

POPULATION SPECIFIC FACT SHEET

What to Know When Assisting Children and Adults in the Autism Community

This fact sheet is intended to help Navigators identify what issues are unique to consumers with autism spectrum disorder so that they can assist them as they make decisions related to their healthcare coverage.

Q1. What do I need to know about autism spectrum disorder?

A1. Autism spectrum disorder (ASD) and autism are both general terms for a type of developmental disability caused by atypical brain development. This disability is characterized, in varying degrees, by difficulties in two domains: 1) *social communication and social interaction*; and 2) *restricted and repetitive patterns of behavior*, including differences in sensory experiences. With the 2013 publication of the DSM-5 (the American Psychiatric Association's diagnostic reference), all autism disorders were merged into one umbrella diagnosis of ASD. Previously, there were distinct diagnostic subtypes, including autistic disorder, Asperger Syndrome, pervasive developmental disorder-not otherwise specified (PDD-NOS), and childhood disintegrative disorder.

In the domain of *social communication and social interaction*, people with ASD¹ demonstrate challenges in social-emotional reciprocity; deficits in nonverbal communicative behaviors used for social interaction; and deficits in developing, maintaining, and understanding relationships. In the second domain of symptoms, people with ASD show repetitive patterns of behavior, including stereotyped or repetitive motor movements; insistence on sameness or inflexible adherence to routines; highly restricted, fixated interests; and hyper- or hypo-reactivity to sensory input, or unusual interest in sensory aspects of the environment. Symptoms can be currently present or reported in past history. In addition to the diagnosis of ASD, each person who is affected should also be evaluated in terms of any known genetic cause (e.g., Fragile X syndrome, Rett syndrome), level of language and intellectual disability, and presence of medical conditions such as seizures, anxiety, depression, and gastrointestinal (GI) problems.

Many adults with autism have developed coping strategies that may serve to mask their diagnosis. The DSM-5 explicitly affirms that such coping strategies should not serve to prevent or make it more difficult for an individual to access an ASD diagnosis, noting that a diagnosis can be made based on present manifestations of autistic traits or "by history," if those traits were present at any period in the individual's life. As with other disabilities, autistic adolescents and adults develop learned behavior and other coping strategies over time. A majority of adults with autism may be undiagnosed at this time.

Each individual with ASD is unique. Many of those on the autism spectrum have exceptional abilities in visual skills, music, and academic skills. Many have normal to above average intelligence, and many persons on the spectrum take deserved pride in their distinctive abilities and atypical ways of viewing the world. Some people with ASD might need support to live independently and, depending on personal and family income, might be

¹ Many people diagnosed with ASD prefer to refer to themselves as "autistic people." Others may refer to themselves or others as "people with autism" or "people with ASD."

eligible for Medicaid Home and Community-Based Services or other help offered by states. About 25 percent of individuals with ASD are nonverbal but can learn to communicate using other means.

Autism statistics from the U.S. Centers for Disease Control and Prevention identify 1 in 68 children as on the autism spectrum. Studies show that ASD is four to five times more common among boys (about 1 in 42) than girls (about 1 in 189). However, research suggests that this gap may be explained in part due to systemic under-diagnosis of women, girls, and people of color, whose autistic traits may manifest differently or be viewed in a different cultural context.

There is no medical test to diagnose autism. Instead, specially trained physicians and other health professionals administer autism-specific behavioral observations. Genetic testing can help guide diagnosis and service provision.

Q2. What type of health care providers does someone with ASD need to have access to?

A2. Each child or adult with ASD is unique, and each autism services and support plan should be tailored to address specific needs. Autistic adults and children require medical services that are at times identical to and at times distinct from the general population, and may require a wide array of different kinds of professionals as well as - in some cases - family-mediated interventions. Some children and adults with ASD can also have chronic conditions such as allergies, gastrointestinal issues, food intolerances and other nutritional issues, epilepsy, immune conditions, sleep disorders, and psychiatric disorders, all of which are commonly associated with ASD but not specific to it. A child or adult with ASD may, therefore, need access to a full range of health professionals, including physicians, specialists such as a neurologist or gastroenterologist, psychiatrists, psychologists, behavioral therapists, occupational therapists, physical therapists, and speech therapists. Interventions for the core symptoms of ASD typically require behavioral analysts and other specialists.

Q3. What are some of the prescription needs that someone with ASD may have?

A3. A number of medical and behavioral issues frequently occur with ASD, including epilepsy, psychosocial disabilities, immune conditions, sleep disorders, or gastrointestinal issues. Some of these concerns may be closely related to the ASD diagnosis, such as anxiety disorders secondary to social and sensory challenges. Medications for these co-occurring conditions may be prescribed by providers with appropriate experience and expertise. Some people with ASD may seek medication to function better in certain social environments.

Q4. What type of therapies (physical, occupational, speech, etc.) and/or devices (durable, disposable, etc.) would someone with ASD potentially require?

A4. There are a variety of ASD services and supports and insurance ideally should provide coverage for the range of treatments needed by a particular individual. Interventions can involve behavioral treatments, physical therapy, occupational therapy, speech therapy and assistive technologies, alone or in some combination.

Many parents and insurance plans may be familiar with certain autism interventions, including Applied Behavior Analysis (ABA), DIR/Floortime, SCERTS (Social Communication, Emotional Regulation, Transactional Supports), and TEACCH, developmental and behavior-based interventions associated with autism spectrum disorder. ABA, DIR/Floortime, SCERTS and TEACCH are well-researched treatment approaches and have each achieved documented successes. Other researched therapeutic interventions emphasize ways of treating underlying sensory, motor, language, executive functioning, and emotional regulation needs through means other than behavior modification. Additional recognized and emerging treatment modalities for children, transitioning youth and adults with ASD include story-based intervention package, supported employment, naturalistic teaching strategies, and modeling. Some families and adults on the autism spectrum prefer intervention types utilizing relationship-based or developmental methodologies.

Further information on services, interventions, and supports for individuals with autism include:

CDC (<http://www.cdc.gov/ncbddd/autism/treatment.html>)
 CMS (<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf>)
 NIMH (<http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>)
 Association of University Centers on Disabilities (<http://www.aucd.org/>)
 Autism Speaks (<http://www.autismspeaks.org/>)
 Autistic Self Advocacy Network (<http://autisticadvocacy.org/>)
 The Arc (<http://www.thearc.org/>)

Q5. What other services and supports, which are not generally medically arranged therapies and devices, are typically required by persons with ASD? Are these arranged and financed in some private health insurance plans or in some Medicaid programs?

A5. The medical and non-medical needs of individuals with ASD will vary throughout the individual's lifespan and development. Technologies such as tablets, computers, and smart phones have become valuable tools in the support and daily lives of individuals with ASD. Many children and adults with ASD use computer or tablet software applications or dedicated speech generating devices to augment communication. These devices can assist in areas ranging from executive functioning to communication and more.

Some autistic people may need community-based supports and services, including help with day-to-day tasks, attendant care, or respite care. These services could also include family training about ASD and services for young adults transitioning into adulthood. Although these services are often not available through traditional insurance, they may be available through a Medicaid home- and community-based services (HCBS) program or waiver. As a result, people with significant support needs may be better served by enrolling in Medicaid or a Medicaid buy-in program, if they are eligible, than by purchasing private insurance. See Fact Sheet #15, "Medicaid Buy-In" (<http://www.nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/fact-sheet-15/>)

Private insurance and Medicaid coverage of technological tools, safety equipment, and family and adult services can be spotty at best. Medicaid provides the relatively comprehensive Early, Periodic, Screening, Diagnostic, and Treatment (EPSDT) benefit for

children, and the Affordable Care Act now includes behavioral health and habilitation services within the essential benefits that every insurance plan within the Marketplace must provide. Nevertheless, not all plans may interpret “habilitative services” and “behavioral health” services to include the specific interventions sought by an autistic person or their family. For example, respite for family caregivers, family training about ASD, and services for young adults transitioning into adulthood may be needed in some circumstances. Some autistic persons may need medical ID bracelets or other tools that can assist them if they become lost. Medicaid-funded supports may also be available to help people stay safe. There has been some effort to document the prevalence and impact of individuals with ASD becoming lost or disoriented, and additional research is needed to develop prevention strategies that families and communities can implement.

Q6. Are there any other unique medical needs that someone with ASD should consider when evaluating a health plan?

A6. The autism spectrum is marked by remarkable variability. Children and adults with ASD may have mild challenges or they may have complex medical needs, many of which have been highlighted in this fact sheet.

Q7. Are there any type of accommodations I should consider when I’m planning to meet with someone with ASD?

A7. Many individuals with ASD have difficulty with sensory input. Textures, sounds, smells, tastes, lighting, and movement can all be overwhelming. Some may have difficulty speaking face to face or over the telephone and may prefer written modes of communication, whereas others may strongly prefer speech to writing. Autistic people with co-occurring learning, cognitive, or intellectual disabilities may ask for information presented in simple, concrete terms, with clear examples. They may also choose to have a supporter, such as a family member or friend, join them and provide assistance when discussing health coverage decisions with a navigator. Navigators should not assume that a person’s need for these forms of support indicates lack of ability to make informed decisions about health coverage, or that the person wishes to be entirely bypassed in favor of communication with the support person.

If an individual with ASD appears uncomfortable, the Navigator should ask how things could be made better and be responsive to requests for accommodation. Above all, Navigators should listen and be attentive; flexibility, patience, and courtesy seldom fail.

Q8. Are there any resources you would recommend to obtain additional information about ASD?

A8. For more information about ASD, please go to the CDC Autism site (<http://www.cdc.gov/ncbddd/autism/treatment.html>) or the NIMH ASD site (<http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>).

The following non-profit organizations also have a significant amount of information on ASD:

- American Academy of Pediatrics (<http://www.aap.org/>)
- Association of University Centers on Disabilities (<http://www.aucd.org/>)

- Autism Speaks (<http://www.autismspeaks.org/>)
- Autism Society of America (<http://www.autism-society.org/>)
- Autistic Self Advocacy Network (<http://autisticadvocacy.org/>)
- National Professional Development Center on ASD (<http://autismpdc.fpg.unc.edu/content/evidence-based-practices>)
- National Standards Project on ASD (<http://www.nationalautismcenter.org/national-standards-project/>)
- OCALI (<http://www.ocali.org/>)
- The Arc (<http://www.thearc.org/>)

Specific information on the Affordable Care Act and people with developmental disabilities can be found at the Autistic Self Advocacy Network’s policy brief, “The Affordable Care Act and the I/DD Community”. (<http://autisticadvocacy.org/policy-advocacy/reports-and-brief-materials/the-affordable-care-act-and-the-idd-community-an-overview-of-the-law-and-advocacy-priorities-going-forward/>). Other state-by-state resources so Navigators can identify what is covered through the Marketplace in their state are the CMS Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD (<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf>) and the Autism Speaks’ “ACA: State by State.” (<http://www.autismspeaks.org/advocacy/insurance/affordable-care-act/states>).

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