CHAPTER 7: AUTISM SPECTRUM DISORDERS

Autism spectrum disorder (ASD) is a developmental disability that impacts a child's communication skills, social interaction, and behavior. There is a great deal of variation in how children with autism are affected by their disability, thus it is termed a spectrum disorder. While some children are severely impacted, others are not. It is important to note that not all children with ASD will need special education in order to learn and be successful in school.

For children who qualify for special education, IDEA defines autism in this way:

> Autism means 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 movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. (IDEA, 2007)

HISTORY OF AUTISM

The word autism comes from the Greek word autos, which means self (NASET, 2024).The first recorded use of this word as a diagnostic term was in 1908 when it was used to describe a group of patients who had been diagnosed with schizophrenia. These subjects were very self-absorbed and consequently, medical professionals decided to label this condition autism to highlight the self-focused component of the disorder. The next major reference to autism came in 1943 when Leo Kanner, an American child psychiatrist, published a paper on his work with 11 children who had a condition that he called "early infantile autism." These children all had above average intelligence but demonstrated a strong desire to be alone as well as an insistence on sameness. A year later, Hans Asperger, a German scientist, described his work with a similar group of children. These boys were also very intelligent but displayed obsessive interests and had difficulty with social interaction. The form of autism described by Kanner and Asperger eventually came to be known as Asperger's syndrome. Clearly autism was gaining some attention from doctors and scientists in the early 20th century, but it was still a fairly unknown diagnosis and little was understood about the condition (National Autistic Society, 2012).

Unfortunately, in the late 1960s Bruno Bettelheim advanced the theory that autism was caused by mothers, accusing them of not providing their children with enough love. He even called them "refrigerator mothers" because of their supposedly cold affect toward their children (Cohmer, 2014). This incorrect theory took scientists in the wrong direction for a long time in their search to better understand autism . It wasn't until the late 1970s that researchers began to consider the role of genetics in autism and to identify brain differences in children with autism. Then, in 1998 a study published in a prominent medical journal linked autism to the measles-mumps-rubella (MMR) vaccine, once again taking researchers and public opinion in the

wrong direction. This study was quickly debunked, and subsequent research has demonstrated no link between autism and vaccines. Unfortunately, more than 20 years later a segment of the public is still fearful of a potential connection between vaccines and autism (Children's Hospital of Philadelphia, 2024).

Fortunately, positive developments were also occurring during this time period. One such development occurred in 1987 when Ivar Lovaas published a study showing that intensive behavior therapy, based on the principles of applied behavior analysis (ABA), had profoundly beneficial effects on the learning outcomes of children with autism. Lovaas' work gave parents hope that these improved outcomes were possible for their children as well (Herman, 2019). Today, ABA continues to be an evidenced-based best practice for teaching children with autism. Additionally, IDEA created a separate category for autism in 1991. Up until this point, children with autism were typically being served under other IDEA categories such as intellectual disability, speech and language disorder, and emotional/behavior disorder (IDEA, 2024).

The next major change came in 2013, when the American Psychiatric Association published the fifth edition of their Diagnostic and Statistical Manual of Mental Disorders (DSM-V). In this edition, the diagnostic category of autism was revised to combine all subcategories, including Asperger's syndrome, under a single umbrella diagnosis of autism spectrum disorder (ASD). The two main focus characteristics under the DSM-V for a diagnosis of ASD are: 1. Impaired social communication and/or interaction and 2. Restricted and/or repetitive behaviors. Children who have impaired communication but do not demonstrate restricted or repetitive behaviors now fall under the newly created category of social pragmatic communication disorder (Autism Speaks, 2022).

SYMPTOMS OF AUTISM

A symptom that is often apparent early on in children with autism is a difficulty with joint attention. For example, a child may not follow another person's gaze or pointed finger to focus on something of interest to the other person. Likewise, the child may not utilize opportunities to draw someone else's attention to the items that they themselves are interested in. This may seem like a small thing, but joint attention is an important precursor for learning and communication. Babies begin this dance of coordinating attention between their caregivers and the objects and events in their environment already at 6 to 9 months of age (Before their first words, 2015; NICHD, 2017).

Children with autism also have trouble with social interactions. It is possible that the struggles these children have with joint attention are connected to their difficulties in understanding and relating to others. Some children with autism may be very interested in those around them, but not know how to interact with them. For example, they may not understand how to get someone's attention, how to join a group, or how to participate in pretend

play. Others may appear to want to be alone or may seem unaware of those around them (CDC, 2024).

Communication skills for children with autism can also be adversely affected. Some children with autism do not speak. Others only repeat the words and phrases they hear, but do not generate typical language. Some prefer to talk about a limit range of topics that are of special interest to themselves such as trains or dinosaurs. Those with more typical language skills may still have difficulty identifying and talking about their feelings and expressing their needs. Many also struggle to understand abstract concepts and figurative language (CDC, 2024; NASET, 2024).

Additionally, children with autism may have strong reactions to various types of sensory input such as particular sounds, smells, or tastes. They may have trouble making eye contact, finding the experience to be too visually intense. Some also do not like to be touched by others and may even have preferred not to be cuddled as babies. They may have trouble adapting to changes in routine and prefer that activities always occur in the same manner or in the same sequence. Their play may have an unusual sensory or repetitive component, such as smelling or licking unusual items or performing certain actions repeatedly, such as spinning the wheels on a toy car or lining up their toys rather than playing with them in a more typical manner (CDC, 2024; NASET, 2024).

DEFINITION

The DSM-V criteria for ASD are as follows:

To meet diagnostic criteria for ASD according to DSM-V, a child must have persistent deficits in each of three areas of social communication and interaction (see A.1. through A.3. below) plus at least two of four types of restricted, repetitive behaviors (see B.1. through B.4. below). Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

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):

   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.

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):

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).

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. (DSM-5, 2013)

PREVALENCE

The rate at which ASD is being diagnosed has increased dramatically in the past twenty years. In 2000, autism was diagnosed in approximately 1 out of every 150 children. In 2020, it was diagnosed at a rate of about 1 in every 36 children. Autism is found at similar levels across all racial, ethnic, and socioeconomic groups; however, boys are 4 times more likely to be

diagnosed with ASD than girls (CDC, 2024). This increased prevalence may be due, in part, to changes in the criteria for the diagnosis. It may also be the result of greater public recognition of the characteristics of autism. In addition, increased recognition has likely led to some children who might have only received a diagnosis of intellectual disability in the past, now correctly being identified as also having autism (NASET, 2024).

CAUSES

While current research shows a genetic connection for autism and has identified neurological differences in the brains of people with autism, no single specific cause of autism has been identified. However, given the variation in both symptoms and levels of severity of the condition, it is likely that autism is the result of a combination of factors. Studies involving siblings provide support for a genetic component to autism. For example, if one child in the family is diagnosed with autism, the chance that a younger sibling will also receive an autism diagnosis is 15%. Studies of twins revealed that if one twin has autism, the chance of the other twin also having autism is much higher when the two are identical twins rather than fraternal twins. Overall, there is strong evidence for an inherited component

and 40-80% of the risk factors for autism are believed to be genetic. It also appears that genetic variations to multiple genes are involved rather than being found on only one specific gene. Interestingly, even though research has been able to identify several genes that are linked to autism, not all people with autism have the same combinations of these genetic differences. (Medline Plus, 2021; (NASET, 2024).

Research has also demonstrated several areas of structural difference between the brains of children with autism and their typically developing peers. These research studies have shown that the neuron fibers connecting various regions of the brain are altered or underdeveloped in children with autism. This includes the corpus callosum, which connects the left and right hemispheres of the brain. This disruption to the structural integrity of the corpus collosum is more prevalent in boys with autism than in girls with autism. While current research has shown that this alteration to the white matter of the brain is strongly correlated with an increased likelihood of developing autism, more research is needed to explore the cause of this disruption and its effect on the symptoms of autism. However, some researchers feel that understanding this disruption in neural connectivity is a key to understanding autism (Ha et al., 2015; Askham, 2020).

Size differences in the structures of the brain have also been identified. While the hippocampus, which acts as a storehouse for memories, is often enlarged, the cerebellum is generally decreased in size for children with autism. The cerebellum is mainly responsible for coordinating motor movement, but also plays a role in learning and social interaction. Overall, though, infants and young children with autism generally demonstrate faster brain growth than typically developing controls. Following a faster expansion of the surface area of the brain's cortex during the first year of life, the brain volume of children with autism continues to grow at a swifter rate during the second year of life. This accelerated growth appears to be mainly in the

frontal and temporal lobes. Excess spinal fluid is also produced during this time of rapid growth. Researchers found that those children with the greatest amount of extra spinal fluid also had more intense symptoms of autism than those with lesser amounts of extra fluid (Ha et al., 2015; Askham, 2020).

Clearly this is an area where continued research is needed. Learning more about the underlying biology of autism should help us to develop better treatments for individuals with autism. It is even possible that subtypes of autism will be identified based on identifiable changes in genetic makeup or in brain structures and this will help us differentiate treatments based on these subtypes. Additionally, identifying these characteristics may help us in our quest to recognize autism earlier and to determine the optimal time for interventions to be implemented (Askham, 2020).

EDUCATIONAL DECISIONS

Students with ASD usually require a school program that implements a structured, direct approach to teaching. As mentioned earlier, applied behavior analysis (ABA) is a research-based method that has been shown to

be very effective for teaching children with autism. ABA is highly structured and emphasizes the use of positive reinforcement for learning and other desired behaviors. ABA can be used to teach academic skills as well as adaptive behavior and functional skills. Lessons are structured around clearly identified outcomes and incorporate a high proportion of active student responding. Teachers provide reinforcement and corrective feedback in a timely manner to maximize learning. ABA is known for an emphasis on data collection and instructional decisions are based on a continuous assessment of progress. ABA based methods can be used when teaching groups as well as for one-to-one instruction (Autism Speaks, 2024).

Many students with autism have communication deficits. Depending on the severity of the deficit, the student may need to be taught another way to communicate. One research-supported method for addressing this need that is based on ABA is the PECS®: Picture Exchange Communication System. The purpose of PECS is to help the student develop functional communication. With this system, a child is taught to communicate using picture cards. The protocol for teaching a child to communicate using PECS follows six very scripted phases. In Phase I, the child learns to request a desired item by handing the corresponding picture card to a communication partner who then gives the requested item to the child. Once able to complete this simple exchange unassisted, the child moves to Phase II. In this phase, the child learns to generalize this communication skill by practicing it with different people and in different places. In Phase III, the number of picture cards is increased, and the child is taught to discriminate between two or more picture card options. In the final phases, the child is taught to create sentences, to respond to questions, and to use descriptors such as color, size, and number. Research on PECS has mainly focused on Phases I through III and has demonstrated positive effects for developing functional communication skills (Ganz & Simpson, 2019).

PECS is one possible augmentative and alternative communication (AAC) method. Other methods include manual sign language and the use of speech-generating devices. Manual sign language uses the hands and fingers to communicate. This system has traditionally been used by the deaf but has also been used effectively with children who have communication deficits. Speech-generating devices utilize computer programs that provide an audible response when the child presses one or more buttons. These methods are intended to compensate for communication deficits and can be used in addition to speech to augment the effectiveness of communication or as an alternative in place of speech. One common concern about teaching a child to use an AAC method is that it will adversely affect speech development. Research to address this concern has shown that none of these AAC methods impedes speech development and, in some cases, even advances the development of spoken speech (Ganz & Simpson, 2019).

Another research-based method for teaching children with autism that was developed from ABA is Pivotal Response Teaching (PRT). This method is based on the assumption that certain behaviors, once learned, will lead to positive adaptation of untrained behaviors and use in untrained settings. Examples of pivotal behaviors include functional communication skills, the ability to make choices, and self-management skills. Teaching pivotal behaviors should increase the efficiency of learning by fostering generalization and shortening the intervention time. Typically, PRT is used in a one-to-one teaching situation and implemented in the context of child-preferred activities (Ganz & Simpson, 2019; Cooper et al., 2020).

Another effective method that can be used to teach complex skills to children with autism is task analysis. This involves teaching a task by breaking it down into smaller steps. Often, a skill is comprised of individual component behaviors that are performed in a consistent sequence known as a behavior chain. Many independent living skills such as cooking, cleaning,

and doing laundry, lend themselves well to being taught using task analysis. Determining how many steps to break a task into depends on the characteristics of the learner. Likewise, determining where to start teaching the sequence of behaviors in the chain is also dependent on the characteristics of the learner. Task analysis is discussed in greater detail in a later chapter (Cooper et al., 2020).

Children with autism may struggle with transitions and may need a warning that a switch in activity is coming. They may also benefit from a routine to follow during a transition. These children can be easily upset by changes in schedule. A predictable routine and a visual schedule of that routine can be helpful for these children. Teachers can also work on normalizing the unpredictable by incorporating an icon such as a question mark into the visual schedule to indicate a change in the routine. It is important to practice these changes in routine regularly so that change because a normal part of the routine (NASET, 2024).

Many children with autism have a very literal understanding of language. It is important for teachers to be aware of this. Use of simple, concrete language will be most effective with these learners. Similes and metaphors can be specifically taught as part of the academic curriculum; however, teachers should avoid the use of sarcasm in their general speech. Because of the impact autism has on language skills, teachers should provide visual supports whenever possible. However, this does need to be balanced with the importance of avoiding overstimulation and minimizing distractions in the classroom. Teachers should prioritize the visuals that are the most functional for their learners. Many learners with autism will also benefit from the option of moving to a calm, quiet space in which to work (NASET, 2024).

Children with autism can greatly differ from each other in terms of their capabilities and their behavior. While we are gaining a better understanding

of autism, the field is quite young and we still have much to learn. Teachers will need to remain aware of new developments in our understanding of this disorder and adjust their teaching accordingly.

CHAPTER 7: SOURCES

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