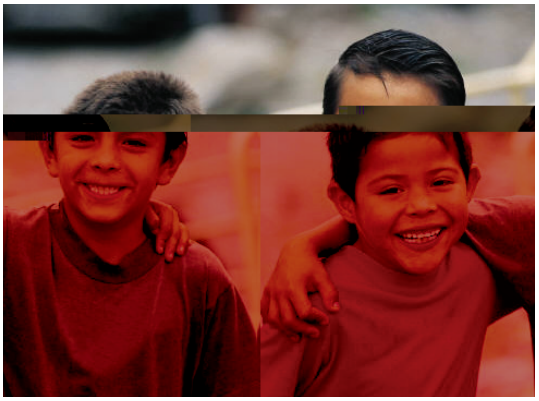
autism
CONSORTIUM

Parent information packet

Resources and timeline planning for your family



www.autismconsortium.org

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Introduction

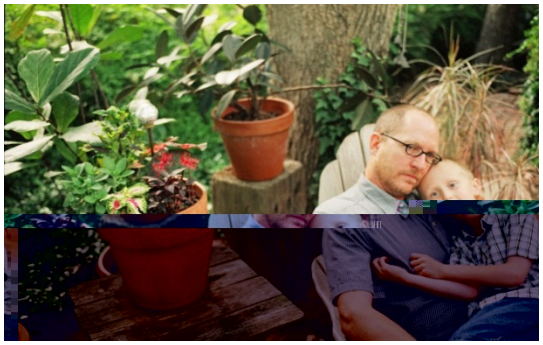
When a child is diagnosed with an autism spectrum disorder (ASD), parents often experience a range of emotions—from disbelief and confusion, to sadness and fear, to feeling overwhelmed and even feeling relieved that they finally know what's going on. This is absolutely normal. All parents ask, "What 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



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

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

Autism Resource Specialists

Boston Medical Center Developmental and Behavioral Pediatrics

Shari King

617-414-3666

Shari.king@bmc.org

Boston Children's Hospital Developmental Medicine Center

Neal Goodman

617-355-6802

Neal.Goodman@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

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

Autism Alliance of Metrowest

In Natick, Serves Metrowest and Middlesex West.

508-652-9900

www.autismalliance.org

Autism Resource Center

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

508-835-4278

www.autismresourcescenteral.org/index.html

Autism Support Center

In Danvers, Serves Northeast region

978-777-9135

www.ne-arcautismsupportcenter.org

Family Autism Center

In Westwood, Serves Norfolk County

781-762-4001, ext. 310

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

Community Autism Resources

In Swansea, Serves Southeastern region, Cape Cod & Islands

508-379-0371

community-autism-resources.com

Community Resources for People with Autism

In Easthampton, Serves Western region

413-529-2428

communityresourcesforautism.org

TILL & Boston Families for Autism

In Dedham, Serves Greater Boston

781-302-4835

www.tillinc.org/autism_training.html

Supported by a grant from the Nancy Lurie Marks Family Foundation

Understanding Autism and Treatments

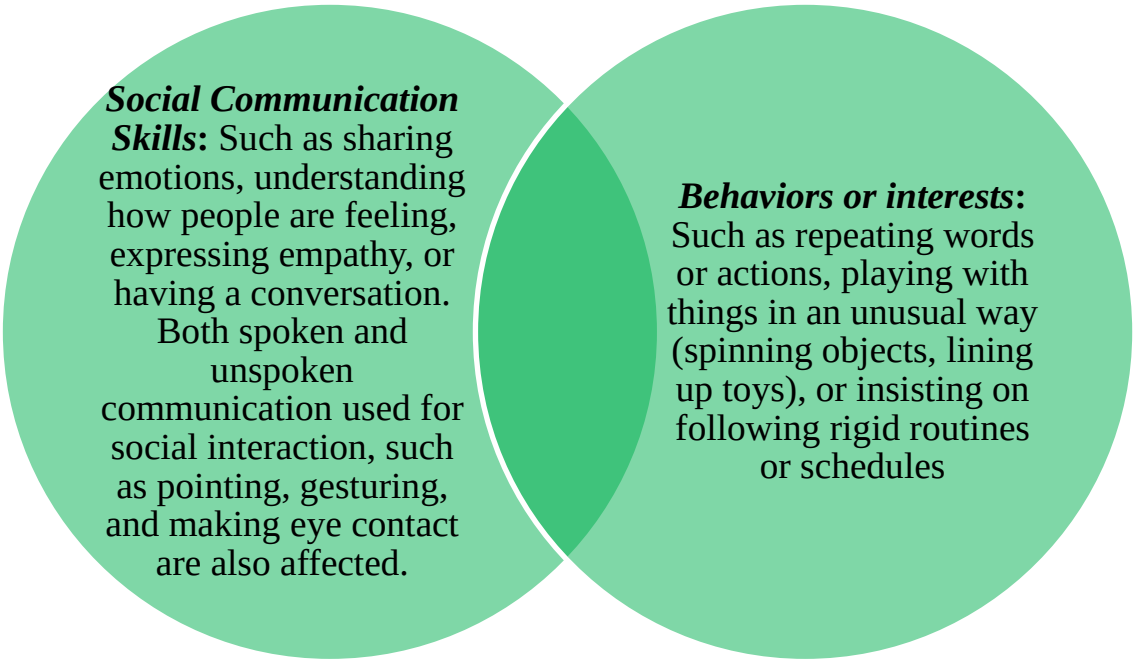
Understanding the diagnosis of Autism Spectrum Disorder (ASD) is an important first step for parents. Though symptoms and severity vary, ASD affects children's ability to communicate and interact with others. Children with ASD can also have difficulty with nonverbal communication, such as eye contact, 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 ASDs. Your child might be described as "autistic," having autistic features, or being "on the autism spectrum." It is referred to as a spectrum because autism affects the skills and abilities of each child differently.

What is Autism Spectrum Disorder?

ASD is a complex neurodevelopment disorder, characterized by a range of social communication and interaction impairments, and restricted, repetitive, and stereotyped patterns of behavior.

It is a "spectrum" disorder because every individual with ASD has symptoms that differ in intensity, ranging from mild to quite severe. Symptoms of ASD are usually noticed in early childhood, but for some may not become obvious until the child is a bit older. All children with ASD, however, have some degree of difficulty in the following two areas:



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 mental health 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 ASDs, visit these websites:

cdc.gov/ncbddd/autism/facts.html

www.aap.org/healthtopics/english/health-issues/conditions/developmental-disabilities/pages/autism-spectrum-disorders.aspx)

www.autismspeaks.org/what-autism

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

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.

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.

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, 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).

Resources

ABA- Applied Behavioral Analysis
http://rsaffran.tripod.com/whatisaba.html

Floortime or DIR
www.floortime.org

PECS – Picture Exchange 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

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

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

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

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

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

Medical professionals might also implement the following therapies:

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

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

For 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 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.

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

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 website. Select a program that uses the approach that feels most appropriate for your child and family and the one recommended by your child’s doctor.

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.

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

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:
    A) MassPAC (www.masspac.org) or www.concordspedpac.org to find listings for your own city or town's Parent Advisory Council.
    B) Federation for Children with Special Needs (www.fcsn.org)
    C) 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.

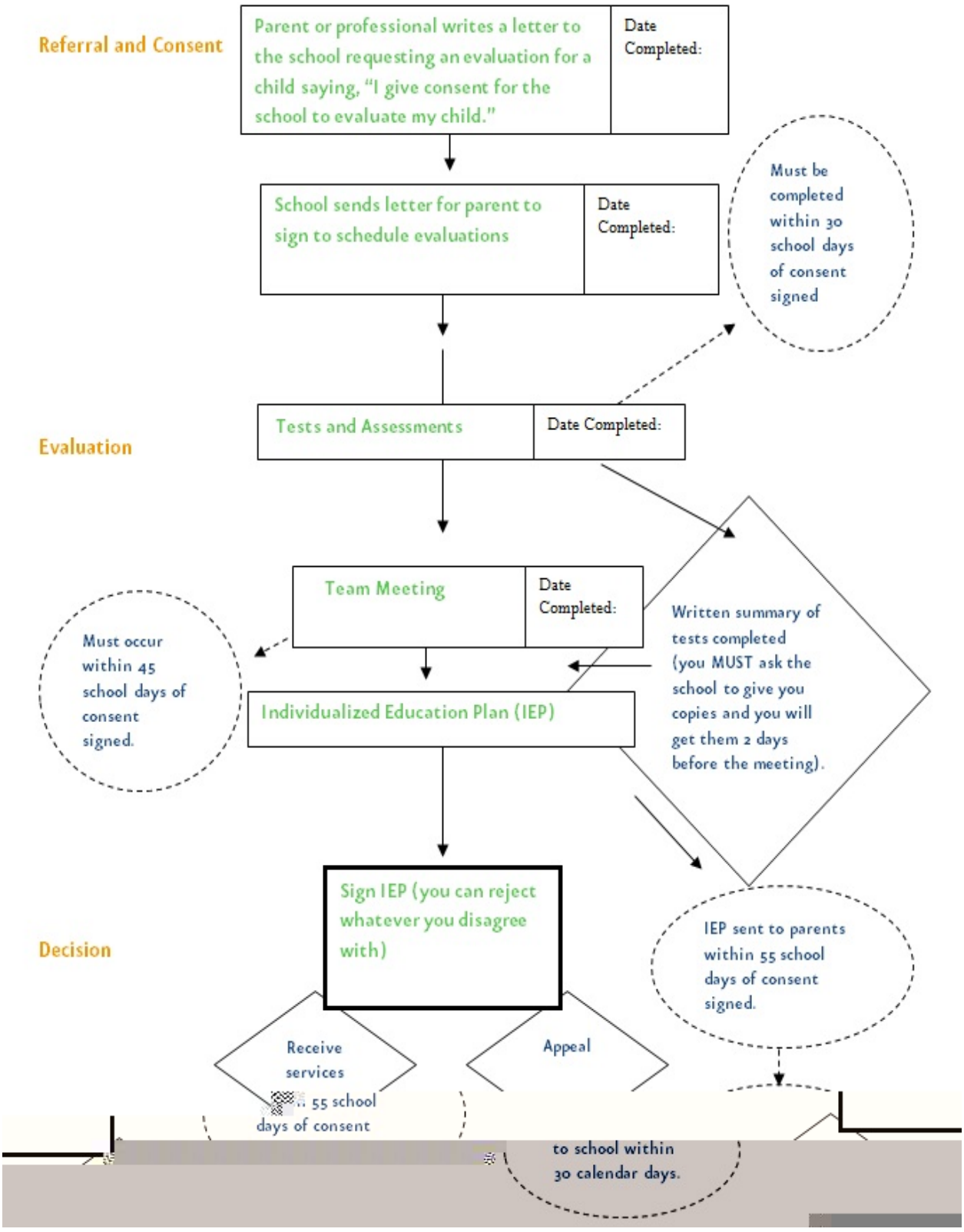
Types of classrooms

- **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.
- **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.

The following assessments may be included with parental consent if the school or the parent asks for them:

- **Health Assessment:** An assessment to identify any medical problems that may affect the student's learning.
- **Psychological Assessment:** An assessment to consider the student's learning abilities and style in relationship to his or her social/emotional development and skills.
- **Home Assessment:** An assessment of family history that may affect the student's learning or behavior of the student at home.

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.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.)

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

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

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

New England States' Department of Education Websites

Massachusetts Department of Elementary and Secondary Education Special Education/Parent Information:
www.doe.mass.edu/sped/parents. html

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/

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

Community Resources

Public awareness of autism is greater than ever, so there is broader understanding of the diagnosis and the challenges faced by these young people 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.

Raising a child with an autism spectrum disorder (ASD) can be overwhelming. You need to know that you are not alone.

Autism Support Centers/DDS

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.

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

Camp Listings

Newsletter

School Vacation Programs

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

Autism Support Centers

Autism Alliance of Metrowest
In Natick; Serves Metrowest, Middlesex West

508-652-9900

www.autismalliance.org

Autism Resource Center
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-arcautismsupportcenter.org

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

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.

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: 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.

Special Olympics Massachusetts: 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

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

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 617-989-8150 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

- 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_groups_sepacs. Also visit www.masspac.org 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 city of Boston. A resource for workshops, parent supports and advocacy. 617-206-4570. www.urbanpride.org

Local ARC

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

New Hampshire:

Autism Society of America (New Hampshire chapter): Offers educational support and resources for parents. Concord. 603-679-2424. www.autism-society-nh.org

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

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

Easter Seals Autism Network, Family Support Program: Offers support meetings, parent education, respite program. Manchester. 603-623-8863. 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

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:

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

Connecticut:

Autism Society of America (Connecticut chapter): 888-453-4975. www.asconn.org

Connecticut Autism Spectrum Resource Center: 203-265-7717. www.ct-asrc.org

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

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

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

Hartford-New Haven Community Parent Resource Center (CPRC): 860-297-4358

www.parentcenternetwork.org

Stamford Education 4 Autism: 203-322-9767. www.stamfordeducation4autism.org

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

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

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

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

Vermont:

Autism Society of America (Vermont chapter): www.autism-info.org

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

Department of Education: 802-828-5116.
www.education.vermont.gov/new/html/pgm_sped.html

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: 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 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 - Childhod.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.

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

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
- The Member Benefit Request Form (MBR) www.mass.gov/eohhs/docs/masshealth/appforms/mbr.pdf
- The Child Disability Supplement www.mass.gov/eohhs/docs/masshealth/appforms/mads-child.pdf

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 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.

Resources for More Information

For assistance applying for MassHealth, CommonHealth, Premium Assistance (800.862.4840), 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-m ail: massfv@csn.org

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 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 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

For more information:

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

Metro Boston
www.mass.gov/Eeohhs2/docs/masshealth/cbhi_metro-boston.pdf

Northeastern Mass
www.mass.gov/Eeohhs2/docs/masshealth/cbhi/brochure_north-eastern-mass.pdf

Southeastern Mass
www.mass.gov/Eeohhs2/docs/masshealth/cbhi/brochure_south-eastern-mass.pdf

Central Mass
www.mass.gov/Eeohhs2/docs/masshealth/cbhi/brochure_central-mass.pdf

Western Mass
www.mass.gov/Eeohhs2/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 (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.

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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/sl100207.htm

When does ARICA go into effect?

ARICA went into effect January 1, 2011, but implementation is based on each policy's specific renewal date. If you have insurance under a policy that is subject to ARICA (see below), the coverage must be provided when the policy renews on or after January 1, 2011, meaning it will go into effect the date that your company's insurance plan renews annually.

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

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.

Resources for More Information

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/

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 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)

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 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 IDA network 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

Will Power Foundation

If you are in Western Mass, you can apply for support for this (and other things) from the Will Power Foundation (www.willpowerfoundation.org) Grants are given up to $500

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

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

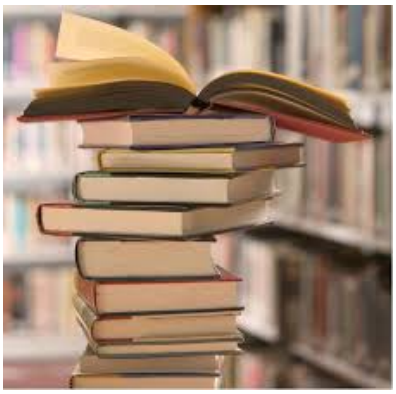
Overcoming Autism: Finding the Answers, Strategies, and Hope that Can Transform by Lynn Kern Koegel and Claire LaZebnik (2005).

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).



Ask your local Autism Support Center about its lending library.

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).

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 Disorders

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).

The Everyday Advocate: Standing Up for Your Child with Autism by Areva Martin (2010).

Wrightslaw: From Emotions to Advocacy: The Special Education Survival Guide by Pam Wright and Pete Wright (2006).

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

60 Social Situations and Discussion Starters to Help Teens on the Autism Spectrum Deal with Friendships, Feelings, Conflict, and More: Seeing the Big Picture by Lisa Timms (2011).

A Spectrum of Relationships: A Guide to Understanding Social Connections for Teens and Adults with Autism and Aspergers Syndrome by C.S. Wyatt (2011).

Adolescents on the Autism Spectrum: A Parent's Guide to the Cognitive, Social, Physical, and Transition Needs of Teenagers with Autism Spectrum Disorders by Chantel Sicile-Kira and Temple Grandin (2006).

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

Asperger Syndrome and Bullying: Strategies and Solutions by Nick Dubin and Michael John Carley (2007).

Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know About the Pre-Teen and Teenage Years by Shana Nichols (2008).

Growing Up on the Spectrum: A Guide to Life, Love, and Learning for Teens and Young Adults with Autism and Aspergers by Lynn Kern Koegel (2010).

Making Sense of Sex: A Forthright Guide to Puberty, Sex and Relationships for People with Asperger's Syndrome by Sarah Attwood (2008).

Perfect Targets: Asperger Syndrome and Bullying – Practical Solutions for Surviving the Social World by Rebekah Heinrichs and Brenda Smith Myles (2003).

Social Skills for Teenagers and Adults with Asperger Syndrome: A Practical Guide to Day-to-day Life by Nancy J. Patrick (2008).

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).

The Bully Blockers: Standing Up for Classmates with Autism by Celeste Shally (2009).

Books in Spanish

El Manual del Autismo: Informacion Facil de Asimilar, Vision, Perspectivas y Estudios de Casos de un Mawestro de Educacian Especial by Jack E. George (2009).

Introduccion al Enfogue ABA en Autismo y Retraso de Desarrollo, Un Manual para Padres y Educadores by Claudio Trivisonno (2010).

Los Trastornos del Espectro de Autismo de la A a la Z by Emily Doyle II 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.

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.