



AutismAlliance
of Michigan



YOUNG CHILD GUIDE TO AUTISM



Families often struggle with obtaining and accepting an autism spectrum diagnosis during a child's early years. Getting an accurate diagnosis early is key to accessing resources, and starting intensive early intervention often lays the foundation for future success. There is a great deal to learn, however autism programs at this age focus on parent education and family goals, as well as the young child.



SCREENINGS

Tools for parents and providers who suspect ASD

Parents are in the best position to monitor their young children. They observe them across settings and over time, and spend a great deal more time with their child than a practitioner does. The most effective assessments are completed when parents and providers partner together-- using tried and tested standardized assessment tools, which have been proven on thousands of other children to be reliable, and partner to truly observe the child and the areas where he or she may be struggling.

Diagnosing autism spectrum disorder (ASD) can be difficult, because there is no medical test, like a blood test, to diagnose the disorders. Doctors look at the child's behavior and development to make a diagnosis.

ASD can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable. However, many children do not receive a final diagnosis until much older, which may delay the therapies or help that they need. A child who is being screened at an older age may also require the use of different screening tools in order to be valid.

Diagnosing an ASD takes two steps:

- 1. Developmental Screening*
- 2. Comprehensive Diagnostic Evaluation*

SCREENINGS cont.

Developmental Screening

Developmental screening is a short test to tell if children are learning basic skills when they should, or if they might have delays. During developmental screening the doctor might ask the parent some questions or talk and play with the child during an exam to see how she learns, speaks, behaves and moves. A delay in any of these areas could be a sign of a problem. A screening tool is a simple pass/fail type inventory where they are either put in an 'at risk' category or not. A screening alone can never confirm a diagnosis of autism, which requires a full diagnostic assessment.

All children should be screened for developmental delays and disabilities during regular well-child doctor visits at:

9 months

18 months

24 or 30 months

Additional screening might be needed if a child is at high risk for developmental problems due to preterm birth, low birth weight or other reasons.

In addition, all children should be screened specifically for ASD during regular well-child doctor visits at:

18 months

24 months

Additional screening might be needed if a child is at high risk for ASD (e.g., having a sibling or other family member with an ASD) or if behaviors sometimes associated with ASD are present

It is important for doctors to screen all children for developmental delays. It is especially to monitor those who are at a higher risk for developmental problems due to preterm birth, low birth weight or having a sibling with an ASD.

If your child's doctor does not routinely check your child with this type of developmental screening test, ask that it be done.

If the doctor sees any signs of a problem, a comprehensive diagnostic evaluation is needed. Parents can find free and downloadable screening tools online and bring them to their child's doctor's appointment if they have concerns. Parents should trust their instincts and avoid a 'wait and see' approach, and avoid waiting for the pediatrician to note red flags.

SCREENINGS cont.

The M-CHAT

The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is a 2-stage parent-report screening tool to assess risk for Autism Spectrum Disorder (ASD). The M-CHAT-R/F is an autism screening tool designed to identify children 16 to 30 months of age who should receive a more thorough assessment for possible early signs of autism spectrum disorder (ASD) or developmental delay.

The American Academy of Pediatrics (AAP) recommends that all children receive autism-specific screening at 18 and 24 months of age, in addition to broad developmental screening at 9, 18, and 24 months. The M-CHAT-R/F, one of the AAP recommended tools, can be administered at these well-child visits.

If you and your physician agree that further screening is needed, you can request a free developmental assessment through your State Department of Health. We provide the contact information for your state's local Early Intervention coordinator on your child's M-CHAT-R/F report.

Early Intervention sites offer further evaluations of your child free-of-charge. These developmental assessments often vary from county to county and may involve a physical exam, a cognitive exam, a hearing assessment and a speech assessment. In addition to these important components of a thorough evaluation, you may also consider genetic testing and/or specialized assessments provided by a medical geneticist, a clinical psychologist, a developmental pediatrician, a pediatric psychiatrist or a pediatric neurologist.



DIAGNOSIS

Children may go through several different types of autism evaluations in order to get into treatment. These may involve different types of professionals and different testing tools. Caregivers must ensure their child has the appropriate assessment in order to get the 'ticket in the door' to services.

Approved Autism Evaluation Center (AAEC):

In Michigan, many private insurance providers require Autism Evaluations to be completed through an AAEC in order for autism therapies, primarily Applied Behavioral Analysis (ABA), to be reimbursed. In general, these centers meet criteria developed in partnership with the Michigan behavioral health care community and use a comprehensive, team approach to diagnosing autism.

A list of approved AAECs can be found at : <http://www.bcbsm.com/>

Educational:

This evaluation is done through the public school district or intermediate school district (ISD) to determine eligibility for special education services, appropriate classroom placement and support services within the school district. The school psychologist, social worker, speech therapist, occupational therapist and teacher generally work together as a team to complete the evaluation. This assessment is usually referred to as an Educational Certification rather than a medical diagnosis.

Medical:

This evaluation is completed by a physician or medical doctor such as a developmental pediatrician, a pediatric neurologist or psychiatrist who usually obtains a patient history and physical examination and makes general behavioral observations during the clinic visit. This assessment does not usually include any standardized testing.

Psychological:

This evaluation is completed by a psychologist who uses standardized testing materials specifically for diagnosing Autism, such as the Autism Diagnostic Observation Schedule (ADOS) or the Autism Diagnostic Interview-Revised (ADI-R). A psychological evaluation for Autism is generally more comprehensive than a medical evaluation and may also include assessment of IQ, developmental level, language, behavior, daily living skills and social abilities. It will often take several hours to complete and includes a parent interview as well as direct observation of the individual being tested.



EARLY ON

Free and Essential birth to three services

Every parent hopes for a healthy baby; however, sometimes things do not go as planned. After birth, the child may be ill or may not appear to be developing at the same rate as other children. The baby may not be doing certain things as smiling, sitting up or speaking like other children their age. Early On services are offered by the Michigan Department of Education. Early On services include intervention relating to physical development, cognitive development, communication skills, self-help/adaptive skills and social/emotional development.

Early On services are provided for infants and toddlers from birth to 36 months of age. If you are concerned about your baby's health or development call 1-800-327-5966 to speak to an Early On representative. Any questions or concerns that you discuss with the MDE Early On representative will be confidential.

Education programs for infants and toddlers (Birth through 36 months) with Autism Spectrum Disorder fall under Part C of IDEA which requires that "to the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate." (34 CFR §303.12(b)) By definition, natural environments mean "settings that are natural or normal for the child's age peers who have no disabilities." (34 CFR §303.18)



INSURANCE

Your policy needs when you have a child with ASD

Autism Mandate/Fund

The legislation took effect on October 15, 2012. SB 414 and 415 mandated the coverage of autism therapy and SB 981 established an Autism Reimbursement Fund, which reimburses insurance companies, third party administrators (TPA) or employers for the costs associated with providing the autism diagnosis and treatment.

Private Insurance:

State Regulated Plans

Benefits for Applied Behavioral Analysis treatment, speech therapy, physical therapy, and occupational therapy are limited to children through the age of 18 (some employers may choose to offer benefits beyond the age of 18, check with your employer). State Regulated plans cannot impose visit or annual dollar limits.

Self-funded (ERISA) Plans

Self-funded (ERISA) plans are not regulated by the State and are not required by law to provide the autism benefit. It is best to contact your employer to inquire if they have adopted the autism benefit. Each plan is determined by your employer and these plans can have age limits, visit/hour limitations and a capped dollar amount. If you find your employer has not adopted the benefit, contact AAoM and we can help you reach out to your employer and explain the benefits of adopting the autism coverage.

Plans on the Marketplace

Plans on the marketplace cover the autism benefit for children through the age of 18 and do not have limitations. Open enrollment to purchase a "Child-only" plan is in November and December 2015 with an effective date of January 1, 2016. Several plan options are available with carriers throughout the State.

INSURANCE cont.

Medicaid

Effective April 1, 2013, Michigan began offering a Medicaid/MiChild benefit to provide treatment and supports for children with autism in our state. The Medicaid/MiChild benefit is available through your local Community Mental Health (CMH) agency. Individuals receiving the Medicaid/MiChild benefit may be eligible for ABA therapy, speech therapy, physical therapy, occupational therapy, respite, family training and community living supports. The process to determine eligibility will include an intake process. If your child is deemed as possibly having an autism eligibility at intake, he or she will undergo a formal CMH eligibility diagnostic process. Depending on the outcome of that process, the amount and types of services the child will receive will be determined.

Behavioral health benefits are currently only available for children 18 months to 20 years old.

Young people up to 20 may be covered under Medicaid. Contact your Department of Health and Human Services for eligibility.

Youth who have “aged out” of foster care can be covered under Medicaid until they reach age 26.

Healthy Michigan Plan:

The Healthy Michigan Plan provides health care benefits to Michigan residents at a low cost so that more people can have health care coverage.

Individuals are eligible for the Healthy Michigan Plan if they:

**Are age 19-64 years*

Have income at or below 133% of the federal poverty level
(\$16,000 for a single person or \$33,000 for a family of four)

**Do not qualify for or are not enrolled in Medicare*

**Do not qualify for or are not enrolled in other Medicaid programs*

**Are not pregnant at the time of application*

**Are residents of the State of Michigan throughout the State.*



MEDICAL MANGEMENT

Medical issues common with ASD

It is not uncommon for children with autism to have other health problems. In fact, there are many medical and psychological conditions associated with autism.

Seizures, GERD (gastroesophageal reflux disorder), constipation, diarrhea, food and environmental allergies, fine and gross motor coordination problems, feeding difficulties and sleep disturbances are among some of the common medical issues seen in children with autism. In addition, there are also other psychological problems that are often seen in children with autism, including Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), and anxiety.

Appropriate management of these associated conditions is essential to maximize the benefit of other autism therapies like ABA, speech and occupational therapy and educational programming. If children are not feeling well, not sleeping or eating well, inattentive, hyperactive, anxious or having seizures, worsening of behavior and limited progress in therapy is often the result.

Regular check-ups with a primary care provider are essential to ensure children with autism are being evaluated for associated medical and psychological problems. Referrals should be made to pediatric neurologists for any concern of seizures. Pediatric gastroenterologists can address problems with reflux, constipation, diarrhea and food allergies or intolerances.

Psychologists can further evaluate symptoms of anxiety, ADHD and OCD. Once children have been further evaluated by specialists, recommendations for additional treatments are made and often include behavioral strategies, changes in diet, and medication therapy, especially for issues such as seizures, GERD, anxiety, OCD, ADHD and sleep.

When medical and other psychological problems commonly associated with autism are identified and managed effectively, behavior is improved and more progress in other therapy and school programming is noticed.



AUTISM THERAPIES

How to prioritize an alphabet-full of therapies.

Caregivers should use the many accredited bodies that tell us which therapies are most effective for autism. There is not one sole treatment for autism, but rather a menu of options for caregivers and individuals to choose from to address the unique needs of the person with autism. We know that the highest number, **over 90%**, of children with autism receive speech therapy given the core communication and social deficits of autism. **Over 50%** receive behavioral intervention or ABA therapy. **Over 75%** receive occupational therapy services. In best situations children will receive a combination of school-based therapy services and outpatient medical or community mental health therapies to augment what they receive in the school system which is driven by their classroom and curriculum needs. We see the use of many other conventional therapies used effectively with children with autism to address specific issues related to toe-walking, low muscle tone, food aversions, fine motor or attentional delays, among others. People with autism also demonstrate a variety of concomitant developmental and medical issues that are addressed through psychological, rehabilitative and medical therapies.

Autism Therapy Disciplines

Autism looks differently in each individual. The shared or core features of autism make speech-language, social, and behavioral treatments among the most popular treatments for autism. A wide variety of mental health and rehabilitation therapists provide therapy for people with autism. Each discipline comes from a different focus of study, background knowledge or expertise and ideas or approaches to therapy. However, these therapies may look similar in the goals that they address and the techniques used to address those goals. Caregivers and individuals with autism have the autonomy to decide which therapies best fit their loved ones circumstance, and should monitor the outcomes of the treatments in which they choose to spend their valuable time.

The Michigan insurance legislation identified core disciplines that should be paid for the treatment of autism including board certified behavior analysts (BCBA), speech-language pathologists (SLP), occupational therapy (OT), physical therapy (PT), and nutrition therapy. All of these therapies have professional organizations and guidelines that monitor their clinical practice, and all except for BCBA's are licensed by the State of Michigan. A bill to license BCBA's in Michigan is currently in progress. The behavior technicians or 'tutors' as they are often referred are non-licensed and often non-degreed staff that work under the supervision and responsibility of the BCBA to regulate them.

AUTISM THERAPIES_{cont.}

Evidence Based Therapies

'Evidence-based' therapies are those that have been proven to be effective in the scientific literature or professional journals. This means that any other individual who use the treatment in the way that it was designed will find the same benefit in persons with autism. We use the National Autism Center's published work in the *National Standards Project* as a guide to identifying which therapies are best proven to be effective. The terms used are:

Established Interventions- those that are well-proven to be effective

Emerging Interventions- those that have one or more study that suggest it is effective; however are in need of additional studies

Unestablished Interventions- those with little or no evidence in scientific literature to assure effectiveness and no way to rule out that they are harmful

The current list of established treatments for individuals under 22 years of age include:

Behavioral Intervention
Cognitive Behavior Therapy
Language Production Training
Modeling
Natural Teaching Strategies
Parent Training
Peer Training
Pivotal Response Therapy
Schedules
Scripting
Self-Management
Social Skills
Story-based Interventions

Emerging therapies for children up to 22 years old include:

Augmentative and Alternative Communication
Developmental Relationship-based Therapy
Exercise
Exposure
Functional Communication Training
Imitation and Imitation Training
Language Training- Production and Understanding
Massage
Multi-Component Therapy
Music therapy
Picture Exchange Communication Therapy
Reductive Therapy
Sign
Social Communication
Structured Teaching
Technology Based Intervention
Theory of Mind Training

AUTISM THERAPIES cont.

Complementary and Alternative Treatments

These fall under the category of Unestablished Treatments for autism and are not typically paid for by insurance companies. They can also consume a lot of time and money for families. Some individuals or families have reported improvement with these therapies; however, their presence in the unestablished category suggests that there is no guarantee of effectiveness. It is suggested that parents should seek early and intensive treatment in evidence-based treatments for autism before moving to unestablished therapies.

Some examples of unestablished therapies include:

- *Animal-assisted therapy*
- *Auditory Integration Training*
- *Concept Mapping*
- *DIR/Floortime*
- *GFCF*
- *Movement-based Intervention*
- *Sense Theatre Intervention*
- *Sensory Therapies*
- *Shock Therapy*
- *Social Behavioral Learning*
- *Social Thinking*

Treatment for Adults with Autism

For individuals over 22-years old, Behavioral Intervention strategies have proven to be effective.

Research on emerging therapies for individuals over 22 years of age with autism have shown promise in Vocational Training.

Unestablished therapies for the adult population include music therapy, modeling, cognitive-behavioral and sensory integration therapies. Some of these interventions may be highly enjoyable for adults on the autism spectrum and could be ways that adults may choose to spend their time regardless of the guarantee of improvement on skills.



PRESCHOOL

Early childhood education options.

Early intervention education programs for children ages 3 through 6 diagnosed with Autism Spectrum Disorder is crucial. Evidence has shown that the earlier the intervention, the better the outcomes. Effective education programs must address all of the child's developmental areas: self-help, communication, physical, academic, and communication. Addressing each of the areas of development at an early age will help in developing a child's independent functioning.

Effective early childhood programs for children with Autism Spectrum Disorder need to include:

- *A strong early childhood curriculum that addresses attending skills, communication, play and social skills.*
- *Structured teaching with visual schedules, work systems, and visual organization to support the child's independence.*
- *A supportive teaching environment that incorporates visual supports, trained support staff and is void of unnecessary auditory and visual distractions.*
- *Opportunities for skill generalization.*
- *Functional behavior assessments as needed.*
- *Behavior plans that are based on functional behavior assessments.*
- *Family involvement, highly trained and effective teams, collaboration and parent education.*
- *Transition planning for moving the child from early childhood programming to elementary school.*
- *Regular and deliberate exposure to typically developing children.*



FINDING SUPPORT & PROVIDERS

Start early protecting your family and finding supports

Finding out your child has Autism can be an overwhelming experience. Sharing your experience with trusted family and friends can help others understand your needs and better support you during this time. Ask for what you need-whether it be emotional support, help with household chores, help watching your children, recommendations of providers or opportunities for your child to play with other children.

While you speak to your doctor about referrals for you child, ask about support groups for families. You may also want to ask about a referral to a psychologist or social worker who works with families who have children with special needs.

Through our MiNavigator Neighborhood Directory, you can search for Family Support including advocacy, training, faith based, legal support, physical mental and emotional support, respite agencies, and support groups:

<http://navigator.autismallianceofmichigan.org/>



WHILE YOU ARE WAITING ON TREATMENT

While you're waiting to get into therapies, make sure to contact EarlyOn for an evaluation and determination of free services your child may qualify through their school district.

<http://navigator.autismallianceofmichigan.org>

In addition, you may want to take time to learn more about Autism. There are many sources of information available including books and online resources.

To learn more about Autism:

<https://autismallianceofmichigan.org/about-autism-2/>

To learn more about Autism therapies:

<https://autismallianceofmichigan.org/about-autism-2/autism-therapies/>

Books, for example:

- Engaging Autism* by Stanley Greenspan
- Uniquely Human* by Barry M. Prizant
- The Out-of-Sync Child* by Carol Kranowitz and Lucy Jane Miller
- More than Words* by the Hanen Centre

In addition to reaching out for resources, spend time observing, playing with, and simply being with your child. Make sure to actively include them in family routines and experiences, and take note of what unique qualities your child has to offer.

Some suggestions of fun activities you can try with your child to keep them active and engaged can be found in our Neighborhood Directory:

<http://navigator.autismallianceofmichigan.org/cat/recreation-leisure/>



We work directly with families, health care providers, employers, first responders and educators to improve the lives of those affected by autism in Michigan.

NEED HELP? CONTACT US TODAY!

877.463.AAOM
www.aaomi.org

