# Autism Spectrum Disorder



# What is autism spectrum disorder?

Autism spectrum disorder (ASD) is a developmental disorder that affects communication and behavior. Although autism can be diagnosed at any age, it is described as a "developmental disorder" because symptoms generally appear in the first two years of life.

According to the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, a guide created by the American Psychiatric Association used to diagnose mental disorders, people with ASD have:

- ▶ Difficulty with communication and interaction with other people
- Restricted interests and repetitive behaviors
- Symptoms that affect the person's ability to function in school, work, and other areas of life

Autism is known as a "spectrum" disorder because there is wide variation in the type and severity of symptoms people experience.

ASD occurs in all ethnic, racial, and economic groups. Although ASD can be a lifelong disorder, treatments and services can improve a person's symptoms and ability to function. The American Academy of Pediatrics recommends that all children be screened for autism. All caregivers should talk to their child's doctor about ASD screening or evaluation.

# What are the signs and symptoms of ASD?

People with ASD have difficulty with social communication and interaction and have restricted interests and repetitive behaviors. The list below gives some examples of the types of behaviors that are common in people diagnosed with ASD. Not all people with ASD will have all behaviors, but most will have several of the behaviors listed below.

Social communication/interaction behaviors may include:

- Making little or inconsistent eye contact
- Having a tendency not to look at or listen to people
- Rarely sharing enjoyment of objects or activities by pointing at or showing things to others
- Failing to, or being slow to, respond to someone calling their name or to other verbal attempts to gain attention
- ▶ Having difficulties with the back and forth of conversation
- ▶ Often talking at length about a favorite subject without noticing that others are not interested or without giving others a chance to respond
- Having facial expressions, movements, and gestures that do not match what is being said
- Having an unusual tone of voice that may sound sing-song or flat and robot-like
- ► Having trouble understanding another person's point of view or being unable to predict or understand other people's actions

Restrictive/repetitive behaviors may include:

 Repeating certain behaviors or having unusual behaviors, such as repeating words or phrases (a behavior called echolalia)

- Having a lasting intense interest in certain topics, such as numbers, details, or facts
- ▶ Having overly focused interests, such as with moving objects or with parts of objects
- Getting upset by slight changes in a routine
- ▶ Being more sensitive or less sensitive than other people to sensory input, such as light, noise, clothing, or temperature

People with ASD may also experience sleep problems and irritability. Although people with ASD experience many challenges, they may also have many strengths, including:

- ▶ Being able to learn things in detail and remember information for long periods of time
- Being strong visual and auditory learners
- Excelling in math, science, music, or art

## What are the causes and risk factors for ASD?

Researchers don't know the exact causes of ASD, but studies suggest that genes can act together with influences from the environment to affect development in ways that lead to ASD. Although scientists are still trying to understand why some people develop ASD and others don't, some factors that increase the risk of developing ASD include:

- Having a sibling with ASD
- Having older parents
- ▶ Having certain genetic conditions (For example, people with conditions such as Down syndrome, fragile X syndrome, and Rett syndrome are more likely than others to have ASD.)
- ▶ Being born with a very low birth weight

Not everyone who has these risk factors develops ASD.

# How is ASD diagnosed?

Doctors diagnose ASD by looking at a person's behavior and development. ASD can usually be reliably diagnosed by the age of two. It is important for those with concerns to seek out an assessment as soon as possible so that a diagnosis can be made, and treatment can begin.

## Diagnosis in Young Children

Diagnosis in young children is often a two-stage process.

### Stage 1: General Developmental Screening During Well-Child Checkups

Every child should receive well-child checkups with a pediatrician or an early childhood health care provider. The American Academy of Pediatrics recommends that all children be screened for developmental delays at their 9-, 18-, and 24- or 30-month well-child visits, and specifically for autism at their 18- and 24-month well-child visits. Additional screenings might be needed if a child is at high risk for ASD or developmental problems. Children at high risk include those who have a family member with ASD, have some ASD behaviors, have older parents, have certain genetic conditions, or who were born at a very low birth weight.

Parents' experiences and concerns are very important in the screening process for young children. Sometimes the doctor will ask parents questions about their child's behaviors and combine those answers with information from ASD screening tools and with his or her observations of the child. To read more about ASD screening tools, visit the Centers for Disease Control and Prevention's (CDC) website at <a href="https://www.cdc.gov/ncbddd/autism/hcp-screening.html">www.cdc.gov/ncbddd/autism/hcp-screening.html</a>.

Children who show developmental differences during this screening process will be referred for a second stage of evaluation.

#### Stage 2: Additional Evaluation

This second evaluation is with a team of doctors and other health professionals who are experienced in diagnosing ASD.

This team may include:

- ▶ A developmental pediatrician—a doctor who has special training in child development
- ▶ A child psychologist and/or child psychiatrist—a doctor who has specialized training in brain development and behavior
- ▶ A neuropsychologist—a doctor who focuses on evaluating, diagnosing, and treating neurological, medical, and neurodevelopmental disorders
- A speech-language pathologist—a health professional who has special training in communication difficulties

This second evaluation may assess:

- Cognitive level or thinking skills
- Language abilities
- ► Age-appropriate skills needed to complete daily activities independently, such as eating, dressing, and toileting

Because ASD is a complex disorder that sometimes occurs along with other illnesses or learning disorders, the comprehensive evaluation may include blood tests and a hearing test.

The outcome of this evaluation will result in a formal diagnosis and recommendations for treatment.

## **Diagnosis in Older Children and Adolescents**

ASD symptoms in older children and adolescents who attend school are often first recognized by parents and teachers and then evaluated by the school's special education team. The school's team may perform an initial evaluation and then recommend these children visit their primary health care doctor or a doctor who specializes in ASD for additional testing.

Parents may talk with these doctors about their child's social difficulties, including problems with subtle communication. These subtle communication issues may include problems understanding tone of voice, facial expressions, or body language. Older children and adolescents may have trouble understanding figures of speech, humor, or sarcasm. Parents may also find that their child has trouble forming friendships with peers.

### **Diagnosis in Adults**

Diagnosing ASD in adults is often more difficult than diagnosing ASD in children. In adults, some ASD symptoms can overlap with symptoms of other mental health disorders, such as anxiety disorder or attention-deficit/hyperactivity disorder (ADHD).

Adults who notice signs and symptoms of ASD should talk with a doctor and ask for a referral for an ASD evaluation. Although testing for ASD in adults is still being refined, adults can be referred to a neuropsychologist, psychologist, or psychiatrist who has experience with ASD. The expert will ask about:

- Social interaction and communication challenges
- Sensory issues

- Repetitive behaviors
- Restricted interests

Information about the adult's developmental history will help in making an accurate diagnosis, so an ASD evaluation may include talking with parents or other family members.

Getting a correct diagnosis of ASD as an adult can help a person understand past challenges, identify his or her strengths, and obtain the right kind of help. Studies are now under way to determine the types of services and supports that are most helpful for improving the functioning and community integration of transition-age youth and adults with ASD.

#### What are treatments for ASD?

Treatment for ASD should begin as soon as possible after diagnosis. Early treatment for ASD is important because proper care can reduce individuals' difficulties while helping them learn new skills and make the most of their strengths.

The wide range of issues facing people with ASD means that there is no single best treatment for ASD. Working closely with a doctor or health care professional is an important part of finding the right treatment program.

#### Medication

A doctor may use medication to treat some symptoms that are common with ASD. With medication, a person with ASD may have fewer problems with:

- Irritability
- Aggression
- Repetitive behavior

- Hyperactivity
- Attention problems
- Anxiety and depression

Read more about the latest news and information on medication warnings, patient medication guides, or newly approved medications at the Food and Drug Administration's website at www.fda.gov.

## Behavioral, Psychological, and Educational Therapy

People with ASD may be referred to doctors who specialize in providing behavioral, psychological, educational, or skill-building interventions. These programs are typically highly structured and intensive and may involve parents, siblings, and other family members. These programs may help people with ASD:

- Learn life skills necessary to live independently.
- ▶ Reduce challenging behaviors.
- Increase or build upon strengths.
- Learn social, communication, and language skills.

#### Other Resources

There are many social services programs and other resources that can help people with ASD. Here are some tips for finding these additional services:

- ► Contact your doctor, local health department, school, or autism advocacy group to learn about special programs or local resources.
- ▶ Find an autism support group. Sharing information and experiences can help individuals with ASD and/or their caregivers learn about treatment options and ASD-related programs.
- Record conversations and meetings with health care providers and teachers. This information helps when it's time to make decisions about which programs might best meet an individual's needs.
- Keep copies of doctors' reports and evaluations. This information may help an individual qualify for special programs.

#### Where can I find resources about ASD?

For more information about ASD, visit:

- Eunice Kennedy Shriver National Institute of Child Health and Human Development www.nichd.nih.gov
- National Institute of Neurological Disorders and Stroke www.ninds.nih.gov
- National Institute on Deafness and Other Communication Disorders www.nidcd.nih.gov
- Centers for Disease Control and Prevention www.cdc.gov
- Interagency Autism Coordinating Committee https://iacc.hhs.gov

# What are clinical trials?

Clinical trials are research studies that look at new ways to prevent, detect, or treat diseases and conditions. The goal of clinical trials is to determine if a new test or treatment works and is safe. Although individual participants may benefit from being part of a clinical trial, participants should be aware that the primary purpose of a clinical trial is to gain new scientific knowledge so that others may be better helped in the future.

Researchers at NIMH and around the country conduct many studies with patients and healthy volunteers. We have new and better treatment options today because of what clinical trials uncovered years ago. Be part of tomorrow's medical breakthroughs. Talk to your doctor about clinical trials, their benefits and risks, and whether one is right for you.

► For more information about clinical trials conducted at NIMH, contact us at 301-496-5645 or nimhcore@mail.nih.gov.

► For questions about participating in research studies that are being conducted at the National Institutes of Health (NIH) and where to find them, contact prpl@mail.cc. nih.gov (link sends email).

For a listing of clinical trials being conducted around the country by NIH and others, be sure to check the ClinicalTrials.gov website at **www.clinicaltrials.gov**.

# **Finding Help**

#### **Mental Health Treatment Locator**

The Substance Abuse and Mental Health Services Administration provides this online resource for locating mental health treatment facilities and programs. The Mental Health Treatment Locator section of the Behavioral Health Treatment Services Locator lists facilities providing mental health services to persons with mental illness. Find a facility in your state at <a href="https://findtreatment.samhsa.gov">https://findtreatment.samhsa.gov</a>. For additional resources, visit <a href="https://findtreatment.samhsa.gov">www.nimh.nih.gov/findhelp</a>.

#### **Questions to Ask Your Doctor**

Asking questions and providing information to your doctor or health care provider can improve your care. Talking with your doctor builds trust and leads to better results, quality, safety, and satisfaction. Visit the Agency for Healthcare Research and Quality website for tips at www.ahrq.gov/patients-consumers.

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NIMH website

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MedlinePlus (National Library of Medicine)

https://medlineplus.gov

(En español: https://medlineplus.gov/spanish)

ClinicalTrials.gov

www.clinicaltrials.gov

(En español: https://salud.nih.gov/investigacion-clinica)

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