Parent Information Packet for Families of Children with Autism Spectrum Disorders

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

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

Understanding the diagnosis of ASD is an important first step for parents. The ASDs are described in detail in “What are PDDs and ASDs?” and include:

* Autistic Disorder
* Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)
* Asperger Syndrome

All ASDs are “pervasive developmental disorders,” meaning that several areas of development are affected. Although every child with an ASD is different, each has difficulties with communication and social interactions. They might also have difficulty with nonverbal communication, such as eye contact, facial expressions, and gestures (such as pointing). Play skills are often delayed and can be repetitive and unusual. Although some children are good-natured and easygoing, others might have difficult behaviors and little tolerance for change or frustration. Because every child’s individual
strengths and challenges vary, each child will need a different combination of programs and services to match his or her individual learning and social profile.

Doctors and other health-care professionals use different labels and language to describe children with ASDs. Your child might be said to have one of the diagnoses listed above – or 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.

After your child has been evaluated by a doctor, psychologist, or other professional or team of specialists, you will get an explanation of the diagnosis and a written report with recommendations for programs and treatments for home and school. You—the parent—know your child’s strengths, challenges, and needs better than anyone else. You are the expert on your child, which makes you the most critical person on your child’s treatment team.

Use the resources in this packet—and others that your health care team will tell you about. Ask questions. Seek advice and assistance. Contact the autism support center in your area (listed below). This is an agency especially created to help you and your family with the many questions you might have. The autism support center staff will help you get the information you need to make decisions about health care, education, social and leisure opportunities, community agencies, organizations and services, and funding sources. Many autism support center personnel are parents of children with autism themselves. They truly understand you. They have stood in your shoes and have learned valuable lessons that can save you time, effort, and worry. They want to help you and your child succeed in whatever you set out to do.

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

AUTISM ALLIANCE OF METROWEST in Natick. Serves Metrowest and Middlesex West. 508-652-9900.  [www.autismalliance.org](http://www.autismalliance.org)


AUTISM SUPPORT CENTER in Danvers. Serves Northeast region. 978-777-9135  [www.ne-arcautismsupportcenter.org](http://www.ne-arcautismsupportcenter.org)

FAMILY AUTISM CENTER in Westwood. Serves Norfolk County. 781-762-4001, Ext. 310  [www.sncarc.org/FAC.htm](http://www.sncarc.org/FAC.htm)

COMMUNITY AUTISM RESOURCES in Swansea. Serves Southeastern region, Cape Cod & Islands. 508-379-0371  [www.community-autism-resources.com](http://www.community-autism-resources.com)

COMMUNITY RESOURCES FOR PEOPLE WITH AUTISM in Easthampton. Serves Western region  413-529-2428  [www.communityresourcesforautism.org](http://www.communityresourcesforautism.org)


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

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What are PDDs and ASDs?

The term PDD or Pervasive Developmental Disorder is used to describe problems in a child's development. PDDs are called “spectrum” disorders because each child has symptoms that differ in intensity, ranging from mild to quite severe. All children with PDD, however, have some degree of difficulty in the following areas:

- **Social skills:** Such as sharing emotions, understanding how people are feeling, expressing empathy, or having a conversation
- **Communication:** Both spoken and unspoken, such as pointing, gesturing, and making eye contact
- **Behaviors or interests:** Such as repeating words or actions, playing with things in an unusual way (spinning objects, lining up toys), or insisting on following rigid routines or schedules

There are five PDDs: Autistic Disorder, Pervasive Developmental Disorder — Not Otherwise Specified (PDD-NOS), Asperger Syndrome, and the less frequently occurring disorders: Rett Syndrome and Childhood Disintegrative Disorder (CDD). **As you can see below, there are three autism spectrum disorders (ASDs).**
Autism Spectrum Disorders (ASDs)

As you can see from the diagram, Autistic Disorder, PDD-NOS, and Asperger Syndrome are under the category of **Autism Spectrum Disorders (ASDs)**.

- **Autistic Disorder** or **Autism** is characterized by difficulties in all three areas (social skills, communication, and behavior/interests — see above).

- **PDD-NOS** or **High-Functioning Autism** describes a child who meets some but not all the criteria for autism or has milder symptoms in one or more areas.

- **Asperger Syndrome** is characterized by relatively good basic language skills but difficulties in social interactions and conversation. A child with Asperger Syndrome might also have intense or restricted interests and/or challenging behaviors.

Your child’s specialists might use slightly different terms to describe your child. But even when professionals don’t always use these terms the same way, they usually agree that a child fits under the broader ASD category.

**Less frequent Pervasive Developmental Disorders**

**Rett Syndrome** is a developmental disorder that begins with normal early development and is followed by loss of motor skills, particularly hand use, and distinct hand movements, such as wringing, regression in skills, and slowed growth.

**Childhood Disintegrative Disorder** begins with normal development until the age of 3 or 4 and is followed by severe loss of communication, social, play, and motor skills.

To read more about ASDs, visit these websites:

- [www.cdc.gov/ncbddd/autism/facts.html](http://www.cdc.gov/ncbddd/autism/facts.html)
- [www.aap.org/healthtopics/autism.cfm](http://www.aap.org/healthtopics/autism.cfm)
- [www.autism-help.org](http://www.autism-help.org)
- [www.autism-pdd.net](http://www.autism-pdd.net)
- [www.autism-society.org](http://www.autism-society.org)
- [www.autismspeaks.org/what-autism](http://www.autismspeaks.org/what-autism)
- [www.iancommunity.org](http://www.iancommunity.org)
How are ASDs Treated?

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

For children under age 3

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

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

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

For children over age 3

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

If you live in another state, ask your child’s doctor how to access local resources.

All good programs for children with an ASD:

- Focus on social and communication skills.
- Use positive behavior supports and strategies.
- Set goals and assess progress regularly.
- Work with your child’s individual needs and interests.
- Have predictable schedules.
- Have a high teacher-to-student ratio.
- Involve the family (for example, parent education or home-based programs).
- Are full day (5 hours), full week (5 days a week), and full year (12 months).
- Are taught by experienced staff who are trained in working with children with ASDs.
- Include transition planning to help a child move smoothly to the next level.
In “ABA” and “Floortime,” two of the most commonly used comprehensive teaching approaches for children with ASDs, providers work step-by-step with a child to build language, social, and play skills. Here is a general description of each approach:

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

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

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

- **Speech-language therapy**, which helps a child learn to understand and express her or himself through language.
- **Total communication interventions**, which involve using language, vocalizations, pictures and gestures as well as sign language and the Picture Exchange Communication System (PECS) – almost any means that a child can and will use to communicate.
- **Occupational therapy, physical therapy and sensory integration therapy**, which respectively focus on a child’s hand and finger skills (fine motor), large muscle (gross motor), and sensory needs.
- **Positive behavioral supports**, which minimize challenging behaviors through rewarding appropriate behaviors, responses, and task completion.

Medical professionals might also implement the following therapies:

- **Medication.** There is no medication specifically for ASD. Some medications can help with symptoms such as hyperactivity, anxiety, compulsive behaviors, attention, or aggression. Ask your doctor for advice as to whether one or more medications might be appropriate for your child and if the benefits outweigh any risks or side effects associated with the medication.
- **Biological therapies**, which include specialized or restricted diets, nutritional supplements and vitamin regimens. Consult your doctor to determine whether these approaches have been demonstrated to be safe and effective.
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 1-800-905-8437 (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.

What happens after a referral?
An EI team will conduct a developmental assessment of your child with your family members present to determine eligibility. This assessment will focus on specific areas of child’s development, including cognitive, speech/language, motor and self-help skills, social and emotional development, and behavior.
If your child is found to be eligible, an Individualized Family Service Plan (IFSP) will be written based on the individual needs of your child and family. EI will begin working with your child and family within 45 days of referral.

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

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

How are services paid for?
In Massachusetts, some, but not all families pay an annual fee based on family size and income. For more information, call 800-905-8437 or go to http://www.mass.gov/Eeohhs2/docs/dph/com_health/early_childhood/annual_fee.pdf

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.
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 disorders 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 on the autism spectrum 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 in the right column on this page. It is also in the booklet: “Information for Families with Children Newly Diagnosed with Autism Spectrum Disorders,” available to families from your Early Intervention provider or can be downloaded from the Early Intervention Parent Leadership website: www.eiplp.org/documents/SSP_Autism0109.pdf.

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

Specialty Service Providers

**BEACON SERVICES:** Serves most communities in the state
508-478-0207 x 247
www.beaconservices.org

**BUILDING BLOCKS:** Serves Northeast region, Boston, and Worcester, 978-762-8352
www.nsarc.org/bblocks_ei.html

**CHILDREN MAKING STRIDES:** Serves Southeast region and Cape Cod, 508-563-5767
www.childrenmakingstrides.com/ intervention.shtml

**HMEA, Inc.:** Serves Central, Northern, Southeast, and Boston areas, 508-298-1170
www.hmea.org/childrens_service1 .html

**LIPTON EARLY ASSISTANCE PROGRAM (LEAP):** Serves Central and North Central regions
978-466-8333

**MAY Institute:** Serves Boston area, South Shore, and North Shore, 781-437-1404
Hampshire & Hampden counties: 413-734-0300
www.mayinstitute.org/services/consultation/home_based.html

**NEW ENGLAND CENTER FOR CHILDREN:** Serves Southborough area
508-481-1015, Ext. 3016
www.necc.org/programs_services/early_childhood_hb.asp

**PEDIATRIC DEVELOPMENT CENTER:** Serves Berkshire County,
413-499-4537, Ext. 106 or 103
www.pediatricdevelopmentcenter. org/ssp.htm

**SERVICENET-REACH PROGRAM:** Serves Hampshire, Hampden, and Franklin counties, and North Quabbin area,
413-397-8986, Ext. 409
www.servicenetinc.org/index.php?id=173
All school systems are required to provide children with disabilities an educational program to meet each child’s needs at the age of three.

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.

For more information about specialty services such as ABA or Floortime, call Tracy Osbahr, Early Intervention intensive services coordinator at 413-586-7525.
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. Legally, you are entitled to and must be informed of all services available to your child. The greater your involvement and voice, the better the outcome.

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

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

1. Ask questions. When you do not understand something at a meeting, ask someone to further explain.
2. Prepare for meetings and phone calls concerning your child. Be familiar with the information that will be discussed and list all concerns that you expect to be addressed.
3. Obtain as much information as you can about the process and your rights. Contact the Federation for Children with Special Needs at 800-331-0688 or visit its website at www.fcsn.org

4. Consider using an advocate. Professional representatives can help you make your voice heard. An educational advocate can be assigned by the Department of Elementary and Secondary Education to act on behalf of a child when the child’s parents are unavailable or have no educational decision-making rights. Private independent advocates are available for all, although families that are 400 percent above the federal poverty level can be charged a fee for services. The Bureau of Special Education Appeals (BSEA) provides a list of free and low-cost advocacy services and attorneys upon request (call 781-338-6400 or visit www.doe.mass.edu/bsea/).

5. Take advantage of parent groups. Other parents are important resources because they are experiencing or have experienced the same or very similar situations to you. The three major parent resources are:
   - MassPAC (www.masspac.org) or www.concordspedpac.org to find listings for your own city or town’s Parent Advisory Council.
   - Federation for Children with Special Needs (www.fcsn.org)
   - Massachusetts Family TIES (www.massfamilyties.org)

6. Notify your child’s primary care provider. Your child’s provider can better serve your child if he/she is aware that your child is receiving a TEAM evaluation. It is important that the doctor know about the proceedings and what services your child receives as a result.

7. Remember to review the education laws before your IEP meeting.

**Important reminders**

- A TEAM evaluation and the services your child may receive are all free.
- All guardians/parents of children in public school (regardless of immigration status) are able to request a TEAM evaluation.

**504 versus an IEP**

504 Plans and IEPs both require students to be evaluated to be able to receive necessary accommodations. However, 504 Plans and IEPs have many differences. 504 plans are not as detailed and the requirements for evaluation are not as specific. Both can technically provide specialized instruction, but because no federal funding accompanies a 504, in practice, schools use a 504 only for accommodations, modifications, (not for specialized instruction, related services, etc.). Section 504 has fewer procedural safeguards to protect the parent and child.

An IEP is a legal document that promotes more effective progress through a specialized instruction with modification of actual program or curriculum materials.
Least Restrictive Environment

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

Types of classrooms

Substantially separate classrooms (self-contained) serve students who require a highly modified curriculum in separate classrooms rather than in general education programs.

Inclusion classrooms serve students with special needs that are able to access the standard preschool curriculum with minor accommodations.
Transition to School Timeline for Parents

Referral and Consent

Parent or professional writes a letter to the school requesting an evaluation for a child saying, “I give consent for the school to evaluate my child.”

School sends letter for parent to sign to schedule evaluations

Evaluation

Must occur within 45 school days of consent signed

Tests and assessments

Team meeting

Written summary of tests completed (you MUST ask the school to give you copies and you will get them 2 days before the meeting)

Individualized Education Plan (IEP)

Sign IEP (you can reject whatever you disagree with)

Decision

Receive services

Appeal

IEP sent to parents within 55 school days of consent signed

Parents return IEP to school within 30 calendar days
What Educational Laws Protect My Child?

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.parentcenternetwork.org/parentcenterlisting.html.

Massachusetts State Laws

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

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

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

“This law requires that IEP teams consider and address in the IEP discussion the following seven specific needs of students with ASDs:

1. **Verbal and nonverbal communication needs:** Impairment in communication is one of the defining characteristics of ASD. Therefore instruction and development of communication skills should be addressed as an essential element of the student's IEP.

2. **The need to develop social interaction skills and proficiencies:** Social skills vary in severity and pervasiveness as well as how they present at different ages and developmental stages. In the most severe expression of qualitative social impairment, students with ASD may consistently appear socially disconnected or avoidant, even with immediate family members. In less severe cases, they may find it difficult to initiate interactions, frequently misunderstand social situations or be unable to maintain a conversation on a subject other than one on a preferred topic. A younger child with ASD may lack variation in spontaneous or social imitative play, lack pretend or imaginary play skills or play with toys in an atypical or repetitive way, e.g. lining up toy cars or spinning the wheels, rather than racing them or engaging in pretend scenarios.

3. **The needs resulting from the student's atypical responses to sensory experiences:** The IEP Team should consider whether a student with ASD exhibits under- or over-sensitivity to particular stimuli, such as tactile, visual, auditory, smell, taste or texture. One and often several of these sensitivities are common in students with ASDs and can cause major discomfort, inattention and negative behaviors.

4. **The needs resulting from resistance to environmental change or alterations in daily routines:** Students with ASDs often have unusual 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 understand or adapt to. Preparing for changes and transitions with visual schedules and supports, multiple verbal reminders and timers often helps to minimize the discomfort and promote greater success, flexibility and independence.

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

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

IEP OPTIONS

Has your child's IEP Team considered all the options? IEPs for children with autism spectrum disorders 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
- Speech & language therapy
- Occupational therapy
- Physical therapy
- Vocational supports
- Life skills training
- Classroom aides
- Transition services
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.

B) 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 ASDs over the age of thirteen, visit www.autismconsortium.org

Federal Laws

There are four federal laws that protect the rights of students with disabilities:
• The Individuals With Disabilities Education Act of 2004
• The No Child Left Behind Act of 2001
• Section 504 of the Rehabilitation Act of 1973
• The Americans with Disabilities Amendments Act of 2008

The Individuals with Disabilities Education Act (IDEA) of 2004

All states get federal money under IDEA and must provide a free, appropriate public education to all eligible children with disabilities. A child can be identified as eligible for special education only after an evaluation has been conducted. Your local school district is responsible for evaluating your child and you will need to ask them to schedule an evaluation. However, you can also submit any evaluations your child has already had for their consideration.

IDEA provides for special education and related services to children in all types of settings – child care, preschool, kindergarten, elementary, middle and high schools. Special education is a means by which children can get the supports and services they need in order to learn and make effective progress. Special education is not a “place” but rather a way for your child to get an appropriate education.

For more information about IDEA, go to www.nclrd.org/content/view/902/456086/

No Child Left Behind Act (NCLB) of 2001

NCLB requires states and school districts to intensify their efforts to improve the academic achievement of public school students considered at risk for school failure. Moreover, the law holds the districts accountable for their schools' performance. The challenging new provisions of NCLB create expanded opportunities for improved academic achievement and documentation of that improved performance. NCLB outlines the requirements for parental involvement, highly qualified teachers,
scientifically-based reading instruction, tutoring and supplemental educational services, research-based teaching methods, and individual school and district report cards.

For more information on NCLB, go to www2.ed.gov/nclb/landing.jhtml

Section 504 of the Rehabilitation Act of 1973 (known as Section 504)

Section 504 and the ADA are federal civil rights laws that prohibit discrimination against those with disabilities. Their goal is to promote equal access to and participation in programs and services for all people with disabilities.

Section 504 applies to all programs and activities that receive federal money, including school districts, Head Start programs, and some private schools. Children with disabilities who are not eligible for special education programs and related services under IDEA might be eligible for services under Section 504. The Section 504 regulations require a school district to ensure that children with disabilities have equal access to educational opportunities, including physical access. If your school district provides after-school programs for students, those programs must also be available for students with disabilities.

To read more about Section 504, go to www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html

The Americans with Disabilities Amendments Act (ADA) of 2008

The ADA gives civil rights protections to individuals with disabilities that are consistent with those provided to people on the basis of race, sex, national origin, and religion. For children with disabilities, ADA guarantees equal opportunity in public accommodations, and state and local government services, including public schools. Most private schools and childcare centers also abide by the ADA.

The goal of the ADA is to remove the barriers that prevent those with disabilities an equal opportunity to share in and contribute to American life. The law is about participation and access to the same kinds of opportunities available to those without disabilities. For example, under the ADA, most public or private agencies cannot refuse to allow your child to participate solely because of a disability.

To read more about this law, go to www.ada.gov/

The above information is derived from the U.S. Department of Education, Office of Educational Research and Improvement, and is used with permission.
What Are Some Community Resources For Families?

The following is a list of resources for children with autism spectrum disorders and their families. Each resource offers a range of different supports and may also have specific eligibility criteria, so it is important for you to contact them directly.

One of the most helpful resources for families with a member with an ASD is your local Autism Support Center. There are currently seven support centers located in Massachusetts that receive funding from the Autism Division at the Department of Development Services. The centers offer information and referral information, parent trainings, workshops and some specialized programs for children, teens and young adults. The centers are often staffed by parents who have a child with ASD, and are there to explain what services and supports your child and family can benefit from. Call and introduce yourself and your child, ask to be put on their mailing lists, and tell them you would like to do an "intake" for services. Many of the centers also offer support groups and information sessions that can be very helpful to families.

The Support Center staff can also explain the benefits of applying for government funds and assistant programs through the Massachusetts Department of Development Disabilities (DDS). In Massachusetts, DDS provides a wide array of services and supports to children under 18 years of age with autism or other conditions. Currently, there are two types of services you can apply for within DDS if your child has an ASD:

1) The DDS “Autism Division” only program is for children diagnosed with an autism spectrum disorder. 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. 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 no or minimal cost to your family. Also note that each center raises private funds so they might coordinate other programs that do have participation fees.

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

2) The DDS “Dual Eligibility” status includes the Autism Division and DDS Children’s Eligibility. If your child also meets this Children’s Eligibility Criteria...
then you may be able to also access DDS service coordination and perhaps family support services based on the availability of funds. In order to be eligibility for DDS Children’s services a child must have a diagnosis of a global developmental delay (under age 5), a diagnosis of a developmental disability (over age 5) and have impaired levels of functioning in at least three 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. If your child is determined Dually Eligible for the Autism Division and DDS Children’s services then you will get connect with a local DDS Area Office to determine what supports are may be available for your child.

For information about the DDS eligibility guidelines and to download the Application for DDS Eligibility, go to www.mass.gov and type “DDS application” in the search engine or go to www.mass.gov/Eeohhs2/docs/dmr/ie_Application_form.pdf. The regional office information is referenced on the same page as the application. It is important to send the completed application to your Regional Eligibility office or call 888-367-4435 with any questions. After you send in your application, you will be contacted for a face to face interview and asked to provide diagnostic information and supporting documentation (for example, a report from a developmental pediatrician, psychologist, an IEP, etc.).

**Autism Resources**

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

**Asperger's Association of New England (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. 800-642-0249. www.disabilityinfo.org/arica

Charles River Center: This 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 a travel readiness program with Logan Airport for families of children with autism who have difficulty with airline travel and security screeners. Please contact them for more detailed information. 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.dougflutiejrfoundation.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 22 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 and type Early Intervention in the Search box 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 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 question 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.


Sibling Support Project: This is a national program dedicated to supporting the concerns of brothers and sisters of people who have special health, developmental, or mental health concerns. There are also local service providers who host workshops, and listservs to support siblings of people with special needs. www.siblingsupport.org

Special Health Needs Community Support Line: Under the Massachusetts Office of Health and Human Services, the support line offers statewide information, help, and referrals for families of children with special health-care needs. Go to www.mass.gov and type Community Support Line in the Search box or call 800-882-1435.

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

Special Education Resources

Children's Law Center of Massachusetts: Provides legal services to low income children, and information and training to parents. 781-581-1977. 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

EdLaw 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 617-989-8150 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

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/

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_groups_sepacs. Also visit www.masspac.org for more information.

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


New Hampshire:


Department of Education: 603-271-3494.  

www.nh.easterseals.com

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

New Hampshire Resource Center on Autism Spectrum Disorders: At the Institute on Disability at UNH. 603-228-4230. www.iod.unh.edu/PriorityAreas/autism

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

Southeastern Regional Education Service Center: Education and behavioral support programs and services for families and schools; has specific autism services. Bedford. 603-206-6800. www.seresc.net/ed_autism.php

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

Department of Elementary and Secondary Education: 401-222-8999.  www.ride.ri.gov

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

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

Maine:
Center for Community Inclusion & Disability Studies at the University of Maine: 207-581-1084. www.ccids.umaine.edu
Department of Education: www.maine.gov/education/speced/index.htm
Developmental Disabilities Council of Maine: www.maineddc.org

Vermont:
Autism Society of America (Vermont chapter): www.autism-info.org
Department of Education: 802-828-5116.  

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

Vermont Autism Task Force: www.autismtaskforce.com

National Resources

American Academy of Pediatrics: www.aap.org/healthtopics/autism.cfm

Autism, Asperger’s and Pervasive Developmental Disorders: Offers comprehensive information, education, articles, and fact sheets.  www.autism-help.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


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

Important Websites

Community Activities/Recreation

Autism Speaks  
www.autismspeaks.org/community/fsdb/category.php?sid=26&cid=33

SpEdChildMass  
www.spedchildmass.com

Federation for Children with Special Needs  
www.fcsn.org

Special Olympics  
www.specialolympicsma.org

Social Skills

Asperger’s Association of New England  
www.aane.org/asperger_resources/social_skills_groups.html

Michelle Garcia-Winner  
www.socialthinking.com/what-is-social-thinking/about-michelle-garcia-winner

Carol Grey/Social Stories  
www.thegraycenter.org/
Why Might a Child Need Mass Health & 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 an autism spectrum disorder) may be eligible for MassHealth/CommonHealth as a secondary insurance. Child disability determinations are made by the federal criteria standards, which are outlined on the Social Security Administration (SSA) website. To read the SSA criteria for Autism Spectrum Disorders, go to: www.socialsecurity.gov/disability/professionals/bluebook/112.00-MentalDisorders-Childhood.htm#112_10

MassHealth, as a secondary insurance payer:

- Pays deductibles and co-payments for doctor’s visits, medications, hospitalizations, therapies, etc. not covered by your other health plan
- May provide additional medically necessary services for children with Autism Spectrum Disorders, including:
  - Behavioral health services – see http://bit.ly/9xPDVc for details
  - Occupational, Physical, and Speech and Language Therapy
  - Diapers for children older than three who do not toilet independently
  - Durable Medical Equipment
  - Personal Care Attendants

See the full chart of MassHealth covered services at http://bit.ly/ap6nDs

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.

**MassHealth/ CommonHealth:** If your family income is greater than 150 percent of the federal poverty level and you have a child with a disability (as defined by the SSA federal criteria listed above) your family may choose to buy into the MassHealth
system, even if you have private health insurance. This type of MassHealth is called MassHealth/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.

**Applying for MassHealth:**

**There are three items you need in order to apply for CommonHealth:**

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

- The MassHealth member booklet
  
  [www.mass.gov/eohhs/docs/masshealth/appforms/member-booklet.pdf](http://www.mass.gov/eohhs/docs/masshealth/appforms/member-booklet.pdf)

- The Member Benefit Request Form (MBR)
  
  [www.mass.gov/eohhs/docs/masshealth/appforms/mbr.pdf](http://www.mass.gov/eohhs/docs/masshealth/appforms/mbr.pdf)

- The Child Disability Supplement
  

Obtain the documents listed above and fill out all of the required information. If you have questions about how to fill out the MBR, call the Massachusetts Family-to-Family Health Information Center (see below). Next, complete the following steps to ensure that your application is processed as efficiently as possible:

1) Fill out a MassHealth Medical Records Release form for every health provider your child sees.
   
   a. Find this form at [www.mass.gov/eohhs/docs/masshealth/appforms/mh-mrr.pdf](http://www.mass.gov/eohhs/docs/masshealth/appforms/mh-mrr.pdf) or call 888-665-9993 to obtain a copy.
   
   b. Fill out one form for each health provider by name. If your child is in Early Intervention or has an IEP or 504 plan at school, include the EI providers’ and/or teachers’ names too. It’s not enough information to just write the primary care office, EI program, school, hospital, or clinic.

2) Include:
   
   a. A copy of your child’s birth certificate or other proof of citizenship
   
   b. Two recent pay stubs for all earned income
   
   c. Documentation of nonworking income like child support or alimony
   
   d. A copy of your child’s IFSP, IEP or 504 plan, and any clinical notes from the doctors

3) **Mail the MBR**, copy of the birth certificate, and documentation of working and nonworking income to:

   MassHealth Enrollment Center
   Central Processing Unit
   P.O. Box 290794
   Charlestown, MA 02129-0214
4) **Mail the Child Disability Supplement, Medical Records Release Forms, and clinical documentation to:**

Disability Evaluation Services  
P.O. Box 2796  
Worcester, MA 01613  
State you have applied for MassHealth for the child and sent the MBR to Charlestown or that you submitted the MBR online.

If your income is more than 150% FPL, you will receive a letter 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. If you have sent the Child Disability Supplement, Medical Records Release forms and clinical document to Disability Evaluation Services, MassHealth will do a disability determination to see if your child is eligible for MassHealth CommonHealth.

After you get the letter stating your child is eligible for either MassHealth Standard or MassHealth CommonHealth, call the MSPCA program to see if 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, you will receive an application for MSCPA. You will fill out part, and your employer will fill out part. If the employer’s plan is eligible for the benefit, and your child has MassHealth Standard, you will get help paying your other health plan premiums. If your child has MassHealth 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.

| For assistance applying for MassHealth. CommonHealth, Premium Assistance, or if you have any questions, please call the Massachusetts Family-to-Family Health Information Center at 1-800-331-0688 ext. 301. (This line is messages only. Your call will be returned.) Or e-mail: massfv@fcsn.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
   • resolve conflicts;
   • learn new ways to do things;
   • make new routines;
   • set limits; and
   • 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 access all of the services available through the CBHI program, your child must first be approved for either Intensive Care Coordination (ICC) services or In-Home Therapy (IHT) services. 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.

You or your child’s doctor or the agency working with your child can also go to an online database to find ICC or IHT agencies that have openings to determine your child’s eligibility for services. To access the 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

To read more about this process, go to: www.mabhaccess.com/docs/MABHAWebsiteSearchGuideUPDATE_09072011.pdf

If you have any questions about CBHI services, call MassHealth at 800-241-2900, visit www.mass.gov/masshealth/cbhi or look at the following brochures:

- Metro Boston
  www.mass.gov/Eeohhs2/docs/masshealth/cbhi/brochureMetroBoston.pdf
- Northeastern Mass
- Southeastern Mass
- Central Mass
- Western Mass
  www.mass.gov/Eeohhs2/docs/masshealth/cbhi/brochureWesternMass.pdf
What is the autism insurance law?

Massachusetts is one of many states with a law requiring health insurers to cover specified services (see right side of this page for the list) for the diagnosis and treatment of autism spectrum disorders. 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 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. If you are covered by a plan that isn’t subject to 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.

What treatments are covered under ARICA?

The law covers the following care prescribed, provided, or ordered for an individual diagnosed with one of the Autism Spectrum Disorders 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.

CONTINUED ON NEXT PAGE
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 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 (781) 642-0248 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.
- Families covered by MassHealth with children under age 9 can also apply for the Massachusetts Children’s Autism Medicaid Waiver through 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.

Is there a limit to the amount of the coverage?
No. The diagnosis and treatment of Autism Spectrum Disorders 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.

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.

What treatments are covered under ARICA? (continued)

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.

For further information about ARICA, contact an Autism Resource Insurance Center information specialist at 781-642-0248 or info@disabilityinfo.org, or visit www.disabilityinfo.org/arica/
Are There Grants 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 Association of New England Family Grant Programs**  
Offers the Rainy Day Fund for Adults 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

**Autism Family Resources**  
Families with a household income below $50,000 can apply for a one-time grant totaling $500. Money may be used to cover therapy equipment, safety equipment, and respite care. 3535 Eastside Hwy. Stevensville, MT 59870  
autismfamilyresources.org/needassistance2.htm

**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/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

**Community Block Grants**  
Home modification grants may be available by contacting your local city government.
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)

Doug Flutie Jr. Foundation for Autism
Provides computers to families of children with autism who otherwise couldn’t afford to buy one under the Laurie Flutie Computer Initiative. 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. http://www.dougflutiejrfoundation.org/Programs.asp

Easter Seals of Massachusetts Assistive Technology Loan Program
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; 508-751-6431 or 508-751-6428, or email MassATLoan@eastersealsma.org. http://ma.easterseals.com/site/PageServer?pagename=MADR_ATLoanpressrelease

Edwin Phillips Foundation
Provides grants directly to families who have children with disabilities, including physical and cognitive challenges. 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. http://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
Provides financing to disabled, cognitive, developmental, environmental sensitivity and neurological disabled persons and their families. Borrowers must reside in the home being modified. Contact RCAP Solutions Financial Services at 978-630-6725. www.rcapsolutions.org/financial_services.htm

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 IDAnetwork website at http://cfed.org/programs/idas/directory_search/

Knights of Columbus
Families with children under the age of 20 who need wheelchair ramps, hearing aids, or stair lifts may be awarded grants of up to $5,000 from the Knights of Columbus Charitable Fund. 470 Washington St, Suite 6, Norwood, MA 02062; 781-551-0628. www.massachusettsstatekofc.org

National Autism Association
Provides a one-time grant up to $1500 to families whose household earns less than $50,000 to help support tuition, supplements/medication, medical evaluation or testing, therapies, etc. 22136 Westheimer Pkwy. #623, Katy, TX 77450; 877-622-2884. www.nationalautismassociation.org/helpinghand.php

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 their child, who must be 16 years of age or less. MN012-S286, PO BOX 41, Minneapolis, MN 55440-0041; 800-992-4459. www.uhccf.org/apply_applicant.html

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. 1640 Nixon Drive, Suite 336 Moorestown, NJ 08057 foundation@wishuponahero.com
What Books Might Be Helpful?

**Learning the Basics**


**Discovering Therapy Approaches**

*Applied Behavioral Analysis (ABA)*


*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

Picture Exchange Communication System (PECS)

Relationship Development Intervention (RDI)

Sensory Processing


Social Communication Emotional Regulation Transactional Support (SCERTS)

Parenting Children with Autism Spectrum Disorders


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).


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


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


Improving Behavior and Emotional Regulation
Freedom from Meltdowns: Dr. Thompson’s Solutions for Children with Autism by Travis Thompson (2008).


**Improving Communication Skills and Social Skills**


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


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


Obtaining Educational Services


Wrightslaw: Special Education Law by Pam Wright and Pete Wright (2007).

Writing Measurable IEP Goals and Objectives by Barbara D. Bateman and Cynthia Herr (2006).

Adolescent Issues


Autism-Aspergers and Sexuality: Puberty and Beyond by Jerry Newport, Mary Newport, and Teresa Bolick (2002).


The Aspie Teen’s Survival Guide: Candid Advice for Teens, Tweens, and Parents, from a Young Man with Asperger’s Syndrome by J.D. Kraus (2010).


Books in Spanish


Los Trastornos del Espectro de Autismo de la A a la Z by Emily Doyle Iland and Barbara T. Doyle (2005).

Books for Children with ASD

Ages 4-8
I Am Utterly Unique: Celebrating the Strengths of Children with Asperger Syndrome and High-Functioning Autism by Elaine Marie Larsen.

Understanding Sam and Asperger Syndrome by Clarabelle van Niekerk.

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.


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.


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.


Ages 9-12

Taking Autism to School by Andreanna Edwards.

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