



Developmental and Behavioral Pediatrics

Autism Spectrum Disorder

Introduction

When a child is diagnosed with an autism spectrum disorder (ASD), parents often experience a range of emotions—from disbelief and confusion, to sadness and fear, to feeling overwhelmed and even feeling relieved that they finally know what's going on. This is absolutely normal. All parents ask, "What do I do next?" Although there is no simple answer to that question, it might be helpful for you to know that there are many promising advances in the treatment of children with ASDs, and that there are many resources to help you. Although no one can predict the future for any child—with or without a diagnosis of autism—the future is much brighter for children diagnosed today than they were even a decade ago.

Local and national sources of information and support for families with a child with an ASD are too numerous to count. Whatever else you might learn from the materials in this packet, always remember this: You are not alone. There are many professionals working hard to find the causes—and new and more effective treatments and resources—for families like yours.

After your child has been evaluated by a doctor, psychologist, or other professional or team of specialists, you will get an explanation of the diagnosis and a written report with recommendations for programs and treatments for home and school. You—the parent—know your child's strengths, challenges, and needs better than anyone else. You are the expert on your child, which makes you the most critical person on your child's treatment team. Use the resources in this packet—and others that your health care team will tell you about. Ask questions. Seek advice and assistance.

One of the most important first steps is to sign up with the autism support center in your area (listed below). This is an agency especially created to help you and your family with the many questions you might have. The autism support center staff will help you get the information you need to make decisions about health care, education, social and leisure opportunities, community agencies, organizations and services, and funding sources. Many autism support center personnel are parents of children with autism themselves. They truly understand you. They have stood in your shoes and have learned valuable lessons that can save you time, effort, and worry. They want to help you and your child succeed in whatever you set out to do. The Support Center staff can also explain the benefits of applying for government funds and assistant programs through the Massachusetts Department of Developmental Disabilities (DDS). In Massachusetts, DDS provides a wide array of services and supports to children under 18 years of age with autism or other conditions.

For information about resources in your area, contact the autism support center nearest you:

Massachusetts Autism Support Centers

Autism Resource Central: In West Boylston; Serves Worcester, North Central & South Valley area

508-835-4278

www.autismresourcecentral.org

Autism Alliance of Metrowest: In Framingham; Serves Metrowest

508-652-9900

www.autismalliance.org

Autism Support: in Danvers; Serves Northeast region

978-777-9135

www.ne-arautismsupportcenter.org

Family Autism Center: In Westwood; Serves Norfolk County

781-762-4001, ext. 310

<http://www.arcsouthnorfolk.org/familyautism-center.html>

Community Autism Resources: In Swansea; Serves Southeastern region, Cape Cod & Islands

508-379-0371

www.community-autism-resources.com

Autism Connections, a Pathways Program: In Easthampton; Serves Western region

413-529-2428

www.communityresourcesforautism.org

TILL & Boston Families for Autism: In Dedham; Serves Greater Boston

781-302-4835

www.tillinc.org/autism_support.html

Understanding Autism and Treatments

Understanding the diagnosis of Autism Spectrum Disorder (ASD) is an important first step for parents. Though symptoms and severity vary, ASD affects children's ability to communicate and interact with others. Children with ASD can also have difficulty with nonverbal communication, such as eye contact, facial expressions, and gestures (such as pointing). Children's play skills are often delayed and can be repetitive and may include avoiding and/or seeking particular sensations. Although some children are good-natured and easygoing, others might have difficult behaviors and show frustration with changes in their routines. Sometimes these behaviors are related to difficulties understanding social interactions or challenges with learning certain skills. Because every child's individual strengths and challenges vary, each child will need a different combination of programs and services to match his or her individual learning and social profile. Doctors and other health-care professionals use different labels and language to describe children with ASDs. Your child might be described as "autistic," having autistic features, or being "on the autism spectrum." It is referred to as a spectrum because autism affects the skills and abilities of each child differently.

What is Autism Spectrum Disorder?

ASD is a complex neurodevelopment disorder, characterized by a range of social communication and interaction impairments, and restricted, repetitive, and stereotyped patterns of behavior. It is a "spectrum" disorder because every individual with ASD has symptoms that differ in intensity, ranging from mild to quite severe. Symptoms of ASD are usually noticed in early childhood, but for some may not become obvious until the child is a bit older. All children with ASD, however, have some degree of difficulty in the following two areas:

Social Communication Skills: Such as sharing emotions, understanding how people are feeling, expressing empathy, or having a conversation. Both spoken and unspoken communication used for social interaction, such as pointing, gesturing, and making eye contact are also affected.

Behaviors or interests: Such as repeating words or actions, playing with things in an unusual way (spinning objects, lining up toys), or insisting on following rigid routines or schedules

For your child to be diagnosed with autism, he or she must meet the symptom criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM5) published by the American Psychiatric Association. This manual is used by mental health providers to diagnose behavioral conditions and by insurance companies to reimburse for treatment. The ASD diagnosis includes a severity scale from mild to severe that helps guide treatment for the child and gives you a greater understanding of where your child is on the "spectrum."

How are ASDs Treated?

The most highly recommended treatment plans for children with autism spectrum disorders (ASDs) begin as soon as possible after diagnosis and include many hours of individual work with a child. Your child's doctor or other specialist will recommend a plan that is specific to your child's needs.

“ABA” and “Floortime,” are two of the most commonly used comprehensive teaching approaches for children with ASDs, providers work step-by-step with a child to build language, social, and play skills. Here is a general description of each approach:

Applied Behavioral Analysis (ABA) builds new skills and eliminates difficult behaviors by breaking tasks down into small steps. This scientifically researched approach is especially effective in gaining the attention of children who can be challenging to reach. ABA can be done in any setting -- at a table, on the playground, or in the classroom -- as long as the provider is a trained ABA professional.

Floortime (also known as DIR – the Developmental, Individual Difference, and Relationship-Based approach) includes highly motivating routines based on the child’s interests and builds social, communication, and play skills through increasingly complex, playful interactions. Similar approaches include Social Communication, Emotional Regulation and Transactional Support (SCERTS) and Relationship Development Intervention (RDI).

In addition to these approaches, most programs for children with ASDs incorporate specific tools such as:

Speech-language therapy, which helps a child learn to understand and express her or himself through language.

Total communication interventions, which involve using language, vocalizations, pictures and gestures as well as sign language and the Picture Exchange Communication System (PECS) – almost any means that a child can and will use to communicate.

Occupational therapy, physical therapy and sensory integration therapy, which respectively focus on a child’s hand and finger skills (fine motor), large muscle (gross motor), and sensory needs.

Positive behavioral supports, which minimize challenging behaviors through rewarding appropriate behaviors, responses, and task completion.

Medical professionals might also implement the following therapies:

Medication There is no medication specifically for ASD. Some medications can help with symptoms such as hyperactivity, anxiety, compulsive behaviors, attention, or aggression. Ask your doctor for advice as to whether one or more medications might be appropriate for your child and if the benefits outweigh any risks or side effects associated with the medication.

Biological therapies which include specialized or restricted diets, nutritional supplements and vitamin regimens. Consult your doctor to determine whether these approaches have been demonstrated to be safe and effective.

For Children under Age 3

In Massachusetts, children under 3 years of age with ASDs are eligible for two sets of related services through the Department of Public Health:

Early Intervention (EI) Services are provided at home or your childcare location, and might include speech therapy, occupational therapy, physical therapy, and a developmental specialist. Read more about EI here: www.mass.gov/dph/earlyintervention. It's important to note that EI is a family-centered program and that supports are available to parents in the form of a social worker or psychotherapist. Many EI agencies also offer playgroups in their offices or in the community once or more a week, and provide transportation so your child can attend the playgroup. In addition, your family will have an EI service coordinator who facilitates all services, including working with your Specialty Services provider, described next.

Specialty Services are key components in the care of a child with an ASD and the services are also provided at home or your child-care location. The providers will use therapy approaches known as "ABA" or "Floortime," or a combination of the two (descriptions of these approaches follow). Experts recommend that children with ASDs receive up to 25 hours a week of intensive services, depending on their individual needs. The ABA/Floortime providers should work closely with your EI therapists.

What is Early Intervention? (For children under age 3) Early Intervention (EI) is a statewide, integrated, developmental program available to families of children birth to 3 years of age. A child may be eligible for EI services if she or he has:

Developmental delays and challenges as a result of a congenital abnormality

An identified disability

If typical development is at risk due to certain birth-related or environmental circumstances.

EI provides services that contribute to the developmental progress of eligible children and supports for the family. Professionals in various disciplines work with children to help them acquire physical, cognitive, communication, and social/emotional skills so they will have the best chance to become happy and healthy members of the community. They might also offer parent support and training, parent and child play groups, swimming programs, and other opportunities to help the child and family thrive.

Who is eligible for EI?

Any child, birth to age 3, and his or her family may be eligible for EI services if the child:

- ♣ Is not reaching age-appropriate milestones in one or more areas of development.
- ♣ Is diagnosed with a physical, emotional, or cognitive condition that may result in a developmental delay.
- ♣ Is at risk for developmental delay due to biological, environmental, or other factors, such as prematurity, major birth trauma, or illness.

How can your child and family become involved with EI?

Anyone in Massachusetts (a parent, doctor, caregiver, teacher, even a friend or acquaintance) can make a referral by calling 800-905-8437 (800-905-TIES), or at <http://massfamilyties.org/ei/eiwelcome.php> without a prescription. Ask for a list of certified Early Intervention programs serving your community and then contact the EI agency directly.

What happens after a referral?

An EI team will conduct a developmental assessment of your child with your family members present to determine eligibility. This assessment will focus on specific areas of child's development, including cognitive, speech/language, motor and self-help skills, social and emotional development, and behavior.

If your child is found to be eligible, an Individualized Family Service Plan (IFSP) will be written based on the individual needs of your child and family. EI will begin working with your child and family within 45 days of referral.

Who provides EI services?

Depending on your child's needs, services are provided by professionals in a specific field. An educator, physical therapist, speech and language pathologist, psychologist, occupational therapist, social worker, nurse, or another specialty service provider may be a member of the team. Your child's pediatrician and other health care providers are also members of the team. You--the parents--are the most important members of your child's team and should feel comfortable contributing your opinions, asking questions, and participating in treatment.

Where and how are services provided?

Often the EI team will serve your child and family in a "natural environment" such as your home, child-care center, playground, or library. Serving children in natural environments helps them get accustomed to and participate in typical community activities and meet other children.

How are services paid for?

In Massachusetts, most health insurances pay for some or all of the cost of services if you give consent to have your insurance billed. The Massachusetts Department of Public Health pays for any cost not covered by insurance, including co-payments and deductibles. For more information, call 800-905-8437 or go to www.massfamilyties.org

What should I do next?

Your child's pediatrician can make the referral, or you can call yourself. If you live in Massachusetts, call the Central Directory for Early Intervention at 800-905-8437 (800-905-TIES) or visit www.massfamilyties.org for a listing of Early Intervention programs serving your community. A member of the EI team will then schedule an evaluation with your family to determine eligibility. If you live in another state, contact your Department of Public Health to find out which agency can help your child.

For Children over Age 3

Children ages 3 and over with ASDs receive their services through their local school district if they are determined to be eligible through a detailed process described in "A Parent's Guide to Special Education" available at https://fcsn.org/parents_guide. Services are almost always provided in school, but home-based services might also be included. Contact the Special Education department in your local school district to begin the process. You can find your school district in the phone book or by visiting the Massachusetts Department of Elementary and Secondary Education website at:

<http://profiles.doe.mass.edu/>. If you live in another state, ask your child's doctor how to access local resources.

All good programs for children with an ASD:

- Focus on social and communication skills
- Use positive behavior supports and strategies
- Set goals and assess progress regularly
- Work with your child's individual needs and interests
- Have predictable schedules
- Have a high teacher-to-student ratio
- Involve the family (for example, parent education or home-based programs)
- Are full day (5 hours), full week (5 days a week), and full year (12 months)
- Are taught by experienced staff who are trained in working with children with ASDs
- Include transition planning to help a child move smoothly to the next level.

How Do I Begin the Special Education Process in my Public School? Whether transitioning from Early Intervention services into the public school system or requesting services once your child is already enrolled, the process may seem a little daunting. Although there are differences among school districts regarding when and how the process is started and completed, the following outline will give you a general idea about what to expect.

What is special education?

It can be many different types of services. Some children need to be educated in a special classroom. Some need additional help in a regular classroom. Others need related services, like speech and language therapy, occupational therapy, ABA and social skills groups to meet their needs. As a parent, you are the best advocate for your child. The greater your involvement and voice, the better the outcome.

What is a TEAM evaluation?

To begin special education services, you should request a TEAM evaluation, sometimes called a "CORE." A TEAM evaluation is a group of assessments that will help the public school system determine whether your child is eligible for special education services (programs and services adapted for the education of children with disabilities or unique needs). The test results will define your child's strengths and areas of need. Your child's eligibility for special education, as well as subsequent program planning, is based upon the results of the TEAM evaluation. The rest of this section is designed to help you understand the TEAM process, your legal rights, and the important deadlines.

Understanding the Process

It is extremely important that you understand everything that occurs throughout the process. The following advice may help you.

- 1) Ask questions. When you do not understand something at a meeting, ask someone to further explain.
- 2) Prepare for meetings and phone calls concerning your child. Be familiar with the information that will be discussed and list all concerns that you expect to be addressed
- 3) Obtain as much information as you can about the process and your rights. Contact the Federation for Children with Special Needs at 800-331-0688 or visit its website at www.fcsn.org
- 4) Consider using an advocate. Professional representatives can help you make your voice heard. To find an advocate that meets your needs, ask your autism resource center for guidance. You can also contact the Federation for Children with Special Needs, www.fcsn.org or the Special Needs Advocacy Network, www.spanmass.org. The Bureau of Special Education Appeals (BSEA) provides a list of free and low-cost advocacy services and attorneys upon request (call 617-626-7250 or visit www.doe.mass.edu/bsea/)
- 5) Take advantage of parent groups. Other parents are important resources because they are experiencing or have experienced the same or very similar situations to you. Two programs that may be helpful are:
 - A) MassPAC (<https://fcsn.org/masspac>) to find listings for your own city or town's Parent Advisory Council
 - B) Massachusetts Family TIES (www.massfamilyties.org)
- 6) Notify your child's primary care provider. Your child's provider can better serve your child if he/she is aware that your child is receiving a TEAM evaluation. It is important that the doctor know about the proceedings and what services your child receives as a result.
- 7) Remember to review the education laws before your IEP meeting. Important Reminders

504 versus an IEP

504 Plans and IEPs both require students to be evaluated to be able to receive necessary accommodations. However, 504 Plans and IEPs have many differences. 504 plans are not as detailed and the requirements for evaluation are not as specific. Both can technically provide specialized instruction, but because no federal funding accompanies a 504, in practice, schools use a 504 only for accommodations, modifications, (not for specialized instruction, related services, etc.). Section 504 has fewer procedural safeguards to protect the parent and child. An IEP is a legal document that promotes more effective progress through a specialized instruction with modification of actual program or curriculum materials.

Terms to Know

Least Restrictive Environment

Both federal and Massachusetts special education laws require that a Team consider appropriate education in the least restrictive environment. If services can be appropriately provided in a less restrictive setting, the Team must choose that type of program and setting. If the student's program requires a more restrictive setting to be successful, then the Team may consider other settings. The Team should look class by class, activity by activity, and only remove your child from the general education classrooms if, and only if, supplemental aids and services would not make it possible for the student to remain in that classroom and make effective progress.

Types of classrooms

- ♣ Substantially separate classrooms (self-contained) serve students who require a highly modified curriculum in separate classrooms rather than in general education programs.
- ♣ Inclusion classrooms serve students with special needs that are able to access the standard preschool curriculum with minor accommodations.

Types of Assessment

- ♣ Specialist Assessment(s): An assessment in all areas related to a suspected disability.
- ♣ Educational Assessment: An assessment that includes information about the student's educational history and overall progress, including current educational standing in key curriculum areas. This assessment should also include information on the student's attention skills, participation behaviors, communication skills, memory, and social relations with groups, peers, and adults. This assessment should also include a narrative description of the student's educational and developmental potential.
- ♣ Health Assessment: An assessment to identify any medical problems that may affect the student's learning.
- ♣ Psychological Assessment: An assessment to consider the student's learning abilities and style in relationship to his or her social/emotional development and skills.
- ♣ Home Assessment: An assessment of family history that may affect the student's learning or behavior of the student at home.

Parent Training and Information Centers

Each state is home to at least one parent center supported by the federal government that serves families of children and young adults from birth to age 22 with any kind of disability. Parent Centers are experts on educational laws and help families obtain appropriate education and services for their children with disabilities; work to improve education results for all children; train and inform parents and professionals on a variety of topics; resolve problems between families and schools or other

agencies; and connect children with disabilities to community resources that address their needs. There are two Massachusetts Parent Training and Information Centers: the Federation for Children with Special Needs (www.fcsn.org) (617-236-7210) which serves families statewide. In addition, Massachusetts has an Autism Special Education Legal Support Center at Massachusetts Advocates for Children that specializes in helping families of children with autism. You can reach their parent helpline at (617) 357-8431 ext. 3224 or visit www.massadvocates.org/helpline/

Massachusetts State Laws (If you live in another state, contact your Parent Information Center to learn about the educational laws that affect your child.)

An Act to Address the Special Education Needs of Children with Autism Spectrum Disorders

In July 2006, Chapter 57 of the Acts of 2006 entitled “An Act to Address the Special Education Needs of Children with Autism Spectrum Disorders” took effect in Massachusetts. The Department of Elementary and Secondary Education issued a “Technical Assistance Advisory” to help school districts understand it. This Advisory is also very helpful for parents who want to learn how the law can help their children with ASDs. For the full text of the Advisory and to read the complete law, go to: www.doe.mass.edu/sped/advisories/07_1ta.html. An excerpt from the Advisory follows. “This law requires that IEP teams consider and address in the IEP discussion the following seven specific needs of students with ASDs:

- 1) Verbal and nonverbal communication needs: Impairment in communication is one of the defining characteristics of ASD. Therefore instruction and development of communication skills should be addressed as an essential element of the student's IEP.
- 2) The need to develop social interaction skills and proficiencies: Social skills vary in severity and pervasiveness as well as how they present at different ages and developmental stages. In the most severe expression of qualitative social impairment, students with ASD may consistently appear socially disconnected or avoidant, even with immediate family members. In less severe cases, they may find it difficult to initiate interactions, frequently misunderstand social situations or be unable to maintain a conversation on a subject other than one on a preferred topic. A younger child with ASD may lack variation in spontaneous or social imitative play, lack pretend or imaginary play skills or play with toys in an atypical or repetitive way, e.g. lining up toy cars or spinning the wheels, rather than racing them or engaging in pretend scenarios.
- 3) The needs resulting from the student's atypical responses to sensory experiences: The IEP Team should consider whether a student with ASD exhibits under- or over-sensitivity to particular stimuli, such as tactile, visual, auditory, smell, taste or texture. One and often several of these sensitivities are common in students with ASDs and can cause major discomfort, inattention and negative behaviors.
- 4) The needs resulting from resistance to environmental change or alterations in daily routines: Students with ASDs often have unusual intense responses to an unexpected change in the environment, such as turning the heat or air conditioning up, painting the walls a different color, even moving the location of a desk or chair. A change in daily routine, such as a fire drill or substitute teacher may also be difficult to understand or adapt to. Preparing for changes and transitions with visual schedules and supports,

multiple verbal reminders and timers often helps to minimize the discomfort and promote greater success, flexibility and independence.

5) The needs resulting from engagement in repetitive activities and stereotyped movements: Students with ASDs may exhibit ritualistic behaviors, movements or language. The educational team should consider their function and the extent to which these activities interfere with engagement in more productive activities such as interacting with peers, playing or learning academic skills.

6) The need for positive behavioral interventions, strategies and supports to address any behavioral difficulties resulting from ASDs: Because of the complex developmental, learning and adaptive needs of students on the autism spectrum, they often exhibit behaviors that are challenging in their intensity and frequency, and they may interfere with social and academic activities. The IEP Team should consider and discuss the need for a functional behavioral assessment (FBA) in order to identify the causes and functions of inappropriate behaviors and design an intervention or management plan based on FBA results and analysis.

7) Other needs resulting from the student's disability that impact progress in the general curriculum, including social and emotional development: A student with ASD often exhibits deficits in executive function, i.e. the ability to plan, organize, make appropriate choices and generalize learned skills to other environments/activities and engage in productive and functional routines. The student may have a tendency to perseverate – to over-focus on small or unimportant features – which may distract him or her from perceiving and understanding the whole activity, procedure or event. The IEP Team should consider the need for structure, academic and social support or different services in the classroom and other environments.”

Has your child’s IEP Team considered all the options?

IEPs for children with autism spectrum disorders might include:

ABA Home programs	Life Skills Training
Summer programs	Classroom Aides
After-school programs	Transition Services
Floor time	Vocational supports
Sensory integration	
Assistive technology	
Socialization supports	
Behavioral supports	
Augmentative communication: e.g., PECS	
Speech & language therapy	
Occupational therapy	
Physical therapy	

Autism Resources

Advocates for Autism-Massachusetts (AFAM): A parent-founded and -driven advocacy group for increasing the awareness of autism spectrum disorders and the current and pending legislation in Massachusetts. 781-891-6270 Judy Zacek. www.afamaction.org

Asperger/Autism Network (AANE): A comprehensive resource and support center serving the Boston and New England area for individuals with Asperger Syndrome and similar spectrum profiles (adults, teens, children) and their families. AANE has an excellent website including a database of support groups, family grants, specialized programs, books and articles, conferences, trainings and more. Staff members include service coordinators for adults, teens, and children. Watertown. 617-393-3824. www.aane.org

Autism Special Education Legal Support Center at Massachusetts Advocates for Children: Through the Autism Legal Helpline, callers receive free technical assistance and answers to their questions about educational rights of children with autism. Boston. 617-357-8431 ext. 3224 www.massadvocates.org/autism-center.php

Doug Flutie Junior Foundation for Autism: Raises public awareness and supports families and organizations through grants. Provides education, resources, and links about autism. 508-270-8855 or 866-3AUTISM. www.dougflutiejrfoundation.org

Healthcare

Why Might a Child Need MassHealth & How do I Apply?

MassHealth is the name of the Massachusetts Medicaid program. If you are over the income level for MassHealth and have private insurance, your child who has a disability (such as an autism spectrum disorder) may be eligible for MassHealth/CommonHealth as a secondary insurance. Child disability determinations are made by the federal criteria standards, which are outlined on the Social Security Administration (SSA) website https://www.ssa.gov/disability/disability_starter_kits.htm

MassHealth, as a secondary insurance payer:

Pays deductibles and co-payments for doctor's visits, medications, hospitalizations, therapies, etc. not covered by your other health plan

Applying for MassHealth:

For assistance with applying for MassHealth contact either:

Autism Resource Central: 508-835-4278

Autism Insurance Resource Center: This Center provides information to the public about insurance coverage under the law, An Act Relative to Insurance Coverage for Autism (ARICA) which took effect in Massachusetts on January 1, 2011. 800-642-0249. <http://massairc.org>

Disclosure Statement:

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