

# NEXT STEPS

## A GUIDE FOR FAMILIES NEW TO AUTISM

*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?"*

### **About This Publication**

This document will provide a general understanding of Autism Spectrum Disorders, an overview of the various treatment options, and brief information about education and services that are helpful to children and adults with autism.



### **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

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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 of America 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.

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### **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>

<b>Treatment Options</b>
<b>EDUCATIONAL</b> <ul style="list-style-type: none"><li>• Applied Behavioral Analysis (ABA); also known as Lovaas, 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>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>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>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>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 ABA services</li></ul>
<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>



**Parents should investigate any and all treatments thoroughly and use caution before committing to any particular treatment.**



*Visit ASA's website to view our Options Policy & Guidelines for Theories & Practices*

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 ASA. Specific treatment, therapy, or services should be provided to an individual only at the direction of the individual's doctor or other qualified professional.



## 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 ASA's on-line referral database Autism Source [www.autismsource.org](http://www.autismsource.org)



**Early intervention can significantly improve the quality of life for individuals with autism.**

## 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.

The determination of an educational approach for students with autism must be based on the needs of each individual child.

## 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.

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,



**It is important for families to plan for adult services years before the individual reaches the age of 21.**

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 of America 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 ASA chapter to find more information about support groups and local resources. Local chapters can be found on the ASA web site at <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).
- 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?

ASA 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. ASA has chapters in nearly every state reaching out with information, support and encouragement.

Chapters are the local arm of ASA; they are the foundation for ASA's success as a grassroots organization. Chapters work toward creating a world where people with ASD are fully included, participat-



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ing 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

#### ASA Web site:

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

#### Your ASA Local Chapter:

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

#### Autism Source:

ASA'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)



## Benefits of ASA Membership

### *The Autism Advocate*

Published four times per year, the *Autism Advocate* magazine offers the latest information on research, legislation, and tips on living with autism. It is a valuable source of education and inspiration to our members.

### National Autism Conference

ASA members may attend the annual conference at discounted rates. The ASA annual conference is the largest national conference focused on autism.

Top autism professionals and families network and participate in workshops and presentations. The conference is held each July in a different city- check our web site for information about this year's conference.

### Outreach and Support

With a network of chapters in nearly every state and through the most comprehensive and popular autism-related Web site on the Internet, the ASA is truly the voice and resource of the autism community.



Education, advocacy, public awareness efforts and the promotion of research form the cornerstones of the ASA's activities.

### Advocacy

ASA's work in Washington, DC not only continues to increase public awareness about Autism Spectrum Disorders but has resulted in millions of dollars devoted towards autism research and services.

Founded in 1965, the mission of the ASA is improve the lives of all

affected by autism. Advocacy, education, support, services, and research form the cornerstones of the ASA's activities. Through its varied benefits and services, the ASA continues to be the voice of the entire autism community.



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