CHAPTER 2
Understanding Autism

Key Terms:

Eugen Bleuler

Leo Kanner

Hans Asperger

Bruno Bettelheim

Diagnostic and Statistical Manual (DSM)

DSM-II

Infantile Autism

DSM-III

DSM-III-R

Ivar Lovaas

DSM-IV

DSM-IV-TR

DSM-5

Autism Spectrum Disorder

DSM-5-TR

Symptoms of Autism

Screening Tools

Diagnostic Tools

Autism and Developmental Disabilities Monitoring (ADDM) Network

Key Points:

* Individuals with autism exhibit deficits in communication and social interaction. They also demonstrate restricted interest in activities, as well as repetitive or other problematic behaviors.

* Early detection of autism's behavioral markers can lead to early diagnosis, early intensive intervention, and improved prognosis.

* A sound diagnostic protocol involves indirect and direct evaluations conducted by a multidisciplinary team of professionals who possess clinical experience with autism.

Understanding Autism

This chapter explores autism – its history, symptoms, detection, evaluation techniques, and prevalence. It starts with a review of the history of autism, highlighting key researchers, clinicians, and events that have occurred over several decades. Next, I will explain the symptoms of autism and why autism is considered a spectrum disorder. Then I will cover detection, looking at when the first signs of autism can be observed, and common "red flags" associated with early detection. A definition of autism will be reviewed based on the most recent changes in the DSM-5.

We will also look at the process of receiving an autism diagnosis and the types of evaluations and assessments that are used. We will close with the prevalence of autism by looking at trends across decades of data in the rates and patterns of autism.

A timeline of significant events that have occurred over the past several decades is provided (Figure 2.1). This chapter will focus on each of these events and provide a detailed account of its significance and impact on autism, and within the field of Applied Behavior Analysis.

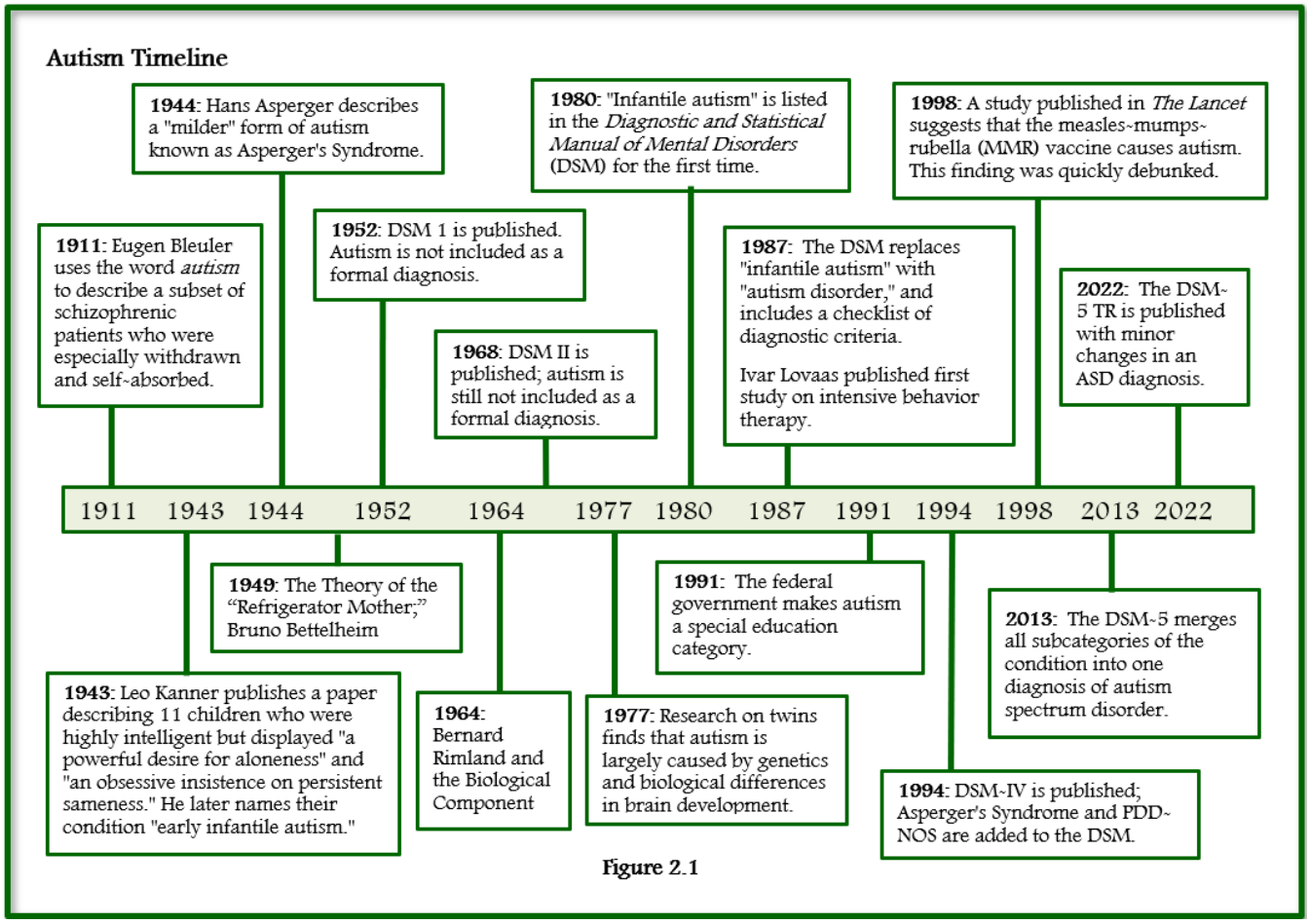
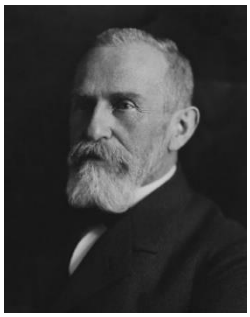


Figure 2.1

Section A: The History of Autism

The Birth of Autism ~ 1911 ~ Eugen Bleuler



Since the term was first mentioned more than a century ago, autism has been a complex, baffling, and fascinating disorder. Autism has been extensively investigated, from its onset of symptoms in infancy to its causes and its prognosis. In 1911, the concept of autism was first used by German psychiatrist Eugen Bleuler to describe the inward behaviors and self-absorbed aspects associated with schizophrenia. In his article "Eugen Bleuler: Centennial Anniversary of His 1911 Publication of Dementia Praecox or the Group of Schizophrenias," McGlashan (2011) states that Bleuler used the word autism to describe symptoms of schizophrenia as,

> "The most severe schizophrenics, who have no more contact with the outside world, live in a world of their own. They have encased themselves with their desires and wishes (which they consider fulfilled) or occupy themselves with the trials and tribulations of their persecutory ideas; they have cut themselves off as much as possible from any contact with the external world. This detachment from reality, together with the relative and absolute predominance of the inner life, we term autism" (p.1102).

"Autism" is Starting to Change ~ 1943 ~ Leo Kanner

Rather than referring to autism as a symptom of schizophrenia, Austrian-born psychiatrist Leo Kanner published in 1943 the article "Autistic Disturbances of Affective Contact," where he speaks of the first description of a group of children, "…whose condition differs so markedly and uniquely from anything so far…" (p. 217).

Kanner borrowed the term "autism" from Bleuler, but instead of using it to describe a symptom of schizophrenia, Kanner applied it as its own clinically unique category, naming it "early infantile autism."

Kanner (1943) used case studies to describe 11 children who came under his care while at Johns Hopkins. The children, ranging from two-and-a-half to 11 years old, all displayed some common characteristics, but defied categorization according to known psychiatric and psychological disorders of the time.

The children in Kanner's case studies were marked by a general sense of independence, accompanied by deficits in the use of language for communicative purposes. Most of the children tended to have more of a fascination for inanimate objects than for people, and even their interactions with people seemed to resemble the types of manipulation one would use with objects.

Even though most of the children in Kanner's report eventually acquired at least some language, there was an almost universal lack of communicative intent in the way the language functioned. For many of the children, their words seemed to be used more for stereotypical routines than to seek out or provide

information. Even when a communicative attempt was made, there were usually significant problems with syntax, semantics, and pragmatics.

Even more significant in Kanner's article were his descriptions of the emotional expression displayed by his participants, or the appearing lack thereof. Almost all the children he described were often lacking facial expressions that would typically correspond to the situations in which the children were involved. While most clinicians of his era would likely have tended to focus upon the cognitive and language anomalies associated with the disorder, Kanner made a remarkable decision to shift a large amount of his focus onto the lack of connectedness, or the affective dissociation that the children in his study displayed. These children simply did not seem to be interested in others, and they appeared to be incapable of initiating or maintaining meaningful social contact with other people.

At the time of his report, the combined symptoms of this "new" disorder were quite similar to other known disorders. Primarily, Kanner's group displayed many symptoms similar to individuals afflicted by psychotic disorders such as schizophrenia to the point where some of the children in his group had previously been diagnosed with them. Kanner, however, noted one significant difference between the children in his group and others diagnosed with schizophrenia: all children first displayed symptoms within the first two years of life. It was this difference in onset of symptoms and the path that the symptoms followed which was the major factor in differentiating autism from schizophrenia (Hommer & Swedo, 2015).

Carried over from the term used by Eugen Bleuler, Kanner chose the word "autism," derived from the Greek word "autos," meaning "self," to describe the children in his report. Kanner wanted to make the distinction between the children he observed, who never established connectedness to the social world, and those who, according to the classic definition of the term, had established relationships with the social world and withdrew these ties upon onset of symptoms (Donnellan, 1985).

However reluctantly adopted, the term has become accepted meaning, and Kanner's group of children has remained a valid case study in the nature of the disorder.

1944 ~ Hans Asperger

No history of autism is complete without touching upon the work of Austrian pediatrician Hans Asperger. During the same year Kanner's influential article was published, Asperger was preparing a separate account of individuals under his own study.

In a moment of significant coincidence, Asperger also chose the word "autism" to describe the children he was studying. By all accounts, the two had no familiarity or even knowledge of each other's work.

Asperger's subjects displayed some of the same lack of social connectedness or social understanding identified by Kanner. Also, similar to Kanner's participants, Asperger's students were subject to preoccupation with objects, routines, or otherwise restricted interests. The difference between the two groups was the seemingly advanced language and writing abilities possessed by some of the children in Asperger's report.

Unfortunately, Asperger's work was predominantly published in German, and coincided with the Second World War. Because of this, and because he did not travel much, his work lay largely undiscovered and unstudied until 1981, when Lorna Wing introduced the English-speaking world to his work. In 1981, she published "Asperger syndrome: a clinical account;" a paper that gave an account of the work conducted by Asperger and coining the term "Asperger's Syndrome" to describe children who shared the social impairments of Kanner's syndrome to varying degrees yet possessed less obvious cognitive and language impairments.

1949 ~ Bruno Bettelheim and Psychoanalysis

During the medical and social climate of the 1940s, disorders like autism were often studied from the perspective of psychoanalysis. The field of neurology was in its infancy, and most behavioral or psychological abnormalities were viewed in terms of psychiatric theories. Their causes were placed upon relationships that went awry, failure to recognize unconscious motives or other theoretical constructs. This is significant because many people who followed Kanner's initial report tended to focus upon the psychoanalytical theories of the day, placing blame for the disorder on the children's families or environments. Kanner himself, while proposing that genetic factors played a part, also suggested that the condition was caused by cold, rigid parenting (Kanner, 1949). The result was the theory of the "refrigerator mother."

Although this theory and the term "refrigerator mother" is traditionally attributed to another Austrian, Bruno Bettelheim, it is more accurate to say that Bettelheim disseminated the theory and further developed it. Bettelheim supported a notion in which blame was placed upon "maternal indifference" that he felt was displayed by many mothers of children with autistic symptoms. The result of this psychodynamic influence, which was adopted by countless professionals working within the fields of psychology and psychiatry, was decades of shame, guilt, and embarrassment for families of children with autism.

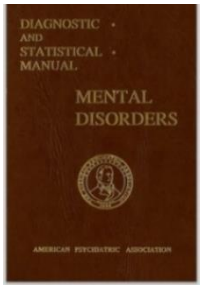
The work of Bettelheim and his contemporaries also created a lingering social stigma surrounding the disorder, which many believe may have stunted exploration and discourse in the field for many years. It also led families to hide the disorder, if possible, with many children with autism placed in institutions during the 1950s and 1960s.

Beyond his theories surrounding the causes of autism, Bettelheim also referred to individuals with autism as possessing repressed or hidden genius. In my opinion, this popular belief led to a cultural and social misunderstanding of the disorder that still exists today.

For example, a common understanding of autism includes figures such as the character of "Raymond" in the movie *Rain Man*. As Raymond, actor Dustin Hoffman demonstrated an uncanny ability to memorize entire phone books and compute dizzying mathematic problems at first glance, while having little ability to relate to others. Part of this portrayal is somewhat accurate, including Raymond's limited interests and his desire to maintain routines. However, his "genius" skills are overemphasized and are not indicative of typical autistic traits.

What frequently *does* occur, though, is a preoccupation or fascination with an extremely narrow range of interests, which may lead to an unbalanced knowledge or understanding of one or more particular subjects. This, in turn, could give the impression to an occasional observer that the individual possesses extraordinary innate talents. Unfortunately, this is often the result of a limited repertoire of interests, combined with an equally bland imaginative repertoire.

1952 ~ First edition of the DSM is published



The Diagnostic and Statistical Manual of Mental Disorders (DSM) was published by the American Psychological Association and is the standard for healthcare professionals diagnosing mental health conditions.

Published in 1952, the first DSM did not include autism as a mental health diagnosis; however, used the term autism under the diagnosis of Schizophrenic reaction, childhood type (American Psychiatric Association, 1952).

The Biological Component ~ 1964 ~ Bernard Rimland

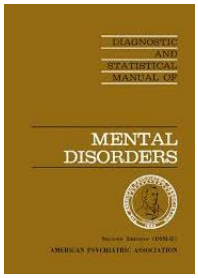
Bettelheim's theories continued to gain and maintain acceptance until the publication of Bernard Rimland's chapter, "The Etiology of Infantile Autism: The Problem of Biological Versus Psychological Causation," in the book, *Infantile Autism*, published in 1964. In this chapter, Rimland (himself the father of a child with autism) questioned the theories surrounding the psychogenic causes of autism popularized by psychoanalysts of the day.

Based on examples that supported the notion of a biological basis for autism, combined with a lack of evidence to support psychogenic theories, Rimland instead proposed that further investigation of autism's biological components was warranted.

He also recognized a genetic component, as supported by several published reports on the higher prevalence of autism in identical twins than in fraternal twins.

In 1965, Rimland and other parents of children with autism founded The Autism Society of America (ASA). The focus of the ASA is to increase autism awareness, advocate for services for individuals with autism, provide information on the latest treatment options, and support research.

1968 ~ DSM-II is published



In the publication of the 2nd edition of the DSM, "autism" still was not included as its own diagnostic category. Similar to the first edition of the DSM, the term autism was mentioned under the category of Schizophrenia, childhood type (American Psychiatric Association, 1968).

Autism and Genetics ~ Infantile Autism: A Genetic Study of 21 Twin Pairs

In 1977, the first study looking at genetics and autism was published (Folstein & Rutter, 1977). This study opened the eyes to the public on the importance of genetics in autism. The authors reviewed 21 pairs of same-sexed twins, in which at least one twin was diagnosed with autism.

Of the 21 twin pairs, 11 were identical twins (monozygotic, or MZ), and 10 were fraternal twins (dizygotic, or DZ). In this study, the authors concluded, "The MZ-DZ difference in concordance for autism and the much larger difference in concordance for cognitive disorder clearly points strongly to the importance of genetic factors in the etiology of autism. Indeed, the size of the MZ-DZ difference, together with the population frequency of autism, indicate a very high "heritability" (p. 307).

Rimland's work became a catalyst for the trends in autism research that continue to this day. Additionally, his proposition removed the shroud of blame and secrecy that surrounded many families dealing with autism. Without fear of judgment, parents were more apt to seek help for their children, and in many cases were able to deal more effectively with each other and with their children.

1980 ~ DSM-III ~ "Autism" Became its own Diagnosis

In the 3rd edition of the DSM, autism was included as a distinct diagnostic category for the first time, differentiating the diagnosis from schizophrenia. Autism and related disorders were grouped under the umbrella of Pervasive Developmental Disorders (PDD).

This term was selected because it more accurately described the core clinical symptoms, as many areas of development are affected at the same time and to a severe degree (American Psychiatric Association, 1980).

Under PDD, autism was referred to as "Infantile Autism," with six characteristics listed in the criteria. In order for this diagnosis to be given, an individual needed to possess each of these characteristics: having an onset of symptoms before 30 months of age, a pervasive lack of responsiveness to people, significant deficits in language development, odd speech patterns (if speech is present), bizarre responses to different aspects of the environment, and last, separating it from the category of

schizophrenia, having an absence of delusions, hallucinations, loosening of associations, and incoherence (American Psychiatric Association, 1980).

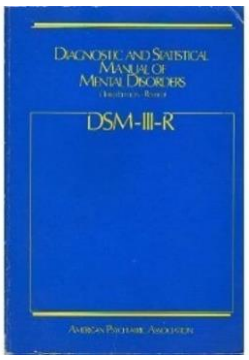
Also included under PDD were Childhood Onset Pervasive Developmental Disorder (COPDD) and Atypical Pervasive Developmental Disorder. The criteria for COPPD included a profound disturbance in social relations (such as inappropriate clinging, lack of peer relationships, and a lack of appropriate affective responsivity) and multiple oddities in behavior (including resistance to change, insistence on doing things in the same manner every time, oddities of motor movements, speech abnormalities, hyper- or hyposensitivity to sensory stimuli, and self-injurious behaviors). These symptoms occurred after 30 months of age, but before the age of 12 years.

The diagnostic criteria of Atypical Pervasive Developmental Disorder (APDD) included distortions in the development of multiple basic psychological functions, but did not meet criteria for infantile autism or childhood onset pervasive developmental disorder (American Psychiatric Association, 1980).

1987 - DSM-III-R

The 3rd edition of the DSM was revised in 1987. Under this revision there were five main changes to the DSM-III (American Psychiatric Association, 1987).

1) The diagnosis of COPDD was removed.
2) The criterion for the onset of autism symptoms was replaced with "Onset during infancy or childhood" (p.39).
3) Infantile autism was changed to Autistic Disorder, and the criteria included a more comprehensive set of conditions.
4) APDD was replaced with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).
5) The conditions under which autism and schizophrenia diagnoses were made were specified, and the boundaries of Autistic Disorder and Pervasive Developmental Disorder with other disorders were considered.



The criteria for autistic disorder were broadened from a list of six items to 16 different criteria. These changes were an attempt to incorporate the entire range of autism over developmental levels and lifespans.

As stated previously, also new in the DSM-III-R was the diagnosis of Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). This category was used when there was "qualitative impairment in the development of reciprocal social interaction and of verbal and nonverbal communication skills, but the criteria are not met for Autistic Disorder, Schizophrenia, or Schizotypal or Schizoid Personality Disorder" (p. 39).

1987 ~ Ivar Lovaas publishes the first study on Intensive Behavior Therapy

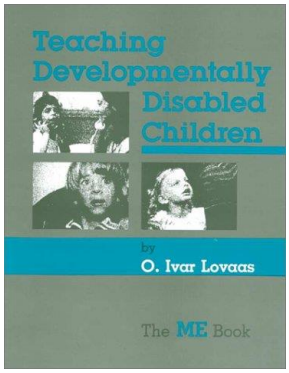
In 1958, after receiving his Ph.D., Dr. Ivar Lovaas worked as an acting assistant professor at the University of Washington under behaviorist Sidney Bijou. During this time, Lovaas supervised graduate students and conducted research at the Child Development Institute under Dr. Bijou. At the University of Washington, Lovaas also met and worked with Don Baer, who introduced him to applied behavior analysis while working with individuals engaging in severe self-harm behaviors. Initially, Lovaas used his training in psychodynamics while working at the Child Development Institute; however, this did not go over too well in the behavioral lab.

Bijou and Baer ignored his attempts and as a result, his efforts decreased over time. Lovaas stated that "Sid and Don ignored all my wonderful psychodynamic insights into clinical problems. I endured a year-long extinction run" (Larsson & Wright, 2011, p.111). It can be seen in his studies how he formed into a behavior analyst, as his interest in psychodynamic approaches faded and recognition of the effects of reliable data were evident.

In 1961, Lovaas accepted a position at the University of California, Los Angeles (UCLA) in the Psychology Department as an assistant professor. While at UCLA, he conducted research with children with autism at the Neuropsychiatric Institute. The research conducted by Lovaas at UCLA was grounded in behaviorism, a relatively newer idea in an age when psychoanalytic theories (Bettelheim), continued to be the most popular therapy for autism. Lovaas published a series of 20 papers on various behavior principles (such as social reinforcement, discrimination training, and teaching imitation skills) while working at the Neuropsychiatric Institute.

"Experimental Studies in Childhood Schizophrenia: Analysis of Self-Destructive Behavior" was published in 1965 in the *Journal of Experimental Child Psychology* and is considered to be the first functional analysis study, demonstrating how the misuse of attention and music can increase self-harm behaviors in a child with autism (Lovaas, Freitag, Gold, & Kassorla, 1965).

In 1973, Lovaas published his first groundbreaking study titled "Some Generalization and Follow-Up Measures on Autistic Children in Behavior Therapy" that analyzed the results of the work he had done with 20 children. Lovaas summarized that there are three variables which produced the most substantial treatment gains: a) intensive treatment, b) family involvement, and c) the age of the child. This was the start of the work Lovaas studied on early, intensive, home-based instruction.



In 1987, a second groundbreaking study was published called "Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children," showing the results of early intensive intervention with another 40 children over a time span of 15 years (Lovaas, 1987). The project was started in 1970 and looked at maximizing behavior treatment gains by treating young children with autism during most of their waking hours.

This behavior treatment looked at training everyone involved in the child's life as well as focused on young children under the age of four years old. The teaching procedures were presented in a teaching manual called, *Teaching Developmentally Disabled Children: The Me Book* (Lovaas, 1981).

This 1987 study used an experimental-control group design. Participants in the study were assigned either to an experimental group (including 19 children) or a control group (with 19 children). Children in the experimental group received more than 40 hours of one-to-one treatment per week; in the control group, children received 10 hours or less of one-to-one treatment per week. The results showed that the children who participated in the experimental group had higher IQ scores and required less restrictive school placements than the children who were placed in the control group. He described nine out of the 19 children in the experimental group as "normal functioning" and possibly even recovered from autism. This statement caused a great debate, where some viewed it as a breakthrough and others openly criticized the interventions.

Several follow-up studies were conducted, and the efforts helped gain extensive acceptance for early intensive behavioral intervention (EIBI), despite the ongoing debate over the interventions used in this research and the degree of its effects.

1990 - Autism becomes a Special Education Category in the Public School System.

Prior to 1990, if a child with autism required special education services, they met eligibility under categories such as mental retardation or speech/language impairment. In a 1990 reauthorization, the Education for All Handicapped Children Act (EHA) became the Individuals with Disabilities Education Act (IDEA). This reauthorization added "autism" as a specific eligibility category for special education services. Under IDEA, autism was defined as "a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three that adversely affects a child's educational performance" (Individuals with Disabilities Education Act, 1990).

Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences" (Individuals with Disabilities Education Act, 1990). IDEA states that if the child shows symptoms after the age of three, he or she can be identified as having autism if the criteria in the definition of autism are met.

According to the National Center for Education Statistics (2023), the number of students with an autism diagnosis receiving special education services under IDEA has steadily increased since 2010 (see Figure 2.2 and 2.3) when autism was included as an eligibility category.

Children 3-21 years old served (in thousands) under Individuals with Disabilities Education Act, Part B, by type of disability:
Selected school years: 2010 - 2011 through 2021 – 2022

	2010–2011	2011–2012	2012–2013	2013–2014	2014–2015	2015-2016	2016-2017	2017-2018	2018-2019	2019-2020	2020-2021	2021- 2022
All disabilities	6,436	6,401	6,429	6,464	6,555	6,677	6,802	6,964	7,134	7,282	7,183	7,259
Autism	417	455	498	538	576	617	661	710	762	803	828	882

Figure 2.2

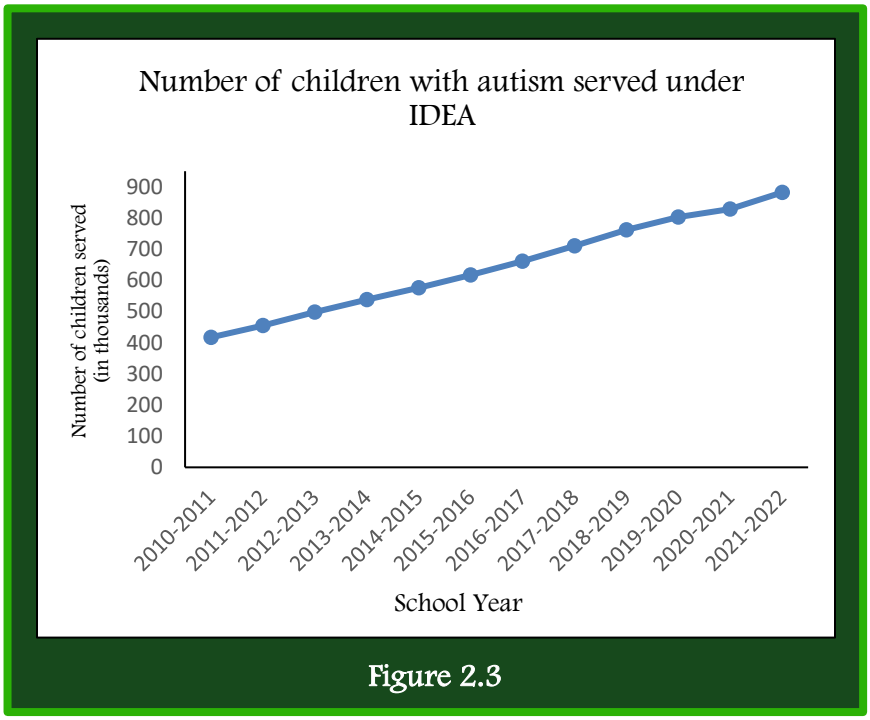


Figure 2.3

During the 2021-2022 school year, 882,000 students with autism were served under IDEA, a significant increase from 10 years earlier in the 2011-2012 school year when 455,000 students with autism received special education services.

With the addition of the autism category to IDEA, children were able to access various special education services. The services that children with autism were eligible for depended on the student's age, nature, and severity of the student's disability, or in the state which the child resides.

Such services that were made available within the public school district under IDEA for students with autism included: communication-related services such as speech and language therapy, behavioral services including behavior management programs and mental health services, Physical Therapy, Occupational Therapy, learning supports, technology aides such as assistive technology services or specialized computer software, and other services such as service coordinators, case managers, specialized transportation, or social work services (Wei, Wagner, Christiano, Shattuck, & Yu, 2014).

1994 - DSM-IV was published - The Pervasive Developmental Disorders

Shortly following the change in federal law to include autism as its own eligibility category for special education services, the DSM was revised again in 1994 and with the updated manual came three new diagnoses. This is the first time in the DSM that autism was recognized as a spectrum disorder.

Under the umbrella of Pervasive Developmental Disorders, Autistic Disorder and Pervasive Developmental Disorder Not Otherwise Specified remained, and added were Rett's Disorder, Childhood Disintegrative Disorder (CDD), and Asperger's Disorder (see Figure 2.4).

The first new diagnosis included in the DSM-IV was called Rett's Disorder. This disorder was originally described by an Austrian physician, Dr. Andreas Rett, in1996, and was characterized by normal early development, followed by the progression of several deficits. Occurring primarily in females, infants with Rett's Disorder displayed typical early development, often through the first five months of life; however, between the ages of five and 48 months, development deteriorated including social unresponsiveness, motor (poorly coordinated gait or trunk movements) and respiratory problems, profound developmental delay (impaired expressive and receptive language development), seizures, subsequent development of stereotyped hand movements, and head growth deceleration during this time period. Although there was no known cure for Rett's Disorder, the symptoms were often treatable and required a multidisciplinary approach to address the wide range of therapeutic needs.

Childhood Disintegrative Disorder (CDD) was the second disorder new to the DSM-IV. Symptoms of CDD were observed before the age of 10 years but were preceded by at least two years of typical development. Children diagnosed with CDD had deteriorating skills in at least two of the following areas: expressive or receptive language, social skills or adaptive behavior, bowel or bladder control, play, or motor skills and abnormalities of functioning in at least two of the following: qualitative impairment in social interaction, qualitative impairment in communication, and the display of restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (American Psychiatric Association, 1994). The criteria also required that these symptoms were not better accounted for by another of the Pervasive Developmental Disorders or by schizophrenia.

The final addition to the DSM-IV was Asperger's Disorder, which was perhaps the most controversial. This disorder was first described in the 1940s by Hans Asperger. Asperger's Disorder was listed in the DSM-IV as a separate disorder from Autistic Disorder; however, many caregivers and professionals will refer to Asperger's Disorder as "high functioning autism." This may be because the criterion for an Asperger's diagnosis stated that there was no significant delay in language, only in social interaction and in the display of restricted repetitive and stereotyped patterns of behavior.

There was no known cure for Asperger's Disorder, but several treatments existed that assisted with decreasing the symptoms of this disorder. The interventions may be different from those used for treating the symptoms of Autistic Disorder due to more typically developing language abilities and the need to focus on social interaction skills and perseverative behaviors and interests.

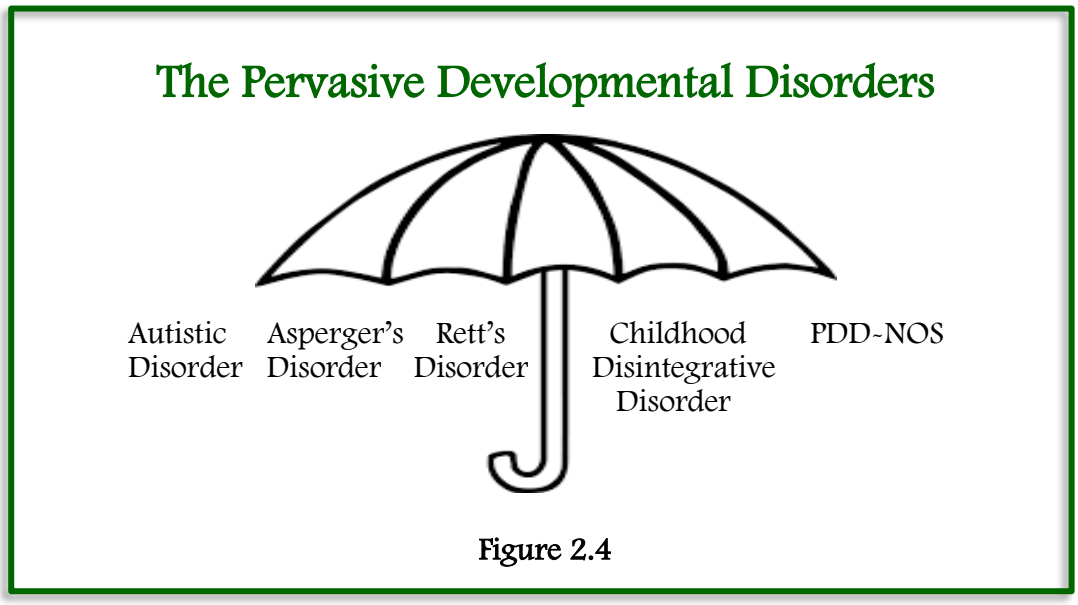


Figure 2.4

1998 ~ Vaccines cause autism

Not long after the addition of the new diagnoses under the Pervasive Developmental Disorders umbrella, a debate arose surrounding the issue of whether childhood vaccinations was a cause of autism. This debate began with the publication of a study in *The Lancet* , a British medical journal which focuses on all aspects of human health. In 1998, an article written by gastroenterologist Dr. Andrew Wakefield linked the Measles, Mumps, and Rubella (MMR) vaccine with autism.

Wakefield (1998) hypothesized that the MMR vaccine caused intestinal inflammation which released proteins harmful to the brain into the bloodstream and caused autism. In his study, Dr. Wakefield described 12 children, all with developmental delays (eight having autism). All the children in his study had intestinal complaints and developed autism shortly after receiving the MMR vaccination. From these results, Dr. Wakefield claimed that the measles and mumps virus was directly linked as the cause of autism.

Immediately after being released, parents and politicians quickly rallied around Dr. Wakefield and his findings. The controversy over whether the MMR vaccine causes autism gained momentum for several years following the publication of the article, resulting in a decrease in the number of parents who decided to have their child vaccinated.

With this decrease in the number of children being vaccinated, the rates of autism continued to increase. At this same time, several epidemiological studies were conducted and published, rebutting the hypothesized link between the MMR vaccination and autism. The hypothesized link between the MMR vaccine and autism was also questioned because a temporal link between each of these occurrences is almost inevitable; both events (onset of symptoms of autism and when children receive their vaccinations) occur in early childhood, at approximately the same time frame.

Due to the results of these studies, an investigation occurred into Dr. Wakefield's study. The outcomes of this investigation showed 1) the study was flawed; pointing out that the study was a small case series that did not have a control group and relied on parental recall and beliefs, 2) ethical violations due to Wakefield conducting invasive investigations on the children without obtaining the required ethical clearances to do so, and 3) there was fraudulent behavior due to "picking and choosing" which data to use in the final write-up of the study and falsifying facts. Wakefield was found guilty of ethical violations, fraud, and misrepresentation, which resulted in the retraction of the article by *The Lancet*.

Thimerosal

Another hypothesis on the cause of autism was formed surrounding the issue of thimerosal. Thimerosal was a compound that contained mercury, which the vials of vaccines were stored in. The thimerosal was used to prevent bacteria during the manufacturing process. With an observed increase in the rate of autism, attention was called to the use of thimerosal as a possible risk factor for autism.

As before, parents, politicians, and proponents of this new hypothesis joined together to publicize this theory, and from the publicity came a variety of remedies including vitamin A and vitamin B supplements, gluten-free and casein-free diets, hyperbaric oxygen chambers, and electromagnetics.

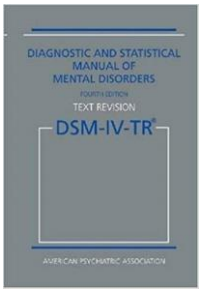
Another example of an unfortunately well-known "cure" that arose from the thimerosal hypothesis was chelation therapy. According to James, Stevenson, Silove, & Williams (2015), "Chelation therapy

involves administering a chelating substance that binds to heavy metals, such as mercury, which then is excreted in urine" (p. 3). If it was the mercury in thimerosal that was the cause of autism, then mercury-chelating agents would be the obvious solution (a.k.a. chelation therapy).

In a study published in 2013, it was reported that almost half a million individuals with autism were subjected to chelation therapy in the United States each year (Brent, 2013). Studies were then conducted to determine if there was a link between thimerosal and autism. Results showed no link between the two, and that the incidence of autism continued to increase even after thimerosal was removed from the vaccinations. With additional studies and scientific evidence, this hypothesis was also discredited and showed no evidence that thimerosal was a factor in causing autism.

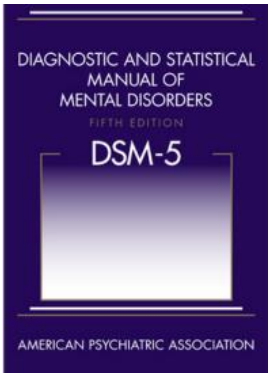
Despite the plethora of research, parents are still hesitant to have their children receive early vaccinations. The bottom line is that autism is a highly complex disorder, and determining the specific cause is even more complex. Several theories have come and gone over the years as to what causes autism, but fortunately, the question of whether vaccinations cause autism can be answered through science.

2000 – Text Revision of the DSM-IV



A text revision of the DSM-IV was published in 2000. The diagnostic categories and the vast majority of the specific criteria for an autism diagnosis were unchanged, including information for Pervasive Developmental Disorders. Changes were made to nine diagnoses including: Dementia Due to Other General Medical Conditions, Dementia of the Alzheimer's Type, Exhibitionism, Frotteurism, Pedophilia, Personality Change Due to a General Medical Condition, Sexual Sadism, Tourette's Disorder, and Voyeurism. In this revision, additional information was included on each diagnosis, as were some of the diagnostic codes to maintain consistency with the ICD (American Psychiatric Association, 2000).

2013 – DSM-5 was published - Autism Spectrum Disorders



With the publication of the DSM-5 came significant changes to the diagnosis of autism. Previously, under the umbrella of Pervasive Developmental Disorders, there were five diagnoses including: Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Rett's Disorder, Childhood Disintegrative Disorder, and Asperger's Disorder. The Pervasive Developmental Disorders were replaced by a single diagnosis, Autism Spectrum Disorder.

This change eliminated Asperger's Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Rett's Disorder, and Childhood Disintegrative Disorder; however, it is important to note that any individual who received a diagnosis of one of these three disorders prior to the new categorization under DSM-5 continued to retain their diagnosis.

Another change that occurred with the coming of the DSM-5 was the reorganization of the core symptom domains. Previously in the DSM-IV, there were three existing domains: Social interaction, Communication, and Restricted/Repetitive Behavior. To receive a diagnosis of one of the Pervasive Developmental Disorders, the individual needed to meet specific criteria in each one of these domains.

In the DSM-5, there are now only two domains: 1) Social Communication and Social Interaction, and 2) Restricted/Repetitive Behavior. These areas come with specific criteria that are still required to obtain an ASD diagnosis.

A third change in the DSM-5 occurred with the addition of specifiers for the level of support needed. The levels of support outline the degree of severity of symptoms that are displayed, and are rated either as a Level 1, Level 2, or Level 3. The goal for adding the severity levels was for clinicians to be able to describe an individual's abilities and needs by providing a level of functioning with the autism diagnosis more precisely.

A final change that occurred in the DSM-5 is the addition of "sensory sensitivity" to the diagnostic criteria. The DSM-5 states: "Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment" (p. 50). This addition now considers symptoms that are often observed such as an indifference to temperature, adverse reactions to loud noises or several people in the room, extreme smelling or touching behaviors, abnormal responses to textures, etc.

A more detailed description of the DSM-5 criteria requirements for autism is outlined later in this chapter.

DSM-5-TR

A text revision was made to the DSM-5 in 2022. With these changes came revisions to the wording within the definition for autism spectrum disorders. Under criterion A, which discusses the differences in social communication and social interaction, the phrase "as manifested by the following" has been to read "as manifested by *all of* the following."

Evolution of the Diagnosis of Autism

Diagnosis	Diagnostic criteria
DSM – 1952 **The term autism was used under the diagnosis of Schizophrenic, childhood type**	
DSM-II – 1968 **The term autism was used under the diagnosis of Schizophrenic, childhood type**	
DSM-III – 1980	
Infantile autism Full syndrome Residual state	- Onset is before 30 months of age - Pervasive lack of responsiveness to other people - Gross deficits in language development - Peculiar speech patterns when speech is present - Bizarre responses to various aspects of the environment - Absence of delusions, hallucinations, loosening of associations and incoherence as in Schizophrenia.
Childhood onset pervasive developmental disorder Full syndrome Residual state	- At least three of the following: a) Excessive anxiety b) Constricted or inappropriate affect c) Resistance to change in the environment or insistence on doing things in the same way every time d) Oddities of motor movement e) Abnormalities of speech f) Hyper- or hypo- sensitivity to sensory stimuli g) Self-mutilation - Absence of thought disorder. - Onset is after 30 months of age to 12 years of age.
Atypical pervasive developmental disorder	- Distortions in the development of multiple basic psychological functions. - Does not meet the diagnostic criteria for infantile autism or childhood onset pervasive developmental disorder. - Onset is not specified.

DSM-III-R – 1987	
Autistic Disorder (AD)	At least eight of the following 16 items are present (at least two from A, one from B, and one from C): A. Qualitative impairment in reciprocal social interaction as manifested by the following: 1) Marked lack of awareness of the existence of feelings of others 2) No or abnormal seeking of comfort at times of distress 3) No or impaired imitation 4) No or abnormal social play 5) Gross impairment in ability to make peer friendships. B. Qualitative impairment in verbal and nonverbal communications, and in imaginative activity, as manifested by the following: 1) No mode of communication 2) Markedly abnormal nonverbal communication, as in the use of eye-to-eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction 3) Absence of imaginative activity, such as playacting of adult roles, fantasy characters, or animals; lack of interest in stories about imaginary events 4) Marked abnormalities in the production of speech, including volume, pitch, stress, rate, rhythm, and intonation 5) Marked abnormalities in the form or content of speech, including stereotyped and repetitive use of speech, idiosyncratic use of words or phrases, or frequent irrelevant remarks 6) Marked impairment in the ability to initiate or sustain a conversation with others, despite adequate speech. C. Markedly restricted repertoire of activities and interests, as manifested by the following: 1) Stereotyped body movements 2) Persistent preoccupation with parts of objects or attachment to unusual objects 3) Marked distress over changes in trivial aspects of environment 4) Unreasonable insistence on following routines in precise detail 5) Markedly restricted range of interests and a preoccupation with one narrow interest D. Onset during infancy or childhood.

Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS)	- Qualitative impairment in the development of reciprocal social interaction and of verbal and nonverbal communication skills. - The criteria are not met for autistic disorder, schizophrenia, or schizotypal or schizoid personality disorder. - Some people with PDDNOS will display a markedly restricted repertoire of activities and interests, while others will not. - Onset is not specified.

DSM-IV – 1987	
Autistic Disorder	A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3): (1) Qualitative impairment in social interaction, as manifested by at least two of the following: (a) Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction (b) Failure to develop peer relationships appropriate to developmental level (c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) (d) Lack of social or emotional reciprocity (2) Qualitative impairments in communication, as manifested by at least one of the following: (a) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime) (b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others (c) Stereotyped and repetitive use of language or idiosyncratic language (d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level (3) Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following: (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus (b) Apparently inflexible adherence to specific, nonfunctional routines or rituals (c) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements) (d) Persistent preoccupation with parts of objects

	B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age three years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play C. The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.
PDD-NOS	This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder. For example, this category includes "atypical autism" -- presentations that do not meet the criteria for autistic disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.
Asperger's Disorder	A. Qualitative impairment in social interaction, as manifested by at least two of the following: (1) Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction (2) Failure to develop peer relationships appropriate to developmental level (3) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people) (4) Lack of social or emotional reciprocity B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following: (1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus (2) Apparently inflexible adherence to specific, nonfunctional routines or rituals (3) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements) (4) Persistent preoccupation with parts of objects C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning. D. There is no clinically significant general delay in language (e.g., single words used by age two years, communicative phrases used by age three years).

	E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood. F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia.
Rett's Disorder	A. All of the following: (1) Apparently normal prenatal and perinatal development (2) Apparently normal psychomotor development through the first five months after birth (3) Normal head circumference at birth B. Onset of all of the following after the period of normal development: (1) Deceleration of head growth between ages 5 and 48 months (2) Loss of previously acquired purposeful hand skills between ages five and 30 months with the subsequent development of stereotyped hand movements (i.e., hand wringing or hand washing) (3) Loss of social engagement early in the course (although often social interaction develops later) (4) Appearance of poorly coordinated gait or trunk movements (5) Severely impaired expressive and receptive language development with severe psychomotor retardation.
Childhood Disintegrative Disorder	A. Apparently normal development for at least the first two years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior. B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas: (1) Expressive or receptive language (2) Social skills or adaptive behavior (3) Bowel or bladder control (4) Play (5) Motor skills C. Abnormalities of functioning in at least two of the following areas: (1) Qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity) (2) Qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)

	(3) Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypies and mannerisms D. The disturbance is not better accounted for by another specific pervasive developmental disorder or by schizophrenia.

DSM-IV-TR – 2000	
Pervasive Developmental Disorders	No changes to the diagnoses under the Pervasive Developmental Disorders.

DSM-5 – 2013	
Autism Spectrum Disorder	Onset – symptoms are usually observed between 12 and 24 months of age; however, symptoms can be seen earlier than 12 months if they are severe or seen later than 24 months if symptoms are more subtle. A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text): (1) Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions. (2) Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication. (3) Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers. *Specify* current severity: **Severity is based on social communication impairments and restricted, repetitive patterns of behavior.** B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

	(1) Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases). (2) Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). (3) Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests). (4) Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement). *Specify* current severity: **Severity is based on social communication impairments and restricted, repetitive patterns of behavior.** C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life). D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning. E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level. *Specify* if: **With or without accompanying intellectual impairment. With or without accompanying language impairment** **Associated with a known medical or genetic condition or environmental factor** (**Coding note**: Use additional code to identify the associated medical or genetic condition.) **Associated with another neurodevelopmental, mental, or behavioral disorder** (**Coding note**: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s]. **With catatonia** (refer to the criteria for catatonia associated with another mental disorder)

DSM-5-TR – 2022	
Autism Spectrum Disorder	Previously stated: "Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text): (1) Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions. (2) Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication. (3) Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers. A text revision was made to the phrase "as manifested by the following" to read "as manifested by *all of* the following."

Section B: Symptoms of Autism

The following story outlines the key concepts which will be discussed next, including various symptoms of the disorder and characteristics. This story also demonstrates two important things: first, the uniqueness of every person with autism, and second, the idea that autism is a *spectrum disorder*, where there are varying degrees of severity and manifestation of symptoms.

Carrie's Story

Let's play a game, okay? I'll give you a bunch of clues, and you try to guess who I am.

I am not a person, place, or thing. You can't see me or touch me or smell me.

I am considered a human condition, but really, I am a collection of symptoms.

He doesn't play with other kids.

She doesn't like it if we drive home a different way.

He'll sit and take the vacuum apart for hours.

She doesn't look at me.

I am the twitching finger and the flapping hand.

I am the silent toddler with downcast eyes and a tippy-toe walk.

I am a diagnosis, a disorder; a box you check on the medical form or a postscript at the end of an email.

P.S. I'm not sure if you've heard, but Jack's been diagnosed

I will make you have bad days and good days and bad days then good.

I live in each and every one of you, whether you know it or not.

I am the cocktail party that makes you shy and the tag on your shirt that makes you itch. I am the sticky crunch of strawberry seeds and the overwhelming hum of the air conditioner.

I make some people jump and flap, while others chew gum or run for miles or twirl their hair.

I am the Baby Einstein DVD on repeat.

I am long, neat rows of Thomas the Tank engines snaking around your family room. Seeing these rows will make you feel frantic; frustrated and nervous and empty.

I am hours of Minecraft.

Some days, I taste like shame and bitterness, burning up from a mother's heart like sour indigestion.

But other days, I taste like the purest joy; like cotton candy and happiness and pride exploding within your heart.

He did it. He said Mama!

You can find me in churches and synagogues and mosques.

I am in schools and movie theaters, playground, and libraries.

For some reason, people celebrate me in April. They use the color blue. But I am actually all the colors of the world; red for Saturday and yellow for the too-bright sun.

But I am also color blind.

I am in India. I am in Jamaica. I am in the Philippines and Wisconsin and Sierra Leone. You can find me in Russia and Japan, San Francisco and Belgium.

Maybe you sit across from me at your dinner table every night, or maybe you look up to see my reflection in the mirror when you brush your teeth before bed.

I live within a 10-year-old boy in New Hampshire. His name is Jack.

One year, I made him afraid of wind. So afraid, in fact, that he would not go outside all winter.

The next year, it was dogs. Because of me, he wouldn't cross the street if someone was walking their Pug or their Golden Retriever.

And this boy Jack, well, I make him work hard for the things that come naturally for others; language and jokes and facial expressions. He spends a lot of his day anxious and confused. I am his enigma wrapped up in Waffle Thursday and Pancake Saturday.

Mom it is Thursday Thursday for waffles for waffles waffles waffles.

I have been around since the beginning of time, despite the façade of normal assembled by generations before you.

There is no normal. I am here to tell you this.

It is up to you how you see me; as a nuisance, a tantrum, a disorder, or a curious lamb wearing the costume of a wolf. Can you look past my long, yellow teeth and matted hair, and find the soft, gentle child underneath?

Because of me, Mozart wrote long, complicated symphonies. His hearing was rumored to be so sensitive, he could tell the difference in the slightest tone.

Historians explain the way Michelangelo made sketch after sketch until the final pose was perfect in his rigid, unbending mind. Because of me, the Sistine Chapel explodes with light and color. Records show that Albert Einstein did terribly in school. He didn't learn the same way as all the other kids.

And Sir Isaac Newton of the fallen apple had no friends. He didn't understand people, and he insisted on a strict, unwavering routine.

And there is Temple Grandin; a woman so intelligent, so compassionate, that she revolutionized the cattle industry through sheer perseverance and determination.

You see, a still mind can still have great thoughts, and within even the quietest person, there is a voice. Or a painting, or a song.

I am so many things. I am hope and possibility. I am music and dreams, kindness and color. I am gravity.

So please, before you panic or judge—before you race for a cure or rush to call me weird - try to remember my value. Remember my goodness.

I will teach you the real meaning of unconditional love; a love so powerful and strong it will rearrange your heart.

At first, you probably won't even realize that you are learning from me. I am so subtle; I am practically invisible.

But every hour, every day, every year, you and I will make our peace. You will step carefully over the long rows of trains, and admire the complicated cities in Minecraft.

Every Thursday at dawn you will turn on all the lights in the kitchen, and take out the waffle iron for a boy who at last said *Mama*.

You will forget normal.

I am autism. And I will make you better. I will make your family better.

If you let me, I will make the world better.

Centers for Disease Control and Prevention (2019)

In Carrie's story, a multitude of different symptoms are presented that children with autism may or may not exhibit. It is important to understand that not only are the symptoms displayed by children with autism different from one child to the next; the severity at which these symptoms occur can differ greatly from child to child. This variation in the symptoms and severity levels is why autism is referred to as a "spectrum disorder."

In other words, our understanding of the disorder is that autism is expressed in many different forms. It helps to think of the "autistic spectrum" as a continuum, with one end considered severe display of symptoms and the other end considered mild display of symptoms. When an individual is diagnosed with ASD, most professionals place them somewhere along this spectrum. Regardless of where they are placed, the common symptoms of autism include communicative deficits, social impairment, and restrictive, repetitive, or stereotypic patterns of behavior.

At the severe end of the spectrum are individuals who may represent the "classic" Kanner-esque description of autistic disorder. These individuals are likely to have significant deficits in, or even absence of, any type of social communication. Restricted interests can take the form of repetitive, non-functional behaviors (stereotypy) such as a repetitive motion like hand flapping, or the use of objects in similar ways (spinning wheels on a toy car, for example). These individuals may never develop spoken language, and it may be challenging to teach new skills.

At the "mild" end of the spectrum are individuals who may have developed fairly refined language skills and may have less obvious cognitive deficits, but still demonstrate qualitative impairments in abstract reasoning, nonverbal communication, and concept formation[1]. Restricted interests within this group might include fascination with a very limited range of subjects (e.g., dinosaurs or 18th century French poetry) and a desire to obsessively acquire and regurgitate information about them.

[1] **Concept formation**: the ability to use known responses, in conjunction with executive function abilities, to formulate novel, generalized, or abstract responses.

Individuals at this end of the spectrum also frequently demonstrate verbosity and one-sided communication styles. Formal language, or the demonstration of rule-governed components of language, is often quite intact. Language comprehension, on the other hand, is often impaired.

All along this continuum, individuals may exhibit different combinations of the core deficits associated with autism spectrum disorders, and to varying degrees. Subsequently, it is becoming increasingly difficult to define a "classic" case of autism. To further complicate matters, not only are there differences between people with autism, but there are also *intra-individual* differences (i.e., within each person) that occur with the disorder. A person subjected to any of numerous variables, including intervention, experience, or lack thereof, and environmental/familial factors. He or she may find themselves at different points along the continuum at different developmental periods in their life. In particular, effective intervention may enable certain individuals to acquire skills that could eventually place them at a different point on the spectrum.

It is also helpful to understand that autism is considered a syndrome, or a disorder characterized by a constellation of common characteristics. One example of this is Down Syndrome, where characteristics include decreased muscle tone at birth, differences in skull shape, differences in facial features and a detectable chromosomal abnormality. Almost all of these are recognizable physical features that are rather easy to detect and observe.

In the case of autism spectrum disorders, however, common characteristics include impairment in communication, impairment in social functioning and stereotypic or repetitive patterns of behavior. This makes the syndrome more challenging to diagnose, as there is no blood, chromosomal/genetic, or other physical tests currently available. Instead, diagnosis of autism spectrum disorder is based on the presence or absence of symptoms, as opposed to purely medical evidence. Because of this, it is increasingly important that diagnosticians become well versed in the characteristics of autism spectrum disorders, so that intervention can take place as soon as possible.

Section C: Detecting Autism

How does a family embark on the journey from giving birth to a child, to suspicion of a problem, to diagnosis, and then to intervention?

In retrospect, most parents of children diagnosed with autism would agree that they sensed something was wrong with their child at a very early stage in his or her development. While most children with autism do not receive a formal diagnosis until they are between two and three years old, behavioral symptoms are usually present at one year, and often earlier. Several studies have demonstrated this by reviewing home movies of children that were filmed years prior to their formal diagnosis (Clifford & Dissanayake, 2008, Ozonoff et. al, 2010; Watson et. al, 2013; Einspieler et. al, 2014). Close inspection of these early videotapes revealed subtle impairments in the child's ability to react to his or her name being called, eye contact and joint attention, and the use of gestures – all skills that would later become diagnostic criteria for autistic disorder.

When parents of children with autism sit down and describe how their child was diagnosed, general patterns and similarities link their stories with those of hundreds of others. Typically, the first sign that something was amiss with a child comes between the ages of 18 - 21 months. Parents routinely describe a total lack of language at this stage in development, when the child should be speaking at least in single words, if not already forming two-word utterances.

The other common scenario involves the child who has developed single-word language, but now, for no apparent reason, has either begun to use his or her words less frequently or has abruptly stopped communicating altogether.

For a brief overview of some common possible indicators of autism, please refer to Figure 2.5.

These symptoms often prompt a visit to the pediatrician who, given no evidence of limitations in other developmental milestones (i.e., the child's motor skills are within normal limits), might suggest a variety of commonly accepted reasons for the child's lack of expressive language. These often include shyness, gender differences ("girls talk earlier than boys"), individual developmental differences or the presence of older siblings who "talk for" the child. In general, however, the parents are left with the message that it is premature to be worrying about a language deficit and that the child will likely outgrow the problem.

According to the DSM-5 and listed on the National Institute of Mental Health's website, the following are possible indicators of ASD:

Social communication/interaction behaviors may include:

* Making little or inconsistent eye contact
* Tending not to look at or listen to people
* Rarely sharing enjoyment of objects or activities by pointing or showing things to others
* Failing to, or being slow to, respond to someone calling their name or to other verbal attempts to gain attention
* Having difficulties with the back and forth of conversation
* Often talking at length about a favorite subject without noticing that others are not interested or without giving others a chance to respond
* Having facial expressions, movements, and gestures that do not match what is said
* Having an unusual tone of voice that may sound singsong or flat and robot-like
* Having trouble understanding another person's point of view or being unable to predict or understand other people's actions

Restrictive/repetitive behaviors may include:

* Repeating certain behaviors or having unusual behaviors
* Having a lasting, intense interest in certain topics
* Having overly focused interests, such as with moving objects or parts of objects
* Getting upset by slight changes in a routine
* Being more or less sensitive than other people to sensory input

National Institute of Mental Health, 2020

Figure 2.5

An additional concern that surfaces during this same time is a drawing inward, or loss of social connectedness on the part of the child. More time is spent in solitary or repetitive play. Physical contact with parents may be avoided or may appear to cause great distress for the child. The parents note that when called by name, the child rarely looks or responds, and simple directives are seemingly ignored.

Social aloofness is also regularly attributed to shyness or explained away as a manifestation of the child's personality. These symptoms of inattentiveness may lead many parents to suspect a hearing loss, and they respond by having their child scheduled for a complete audiological screening. If the results of the audiological exam rule out hearing loss, the parents are met with another dead end.

Finally, during the second and third years of development, a marked interest in repetitive or ritualistic activities will emerge, to the exclusion of age-appropriate play. Visual order may become paramount, with the child compelled to line up all toys, books or stuffed animals or place them in specific locations or in specific order. Play activities may lose all social significance and become solitary endeavors that involve a fascination with specific toys or parts of toys, the repetitive manipulation of objects, or the rhythmic movements of the child's own body. Interruption of these behaviors may cause the child to fly into a rage that does not stop until the disruption ceases, and the ritual can be resumed.

Parental response to the display of repetitive or ritualistic activities is typically one of tacit acceptance. The ritualistic play is explained as merely one of the child's odd little quirks, and not of any real consequence – a belief that is heavily reinforced following disastrous attempts at redirecting or interrupting these behaviors. Simply allowing the child to continue the repetitive behavior far outweighs dealing with the severity of tantrum, aggression, and self-harm behavior that may result from directly trying to stop it. The family simply adapts and adjusts their lifestyle to accommodate the child's rituals or to ensure that those who come in contact with the child keep his or her "world" just the way he or she likes it.

Unfortunately, the display of these symptoms taken in combination strongly suggests a diagnosis of autism. Moreover, the misguided search for answers from professionals, family, and friends may lead to a waste of valuable time. Normally, referral to an "autism expert" such as a developmental psychologist or pediatric neurologist did not occur until these early symptoms became seriously problematic and interfered with the child's or the family's functioning, often around age two or three.

This illustration of the plight of parents seeking a diagnosis is not intended to suggest that pediatricians, audiologists, or the parents themselves are culpable for a misdiagnosis or delay in the correct diagnosis of autism. Until recently, diagnostic criteria for autism were not widely disseminated among primary care professionals, let alone available to the general parent population. Now, when you walk into a pediatrician's office, you may be asked to fill out a questionnaire focused on your child's development, and if they are meeting certain milestones. It is meant to be a screening to determine if there are apparent red flags in the child's development.

What hopefully will be understood from this illustration is that while autism may present itself in myriad individual manifestations, there does exist a core set of behavioral symptoms that most parents encounter within the first two years. Early detection of these markers can lead to early diagnosis, early intensive intervention and, as research has shown, a significantly improved prognosis (Rogers, Vismara, Wagner, McCormick, Young, & Ozonoff, 2014, Dawson & Bernier, 2013).

There has been a growing body of research on earlier identification of the "red flags" of autism, even as early as infancy. In a study published in 2013, Rebecca Landa and colleagues found that some children can reliably be diagnosed with autism by 14 months of age, while others not until 36 months of age. The study finds that after 36 months of age, there are no differences in symptoms (Landa, Stuart, Gross, & Faherty, 2013).

Several other studies have looked at specific symptoms displayed in infancy that led to a later diagnosis of autism such as eye gaze and eye contact (Elsabbagh et. al, 2012; Jones & Klin, 2013), visual attention (Chawarska, Macari, & Shic, 2013; Elsabbagh et. al, 2013; Shic, Macari, & Chawarska, 2014), social

communication behaviors (Lloyd-Fox et. al, 2018; Ozonoff et. al, 2010; Poon, Watson, Baranex, & Poe, 2012; Rozga et.al, 2011), and sensory responsiveness (Baranek et. al, 2018; Damiano-Goodwin, et. al, 2018).

Although the research in detecting the indicators of autism in infancy is promising, currently, the official diagnosis of autism is not usually given until the age of two to three years. The growing body of research on autism and infancy gives parents and caregivers tools to "be on the lookout" for signs much earlier than when an official diagnosis is made. As seen in the body of literature, the earliest signs of autism involve the absence of "normal" behaviors and not the presence of "abnormal" behavior. By knowing what you are looking for, early signs of autism can be more reliably detected which can lead to major, long-term positive effects on symptoms and skills later in life.

Section D: Defining Autism

The DSM-5 is perhaps the most widely used resource for classifying and diagnosing autism spectrum disorders, but there are others, including the revision of the *International Classification of Diseases and Related Health Problems, 10th revision, Clinical Modification* (ICD-10-CM), and Zero to Three's DC: 0-5™ *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood.*

Additionally, U.S. Federal education law has a definition of autism, not necessarily for diagnostic purposes, but for eligibility for services that are provided to individuals meeting this definition. In 2004, Congress reauthorized the Individuals with Disabilities Education Act (IDEA) and made revisions significant enough that it was renamed to the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA).

Some of the revisions in IDEIA called for early intervention for students, greater accountability, and improved educational outcomes, and raised the standards for instructors who teach special education classes. IDEIA continues to define autism as

> "A developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movement, resistance to environmental change or change in daily routine, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance" [Individuals with Disabilities Improvement Act, 2004].

According to the DSM-5, the symptoms of autism are persistent impairment in everyday functioning in the areas of reciprocal social communication and interaction as well as restricted, repetitive patterns of behaviors, interests, or activities. These symptoms are present from early childhood, with a wide range in the severity of these symptoms; therefore, autism is considered a spectrum disorder.

Diagnostic Criteria for Autistic Disorder

Within the DSM-5, each of the domains listed in Figure 2.6 is expanded upon with specific clinical features described in greater detail. For a diagnosis of autism to be made, a set number of these clinical features must be present in each domain.

Domains Addressed in DSM-5 Definition of Autism

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest). Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

C. Symptoms must be present in the early developmental period (but may not become fully manifested until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur, to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Figure 2.6

The spectrum of autism varies greatly from one end to the other. To better help clinicians describe each case of autism, the DSM-5 includes three "levels of support" (see Figure 2.7). These levels correspond with the level of severity of symptoms displayed within the domains. Clinicians are to include the level of severity within their diagnosis. The goal was to be able to describe an individual's abilities and needs by providing a level of functioning with the autism diagnosis more clearly.

The spectrum of autism varies greatly from one end to the other. To better help clinicians describe each case of autism, the DSM-5 includes three "levels of support" (see Figure 2.7). These levels correspond with the level of severity of symptoms displayed within the domains. Clinicians are to include the level of severity within their diagnosis. The goal was to be able to describe an individual's abilities and needs by providing a level of functioning with the autism diagnosis more clearly.

Severity Level	Social Communication	Restricted, repetitive behaviors
Level 3 "Requiring very substantial support"	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.
Level 2 "Requiring substantial support"	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 who 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.
Level 1 "Requiring support"	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 can 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.

Figure 2.7

Another change with the publication of the DSM-5 was the addition of Social Communication Disorder. This disorder includes some, but not all the symptoms of autism spectrum disorder. Some say that Social Communication Disorder is a milder form of autism, similar to the criteria listed under DSM-IV's Asperger Syndrome and PDD-NOS. It is important to note however that under DSM-5, Social Communication Disorder does *not* fall under the category of Autism Spectrum Disorder. Autism Spectrum Disorder and Social Communication Disorder are listed as two distinct diagnoses with their own set of criteria. I will focus primarily on autism spectrum disorders as defined by the DSM-5.

Section E: Diagnosing Autism

As parents search for reasons or explanations for their child's atypical development, they are quite often led along a rather convoluted path from pediatrician to audiologist, to speech/language pathologist, to developmental specialist, to various psychologists, or eventually to a neurologist. Unfortunately, many of these professionals whom the parents meet along the way may not have had any direct experience with autism, and the elusive diagnosis may not be made for months or even years. In the meantime, the undiagnosed child does not receive the therapy that he or she most desperately needs.

When a diagnosis is made, it usually comes from a child psychiatrist, neurologist, or licensed psychologist. Although the criteria for assigning the diagnosis of autism typically fall within the parameters laid out in the DSM-5, the actual interview and assessment tools used by these professionals to evaluate children can vary substantially. Both factors, the delays in detecting and diagnosing children with autism and the lack of a consistent or systematic protocol for conducting diagnostic activities, have led some professionals in the field to seek standards.

Although the process of assessing for autism can be quite complex, research has shown that an autism diagnosis can consistently be made in the second year of life (Steiner, Goldsmith, Snow, & Chawarska, 2012). The Centers for Disease Control and Prevention (CDC) stress the need for early screening and diagnosis. Two main steps are involved in the diagnosis of autism: 1) Developmental Screening and 2) Comprehensive Diagnostic Evaluation.

Developmental Screenings

A developmental screening is the administration of a standardized tool that assists with the identification of children who may be at risk of a developmental disorder. It is important to remember that the developmental screening does not result in a diagnosis of autism or other developmental disorder; it only identifies the areas where the child's development is different from other children his or her age. If the screening tool shows positive results of someone who is at risk, a referral should be made to early intervention services.

Developmental screenings are often completed during the child's well-visit check-ups with their pediatrician. It is recommended for all children to be screened for developmental delays and disabilities during regular well-child visits at nine months, 18 months, and either 24 or 30 months (Hyman, Levy, & Myers, 2020). In addition to this, all children should be screened specifically for autism during their regular well-child doctor visits at 18 months and 24 months. It is also recommended that additional screening may be required if a child is at high risk for ASD or if behaviors sometimes associated with autism are observed (Hyman, Levy, & Myers, 2020).

The Centers for Disease Control and Prevention (2020) provide the following flowchart (see Figure 2.8) as an example of how developmental screenings activities might occur:

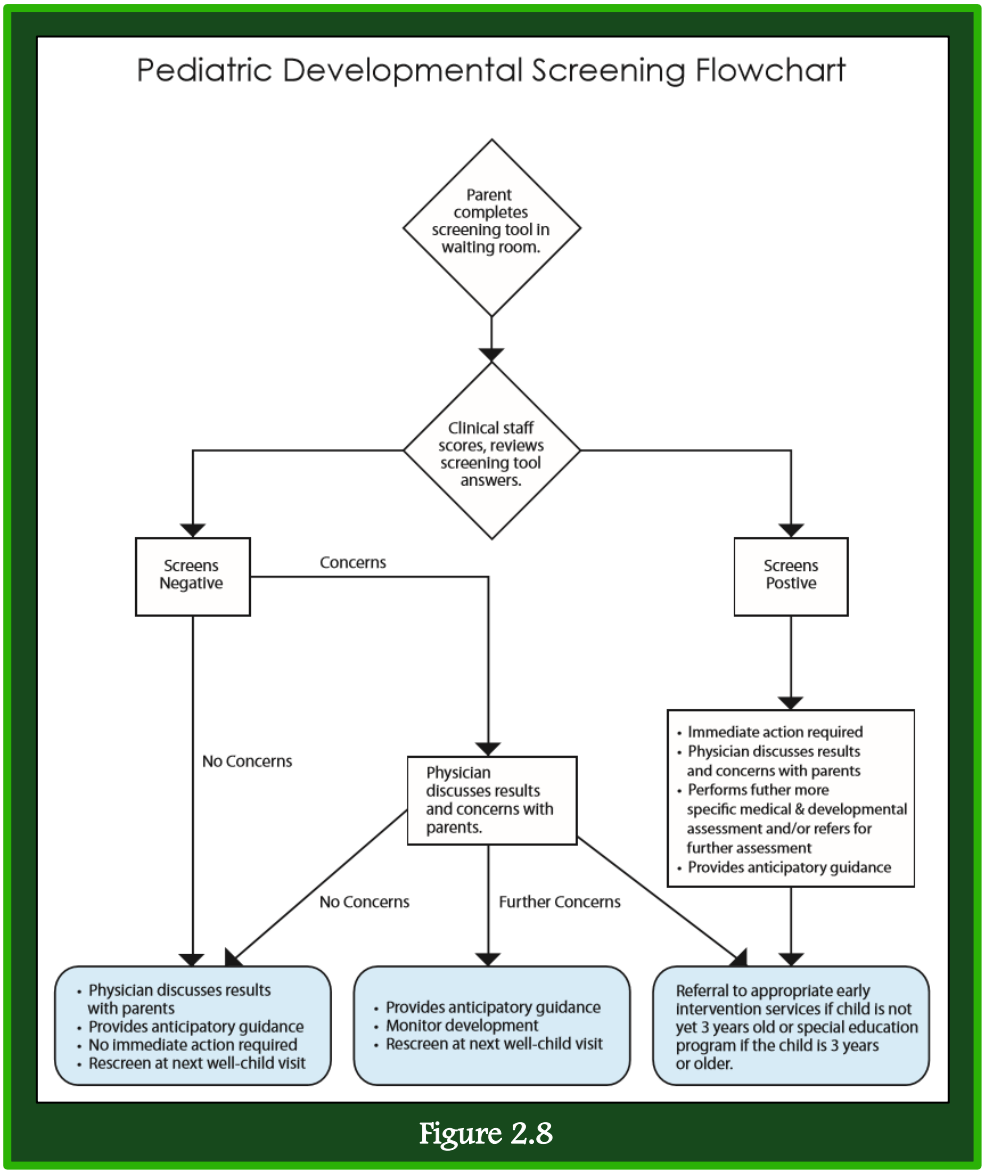


Figure 2.8

There is an exhaustive list of developmental screening tools available; however, listed below are examples of those that are more commonly used that have high reliability and validity used for general development and autism.

a) Ages and Stages Questionnaires – 3rd Edition (ASQ-3) – a developmental screening tool which contains 21 age-specific questionnaires completed by the child's parent or caregiver. The ASQ-3 is for children between the ages of 1 through 66 months and evaluates five domains including: communication, gross motor, fine motor, problem solving, and personal-social. Each questionnaire in the ASQ-3 contains 30 items and is completed in approximately 10 - 15 minutes. The ASQ-3 is used worldwide with evidence of high reliability and validity.

b) Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP) – a language screening tool that measures the following seven language predictors in young children: Emotion and Eye Gaze, Gestures, Communication, Sounds, Words, Understanding, and Object Use. There are three main components to the CSBS DP: the Infant- Toddler Checklist, Caregiver Questionnaire, and Behavior Sample. The Infant-Toddler Checklist contains 24 items and is completed every three months for children between six and 24 months of age. The Infant-Toddler Checklist assesses the areas of social, speech, and symbolic, and is used only to determine if further information or evaluation is needed. The Caregiver Questionnaire includes a four-page questionnaire completed by the child's parent/caregiver in approximately 15-20 minutes. Following the questionnaire, the Behavior Sample is completed. While being videotaped, the caregiver interacts with the child using a naturalistic procedure. This procedure uses communicative temptations, book sharing, symbolic play, language comprehension probes, and constructive play. The results of the interaction are converted on 22 five-point scales, organized in seven clusters: Communicative Function, Communicative Means—Gestural, Communicative Means—Vocal, Communicative Means—Verbal, Reciprocity, Social-Affective Signalling, and Symbolic Behavior.

c) Parents' Evaluation of Developmental Status (PEDS) – used to assist with detecting early developmental and behavioral concerns. The PEDS is a parent-completed questionnaire that gathers information in the areas of global/cognitive, expressive language and articulation, receptive language, fine and gross motor, behavior, social-emotional, self-help, and school. The PEDS contains 10 items and takes approximately 30 minutes to complete. The intended age range is from birth through eight years and can be used across several different settings such as medical practices, early childhood programs, and training programs.

d) Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT – R/F) – currently one of the most widely used screening tools used for toddler screening for autism (Robins, Casagrande, Barton, Chen, Dumont-Mathieu, & Fein, 2014). The M-CHAT – R/F is a free, two-step screening tool for children 16-30 months of age. The M-CHAT – R/F is intended to be used during a child's well-visit check-ups; however, it can be used by specialists or other professionals at any time to assess the risk for autism. The M-CHAT-R/F contains 20 questions and is completed by the parent/caregiver within 5-10 minutes.

e) Screening Tool for Autism in Two-year-olds (STAT) – an interactive measure for children ages 24–35 months that can be administered by various early childhood professionals. It consists of a 20-minute play session with several activities that test for motor imitation, pretend and reciprocal play, and nonverbal communication. The STAT is designed to differentiate autism from other developmental disorders.

Comprehensive Diagnostic Evaluation

If the initial screening results raise a concern, the child should then receive a comprehensive diagnostic evaluation. This process should be conducted by a specialist, or a team of specialists experienced in making the diagnosis of autism. This evaluation relies on two main sources of information – parents'/caregivers' descriptions of their child's development and the clinician's observation of the child. While evaluating for autism, no single tool should be used as the basis for the diagnosis.

Listed below are commonly used *diagnostic tools* when assessing for an autism diagnosis.

a) The Gilliam Autism Rating Scale: 3rd Edition (GARS-3) – a checklist used by parents, teachers, and professionals to identify and estimate the severity of autistic symptoms. Designed for ages 3 to 22 years, items on the GARS-3 are based on the DSM-5 and are centered on six subscales: Restrictive/Repetitive Behaviors, Social Interaction, Social Communication, Emotional Responses, Cognitive Style, and Maladaptive Speech. Still included in the GARS-3 is the separate booklet referred to as *Instructional Objectives for Children Who Have Autism*, which aids in the formulation of instructional goals and objectives based on the results of this assessment. This is important because it links the results of an assessment directly to instruction based on the identified strengths and needs.

b) The Autism Diagnostic Interview-Revised (ADI-R) – the "gold standard" interviewing instrument in current research protocols. The benefits of this assessment include the use to diagnose autism, plan treatment, and distinguish autism from other developmental disabilities. It is implemented with children and adults with a mental age above 2.0 years. The ADI-R is a comprehensive structured parent interview that takes approximately one to two hours to administer and requires specific training and validation procedures. Due to these restrictions, the practicality of its use in primary care settings is questionable.

c) Childhood Autism Rating Scale, Second Edition (CARS2) – revised in 2010, the CARS2 is a 15–item structured interview and observation instrument for children over 24 months of age. The CARS2 includes three forms. First is a questionnaire for parents and caregivers to complete. The other forms consist of two rating scales. The standard version (CARS-ST) is used with young children or those children who have communication or intellectual delays. The other version is for individuals who possess higher-level skills, older than five years and verbally fluent.

d) Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) – released in 2012, the ADOS-2 is a semi-structured observational assessment in the areas of communication, social interaction, play, and restricted and repetitive behaviors. The ADOS-2 presents different activities that elicit behaviors that are directly related to the symptoms of autism. Five modules are included in the ADOS-2; however, the child is given only one module based on his or her expressive language level and chronological age. The ADOS-2 can be administered to children as young as 12 months through childhood. As with the ADI-R, the ADOS-2 requires specific training and validation procedures. Each module in the ADOS-2 takes approximately 40 – 60 minutes to administer.

In addition to the various tools listed here, the DSM-5 also provides standardized criteria that can assist with the diagnosis of autism, focusing on deficits in social communication, social interaction, and restricted, repetitive patterns of behavior.

Other Diagnostic Tools

Additional assessments deemed critical in the diagnostic protocol were speech-language evaluations, cognitive and adaptive skills assessments, sensorimotor skill assessments, as well as neuropsychological, behavioral, and academic assessments. Regarding these other disciplines, evaluators or test administrators in these areas must have experience and expertise in treating children with autism. These include speech/language pathologists, psychologists, occupational therapists, teachers, and behavior analysts. Evaluating the family's functioning and ability to understand and/or deal with the diagnosis are also seen as critical pieces of the diagnostic puzzle.

A new study has been published that found most toddlers who screen positive for autism do not receive referrals for early intervention and additional testing (Wallis, Guthrie, Bennett, Gerdes, Levy, Mandell, & Miller, 2020). This study looked at 2,882 children who screened positive on the M-CHAT-F. Although the American Academy of Pediatrics recommends that all doctors refer children who score positive on the screening tool for further evaluation, this study found that only 4% of these children were referred for additional testing. Other studies have found similar results showing a low percentage of children who screened positive on the initial screening tool being referred to additional follow-up tests and services (King, Tandon, Macias, Healy, Duncan, Swigonski, et al., 2010; Windham et al., 2014, Hyman, Levy, & Myers, 2020).

What does this mean to us? We need to continue advocating for parents who have concerns about their child's development at an early age. We also need to continue to research decision-making processes of providers in response to a positive screening for autism so children who receive positive results can begin their path to earlier treatment and intervention possibilities.

Section F: The Prevalence of Autism

When autism first caught the eye of the scientific community, it was considered a rare, albeit severe, disorder. Noting two essential criteria, "a profound lack of affective contact" and "repetitive, ritualistic behavior, which must be of an elaborate kind," autism was considered to be a very remarkable disorder (Eisenberg & Kanner, 1956). While no major epidemiological studies were completed during this era, most professional estimates regarding the disorder placed its prevalence near 1-2 children per 10,000. Using the same diagnostic criteria mentioned above, Lotter (1966) conducted an epidemiological study that placed prevalence at 0.45 per 1,000 individuals.

Several more studies conducted in the following years yielded similar low prevalence rates. However, when the third edition of the Diagnostic and Statistical Manual of Mental Disorders was published, new diagnostic criteria were introduced, which were then refined in the 1987 version of the manual. Based on criteria from the DSM-III and the DSM-III-R, at least 12 notable epidemiological studies examining the prevalence of autistic disorders were conducted between 1983 and 1997.

Prevalence rates for these studies ranged from 0.25 cases per 1,000 (Ritvo, et al., 1989) to 1.60 per 1,000 (Ishi & Takahashi, 1983). Between 1996 and 1998, at least seven other widely read studies were conducted, using diagnostic criteria found in the International Classification of Diseases, 10th edition (ICD-10). Within these studies, prevalence rates ranged from 0.54 cases of autism per 1,000 (Fombonne, et al., 1997) to six cases per 1,000 (Kadesjö, Gillberg, & Hagberg, 1999).

Citing many of the above studies, the conducted a very large-scale epidemiological study of autism prevalence in Brick Township, New Jersey in 1998. The study utilized diagnostic criteria from the DSM-IV for autism spectrum disorders. The results of this study indicated a prevalence of autistic disorder at 4.0 cases per 1,000 for children aged 3-10 years (Centers for Disease Control and Prevention, 2000). The overall rate for children of the same age who met the criteria for autistic disorder, as defined in DSM-IV, and other spectrum disorders (ASD) was 6.7 cases per 1,000 (Centers for Disease Control and Prevention, 2000).

The Brick Township study was the first, large-scale contemporary prevalence study in the United States that used very intensive identification methods. It yielded results similar to those found in studies conducted abroad during the same time period. Because of this, it has been considered for several years

to be a hallmark study on autism prevalence, with its results frequently used in a wide variety of settings to support the notion that autism is indeed a disorder worthy of the public's close attention.

In February of 2007, the CDC announced the results of its first multi-community prevalence study, based on information collected from the Autism and Developmental Disabilities Monitoring (ADDM) Network during the reporting year of 2002. This study reported the results of data collected across 14 different sites spanning the United States. The study examined the records of eight-year-old children (because most individuals with ASD have been identified by that time). It concluded that autism's prevalence was (on average) around 6.6 - 6.7 per 1,000 eight-year-olds, or that approximately one in 150 children were on the autistic spectrum (Centers for Disease Control and Prevention, 2007).

Over several decades, the prevalence of autism has continued to increase (see Figure 2.9). Most recently and perhaps the most significant prevalence figures yet are the ones produced by the CDC which covered the year 2020. In March 2023, the CDC released in its Morbidity and Mortality Weekly Report the *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020.* Recent estimates reveal that one in 36 children aged eight years was estimated to have ASD (Centers for Disease Control and Prevention, 2023).

Identified Prevalence of Autism Spectrum Disorder 2000 - 2020

Birth Year	*Year data was collected*	*Year data was reported*	*Number of sites*	*Prevalence per 1,000 8-year-old children*	*Autism Rate*
1992	*2000*	*2007*	*6*	*6.7*	*1 in 150*
1994	*2002*	*2007*	*14*	*6.6*	*1 in 152*
1996	*2004**	*2009*	*8*	*8*	*1 in 125*
1998	*2006*	*2009*	*11*	*9*	*1 in 110*
2000	*2008*	*2012*	*14*	*11.3*	*1 in 88*
2002	*2010*	*2014*	*11*	*14.7*	*1 in 68*
2004	*2012*	*2018***	*11*	*14.5*	*1 in 69*
2006	*2014*	*2018*	*11*	*16.8*	*1 in 59*
2008	*2016*	*2020*	*11*	*18.5*	*1 in 54*
2010	*2018*	*2021*	*11*	*23*	*1 in 44*
2012	*2020*	*2023*	*11*	*27.6*	*1 in 36*

* A smaller-scale study was conducted in 2004. Only sites that had the time and resources to collect data were included. Caution is needed when comparing the results from 2004 to other surveillance years.

** The 2016 report was corrected and republished in 2018.

Figure 2.9

Today, autism is recognized in many circles as an "epidemic" or "crisis" that is directly impacting the lives of many millions of Americans. Thanks to devoted parents, committed researchers, and nothing short of a media frenzy, autism has become the subject of close scrutiny, as well as a great deal of hype.

What is important to understand is this: while the rates found in the studies have increased as the years have passed, many believe they reflect an increase in *diagnoses* of ASD, as opposed to an increase in actual prevalence.

It can be argued that we have become much more skilled at identifying individuals who have autism spectrum disorder. With awareness of ASD increasing globally, deeper knowledge has undoubtedly made its way to physicians and other diagnosticians who may not have been as familiar with ASD 20 years ago. In other words, the perceived increase in prevalence could be attributed, in part, to better diagnostic tools and a greater sense of awareness.

The above arguments noted, many of the professionals conducting research on the neurobiological elements of autism, as well as many diagnosticians, continue to contend that they are simply seeing more children with autism than ever before. Science will eventually unravel the mysteries surrounding its causes and prevalence. Until then, it is safe to say that autism and related spectrum disorders are having quite a significant impact on a global scale.

Today, it is common for classroom teachers to have some experience with individuals with ASD. Likewise, it is common to encounter people with family members or friends who have been touched by the disorder in one way or another. Autism knows no ethnic, cultural, racial, economic, or gender boundaries. It is a global disorder – which is why it has become increasingly important for us to identify appropriate and effective interventions for children with ASD.

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