

## Guide for Parents/Caregivers: Getting a Medical Diagnosis of Autism in Children

The diagnosis of Autism spectrum disorder (ASD) can involve both medical and educational professionals, each with unique goals and methods. A medical diagnosis determines if an individual meets the criteria for Autism through assessments by healthcare experts, while an educational diagnosis assesses how Autism impacts learning and is conducted in schools by a multidisciplinary team. Medical diagnosis leads to medical interventions, while educational diagnosis informs the creation of individualized education plans (IEP) for academic and social support. For more information about medical versus educational diagnoses, please refer to Autism Society of America's guide to Identifying Autism.

Autism 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.

This guide aims to help inform you about the medical diagnosis for Autism and items to consider throughout the diagnostic process.

### What to do while waiting for an Autism Diagnosis

While waiting for an evaluation for a possible Autism diagnosis, children can engage in a variety of therapies and interventions aimed at supporting their development and addressing potential challenges. Early intervention services are key, and can encompass speech therapy to enhance communication skills, occupational therapy to address sensory processing and daily living activities, and developmental interventions tailored to individual needs. Children who experience delays in reaching motor milestones, such as sitting, crawling, standing, or walking, may benefit from physical therapy to support their motor development and progression. Alternative therapies such as music or art therapy can also aid in self-expression and emotional regulation. Talk to your child's pediatrician to determine the most suitable interventions for your child's unique needs and strengths during this waiting period. Your child's pediatrician can put in referrals for therapies while you wait.

Contact your [county's board of developmental disabilities](#) to determine if your child is eligible for support services. All referrals for children under three are made through Ohio (Part C) Early Intervention (Help Me Grow). You can self-refer [here](#). Early intervention involves providing specialized support and services to infants, toddlers, and young children with developmental delays or disabilities to maximize their developmental potential and improve outcomes.

Early intervention services from your county's board of developmental disabilities/[Help Me Grow](#) typically includes:

- Developmental evaluation to identify areas of concern.
- Individualized Family Service Plans (IFSPs) developed in collaboration with the child's family. An IFSP is a customized plan designed to address the developmental needs of birth to three-year-olds with disabilities. The plan states the family's desired outcomes for their child and themselves and describes when, where, and how services will be delivered.

- Parent education and support to help families understand their child's [development](#) and learn strategies to support their child's growth and learning.

Contact the Director of Student Services at your [local school district](#) to request an [initial evaluation for special education and related services](#). If your child qualifies for services, an Individualized Education Program (IEP) will be developed. An IEP is a personalized plan developed for students who qualify for special education services to outline their goals, types of assistance, and accommodations. You can learn more about the IEP evaluation process [here](#).

### Ways to get a Medical Autism Diagnosis

A diagnosis of Autism is typically made by a specialist such as a psychologist or developmental pediatrician after assessing a person's symptoms and conducting diagnostic tests. They rely on guidelines outlined in the [Diagnostic and Statistical Manual \(DSM-5\)](#) published and updated in 2013 by the American Psychiatric Association. It's important to understand that a brief observation in a single setting isn't sufficient for an accurate diagnosis. Instead, the specialist considers the person's developmental history and seeks input from parents, caregivers, and/or teachers to gain a comprehensive understanding of their abilities and behaviors.

### Importance of Collaboration

A multidisciplinary team is the gold standard during a medical Autism evaluation because it combines expertise from various fields like psychology, pediatrics, speech-language pathology, occupational therapy, and others. This approach ensures a thorough assessment of the individual's strengths and challenges, leading to more accurate diagnoses and tailored intervention plans. It also allows for early identification of co-occurring conditions and provides comprehensive support for families.

### Types of Assessments

Several assessments are commonly used to diagnose Autism in children. Different assessments serve different purposes and provide complementary information, allowing diagnosticians to make a more accurate and nuanced diagnosis. For example, observational assessments like the Autism Diagnostic Observation Schedule (ADOS) provide direct observation of a child's social interaction, communication, and behavior, while parent interviews such as the Autism Diagnostic Interview-Revised (ADI-R) gather detailed information about the child's developmental history and daily functioning. Additionally, screening tools like the Social Communication Questionnaire (SCQ) help identify red flags for Autism, prompting further evaluation if needed. By using a combination of assessments, diagnosticians can gather a comprehensive understanding of the individual's strengths, challenges, and developmental history, leading to a more accurate diagnosis and appropriate intervention planning tailored to the individual's needs. Some common assessments include:

- **Autism Diagnostic Observation Schedule (ADOS):** The ADOS is a standardized observational assessment used to evaluate communication, social interaction, play, and repetitive behaviors associated with Autism. It involves structured interactions between the examiner and the child to assess behaviors relevant to an Autism diagnosis.
- **Autism Diagnostic Interview-Revised (ADI-R):** The ADI-R is a semi-structured parent interview that gathers information about the child's developmental history, social interactions, communication skills, and repetitive

behaviors. It provides valuable insights into the child's behavior across different settings and developmental stages.

- **Childhood Autism Rating Scale (CARS):** The CARS is a rating scale completed by a clinician based on observations and interactions with the child. It assesses various aspects of behavior associated with Autism, including social skills, communication, and repetitive behaviors.
- **Gilliam Autism Rating Scale (GARS):** The GARS is a questionnaire completed by parents, teachers, or caregivers to assess behaviors associated with Autism. It evaluates social interaction, communication, stereotyped behaviors, and developmental concerns.
- **Vineland Adaptive Behavior Scales (Vineland-II):** The Vineland-II assesses adaptive behavior skills in individuals with developmental disabilities, including those with autism. It measures communication, daily living skills, socialization, and motor skills through parent or caregiver interviews.
- **Social Communication Questionnaire (SCQ):** The SCQ is a screening tool completed by parents or caregivers to assess communication and social skills in children. It helps identify behaviors associated with Autism and indicates if further evaluation is needed.
- **M-CHAT (Modified Checklist for Autism in Toddlers):** The M-CHAT is a screening tool used to assess Autism risk in toddlers aged 16-30 months. It consists of a series of yes/no questions completed by parents or caregivers about the child's behavior and development.
- **Developmental and Behavioral Pediatric Evaluations:** Developmental and behavioral pediatric evaluations involve comprehensive assessments conducted by developmental pediatricians to evaluate developmental milestones, behaviors, and medical history to diagnose autism and other developmental disorders.

These assessments are typically administered by trained professionals, such as psychologists, developmental pediatricians, or speech-language pathologists, as part of a comprehensive evaluation process to diagnose Autism in children.

### Considerations

- Some providers take insurance, while others are self-pay. Before you begin the diagnostic process, ask if the provider takes your specific insurance. It's best to receive clarity on costs associated with the process before beginning.
- Many providers have wait lists for Autism assessments. Be sure to ask for approximate wait times and call periodically to get updates on your child's place on the list. Also, don't hesitate to get your child on more than one provider's wait list.
- The diagnostic process typically consists of multiple appointments. Be sure to ask how many appointments the diagnostic process entails with each provider and how long it will take from start to finish.
- After the diagnostic process is completed, many – but not all, diagnosticians provide comprehensive feedback and a written report explaining all test results. This report is vital as it serves as official documentation, guiding intervention, educational planning, and access to services. It provides detailed information about the diagnosis, recommendations for therapies, and legal protections against discrimination. Additionally, it aids in

future planning and ensures the best outcomes for the individual and their family. Be sure to ask the provider if this is part of the diagnostic process, and if not, ask what steps need to be taken to receive this report.

- Parents/caregivers should ask the provider's office if they will schedule an appointment to review the findings of the Autism assessment process.
- Applied Behavior Analysis (ABA) Therapy, along with a specific number of hours, may be recommended as part of your child's therapy. Please see ASGA's [Making Informed Decisions Guide](#) as you consider this therapy.

### **ASGA's Newly Diagnosed Guide**

Please reach out to ASGA through our HelpLine (330-941-1441 x1) or email us at [info@autismakron.org](mailto:info@autismakron.org) for a free copy of our Newly Diagnosed Guide, which includes steps to take after receiving an Autism diagnosis and items to consider as you begin your journey. Our HelpLine is a FREE service that provides a caring support system to listen to concerns and help solve problems. It connects people to Autism-related resources and services in the counties of Medina, Portage, Stark, Summit, and Wayne.

### **Making Informed Decisions**

Autism Society of Greater Akron affirms that each person who experiences Autism is a unique individual. To the maximum extent possible, informed decisions should be made by the individual with Autism and their family members in partnership with a multidisciplinary team. ASGA does not endorse any specific diagnostician, recognizing that there isn't a universal approach suitable for all individuals with Autism. It's recommended to explore various diagnosticians and understand different viewpoints to find the provider best suited to your needs and those of your Autistic individual. When considering interventions or therapies, be cautious of providers making unrealistic promises or claims of "cures," and seek evidence-based practices supported by scientific data. Don't hesitate to seek guidance from impartial sources, gather feedback from others who have used similar services, or reach out to ASGA at 330-940-1441 x1 or [info@autismakron.org](mailto:info@autismakron.org).

### **Disclaimer**

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