



autism
CONSORTIUM

Parent information packet

*Resources and
timeline planning
for your family*



www.autismconsortium.org

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Introduction

When a child is diagnosed with Autism Spectrum Disorder (ASD), parents often experience a range of emotions—from disbelief to confusion, from sadness to fear, from feeling overwhelmed to feeling relieved that they finally know what’s going on with their child. 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 ASD, and that there are many resources to help you on this journey. Although no one can predict the future for any child—with or without a diagnosis of ASD—the future is much brighter for children diagnosed today than it was even a decade ago.

Local and national sources of information and support for families with a child with 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. And there are many others who are there to support you along this journey.

After your child has been evaluated by a doctor, psychologist, or other professional or team of specialists, you will get an explanation of the ASD 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.



You, the parent, know your child’s strengths, challenges, and needs better than anyone else.

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 on the next page). Your local autism support center is there to help you and your family with any questions you might have. The staff will 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 ASD 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 rest of this packet provides comprehensive information on all aspects of ASD, from education laws to disability organizations to insurance coverage to a detailed list of books you might find helpful, and much more.

Autism Resource Specialists

Boston Medical Center Developmental and Behavioral Pediatrics

Shari King
617-414-3666
Shari.king@bmc.org

Lauren Bartolotti
617-414-3691
Lauren.bartolotti@bmc.org

Boston Children's Hospital Developmental Medicine Center

Neal Goodman
617-355-6802
Neal.Goodman@childrens.harvard.edu

Boston Children's Hospital Neurology Foundation

Hillary Greene
617-355-2545
hillary.greene@childrens.harvard.edu

Floating Hospital for Children at Tufts Medical Center

Bernadette Murphy Bentley
617-636-1305
Bbentley@tuftsmedicalcenter.org

Lurie Family Autism Center Mass General Hospital for Children

Suzanne Bloomer
781-860-1728
Sbloomer@partners.org

University Massachusetts Medical School

Kelly Hurley
774-442-2269
hurleyk@ummhc.org

Autism Support Centers

Sign up with a center in your area to learn about important programs and activities for your child and family.

Autism Alliance of Metrowest

In Natick

Serves Metrowest and Middlesex West

508-652-9900

www.autismalliance.org

Autism Resource Center of Central Massachusetts

In West Boylston

Serves Worcester, North Central & South Valley areas

508-835-4278

www.autismresourcecentral.org/

Autism Support Center

In Danvers

Serves Northeast region

978-777-9135

www.ne-arc.org/services/autism-services/autism-support-center/

Community Autism Resources

In Swansea

Serves Southeastern region, Cape Cod & Islands

508-379-0371

www.community-autism-resources.com

Community Resources for People with Autism

In Easthampton

Serves Western region

413-529-2428

www.communityresourcesforautism.org

Family Autism Center

In Westwood

Serves Norfolk County

781-762-4001, ext. 310

www.arcsouthnorfolk.org/family-autism-center.html

TILL Autism Support Center

In Dedham

Serves Greater Boston

781-302-4835

www.tillinc.org/autism_support.html

Supported by a grant from the Nancy Lurie Marks Family Foundation

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 ASD. 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.

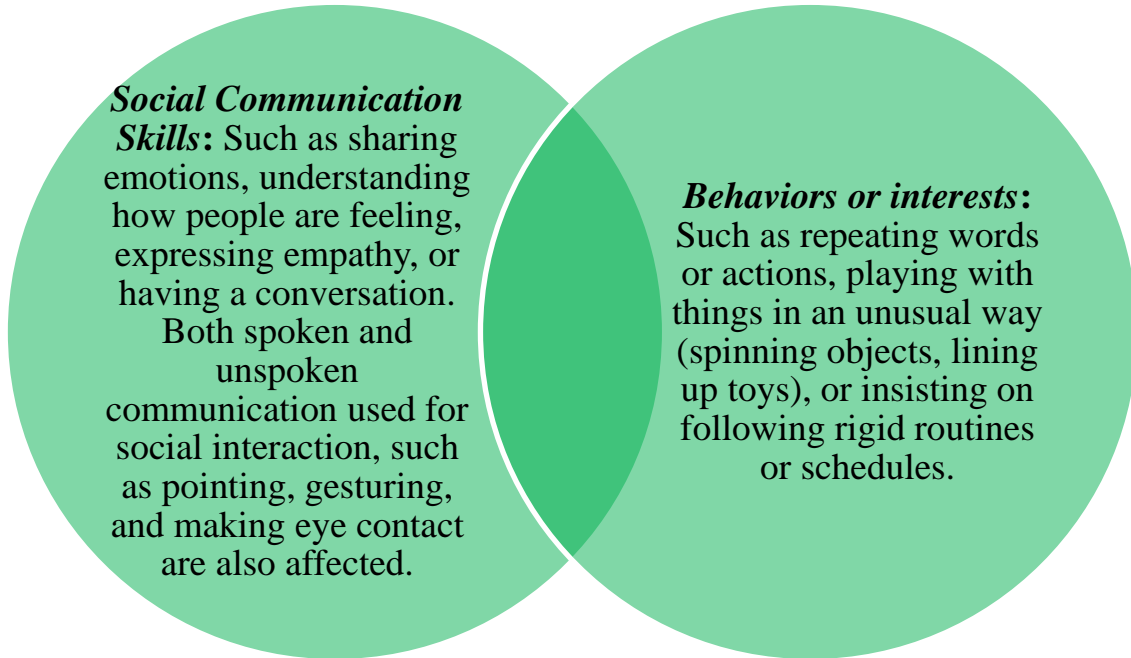
What is Autism Spectrum Disorder?

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:



For the most up to date information on resources visit
www.autismconsortium.org



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 (DSM) published by the American Psychiatric Association. This manual is used by providers to diagnose behavioral conditions and by insurance companies to reimburse for treatment. Prior to the May 2013 publication of the DSM-5 diagnostic manual, there were recognized distinct subtypes of autism, including autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger syndrome. In DSM-5, all three autism disorders were merged into one umbrella diagnosis of ASD.

Also, the ASD diagnosis now 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”. Another change was the decrease in the number of symptom domains from three to two. In the DSM-IV, autism is characterized by delays or abnormal functioning in one or more of the following domains:

1. Social interaction
2. Communication
3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities

In the DSM-5, there are two domains:

1. **Social communication domain**, which was created by merger of key symptoms from the DSM-IV social and communication domains, with focus on social interaction and not on the level of language skills, and
2. **Fixated interests and repetitive behavior or activity.**

Overall, the new diagnostic criteria in the DSM-5 are helping clinicians more accurately diagnose ASD by recognizing the differences from person to person, instead of providing general labels that were not being consistently applied across different clinics and centers.

To read more about ASD, visit:

American Academy of Pediatrics

www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Autism-Spectrum-Disorders.aspx

Autism Speaks

www.autismspeaks.org/what-autism

Centers for Disease and Control and Prevention

www.cdc.gov/ncbddd/autism/index.html



For the most up to date information on resources visit
www.autismconsortium.org

How is ASD Treated?

The most highly recommended treatment plans for children with Autism Spectrum Disorder (ASD) 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

For Children under Age 3

In Massachusetts, children under 3 years of age with ASD 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 ASD 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.

For Children over Age 3

Children ages 3 and over with an ASD 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 in English, Spanish, and Portuguese at

All good programs for children with 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 ASD.
- Include transition planning to help a child move smoothly to the next level.

www.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.

In “ABA” and “Floortime,” two of the most commonly used comprehensive teaching approaches for children with ASD, 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 ASD incorporate specific tools such as:

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

Treatment Resources

ABA- Applied Behavioral Analysis

www.asatonline.org/for-parents/learn-more-about-specific-treatments/applied-behavior-analysis-aba/

Floortime or DIR

www.icdl.com/DIR

PECS – Picture Exchange Communication System

www.pecs-usa.com

SCERTS-Social Communication, Emotional Regulation and Transactional Support

www.scerts.com

RDI – Relationship Development Intervention

www.rdiconnect.com

Sensory Processing/Integration Disorder

www.spdfoundation.net

General Information and research summaries of treatment options

www.asatonline.org/for-parents/learn-more-about-specific-treatments/

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 the most up to date information on resources visit
www.autismconsortium.org

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) without a prescription. Ask for a list of certified Early Intervention programs serving your community and then contact the EI agency directly.



Anyone in Massachusetts (a parent, doctor, caregiver, teacher even a friend or acquaintance) can make a referral by calling 1-800-905-8437

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 your 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 costs 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.

More Online

For a thorough list of programs in your community and other information, visit

www.massfamilyties.org

Other resources available:

Parent-to-parent matching

Online resource database

Workshop listings

What Are Specialty Services? (For children under age 3)

The Massachusetts Department of Public Health has set up a system to provide intensive intervention to children with autism spectrum disorder who are enrolled in Early Intervention. In addition to the comprehensive services provided by your local early intervention program, you may choose to have additional help from a **Specialty Service Provider**. These providers have particular expertise in the area of autism. They offer highly structured, individualized treatment programs that promote communication and social skills and address behavior that interferes with learning.

Who is eligible for Specialty Services?

A child who is enrolled in an Early Intervention Program who receives a diagnosis of Autism Spectrum Disorder from a physician or psychologist is eligible for Specialty Services.

Who are Specialty Service Providers?

Specialty Service Providers are agencies who have demonstrated expertise in the area of autism spectrum disorders and have been approved by the Department of Public Health to work in conjunction with Early Intervention Programs to serve children under age 3 with this diagnosis. Each agency covers a particular geographic area.

How do I find a Specialty Service Provider?

The list of approved providers is on page 15. A list of approved providers can also be found on the Massachusetts Early Intervention Training website:

www.eitrainingcenter.org/community/?p=service

How can my child be referred to a Specialty Service Provider?

You may contact the provider yourself or you may ask your Early Intervention Service Coordinator to make the contact for you.

May I interview more than one Specialty Service Provider?

Yes. You may set up an intake appointment with more than one Specialty Service Provider. Read more about the Programs' philosophy and approach by visiting their website. Select a program that uses the approach recommended by your child's doctor and that feels most appropriate for your child and family.

What are the costs associated with Specialty Services?

At the present time, Specialty Services are provided at no direct cost to families.

Do Specialty Service Providers offer services such as speech/language therapy, occupational therapy, and physical therapy?

No; not routinely. Some Specialty Service Providers have speech, occupational, and physical therapists on staff who consult to children receiving intensive intervention from time to time, but these types of therapy services are not part of the Specialty Service system. Your child will continue to receive the services specified on his/her Individualized Family Service Plan through your Early Intervention program.

How are the numbers of hours of intervention determined?

Most Specialty Service Providers start with five to six hours of intervention per week and then increase those hours as the child's ability to adapt to the structure of the sessions grows. The family's schedule, the age of the child, his/her learning style and behavioral characteristics, and rate of progress will also be considered in developing treatment plans. No formula dictates how much service is sufficient for any particular child. The quality of the instructional sessions and the degree of continuity across the child's day may be more important than the number of hours provided.

Remember that all of the Specialty Service Providers will be working closely with you and any of your child's caretakers to promote social skills and communication and to manage behavior that interferes with learning.

Are parents expected to be involved in Specialty Service intervention?

Most definitely! Research indicates that children whose parents are very involved in the various aspects of their intervention are more likely to make progress. Specialty Service Providers expect that parents will learn and use strategies that can help their children progress.

What will happen when my child turns three and is no longer eligible for EI?

Children are not eligible for Early Intervention or Specialty Services after their third birthdays. Some Specialty Service Providers, however, have staff available if schools want to hire them for direct service, consultation, and/or staff training after the child turns 3.

How should parents prepare for their child's transition to preschool?

The transition from early intervention to preschool can be an emotional time for any parent, and when you have a child with Autism Spectrum Disorder (ASD), the issues you face may become even more complex. When your child turns two-and-a-half it is time to work with your EI provider to begin preparing for an effective transition to preschool.

The Individuals with Disabilities Education Act (IDEA) requires a minimum of a 3-month transition period from early intervention to preschool. During this period, evaluations and meetings are scheduled as mandated by the IDEA law. Spending extra time on the transition process will not only reduce the uncertainty you might be feeling but also help your child adjust more easily to preschool.

To help ensure a smoother transition process, here are several things you can do:

- Consent process
- Review IEP timeline (page 22)
- First, schedule a Transition Planning Meeting with your Early Intervention team as soon as possible but no fewer than 90 days before your child's third birthday, to help determine your next steps in transitioning your child to preschool.
- With support from the Early Intervention team, schedule a meeting with your local public school district to develop an appropriate plan to map out the Special Education services your child might be eligible to receive following Early Intervention.

Additional Resources

To learn more about transitioning to early education:

[Best Practices in Early Childhood Transition: A Guide for Families](#)

Published by the Departments of Early Education, Public Health, and Education, it's filled with useful information and suggestions to help you plan a smooth transition to preschool.

www.mass211.org/images/BestPracticesGuide.pdf

[The Federation for Children with Special Needs](#)

is an excellent resource for connecting with other parents with preschool-aged kids. www.fcsn.org. One of the Federation's many programs you might want to acquaint yourself with is:

[Massachusetts Family TIES](#)

Family TIES publishes a free, annually updated resource guide. They also offer information and referral services at 1-800-905-8437. www.massfamilyties.org

[Child Care Choices of Boston \(CCCB\)](#)

serves as the Child Care Resource and Referral Agency for Boston, Brookline, Chelsea, Revere and Winthrop. Each year, CCCB provides thousands of low-income families with voucher management services that enable them to access affordable child care.

www.childcarechoicesofboston.org/index.asp

To find a child care resource & referral agency near you, visit this online directory:

www.eec.state.ma.us/ChildCareSearch/CCRR.aspx

- Plan to visit preschool programs you are seriously considering. Schedule a visit during times when you can observe the typical activities each program offers and see if you can also arrange to have your child participate in their activities as a way of trying them out.

Specialty Service Providers

Amego

Services provided: ABA

Serves: Most of Southeast region, some South Shore communities.

508-455-6220

www.amegoinc.org/

Applied Behavioral Learning Services

Services provided: ABA

Serves: Boston, Metrowest, and the West.

617-467-4136

www.ablspartners.org/

Beacon ABA Services

Services provided: ABA

Serves: Most communities except Berkshire, Dukes, and Nantucket counties.

508-478-0207 ext. 315

www.beaconservices.org

Behavioral Concepts

Services provided: ABA

Serves: Central Region.

774-573-0291

www.bciaba.com/

Building Blocks

Services provided: Floortime. Early Start Denver Model-based program of ABA

Serves: Northeast region, Boston, Worcester, and some surrounding communities.

978-824-2326

www.ne-arc.org/services/autism-services/building-blocks-intensive-early-intervention-0-3-years/

Children Making Strides

Services provided: ABA

Serves: Most of Southeast region.

508-563-5767

www.childrenmakingstrides.com/intervention.shtml

Community Health Link

Services provided: ABA

Serves: Central and North Central regions.

978-401-3841

www.communityhealthlink.org/chl/index.php/services-for-young-children/lipton-early-assistance-program

Futures Behavior Therapy Center

Services provided: ABA

Serves: Most of the Northeast.

978-969-2894

www.futuresbtc.com

HMEA, Inc.

Services provided: ABA

Serves: Central, Southeast, Metrowest, and Greater Boston.

508-298-1170

hmea.org/services/childrens-services/

Make a Difference in Children

Services provided: ABA

Serves: Attleboro, Brockton, Norwood, Taunton, and surrounding communities.

508-455-2379

www.makeadifferenceinchildren.net

The May Center

Services provided: ABA

Serves: Eastern Massachusetts

781-437-1382

Serves: Western Massachusetts.

413-734-0300

www.mayinstitute.org/autism-developmental-disabilities-services/childrens-services/early-intervention.html

New England Center for Children

Services provided: ABA

Serves: Boston, most communities in Metrowest and Central regions.

508-481-1015

www.necc.org/programs-and-services/programs.aspx

Pediatric Development Center

Services provided: Floortime

Serves: Berkshire County.

413-499-4537, Ext. 106 or 103

www.pediatricdevelopmentcenter.org/ssp.htm

RCS Behavioral & Educational Consulting

Services provided: ABA

Serves: Most communities in the Northeast.

508-650-5946

www.progressforallchildren.com/

Reach Educational Services

Services provided: ABA

Serves: Cape Cod & Islands, Plymouth area.

508-932-8526

www.reachedu.com

Servicenet – Reach PGM

Services provided: Floortime

Serves: Hampshire, Hampden, and Franklin counties, and North Quabbin area.

413-397-8986, ext. 409

www.servicenet.org/content/reach-early-intervention-program

Spectrum Autism Treatment

Services provided: ABA

Serves: Southeast region excluding Cape Cod & the Islands.

774-206-1125

www.spectrum-atc.com

For more information about specialty services such as ABA or Floortime, call Tracy Osbahr, the Early Intervention Intensive Services Coordinator, at 413-586-7525.

Information provided by the Early Intervention Program within the Massachusetts Department of Public Health (DPH).



For the most up to date information on resources visit
www.autismconsortium.org

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 evaluation.” 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.

Types of Assessments that may be included in a Team evaluation:

Specialist Assessments

Educational Assessment

Health Assessment

Psychological Assessment

Home Assessment

ABA Assessment

Speech Assessment

Occupational Therapy Assessment

Physical Therapy Assessment

Augmentative Communication Assessment

Transition Assessment

Note: Some assessments will only occur at the request of the school or caregiver. Discuss which assessments should be included in the Team evaluation with your child’s provider.

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) Take advantage of parent groups. Other parents are important resources because they are experiencing or have experienced similar situations to you. Two programs that may be helpful are:
 - A) MassPAC (www.masspac.org) or www.concordspedpac.org to find listings for your own city or town's Parent Advisory Council.
 - B) Massachusetts Family TIES (www.massfamilyties.org)
- 5) Consider using an advocate. Professional representatives can help you make your voice heard. To find an advocate that meets your needs, ask your autism support center for guidance. You can also contact the Federation for Children with Special Needs

Important Reminders

When your child is two years old:

- Notify public preschool that your child is receiving EI.
- Meet with your EI service coordinator to review your child's IFSP.
- Begin planning the transition from EI by preparing a unique transition checklist for your child

When your child is two-and-a-half years old:

- Transition meeting needs to be arranged by your EI service coordinator and held at least 90 days before your child's third birthday, and a representative from your local public preschool should be invited to the meeting.
- Review your plan for supporting your child's transition skills
- Plan visits to programs & activities that are of interest to you and you think may be appropriate for your child. These may include recreation programs, library groups, child care settings and public preschools. They may or may not be something you want to include in your child's preschool program.

Remember:

- A Team evaluation and the services your child may receive are all free.
- All guardians/parents (regardless of immigration status) are able, and should request a Team evaluation in writing to your public school district's office.

www.fcsn.org or the Special Needs Advocacy Network www.spanmass.org/id4.html. For additional advocate listings, go to the [AC resource database](#) and click the category Educational Advocates. The Bureau of Special Education Appeals (BSEA) provides a list of free and low-cost advocacy services available at www.mass.gov/anf/hearings-and-appeals/bureau-of-special-education-appeals-bsea/directoryoflegaladvocacyservices.html

- 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 and do not sign off on anything you don't understand or disagree with.

For more information visit the Massachusetts Department of Elementary and Secondary Education: www.doe.mass.edu/sped/

What should I do if the school disagrees with the services I am seeking for my child?

Sometimes parents and school officials disagree on the program or services a student needs. Parents might also have concerns that special education regulations and laws are not being followed.

The first place you can go for help is the Federation for Children with Special Needs (visit www.fcsn.org or call 617-236-7201). FCSN is a federally funded nonprofit organization that is staffed by experts in special education law. Explain your situation and ask for their guidance. If they recommend that you get a special education advocate to assist with your situation, ask for a list of advocates or visit www.spanmass.org to find an advocate in your area that specializes in helping students with ASD.

Another approach is to contact the Massachusetts Department of Elementary and Secondary Education (DESE) directly. DESE has created the Problem Resolution System (PRS) to "address complaints from the public about students' educational rights and the legal requirements for education." To get help with your particular situation:

- 1) Call (781) 338-3700 and ask to speak to the Problem Resolution Systems specialist who covers your school district (or you can visit www.doe.mass.edu/pqa/prs/specialist-list.html to find the direct phone number for your district's PRS specialist).
- 2) The PRS specialist will talk with you about your problem, answer your questions, and discuss steps that you might take on your own to resolve the problem. You have several options at this point:
 - A) Use the information the PRS specialist give you to go back to the school district and try again to resolve the disagreement;

- B) Ask the PRS specialist to contact the district on your behalf to try to solve the problem (IMPORTANT: If you do not want the PRS specialist to contact your district, BE SURE TO TELL THEM YOU DO NOT GIVE CONSENT FOR THEM TO DO SO);
- C) Hire an advocate; and/or
- D) File a formal complaint.

If you choose to file a formal complaint, federal law requires that it be done in writing and that you send the complaint to both the Department of Elementary and Secondary Education and your school district. To file a complaint, you can either print it out and complete the Problem Resolution Intake form that is available online at www.doe.mass.edu/pqa/prs/IntakeForm.pdf, or you can call (781) 338-3700 and ask for the Problem Resolution Intake form to be mailed to you.

For more detailed information on the PRS process, visit www.doe.mass.edu/pqa/prs/

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 and 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.

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.

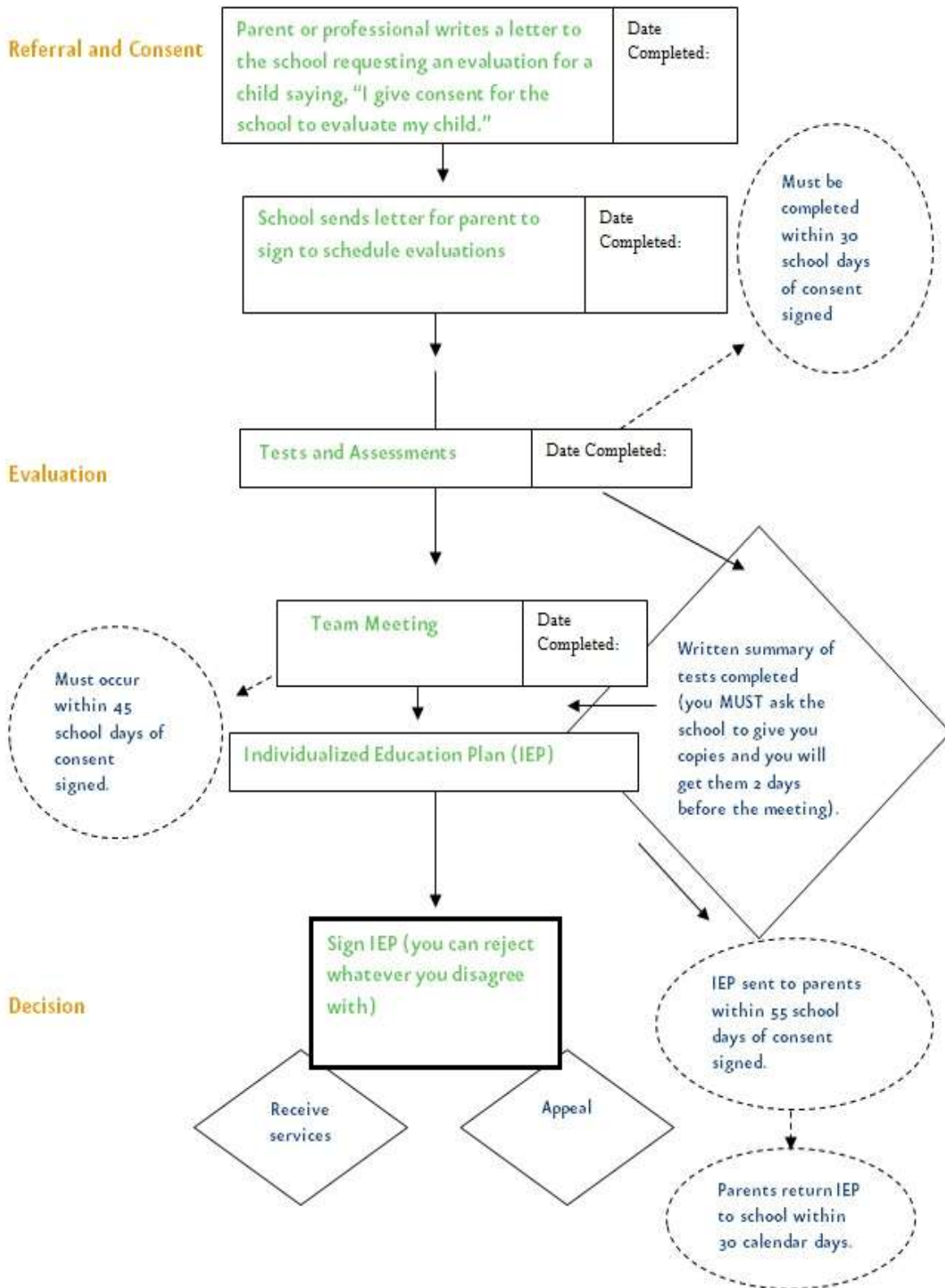
Types of classrooms

- **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 curriculum with minor accommodations.
- **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.

For the most up to date information on resources visit
www.autismconsortium.org

Transition to School Timeline for Parents



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, and **Urban Pride** (www.urbanpride.org) (617-206-4570, ext. 301) which helps families living in Boston. 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. 224 or visit www.massadvocates.org/autism-center.php.

In New Hampshire, contact your Parent Information Center at 603-224-7005 or 800-947-7005, or visit the website at www.picnh.org.

For families living in Rhode Island, you can reach the Rhode Island Parent Info Network (RIPIN) at 401-270-0101 or 800-464-3399, or go to www.ripin.org.

To locate the Parent Center in any other state, call 1-888-248-0822 or go to www.parentcenterhub.org/find-your-center/

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 Disorder

In July 2006, Chapter 57 of the Acts of 2006 entitled “An Act to Address the Special Education Needs of Children with Autism Spectrum Disorder” 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 ASD. 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 ASD:

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 ASD and can cause major discomfort, inattention and negative behaviors.

IEP Options

Has your child's IEP Team considered all the options? IEPs for children with autism spectrum disorder might include:

- ABA
- Home programs
- Summer programs
- After-school programs
- Floor time
- Sensory integration
- Assistive technology
- Socialization supports
- Behavioral supports
- Augmentative communication: e.g., PECS, iPad, etc.
- Speech & language therapy
- Occupational therapy
- Physical therapy
- Vocational supports
- Life skills training
- Classroom aides
- Transition services

- 4) **The needs resulting from resistance to environmental change or alterations in daily routines:** Students with ASD often have unusual or 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 for a child 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 ASD 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 ASD:** 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.”

An Act Relative to Bullying in Schools

In May 2010, Chapter 97 of the Acts of 2010 entitled “An Act Relative to Bullying in Schools” took effect in Massachusetts and has specific requirements for students with autism and for students with other disabilities that affect social skills development. The Department of Elementary and Secondary Education prepared a Technical Assistance Advisory to guide districts on how to implement the law (which is also very useful for families) and can be read here: www.doe.mass.edu/sped/advisories/11_2ta.html

According to the Advisory, Section 8 of the law states: **“For students identified with a disability on the autism spectrum, the IEP Team must consider and specifically address the skills and proficiencies needed to avoid and respond to bullying, harassment, or teasing.”** (G.L. c. 71B, §3, as amended by Chapter 92 of the Acts of 2010.)

In addition, the Advisory states: “The skills and proficiencies that a school district may incorporate into its general curriculum, or that an IEP Team may identify in the student's IEP, may include but are not limited to the following core categories:

- **Self-Awareness:** accurately assessing one's feelings, interests, values, and strengths/abilities, and maintaining a well-grounded sense of self-confidence.
- **Self-Management:** regulating one's emotions to handle stress, control impulses, and persevere in overcoming obstacles; setting personal and academic goals and then monitoring one's progress toward achieving them; and expressing emotions constructively.
- **Social Awareness:** taking the perspective of and empathizing with others; recognizing and appreciating individual and group similarities and differences; identifying and following societal standards of conduct; and recognizing and using family, school, and community resources.
- **Relationship Skills:** establishing and maintaining healthy and rewarding relationships based on cooperation; resisting inappropriate social pressure; preventing, managing, and resolving interpersonal conflict; and seeking help when needed.
- **Responsible Decision-making:** making decisions based on consideration of ethical standards, safety concerns, appropriate standards of conduct, respect for others, and likely consequences of various actions; applying decision-making skills to academic and social situations; and contributing to the well-being of one's school and community.”

For laws related to future educational planning for students with ASD over the age of thirteen, visit www.autismconsortium.org/attachments/Transition_Manual-8.12.pdf

New England States' Department of Education Websites

Massachusetts Department of Elementary and Secondary Education Special Education/Parent Information:

www.doe.mass.edu

Connecticut State Department of Education

www.sde.ct.gov

State of Maine Department of Education

www.maine.gov/education/

New Hampshire Department of Education

www.education.nh.gov/

Rhode Island Department of Elementary and Secondary Education

www.ride.ri.gov/

Vermont Department of Education

www.education.vermont.gov/

Community Resources

Public awareness of autism is greater than ever, so there is broader understanding of the diagnosis and the challenges faced by individuals with autism and their families.

There are also many more professionals coming into the field to provide clinical care, and a much more diverse corps of service providers who are available to help families.

Autism Support Centers/DDS

One of the most helpful and supportive resources for families are the local autism support centers, located all across Massachusetts. There are currently seven support centers that receive funding from the Autism Division at the Department of Developmental Services. The centers offer a wide range of information and resources, parent trainings, workshops and often times specialized programs for children, teens and young adults. The centers can also refer to other community supports and resources, and are often staffed by parents who have a child with ASD who are available to explain what services and supports your child and family may benefit from. Many of the centers also offer support groups that can be very helpful to families.

To get connected to your local autism support center, call and introduce yourself as well as your child. You should also ask to be put on their mailing lists, and tell them you would like to do an “intake” for services. The Support Center staff can explain the benefits of applying for government funds and

Autism Support Centers

Autism Alliance of Metrowest

In Natick; Serves Metrowest, Middlesex West

508-652-9900

www.autismalliance.org

Autism Resource Center of Central Massachusetts

In West Boylston; Serves Worcester, North Central & South Valley areas

508-835-4278

www.autismresourcecentral.org

Autism Support Center

In Danvers; Serves Northeast region

978-777-9135

<http://www.ne-arc.org/services/autism-services/autism-support-center>

Family Autism Center

In Westwood; Serves Norfolk County

781-762-4001, ext. 310

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

Community Autism Resources

In Swansea; Serves Southeastern region, Cape Cod & Islands

508-379-0371

www.community-autism-resources.com

Community Resources for People with Autism

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

assistant programs through the Massachusetts Department of Developmental Services (DDS). In Massachusetts, DDS provides a wide array of services and supports to children under 18 years of age with autism or other conditions. Currently, there are two types of services you can apply for within DDS if your child has ASD.

- 1) The DDS **“Autism Division” only status** for children diagnosed with ASD. Most children who qualify for these services do not have a secondary diagnosis of intellectual disability, global developmental delays or significant functional impairments, and therefore do not qualify for DDS Children’s Eligibility or “Dual Eligibility”. Please remember to contact your local support center and complete the intake process, so that your family can access community-based social skills, sensory and family programs that are individually coordinated by the Autism Support Centers. These programs are of minimal or no cost to your family. Also note that each center raises private funds so they may coordinate other programs that do have participation fees.

For more information about the DDS Autism Division, contact the Autism Support Center listed on the previous page that serves your area.

- 2) The DDS **“Dual Eligibility” status includes the Autism Division and DDS Children’s Eligibility**. If your child also meets Children’s Eligibility Criteria then you may be able to also access DDS service coordination and many other family support services based on the availability of funds. In order to be eligible for DDS Children’s services a child must have a diagnosis of a global developmental delay (under age 5), diagnosis of a developmental disability (over age 5) and have impaired levels of functioning in at least three of the following areas: self-care; communication; learning; mobility; self-direction and (for age 14 and older) capacity for independent living and economic self-sufficiency. The DDS eligibility team will review your child’s documentation and come out for an in-home assessment to determine eligibility. If your child is determined Dually Eligible for the Autism Division and DDS Children’s services then you will get connected with a local DDS Area Office to determine what supports may be available for your child and family

Autism Support Centers

Some of the services offered at Autism Support Centers are:

- Information and Referrals
- Lending Library
- Parent Support Groups
- Sibling Workshops
- Trainings and Consultations
- Speaker Series
- Open Gym and Swim Sessions
- Family Events and Outings
- Summer Camp and Program Listings
- School Vacation Programs
- Newsletter



Raising a child with Autism Spectrum Disorder (ASD) can be overwhelming. You need to know that you are not alone.

Autism Resources

Advocates for Autism-Massachusetts (AFAM): A parent-founded and -driven advocacy group for increasing the awareness of autism spectrum disorder 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 high-functioning autism (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 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 and the Autism Omnibus Bill, which was signed by the Governor on August 6, 2014. 800-642-0249. www.disabilityinfo.org/arica

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. 224. www.massadvocates.org/autism-center.php

Charles River Center: Provides employment and job training, residential homes, therapeutic day programs, and recreational programs for children and adults with developmental disabilities. The Center also coordinates Wings for Autism, a travel readiness program at Logan Airport for families of children with autism who have difficulty with airline travel and security screeners. 781-972-1000. www.charlesrivercenter.org/

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.flutiefoundation.org/

Massachusetts Disability Resources

ARC of Massachusetts: A statewide resource that provides advocacy and support for individuals with intellectual and developmental disabilities, such as autism, through the 17 ARC chapters. 781-891-6270. www.arcmass.org.

Department of Public Health / Children & Youth With Special Health Care Needs (CYSHCN) Program: The CYSHCN program helps families coordinate their child's medical, social and educational needs. This program offers a **Community Support Line** where Resource Specialists offer technical assistance to parents. The **Care Coordination Program** has Care Coordinators, who speak both English and Spanish, available to provide consultative services to parents who have a child with complex medical needs. 800-882-1435. www.mass.gov/dph/specialhealthneeds

Early Intervention and Specialty Service Providers: For information about services for children under three in Massachusetts, go to www.mass.gov/dph/earlyintervention or call 800-905-8437. For information about Specialty Services such as ABA or Floortime, call Tracy Osbahr, Early Intervention intensive services coordinator at 413-586-7525.

Family Ties of Massachusetts: A statewide information and parent-to-parent support program for families of children with special needs and chronic illnesses. Offers a comprehensive resource directory. 800-905-TIES (8437) or 617-541-2875. www.massfamilyties.org

Mass Family Voices/Massachusetts Family-to-Family Health Information Center: This center is staffed by parents who provide free, confidential assistance to help families raising children with special healthcare needs become more knowledgeable about healthcare services and supports as well as receive assistance in obtaining those benefits. 800-331-0688 x. 210 www.massfamilyvoices.org

Mass Family Voices Listserv: This listserv allows families raising children and youth with special healthcare needs to share resources and information, post questions and answers, so that listserv members can learn and support each other. Membership is free and confidential. Please send an e-mail to massfv@fcsn.org for more details.

Parent/Professional Advocacy League (PAL): Statewide parent support organization for children's emotional, behavioral, and mental health needs. 617-542-7860 or 866-815-8122, Boston. 508-767-9725, Worcester. www.ppal.net

Sibling Support Project: Sibshops is a program developed by the national Sibling Support Project, specifically for brothers and sisters of a person with special needs. The program recognizes and appreciates that every brother and sister has different feelings, thoughts, and emotions, and allows opportunities for expressing each in a unique way. They celebrate all that brothers and sisters have to offer and provide programs that are designed to be engaging, fun and informative! Sibshops is a chance for siblings to meet

new friends, and receive support and encouragement. To find a Sibshop near you visit: www.siblingsupport.org/sibshops/find-a-sibshop

Special Olympics Massachusetts: Provides year-round sports training, athletic competition and other health related programming for athletes with intellectual disabilities throughout the state. 508-485-0986 or www.specialolympicsma.org/

Sped Child Mass: This website has Massachusetts workshops and resources for children with special needs, along with pertinent news. www.spedchildmass.com



The Autism Consortium has a comprehensive **Resource Database** with hundreds of autism-related listings, such as summer camps, after-school programs, ABA providers, social skills groups, education consultants, and much more!

Some helpful websites and downloads: Massachusetts Department of Education/Special Education/Parent Information
www.doe.mass.edu/sped/parents.html

A Parent's Guide to Special Education
www.fcsn.org/parents-guide

Special Education Resources

Children's Law Center of Massachusetts: Provides legal services to low income children, and information and training to parents. 888-KID-LAWS. www.clcm.org

Disability Law Center: Offers legal advice for children who have disabilities; sometimes takes cases for free. Boston, 617-723-8455 or 800-872-9992. Western Massachusetts, 413-584-6337 or 800-222-5619. www.dlc-ma.org/Priorities/index.html

Ed Law Project: Provides legal representation, technical assistance, and training to families of low-income children in Boston in danger of not receiving appropriate education services. Call Marlies Spanjaard at 617-989-8347, Bryna Williams at 617-988-8363 or visit www.youthadvocacydepartment.org/edlaw/edlaw-about.html

Federation for Children with Special Needs: Updated federal and state special education laws, advice, information, and access to advocacy, IEP development and related resources, parent information guides, and statewide parent workshops. Boston office 617-236-7210 or 800-331-0688. Western Mass. office 413-323-0681 or 866-323-0681. www.fcsn.org

- Parent Training and Information – Spanish www.fcsn.org/pti/espanol/index.php
- Parent Training and Information – Portuguese www.fcsn.org/pti/portuguese/index.php

Parent Advisory Council (PAC): A PAC is a group of parents in your city/town whose children are receiving special education services from the school district. They have information about local services, and offer workshops and the opportunity to network with other parents. To find the PAC for your school district, ask your district's special education office or visit www.concordspedpac.org/Pacs-in-Mass.html or www.spedchildmass.com/support_sepacs . Also visit www.fcsn.org/masspac/ for more information.

Special Needs Advocacy Network (SPAN):

Provides a list of special education advocates.

Fees vary. Also offers workshops. 508-655-7999. www.spanmass.org

Massachusetts Dept. of Elementary and Secondary Education, Special

Education: The state's official website for parents of children ages 3 through 22 eligible for special education. Provides state and federal regulations, information on IEPs and parent rights and procedural safeguards manual for working with your district's special education department. 781-338-3000. www.doe.mass.edu/sped/parents.html

Program Quality Assurance: Call if you are having problems with the school district and ask to speak to the contact person for your town or city. 781-338-3700. www.doe.mass.edu/pqa/

SPED Watch: Grassroots nonprofit social change movement working to secure the educational rights of all Massachusetts schoolchildren with disabilities. www.spedwatch.org

Urban PRIDE: For families of kids with disabilities living in the city of Boston. A resource for workshops, parent supports and advocacy. 617-206-4570. www.urbanpride.org

New Hampshire:

Autism Resource Center at Crotched Mountain: No cost for services. Helps parents advocate for their child, find funding sources, explore treatment options, and navigate services. 603-226-2900, ext. 29. www.crotchedmountain.org/autismresource/

The Birchtree Center: Provides specialized educational services for children and youth with autism. Portsmouth. 603-433-4192. www.birchtreecenter.org/

Department of Education: 603-271-3494. www.education.nh.gov/instruction/special_ed/index.htm

Local Arc

Your Local Arc or Autism Support Center may be able to provide additional support regarding your child's IEP

Easter Seals Autism Network, Family Support Program: Offers therapies, social skills groups, camps. Manchester. 603-893-0984. www.easterseals.com/nh/our-programs/autism-asd-services/

Jacob's Bridge Through Autism: Developed by parents, has listing of local and national resources. Plymouth. www.jbtautism.org

Nashua Autism Network: Autism news, resources, and support in the Nashua area. www.nashuaautismnetwork.com/

New Hampshire Council on Autism Spectrum Disorders: Established by the state legislature to improve services and supports for those impacted by ASD. www.nhvirtualautismcenter.info/

Parent Information Center: Information about special education laws and advocacy in New Hampshire. 603-224-7005. www.parentinformationcenter.org

Rhode Island:

Autism Project of Rhode Island: Family support, resources, and education. 401-785-2666. www.theautismproject.org

Autism Society of America (Rhode Island chapter): 401-595-3241. www.asa-ri.org

Families for Effective Autism Treatment of Rhode Island: 401-886-5015. www.featri.org

Rhode Island Developmental Disabilities Council: 401-737-1238 www.riddc.org

Rhode Island Department of Education special education services: 401-222-4600. www.iser.com/state-gov/special-needs-RI.html

Rhode Island Disability Law Center: 401-831-3150. www.ridlc.org

Parent Training and Information Centers & Community Parent Resource Centers

Each state has at least one parent center serving families of children and young adults from birth to age 22 with disabilities. Parent Centers help families obtain appropriate education and services for their children with disabilities; train and inform on a variety of topics; resolve problems; and connect children to community resources that address their needs.

For information and to locate the Parent Center in your state, go to www.taalliance.org/ptidirectory/pclist.asp or call 888-248-0822

Massachusetts:

Federation for Children with Special Needs

Service Area: Statewide

www.fcsn.org

800-331-0688

Urban Pride

Service Area: Boston

www.urbanpride.org

617-206-4570

Rhode Island Parent Information Network: 401-270-0101. www.ripin.org

Connecticut:

Autism Families Connecticut: www.autismfamiliesct.org/

Autism Services and Resources Connecticut: 203-265-7717.
www.autismconnecticut.org

Connecticut Collaborative to Improve Autism Services: 800-505-7000.
www.ct.gov/dph/cwp/view.asp?a=3138&q=499610

Connecticut Families for Effective Autism Treatment: 860-571-3888.
www.ctfeat.org

Connecticut Family Support Network: 203-710-3041. www.ctfsn.org/

Connecticut Parent Advisory Center: 860-739-3089. www.cpacinc.org

Connecticut State Department of Education: 860-713-6543. www.sde.ct.gov

Maine:

Autism Society of America (Maine chapter): 800-273-5200. www.asmonline.org

Children's Behavioral Health Services (Department of Health & Human Services): (207) 287-5060. www.maine.gov/dhhs/ocfs/cbhs/index.shtml

Developmental Disabilities Council of Maine: www.maineddc.org

Disability Rights Center: 800-452-1948. www.drme.org

Maine Autism Alliance: www.maineautism.org

Maine Autism Spectrum Resource Center: 207-581-1084.
www.ccids.umaine.edu/resources/maineasrc/

Maine Parent Federation: 800-870-7746. www.startingpointsforme.org

Woodfords Family Services: 207-680-4790. www.woodfords.org

Vermont:

Autism Puzzle Foundation: www.vtautispuzzle.org

Autism Support Daily: 802-985-8773 www.autismsupportdaily.com

Department of Health: www.healthvermont.gov/family/autism.aspx

Vermont Division of Disability Autism Supports: 802-241-2863.
www.ddas.vermont.gov/ddas-programs/programs-autism-default-page

Vermont Family Network: www.vermontfamilynetwork.org/i-need-help-with/developmental-disabilities/autism/new-diagnosis-asd/

Vermont Autism Task Force: www.vtautismtaskforce.org

National Resources

American Academy of Pediatrics: <http://asdinfo.org/XKNIIM>

Autism Now: www.autismnow.org

Autism Society of America: Oldest parent advocacy group. Offers many resources. Provides annual conference and state chapters. www.autism-society.org

Autism Speaks: Funds global research into the causes, prevention, treatments and cure for autism; and raises public awareness about autism and its effects on individuals, families and society. www.autismspeaks.org Also offers a free comprehensive guide to the first 100 days after diagnosis which is available in English and Spanish. Download it from www.autismspeaks.org/docs/family_services_docs/100_day_kit.pdf

Interactive Autism Network: www.iancommunity.org

Wrights Law autism information: Special education laws and advocacy information. www.wrightslaw.com/info/autism.index.htm

Yellow Pages for Kids with Disabilities: Comprehensive list of resources by state for children with all disabilities. www.yellowpagesforkids.com



For the most up to date information on resources visit
www.autismconsortium.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 Standard and have private insurance, your child who has a disability (such as ASD) is eligible for MassHealth/CommonHealth as a secondary insurance.

What are the benefits of having CommonHealth as a secondary insurance payer?

- Pays deductibles and co-payments for doctor's visits, medications, hospitalizations, therapies, etc. to providers who take your primary insurance and CommonHealth.
- May provide additional medically necessary services for children with Autism Spectrum Disorder, including:
 - ABA therapy
 - Diapers and pull-ups for children older than age 3
 - Personal Care Attendants
 - Behavioral health services under Children's Behavioral Health Initiative
 - Occupational, Physical, and Speech and Language Therapy
 - Durable Medical Equipment

Types of MassHealth:

MassHealth Standard: If your family income is less than 150 percent of the federal poverty level, your child may be eligible for MassHealth Standard. Even if you have private health insurance, your child can also have MassHealth Standard at no additional cost to your family. MassHealth Standard will pay for deductibles, co-payments and other additional costs not covered by your private insurer; however your child must be seen by a provider who takes MassHealth.



There is a single application for all MassHealth but you must also fill out the Child Disability Supplement.

To view the Federal Poverty Level (FPL) Guidelines and use an on-line calculator to determine your family's FPL, please visit: www.safetyweb.org/fpl.php

MassHealth/ CommonHealth: If your family income is greater than 150 percent of the federal poverty level and you have a child with a disability your family may choose to

buy into the MassHealth system, even if you have private health insurance. This type of MassHealth is called CommonHealth. CommonHealth is a way to supplement private health insurance coverage for a child with a disability. **You pay a premium based on your family income. The premium may be eliminated if you are eligible for Premium Assistance, which is not based on income.** We encourage all families to first go through the CommonHealth application process for their child, and then apply for Premium Assistance to determine whether CommonHealth is a financially viable option for the family. **To apply for Premium Assistance after your child is found eligible for CommonHealth, call (800) 862-4840.**

Applying for MassHealth or CommonHealth:

There are several ways to apply for coverage under MassHealth or CommonHealth.

You can call 888-665-9993 and ask them to mail you all three items, or you can download them yourself:

- 1) Call MassHealth Customer Service at 800-841-2900 and ask them to mail you the Application for Health Coverage and the Child Disability Supplement. When you receive them, follow the steps below.
- 2) Or you can download the documents yourself from the links below:
 - A) The MassHealth Application for Coverage, available at: www.mass.gov/eohhs/docs/masshealth/membappforms/aca-2-english.pdf. When you have completed the application, either fax it to MassHealth at 617-887-8770 or mail it to MassHealth at: Health Insurance Processing Center, P.O. Box 4405 Taunton, MA 02780.
 - B) The Child Disability Supplement. Available at www.mass.gov/eohhs/docs/masshealth/appforms/mads-child.pdf. When you have completed the Disability Supplement and all its attachments, mail it to Disability Evaluation Services, PO Box 2796, Worcester, MA 01613.

Resources for More Information

For help applying for MassHealth, CommonHealth, Premium Assistance, or if you have any questions, call the Massachusetts Family-to-Family Health Information Center at 1-800-331-0688 ext. 301. Or e-mail: massfv@csn.org

If you need help completing the MassHealth application or Child Disability Supplement, call the Massachusetts Family-to-Family Health Information Center at 800-331-0688, ext. 301.

NOTE: If your income is more than 150% FPL, you will receive a letter from MassHealth stating your child is denied because your income is too high. Don't worry. All this means is that your child does not qualify for MassHealth Standard. MassHealth will still do a disability determination to see whether your child is eligible for CommonHealth.

After you get the letter stating that your child is eligible for either MassHealth Standard or MassHealth CommonHealth, it is very important that you immediately call the Premium Assistance program at 800-862-4840 to see whether you can get help paying your other health insurance premiums.

If your employer's health plan is in their database, they will set up the benefit for you. If it is not in their database, the Premium Assistance program will send you an application for Premium Assistance. You fill out part of the application, and then you give the application to your employer to fill out the rest of it and then they will send it to Premium Assistance. If your employer's plan is eligible for this benefit, and your child has MassHealth Standard, you will get help paying your other health plan premiums. If your child has CommonHealth, those premiums will be reduced or you will get money to help pay your other health plan premiums.

Portions of this article were written by the Massachusetts Family-to-Family Health Information Center at the Federation for Children with Special Needs.

Please note that as of March 31, 2014, MassHealth applications are temporarily being approved automatically with coverage due to expire on December 31, 2014. If your child received a temporary approval for MassHealth coverage you will need to reapply to MassHealth before your child's coverage expires. Reminder notices were sent out in September 2014. Anyone who is currently receiving temporary coverage has to reapply to determine MassHealth eligibility.

In addition, families who receive a MassHealth Monthly Premium Assistance Bill during this time should fax a copy of the invoice to Lekecia Powell-Watkins at 617-886-8400.

Please remember to contact the following agencies if you need additional information regarding MassHealth and/or Premium Assistance:

Autism Insurance Resource Center at 800-642-0249 or www.disabilityinfo.org/arica

Massachusetts Family-to-Family Health Information Center at 800-331-0688 ext. 301
(This line is messages only, however your call will be returned.)

**For the most up to date information on resources visit
www.autismconsortium.org**

Children’s Behavioral Health Initiative

Program for Children/Youth with Emotional, Behavioral, or Mental Health Issues:

MassHealth offers a program called the Children’s Behavioral Health Initiative (CBHI) for children and youth under age 21 with severe emotional, behavioral, or mental health issues who have any type of MassHealth except MassHealth Limited. Not every child with behavioral health concerns will be eligible—the application process for CBHI services is described on the next page. There are six services available under CBHI:

- 1) **In-Home Therapy (IHT):** If your child’s behavior is making daily life hard for the family, In-Home Therapy might be the right service for your child and family. Counselors will work with your whole family, helping you as a parent to help your child. IHT can help your child and family to
 - A) Resolve conflicts;
 - B) Learn new ways to do things;
 - C) Make new routines;
 - D) Set limits; and
 - E) Find community resources
- 2) **Intensive Care Coordination (ICC):** ICC might be the right service for you if your child has serious emotional or behavioral needs or if you need help getting all the adults in your child’s life to start working together. A Care Coordinator will help you bring together the main adults in your child’s life, so that everyone is working together to help your child. You choose who is on your team, including professionals (therapists, social workers, teachers) and your personal supports (friends or relatives).
- 3) **Therapeutic Mentoring Services:** Some children want to get along with others, but need help and practice learning to talk or act in new ways. A Therapeutic Mentor will go with your child to the places where the child has the most trouble and teach him or her new skills, such as better ways to talk or act with other children and adults.
- 4) **Family Support & Training (Family Partners):** Family Partners help parents and caregivers to help their children reach their treatment goals. They are parents or caregivers of children with special needs – they’ve “been there,” understand what families go through, and can share their experiences. Family Partners are not behavioral health professionals, but work closely with parents to help them get the services their children need.
- 5) **In-Home Behavioral Services:** Sometimes a child will do something over and over that bothers other people or harms the child. If it is very hard to get this child to act differently, a therapist will work with you and others in your child’s life to try new ways to help your child change these behaviors
- 6) **Mobile Crisis Intervention (MCI):** Mobile Crisis Intervention is for when your child or teen is having a crisis and needs help right away. MCI teams are

available 24 hours a day, 7 days a week. A trained team will come to a home, school, or other places in the community to help your child with the crisis. The team will help you get other services for your child and family.

Applying for CBHI Services:

To be eligible for CBHI services, a youth must typically apply to one of the following “hub” services: Intensive Care Coordination (ICC) or In-Home Therapy (IHT). However, children with ASD might be able to bypass these hub services by seeking a “hub waiver” and applying directly for In-Home Behavioral Services (IHBS). To learn more about the hub waiver process, visit

www.masspartnership.com/provider/pdf/MBHPIHBSHubWaiverCommunicationMarch2012.pdf

To start the application process, you or your child’s doctor or any public or private organization who knows your child can call the number on the back of the child’s MassHealth card or call MassHealth at 800-841-2900 and say that the child might have a behavioral health problem and might need CBHI services. Explain that this is for a child with autism and that a hub waiver might be necessary.

Another way that you or your child’s doctor or the agency working with your child can apply for CBHI services is to go to an online database to find ICC, IHT, or IHBS agencies that have openings to determine your child’s eligibility for services. To access the CBHI database:

- 1) Go to www.mabhaccess.com
- 2) Click on “Login”
- 3) Log in as a guest user
- 4) Select the service you want to search for in the drop-down box (ICC or IHT)
- 5) Type your zip code and desired service
- 6) Click on “Search”
- 7) Click on “Select” and scroll to the bottom of the page for the provider contact
- 8) Call the provider and ask to do application for CBHI services for your child. If you are applying for IBHS, remember to mention that you are seeking a hub waiver.

To read more about this process, go to:

www.mabhaccess.com/docs/MABHAWebsiteSearchGuideUPDATE_09072011.pdf

For more information:

If you have any questions about CBHI services, call MassHealth at 800-241-2900, visit:

www.mass.gov/eohhs/gov/commissions-and-initiatives/cbhi/

Metro Boston

www.mass.gov/eohhs/docs/masshealth/cbhi/brochure-metro-boston.pdf

Northeastern Mass

www.mass.gov/eohhs/docs/masshealth/cbhi/brochure-north-eastern-mass.pdf

Southeastern Mass

www.mass.gov/eohhs/docs/masshealth/cbhi/brochure-south-eastern-mass.pdf

Central Mass

www.mass.gov/eohhs/docs/masshealth/cbhi/brochure-central-mass.pdf

Western Mass

www.mass.gov/eohhs/docs/masshealth/cbhi/brochure-western-mass.pdf

Act Relative to Insurance Coverage for Autism (ARICA)

What is the Autism Insurance Law?

Massachusetts is one of many states with a law requiring health insurers to cover specified services for the diagnosis and treatment of autism spectrum disorder. The law is called ARICA (An Act Relative to Insurance Coverage for Autism) and went into effect on January 1, 2011 (or on the day in 2011 that your insurance plan renewed.)

Although ARICA calls for insurance providers to cover medically necessary autism treatment, not all Massachusetts insurance plans are required to comply with it. Plans that are not subject to ARICA include Massachusetts Medicaid (or MassHealth) and “self-insured” (also known as ERISA) plans. However, it is sometimes possible for individuals who have coverage under these plans to obtain ARICA-mandated benefits. In addition, with the passage of the Massachusetts Autism Omnibus bill in August 2014, families who have MassHealth might be able to access medically necessary treatment, including ABA, when the Omnibus bill is fully funded by the federal government. To learn more about the bill and how it might affect your family, visit the Autism Insurance Resource Center at www.disabilityinfo.org/arica.

For a brief overview of ARICA, please refer to the specific information in the following Frequently Asked Questions (FAQs), prepared by the Autism Insurance Resource Center, a division of New England INDEX/UMass Medical School Shriver Center.

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What does ARICA do?

ARICA requires health insurers in Massachusetts to provide coverage for the diagnosis and treatment of Autism Spectrum Disorder. You can find the text of the law at www.mass.gov/legis/laws/seslaw10/s1100207.htm

What types of policies does ARICA cover?

Massachusetts legislation can only affect certain types of health care policies, so coverage under ARICA will depend on the type of policy you have. Private insurers, employees and retirees under the state plan, hospital service plans and HMOs are all required to comply with the mandate. Self-funded plans are regulated by the Employee Retirement Income Security Acts (or ERISA) – which is federal law. This includes many of the State’s largest employers. ERISA plans are not subject to State laws and not required to provide coverage under ARICA.

How can I find out if I have coverage under ARICA?

Contact your employer to verify that your policy is subject to the new law, and if so, what annual date your group policy renews. Even if your company is regulated by ERISA they may, as practice, comply with State laws. In addition, there is language in the recently enacted federal health care reform that will eventually cover autism treatment. If you are covered by an ERISA plan, please contact the Autism Insurance Resource Center at (774) 455-4056 for additional information and assistance in advocating for coverage with your company.

Are individuals or family members covered for services under MassHealth or CommonHealth?

These plans are not subject to the new law, but consumers should know the following:

- MassHealth may cover co-pays and deductibles for some ARICA-mandated treatments covered by private insurance.
- The Premium Assistance Program can help subsidize purchase of private insurance policies and policies through Commonwealth Choice that will cover ARICA. Note: This is a limited program with specific application windows; check with the Autism Insurance Resource Center for more information.
- Families covered by MassHealth with children under age 9 can also apply for the Massachusetts Children's Autism Medicaid Waiver through the Department of Developmental Services (DDS). **Note:** This is a limited program with specific application windows; check with DDS for more information.
- In certain cases, consumers may be able to access some treatments through the Early Prevention, Screening, Diagnosis and Treatment (EPSDT) Program.

What treatments are covered under ARICA?

The law covers the following care prescribed, provided, or ordered for an individual diagnosed with an Autism Spectrum Disorder by a licensed physician or a licensed psychologist who determines the care to be medically necessary:

Habilitative or Rehabilitative care – this includes professional, counseling and guidance services and treatment programs, including but not limited to, applied behavior analysis supervised by a board certified behavior analyst, that are necessary to develop, maintain and restore, to the maximum extent practicable, the functioning of an individual.

Pharmacy care - medications prescribed by a licensed physician and health-related services deemed medically necessary to determine the need or effectiveness of the medications, to the same extent that pharmacy care is provided by the insurance policy for other medical conditions.

Psychiatric care - direct or consultative services provided by a psychiatrist licensed in the state in which the psychiatrist practices.

Psychological care -direct or consultative services provided by a psychologist licensed in the state in which the psychologist practices.

Therapeutic care - services provided by licensed or certified speech therapists, occupational therapists, physical therapists or social workers.

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Note: The above information was prepared by the Autism Insurance Resource Center, a division of New England INDEX/UMass Medical School Shriver Center.

Is there a limit to the amount of the coverage?

No. The diagnosis and treatment of Autism Spectrum Disorder will not be subject to any annual or lifetime dollar or unit of service limitation on coverage which is less than any annual or lifetime dollar or unit of service limitation imposed on coverage for the diagnosis and treatment of physical conditions.

Resources for More Information

For further information about ARICA, contact an Autism Resource Insurance Center information specialist at 774-455-4056 or 800-642-0249 or info@disabilityinfo.org. Or visit www.disabilityinfo.org/arica/

Is there an age limit to this coverage?

There is no age limit.

How are education services affected?

ARICA does not affect educational services provided under an IFSP, IEP or ISP. Insurers are not required to pay for in-school services. Conversely, under IDEA, schools may not require parents to access private insurance for services that are part of FAPE.

Are social skills groups covered?

Yes, per the parameters of covered treatments described above.

Are communication devices covered?

ARICA does not require coverage for devices, but will cover the therapy required to program and use the device.

How are education services affected?

ARICA does not affect educational services provided under an IFSP, IEP, or ISP. Insurers are not required to pay for in-school services. Conversely, under IDEA, schools may not require parents to access private insurance for services that are part of a Free and Appropriate Public Education (or FAPE).

**For the most up to date information on resources visit
www.autismconsortium.org**

Grants/Financial Assistance Programs

Are There Any Programs I Can Apply For?

All too often, parents of children with ASD incur unexpected and immense out-of-pocket costs for treatments and services. Unfortunately, in many cases insurance companies do not cover these expenses. Through the generosity of foundations and, sometimes, public funding, applicable grants might help parents offset these costs. Read each option carefully and understand that specific criteria pertain to each. Please note that this is not an exhaustive list, and information is subject to change.

Act-Today for Autism

Awards grants up to \$5000 to families, with priority given to those with a household income under \$100,000. Funding may be used for ABA, speech, OT, medications, & home safety devices. 19019 Ventura Blvd. Suite 200 Tarzana, CA 91356; 818-705-1625. www.act-today.org/act-today-grant-program.php

Asperger/Autism Network Family Grant Programs

Offers the Rainy Day Fund for Adults with Asperger Syndrome in crisis (\$50-\$100) or Family grants: Sponsored for a child with Asperger Syndrome or closely related disorder, such as PDD-NOS or high-functioning autism. 617-393-3824. www.aane.org/aane_services/grant_programs.html

Catastrophic Illness in Children Relief Fund

Provides financial assistance to families in Massachusetts for expenses incurred for the medical and related needs of children under age 22 who are not otherwise covered by insurance, federal or state health-care assistance. 800-882-1435 or 617-624-6060. www.mass.gov/eohhs/gov/departments/dph/programs/family-health/cicrf/

Children's Charity Fund

Provides funds for medical or educational supplies, open to all incomes. 6623 Superior Ave Suite B, Sarasota, FL 34234; 800-643-5787. www.childrenscharityfund.org

Consumer Empowerment Funds Program

Provides funds for individuals who are legal MA residents with developmental disabilities and/or a family member or guardian to attend conferences, trainings, or other events. Applications must be approved before the event and be based upon set program

guidelines. 1150 Hancock Street, 3rd Floor, Suite 300 Quincy, MA 02169. 617-770-7676 ext.115. <http://www.mass.gov/anf/employment-equal-access-disability/disability-info-and-resources/dev-disabilities-info/citizen-empowerment/council-empowerment-funds-program.html>

The Department of Early Education and Care (EEC)

Provides assistance, information and funding options for services and child care for children, birth to age 5, and their families. 617-988-6600. www.mass.gov/edu/birth-grade-12/early-education-and-care/financial-assistance/financial-assistance-for-families/

Doug Flutie Jr. Foundation for Autism

Provides grants to New England families of children with ASD under the Joey's Family Fund Grant Program. Provides a one-year subscription and free activation to LoJack SafetyNet under the Flutie Family Safe & Secure Program to families who could not otherwise afford it. 508-270-8855, Framingham, MA. www.flutiefoundation.org

Easter Seals of Massachusetts Assistive Technology Loan Programs

Offers Massachusetts residents with disabilities and their families low-interest cash loans they can use to purchase assistive technology, devices and services that will increase their independence. The program also loans low-cost assistive devices through its Long-Term Device Loan Program; 800-244-2756, www.easterseals.com/ma/our-programs/assistive-technology/loan-programs.html

Edwin Phillips Foundation

Provides grants directly to families in Plymouth County who have children with disabilities. Funds can be used for more expensive projects or services such as assistive technology or home modifications. P.O. Box 610075, Newton, MA 02461-0075. www.edwinphillipsfoundation.org

Financial Assistance

Autism Speaks maintains a database of local and national foundations and agencies that offer grants and support for families who are dealing with an autism diagnosis. www.autismspeaks.org/family-services/community-connections/financial-assistance

First Hand Foundation

Provides funds to families with limited incomes for Medical/psychiatric services, vehicle modification, transportation or items not covered by insurance. 2800 Rockcreek Parkway, Kansas City, MO 64117; 816- 201-1569. www.cerner.com/firsthand/FirstHand_1a.aspx?id=28729

Home Modification Loan Program

State-wide program. Provides home modification financing to people with disabilities and their families. Borrowers must reside in the home being modified. Visit: www.mass.gov/eohhs/consumer/disability-services/housing-disability/home-mod-loan/hmlp-cities-and-towns.html to find the agency that services your town. To learn more visit: www.mass.gov/eohhs/docs/mrc/hmlp-brochure-2014.pdf or call Susan Gilham at 617-204-3739.

Individual Development Accounts

IDAs are special savings accounts that match the deposits of low and moderate income people to save towards the purchase of a lifelong asset, such as a home. To find a program near you, go to the IDA network website at www.cfed.org/programs/idas/directory_search/

National Autism Association

Provides a one-time grant up to \$1,000 to families whose household earns less than \$50,000 to help support medical treatment, lab testing, supplements or therapy ONLY. 877-622-2884. www.nationalautismassociation.org/family-support/programs/helping-hand/

Social Security Disability Insurance

Provides benefits to families because of a child's disability, depending on income. To apply, call 800-772-1213. www.socialsecurity.gov/disability/disability_starter_kits_child_eng.htm

United HealthCare Children's Foundation

Households with private-pay or employer insurance (MassHealth/Medicaid subscribers do not qualify) may receive up to \$5,000 annually/\$10,000 lifetime to support the medical needs of their child, who must be 16 years of age or less. 855-698-4223. www.uhccf.org/apply

Will Power Foundation

Provides grants for Western Massachusetts families who have individuals with different abilities. \$500/limit a year. 413-559-0066. www.willpowerfoundation.org

Wish Upon a Hero Foundation

Individuals and families with financial need may submit "wishes" to this organization, which provides grants and other forms of charity to chosen applicants. 856-874-4444. 1640 Nixon Drive, Suite 336 Moorestown, NJ 08057 info@wishuponahero.org

Books

What Books Might Be Helpful?

Learning the Basics

Could It Be Autism? A Parent's Guide to the First Signs and Next Steps by Nancy D. Wiseman (2007).

Demystifying Autism Spectrum Disorders: A Guide to Diagnosis for Parents and Professionals by Carolyn Thorwath Bruey (2004).

Early Intervention and Autism: Real Life Questions, Real Life Answers by James Ball (2008).

Helping Your Child with Autism Spectrum Disorder: A Step-By-Step Workbook For Families by Stephanie B. Lockshin, Jennifer M. Gillis and Raymond G. Romanczyk (2005).

Overcoming Autism: Finding the Answers, Strategies, and Hope that Can Transform by Lynn Kern Koegel and Claire LaZebnik (2005).

The Autism Mom's Survival Guide (and Dads Too!): Creating a Balanced and Happy Life While Raising a Child with Autism by Susan Senator (2010).

Discovering Therapy Approaches

Applied Behavioral Analysis (ABA)

A Work in Progress: Behavioral Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism, editors Ron Leaf and John McEachin (1999).

ABA Program Companion: Organizing Quality Programs for Children with Autism and PDD by J. Tyler Fovel (2002).

Behavioral Interventions for Young Children with Autism: A Manual for Parents and Professionals, Editors Catherine Maurice, Gina Green, and Stephen Luce (1996).

Raising a Child with Autism: A Guide to Applied Behavioral Analysis for Parents by Shira Richman (2000).



Ask your local Autism Support Center about its lending library.

Right from the Start: Behavioral Intervention for Young Children with Autism by Sandra L. Harris and Mary Jane Weiss (2007).

Teaching Individuals with Developmental Delays: Basic Intervention Techniques by Ivar Lovaas (2002).

Floortime

Engaging Autism: Using the Floortime Approach to Help Children Relate, Communicate, and Think by Stanley Greenspan and Serena Weider (2009).

Picture Exchange Communication System (PECS)

Picture's Worth: PECS and Other Visual Communication Strategies in Autism by Andy Bondy and Lori Frost (2011).

Relationship Development Intervention (RDI)

Relationship Development Intervention with Young Children: Social and Emotional Development Activities for Asperger Syndrome, Autism, PDD, and NLD by Steven E. Gutstein and Rachelle K. Sheely (2002).

Sensory Processing

The Out-of-Sync Child: Recognizing and Coping with Sensory Processing Disorder by Carol Stock Kranowitz (2006).

The Out-of-Sync Child Has Fun: Activities for Kids with Sensory Processing Disorders by Carol Stock Kranowitz (2006).

Raising a Sensory Smart Child: The Definitive Handbook for Helping Your Child with Sensory Processing Issues by Lindsey Biel and Nancy Peske (2007).

Sensational Kids: Hope and Help for Children with Sensory Processing Disorder by Lucy Jane Miller and Doris A. Fuller (2007).

Social Communication Emotional Regulation Transactional Support (SCERTS)

The SCERTS Model: A Comprehensive Educational Approach for Children with Autism Spectrum Disorders by Barry M. Prizant, Amy M. Wetherby, and Emily Rubin (2005).

Parenting Children with Autism Spectrum Disorder

1001 Great Ideas for Teaching and Raising Children with Autism or Asperger's, Revised and Expanded 2nd Edition by Ellen Notbohm, Veronica Zisk, and Temple Grandin (2010).

Activity Schedules for Children with Autism: Teaching Independent Behavior by Lynn McClannahan (2010).

Asperger's and Girls by Tony Attwood, Temple Grandin, Teresa Bolick, and Catherine Faherty (2006).

Autism Solutions: How to Create a Healthy and Meaningful Life for Your Child by Ricki G. Robinson (2011).

Can't Eat, Won't Eat: Dietary Difficulties with Autistic Spectrum Disorders by Brenda Legge (2007).

Get Out, Explore, and Have Fun! How Families of Children with Autism or Asperger Syndrome Can Get the Most Out of Community Activities by Lisa Jo Rudy (2010).

Healthcare for Children on the Autism Spectrum: A Guide to Medical, Nutritional, and Behavioral Issues by Fred Volkmar and Lisa Wiesner (2004).

Just Take a Bite: Easy, Effective Answers to Food Aversions and Eating Challenges! By Lori Ernsperger, Tania Stegen-Hanson, and Temple Grandin (2004).

More Than A Mom: Living a Full and Balanced Life When Your Child Has Special Needs by Amy Baskin and Heather Fawcett (2006).

Raising Your Spirited Child: A Guide for Parents Whose Child is More Intense, Sensitive, Perceptive, Persistent, and Energetic by Mary Sheedy Kurcinka (2006).

Siblings of Children with Autism: A Guide for Families by Sandra L. Harris and Beth A. Glasberg (2003).

Straight Talk about Psychiatric Medications for Kids by Timothy Wilens (2006).

Teach Toileting: A Revolutionary Approach for Children with Autism Spectrum Disorders and Other Special Needs by Deborah Bialer (2009).

Ten Things Every Child with Autism Wishes You Knew by Ellen Notbohm (2005).

Toilet Training for Individuals with Autism or Other Developmental Issues by Maria Wheeler and Carol Stock Kranowitz (2007).

Visual Supports for People with Autism: A Guide for Parents and Professionals by Marlene Cohen and Sloan (2007).

Improving Behavior and Emotional Regulation

Freedom from Meltdowns: Dr. Thompson's Solutions for Children with Autism by Travis Thompson (2008).

My Book Full of Feelings: How to Control and React to the Size of Your Emotions by Amy V. Jaffe and Luci Gardner (2006).

No More Meltdowns: Positive Strategies for Managing and Preventing Out-Of-Control Behavior by Jed Baker (2008).

The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children by Ross W. Greene (2010).

The Incredible 5-Point Scale: Assisting Students with Autism Spectrum Disorders in Understanding Social Interactions and Controlling Their Emotional Responses by Kari Dunn Buron and Mitzi Curtis (2004).

When My Worries Get Too Big: A Relaxation Book for Children Who Live with Anxiety by Kari Dunn Buron (2006).

Improving Communication Skills and Social Skills

Do-Watch-Listen-Say: Social and Communication Intervention for Children with Autism by Kathleen Ann Quill (2000).

More Than Words: Helping Parents Promote Communication and Social Skills in Children with Autism Spectrum Disorder by Fern Sussman (1999).

Social Communication Cues for Young Children with Autism Spectrum Disorders and Related Conditions: How to Give Great Greetings, Pay Cool Compliments and Have Fun With Friends by Tarin Varughese (2011).

Teaching Language to Children with Autism or Other Developmental Disabilities by Mark L. Sundberg and James W. Partington (2010).

The New Social Story Book, Tenth Anniversary Edition: Over 150 Stories that Teach Everyday Social Skills to Children with Autism or Asperger's, and Their Peers by Carol Gray and Tony Attwood (2010).

The Verbal Behavior Approach: How to Teach Children with Autism and Related Disorders by Mary Barbera and Tracy Rasmussen (2007).

Thinking About You, Thinking About Me by Michelle Garcia Winner (2007).

With Open Arms: Creating School Communities of Support for Kids with Social Challenges Using Circle of Friends, Extracurricular Activities, and Learning Teams by Mary Schlieder (2007).

You are a Social Detective: Explaining Social Thinking to Kids by Michelle Garcia Winner, Pamela Crooke, and Kelly Knopp (2010).

Improving Organization and Executive Functioning Skills

Executive Skills in Children and Adolescents: a Practical Guide to Assessment and Intervention by Peg Dawson and Richard Guare (2010).

Late, Lost, and Unprepared: A Parents' Guide to Helping Children with Executive Functioning by Joyce Cooper-Kahn and Laurie Dietzel (2008).

Strategies for Organization: Preparing for Homework and the Real World by Michelle Garcia Winner (2005).

Obtaining Educational Services

How to Compromise with Your School District without Compromising Your Child: A Practical Guide for Parents of Children With Developmental Disorders by Gary Mayerson (2004).

IEP and Inclusion Tips for Parents and Teachers: Handout Version by Anne Eason and Kathleen Whitbread (2006).

The Complete IEP Guide: How to Advocate for Your Special Ed Child by Lawrence Siegel (2011).

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Ages 4-8

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What It Is to Be Me! An Asperger Kid Book by Angela Wine.

Ages 9-12

A Special Book about Me: A Book for Children Diagnosed with Asperger Syndrome by Josie Santomauro.

Can I Tell You About Asperger Syndrome? A Guide for Friends and Family by Jude Welton.

Different Like Me: My Book of Autism Heroes by Jennifer Elder.

Books for Siblings

Ages 4-8

All About My Brother by Sarah Peralta.

Everybody Is Different: A Book for Young People Who Have Brothers or Sisters With Autism by Fiona Bleach.

Ian's Walk: A Story about Autism by Laurie Lears.

My Brother Charlie by Holly Robinson Peete.

Ages 9-12

Autism Through a Sister's Eyes by Eve B. Band.

Rules by Cynthia Lord.

Sometimes My Brother: Helping Kids Understand Autism Through a Sibling's Eyes by Angie Healy.

Books to Teach Other Children about Autism

Ages 4-8

A Friend Like Simon by Kate Gaynor and Catriona Sweeney.

My Friend Has Autism by Amanda Doering Tourville and Kristin Sorra.

My Friend With Autism: Enhanced Edition with CD by Beverly Bishop.

Ages 9-12

A Is for Autism F Is for Friend: A Kid's Book for Making Friends with a Child Who Has Autism by Joanna L. Keating-Velasco.

Taking Autism to School by Andreanna Edwards.

The Autism Acceptance Book: Being a Friend to Someone with Autism by Ellen Sabin.