouth. Not every child can grasp the objective of a lesson without having practiced the skill multiple times, though Andy can. Andy's response demonstrates annoyance, but also an obliviousness that it did not even occur to him that his peers might have been struggling, because he himself found no issues with the lesson at hand. This black-and-white, seemingly self-absorbed attitude is common in many children with autism. Children on the spectrum need to be taught how to see others' perspectives, be empathetic, and properly use social skills in order to build relationships.

Teachers need to stay vigilant in learning how to individualize instruction for children with autism, while still integrating them into the classroom culture and assisting them with socialization. This thesis will help to inform teachers of how to interact with children on the autism spectrum, ways to intervene and accommodate their needs, and attitudes and beliefs about the DSM-5's influence on this disability category. My hope is that with guides such as these, we will become more educated on this type of learner that we may come across in our classrooms.



# **A Brief History of Autism Spectrum Disorders**

Autism is not just a disorder of childhood but a truly developmental disorder that affects development and is itself manifested differently across the lifespan.

— Catherine Lord

In 1943, Dr. Leo Kanner, the first to describe infantile autism as a discrete disorder, observed a unique population of children displaying unusual, yet specific, behaviors (Peerenboom, 2003). Each child demonstrated a lack of development in language and communication skills, difficulty with initiating and maintaining relationships with others (including their own parents), and terrible distress if experiencing changes to their routine and environment. Dr. Hans Asperger, another researcher at the time, studied related behaviors in a different group of children, though these children did not appear as impaired in the areas of communication and socialization as Kanner's group. Pioneers in the field, these researchers helped develop the spectrum of disorders we now understand as autism, although specifying what constitutes an autism diagnosis, how it is caused and treated, and the terminology and language we use to identify this population of children still baffles many experts in the field.

The U.S. Office of Special Education Programs (2012) cites the IDEA definition of autism as a developmental disability that significantly affects verbal and nonverbal communication, social interaction, and is often associated with rigidity in behavior and restricted interests. These characteristics, in addition to engaging in stereotyped movements and resistance to change, adversely affect a child's educational performance. Since its introduction to society in the early 1940s, the image of autism has shifted over time. In the 1960s and 1970s, researchers and psychologists published literature describing the attributes of individuals with autism, and though the children described in each study share similar characteristics, the abundance of research in the history of the field has exposed varying degrees of severity, abilities, and behaviors of such individuals. According to Happé and Frith (1996) Wing and Gould's 1979 epidemiological study,

“...introduced the notion of a triad of co-occurring impairments in socialization, communication, and imagination, which marked out children already diagnosed by Kanner’s criteria for autism, but also applied to a wider sample of children,” (p. 1378). This helped to form the basis for the definition of autism in the DSM-III-R and raised awareness that degrees of impairment in these areas can vary according to age and ability. Since its discovery, autism prevalence has rapidly increased, requiring revisions to established and accepted definitions of autism. Later, with Wing and Gould’s publications, and the increase in ASD diagnoses, the DSM-IV-TR made revisions to include additional classifications considered as subtypes of autism, including Asperger syndrome, PDD-NOS, Rett syndrome, and Childhood Disintegrative Disorder (CDD) to name a few, which helped categorize individuals displaying a range of autism-like behaviors. Its current update, the DSM-5, again alters the definition and symptoms required for an official diagnosis of autism, which happens to remove the specified subtypes from the spectrum. The umbrella term, “Autism Spectrum Disorders” is now the generalized, accepted classification.

What does autism really look like? At its foundation, ASD is defined by characteristics initially grounded in Kanner’s work. Catherine Lord (2010) refers to three core domains that describe autism, including social, communication, and restricted and repetitive behaviors and interests. What challenges so many researchers and professionals in finding common ground in what constitutes an ASD diagnosis is that its cause is generally unknown, and the categories for classification are broad enough that identification is fairly subjective. Etiology for autism goes back as far as the 1950s, in which doctors presumed that ASD was caused by “refrigerator mothers,” or mothers that

did not display enough affection for their child and were the ones to blame (Waterhouse, 2008, p. 275). Other theories point to genetic and environmental factors that have an adverse effect on the development of language and social interaction skills, as well as the incidence of unusual, restricted and repetitive behaviors in these types of children. There is also not a “cover all” assessment that can be administered to a child that would help determine an accurate, definitive diagnosis. There are several rating scales and interview probes that professionals typically use to diagnose ASD, but there is much room for subjectivity in interpretation.

Creating a conclusive definition of autism that is accepted by society’s standards is a daunting task. In many articles of research, it appears that even the experts are stumped as to what autism really is. This is due to the fact that the symptoms associated with the domains mentioned above vary greatly across and within children over time. With the DSM-IV-TR recognition of subtypes of autism, such as Asperger syndrome, we have seen children that are excited to communicate with others, but may overdo it. They may talk at length about topics of interest to them, even if their conversation partner is uninterested, or have difficulty accepting another’s point of view. They may lack the appropriate politeness that our society has come to require in conversation. Another child may respond oppositely in a social context, by withdrawing from an interaction, refusing to make eye contact, and even ignoring their peer. These examples paint two distinctive pictures of children, both demonstrating a range of autism-like traits. Perhaps it would seem practical to identify the first child as having Asperger syndrome and the second having autism, but according to today’s DSM-5, both of these children would have a general autism spectrum disorder label. Their dissimilarities call into question whether

these children should even have the same broad classification; however, this is what makes determining what autism is even more difficult. Within this one category – communication – both of these children show opposite characteristics, yet still meet the requirements for an ASD diagnosis, when also considering their social skills and repetitive behaviors. As more children are diagnosed each day with autism, we learn more information about how this disorder can manifest given a variety of conditions, such as environment, time of onset, and access to intervention.

Autism is a lifelong condition that has no cure, though professionals have discovered many therapies and interventions that assist children with ASD in accessing communication, social interaction, and even using those repetitive behaviors in more positive ways. As we know, each child diagnosed with ASD has unique characteristics that make her/him different from others in the community. That being said, in order for an intervention to be successful, it must be individualized to meet the needs of the child. Presently, many researchers have developed and found success with interventions that can be implemented in schools and at home. Lindgren and Doobay (2011) note examples such as applied behavior analysis, functional communication training, pivotal response training, and antecedent-based interventions, as well as social skills training and play and cognitive behavioral therapies. Use of assistive technology has also been helpful for children with autism, especially when there is a visual component, as many of them are visual learners.

To grow into a successful adult, children need to have experiences with communicating and socializing with peers in safe environments. Children often first learn to interact with others at a young age through play. In these settings, they also learn to

communicate with one another, which appear like natural occurrences throughout the day. As Deris and Di Carlo (2013) explain, “These characteristics can be manifested in the classroom, causing the child to have difficulties relating socially, making transitions, managing changes in their routine and identifying and processing information from their environments,” (p. 52). Without strategic interventions, children with autism are left at a disadvantage in accessing knowledge academically, socially, and emotionally.

In recent years, it seems that more children diagnosed with autism are being placed in inclusive settings in which they have access to typically developing peers. Previously, children with ASD, as well as children with other disability classifications, were kept separate from non-disabled peers, due to the belief that their learning differences negatively impacted classroom discourse. In fact, the opposite has been found to be true, and there are many benefits to inclusive educational settings, as stated by Barton (2012). “The benefits of inclusive classrooms include generalization of social skills across people, which is an essential component of effective curricula for children with autism,” (Barton, 2012, p. 7). What makes this type of setting special is that it’s a two-way street. Not only do children with autism benefit from working with typically developing peers to practice social and communication skills, but typically developing children learn beneficial skills as well, such as patience, learning other perspectives and viewpoints different from their own, and exposure to individuals who may think in more creative, diverse ways. Creating opportunities for children to work collaboratively with like- and unlike-minded peers opens them to a new world of thinking and understanding the world around them, and preparing children with autism for the outside world through methods of interaction and communication is imperative.

## **An Increased Prevalence**

I don't like to hear the rise in prevalence described as an 'autism epidemic'. I don't like to read of someone 'suffering' from autism. I am not saying suffering isn't involved, but again, the word makes it sound as if autism is something imposed on a potentially 'normal' person. Autistic is what my sons are. To describe them, as 'suffering' from autism is not so different from describing me as 'suffering' from being female.

— Charlotte Moore

Leo Kanner's original publication in 1943 referred to eleven children with what he described as autism, characterized by resistance to change and severe impairments in communication and social interaction skills. Decades following his research, autism was thought to be a rare condition, with prevalence rates of about 1 in 2,500 children diagnosed (Wing & Potter, 2002, p. 151). It was not until the 1960s when parents increasingly disregarded Kanner's original theory that they were the ones to blame for their children's diagnoses and demanded that researchers dig deeper into the world of autism. The snowball effect that occurred after this was remarkable. Experts began to identify more children that shared characteristics with Kanner's group of children, though they differed slightly. Wing and Gould's discovery in the late 1970s that autism existed on a spectrum was earth shattering. As Wing and Potter (2002) note, "The essential point of the spectrum concept was that each of the elements of the triad could occur in widely varying degrees of severity and in many different manifestations," (p. 154). This breakthrough required later editions of the DSM to revise its diagnostic criteria for autism to consider the characteristics of the children being diagnosed.

An important factor when contemplating the prevalence of autism is that this increase has affected many variants within the population of children globally. It has become commonplace that males are overrepresented in special education, and the same can be true for incidences of autism. Across multiple studies and states, there is a higher prevalence of autism in boys than girls. Newschaffer and Curran (2003) state that males are diagnosed three to four times that of females. While scientists and researchers have not given tremendous thought to the idea that autism could be sex-linked, it is curious whether there are biological factors at play in the diagnosis of autism. Park (2017)



discusses whether brain structures, which differ between men and women, specifically the thickness of the cortex, may have a causal role in ASD diagnosis. Men tend to have thinner cortex measurements than women, which aids in distinguishing male and female skulls. Her article cites research conducted by Christine Ecker, a neuroscience professor, in which she and her colleagues compared cortical thickness in men and women with and without ASD. “The thinner the cortex, the more likely the person was to have ASD...It’s possible that the thicker cortex in women might be protective against developing autism,” (Park, 2017). While this theory in no way proves that autism is genetically disposed onto men, it does provide a possibility for why we see far more male ASD diagnoses in schools.

The ever-changing diagnostic criteria for autism is just one of several theories regarding an increased prevalence in autism spectrum disorders. Environmental and biological factors have been considered, as well as an inaccurate yet widespread vaccination theory that caused major turmoil and turned the world on its head (Whitehouse, 2013). A growing awareness and better understanding – though not complete – of autism by parents and teachers has likely had an effect on the number of children being recommended for evaluations, thereby increasing the amount of diagnoses made. Perhaps over time, as populations have grown, an increase in autism incidence has just grown along with them? The most current reports shared by the Centers for Disease Control and Prevention (2014) estimate that autism is now prevalent in 1 in 45 children – quite a difference from Kanner’s original assertions. It seems remarkable that in 75 years, over 50 times as many children are given an autism diagnosis today. How is this *really* possible?

Identifying a cause for autism has troubled researchers for decades. Multiple studies attempt to point to environmental and genetic factors that are believed to have contributed to the child's development, which exposed the child to ASD, yet there has been no true evidence proving these types of theories. In her article, Waterhouse (2008) cites various research studies which describe the numerous proposals and rejections of what causes autism as well as what causes the rate of diagnoses to increase. Gupta and Slate's 2007 study discovered genetic mutations that related to autism, causing cognitive and social impairments. The researchers theorized that underdeveloped genes that could affect an array of deficits, such as cognitive and social impairments, could cause autism (Waterhouse, 2008, p. 281). Genetics likely does play some factor in an increase in prevalence due to the fact that there is evidence that it runs in families. In the last few decades, twin studies have taken place to determine how likely genetic factors explain autism etiology. Wing and Potter (2002) note, "Asperger [1944; 1991] observed that traits related to his syndrome were often seen in the parents of the children concerned," (p. 157). Typically, children with autism have siblings and parents who may show milder symptoms of the autism spectrum, indicating that there is a genetic link; it just has not been specifically determined quite yet.

There has been much speculation regarding the effect of a child's environment as well. According to Wing and Potter (2002), many suggestions have been offered concerning causes of autism due to environmental factors, including the child's diet, allergies, pollutants, and vaccinations. For a while the largest environmental factor that was thought to be the cause of autism and reason for an increased prevalence in the rate of the disorder was due to a British researcher, Andrew Wakefield, who in 1998

published findings in a journal of a link between vaccinations and autism. Vaccinations have been used historically to prevent future diseases, which has helped hinder epidemics and saved populations of people from suffering and death. Whitehouse (2013) explains that the data was found to be false and the study was retracted from the journal, yet the damage was done. This publication caused an incredible distrust of vaccines and many parents stopped vaccinating their children altogether. Serious outbreaks of diseases, that had been preventable for long periods of time, such as the measles, mumps, and rubella, were occurring in many countries around the world, including the United States. Doctors are still adamant to this day that vaccines do not cause autism and enough research has been conducted to provide evidence that this is true, but the skepticism and uncertainty that Wakefield's ideas exposed, however frightening, do not explain a theory for the increased prevalence of autism.

Another theory for why the prevalence of autism has risen in the last few decades can be attributed to comorbidities with other disorders. Kanner's original work hypothesized that autism was a unique disorder, characterized by specific parameters for diagnosis. As Wing and Potter (2002) note, later research acknowledges that autism spectrum disorders can co-occur with other developmental disabilities. The authors mention epilepsy, language disorders and motor coordination difficulties, aspects of which underlie autism spectrum disorders. If the social impairments are not recognized, diagnostic confusion can occur, thereby skewing the number of children diagnosed with ASD. In the past, it is possible that children who displayed autism characteristics were thought to be presenting as different disorders and autism was "missed." Toth and King (2008) note other conditions commonly co-occurring with autism, such as depression,

anxiety disorders, schizophrenia, ADHD, intellectual disabilities, and behavior problems. It has not been proven whether autism is more likely in children with these conditions or disorders, but it raises several questions. How many children were inaccurately diagnosed – or their diagnoses were incomplete – over the years? Is it possible that with better evaluations, changing diagnostic criteria, and a growth of awareness surrounding autism, people with ASD are identified more readily than in the past? When children were sent to mental institutions in the past for reasons of ‘insanity,’ were they on the autism spectrum in actuality?

Perhaps the largest reason for why the prevalence rate of autism in children has increased is due to changes in diagnostic criteria. With changing versions of the DSM throughout the last few decades, the definition of what classifies autism has shifted, thereby widening the range of possibilities when considering certain characteristics that children demonstrate. For example, when changes were made from the DSM-III to the DSM-III-R, the concept of autism was broadened, which contributed to the increase in prevalence over time, (Waterhouse, 2008, p. 275). This version of the DSM introduced the diagnostic criteria for pervasive developmental disorders (PDD), which shifted autism from a psychiatric to a developmental disorder. The DSM-IV-TR introduced more subtypes of autism, including Asperger syndrome, Rett syndrome, Childhood Disintegrative Disorder, and a more refined version of PDD, PDD-NOS (Wing & Potter, 2002, p. 153-154). Kulage, Smaldone, and Cohn (2014) indicate in the DSM-IV-TR alone, “...there are a total of 2,027 possible combinations of criteria to arrive at a diagnostic threshold for any one of three autism spectrum disorders [AD, AS, PDD-

NOS],” (p. 1918-1919). Such broad scopes for what determines a diagnosis of ASD has a direct impact on how children are identified when being observed and evaluated.

Prevalence is widespread globally, and this idea that prevalence has increased due to changes in diagnostic criteria is not new. According to Haelle (2015), in the 1980s-1990s, national data cited an increase of 60% of children diagnosed with autism after considering the spectrum of disorders discovered by Wing and Gould’s study in 1979. Whitehouse (2013) offers a perspective for why prevalence has so readily increased due to diagnostic changes in criteria. “The expansion of diagnostic boundaries has meant that individuals, who previously would have been placed under a different ‘diagnostic banner,’ are now more likely to receive a primary diagnosis of autism,” (p. 15). The broad diagnostic criteria have certainly opened the floodgates for autism diagnosis.

Diagnostic substitution can also be attributed to an increased prevalence of autism. Shattuck (2006) defines this premise as, “The same child who might have received some other disability label 15 years ago is now being identified with autism because of shifting referral and diagnostic processes,” (p. 1029). As the diagnostic criteria regarding autism and other developmental disabilities has changed, labeling practices and referral recommendations have been altered as well. Given ASD’s vast history, depending on when a child was initially evaluated depended largely on whether they may receive an autism diagnosis. Zablotsky, Black, Maenner, Schieve, and Blumberg (2015) explain that these practices may change due to similarities in symptoms, causing classifications to be made under different categories during different time periods. Over time, parents may decide that the initial diagnosis their child received does not adequately describe their characteristics, seek out a new evaluation, and are

found to have a different diagnosis in the present than originally believed in the past due to these changes in diagnostic criteria and practices.

According to Coe et al. (2007), “Diagnostic substitution and identification of previously undetected cases each accounted for about one-third of the increase in the administrative prevalence of autism from 1996 to 2004,” (p. 1045). Diagnostic substitution has decently contributed to the rise of autism diagnoses throughout the United States. Though the increase in diagnostic criteria allowed for more children to be identified as having ASD, the similarities amongst the classifications made it difficult for evaluators to categorize individuals effectively and accurately. Co-occurring with the changes in diagnostic criteria and diagnostic substitution, the subjectivity of each evaluation must be considered. Unfortunately, children cannot be diagnosed with autism based off a blood test, or an examination of genetic markers. This being the case, it is up to the expertise of clinicians and practitioners who have had experience in working with children with autism. It is expected that they understand what autism looks like, though this is incredibly subjective. It is troubling to wonder what happens to the children that they miss in their diagnostic identification.

Whitehouse (2013) explains that autism is primarily diagnosed through observations, where practitioners use principles and scales to describe people with significant impairments in areas such as communication and social skills, as well as repetitive behaviors. “A diagnosis based on behavior is inherently subjective. The dividing line we draw between ‘disordered’ and ‘normal’ is often blurry and can lead to considerable debate. One clinician’s ‘disordered’ is often another clinician’s ‘normal,’” (p. 13). As the DSM has been changed, so has the definition of autism. For example,

prior to the 3<sup>rd</sup> version of this manual, autism did not exist as a disability classification. Once that was implemented, evaluators had to look for specific cues and characteristics of ASD in children. Klin, Volkmar, and Sparrow (2000) note that within the realm of social and communication functioning alone, the characteristics span a wide range, leaving room for subjective decisions that vary from one clinician to the next. Presently, with the DSM-5, it is even more subjective for evaluators to identify a child with ASD. The subtypes of autism have been removed from diagnostic criteria practices and an implementation of a severity scale has replaced them. The levels are indicative of the amounts and types of services in place to help a child with ASD succeed: Level 1, “Requiring support”; Level 2, “Requiring substantial support”; and Level 3, “Requiring very substantial support,” (Autism Speaks, 2018). It is unclear what the distinction is between “requires substantial support” and “requires very substantial support.” Clinicians have different views about what constitutes severity, and the subjectivity involved in declaring one child is displaying autism characteristics but another is not, seems superficial.

Another side to consider in the prevalence theory is what autism diagnosis means for a family. Some families may be in denial and perceive that there is something “wrong” with their child. Other families find comfort in the fact that their child’s difficulties finally have a name and description, which lay out a path for accessing services. An interesting perspective affecting prevalence is when one considers why a family may *want* an autism diagnosis for their child. In many ways, autism is a gift because it provides services to children. Kulage, Smaldone, and Cohn (2014) provide an example depicting a child who does not exactly meet the criteria markers for autism, but

still would benefit from services that provide social and educational assistance, creating a stronger likelihood of success and independence later in life. Parents want what is best for their children, and the fact that diagnostic criteria can potentially exclude certain children from receiving services that would greatly assist them may impact a parent's decision in accepting an ASD diagnosis.

In past decades, primarily before autism was consistently diagnosed amongst the childhood population, there was a larger prevalence of children with intellectual disabilities. Many parents were unhappy with the label, "mental retardation," and purposefully advocated for diagnoses with less stigmatizing labels. At that time, autism fit the bill. Whitehouse (2013) quotes this idea perfectly by coining the phrase, "‘upgrading’ of symptoms," (p. 15). *(Note: it is also quite interesting to see how this preference in label still has its roots today, as autism is often stigmatized – many people were upset when Asperger syndrome was removed from the DSM-5 because it carried less “shame” than autism).* As services have become more readily available, parents are more willing to think about and accept a diagnosis of autism if they are concerned about how their child is developing. Interestingly, this can have an effect on clinicians as well. "Professionals are more likely to make a diagnosis of an autistic condition if they know that it will lead to appropriate help for the child or adult and the family concerned," (Wing & Potter, 2002, p. 157). In other instances, government policies have provided families with funding toward health services if their child had an autism diagnosis in the past, which most likely affected a family's willingness to accept the autism label for their child (Coo et al., 2007, p. 1044). Once parents and professionals become more



comfortable with the autism label, it can increase the amount of children being diagnosed with ASD, thereby directly contributing to the prevalence rate of autism.

This entire discussion on the autism prevalence rate increasing has been based mostly on the population of ASD diagnoses made within few racial groups. Furfaro (2017) discusses the racial disparity among diagnoses across racial and ethnic groups in her article. Predominantly, white children are diagnosed with autism whereas other racial and ethnic groups, such as black and Hispanic children, are not. Her article discusses the ASD prevalence rates over time within and across these groups, citing an increased awareness of autism to be the likely culprit of a higher diagnosis rate. Furfaro (2017) notes that it may not be the racial groups as much as socioeconomic classes that have an effect on the increased prevalence, indicating that a lack of access to diagnostic and early intervention services may contribute to the lower prevalence of autism in minority populations. A similar sentiment is shared from the perspective of a black father, Michael D. Hannon, where he regales personal experiences from raising a son with autism and compares them to other families' experiences. "The distribution of disability is tied to the degree of social advantage when variables such as race, ethnicity, socioeconomic status, gender, and age are considered," (Hannon, 2017, p. 154). He also notes that minority groups, specifically black children, are more likely to receive a conduct or adjustment disorder diagnosis before one for autism. Autism spectrum disorders are not race-specific, though the slanted population distribution may dictate this phenomenon.

Many wonder if the increased prevalence of autism is simply due to growing awareness of the spectrum. Hanson, (as cited in Sifferlin, 2015) states, "As people become more aware of the term autism over time, it's causing parents to have their kids

be examined more often.” Since the diagnostic criteria has widened, more people have been diagnosed, which has provided the public with more information and research (Wing, 2005, p. 199). The vaccination debate brought the concept of autism into the forefront of people’s minds, albeit in a deceitful, inaccurate model; however, it may have gotten families to face the possibly uncomfortable or upsetting question, *does my child have autism?* As Wing and Potter (2002) note, autism was first thought to be a childhood disorder, but with spreading knowledge of Asperger syndrome, awareness was heightened that autism persists into and throughout adulthood, especially in those displaying high intelligence and ability. Increased awareness has alarmed families, but has been a positive for many because it has allowed them to consult with professionals earlier. The earlier a diagnosis, the better the outcome, because the child then has access to early intervention services, which make a tremendous difference in cognitive, social, and communicative functioning that affects the child for the rest of their life.

At this juncture, there are a variety of reasons that the autism prevalence has increased to 1 in 45 children. This is a staggering statistic – it seems that it is now more common to have children in classrooms with autism than classrooms without. The takeaway is that autism is a very real condition affecting many people in society, and it is up to researchers, clinicians, teachers, and parents to help these children access the services they need to be successful so they can aim for greatness.

## **Assessment Process and Diagnosis**

When you take a drug to treat high blood pressure or diabetes, you have an objective test to measure blood pressure and the amount of sugar in the blood. It is straightforward. With autism, you are looking for changes in behavior.

— Temple Grandin, 1996

The widening of the autism spectrum has allowed for further expansion into diagnostic criteria, making a definitive process for identifying autism more difficult. ASD is not simple to diagnose due to the variety of symptoms and behaviors that a child can exhibit. It is challenging to pinpoint the exact description of a child with autism, and professionals disagree on what probes and assessments to use to determine an ASD diagnosis. How can we possibly develop a set of evaluation procedures, checklists, and scales if we are unsure of what exactly constitutes ASD?

It can make a significant difference in the child's success depending on when a diagnosis is made. Aspy and Grossman (2007) cite the necessity for early identification. "There is typically a delay of two to three years after symptoms first become apparent. Because early intervention makes a critical difference in the progress of people with ASDs, delay in identification is a matter of great concern," (p. 12). Autism symptoms can appear between 12-18 months of age (Bleicher, 2013) with parents or teachers often being the first to notice abnormalities in the child's development. There are many scales that parents can use themselves as an initial screening measure to determine if the behaviors their child exhibits matches a child with ASD. According to the National Institute of Mental health (2016), checklists can be used to help gather information regarding social and communication development and though they cannot serve as an official diagnosis, they can serve as a need for a referral for a possible ASD diagnosis (NIMH, 2016). When parents first question whether their child may have ASD or is starting to exhibit behaviors commonly associated with autism (e.g., regression in speech, lack of interest in social interaction, restrictive, repetitive movements, etc.) it is imperative that they seek out professional assistance.

Evaluating a child for an autism spectrum disorder requires the consideration of many factors, including the behaviors a child exhibits, and which assessment type would be most useful in identification. Once parents have considered the possibility that their child may have an autism spectrum disorder, they should immediately seek out professional assistance. “Even the best instruments are meaningless when those interpreting them do not have the training and experience to make accurate judgments” (Aspy & Grossman, 2007, p. 12). These trained clinicians, consisting of neurologists, psychologists, and pediatricians must have a professional background in child psychology, behavior, and autism spectrum disorders to ensure that the results are reliable. Unfortunately, because the spectrum has become so wide and the diagnostic criteria have changed considerably, the chance for misidentification is apparent. Safran, Safran, and Ellis (2003) explain that once a child is deemed to be at-risk, a battery of comprehensive, interdisciplinary assessments must be conducted by these trained professionals. In addition to checklists and assessments, some of the best information a clinician can use to inform their diagnosis comes from interviews with family members.

A trained clinician can choose from a range of assessments to evaluate children who are believed to have an ASD. Certain assessments have more notoriety than others due to their effectiveness in identifying children with autism. For example, Catherine Lord and her colleagues developed two assessment probes, the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview - Revised (ADI-R), which are considered “gold standard” evaluations in classifying and identifying autism in children (Lord, 2010, p. 816). Other assessments are widely used as well, such as the GARS and CARS, SIB-R, PL-ADOS, and DB-DOS (detailed description for each

instrument follows). Though no longer a category of autism, there are certain evaluations that trained clinicians have used in successful identification of Asperger syndrome. The following provides an overview of common batteries used in the evaluation process for autism spectrum disorders.

### **Assessments Used in Identifying Autism Spectrum Disorders**

**Autism Diagnostic Observation Schedule (ADOS).** The ADOS is a standardized assessment created by Lord and colleagues used to identify and diagnose autism. It is widely used and considered the “gold standard” for autism assessment (Barton, 2012, p. 31). The tool is split into four modules categorized by the child’s age and level of expressive communication, and assesses the areas of communication, social interaction, and play behaviors. According to Chlebowski, Green, Barton, and Fein (2010), the tool uses planned social interactions to encourage a child to initiate and respond in a natural setting. The purpose is to measure social communication in real time through direct interaction with, and observation by, a trained clinician (Lord, 2010, p. 818). The test session should take about 30-45 minutes, and during this time it is important to assess a child’s ability to engage with an unfamiliar person through activities, toys and games while responding to prompts from the clinician. According to Lord (2010), if a child cannot pass an item, the clinician simplifies the task using backward chaining. Once the child is able to accomplish the item, the child receives an “emerging” score, and the clinician notes their level of support on those items for reference in future program planning. The assessment also includes the sequence in

which the items should be presented as well as what specific behaviors the clinician should actually observe and note in their data.

**Autism Diagnostic Interview - Revised (ADI-R).** Another “gold standard” assessment, this interview-based assessment addresses the developmental and behavioral aspects of autism. It is considered appropriate for use with children aged two and older and, as Murray, Mayes, and Smith (2011) note, “Significantly differentiates children with autism from non-autistic clinical and typical children,” (p. 1588). As Safran, Safran and Ellis (2003) explain, the parent or caregiver responds to prompts presented by a trained clinician in the assessment. The interview lasts from 2-3 hours, where the interviewer “codes the behaviors on a 0-3 severity scale to help determine the severity of autistic traits,” (p. 156). Questions on this assessment contain items related to social interaction, communication, and repetitive behaviors. “This interview includes 93 items, which are high standardized and designed to elicit information about family history and the child’s current levels of functioning, developmental history, communication, social and play behaviors, interests, and atypical behaviors,” (Barton, 2012, p. 32). When first created, the ADI was incredibly long and took almost four hours to administer and required more frequent visits for the child’s parent/caregiver. This assessment provides the evaluator with an excellent picture of the child through the parents’ eyes in the domains that define autism (Lord, 2010, p. 820). What differentiates this assessment from others is that it does not replace a medical history or physical exam; rather, it includes questions regarding early behaviors and how the child has changed over time. This assists test clinicians in acquiring a broader sense of the child, going beyond what is typically accessible information gathered through teacher forms and phone calls (Lord, 2010, p.

820). The open-ended questions about the child allows test clinicians to gather more useful information from parents than other instruments, such as scales that rely on pointed questions. Since the original ADI was so long, clinical researchers reviewed the assessments by rewriting and reorganizing the sequence of questions. The ADI-R is time-consuming to administer, taking over two hours to score, and requires extensive training for clinicians. The ADI-R is also an expensive option when choosing evaluation instruments to detect ASD.

**Pre-Linguistic Autism Diagnostic Observation Scale (PL-ADOS).** The ADOS was initially intended for children ages five and up with relatively fluent speech. According to Lord (2010), many autism clinics were beginning to get referrals for children under age 5 without fluent speech, and a modification of the ADOS was necessary. DiLavore, a special educator and clinical researcher, developed the Pre-Linguistic Autism Diagnostic Observation Schedule. Initial plans were to begin with the original ADOS tasks using more age-appropriate toys, it was apparent that the original ADOS structure was inappropriate for this age group. “Two- and three-year-olds do not usually sit at a table for an hour while an adult hands them different toys. Nor is this an appropriate situation in which to evaluate reciprocal social behavior and spontaneous communication,” (Lord, 2010, p. 820). This assessment also yielded unexpected results. The PL-ADOS provided a way for family members to witness and participate in interactions with their children. The clinicians were able to demonstrate what they saw when working with the child and give the caregivers an opportunity to see what their children were able to do or not do in response to social communication and interaction.



**Childhood Autism Rating Scale (CARS).** This rating scale measures behaviors related to autism categorized into 14 domains. The assessment is administered by a trained clinician who uses this scale to detect and diagnose autism. According to Chlebowski, Green, Barton, and Fein (2010), a 15th domain also exists, which measures “general impressions of autism,” (p. 788). The CARS relates to social communication skills, activity level, object and body use, and relationships. Test clinicians interview parent/caregivers of the child and uses that information to gather data for the scale. As Barton (2012) explains, the scale for each item ranges from 1, typical, to 4, severely abnormal for the child’s age. Though it is widely used, there are many issues with considering it as a means to diagnosing autism. Researchers, such as Catherine Lord, have found that this particular scale appears to “over-diagnose” young children as having autism, and has consistently classified children with intellectual disabilities as having autism in the past. Considering the negative impacts this could generate, supporters of the scale defend it due to its strong internal consistency and inter-rater reliability. It is best used as one of many different assessments to gather data for identification of autism in children.

**Gilliam Autism Rating Scale (GARS).** Another rating scale, the GARS is a norm-referenced assessment that can be used to diagnose and assess the severity of autism in both children and adults age 3-22. It uses a semistructured interview format to gather information from parents, caregivers and teachers (Barton, 2012, p. 33). This instrument is used as a rating scale, which yields an Autism Quotient, representing the likelihood of autism in an individual. According to Lecavalier (2005), the scale contains fifty-six items, which are categorized by four subscales – Stereotyped Behaviors,

Communication, Social Interaction, and Developmental Disturbance – and are rated on a scale ranging from never to frequently observed. There are many weaknesses associated with this scale because it does not contain good reliability and validity measures, though, support for this scale stems from its quick and simple administration (about 10-20 minutes) and scoring as well as its ability to indicate severity of autism in particular populations and measure specific behaviors. Like the CARS, the GARS assessment is meant to be used as a supplement in conjunction with other assessments used to identify autism.

**Autism Spectrum Screening Questionnaire (ASSQ).** The ASSQ evaluates a child's behavior based on twenty-seven behavioral descriptions rated on a 3-point scale, not present ("0"), somewhat present ("1"), or definitely present ("2"). According to Campbell (2005) the score indicates if the "child stands out as different from other children of his/her age," (p. 29). The items on the scale address problems in social interaction, communication, restricted and repetitive behavior, motor clumsiness and associated symptoms such as the presence of motor tics (Campbell, 2005, p. 29). This assessment is used as a screening measure and takes approximately 10 minutes to identify children that may require further comprehensive evaluations to determine if Asperger disorder or high-functioning autism are present.

**Checklist for Autism Spectrum Disorder (CASD).** Murray, Mayes, and Smith (2011) describe the CASD as a semistructured interview with the parent. Information from the child's teacher or childcare provider and observations of the child are used to determine a score on the scale as well. There are thirty items on the scale marked either as present or absent (currently or in the past) by the clinician based on the information

gathered from the interview. It is a norm-referenced assessment meant to be used with individuals age 1-17 with IQs of 9-146. It is important to note that this scale is based on the belief that autism is a single spectrum disorder, consistent with the DSM-5. The assessment has demonstrated that it can "...Differentiate children with autism from children with ADHD and from typical children... and has 90% agreement between the CASD completed by a clinician and the CASD independently completed by the parent," (Murray, Mayes, & Smith 2011, p. 1587). It also has been found to be effective in identifying children across the length of the spectrum and has high diagnostic agreement with other instruments measuring autism characteristics.

**Scales of Independent Behavior (SIB-R).** Lecavalier (2005) defines the Scales of Independent Behavior - Revised assessment as a standardized measure of adaptive behavior. Containing fourteen subscales, the SIB-R is categorized into four areas: (a) motor skills, (b) social and communication skills, (c) personal living skills, and (d) community living skills (Lecavalier, 2005, p. 797). The rating scales measure sixteen to twenty items in increasing developmental difficulty and evaluators use a four-point Likert scale ranging from 0 "Never or rarely - even if asked," to 3, "Does very well - always or almost always - without being asked," (Lecavalier, 2005, p. 797). Typically administered in an interview format, a checklist format is acceptable at times as well. This evaluation is used to assess as young as early infancy to adulthood.

**Vineland-3.** This assessment is a standardized measure of adaptive behavior, or the functional living skills that people use each day. The abilities that are measured focus on what the child *actually* does in daily life. Pearson (2016) describes their assessment as normed, and examinees scores are compared to similar aged peers. The assessment is

administered to someone close to the child who knows them well, typically a parent or teacher. It is administered interview-style, with the interviewee providing information about areas where the child is performing similar and dissimilar to his peers. The Adaptive Behavior Composite (ABC) provides an overall summary score of the child's achievement on the Vineland-3. This score is calculated based on the progress in four domains: "Communication," which assesses the exchange of information with others, processing information, verbal expression, and reading and writing; "Daily Living Skills", assessing performance on practical, everyday tasks deemed appropriate within the school setting (e.g., self-care, using numerical concepts and meeting expectations); "Socialization," which reflects student functioning in social situations such as in interpersonal relationships, play and coping skills and leisure activities; and "Motor Skills," where gross and fine motor abilities are assessed (Pearson, 2016, p. 7). There is an additional domain, Maladaptive Behavior, which provides a brief description of problem behaviors. This serves the evaluator when attempting to diagnose or plan an intervention for a particular child.

After speaking with Dr. Dorrie Bernstein, a child psychologist with a history of working with children on the autism spectrum, she explained that this particular assessment helps her gather data from a parent about their child's development, (D. Bernstein, personal communication, December 8, 2017). She explains that this method of assessment provides her with extensive information about the child, giving her a clearer picture of who the child is in everyday life.

**Behavior Assessment System for Children (BASC-II).** Another norm-referenced test, the BASC-2 assesses behavior and self-perceptions of children and young

adults ages 2-25. There are multiple forms of this assessment, depending on who is administering the section (e.g., Parent, Teacher, Self). Each scale is categorized into three forms by age and both the parent and teacher scales are rated based on a 4-point scale. The Self-Report is administered orally, and children respond with a “yes” or “no” answer. The Community-University Partnership for the Study of Children, Youth and Families (2011) describe uses for the assessment tool in treatment program planning, evaluation and intervention, determining school classification and programming, and assisting in pinpointing problem behaviors. In addition to the different scales, depending on who is administering the assessment, Structured Developmental History interviews and Student Observation Systems are also available for a clinician to evaluate classroom behavior directly (Community-University Partnership for the Study of Children, Youth and Families, 2011). The publisher denotes this assessment as a “Level C” qualification, indicating that it is meant to be used by professionals with either masters or doctoral level degrees in education, psychology, or is a trained clinical evaluator.

**Child Behavior Checklist (CBCL).** The Child Behavior Checklist is a questionnaire completed by parents of children with behavioral and/or emotional problems. According to Hus and Lord (2013) there are different forms depending on the age of the child. Both the 18-month - 5-year age range and 6-18 year age range forms provide standardized T-scores for “Internalizing (CBCL-I) and Externalizing (CBCL-E) domains,” (p. 374). Prompts on the questionnaire attempt to establish background information on the child, such as hobbies, chores at home, and teams they are on. Once that information is gathered, the questions become more specific, such as asking parents to compare their child’s exhibited behaviors to other children their age. After studying a

sample of the checklist, it seems that children are rated on a 3-point scale to assess situations and scenarios. A scale indicating “not true, sometimes true, and always true” seems to leave a lot of room for subjectivity, so this checklist must be used in conjunction with other assessments, preferably ones conducted by trained clinicians.

**Asperger Syndrome Diagnostic Scale (ASDS).** This test specifically measures the presence of absence of behaviors related to Asperger syndrome. It is a norm-referenced assessment with 50-items categorized into five subscales: language, social, maladaptive, cognitive, and sensorimotor (Campbell, 2005, p. 26). This scale is used to identify people ages 5-18 with Asperger syndrome, document the progression of behaviors, formulate target goals for IEPs, and for use in research. Campbell (2005) states that raters can be general education teachers, special education teachers, paraprofessionals, or parents, so extensive training is not required; however, the rater should have a developed relationship with the child. According to Boggs, Gross, and Gohm (2006), the scores are categorized on the protocol as very unlikely, unlikely, possible, likely, or very likely indicative of an Asperger diagnosis. Scores are calculated with a point value of 1 or 0, whether behaviors were observed or not observed, respectively, and takes about 10-15 minutes to complete.

### **Diagnosis vs. Eligibility**

According to Aspy and Grossman (2007), the terminology surrounding ASD assessment can be confusing. “...The terms ‘medical diagnosis,’ ‘diagnosis’ and ‘eligibility’ are often misunderstood. While the term ‘medical diagnosis’ is often used, it is a misnomer. ‘There are no medical tests for diagnosing autism,’” (p. 12). As we know,

there is no surefire way to identify autism in individuals; however, using certain assessments listed above, observing the child's behaviors, communication, and development, and speaking with those closest to the child can provide the most accurate diagnosis of autism. Aspy and Grossman (2007) also note that the term "diagnosis" falsely presumes that the identification must be made by a medical professional. Since the diagnosis is not medical, many specialized teams do not have members with medical training on the board.

The difference between diagnosis and eligibility is not obvious (see Table 1). The DSM-IV-TR refers to identification of autism in individuals as a diagnosis; however, this term is more widespread in the private sector. When assessing children for special education services in the public school setting, a battery of assessments are provided to determine eligibility for services and to assist in planning an educational program (Aspy & Grossman, 2007, p. 12). When providing an autism diagnosis or determining if a child is eligible for special education services to assist with behaviors associated with autism, it is imperative that the evaluator be knowledgeable and experienced to prevent misdiagnosis.

### **Controversies Surrounding Assessment Protocol**

**Misdiagnosis.** When assessing a child to determine if they may show signs of autism, it is crucially important to have the child tested as soon as possible by experienced, knowledgeable evaluators. For the assessments to demonstrate quality and reliable results, the test clinicians should have demonstrated experience administering these types of assessments, as well as literature and research-based knowledge on the

large autism spectrum. Rachel Ehmke (n.d.) suggests a devastating reality of misdiagnosis: with such a diverse spectrum, children with autism can mistakenly be identified with a different disorder, or are not given a diagnosis at all. There are so many subtleties in the range of disorders on the spectrum that are often overlooked as well (Safran, Safran, & Ellis, 2003, p. 155). Aspy and Grossman (2013) include a quote from Wilkinson (2008) in their chapter on assessing and diagnosing Asperger syndrome. Wilkinson states, “The consequences of a missed or late diagnosis include social isolation, peer rejection, lowered grades, and a greater risk for mental health and behavioral distress such as anxiety and depression during adolescence and adulthood,” (p. 23). This can be devastating for families attempting to figure out what is going on with their child, as well as be a detriment to the child because he is unable to receive the services he needs.

**Reliable Evaluations and Their Evaluators.** Autism spectrum disorders cannot be diagnosed medically; therefore identification is determined by using checklists, scales, and diagnostic evaluations. There may be issues with the reliability of these measures because they are often left to the interpretation and discretion of the evaluator. On checklists, parents may not rate their child as demonstrating certain behaviors or having more severe symptoms than is the case. The opposite is true as well – parents may miss specific behaviors that indicate certain diagnoses. To avoid this, experienced test clinicians interview parents using items such as the ADI-R to gather developmental history information on the child. Checklists and rating scales are not tools that should necessarily carry much weight in the decision to diagnose a child with autism either. According to Lecavalier (2005), “ASDs have proven to be especially difficult to capture



with information based on rating scales because of their heterogeneous and changing nature,” (p. 804). It can also be challenging to distinguish between autism and other disorders, even using “gold standards” such as the ADOS.

### **Best Practices**

Donna Murray, the senior director of the Autism Speaks Autism Treatment Network, (n.d.) is of the opinion that diagnosing ASDs are challenging and requires direct observation, examination and assessment, and reports from parents and teachers to assist with the process. Parents can conduct the initial screening checklists to see if their child is similar to one with ASD in the “triad of co-occurring impairments” (Happé & Frith, 1996, p. 1378) in areas of communication, social skills, cognition, and behavior. While the results can provide information about autism, parents should have their child officially evaluated by trained professionals who know exactly what to look for, and what instruments to use, when diagnosing ASD or other developmental disorders. Measurement reviews, as those offered above suggest that the “gold standard” instruments, such as the ADOS and ADI-R, will provide the most comprehensive results, and have the most grounding in scientifically based practice. It is important to remember that autism exists across a spectrum, and the many subtleties that can constitute autism make reaching a diagnosis that much more challenging, so working with a trained, interdisciplinary team is a must.

Autism is typically discovered in early childhood, so parents should look into early intervention therapies that can assist their child in acclimating to new settings and playing and working with others. Once a diagnosis has been determined for a school-age

child, it is imperative that parents and teachers work together to best fit the needs of the student. Assessing children on the autism spectrum can be a long, trying process for the families involved, especially when diagnosis does not seem to be very near. The earlier an ASD is discovered, the better: implementing early intervention and working on the skills necessary to be successful once the child reaches school age is the goal.

# **Evidence-Based Interventions and Strategies**

If they can't learn the way we teach, we teach the way they learn.

— O. Ivar Lovaas

It cannot be emphasized enough, that children need to be assessed as soon as possible when autism is suspected. Trained clinicians are expected to score and interpret the results from the evaluations to begin developing plans for future academic, behavioral, and social skills interventions. If evaluated prior to age five, children who are diagnosed with ASD can obtain early intervention services. According to Lindgren and Doobay (2011), “Early intervention can make a significant difference in improving cognitive and social development for children with ASD,” (p. 22). The earlier the services are in place, the sooner children can access interventions to better assist them with their communication, social skills, and repetitive behaviors.

There are a multitude of therapies and interventions supported by evidence-based practice that have proven successful for children with autism. As Safran, Safran and Ellis (2003) note, any intervention, treatment, or strategy implemented must be individualized to accommodate the needs of that particular student. Simply expressed, the strategies must have relevance to the child and be motivating for them to have an impact. Teacher and parent observations in concordance with the assessment results help establish areas of strength and weakness. This information is needed to determine the types and methods of interventions that will best fit the needs of the student.

When deciding on which interventions to implement with a child with ASD, it is suggested that a parent or teacher look to evidence-based practices, grounded in scientific research, because these strategies have been proven successful for other children in the autism community. As Ferreri and Plavnick (2012) note, “The heterogeneity of individuals with autism spectrum disorders requires that service providers become familiar with a range of evidence-based practices and learn to select a practice that is best

suited to the needs of a specific child,” (p. 192). The following provides brief descriptions of therapeutic interventions found to assist children on the spectrum in the areas of communication, social interaction, and behavior.

**Applied Behavior Analysis (ABA).** Applied behavior analysis focuses on teaching socially appropriate behaviors using reinforcers. Rachel Ehmke (2018) quotes a neuropsychologist, Dr. Epstein, in her article, who explains the basis for ABA. Epstein states, “Behaviors that are reinforced will increase; behaviors that are not reinforced will reduce and eventually disappear,” (Ehmke, 2018). Certified ABA therapists using this intervention aim to modify a child’s behavior to produce a more favorable outcome by reinforcing positive behaviors and “punishing” negative or harmful behaviors. To do this, it is necessary to determine the antecedents and consequences immediately before and after the behavior occurs. The antecedent is considered a “trigger,” indicating that what happens directly before the undesirable behavior may serve as a cause of the problem behavior. The consequence is what happens immediately after the behavior has occurred. Focusing on antecedents and consequences can help therapists determine what may cause the problem behaviors so they can attempt to prevent them from occurring. The hope is that eventually the unwanted behaviors will decrease and fade out completely.

There is much controversy surrounding applied behavior analysis, and many people in the autism community have mixed feelings regarding this intervention strategy and others that are based in this practice. Those who support applied behavior analysis refer to the scientifically based evidence that demonstrates the effectiveness of ABA therapy for children with autism. Walsh (2011) states that children are able to work with highly trained professionals and receive intensive, quality instruction to learn adaptive,

communication and social skills. As a parent with a child with ASD, she refers to the idea that people on the spectrum are often thought of as less capable members of society because of their diagnosis. ABA can provide children with autism the skills they need to communicate and socialize with peers. “Behavior intervention can be used to teach and support learning the social skills necessary to successfully interact with their peers,” (Walsh, 2011, p. 75). As children with autism can be rigid, the structured, routine-based method of applied behavior analysis is often a popular intervention choice.

Though it is one of the more commonly implemented therapies for children with autism, applied behavior analysis is not all positive. Kapp, Gillespie-Lynch, Sherman, and Hutman (2013) mention that there are parents and self-advocates who criticize ABA because they believe the focus is too narrow and forces compliance and “normalization,” (p. 60). For example, many children with autism engage in self-stimulatory behaviors (e.g., “stimming”), which those without ASD do not. Stout (n.d.) believes that for children with ASD, there is a self-serving purpose behind these actions, and unless the child is causing harm to himself or others, there is no reason to diminish the behavior. Others disagree, and some ABA therapies try to squelch or punish “unusual” behaviors, not because they are harmful, but to make the children appear more “normal,” (Stout, n.d.). Others against the implementation of ABA therapy disagree with the reward/punishment system interwoven in the interventions, because it can produce dependency as well as cause misunderstandings about how to interact with others. For example, if a child performs a behavior correctly, immediately giving them a toy as a reward does not necessary teach them that what they completed was right; rather, it teaches them, “If I do this, then I will get that.” This unrealistic lesson may ill-prepare

children with autism to enter the real world if these reinforcers are not faded out appropriately. Ehmke (2018) notes newer approaches to applied behavior analysis consist of incidental teaching, which Catherine Lord describes as “taking advantage of something the child is doing anyway,” rather than forcing them into a specific therapy.

**Pivotal Response Training (PRT).** Based in ABA-methodology, pivotal response training is an intervention to assist children in acquiring communication and social skills while minimizing negative behaviors and disruptive self-stimulatory behaviors. According to Lindgren and Doobay (2011), pivotal response training is child-initiated based upon their interests, and can be implemented by teachers and related service providers. Autism Speaks (n.d.) is of the opinion that the focus is less on targeting individual behaviors, and instead on pivotal areas of a child’s development, including motivation, response to multiple cues, self-management, and the initiation of social interaction. The goal is that in remediating and focusing on these areas, the child will learn to transfer these skills into other areas, such as social interaction, communication, behavior, and academics. Though typically implemented with preschool and younger elementary school children, research has shown that this intervention would be beneficial for adolescents and adults as well.

**Discrete Trial Training (DTT).** Sometimes referred to as the “Lovaas therapy,” in reference to a professor from UCLA, discrete trial training is grounded in behavioral learning theory and is another subset of applied behavior analysis. The earliest form of ABA therapy, it is extensively structured and implemented in a way to break down skills into “discrete components,” (Ehmke, 2018). In this intervention, the therapist leads the child through an activity, learning in a step-by-step fashion, and then repeats the process

for a given number of trials. The activity is meant to be completed exactly the same way, over and over again, and the child is either rewarded with an incentive for successful trials or “punished,” (e.g., not incentivized or praised) for exhibiting unwanted behaviors or unsuccessful completion. Lindgren and Doobay (2011) state, “Research indicates that DTT can produce powerful behavioral outcomes in the areas of language, motor skills, imitation and play, emotional expression, academics, and the reduction of self-stimulatory and aggressive behaviors,” (p. 13). This intervention must be administered by a trained professional DTT-therapist who engages in modeling, prompting, errorless learning, and other tactics to lessen problem behaviors for children with autism. It is one of the more expensive intervention options, due to the frequency and time allotment required for each session.

**Functional Communication Training (FCT).** Functional communication training is an intervention targeted to improve behavior through lessons in effective communication. “After the communicative ‘functions’ of disruptive behaviors are determined through functional behavioral analysis, socially appropriate behaviors are taught as replacements for problem behaviors,” (Lindgren & Doobay, 2011, p. 13). This type of intervention is typically reserved for children on the autism spectrum who display severe behaviors. According to Tiger, Hanley and Bruzek (2008), aggressive and self-injurious behaviors are most often targeted during functional communication training; however, bizarre vocalizations, stereotypy, inappropriate sexual behavior, self-restraint, and inappropriate communicative behaviors can be addressed as well. To determine reinforcers for the problem behaviors, a functional behavioral analysis (FBA) is conducted to pinpoint conditions under which the problem behaviors are likely to occur.



Following the FBA, the therapists teach socially acceptable communicative responses and promote the use of these through reinforcers that are relevant to the child with ASD. After successful trials, the therapist will then teach these strategies to parents and teachers to help transfer the skills, with success being determined by “the extent to which communication occurs in the presence of all relevant caregivers and in all relevant settings,” (Tiger, Hanley, & Bruzek, 2008, p. 16). This intervention should be implemented by a well-trained FCT-practitioner.

**DIR Floortime.** The Developmental, Individual Difference, Relationship-Based Model of Intervention (DIR) was created by Stanley Greenspan and Serena Wieder, who were the first to consider how emotional development relates to sensory processing, and how relationships are the “pivotal force” that nurtures development (“DIR Floortime Model Training,” n.d.). This intervention helps parents and children with autism enjoy emotional interactions in meaningful ways, which the founders credit as the foundation necessary for all types of development. It is completely child-led by “joining the child where they are.” The therapist who runs the intervention is typically highly-trained and certified in the DIR Floortime Model and may come from a host of different backgrounds, including medical, occupational and physical therapies, special education, or early intervention practices, making it a truly integrated, multidisciplinary approach for working with children on the autism spectrum (“DIR Floortime Model Training,” n.d.). It is suggested the parents engage in DIR with their child regularly throughout the day, with and without the support of the therapist. This intervention helps with social interaction and relationship-building skills, areas that are difficult for children with

autism to excel in. With practice in this model, these children can learn to transfer these skills to classrooms and other settings.

### **Treatment and Education of Autistic and Related Communication**

**Handicapped Children (TEACCH).** Peerenboom (2003) describes TEACCH as a structured program used as an intervention to improve social, adaptive living, vocational, leisure, and communication skills. Teaching is categorized into four domains: physical organization, task organization, visual schedules and work systems (Peerenboom, 2003). The TEACCH approach aims to adapt the physical environment to best fit the needs and strengths of the child with ASD. Since children on the spectrum may be disorganized, it is helpful for each item within a physical boundary to have a distinct purpose meant to assist the child, as well as corresponding labels and images. Introducing task organization and work systems for the child with autism helps to structure and clarify expectations and activities for the student (Peerenboom, 2003). The TEACCH intervention suggests the implementation of visual schedules that can serve as a reminder of upcoming activities as well as behavior reminders with the inclusion of reinforcers as well. In this program, it is imperative that the professionals implementing the intervention have a close relationship with the parents of the child with autism because TEACCH recognizes that parents are the “experts” on their own children and their opinions and commentary on intervention is valuable (Peerenboom, 2003). Creating this partnership allows for an easier generalization of skills across school and home settings.

## **Other Interventions**

There are a variety of supports that can be integrated into academic and home settings to fit the needs of students with autism. Deris and Di Carlo (2013) note the characteristics of children with ASD directly relate to effective interventions for this population. “Children with autism tend to be visual learners, materials need to be clearly organized for children with autism, and children with autism learn best when sensory stimuli are kept to a minimum,” (p. 55). It is imperative that the interventions are best suited for the child for which they are intended.

Any child can benefit from using visuals as a support, but especially a student with autism spectrum disorder. Educators should attempt to provide interventions using multiple modalities not only to help teach the information in multisensory formats, but to help the child access the information repeatedly. Modeling is an important strategy to use with children with autism because it allows them to visualize certain skills and then participate in practicing them. Ferreri and Plavnick (2012) introduce an intervention in their chapter that can make a world of difference for a child with autism: video modeling. The authors explain that a teacher or parent can pre-record a video modeling a particular skill that they want the child to work on. From there, the child with autism can watch and re-watch the video of the demonstration, practicing the skill alongside the video, as many times as they want (Ferreri & Plavnick, 2012, p. 206). Since the model comes through a technological format, it is appealing to children and students with autism and is easily accessible from a computer. Teachers can make videos like these and email them to parents to allow the students to practice at home. Parents can create their own video

models to teach adaptive, home skills to their children as well, such as how to brush their teeth, get dressed, and organize their backpack before heading to school.

**Communication and social interaction.** To assist children with autism in acquiring communication skills, parents and teachers should ensure that they deliver the lessons in small chunks to prevent the child from becoming overwhelmed. For example, when teaching a child how to have a conversation, there are many skills involved which can be troublesome for a child with ASD, including but not limited to the greeting, making eye contact, topic maintenance, facial expressions, gestures, reciprocity, and completing the conversation. Breaking these sub skills down and gradually increasing the amount of factors in practice conversations can better assist a child with autism in maintaining communication skills (Toth & King, 2008). Teaching students with autism how to communicate with others has a direct impact on their ability to connect with their peers.

An intervention strategy that works wonderfully for all students, but particularly for students with autism spectrum disorders is using social stories. Created by Gray and colleagues in 1995, social stories depict scenarios that a child with autism may have previously experienced or can be created in preparation for future situations utilizing both words and visuals. Social stories are individualized to the student and often contain images of the student himself to help familiarize the concepts and messages within the stories (Klin, Volkmar, & Sparrow, 2000). Social stories are a great tool for educators to provide students with autism because it gives them a safe, personalized space to rehearse and refine their communication and interaction skills. Another strategy similar to a social story is a “comic strip conversation,” which is created by the student himself (Safran,

Safran, & Ellis, 2003, p. 162). Here, with teacher support, students with autism can write a script and pair words with visuals to help the student visualize different social scenarios and assist in processing social dynamics.

Once students have had adequate practice with a social story, introducing a peer mentor can provide opportunities for social interaction and help bridge a connection between children with autism and their typically developing peers (Safran, Safran, & Ellis, 2003, p. 161). A strategy that I personally have seen success with is starting a “circle of friends” group, consisting of a few peers who agree to interact as friends with the child with autism and one another in order to model positive interactions and provide social support for the student. Most children on the autism spectrum are considered “loners;” however, it is not by choice. They want to have friends and get along with their peers just as much as any other child, but they sometimes need additional support and strategies to learn how to do so. Introducing a computer program or iPad app that teaches social skills and emotional understanding is another strategy that can be used as an intervention to support the child’s needs. Sorensen (2009) explains that children with ASD often like using the computer and other forms of technology, so these programs assist the child’s needs while remaining relevant and motivating. There are several programs that provide “emotion training,” consisting of software that displays facial expressions and lets the user decide which emotion is portrayed, (Sorensen, 2009, p. 19). Another technological intervention Sorensen reviews in his research is the Portable Affect Recognition Learning Environment, (PARLE), project. Taking techniques from Social Skills Training, this program operates from a phone or tablet. For example, a person with autism can utilize this software when involved in a social situation but is

unable to understand or relate to where the conversation is headed. They can consult the PARLE system to help decipher the hidden meaning behind what is being said and receive a generated reply that they can comprehend so they know how to respond to their conversation partner (Sorensen, 2009, p. 20).

Alternate forms of communication can be a tremendous aid for children with autism because it provides them with a voice. There are many ways that parents and teachers can access Alternative and Augmentative Communication (AAC) to fit the needs of a child with autism, such as using computer technology and visuals. One form of an AAC system that has been shown to help children communicate and socially interact with others is through the use of the Picture Exchange Communication System (PECS). Developed by Andy Bondy and Lori Frost, PECS is a system that can be used to assist children in communication exchange with a peer or an adult using pictures to indicate what they want or need. With initial prompting from their conversation partner, children can eventually build the skills to string words together to create sentences that indicate their desire or need ("Picture Exchange Communication System, PECS," n.d.). PECS consists of several phases that teach the child to communicate across settings to help maintain and generalize skills.

**Behavior.** Behavioral challenges that a student with autism faces is most often the first area that teachers and parents wish to remediate for the child. It is in this area where deficits can have far-reaching isolation effects for the child attempting to navigate school. Klin, Volkmar, and Sparrow (2000) suggest creating a system in which behavioral management is analyzed to ensure that interventions best fit the problem areas:

It is helpful to compile a list of frequent problematic behaviors such as perseverations, obsessions, interrupting behaviors, or any other disruptive behaviors and then devise specific guidelines to deal with them whenever the behaviors arise. These guidelines should be discussed with the individual in an explicit, rule-governed fashion and all professionals involved should be aware of the program so that clear expectations are set and consistency across adults, settings, and situations is maintained. (p. 360)

It can be challenging for students with autism to operate in a typically developing environment. Safran, Safran, and Ellis (2003) refer to this concept of “hidden curriculum” in their text, which they define as an understanding of social awareness and expectations that come instinctively to most students but not necessarily by students with autism. Children with ASD may experience overload as they try to disentangle themselves from the complexities involved in being a member of a school environment with non-disabled peers. “As individuals attempt to navigate the social world, balance academic tasks, process sensory information, and cope with the often-confusing environment, they experience extreme levels of stress and frustration,” (Safran, Safran, & Ellis, 2003, p. 159). Interventions that teachers, parents, and related service providers can teach a child with ASD to best equip them for the situations where they feel this “overload” may occur include self-awareness instruction. By examining past difficult situations and determining how their escalation hit a breaking point and caused emotional distress for the student, they can review these experiences together and teach the child to notice at what point the anxiety, stimulation, or challenge starts to become too great, and provide the child with strategies to calm himself down before he hits that breaking point.

Strategies may include getting a break time, going for a walk, taking deep breaths, or writing about it in a journal, to name a few.

Interventions that can be used across settings give the child the tools he needs to function in a communicative or social situation without further isolating himself. Klin, Volkmar, and Sparrow (2000) suggest teaching problem-solving skills and strategies that contain behavioral routines. This can assist the child in handling situations that are troublesome and should be taught in an explicit, rote-fashion for comprehension (Klin, Volkmar & Sparrow, 2000). Teaching children to recognize their own emotions can help them have more control over these situations as well.

Finding ways to routinize behavioral, communicative, and socialization impulses for a child with ASD using strategies that fit their needs, is the most important goal to assist them in participating in these areas of challenge.



## **From the DSM-IV-TR to DSM-5: Changes, Concerns, and Criticisms**

Why do I accept that the same diagnosis is right for two such different boys?

Because I believe that their behaviours are their own unique version of the same core problems.

— Charlotte Moore

Saying someone has autism provides almost no information about the type of treatment they need; this is the opposite of personalized medicine.

— Alison Singer

The Diagnostic and Statistical Manual of Mental Disorders (DSM) has seen numerous changes since its initial creation post-World War II in the early 1950s. Five editions later, the establishment of the DSM as a tool to determine mental and behavioral diagnoses in patients has had far-reaching effects. Blashfield, Keeley, Flanagan, and Miles (2014) describe the variations of the DSM throughout history in their article, including not only the factual evidence regarding the changes, but also the perceptions and favorability of these changes. Though originally created to serve as a categorization system in the United States to classify mental disorders, today it impacts whether or not a child receives adequate education services, particularly in the subgenre concerning autism spectrum disorders.

The most recent change, from the DSM-IV-TR to DSM-5, has left many in the autism spectrum category feeling anxious and unsure of what the future may hold for them regarding their access to services and methods of identification. Many people are uncomfortable with change, especially when it can have a direct impact on one's life. Blashfield, Keeley, Flanagan, and Miles (2014) cite initial hesitation from the public when the DSM-III changed to the DSM-IV-TR. The authors state, "Researchers needed stability in the definition of categories in order to perform useful studies of psychopathy. Clinicians, likewise, were confused by and had difficulty adjusting to changes in the fundamental terminology that organized the diagnostic process," (p. 37). It would appear that concerned members of society are grappling with how best to acclimate to current changes between the fourth and fifth editions of the DSM. This section aims to compare the two editions of the DSM in an attempt to see how this change can have potentially positive and negative effects on members of the ASD community.

## **Redefining the Criteria: DSM-5**

Redevelopment of the DSM began in 1999 after the release of the fourth edition in 1994. Members of the American Psychological Association's (APA) Neurodevelopmental Disorders Work Group were assigned to reconsider stipulations that the DSM-IV-TR contained to reflect more accurate and up-to-date information ("Answers to Frequently Asked Questions About DSM-5," n.d.). After revisions, the DSM-5 requires that clinicians use new diagnostic criteria when assessing a child for autism spectrum disorders. A table, adapted from Harker and Stone's (2014) comparison chart, demonstrates the changes that have had the greatest impact on autism diagnosis (see Table 2). One of the greatest changes from the DSM-IV-TR to the DSM-5 is the removal of the subcategories of autism. According to Jabr (2012), the rationale behind this decision is that the conditions share so many similarities in symptoms that they do not necessitate separate categories; rather, they can all fall on the same continuum, or spectrum. Another difference between the two editions is the criteria requirements. Previously, symptoms were categorized based upon three domains - communication, social interaction, and restricted behaviors and interests - and to qualify for a diagnosis, a patient must meet six of twelve symptoms across the domains, at least two occurring in social interaction and at least one occurring in both communication and restricted, repetitive and stereotyped patterns of behavior. DSM-5 changes now divide ASD symptoms into two domains, social communication (A) and restricted, repetitive behaviors and interests (B), where patients must meet all criteria requirements in category A and at least two in category B. "The APA collapsed the social interaction and communication groups from DSM-IV into one group in the new edition because research

in the last decade has shown that the symptoms in these groups almost always appear together,” (Jabr, 2012). The children who display deficits in communication and social interaction but not in the restricted, repetitive behaviors, are instead diagnosed with Social (Pragmatic) Communication Disorder (SCD), a new classification that describes difficulties in the social use of verbal and nonverbal communication. SCD is considered a “safety-net” diagnosis for children who do not fully meet the diagnostic criteria for ASD, though would still benefit from related services. It is hypothesized that many children who previously would have been diagnosed with Asperger syndrome or PDD-NOS will fall into this category. Others, such as Rett syndrome and CDD, are no longer included in the ASD diagnosis.

If a child is positively identified as having an ASD, the DSM-5 assigns a level of severity, indicating the amount of supports this child may require from related service professionals (see Table 3). Positive changes include a revision to the age of onset. Symptoms no longer have to be present at the time to receive an autism diagnosis. Instead, they can currently be present or reported in early developmental histories (“Answers to Frequently Asked Questions About DSM-5,” n.d.). Additionally, once absent from the preceding DSM versions, new DSM-5 criteria include sensory experiences, both heightened and dulled, as a feature and symptom of ASD.

An attraction for revising the fourth edition of the DSM was its low specificity rate. In his article, Jabr (2012) includes a quote from Catherine Lord diminishing the reliability of the DSM-IV-TR diagnostic criteria. “If the DSM-IV criteria are taken too literally, anybody in the world could qualify for Asperger’s or PDD-NOS... We need to make sure the criteria are not pulling in kids who do not have these disorders.” As part of

the APA Neurodevelopmental Disorders Work Group, Lord and colleagues reexamined the criteria of the DSM-IV-TR to make it more specific to ensure that proper ASD diagnoses were being made. However valiant the attempt, it now appears that the DSM-5 criteria are a bit too strict, and there is a recognized fear that certain children who previously would have been diagnosed with autism or one of the subcategories will now be missed. William Mandy, a professor from University College London, states, “They got the major changes right, but recent evidence shows that borderline people might miss out on a diagnosis in DSM-5 because they don’t have clinical levels of some symptoms, such as repetitive behavior. The real issue is threshold,” (Jabr, 2012). In contrast, some people prefer the stricter criteria, such as psychiatrists who do not believe that certain people diagnosed with Asperger or PDD-NOS do not have autism, so they should not be included in the definition of ASD. Jabr (2012) explains that others, such as parents of children with more severe autism, agree that the higher specificity will provide more opportunities for services and supports to be granted to their children over others with milder symptoms, because they are “most in need.”

In her presentation at Bank Street College, Catherine Lord (2013) explains the reclassification of children with autism under the DSM-5. Previously, autism encapsulated a spectrum with differentiated sections, such as Asperger, PDD-NOS, Rett Syndrome, and Childhood Disintegrative Disorder (CDD). In addition to this change, the criteria that constitutes an ASD diagnosis has shifted as well, changing from three domains, social reciprocity, speech and communication, and repetitive behaviors, to two (Lord, 2013). Under the DSM-5, children are now assessed and identified on the basis of social communication and fixated interests and repetitive behavior criteria. Lord (2013)

claims that this newer version is not eliminating domains; rather, this manual is instead “re-sorting” them. “There wasn’t much logic in the DSM-IV-TR between what was nonverbal communication and basic aspects of social behavior...this change also gives more freedom to acknowledge that we really need to know and understand expressive and receptive language levels,” (Lord, 2013). Lord also mentions an important caveat undergoing the DSM-5. People can receive an autism diagnosis based on early history, not just current behavior, which is especially helpful for parents when attempting to determine what may be going on with their child. Past history is not ignored; rather, it is considered evidence for providing an ASD diagnosis.

Kulage, Smaldone, and Cohn (2014) conducted a review of various studies to determine how the changes to the DSM-5 may affect how autism is diagnosed. Based upon a literature review cited by Woolfenden et al., the authors conclude that the identification of autism based on DSM-IV-TR criteria compared to the identification of autism based on DSM-5 criteria has not changed much and the diagnosis is fairly stable (Kulage, Smaldone & Cohn, 2014). The same could not be said for Asperger disorder and PDD-NOS; however, as these aspects of the spectrum did not clear the more restrictive DSM-5 criteria. Public perception of the DSM-5 has not been strong, given many people believe higher specificity rates will cause a reduction in the number of accurate diagnoses, thereby missing people who would have previously qualified for ASD services. The DSM-5 created a new diagnostic category, called Social Communication Disorder (SCD). Though not included within autism spectrum disorders, SCD is “intended to provide diagnostic coverage for those individuals with symptoms in the social-communication domain but who have never displayed repetitive, restricted

behaviors or interests,” (Kulage, Smaldone, & Cohn, 2014, p. 1929). In this way, the authors of the most recent DSM provide services for those who display some autism characteristics, but whose characteristics do not completely cover the domains of social communication and repetitive, restricted behaviors.

A concern that many in the autism community feared would become apparent is what their new status would be after the installation of the DSM-5. Smith, Reichow, and Volkmar (2015) describe a controversial decision that ultimately was accepted to “grandfather-in” cases of people with pre-existing ASD prior to the implementation of the DSM-5. “Individuals diagnosed prior to the publication of the DSM-5 should maintain a diagnosis of ASD and continue to receive the same level of services they have been receiving,” (Smith, Reichow, & Volkmar, 2015, p. 2548). The American Psychological Association criteria also explicitly mention that those with a well-established DSM-IV-TR diagnosis of Asperger syndrome and PDD-NOS should also retain their diagnoses in the DSM-5 (Kulage, Smaldone, & Cohn, 2014). While this appears to be a victory for those with an autism spectrum disorder identified prior to the DSM-5, it does not account for those identified after its implementation.

Accompanying the concern of whether or not those previously diagnosed with ASDs would be eligible for the same services granted to them prior to the DSM-5, another fear for those in this population was if their established diagnoses, or for lack of a better term, labels, would be discontinued. Ohan, Ellefson, and Corrigan (2015) conducted a study in which they presented a vignette of a child with symptoms of autism to 465 American adults that included ASD and Asperger labels, or no label, to determine whether their attitudes toward the child was more or less stigmatized depending on the

different labels. The researchers found that the adults did not react any more positively to the child when thinking he had an Asperger label than those who believed he had an autism label. “Not only does this fail to support concerns that an ASD label will lead to more negative perceptions relative to Asperger’s, it suggests that either label is helpful on increasing help-seeking and optimism about treatment success,” (Ohan, Ellefson, & Corrigan, 2015, p. 3387-3388). Essentially speaking, the participants did not feel more negative about the child when he was given an ASD label than when he had an Asperger label, indicating that there was not stigma attached to the label of ASD. It should be stated that this statement is based upon one study, and it cannot replace and/or reduce the feelings of those with autism spectrum disorders who have to face the possibility of a new name for their diagnosis.

When determining the accuracy rate of assessment criterion, test developers, researchers and clinicians must consider the sensitivity and specificity of the probes. Sensitivity is considered to measure true positives, and specificity is considered to measure true negatives. The more sensitive the criteria (in diagnosing ASD), the more likely someone will correctly be identified as having ASD. The less sensitive the criteria (in diagnosing ASD), the less likely someone will be identified as having ASD. The more specific the criteria (in diagnosing ASD), the more likely the person will be identified as NOT having ASD. The less specific the criteria, the less likely the person will be identified as NOT having ASD. According to results from Kulage, Smaldone, and Cohn’s (2014) systematic review, DSM-5 criteria will be less sensitive to achieve a higher specificity rate, indicating that fewer children will be diagnosed with ASDs under DSM-5 than previously under DSM-IV-TR. This will most likely affect those with a PDD-NOS



diagnosis. This presents a problem when considering how services are affected by a true diagnosis of autism. If children are misidentified, or they do not meet the requirements set forth by the DSM-5 that indicate an autism diagnosis, this means they are not eligible for services that may benefit and make a difference for them.

There is a percentage of people who display social communication difficulties but do not meet requirements for the restricted, repetitive behaviors - all components are required in order to be identified as having autism. The DSM-5 created a new diagnosis, Social (Pragmatic) Communication Disorder (SCD), to serve as a “safety net” diagnosis in the chance that the new criteria does not “catch” their autism (Kulage, Smaldone, & Cohn, 2014, p. 1929). It was the hope that children previously diagnosed with PDD-NOS would meet the definition of SCD; however, the authors cite shortcomings for SCD in respect to its intended purpose. “Only a minority of individuals who met DSM-IV-TR criteria for PDD-NOS and fail to meet ASD DSM-5 criteria will qualify for a diagnosis of SCD,” (Kulage, Smaldone, & Cohn, 2014, p. 1930). What does this mean for the future of those previously diagnosed with PDD-NOS? If SCD is not accurately identifying children as having an autism spectrum disorder, considering PDD-NOS was formerly considered part of the autism spectrum, how can the DSM-5 criteria be trusted to “catch” individuals who previously had been identified? “It is likely that a large number of individuals will fall outside of DSM-5 severity thresholds for receiving state-funded, school-supported, and/or insurance-covered services for their developmental, social, and communication deficiencies,” (Kulage, Smaldone, & Cohn, 2014, p. 1930). If this is a common occurrence, think of the number of children being tested for autism who

are coming up as false negatives on test criteria - without proper identification using these criterion, these children are not accessing the services they are entitled to.

DSM-5 criteria change the face of autism spectrum disorders, starting with their name. Rather than categorizing people displaying autism characteristics and grouping them by ability, behaviors, and development, as previously considered under DSM-IV-TR criteria, the DSM-5 instead refers to children in this IDEA classification as having, “an autism spectrum disorder,” which is an umbrella term dedicated to covering an incredibly wide spectrum of abilities. Ohan, Ellefson, and Corrigan (2015) describe how certain individuals feel personally affected by the changes in terminology and fear that their previous identify (e.g., “Aspie”) will be forgotten and instead they will be renamed to “child with autism,” which tends to have a more negative connotation attached, though without merit (p. 3384). “Members of a group are seen as homogeneous. Thus, applying an ASD label to those who have Asperger disorder should increase stigma because they will be seen as the same as those with autism, despite having milder symptoms,” (p. 3384). Though there is not scientific grounding in this phenomenon, can this have an effect on the methods through which children are remediated? Would the interventions suggested be different depending on whether the child was classified as having autism, or classified as having Asperger syndrome?

The Smith, Reichow, and Volkmar (2015) study results indicated that substantial number of individuals previously diagnosed with an autism spectrum disorder under DSM-IV-TR criteria might not meet newer diagnostic criteria for autism under DSM-5 criteria. A major concern for many parents with children who have autism is obtaining services. Without meeting diagnostic criteria under DSM-5, these individuals are no

longer eligible for educational, vocational, and adaptive skill services (Smith, Reichow & Volkmar, 2015). It appears that those who fall at opposite ends of the autism spectrum, such as those once considered to have Asperger and PDD-NOS, are most likely the majority of individuals who will not meet DSM-5 criteria requirements to obtain the ASD diagnosis and receive the services to which they are entitled.

Catherine Lord's 2013 presentation describes criticisms and concerns surrounding DSM-5 criteria as well. In terms of sensitivity, she agrees that prioritizing sensitivity makes sense, but can have dangers. She states, "We are far more worried about misidentifying someone with autism than over-identifying," (Lord, 2013). She claims there is a belief that the "over-diagnosed" population will eventually "screen themselves out," which is not necessarily true (Lord, 2013). This also can potentially take away services from others, the "misidentified," who really would benefit from having them. Additionally, it is important to recognize that the diagnostic criteria used to identify autism are not actual diagnoses. Lord (2013) shares that we can have perfect diagnostic criteria and horrible diagnoses, and a multitude of factors can affect children and their lives that may make a huge difference when considering a diagnosis.

Five years since its implementation, the fifth revised edition of the Diagnostic and Statistical Manual for Mental Disorders proposed many changes that have directly affected the number of identified cases of ASD, terminology, and access to services. It is unclear at this time whether the stricter criteria are more or less harmful than the looser DSM-IV-TR criteria. Children who previously would have been eligible for services under DSM-IV-TR are at a disadvantage if they are no longer entitled to those services under DSM-5. On the other hand, some people feel that services should be reserved for

those who true cases of autism because they are the most in need of these supports.

Blashfield, Keeley, Flanagan, and Miles (2014) describe the goals that the APA Neurodevelopmental Work Group set out to achieve with the latest edition of the DSM-5. In 2013, two of goals included the creation of criteria with greater specificity and added measures of symptoms and severity (Blashfield, Keeley, Flanagan & Miles, 2014). These goals were achieved, but were they for the better? In time, it will become apparent whether this edition of the DSM needs to be further revised to better accommodate the needs of the autism population.

## **What's in a Name? Labeling Children with Autism**

I might hit developmental and societal milestones in a different order than my peers, but I am able to accomplish these small victories on my own time.

— Haley Moss

The language we use to “brand” ourselves can dictate how we are perceived by our peers within society. It is interesting to think about the impact that one description, title, label, stigma - one description can have an intense influence on who it is that others believe us to be. In the world of education, labels are often assigned to particular students as a means of classifying ability in order to receive supports and services. Typically, after a child who had been struggling in school is evaluated and then given an IDEA classification, teachers see this in a positive light because it helps guide educational planning and allows the child to receive the necessary related services he needs to be more academically successful. On the other hand, labels can be seen as stigmatizing; pigeonholing students into a specific set of parameters from which they cannot break free. Previously, children on the autism spectrum were classified into subsets such as Autism, Asperger Syndrome, Rett Syndrome, PDD-NOS, and Childhood Disintegrative Disorder. This categorization helped to differentiate severity, ability, and behavioral characteristics that may have existed on the wide spectrum, but with the adoption of the DSM-5, those classifications no longer exist. Now an umbrella term, children are classified as having an Autism Spectrum Disorder, thereby lumping all individuals who meet the diagnostic criteria listed under the DSM-5 into one label.

The labels in which we define children can impact how they are treated by teachers, peers, and society at large. In her study on the impact that disability and stigma have on families in their relationships with children’s teachers, Lalvani (2015) asserts that parents often disagree with the idea of labeling because they fear it will alter the perception of their child. For example, if a child is called “autistic,” adults may believe that the child has minimal language and cognitive function, simply because of the way

the child is described. Rather than seeing the whole child - their interests, broad knowledge base, desire for social interaction, or possible savant skills - they may be “talked down to,” because the perception is that they are less capable because they have autism. For whatever reason, society has collectively decided that once we bestow a label upon someone, the other facets of their humanity are diminished.

An implication commonly referred to in Lalvani’s (2015) study is the perception of a child once it is discovered that they have some kind of variation. In her work, she discusses the different opinions expressed by parents and teachers. One such example is highlighted here, when she remarks, “Some children were viewed as having the capability to successfully learn school curricula or as having “gifts,” while children who had difficulties in school were viewed by many teachers as “being wired differently,” (Lalvani, 2015, p. 385). This exemplifies how people may think upon learning that a child has a specific label. Presuming that Asperger syndrome still existed, one may believe that a child with Asperger stands a better chance for academic and social success than a child with autism, simply because Asperger has notably been viewed as a “more capable” diagnosis than autism. Now that the DSM-5 has eliminated the categorization of the spectrum, parents may feel that their child will be viewed as less capable because they are not given the more esteemed Asperger diagnosis. It is important to note that the removal of Asperger syndrome from the DSM-5 does not mean that this population of people has been removed from society - there will still be children who, under different circumstances, would have once received the Asperger diagnosis - and simply because the label is extinct, does not mean that the collective spectrum will only exhibit typical autism characteristics instead.

Upon learning that a child has autism, it is unfortunate that the first reaction is often one of pity. People with autism spectrum disorders are often perceived as being disadvantaged because there is a negative connotation associated with it; however, some people believe that those with autism spectrum disorders are brilliant and consider it to be a gift. Kapp, Gillespie-Lynch, Sherman, and Hutman (2013) refer to distinctive models regarding the perception of autism. According to the authors, the medical model aims to normalize children with autism, reduce their symptoms and behavioral characteristics, and eliminate deficits that cause functional impairments (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013). The medical model is closely aligned to those who believe that autism is a stigma that should be diminished. An opposite model, the neurodiversity movement, instead celebrates autism identification, viewing it as a part of “natural human variation,” (p. 60). Many people see autism as a benefit because it creates a new way of thinking. Temple Grandin, a famous advocate for the autism community, once explained that she thinks in pictures and was unaware that others around her did not (Weintraub, 2013). What a powerful statement this is - Temple Grandin, a celebrated, successful author, a woman with autism, has the ability to literally see images in her head as she attempts to problem solve. It is quite remarkable to think about how some of the greatest minds in the world have achieved so much, simply because they view the world differently, or think differently. Autism spectrum disorders can cause children to exhibit problematic behaviors, and by no means is it easy for a parent to raise a child with autism because of the stigma attached to it, but there is also the possibility that people with autism can also open society to a new world of thinking.



Society needs to be careful when considering the labels we use to describe children. Autism spectrum disorders are recognized as a classification under IDEA; however, autism is only one facet. There can be challenges in communication, social interaction, and behavior, but there are also wondrous characteristics in these individuals as well. There is a quote by Dr. Colin Zimbleman that has a striking effect on the ways in which we view children on the autism spectrum. He states, “Autism offers a chance for us to glimpse an awe-filled vision of the world that might otherwise pass us by.” What if society began to perceive children with autism as more than just their label, and instead could see their abilities and strengths shine through? It is believed that Albert Einstein may have been on the autism spectrum - imagine if society only viewed his “quirks” as his level of potential?

“Parents had strong reactions to specific disability labels which they viewed as less acceptable than others, and many went to great lengths to advocate for the classification of their children under labels they believed were less stigmatizing,” (Lalvani, 2015, p. 383). Children with autism are not “aloof,” in fact; they can be quite adept at understanding the way they are perceived. The labels we provide to children can accelerate or stunt their growth. When we have attitudes like the one above, it insinuates that the children with these labels have something wrong with them. Learning that their child is diagnosed with an autism spectrum disorder is not always the easiest for families to hear, often because of the stereotypes to which they have been exposed in the media and society. It is time that the dynamic shifts permitting recognition of all of the sides of autism, and to understand that stigma is constructed.

## Conclusion

The difference between high-functioning and low-functioning is that high-functioning means that your deficits are ignored, and low-functioning means that your assets are ignored.

— Laura Tisoncik

There needs to be a lot more emphasis on what a child can do instead of what he cannot do.

— Dr. Temple Grandin

Autism is still a relatively misunderstood diagnosis. Though there is an abundance of research on the subject, such as causes, symptoms, and methods of treatment and intervention, professionals still seem to be discovering new behaviors and characteristics that could meet diagnostic criteria. With the adoption of the DSM-5, fewer children are being identified for having an ASD than before. After completing the research for this thesis, what concerns me is the idea that autism diagnosis can drop because new diagnostic instruments may misdiagnose children with autism. The prevalence rate had been steadily increasing since Wing and Gould's (1979) discovery of the spectrum of disorders. While I can admit that possibly more children were likely diagnosed under DSM-IV-TR criteria than there should have been, I find it difficult to comprehend that the newer diagnostic tools and criteria are *so improved* that professionals are now catching an accurate representation of the autism population. I wonder how many children are not meeting the criteria for ASD or SCD, and are instead being left behind? The fact of the matter is, autism is not going anywhere, and as educators we need to learn as much as we can about the different variations our students display so we can best accommodate their needs. We need to throw away our preconceived notions of what a child with autism may look like, and instead open our minds and our hearts to the potential of these students while leaving our own biases and stereotypes behind.

This paper was created with educators in mind for how best to work with families and children within the autism community. Prior to this report I had little information regarding how to work with children on the autism spectrum and wanted to gain a deep understanding of how these children may exhibit behavior when I come across them as students in my classroom. The research conducted for this study was extensive and will

be useful as I prepare for a classroom of unique individuals in the future. In terms of further research, studying how the DSM-5 criteria have affected the autism population in more recent years should be conducted. Many of the articles and journals I studied were written fairly recently after the document (DSM-5) was adopted in 2013. Now, several years later, I am most curious about what the future of autism spectrum disorders will look like under the current diagnostic criteria and whether professionals in the APA will consider loosening the restrictions. Keeping up to date with treatments and interventions that best serve this community is imperative as well. Finally, breaking down the barriers that the harmful stereotypes and stigma have created is necessary for teachers, parents, and students to educate one another and work together to provide academic, social, and communication supports to help the child with autism feel success in school and the outside world.

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## Tables

Table 1

<b>DIAGNOSIS VERSUS ELIGIBILITY</b>	
<b>DIAGNOSIS</b>	<b>ELIGIBILITY</b>
Based on a set of criteria (e.g., <i>DSM-IV-TR</i> ).	Based on federal law (IDEA).
Refers to a specific disorder (e.g., autistic disorder, Asperger's disorder).	Refers to a broad disability category.
Used in private settings.	Used only in public school system.
May be determined by an individual or team.	Must be determined by a team.

Table 1. Diagnosis vs. Eligibility, *Autism Advocate*.

Table 2

	<b>DSM-IV-TR</b> <i>Pervasive Developmental Disorders</i>	<b>DSM-5</b> <i>Autism Spectrum Disorder (ASD)</i>
<b>Subcategories</b>	Autism, Asperger syndrome, PDD-NOS, Rett syndrome, Childhood Disintegrative Disorder	<b>None</b> - ASD encompasses former subcategories of Pervasive Developmental Disorders
<b>Requirement for Diagnosis</b>	Must meet 6 of 12 behavioral criteria, with at least two from category A.1, one from category A.2, and one from category A.3	Must meet all three behavioral criteria in category A and at least two in category B
<b>Criteria Domains</b>	Three - language/communication, social interaction, and repetitive behaviors	Two - social communication and restricted, repetitive behaviors

Table 2. Adapted from Harker and Stone's (2014) DSM-IV-TR and DSM-5 chart.

Table 3

	<b>SOCIAL COMMUNICATION</b>	<b>RESTRICTED, REPETITIVE BEHAVIORS</b>
<b>LEVEL 1</b> <i>“Requiring Support”</i>	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.
<b>LEVEL 2</b> <i>“Requiring substantial support”</i>	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
<b>LEVEL 3</b> <i>“Requiring very substantial support”</i>	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Table 3. The Levels of Autism, *Autism Speaks*.