FACTS About Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is the fastest-growing diagnosis among developmental disabilities in the United States. As an agency serving people with ASD and their families, the Office for People With Developmental Disabilities (OPWDD) must respond to this increase in ASD by not only providing quality supports and services that meet the needs of those in our care, but by offering much needed information, as well. This booklet, “Facts About Autism Spectrum Disorder” is one way OPWDD strives to educate people about the disorder and the services we provide to support people with ASD.

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What Is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that affects how a person acts and interacts with others, communicates and learns. Although knowledge of the possible causes and effective treatment of ASD is growing, to date, no cure exists. Research has suggested that both genetic and non-genetic (environmental) factors are associated with ASD. Symptoms are often noticed early in the child’s development.

In the past, Autism Spectrum Disorder was separated into different diagnoses that shared some common features. These diagnoses included autistic disorder, Asperger’s syndrome, pervasive developmental disorder and other disorders. Today, people who previously were diagnosed with one of the specific disorders are now included under a single category: Autism Spectrum Disorder. The word “spectrum” is important in understanding ASD because it refers to the wide range of behavioral signs, symptoms and degrees of severity that affect individuals. Each individual on the autism spectrum is just that – an individual. Their unique characteristics and needs are specific to them alone. Still, despite the range of symptoms, people with ASD often have similarities. They tend to have difficulty communicating and socializing; tend to be inclined toward unusual, repetitive behaviors; may be resistant to change; and may become over-focused on a very narrow interest. Many people with ASD also have different ways of learning, paying attention and reacting to different sensations and situations.

The symptoms of ASD are often evident early in life, usually before the age of three, although sometimes the disorder is not noticed or diagnosed until the child reaches school age or later. Individuals with ASD have difficulty making eye contact, reading other people’s faces, understanding nonverbal cues and gestures and interacting with others. They may engage in repetitive or unusual movements such as twirling, rocking, hand flapping or clapping, posturing or self-injurious behavior such as headbanging, slapping or biting themselves. Some individuals may develop speech slowly or may not talk at all, and some may refer to themselves by name instead of using “I” or “me.” Echolalia – the repeating of all or part of what is said to them by someone else – is another common speech pattern among individuals with ASD.

Some individuals with ASD may not have language or cognitive delays, but still have impairments in social behavior and communication and display unusual behaviors and interests. They may have unique speech patterns or speak in a monotone or rhythmic voice. Individuals with ASD often have difficulty engaging in conversations, reading social cues and developing social relationships. They may also find it difficult to express and classify their
feelings or to connect with and understand others’ experiences. It is not uncommon for individuals with ASD to develop an obsessive interest in one narrow, specific subject and to become “experts” on that subject. They can also be sensitive to different stimuli, such as sounds or noise level, the texture of certain materials or certain foods or types of food. They often follow strict schedules to feel in control.

Who Does Autism Spectrum Disorder Affect?

ASD occurs in all racial, ethnic and socioeconomic groups. Boys are about 4 times more likely to be affected than girls. Children who have a sibling or a parent with an ASD are at greater risk of having ASD. Scientists don’t yet know the exact causes of ASD, but research suggests that genes and environment may play an important role.

How Common Is Autism Spectrum Disorder?

In the past 20 years, ASD has been the fastest-growing diagnosis among the developmental disabilities in the United States. The Centers for Disease Control and Prevention (CDC) estimates that 1 in 59 children have ASD. At this rate, ASDs are more common than pediatric cancer, diabetes and AIDS combined.

The reasons for the increased prevalence rates of ASD are not entirely understood, but factors that may affect the prevalence rates include changes in the diagnostic criteria over time, increased awareness of the disorder, better surveillance methods, and/or a true increase in the frequency of ASD.

Does My Child Have Autism Spectrum Disorder? — Getting an Early Diagnosis

There is no genetic test for ASD, but there are prenatal tests for other conditions sometimes associated with ASD such as Fragile X syndrome or Rett syndrome. The fact that ASD is now known to have a genetic link offers hope that prenatal screening and diagnosis will be possible someday.

Research shows that when parents believe something is different with their child, they are often correct. Parents should gather information and seek guidance if they have concerns about their child’s development. Experience is showing that the earlier children can be diagnosed and begin treatment, the more effective treatment can be. All young children should be monitored to make sure they are reaching developmental milestones on time. The American Academy of Pediatrics (AAP) recommends that all children be
screened for indications of ASD at every well-child preventive care visit. Any concerns raised during surveillance should be addressed promptly with standardized developmental screening tests. In addition, screening tests should be administered regularly at the 9-, 18-, and 24- or 30-month visits.

Some “red flags” for atypical development in children include:

- As early as infancy, a baby with ASD may be unresponsive to people or focus on one item for long periods of time
- Lack of response to name
- Poor eye contact
- No smiles or warm expressions by 6 months or thereafter
- Lack of sharing interests or enjoyment
- No babbling by 1 month
- No words by 16 months
- Any loss of early speech or movement or social skills at any age
- Lack of pointing, reaching or waving gestures by 1 month
- Impaired ability to relate to peers
- Impaired ability to begin or maintain a conversation with others
- Disinterest in play or in play with others
- Repetitive or unusual use of language
- Restricted patterns of interest that are atypical in intensity or focus
- Obsession with certain subjects or repetitive movements with objects
- Rigid insistence on specific routines or rituals

In New York State, only appropriately licensed clinicians can make a formal diagnosis. However, a complete evaluation, prior to diagnosis, can involve assessment by several professionals (psychologist, speech therapist, neurologist, psychiatrist and others) working together as a multidisciplinary team. Because hearing problems may cause behaviors that could be mistaken for ASD, children with delayed speech development should also have their hearing tested. After a thorough evaluation, the team or the individual specialists usually meet with parents to explain the results and present a formal diagnosis.
Treatment Options

Helping someone with ASD to reach their full potential typically involves finding ways to increase their communication and social skills and diminish any inappropriate behaviors. Both educational and behavioral intervention, medication may help achieve these goals.

- Educational/Behavioral Interventions: Specially trained and certified practitioners known as Licensed Behavior Analysts (LBA) or Applied Behavior Analysts (ABA) can evaluate an individual to determine what may be contributing to problem behaviors and develop a plan to encourage the development of positive behaviors. Speech and language therapists can identify a child’s communication needs. Through targeted, intensive, skill-oriented training sessions, therapists can then help a child build social and language skills. Family education and counseling for the parents and siblings of children with ASD often help families cope with the challenges of living with a child who has ASD.

- Medications: Doctors may recommend medications to help reduce symptoms of anxiety, depression or attention deficit hyperactivity disorder (ADHD) which can accompany an ASD. Antipsychotic medications are sometimes used to treat agitation or severe behavioral problems. Seizures, if they are evident, can be treated with one or more of the anticonvulsant drugs. Stimulant drugs are sometimes used effectively to help decrease impulsivity and hyperactivity.

After the Diagnosis—Mapping a Course

After a family receives a diagnosis of ASD for their child, it is critical that they seek assistance as soon as possible. Research indicates that early intervention in an appropriate educational setting for at least two years around the pre-kindergarten years can result in considerable improvements for many children. Intervention programs focus on reducing inappropriate or undesirable behaviors and developing social, communication and cognitive skills. Accessing the best services for a child and understanding the entities that provide services to people of different ages and disabilities can be a challenging task. In New York State, services for children with ASD come primarily from the Department of Health (DOH), the State Education Department (SED) and the Office for People With Developmental Disabilities (OPWDD). Obtaining help in mapping a course through these systems is essential. The diagnosing physician is key to getting started. He or she should refer parents to the age-appropriate service systems (described below). The
professionals in these systems will work with parents to help plan treatment, intervention and educational services appropriate and most effective for their child.

**Services for Children**

**Early Intervention – Birth to Age three**

Children under the age of three years old can receive Early Intervention (EI) services provided by the New York State Department of Health through local public health offices. EI services provide screening and assign a case manager to create an Individualized Family Services Plan (IFSP) for the child and guide the family through the process of identifying and accessing the services needed. All EI services are individualized to the needs of the child and family. EI services include speech, physical and occupational therapy, psychological and social work services, special instruction, family support groups and assistive technology. EI services are provided at home or at the child’s daycare setting.

**Special Education and OPWDD Services – Ages three to 21**

If the child is three years of age or older, parents should contact their local public school district to arrange for special education services. These services are free and include comprehensive assessment of a child’s educational needs, speech and language therapy, occupational therapy, physical therapy, curriculum modifications, one-on-one or shared aides and other educational supports as needed. Prior to age five, special education is typically provided in a pre-school setting. After age five, it is provided in a public-school setting or in specialized schools that serve individuals with more significant educational needs.

It is important for parents or guardians to be active and involved in the special education process, and there are several important rights provided to them to ensure opportunities to be involved and heard. Parents have the right to: receive copies of the school district’s evaluation of their child; request that the school district pay for an independent educational evaluation (IEE) of their child by a qualified examiner who does not work for the school district; request that educational records be amended; and request mediation and impartial hearings to resolve any disagreements between them and the school district.

It is important to understand, however, that special education services are provided by local school districts to support individuals in their education. A student with ASD may also need services that are not educational in nature.
These students may qualify for services from OPWDD that range from respite (caregiver time-outs) and family training to crisis intervention, behavioral supports and Care Management. Parents should contact their local Developmental Disabilities Regional Office (DDRO) to begin the process of determining their child’s eligibility for OPWDD services.

From High School to Adulthood – Transition Services for Ages 15 - 21

As a child approaches adulthood and the end of their high school education, it is important for the student and parents to take part in a planning process that will prepare that child for a successful future. This process, referred to as transition planning, is intended to enable youth with disabilities to live, work and continue to learn in the community as adults – with supports if necessary.

The transition planning process begins with the school district conducting a vocational assessment of the student as early as age 12. This assessment, which is based on a review of school records, comprehensive assessments and parent and student interviews determines vocational skills, aptitudes and interests. The process, which begins in earnest and by law, at age 15, is intended to look beyond the traditional educational focus of the IEP. Students and parents should be actively involved in this process. As transition planning continues up to the student’s completion of school, it is important that the student’s transition goals be included in their IEP, with progress and updates noted annually.

Transition from school to work requires a collaborative effort among schools and adult workforce programs. While schools are responsible for providing transition planning and services, the New York State Education Department assists students with disabilities in the transition process in obtaining employment in integrated employment settings through their Adult Career and Continuing Education Services Vocational Rehabilitation program, better known as ACCES-VR. ACCES-VR counselors guide individuals through the vocational rehabilitation process to help them reach their employment goals. Services may include vocational assessment, vocational counseling, assistance with transition from school to work, job training and placement, job follow-up and other services to support employment goals.

By the time a student reaches adulthood, plans should be in place – based on their abilities and desires – to continue education or training, find work or receive the kinds of supports and services needed to allow them to pursue their desires. School district personnel can assist a family in understanding the array of services available once school ends and what options might be most rewarding and successful for the young adult.
Services for Adults

In addition, just as with school age students, an adult with ASD may qualify for supports and services through OPWDD and a network of voluntary service providers from throughout New York State. These services can range from supervised residential services to in-home habilitation services, supported employment, caregiver respite, family support services or clinical therapies. Individuals with ASD or their families should contact their local Developmental Disabilities Regional Office and attend a Front Door Information Session (https://opwdd.ny.gov/welcome-front-door/information_sessions) to begin the process of determining their eligibility and learn about accessing services.