Autism Spectrum Disorder (ASD)

What is autism spectrum disorder (ASD)?

- Autism spectrum disorder (ASD) is a group of developmental disabilities caused by a problem with the brain. Children with ASD have trouble in 3 core areas of their development. They have
 - Language difficulties, especially an impaired efficacy of communication
 - Impaired social interactions
 - Restricted interests or behaviors that are repeated often (called *stereotyped* behaviors)
- Autism spectrum disorder is present from birth but cannot be diagnosed in the first few months until the child further develops. Screening for early identification and treatment of ASD is progressing, but the age of diagnosis can still vary depending on the child's characteristics.

How common is it?

- Recent statistics estimate that as many as 1 in 68 children in the United States may be diagnosed as having ASD.
- Approximately 24,000 children are diagnosed as having ASD each year, with an estimate of 500,000 children, adolescents, and young adults birth through 21 years with ASD.
- Autism spectrum disorder occurs more frequently in boys than in girls.
- There is no evidence to suggest or to support the notion that vaccines cause ASD.

What are some common characteristics of children who have ASD or of ASD as children present with it?

- Most children with ASD do not have physical features that would suggest differences from other children, but they may communicate, interact, behave, and learn in ways that are different.
- These children may have problems with social, emotional, and communication skills.
- Children with ASD might
 - Avoid eye contact.
 - Fail to respond to their names when called.
 - Fail to look in the direction of interesting objects pointed out to them and fail to point to those objects themselves (this deficit is called a *joint-attention deficit*).

- Move away from others or not interact with them.
- Echo words or phrases in place of conversational language (this repetition is called *echolalia*).
- Repeat actions such as rocking, hand flapping, and handling an object in the same way.
- Regress in their development or lose skills they once had, such as language (usually before 2 years [ie, 24 months] of age).
- Have difficulty communicating and expressing their own needs.
- Become upset when things change or when it is time to transition to a new activity.
- Have unusual reactions to sensory stimuli (eg, smells, tastes, sounds, touches). These reactions can range from trying to block out the stimulus to not responding to pain or something that others find scary or dangerous.
- Prior to a child's diagnosis, parents/guardians and teachers and caregivers may observe signs of ASD. This child may
 - Play with toys in an unusual manner (eg, lining cars up, instead of driving them around).
 - Not have an interactive gaze.
 - Not match facial expression with eye contact.
 - Lack the alternating to-and-fro pattern of vocalizations between infant and parents/guardians that usually occurs at approximately 6 months of age (ie, an infant with ASD may vocalize without regard for the parent's/ guardian's speech).
 - Not turn to or acknowledge the voice of their parents/ guardians or teacher or caregiver.
 - Have disregard for vocalizations (eg, lack of response to name) yet keen awareness of environmental sounds.
 - Have delayed onset of babbling past 9 months of age.
 - Have decreased or absent use of pre-speech gestures (eg, waving, pointing, showing).
 - Not seem to be interested in social chatting.
 - Want to socialize with other children but have difficulty with interactive conversation and play.
- In addition, it is important to know that children with ASD
 - Can and do form emotional attachments, although there is often some impairment in these relationships.
 - Have characteristics and behaviors that often improve with intervention but do not outgrow and are not cured of an ASD.
 - Have uneven learning and cognitive skills.
 - May have some degree of intellectual disability. (About 50% have an intellectual disability.)

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- Often have difficulty with understanding instructions and can develop confusion and anxiety, resulting in a behavioral outburst that is misinterpreted as nonadherence or aggression.
- Come from families of all races and socioeconomic backgrounds.
- Often will require varying levels of support to maintain a home and job as they become adults.

Who might be on the treatment team?

The treatment team for a child with ASD should include a pediatrician/primary care provider in the medical home, and it may include a developmental-behavioral pediatrician, a pediatric neurologist, a child psychiatrist, a child psychologist, a speech-language therapist, a behavioral specialist, a special education teacher, and an occupational therapist.

What are some elements of a Care Plan for children with ASD?

- Most research supports intense behaviorally based intervention for symptoms of ASD using structured teaching and the principles of applied behavioral analysis.
- Speech-language therapy is the most common therapy provided for children with ASD, because speech is often delayed. Children with ASD need to learn how to communicate using language and nonverbal approaches. Speech-language therapists address deficits in joint attention as a first step in teaching oral language. They may also use picture exchange systems, signing, or typing as a bridge to oral communication with these children.
- *Occupational therapy* may help children learn self-help and manipulative skills as well as how to accept and respond more typically to sounds, smells, and touch.
- Children who are younger than 3 years (ie, 36 months) may receive their therapies through *early intervention* services. Early intervention is a system of services to support infants and toddlers with disabilities and their families.
- Children 36 months and older may receive special education and related services through the public schools. The behavioral and educational intervention is designed to help children with ASD succeed in school.

What adaptations may be needed?

Medications

- Medications may be used to help a child with ASD manage anxiety, obsessions, hyperactivity, irritability, or aggression.
- Talk with the child's parents/guardians about any medications that the child might be taking and what side effects might occur from them.
- All staff who will be administering medication should have medication administration training (see Chapter 6).

Dietary Considerations

- There are many unproven dietary treatments of ASD that may not necessarily be recommended or directed by the child's treatment team.
- Families of children with ASD may use gluten- and casein-free diets, medication to treat yeast infections, and vitamins, although no medical evidence supports their use at this time, and some may have significant side effects.
- Program staff should develop and discuss with families their policies about implementing special instructions that are not part of a medically recommended Care Plan. In general, any such instructions that a program is inclined to include for a child should be reviewed with his or her health care professional to be sure they do not pose risks of injury or illness for the child or staff.

Physical Environment and Other Considerations

- Classroom placement and teacher selection should be considered; choosing a supportive classroom environment is essential. The teacher or caregiver, other children in the group, and room layout should be selected so that all children can have their individual needs met.
- Structure helps children with ASD understand their surroundings and what is expected of them. Structure is a form of behavior management that helps children with ASD anticipate what is expected of them, be calmer, be less agitated, and be more successful with learning. Some helpful structure tools can be
 - Classroom organization and arrangement
 - Individual daily schedules
 - Individual work systems
 - Visual charts and schedules

Autism Spectrum Disorder (ASD) (continued)

- In addition, it is important to know that children with ASD
 - Can and do form emotional attachments. They need to be prepared for changes in staff or in the routine of the day.
 - Have characteristics and behaviors that often improve with intervention, but they continue to demonstrate symptoms of ASD.
 - Have uneven learning and cognitive skills.
 - May have some degree of intellectual disability (about 50% of these children have an intellectual disability).
 - Often have difficulty with understanding instructions, which leads to confusion and anxiety, resulting in a behavioral outburst that is misinterpreted as nonadherence or aggression.
 - Come from families of all races and socioeconomic backgrounds.
 - Often will require varying levels of support as they become adults.

What should be considered an emergency?

- Wandering is a major cause of death of people with ASD; almost half of all their families report it. Adequate adult support in a classroom and environmental modifications are needed if a child is known to wander.
- Behavioral dyscontrol requires that a behavioral plan be put into place for the safety of the child, staff, and peers.
- Seizures should also be considered (about 25% of people with ASD have seizures, most either before 24 months of age or in adolescence).
- Children with ASD may need extra time and supervision in a programmatic (facility) emergency such as a fire. This possibility should be taken into consideration in emergency planning.

What are some resources?

- American Academy of Pediatrics: https://shop.aap.org, 1-866-843-2271
 - Autism Spectrum Disorders: What Every Parent Needs to Know (book)
 - *Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians* (toolkit)
 - Caring for Our Children: National Health and Safety Performance Standards; Guidelines for Early Care and Education Programs, 3rd Edition (book), http://cfoc. nrckids.org/CFOC
 - Standard 2.2.0.6, Discipline Measures
 - Standard 2.2.0.8, Preventing Expulsions, Suspensions, and Other Limitations of Services
 - Standard 2.3.3.1, Parents'/Guardians' Provision of Information on Their Child's Health and Behavior
 - Understanding Autism Spectrum Disorder (brochure)
- Autism Science Foundation: http://autismsciencefoundation.org, 914/810-9100
- Autism Society: www.autism-society.org, 1-800-328-8476
- Autism Speaks: www.autismspeaks.org, 1-888-288-4762
- Centers for Disease Control and Prevention: "Learn the Signs, Act Early" (Web page), www.cdc.gov/actearly, 1-800-CDC-INFO (1-800-232-4636)
- First Signs Inc: www.firstsigns.org
- National Dissemination Center for Children with Disabilities, Center for Parent Information and Resources: www.parentcenterhub.org, 973/642-8100

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