# WHAT TO EXPECT WHEN YOU SUSPECT AUTISM

A step-by-step guide from diagnosis to treatment at every age.

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# What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) (American Psychiatric Association, 2013) in which there are persistent deficits in social communication and social interaction across multiple contexts and restricted, repetitive patterns of behavior, interests, or activities. The classification of ASD had changed with the publication of the DSM-V.

The DSM-V documented that persistent deficits in social communication and social interaction can be exhibited by the following:

- Deficits in social-emotional reciprocity
- Deficits in non-verbal communication used for social interaction
- Deficits in developing, maintaining, and understanding relationships

Restricted, repetitive patterns of behavior, interests, or activities exhibited by at least two of the following:

***...the symptoms ... result in clinically significant impairment in the child's social and/or academic functioning...***


- Stereotyped or repetitive motor movements, use of objects, or speech
- Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
- Highly restricted, fixated interests that are abnormal in intensity or focus

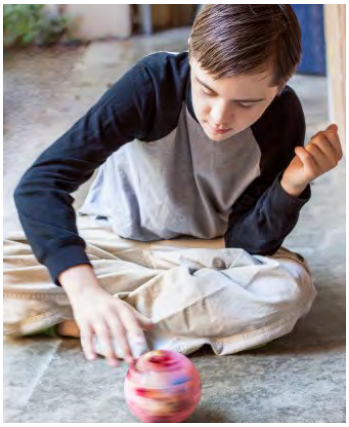
- Hyper or hyporeactivty to sensory input or unusual interest in sensory aspects of the environment.

The DSM-V indicates that the above symptoms must be present in the early development period to some degree; however, may not become fully visible until later in life. In addition, the symptoms must result in clinically significant impairment in the child's social and/or academic functioning.

## How is Autism Spectrum Disorder classified?

The DSM-V created a three-tier level of classifying the diagnosis of ASD based upon severity level.

### *Level 1: "requiring support"*



These children may appear to have decreased interest in social interactions. For example, they may utilize full sentences; however, have difficulty engaging in back and forth social conversation. The restricted and repetitive behaviors cause significant interference with functioning in one or more contexts.

### *Level 2: "requiring substantial support"*

These children exhibit significant concerns with verbal and nonverbal social communication skills and exhibit social impairments even with supports in place. The children often exhibit limitations with the frequency of social interactions and abnormal responses to social interactions. The frequency and severity of restricted and repetitive behaviors occur enough that they are evident by outside observers.

### *Level 3: "requiring very substantial support"*

There are very severe deficits with these children's verbal and nonverbal social communications skills which have a significant negative impact on daily functioning. These children frequently present with only a few words, rarely initiate social interaction, and

often only approach others to meet their specific needs. The restricted and repetitive behaviors are extreme and result in significant difficulty and distress coping with change.

## What Happened to Asperger's Disorder?

Prior to the summer of 2013 and the publication of the DSM-V, children could meet criteria for a variety of neurodevelopmental and social conditions including: autism, Asperger's Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified. There have been a few reasons posited as to why the American Psychiatric Association decided to collapse the previous diagnosis into one disorder. A presentation given by the Autism Research Institute in 2012 explained that there were two main reasons that that the American Psychiatric Association decided to use an umbrella term of ASD: 1) the prior classification system was not precise enough in that there was a fair amount of variability in classification of symptoms across clinicians and 2) autism is defined by a common set of behaviors and should be classified by a single name based upon severity level.
The American Psychiatric Association did provide some safeguards for individuals who had previously met clinical criteria for a diagnosis of Asperger's Disorder or Pervasive Developmental Disorder, Not Otherwise Specified. Specifically, it is stated in the DSM-V that "Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's Disorder, or Pervasive Developmental Disorder, Not Otherwise Specified should be given the diagnosis of Autism Spectrum Disorder."

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## How Common Is ASD?

Research has indicated an increase in the frequency of ASD in children. In 2002 the Centers for Disease Control and Prevention (CDC) estimated that the prevalence rate of ASD was 1 in 150 individuals in the United States (Wolf & Paterson, 2010). However, recent estimates published by the CDC indicate that the prevalence of ASD is about 1 in 68 children (Baio, 2014). The CDC has speculated that the increase in the frequency of the diagnosis is likely an attribute of increased sophistication with the initial diagnosis, school screenings and assessments, and an increase in acceptance of the diagnosis and label.

## Are there differences in the frequency of the diagnosis based upon the sex of the child?

Autism, like most neurodevelopmental conditions, has a much higher incidence rate in boys than girls. Studies have indicated that the frequency rates are 4-5 times more common in boys than girls (Wolf & Peterson, 2010).

## Are there differences in the frequency of diagnosis across countries/cultures?

The CDC in 2014 indicated that the frequency of a diagnosis of ASD is consistent across continents including Asia, Europe, and North America.

## Causes of Autism Spectrum Disorder

Research has not indicated any specific single causal mechanism that would be the trigger for ASD. Studies have indicated that there

is a genetic risk for the condition in that there is an increased risk for siblings to have ASD after the birth of one child with the disorder. That being said, these studies have also indicated that the condition is not completely a genetic disorder in that the rates of the condition among identical twins is not one hundred percent (Ozonoff, 2010).

There has been speculation that environmental factors may posit some impact on the development of the condition. For example, prior researchers have suggested that factors including vaccination, heavy-metal or pesticide exposure, viral agents, and food products may interact with genetic susceptibility to trigger ASD. It is important to document that no studies have found any causal relationship between environmental factors and ASD. There have been ample studies that indicate that vaccinations do not lead to an increase in the onset of ASD.

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There have also been studies that indicate brain mechanisms that are often found in children with a diagnosis of ASD. For example, studies have indicated that macrocephaly, which is unusually large head size, have been found in approximately 20% of children with ASD. It was indicated that this increase in head size is not present at birth but apparent by the time the child turns one (Ozonoff, 2010). Other researchers have indicated that a network of limbic system and social brain structures are actively involved in children with a diagnosis of ASD (Wolf & Paterson, 2010).

## How is ASD Diagnosed?

A diagnosis of ASD requires an early history of impairment. As such, assessment of a child's current level of functioning alone is not sufficient. There needs to be an evaluation and information of the child's functioning with regard to social, language, and behavioral functioning from when he or she was young. There are numerous measures that are created to provide clinicians with clinical and diagnostic information regarding functioning. These include: structured clinical interviews with parents/ parents completion of rating scales, observational measures designed to provide specific information about the child's language functioning, social relatedness, and behavioral regulation, as well as neuropsychological assessments to provide in-depth information about a variety of cognitive skills (Wolf, Fein, & Akshoomoff, 2007).


### *What is a structured clinical interview?*

In a structured clinical interview, the clinician will ask parents about specific questions regarding a child's social, language, and behavioral development in a semi-formal manner. There are instruments created in which the clinician can actually obtain a criterion score regarding the child's functioning in the specific domains associated with ASD. Furthermore, there are a variety of well-normed parent and teacher report forms that provide in-depth information regarding in comparison to children who have a diagnosis of ASD to those who do not.

### *What are observational measures?*

There are a variety of play-based semi-structured measures that provide specific information regarding the child's social interaction, communication, play and imagination, and engagement in repetitive behaviors and interests. These measures are also normed on children who have a diagnosis of ASD and those that do

not so there can be comparison as to whether or not the specific child meets criteria for what would be expected from a diagnosis of ASD.

## What are neuropsychological measures?

Neuropsychological testing is comprised of evaluating a host of neuro-cognitive skills including the child's cognitive abilities, academic achievement, attentional regulation, impulse control, memory, and social-emotional functioning.

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Research has indicated that language impairment in children with a diagnosis of ASD is often apparent early in life. The use of gesture to help facilitate communication is also often notably restricted or not present.

Prior studies (Ozonoff, 2010 & Wolf et. al., 2007) have indicated that children with ASD often perform well on tasks that require visual spatial processing and attention to visual details.

There have been comparisons regarding the different clinical profiles of children with ASD and ADHD. Children with ASD were found to exhibit average performance in tasks assessing their sustained attention, which is the ability to initiate and maintain attentional regulation to a fairly boring and mundane task for an extended period of time. However, these children often have

difficulty switching attention between tasks and may also lack the ability to stop attending to tasks. Children with ADHD often have the opposite profile in that they are able to disengage from tasks and shift focus; however, have difficulty with being able to sustain attention for lengthy periods of time.

***Taken altogether, the diagnosis of ASD should be made by compiling information from several sources.***

Taken altogether, the diagnosis of ASD should be made by compiling information from several sources. Parents and teachers should provide information regarding the child's social communication and any repetitive behaviors, and there should be some formal testing that provides statistical information regarding the child's social language and any restricted or repetitive behaviors. Furthermore, there should be some form of neuropsychological assessment in order to provide information the child's cognitive functioning, academic skill sets, visual processing, attention, and memory. All of this data would not only help guide the clinician in making the initial diagnosis, but also in being able to effectively and efficiently develop specific interventions and accommodations that would best suit the child.

## What does ASD look like throughout the lifespan?

There has been data to indicate the major characteristics associated with a diagnosis of ASD are different throughout the lifespan of the individual. (Wolf & Paterson, 2010).

### *Infants:*

Studies have shown that infants who are later diagnosed with ASD are often described as being irritable, have difficulties with transitions, avoid eye contact, do not respond to their name, do not engage in social smiles, exhibit a lack of social interest, and have difficulty imitating actions.

### *Childhood:*

Children with ASD frequently exhibit concerns with sensory impairments, sleeping and eating difficulties, anxiety, and disruptive behaviors. With regard to eating, the main concerns that are evident are associated with sensory regulation, meaning the children will avoid certain tastes or textures.

### *Adolescence:*

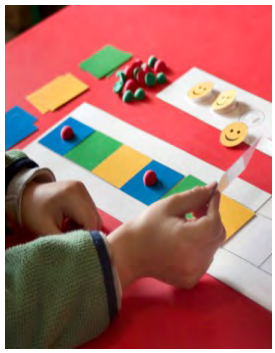
The main oncern that is often evident in adolescents with a diagnosis of ASD are mood-related issues. There are also concerns regarding possibly being manipulated or victimized by peers.

# What Interventions are Available for Children with ASD

There have been many interventions that have been implemented for children with a diagnosis of ASD. Behavioral therapies, including Applied Behavior Analysis (ABA) have received the most empirical support for generating positive outcomes in these children. In fact, behavioral therapy is currently the only form of treatment for ASD that has been empirically validated (National Resource Council, 2001). There is some research indicating that pharmacological intervention may prove beneficial for children with a diagnosis of ASD. Furthermore, children with ASD often benefit from specific social skill training, since deficits in social functioning are prevalent in this population.

## *What is ABA Therapy?*

Applied Behavior Analysis (ABA) Therapy is a scientifically based intervention that uses the principles of behavior to improve socially significant behaviors and to reduce socially inappropriate behaviors (Cooper, Heron, & Heward, 1989). Autism is a diagnosis based on behavioral deficits and excesses that, in most cases, can be increased or decreased by manipulating the environment around a child (Maurice, Green, & Luce, 1996).



*An ABA Therapy program generally teaches all behaviors/skills that a child with autism is lacking.*

An ABA Therapy program generally teaches all behaviors/skills that a child with autism is lacking. ABA Therapy accomplishes this task by breaking down those skills into small manageable goals. Simple behaviors are taught systematically into "complex and fluid combinations" of typical, age-appropriate responses. Correct responses are immediately followed by reinforcement which increases the likelihood of future correct responding (Maurice, Green, & Luce, 1996). Once these skills are learned in a controlled setting, the skills are then also reinforced in the child's natural environment. Example of skills areas include, but are not limited

to: receptive language, expressive language, imitation, social, independent play, requests, visual/perceptual skills.

ABA Therapy also focuses on decreasing inappropriate behaviors by using interventions based on the functions of those particular behaviors. Functions of behaviors are determined by functional behavior assessments. Once the function/s of the behavior are determined a behavior intervention plan is written. Data are continually taken on the behavior and compared to baseline. The data illustrates whether the intervention is successful or not in decreasing the behavior. Changes to the intervention are made accordingly. Interventions should be carried out consistently across all aspects of a child's environment for the most success.

## How is Medication Utilized for Children with ASD?

There are no medications that are utilized for the core symptoms of social language deficits and restricted behaviors seen in children with ASD. Medications are often utilized to treat a variety of the co-existing symptoms seen in children with ASD such as disruptive behaviors, self-injury, mood, anxiety, and attentional regulation. (Wolf & Paterson, 2010).

## What Social Skills Interventions are Beneficial for ASD?

There have been numerous interventions created that help address social skill development. Since many children with ASD struggle with inferencing it is often found that these social skills need to be explicitly taught to children. (Wolf & Paterson, 2010). Research has documented that through direct teaching of social skills,

children with ASD can exhibit definite improvement with a variety of tasks including: greeting, play skills, social initiation, eye contact, sharing of personal experiences, interest in same age peers, problem solving skills, emotional knowledge, conversation skills, and increased social interaction time with peers.

## School Accommodations for Children with ASD

There is no universal best fit regarding interventions or services for children with a diagnosis of ASD. School interventions are based upon the individual needs of the child. School interventions need be based upon the least restrictive environment for that child. What is important to realize is that the least restrictive environment is completely based upon the child's specific needs (Maedgen & Semrud-Clikeman, 2007). For some children, the least restrictive environment might be the mainstream classroom with additional supports and services while for other children, the least restrictive environment might be a therapeutic placement.

*School interventions are based upon the individual needs of the child... based upon the least restrictive environment for that child.*

It is also important for parents to understand that just because a child has a medical diagnosis of ASD, he or she does not automatically qualify for school based accommodations and services. It is always important to gather school-based data as the laws for special education services dictate that there must be educational impairment from the diagnosis of ASD.

Once the child is found to qualify for intervention services in the school, the academic team will work with his or her parents to determine what services would be beneficial. Services in the school can range from any combination of: Special education resource support to address academic concerns, speech and

language therapy, occupational therapy to address sensory needs and motor concerns, physical therapy to address any issues relating to mobility in the environment, and social work support to help address socialization.

***To learn more about Autism, it's symptoms and services, visit***

***AutismClinic.info***

# About the Authors

**Gregory Stasi, *Ph.D.***, is a licensed Clinical Psychologist who graduated from Purdue University with a Bachelor Degree in Psychology. He went on to earn his Masters and Doctorate at the Illinois Institute of Technology where he made his decision to focus his career on pediatric neuropsychology. Dr. Stasi has worked and studied at numerous medical centers including: The University of Chicago Medical Center and the University of Minnesota Medical Center. Prior to working at North Shore Pediatric Therapy, Dr. Stasi was a faculty member at Rush Presbyterian St. Luke's Hospital and was a neuropsychologist at the Rush Neurobehavioral Center. Dr. Stasi has extensive experience with the assessment and diagnosis of a variety of conditions including: learning disorder, ADHD, Autism Spectrum Disorders, and social/emotional concerns. Dr. Stasi also has numerous publications and presented at professional conferences on a variety of topics including learning disabilities, ADHD, and Autism Spectrum Disorder.

**Annie Goldberg, M.A., BCBA,** is a Board Certified Behavior Analyst specializing in providing ABA services for children with autism. Through the use of principles of behavior, Annie specializes in increasing skill development and decreasing maladaptive behaviors of children with autism. Annie Goldberg received her Master's in Clinical Psychology with a specialization in Applied Behavior Analysis from The Chicago School of Professional Psychology. She was initially trained at the Lovaas Institute for Early Intervention. Additionally, Annie completed over 1500 hours of clinical experience at various companies around the Chicagoland area.

# Resources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