NASET's Educating Children with Severe Disabilities Series

Overview of Autism Spectrum Disorders

Autism spectrum disorder (ASD) is a developmental disability caused by differences in the brain. Some people with ASD have a known difference, such as a genetic condition. Other causes are not yet known. Scientists believe there are multiple causes of ASD that act together to change the most common ways people develop. We still have much to learn about these causes and how they impact people with ASD.

People with ASD may behave, communicate, interact, and learn in ways that are different from most other people. There is often nothing about how they look that sets them apart from other people. The abilities of people with ASD can vary significantly. For example, some people with ASD may have advanced conversation skills whereas others may be nonverbal. Some people with ASD need a lot of help in their daily lives; others can work and live with little to no support.

ASD begins before the age of 3 years and can last throughout a person's life, although symptoms may improve over time. Some children show ASD symptoms within the first 12 months of life. In others, symptoms may not show up until 24 months of age or later. Some children with ASD gain new skills and meet developmental milestones until around 18 to 24 months of age, and then they stop gaining new skills or lose the skills they once had.

Parents are usually the first to notice unusual behaviors in their child. In some cases, the baby seemed "different" from birth, unresponsive to people or focusing intently on one item for long periods of time. The first signs of an ASD can also appear in children who seem to have been developing normally. When an engaging, babbling toddler suddenly becomes silent, withdrawn, self-abusive, or indifferent to social overtures, something is wrong. Research has shown that parents are usually correct about noticing developmental problems, although they may not realize the specific nature or degree of the problem.

The pervasive developmental disorders, or autism spectrum disorders, range from a severe form, called autistic disorder, to a milder form, Asperger syndrome. If a child has symptoms of either of these disorders, but does not meet the specific criteria for either, the diagnosis is called pervasive developmental disorder not otherwise specified (PDD-NOS). Other rare, very severe disorders that are included in the autism spectrum disorders are Rett syndrome and childhood disintegrative disorder. This brochure will focus on classic autism, PDD-NOS, and Asperger syndrome, with brief descriptions of Rett syndrome and childhood disintegrative disorder on the following page.

What Are the Autism Spectrum Disorders?

The autism spectrum disorders are more common in the pediatric population than are some better known disorders such as diabetes, spinal bifida, or Down syndrome. Prevalence studies have been done in several states and also in the United Kingdom, Europe, and Asia. Prevalence estimates range from 2 to 6 per 1,000 children. This wide range of prevalence points to a need for earlier and more accurate screening for the symptoms of ASD. The earlier the disorder is diagnosed, the sooner the child can be helped through treatment interventions. Pediatricians, family physicians, daycare providers, professionals, and parents may initially dismiss signs of ASD, optimistically thinking the child is just a little slow and will "catch up."

Although early intervention has a dramatic impact on reducing symptoms and increasing a child's ability to grow and learn new skills, it is estimated that *only 50 percent of children are diagnosed before kindergarten*.

All children with ASD demonstrate deficits in 1) social interaction, 2) verbal and nonverbal communication, and 3) repetitive behaviors or interests. In addition, they will often have unusual responses to sensory experiences, such as certain sounds or the way objects look. Each of these symptoms runs the gamut from mild to severe. They will present in each individual child differently. For instance, a child may have little trouble learning to read but exhibit extremely poor social interaction. Each child will display communication, social, and behavioral patterns that are individual but fit into the overall diagnosis of ASD.

Children with ASD do not follow the typical patterns of child development. In some children, hints of future problems may be apparent from birth. In most cases, the problems in communication and social skills become more noticeable as the child lags further behind other children the same age. Some other children start off well enough. Oftentimes between 12 and 36 months old, the differences in the way they react to people and other unusual behaviors become apparent. Some parents report the change as being sudden, and that their children start to reject people, act strangely, and lose language and social skills they had previously acquired. In other cases, there is a plateau, or leveling, of progress so that the difference between the child with autism and other children the same age becomes more noticeable.

ASD is defined by a certain set of behaviors that can range from the very mild to the severe. The following possible indicators of ASD were identified on the Public Health Training Network Webcast, Autism Among Us.

POSSIBLE INDICATORS OF AUTISM SPECTRUM DISORDERS

- Does not babble, point, or make meaningful gestures by 1 year of age
- Does not speak one word by 16 months
- Does not combine two words by 2 years
- Does not respond to name
- Loses language or social skills

SOME OTHER INDICATORS

- Poor eye contact
- Doesn't seem to know how to play with toys
- Excessively lines up toys or other objects
- Is attached to one particular toy or object
- Doesn't smile
- At times seems to be hearing impaired

SOCIAL SYMPTOMS

From the start, typically developing infants are social beings. Early in life, they gaze at people, turn toward voices, grasp a finger, and even smile.

In contrast, most children with ASD seem to have tremendous difficulty learning to engage in the give-and-take of everyday human interaction. Even in the first few months of life, many do not interact and they avoid eye contact. They seem indifferent to other people, and often seem to prefer being alone. They may resist attention or passively accept hugs and cuddling. Later, they seldom seek comfort or respond to parents' displays of anger or affection in a typical way. Research has suggested that although children with ASD are attached to their parents, their expression of this attachment is unusual and difficult to "read." To parents, it may seem as if their child is not attached at all.

Parents who looked forward to the joys of cuddling, teaching, and playing with their child may feel crushed by this lack of the expected and typical attachment behavior.

Children with ASD also are slower in learning to interpret what others are thinking and feeling. Subtle social cues—whether a smile, a wink, or a grimace—may have little meaning. To a child who misses these cues, "Come here" always means the same thing, whether the speaker is smiling and extending her arms for a hug or frowning and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world may seem bewildering. To compound the problem, people with ASD have difficulty seeing things from another person's perspective. Most 5-year-olds understand that other people have different information, feelings, and goals than they have. A person with ASD may lack such understanding. This inability leaves them unable to predict or understand other people's actions.

Although not universal, it is common for people with ASD also to have difficulty regulating their emotions. This can take the form of "immature" behavior such as crying in class or verbal outbursts that seem inappropriate to those around them. The individual with ASD might also be disruptive and physically aggressive at times, making social relationships still more difficult. They have a tendency to "lose control," particularly when they're in a strange or overwhelming environment, or when angry and frustrated. They may at times break things, attack others, or hurt themselves. In their frustration, some bang their heads, pull their hair, or bite their arms.

COMMUNICATION DIFFICULTIES

By age 3, most children have passed predictable milestones on the path to learning language; one of the earliest is babbling. By the first birthday, a typical toddler says words, turns when he hears his name, points when he wants a toy, and when offered something distasteful, makes it clear that the answer is "no."

Some children diagnosed with ASD remain mute throughout their lives. Some infants who later show signs of ASD coo and babble during the first few months of life, but they soon stop. Others may be delayed, developing language as late as age 5 to 9. Some children may learn to use communication systems such as pictures or sign language.

Those who do speak often use language in unusual ways. They seem unable to combine words into meaningful sentences. Some speak only single words, while others repeat the same phrase over and over. Some ASD children parrot what they hear, a condition called *echolalia*. Although many children with no ASD go through a stage where they repeat what they hear, it normally passes by the time they are 3.

Some children only mildly affected may exhibit slight delays in language, or even seem to have precocious language and unusually large vocabularies, but have great difficulty in sustaining a conversation. The "give and take" of normal conversation is hard for them, although they often carry on a monologue on a favorite subject, giving no one else an opportunity to comment. Another difficulty is often the inability to understand body language, tone of voice, or "phrases of speech." They might interpret a sarcastic expression such as "Oh, that's just great" as meaning it really IS great.

While it can be hard to understand what ASD children are saying, their body language is also difficult to understand. Facial expressions, movements, and gestures rarely match what they are saying. Also, their tone of voice fails to reflect their feelings. A high-pitched, sing-song, or flat, robot-like voice is common. Some children with relatively good language skills speak like little adults, failing to pick up on the "kid-speak" that is common in their peers.

Without meaningful gestures or the language to ask for things, people with ASD are at a loss to let others know what they need. As a result, they may simply scream or grab what they want. Until they are taught better ways to express their needs, ASD children do whatever they can to get through to others. As people with ASD grow up, they can become increasingly aware of their difficulties in understanding others and in being understood. As a result they may become anxious or depressed.

Repetitive Behaviors

Although children with ASD usually appear physically normal and have good muscle control, odd repetitive motions may set them off from other children. These behaviors might be extreme and highly apparent or more subtle. Some children and older individuals spend a lot of time repeatedly flapping their arms or walking on their toes. Some suddenly freeze in position.

As children, they might spend hours lining up their cars and trains in a certain way, rather than using them for pretend play. If someone accidentally moves one of the toys, the child may be tremendously upset. ASD children need, and demand, absolute consistency in their environment. A slight change in any routine—in mealtimes, dressing, taking a bath, going to school at a certain time and by the same route—can be extremely disturbing. Perhaps order and sameness lend some stability in a world of confusion.

Repetitive behavior sometimes takes the form of a persistent, intense preoccupation. For example, the child might be obsessed with learning all about vacuum cleaners, train schedules, or lighthouses. Often there is great interest in numbers, symbols, or science topics.

PROBLEMS THAT MAY ACCOMPANY ASD

Sensory problems. When children's perceptions are accurate, they can learn from what they see, feel, or hear. On the other hand, if sensory information is faulty, the child's experiences of the world can be confusing. Many ASD children are highly attuned or even painfully sensitive to certain sounds, textures, tastes, and smells. Some children find the feel of clothes touching their skin almost unbearable. Some sounds—a vacuum cleaner, a ringing telephone, a sudden storm, even the sound of waves lapping the shoreline—will cause these children to cover their ears and scream. In ASD, the brain seems unable to balance the senses appropriately. Some ASD children are oblivious to extreme cold or pain. An ASD child may fall and break an arm, yet never cry. Another may bash his head against a wall and not wince, but a light touch may make the child scream with alarm.

Intellectual Disability. Many children with ASD have some degree of mental impairment. When tested, some areas of ability may be normal, while others may be especially weak. For example, a child with ASD may do well on the parts of the test that measure visual skills but earn low scores on the language subtests.

Seizures. One in four children with ASD develops seizures, often starting either in early childhood or adolescence.4 Seizures, caused by abnormal electrical activity in the brain, can produce a temporary loss of consciousness (a "blackout"), a body convulsion, unusual movements, or staring spells. Sometimes a contributing factor is a lack of sleep or a high fever. An EEG (electroencephalogram—recording of the electric currents developed in the brain by means of electrodes applied to the scalp) can help confirm the seizure's presence. In most cases, seizures can be controlled by a number of medicines called "anticonvulsants." The dosage of the medication is adjusted carefully so that the least possible amount of medication will be used to be effective.

Fragile X syndrome. This disorder is the most common inherited form of mental retardation. It was so named because one part of the X chromosome has a defective piece that appears pinched and fragile when under a microscope. Fragile X syndrome affects about two to five percent of people with ASD. It is important to have a child with ASD checked for Fragile X, especially if the parents are considering having another child. For an unknown reason, if a child with ASD also has Fragile X, there is a one-in-two chance that boys born to the same parents will have the syndrome.5 Other members of the family who may be contemplating having a child may also wish to be checked for the syndrome.

Tuberous Sclerosis. Tuberous sclerosis is a rare genetic disorder that causes benign tumors to grow in the brain as well as in other vital organs. It has a consistently strong association with ASD. One to 4 percent of people with ASD also have tuberous sclerosis.

The Diagnosis of Autism Spectrum Disorders

Although there are many concerns about labeling a young child with an ASD, the earlier the diagnosis of ASD is made, the earlier needed interventions can begin. Evidence over the last 15 years indicates that intensive early intervention in *optimal educational settings for at least 2 years during the preschool years* results in improved outcomes in most young children with ASD. In evaluating a child, clinicians rely on behavioral characteristics to make a diagnosis. Some of the characteristic behaviors of ASD may be apparent in the first few months of a child's life, or they may appear at any time during the early years. For the diagnosis, problems in at least one of the areas of communication, socialization, or restricted behavior must be present before the age of 3. The diagnosis requires a two-stage process. The first stage involves developmental screening during "well child" check-ups; the second stage entails a comprehensive evaluation by a multidisciplinary team.