



# Autism Connections

a Pathlight program

SUPPORT

RESOURCES

INFORMATION

Autism Connections provides support to individuals with autism and their families by fostering community collaboration, support for inclusion, and understanding of autism through a qualified and experienced staff.



## About Autism Connections

Autism Connections was founded in 1989 by parents of children with autism. Our goal is to help families, schools, professionals, agencies, and communities understand autism, promote the well-being of individuals with autism, and foster their inclusion in the community.

We help families build on their strengths, work together to create a positive vision for the future, and help children learn, grow, and be welcomed, fully included members of their communities.

Autism Connections is directed by parents and other family members in partnership with autism professionals and other concerned citizens.

## Overview of Services

Autism Connections provides the following services to children and adults with autism, their families, friends, and professionals in western Massachusetts:

### \* Autism Center

- Information and Referral
  - Monthly newsletter
  - Resource center
  - Information packets on a variety of autism related topics
  - Online resource and referral directory
  - Young adult and adult connections/support and social skills groups
  - Parent-parent connections and support groups
  - Education Advocacy (fee-based)
  - Social, sensory, and recreational activities
  - Education and training: workshops and small group clinics (free)
  - Annual Autism Conference
  - Training for schools and other organizations (fee-based)
  - Family and community focused events

### \* Direct Services

(by Department of Developmental Services referral)

- Individualized adult and child family-based supports
- Intensive family supports
- Children's Waiver Program
- Agency with Choice





Our program includes training in how to seek out experiences in the community that interest each student, giving them access to the same opportunities as their typical peers.

## Contact Us

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Easthampton, MA 01027  
Telephone: 413-529-2428  
Fax: 413-529-2567

100 North St. Suite 322  
Pittsfield, MA 01201  
Telephone: 413-443-4780  
Fax: 413-443-6581

[autismconnectionsma.org](http://autismconnectionsma.org)  
[autismconnections@pathlightgroup.org](mailto:autismconnections@pathlightgroup.org)

## What is Autism?

Autism is a complex developmental disability that typically appears during the first two years of life. It is the result of a neurological disorder that affects development in the areas of social interaction and communication skills. Both children and adults with autism typically show difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities.

Autism may affect an individual's ability to:

- communicate
- relate to people
- respond to pain, touch, sound, and taste
- learn and think in typical ways

It is estimated that autism occurs in as many as 1 in 68 individuals—more than 1.5 million people in the United States. Autism knows no racial, ethnic, or social boundaries; family income levels; lifestyle choices; or educational levels, and can affect any family and any child. And although the overall incidence of autism is consistent around the globe, it is diagnosed four times more often in boys than in girls.



[WWW.AUTISMCONNECTIONSMA.ORG](http://WWW.AUTISMCONNECTIONSMA.ORG)

800-536-2910

[INFO@PATHLIGHTGROUP.ORG](mailto:INFO@PATHLIGHTGROUP.ORG)



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Springfield, MA 01104  
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### About Pathlight

#### Autism Connections is a Pathlight program

Pathlight is a 501(c)3 non-profit Massachusetts corporation with offices in Pittsfield, Springfield, Greenfield, Easthampton, and Hadley. It was founded in 1952 by five mothers of children with developmental disabilities.

The majority of Pathlight's revenue comes through state agencies, including the Massachusetts Department of Developmental Services and the Massachusetts Department of Medical Assistance. Pathlight also raises money from a broad network of generous donors. We gratefully accept support from individuals, businesses, and foundations.

# Ten Things Every Child with Autism Wishes You Knew

By Ellen Notbohm  
South Florida Parenting

Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute is the inconsistency. There is little argument on any level but that autism is baffling, even to those who spend their lives around it.

The child who lives with autism may look "normal," but his or her behavior can be perplexing and downright difficult. Today, the citadel of autism, once thought an "incurable" disorder, is cracking around the foundation. Every day, individuals with autism show us they can overcome, compensate for, and otherwise manage many of the condition's most challenging aspects. Equipping those around our children with a simple understanding of autism's most basic elements has a tremendous effect on the children's journey towards productive, independent adulthood. Autism is an extremely complex disorder, but we can distill it to three critical components: sensory processing difficulties, speech/language delays and impairments, and whole child/social interaction issues.

Here are 10 things every child with autism wishes you knew.

**1. I am a child with autism.** I am not "autistic." My autism is one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)?

**2. My sensory perceptions are disordered.** This means the ordinary sights, sounds, smells, tastes and touches of everyday life that you may not even notice can be downright painful for me. The very environment in which I have to live often seems hostile. I may appear withdrawn or belligerent to you, but I am really just trying to defend myself. A "simple" trip to the grocery store may be hell for me. My hearing may be hyper acute. Dozens of people are talking at once. The loudspeaker booms today's special. Muzak whines from the sound system. Cash registers beep and cough. A coffee grinder is chugging. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can't filter all the input, and I'm in overload! My sense of smell may be highly sensitive. The fish at the meat counter isn't quite fresh, the guy standing next to us hasn't showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, and they're mopping up pickles on Aisle 3 with ammonia. ... I can't sort it all out, I'm too nauseous.

Because I am visually oriented, this may be my first sense to become over stimulated. The fluorescent light is too bright. It makes the room pulsate and hurts my eyes. Sometimes the pulsating light bounces off everything and distorts what I am seeing. The space seems to be constantly changing. There's glare from windows, moving fans on the ceiling, so many bodies in constant motion, too many items for me to be able to focus - and I may compensate with tunnel vision. All this affects my vestibular sense, and now I can't even tell where my body is in space. I may stumble, bump into things, or simply lay down to try and regroup.

**3. Please remember to distinguish between won't (I choose not to) and can't (I'm not able to).**

Receptive and expressive languages are both difficult for me. It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, this is what I hear: "\*&^%\$#@, Billy. #\$\$%^&^%\$&\*" Instead, come speak directly to me in plain words: "Please put your book in your desk, Billy. It's time to go to lunch." This tells me what you want me to do and what is going to happen next. Now it's much easier for me to comply.

**4. I am a concrete thinker.** I interpret language literally. It's very confusing for me when you say, "Hold your horses, cowboy!" when what you really mean is "Please stop running." Don't tell me something is a "piece of cake" when there is no dessert in sight and what you really mean is, "This will be easy for you to do." When you say, "It's pouring cats and dogs," I see pets coming out of a pitcher. Please just tell me, "It's raining very hard." Idioms, puns, nuances, double entendres and sarcasm are lost on me.

**5. Be patient with my limited vocabulary.** It's hard for me to tell you what I need when I don't know the words to describe my feelings. I may be hungry, frustrated, frightened or confused, but right now those words are beyond my ability to express. Be alert for body language, withdrawal, agitation, or other signs that something is wrong.

There's a flip side to this: I may sound like a little professor or a movie star, rattling off words or whole scripts well beyond my developmental age. These are messages I have memorized from the world around me to compensate for my language deficits, because I know I am expected to respond when spoken to. They may come from books, television or the speech of other people. It's called echolalia. I don't necessarily understand the context or the terminology I'm using, I just know it gets me off the hook for coming up with a reply.

**6. Because language is so difficult for me, I am very visually oriented.** Show me how to do something rather than just telling me. And please be prepared to show me many times. Lots of patient repetition helps me learn.

A visual schedule is extremely helpful as I move through my day. Like your day planner, it relieves me of the stress of having to remember what comes next, makes for smooth transitions between activities, and helps me manage my time and meet your expectations. Here's a great web site for learning more about visual schedules <http://www.cesa7.k12.wi.us/newweb/content/rsn/autism.asp>

**7. Focus and build on what I can do rather than what I can't do.** Like any other human, I can't learn in an environment where I'm constantly made to feel that I'm not good enough or that I need fixing. Trying anything new when I am almost sure to be met with criticism, however constructive, becomes something to be avoided. Look for my strengths and you'll find them. There's more than one right way to do most things.

**8. Help me with social interactions.** It may look like I don't want to play with the other kids on the playground, but sometimes it's just that I simply don't know how to start a conversation or enter a play situation. If you can encourage other children to invite me to join them at kickball or shooting baskets, I may be delighted to be included.

**9. Try to identify what triggers my meltdowns.** This is termed "the antecedent." Meltdowns, blowups, tantrums or whatever you want to call them are even more horrid for me than they are for you. They occur because one or more of my senses has gone into overload. If you can figure out why my meltdowns occur, they can be prevented.

**10. If you are a family member, please love me unconditionally.** Banish thoughts such as, "If he would just ..." and "Why can't she ... ?" You didn't fulfill every last expectation your parents had for you, and you wouldn't like being constantly reminded of it. I didn't choose to have autism. Remember that it's happening to me, not you. Without your support, my chances of successful, self-reliant adulthood are slim. With your support and guidance, the possibilities are broader than you might think. I promise you I'm worth it.

It all comes down to three words: Patience. Patience. Patience.

Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. I may not be good at eye contact or conversation, but

have you noticed I don't lie, cheat at games, tattle on my classmates, or pass judgment on other people?

You are my foundation. Think through some of those societal rules, and if they don't make sense for me, let them go. Be my advocate, be my friend and we'll see just how far I can go.

I probably won't be the next Michael Jordan, but with my attention to fine detail and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh.

They had autism too.

*Freelance writer and consultant Ellen Notbohm is a columnist for Autism/Asperger's Digest and co-author of 1001 Great Ideas for Teaching and Raising Children With Autism Spectrum Disorders (Future Horizons). She favors "common sense" approaches to raising her sons with autism and AD/HD. She lives in Oregon.*





## **Massachusetts Department of Developmental Services**

Massachusetts has a comprehensive system of specialized services and supports to give individuals with intellectual disabilities the opportunities to live the way they choose. The Department is the state agency that manages and oversees this service system. Every day, we provide these specialized services and supports to approximately 32,000 adults with intellectual disabilities and children with developmental disabilities. The types of specialized services and supports include day supports, employment supports, residential supports, family supports, respite, and transportation. We provide these services through facilities and community-based state operated programs and by contracting with 235 private provider agencies.

**[www.mass.gov/eohhs/gov/departments/dds/](http://www.mass.gov/eohhs/gov/departments/dds/)**

### **Important DDS Telephone Numbers**

**DDS Intake and Eligibility Determination: (413) 205-0940**

DDS Area Offices:

Franklin/Hampshire: (413) 586-4948

Holyoke/Chicopee: (413) 535-1022

Springfield/Westfield: (413) 784-1339

Berkshire: (413) 447-7381

# Autism Insurance Resource Center

at New England INDEX

[www.disabilityinfo.org](http://www.disabilityinfo.org)

781-642-0248

[info@disabilityinfo.org](mailto:info@disabilityinfo.org)

## The Massachusetts Autism Insurance Law (aka ARICA) Frequently Asked Questions

FAQs [en Español](#), [bằng tiếng Việt](#) at [www.disabilityinfo.org/arica/](http://www.disabilityinfo.org/arica/)

### **What does ARICA do?**

ARICA requires health insurers in Massachusetts to provide coverage for the diagnosis and treatment of Autism Spectrum Disorder, which currently affects 1 in every 110 individuals. The text of the law can be found at <http://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 would all be 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 us 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 programs 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 Program (EPSDT).

**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.

**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.
- *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.

**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.

For further information, contact an information specialist at 781-642-0248 or e-mail us at [info@disabilityinfo.org](mailto:info@disabilityinfo.org)

Last updated Sept 27, 2011

For the most current version, please check our website <http://www.disabilityinfo.org/arica/>

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The Autism Insurance Resource Center is a division of New England INDEX/UMass Medical School Shriver Center. Partial funding for the Center is provided through grants from the Massachusetts Developmental Disabilities Council (MDDC), Massachusetts Department of Developmental Services (DDS), Autism Speaks, and the Doug Flutie Jr. Foundation for Autism. New England INDEX is a state-wide information and referral service for people with disabilities. Online access to comprehensive resources is available at [www.disabilityinfo.org](http://www.disabilityinfo.org).



# Welcome To Holland



I am often asked to describe the experience of raising a child with a disability -- to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this . . .

When you're going to have a baby, it's like planning a fabulous vacation trip -- to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

There had been an unexpected change in the flight plan. Your plane landed in Holland and there you must stay.

The important thing is that you haven't taken you to a horrible, disgusting, filthy place that's full of pestilence, famine and disease. It's just a different place. So, you're forced go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you have been there for a while and catch your breath, you look around and you begin to notice that Holland has windmills . . and Holland has tulips . . . Holland even has Rembrandts!

But, everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that is where I was supposed to go. That is what I had planned."

That pain of that will never, ever go away because the loss of that dream is a very significant loss. But if you spend your whole life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special and very lovely things in Holland . . .

~ Emily Pearl Kingsley



## *Next Steps* A GUIDE FOR FAMILIES NEW TO AUTISM

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This document can be found on the web site of the Autism Society free for download and duplication.

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*Long before receiving the diagnosis of Autism Spectrum Disorder, parents suspect that something is different about their child. After testing and consultation confirm the parents' suspicions, the first questions that often arise are: "Where do we go from here? What do we do next?"*

### WHAT IS AN AUTISM SPECTRUM DISORDER?

Autism Spectrum Disorders (ASD) are complex neurological disorders that affect individuals in the areas of social interaction and communication. Autism and its associated behaviors have been estimated to occur in at least 1 in 175 individuals (Centers for Disease Control and Prevention, 2006). Autism is referred to as a spectrum disorder - meaning the symptoms can occur in any combination and with varying degrees of severity.

The characteristic behaviors of ASD may or may not be apparent in infancy, but usually become obvious during early childhood (24 months to 6 years). ASD affects individuals in every country and region of the world and knows no racial, ethnic, nor economic boundaries.



## WHAT ARE PDDs?

Pervasive Developmental Disorders is the “umbrella term” for a group of disorders that includes Autism, Asperger’s Disorder, Childhood Disintegrative Disorder, Rett’s Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). According to the *Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)*, published by the American Psychiatric Association, individuals receive the diagnosis of PDD-NOS when they do not meet the criteria for a specific PDD but exhibit related symptoms. See the Autism Society Web site ([www.autism-society.org](http://www.autism-society.org)) for detailed descriptions of each of the Pervasive Development Disorders.

## WHAT CAUSES AUTISM?

Autism has no single cause. It was once thought to be a psychological disorder caused by traumatic experiences, leading to emotional and social withdrawal. This is not true. Today, researchers believe that several genes, possibly in combination with environmental factors, may contribute to autism. Some studies of individuals with autism have also shown abnormalities in several regions of the brain, including the cerebellum, amygdala, and hippocampus. While these findings are substantial, they require further study.

## HOW CAN AUTISM BE TREATED?

There is currently no cure for autism. However, continued research has provided a clearer understanding of the disorder and has led to better treatments and therapies. Studies have shown that appropriate educational intervention can lead to better outcomes for children with autism. Early intervention can significantly improve the quality of life for individuals with autism, however, the majority of individuals with ASD will continue to exhibit some symptoms in varying degrees throughout their lives and may require lifelong care and supervision.

The most effective programs share an emphasis on early, appropriate, and intensive intervention. To accommodate the diverse needs of individuals with ASD, effective approaches should be flexible, re-evaluated regularly, and provide the child with opportunities for generalization. Parents should investigate any and all treatments thoroughly and use caution before committing to any particular treatment.

The following table lists some of the most common approaches for treating autism:<sup>1</sup>

TREATMENT OPTIONS	
<b>EDUCATIONAL</b> <ul style="list-style-type: none"><li>Applied Behavioral Analysis (ABA); also known as Lovaas,</li><li>Discrete Trial Teaching, or Intensive Behavioral Intervention</li><li>Developmental, individual-difference, Relationship-based (DIR); also known as Floor Time</li><li>Social Skills and Social Stories</li><li>TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped Children)</li></ul>	<b>1</b>
<b>BIOMEDICAL</b> <ul style="list-style-type: none"><li>Diets of Varying Types</li><li>Vitamin Therapies</li><li>Medication (e.g., to reduce symptoms of autism, including aggression, self-injury, hyperactivity, mood disorders, etc.)</li></ul>	<b>2</b>
<b>INTENSIVE AUTISM SERVICES</b> <ul style="list-style-type: none"><li>Treatment provided by a team of individuals in the home, classroom, or community; may include ABAServices</li></ul>	<b>3</b>
<b>SPEECH-LANGUAGE THERAPY</b> <ul style="list-style-type: none"><li>Treatment for Auditory Processing Disorders</li><li>Oral Motor Treatment for Articulation</li></ul>	<b>4</b>
<b>COMMUNICATION</b> <ul style="list-style-type: none"><li>Picture Exchange Communication System (PECS)</li><li>American Sign Language (ASL)</li><li>Visual Strategies; using pictures for communication</li><li>Facilitated Communication</li></ul>	<b>5</b>
<b>SENSORY THERAPIES</b> <ul style="list-style-type: none"><li>Occupational Therapy</li><li>Sensory Integration Therapy</li><li>Auditory Integration Training</li><li>Developmental Optometry</li></ul>	<b>6</b>
No two individuals with ASD are alike; therefore, treatment outcomes will vary. Remember to research each therapy approach carefully. Books and other information about these and other treatments are available, and much information can be found on the internet.	

<sup>1</sup> This list is not meant to be comprehensive nor should it be considered an endorsement by the Autism Society. Specific treatment, therapy, or services should be provided to an individual only at the direction of the individual’s doctor or other qualified professional.



EARLY INTERVENTION CAN  
SIGNIFICANTLY IMPROVE THE QUALITY  
OF LIFE FOR INDIVIDUALS WITH AUTISM.



## INSURANCE, MEDICAL ASSISTANCE, AND STATE FUNDING

Services such as speech, physical, and occupational therapy may be covered by the family's insurance plan or Medical Assistance. Parents should check with their insurance provider(s) and State Developmental Disabilities Administration\* to find out what services are covered and if any state assistance exists for families with autism. Funding varies state-by-state and county by county.

## MEDICAL ASSISTANCE

There are several types of Medical Assistance (MA), sometimes referred to as Title 19, available to parents of children with severe disabilities. Acquiring assistance may depend on income, age, or disability. If this program is available in your state, it allows individuals under the age of 18 to obtain MA funding regardless of family income. MA may cover expenses related to various therapies as well as other medical benefits. For information, contact your state Department of Health and Human Services or Developmental Disabilities Administration.\*

*\* These and other useful services and supports can be found in the Autism Society's on-line referral database Autism Source [www.autismsource.org](http://www.autismsource.org)*

## EARLY INTERVENTION SERVICES: BIRTH TO 3

Local state and county programs provide developmental and other supportive services to children with developmental disabilities from birth up to age three.\* Sometimes this program is called Birth to Three, sometimes it is called Child Find or other similar name. Usually, a team of professionals will come to the home, evaluate the child, and provide necessary services at no cost to the family. Services may include group or individual speech therapy, physical therapy, occupational therapy, or group play programs designed for children with developmental delays. As with all other services, these vary by state and county. Your local educational authority\* can point you to the Birth to 3 program for your area.

## EARLY CHILDHOOD PROGRAMS

Once a child reaches the age of 3, your local education agency will assist in the transition to the public school-based Early Childhood Program. If a child has not participated in a "Birth to 3" program or is over the age of 3, families should contact their local or county special education program to enroll their child in the local school-based program. Often parents prefer to homeschool their young children with autism until they feel they are ready for a group setting. State and county guidelines and funding vary widely so please check with your state or county school system for information, as funding availability changes from county to county and state to state, and even year to year.

Another option for families is the Head Start program. Head Start is a day care program that is required to accept a certain number of children with disabilities. Also, remember that day care agencies in some communities will accept children with ASD. Some young children with ASD can benefit not only from individualized teaching, but also from settings where caring and learning are fostered in a group.

## SCHOOL-BASED PROGRAMS

All public schools must provide services for children with ASD from ages 3 through 21. The public school must evaluate your child for a suspected disability, develop an appropriate educational plan and provide related services as indicated by the evaluation. The role of the evaluation is to identify if an educational disability exists, not to make a medical diagnosis. The educational evaluation team must include a professional with knowledge and experience in the area of autism. A child must have an educational evaluation to receive services in the public schools.

## SPECIAL EDUCATION FOR SCHOOL-AGED CHILDREN

The determination of an appropriate educational approach for students with ASD must be based on the needs of each individual child. Careful assessment by a team of professionals in consultation with parents or guardians will help determine an appropriate educational program for each student.





IT IS IMPORTANT FOR FAMILIES TO  
PLAN FOR ADULT SERVICES YEARS BEFORE  
THE INDIVIDUAL REACHES THE AGE OF 21.



Regardless of the child's level of disability, studies show that children with ASD respond well to a highly-structured educational setting with appropriate support and accommodations tailored to individual needs. The educational program should build on the interests of the child and use visuals to accompany instruction. When necessary, it should incorporate other services, such as speech or occupational therapy, to address motor skill development and sensory integration issues. A tailor-made, individualized IEP (Individual Educational Plan) is critical for the child's success in school.

## TRANSITION

The term "transition" refers to one of the more critical times when individuals with ASD plan to leave the security of services through the public school system to the uncertainty of adult services. The transition from high school to continuing study or employment can be made easier through transition planning, which must be included in the child's IEP, beginning at age 16. With good transition planning, a student with ASD can have an opportunity to experience higher education, employment, and independent living. Parents, school officials, and agency personnel work together to make the transition as smooth as possible for the student.

## EMPLOYMENT CHOICES

As adults, some individuals select occupations that involve routines and don't need a great deal of social interaction. Remaining deficits can interfere with the achievement of job status related to their educational level. Some adults with ASD have jobs in areas such as data entry, medical transcription, janitorial services, chemistry, piano tuning, computer analysis, and bookkeeping. Others work in supported or sheltered employment. State agencies and local service providers are the best sources of information about local employment opportunities for individuals with autism.

It is important for families to plan for adult services years before the individual reaches the age of 21. There may be long waiting lists for services, and navigating the maze of services can be a challenge. Contact your local Developmental Disabilities Administration in your state for more information.

## PARENT AND FAMILY SUPPORT

Raising a child with ASD can be a challenge. Communication and support from family and friends can help parents as they prepare to take the next steps to helping their child. While you are your child's best advocate, you are not alone. More and more parents of children with autism are coming together to help one another through support groups.

Support groups are a vital resource for parents looking for answers to their many questions. Local parents who are a few years ahead with their child's education can provide invaluable information that will save you precious time. Part of the mission of The Autism Society includes fostering such groups through local chapters. Your state agencies can also provide you with information on financial assistance, education, and respite care. Contact your local chapter of The Autism Society to find more information about support groups and local resources. Local chapters can be found on The Autism Society web site at [www.autism-society.org/chapters](http://www.autism-society.org/chapters).

## THE FUTURE

Much has been learned about autism spectrum disorder in the last 10 years. Now, with appropriate treatment, many children with autism grow to become active, participating members of their communities. People with ASD can learn to compensate for and cope with their disability, often quite well. While each individual is unique, it may help to know that:

- Children with ASD are learning in regular education classrooms with and from their peers.
- Students with ASD continue their education beyond high school. Some people with ASD graduate from college.
- Adults with ASD, even those who face challenging symptoms, are capable of holding jobs in the community.
- Most people with ASD are living in a home or community setting.
- People with ASD receive assistance and support in the natural settings of daily life (at school, on the job, and in their homes).



WHILE YOU ARE YOUR CHILD'S  
BEST ADVOCATE, YOU ARE NOT ALONE.



THE DETERMINATION OF AN EDUCATIONAL  
APPROACH FOR STUDENTS WITH AUTISM MUST BE  
BASED ON THE NEEDS OF EACH INDIVIDUAL CHILD.

- People with ASD are becoming self-advocates. Some are forming networks to share information, support each other, and have their voices heard in the public arena.
- More frequently, people with ASD are attending and/or speaking at conferences and workshops on autism.
- People with ASD are providing valuable insight into this disability by publishing articles and books and by appearing on television specials about their lives and their disabilities.

In conclusion, as difficult as the diagnosis of autism can be for your family, remember that with proper resources, support and education, loved ones with autism will prosper.

## WHERE CAN I GET MORE INFORMATION?

The Autism Society chapters are your very best source of information and support. Most chapters are volunteer-led by parents of children or adults on the autism spectrum. The Autism Society has chapters in nearly every state reaching out with information, support and encouragement.

Chapters are the local arm of the Autism Society; they are the foundation for the Autism Society's success as a grassroots organization. Chapters work toward creating a world where people with ASD are fully included, participating members of their communities. Chapters enhance community awareness, provide education for professionals and parents, and maintain supportive, informative networks comprised of parents, professionals, and community leaders.

## FOR MORE INFORMATION

### The Autism Society Web site:

[www.autism-society.org](http://www.autism-society.org)

### Your Local Chapter of The Autism Society

[www.autism-society.org/chapters](http://www.autism-society.org/chapters)

### Autism Source

The Autism Society's on-line referral database where you can find doctors, schools, information and support, service providers and much more.

[www.autismsource.org](http://www.autismsource.org)

### Government Agencies

#### Developmental Disability Planning Councils:

[www.naddc.org](http://www.naddc.org)

#### Administration on Developmental Disabilities:

[www.acf.dhhs.gov](http://www.acf.dhhs.gov)

#### Protection and Advocacy Agencies:

[www.protectionandadvocacy.com](http://www.protectionandadvocacy.com)

#### Office of Spec. Education & Rehabilitative Services:

[www.ed.gov/offices/OSERS](http://www.ed.gov/offices/OSERS)

#### Centers for Medicaid and Medicare Services:

[www.cms.hhs.gov](http://www.cms.hhs.gov)

#### Parent Information Training Centers:

see [www.autismsource.org](http://www.autismsource.org) for links by state

#### State Insurance Commissioners:

see [www.autismsource.org](http://www.autismsource.org) for links by state

#### National Information Center for Children and Youth with Disabilities:

[www.nichcy.org](http://www.nichcy.org)





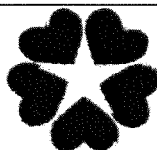
LOOKING FOR AUTISM RESOURCES? VISIT [WWW.AUTISMSOURCE.ORG](http://WWW.AUTISMSOURCE.ORG)



4340 East-West Highway, Suite 350  
Bethesda, Maryland 20814  
Phone: 301.657.0881 or  
1.800.3AUTISM  
Fax: 301.657.0869  
Web: [www.autism-society.org](http://www.autism-society.org)



If you appreciated the information contained in this publication, please consider offering support through a donation that will continue the availability of this information to others in need. Help us continue the work so vital to the autism community by making a tax-deductible donation at [www.autism-society.org/donate\\_home](http://www.autism-society.org/donate_home).



FEDERATION FOR CHILDREN  
WITH SPECIAL NEEDS

617-236-7210

[www.fcsn.org](http://www.fcsn.org)

### **Family TIES of Massachusetts**

#### ***Statewide network for parents of children with special needs***

- Maintains an informative website, [www.massfamilyties.org](http://www.massfamilyties.org)
- Information and referrals to programs and resources for children with special needs
- Parent-to-Parent support for families seeking emotional support on issues related to parenting a child with special needs
- Free parent workshop "Let's Get Organized"
- Information on its website related to Emergency Preparedness
- Variety of opportunities for parents of children with special needs to offer their expertise through its Parent Advisors Program

### **Massachusetts Family Voices, our Family-to-Family Health Information Network**

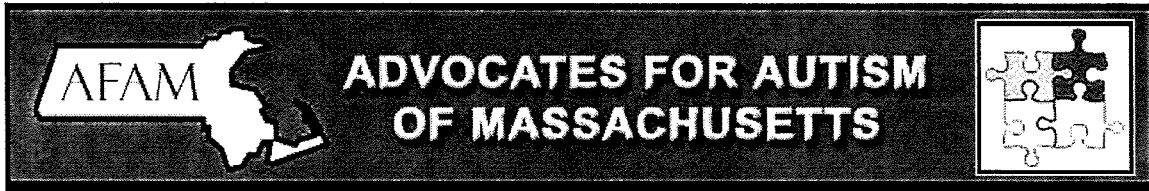
#### ***Resource for information related to health services and insurance***

- Maintains an informative website, [www.massfamilyvoices.org](http://www.massfamilyvoices.org)
- Offers information relative to health and insurance services
- Manages an active listserv
- Offers an annual free conference to emerging parent leaders, Joining Voices

### **Parent Training and Information Center (PTI)**

#### ***Resource around issues of special education in Massachusetts***

- Free telephone advice and comprehensive website to parents who are having difficulties navigating the special education system, [www.fcsn.org/pti](http://www.fcsn.org/pti)
- Free parent workshops on a variety of topics related to special education
- Parent Consultant/Advocate Training Institute offered six times a year across the state, teaching interested individuals about the laws, rights, and responsibilities related to special education in Massachusetts



*A Unified Voice for Individuals with  
Autism Spectrum Disorder and Their Families*

**Advocates for Autism of Massachusetts (AFAM)** was formed in 2004 to address the need for public advocacy on behalf of individuals, families and professionals who provide support for people with Autism Spectrum Disorder (ASD), which also encompasses Asperger's Syndrome and high-functioning Autism. The organization provides a vital arena for mobilizing those of us who support those with ASD in our day-to-day lives, as the most eloquent and persuasive spokespeople for our concerns.

**What is advocacy?** Advocacy means giving support to a cause – in this case, to the effort to enhance the lives of individuals on the spectrum and their families by providing meaningful services and supports. Advocacy means lending your voice, giving active verbal support for these efforts so public officials – and society in general -- will understand the urgency of the needs of our families.

**In these challenging times, AFAM has intensified its activities on behalf of the autism community**, collaborating with other disability groups to organize vigils at the State House aimed at preventing the loss of millions of dollars of funding for services for individuals with disabilities, advocating for the passage of landmark legislation, and raising awareness of the needs of both children and adults on the autism spectrum. This past year we have achieved several **major successes**, including:

- passage of An Act Relative to Insurance Coverage for Autism (ARICA);
- passage of the Augmentative and Alternative Communications Bill;
- passage of the Anti-Bullying Bill; and
- publication of a study, *Awash in Autism: Why We Must Begin to Address the Critical Need for Services for Adults with Autism in Massachusetts*.

These are significant accomplishments, but **our work must go on**. As we look ahead, AFAM will continue to advocate for expanded funding for Family Support, Turning 22, and other items in the Massachusetts budget that have a direct impact on our families. And we will focus increased energy on the urgent need for adult services for individuals on the autism spectrum.

**Why You Should Join AFAM:** AFAM is **your voice** on Beacon Hill, advocating for the services you and your family need: early intervention, special education, residential, transportation and employment services, flexible supports, respite care and so much more. By lending your voice to our efforts, you can help secure these things for children and adults with ASD.

**How You Can Help:** Become involved! To learn more about Advocates for Autism of Massachusetts, please visit our Website at [www.afamaction.org](http://www.afamaction.org) or email us at [office@afamaction.org](mailto:office@afamaction.org) or call 781- 891-6270, ext. 102.

**AFAM**  
**217 South Street**  
**Waltham, Ma 02453**  
**781-891-6270, ext. 102 [www.afamaction.org](http://www.afamaction.org)**

**AFAM Member Organizations**

Autism Support Center - Danvers  
Autism Resource Center of Central Massachusetts - W. Boylston  
Community Autism Resources - Swansea  
Autism Society of America, Massachusetts Chapter - Wellesley  
Community Resources for People with Autism - Easthampton  
Asperger's Association of New England - Watertown  
Family Autism Center - Westwood  
TILL's Autism Support Center - Dedham  
Autism Alliance of Metrowest - Natick  
Doug Flutie, Jr. Foundation for Autism - Framingham  
The Arc of Massachusetts - Waltham  
Massachusetts Advocates for Children - Boston  
Autism Speaks Greater Boston Chapter - Dedham  
Charles River Center - Needham

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**Yes, I want to support AFAM!**

- ☐ Supporter (Up to \$50)  
☐ Friend (\$51 - \$149)  
☐ Advocate (\$150 - \$299)  
☐ Leader (\$300 and above)

Amount enclosed: \$ \_\_\_\_\_

**Note:** These categories are for individual/family supporters only.  
Organizational/professional/corporate sponsorships are also available. Please contact  
AFAM about sponsorship opportunities.

**Name** \_\_\_\_\_ **Phone:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**City :** \_\_\_\_\_ **State:** \_\_\_\_ **Zip:** \_\_\_\_ **E-Mail** \_\_\_\_\_

**Method of Payment:**

- ☐ Check (enclosed)  
☐ Visa  
☐ Mastercard

Card Number: \_\_\_\_\_ Exp date \_\_\_\_\_

Signature: \_\_\_\_\_

Please make checks payable to The Arc of Massachusetts with AFAM in the notation  
line and mail to: AFAM, 217 South Street, Waltham, MA 02453