



**Autism
Society**
Massachusetts



GUIDE TO AUTISM SERVICES IN MASSACHUSETTS

Pursuing a Diagnosis



Welcome

Welcome to the Autism Society of Massachusetts! We are honored to connect with you and support you on your journey. As an affiliate of the Autism Society of America, our mission is to create a world where everyone in the Autism community is connected to the resources they need to live fully.



We understand that every individual's experience with Autism is unique, and we are here to provide support, advocacy, education, and resources to individuals with Autism, their families, and professionals.

How We Can Help:

- Information and Referral
- Education & Training
- Safety Resources and Trainings
- Awareness & Advocacy
- Public Policy



You are not alone. Whether you are looking for guidance, community, or ways to get involved, the Autism Society of Massachusetts is here for you. Visit our website to explore our programs, events, and resources.

Learn more at www.autismsocietyma.org



With support and community,
The Autism Society of Massachusetts



WHAT IS AUTISM?



What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder (ASD), hereafter referred to as Autism (which includes Asperger's Disorder and Pervasive Developmental Disorder – Not Otherwise Specified [PDD-NOS]), is a complex, lifelong developmental condition that typically appears during early childhood and can impact a person's social skills, communication, relationships, and self-regulation. The Autism experience is different for everyone. It is defined by a certain set of behaviors and is often referred to as a “spectrum condition” that affects people differently and to varying degrees.

While there is currently no known single cause of Autism, early diagnosis helps a person receive resources that can support the choices and opportunities needed to live fully.

Prevalence

Autism is prevalent across the world, although tracking rates can vary due to differences in reporting. In 2023, the Centers for Disease Control and Prevention (CDC) [issued its Autism prevalence report](#).

- The report concluded that the prevalence of Autism had risen to 1 in every 31 – more than three times as great as the 2004 rate of 1 in 125.
- The median age of diagnosis remains 47 months, or about 4 years of age, well past those critical early developmental years. This gap reflects a continuing need for universal screening, better pediatrician training, and systems that connect families to services when concerns first arise, not just at formal diagnosis.
- While the data shows encouraging signs of progress in identification across demographic groups, significant disparities remain. Black, Hispanic, and Indigenous children are more likely to be diagnosed later or only when additional intellectual disabilities are present.
- There are systemic disparities in access to early intervention, especially for families without public or comprehensive insurance, or those navigating complex eligibility criteria.

SIGNS & CHARACTERISTICS

Autism impacts an individual throughout the lifespan. However, research shows that early diagnosis can lead to improved quality of life. The behaviors of Autism may be apparent in infancy, but they usually become clearer during early childhood. As part of a regular health visit, your child's doctor should perform developmental screenings focused on Autism. This screening is recommended at ages 18 and 24 months for all children.

Your doctor will encourage you to ask specific questions about your child's developmental progress. **The National Institute of Child Health and Human Development (NICHD)** developed a detailed list of behaviors, listed in four categories: communication, social behavior, stereotyped behavior, and other behavior.

Social Behavior



- Prefers solitary or parallel play rather than engaging in associative or cooperative play with other children
- Preference for predictable, structured play over spontaneous play or make-believe play
- May not respond to name being called
- Struggles to make eye contact to communicate interests and/or needs

Communication



- Develops speech later than typical or not at all (nonspeaking)
- Repetition in language or movement, such as repeating the same word or sounds, hand flapping or any repeated movement
- Atypical nonverbal communication, including avoiding eye contact, giving few facial expressions or having a monotone voice

Stereotyped Behavior



- Extremely distressed by changes, including new foods or changes in routine or schedule
- Strong, persistent interest in a specific topic, part of a toy, or item

Other Behavior



- These characteristics vary widely and do not necessarily mean your child has Autism. However, if your child is showing these behaviors, a screening is encouraged. Many families start by voicing their concerns with their child's primary doctor, with referrals being made to a specialist for further evaluation.

CAUSES & FACTORS



There is no known single cause for Autism, but it is generally accepted that it is caused by differences in brain structure or function. Brain scans show differences in the shape and structure of the brain in people with Autism compared to in neurotypical development. Researchers do not know the exact cause of Autism but are investigating a number of theories, including the links among heredity, genetics, and medical problems. There has been misinformation about the cause of Autism. It is not caused by vaccines or due to parenting style or nutrition.

In many families, there appears to be a pattern of Autism or related disabilities, further supporting the theory that the disorder has a genetic basis.

While no one gene has been identified as causing Autism, researchers are searching for irregular segments of genetic code that people with Autism may have inherited. It also appears that some people are born with a susceptibility to Autism, but researchers have not yet identified a single “trigger” that causes Autism to develop.

Other researchers are investigating the possibility that under certain conditions, a cluster of unstable genes may affect brain development in an unexpected way, resulting in Autism. Still other researchers are investigating complications during pregnancy or delivery as well as environmental factors such as viral infections, metabolic imbalances, and exposure to chemicals.

SCREENING & DIAGNOSIS



When family members or support providers become concerned that a child is not following a typical developmental course, they turn to experts, including psychologists, educators and medical professionals, for a diagnosis. An early Autism diagnosis can provide the basis for appropriate educational and home-based support. There are many differences between a medical diagnosis and an educational determination, or school evaluation, of a disability.

Medical Diagnosis

A medical diagnosis is made by a psychologist, developmental pediatrician, or other specialized physician based on an assessment of symptoms and diagnostic tests. A medical diagnosis of Autism spectrum disorder is most frequently made according to the Diagnostic and Statistical Manual (DSM-5, released 2013) of the American Psychiatric Association. This manual guides physicians in diagnosing Autism spectrum disorder according to a specific set of criterion. A skilled practitioner can initiate the assessment, but the evaluation process may vary based on the professional conducting it, the individual's age, the severity of their needs, and the available local resources. A medical assessment for autism typically includes:

- A medical history of the mother's pregnancy
- Developmental milestones
- Sensory challenges
- Medical illnesses, including ear infections and seizures
- Any family history of developmental disorders
- Any family history of genetic and metabolic disorders
- An assessment of cognitive functioning
- An assessment of language skills
- An Autism-specific observational test, interview or rating scale

Diagnostic Tools

While there is not a single behavioral or communication test that can detect Autism, several Autism-specific tools are now being used for formal diagnosis. These include the Autism Diagnostic Observation Schedule, Second Edition (ADOS™-2), the Autism Diagnostic Interview (ADI), the Screening Tool for Autism in Toddlers (STAT), the Childhood Autism Rating Scales (CARS), and the Tele-ASD-Peds for diagnosis for use in telehealth. All of these tests should be used as part of a larger assessment, and not just on their own, as the determination of Autism is best completed with multiple sources of information.

SCREENING & DIAGNOSIS



Educational Determination

An educational determination is made by a multidisciplinary evaluation team of various school professionals. The evaluation results are reviewed by a team of qualified professionals and the parents to determine whether a student qualifies for special education and related services under the Individuals with Disabilities Education Act (IDEA) (Hawkins, 2009).

An educational determination can qualify an individual for support within school settings. However, an educational determination is not the same as a medical diagnosis, and often will not qualify an individual for therapies and support outside of school that would typically be covered by insurance or Medicaid. Additionally, a medical diagnosis of Autism does not guarantee an educational determination.

Screening

Early identification is associated with dramatically better outcomes for people with Autism. The earlier a child is diagnosed, the earlier they can begin benefiting from early intervention therapies and education. The Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities (NCBDD) recommends that all children be screened for Autism by their family pediatrician three times by the age of three – at nine, 18, and 24 or 30 months. Intervention should start when an Autism diagnosis is suspected, rather than when a formal diagnosis is made.

The advantages of early intervention cannot be overemphasized. Children who receive early intervention can make tremendous strides in their overall skill development, leading to improved quality of life. The CDC provides a wealth of information on the early signs of Autism through its "Learn the Signs. Act Early" initiative.

While there is no one behavioral or communication assessment that can detect Autism, several screening instruments have been developed for use in determining if a child might need further evaluation for developmental delay and/or Autism, including the Ages and Stages Questionnaire (ASQ) and the Modified Checklist for Autism in Toddlers (M-CHAT).

DIAGNOSIS CENTERS IN MA



Where to go for an Evaluation

Families seeking an Autism diagnosis in Massachusetts have access to several reputable hospitals offering comprehensive evaluation and support services. There can be extensive waitlists. We recommend asking to be put on the cancellation list. These centers offer specialized services to support families seeking autism diagnoses and related care. Here are some prominent centers in Massachusetts.

Autism Spectrum Center at Boston Children's Hospital

Boston, MA

Provides comprehensive, family-centered diagnostic and care services for children with autism spectrum disorder, including evaluations, specialty care, and support services.

<https://www.childrenshospital.org/programs/autism-spectrum-center>

Lurie Center for Autism at Massachusetts General Hospital

Lexington, MA

A multidisciplinary program dedicated to treating individuals with Autism and other developmental disorders across the lifespan.

<https://www.massgeneral.org/children/autism/lurie-center>

The Autism Program at Boston Medical Center

Boston, MA

Assists and empowers Autistic individuals and their families through direct patient support, provider education, and community-based outreach.

<https://www.bmc.org/pediatrics-autism-program>

Bressler Program for Autism Spectrum Disorder at Massachusetts General Hospital

Boston, MA

Offers comprehensive psychiatric assessments for intellectually intact individuals with autism spectrum disorder and associated psychiatric conditions.

<https://www.massgeneral.org/psychiatry/treatments-and-services/clinical-and-research-program-for-autism-spectrum-disorder>

www.autismsocietyma.org

DIAGNOSIS CENTERS



Autism Spectrum Disorders Program at Beth Israel Deaconess Medical Center

Boston, MA

Provides evaluations and interventions, including behavioral and communication therapy, occupational therapy, and speech therapy for individuals with autism spectrum disorder.

<https://www.bidmc.org/conditions-and-treatments/mental-and-behavioral-health/autism-spectrum-disorder>

Center for Children with Special Needs at Tufts Medical Center

Boston, MA

Offers evaluation, diagnosis, advocacy, and support for children with special needs, including autism spectrum disorders.

<https://www.tuftsmedicine.org/services-treatments/pediatrics/center-children-special-needs>

UMass Chan Medical School - The Center for Autism and Neurodevelopmental Disorders (CANDO)

Worcester, MA

Provides comprehensive diagnostic evaluations and specialized care for individuals with autism.

<https://www.umassmed.edu/psychiatry/clinicalservices/child-adolescent-clinical-services/cando/>

Tips For Getting a Diagnosis

In addition to the providers listed here, there are many smaller practices across Massachusetts that may offer services. We recommend contacting your insurance company to request a list of in-network providers, as this can help identify additional options.

Because many providers have waiting lists, consider joining multiple waitlists and asking to be added to cancellation lists, which may allow you to access services sooner.



PREPARING FOR AN ASSESSMENT

Preparing for an Autism assessment often happens over time and in stages. Understanding what to expect and how to prepare can help reduce stress and ensure you feel ready on the day of the appointment. Before scheduling or early in the process, it's important to contact your insurance company. Ask whether the assessment is covered under your plan, if there will be any out-of-pocket costs, whether a referral is required, and if the provider is considered in-network. Having this information early can help prevent unexpected delays or expenses.

Several months before the appointment, the provider may request documentation. This is a good time to begin gathering records such as early intervention reports, school evaluations, therapy notes, or previous assessments. Some families also find it helpful to take short videos of their child in everyday situations—such as playing, communicating, or engaging in preferred activities—to help the clinician better understand their strengths and challenges across settings.

About one month before the appointment, confirm that any required referrals have been completed and submitted. Many providers will ask you to complete questionnaires or forms about your child's development, behaviors, and concerns. Starting these forms early allows you time to reflect and provide thoughtful responses without feeling rushed.

In the week leading up to the appointment, review any remaining paperwork to be sure it is complete. Confirm the office location, parking details, and appointment time. If you've collected videos or notes, organize them so they're easy to access during the visit if needed.

The night before the appointment, pack a bag with items that may help your child feel comfortable, such as snacks, drinks, favorite toys, or comfort items. Be sure to include your insurance card, any required co-pay, and a fully charged phone with a charger. Try to prioritize rest for both you and your child, knowing that you've prepared as best you can.

On the day of the appointment, aim to eat ahead of time and arrive early to allow extra time for traffic and parking. Bring your packed bag and take a deep breath—this appointment is an important step toward understanding your child's needs and accessing the right supports.



About Us

The Autism Society of Massachusetts is dedicated to empowering individuals with autism and their families by providing education, advocacy, and community support. Our mission is to create a more inclusive world where individuals with autism have access to the resources, opportunities, and understanding they need to thrive. With a commitment to lifelong support, we work to foster acceptance, improve awareness, and connect families and professionals with essential tools and information. Through collaboration and education, we strive to make Massachusetts a place where every individual with autism is valued, supported, and included.

Services



Information and Referral



Education and Training



Resource Guides



Awareness and Advocacy



Public Policy



Safety Resources



First Responder Programs