

NEXT STEPS

A guide for families new to autism



Produced by the Autism Society of America through a grant by ShopKo Stores Inc., this booklet outlines the diagnosis of autism and provides helpful information and statewide resources for Wisconsin families.

Second Edition 2002

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The Autism Society of Wisconsin is a statewide chapter of the Autism Society of America. Our non-profit organization encourages grassroots involvement from local chapters, support groups, agencies, and others interested in helping to promote awareness, understanding, well-being and lifelong opportunities for individuals with Autism Spectrum Disorder throughout Wisconsin.

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**Special Education
Department**

The goal of CESA 7 Department of Special Education is to work in partnership with school districts and parents in northeast Wisconsin to provide leadership, support and training in all disability areas including autism to help facilitate change and continuous improvement in our schools so that all children will achieve educational excellence.

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Long before they receive 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?*

The goal of this booklet – “Next Steps: A Guide for Families New to Autism” – is to provide parents and others touched by autism with the answers to those questions. The booklet was developed by the Autism Society of America (ASA) and the Autism Society of Wisconsin (ASW), and was made possible through a grant from ShopKo Stores Inc.

ABOUT THIS BOOKLET

This “Next Steps” booklet provides a general understanding of Autism Spectrum Disorders, an overview of the various treatment options, and a summary of the services available in the state of Wisconsin. It was designed to be helpful to everyone affected by autism, including:

- **Parents**
- **Family Members**
- **Doctors**
- **Caregivers**
- **Therapists**
- **Educators**

Trying to find the appropriate treatment and education for someone affected by autism can be challenging. The ASA and the ASW encourage you to help educate others affected by autism by making this booklet available in schools, offices, hospitals, and treatment centers.



WHAT IS AN AUTISM SPECTRUM DISORDER?

Autism is a complex neurological disorder affecting individuals in the areas of social interaction and communication. Autism and its associated behaviors have been estimated to occur in at least 1 in 250 individuals (Centers for Disease Control and Prevention, 2002).

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 (18 to 24 months), 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.

Pervasive Developmental Disorders

Autistic Disorder	Childhood Disintegrative Disorder
Asperger’s Disorder	PDD-NOS
Rett’s Disorder	

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. 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 interventions can positively change autism's associated behaviors. 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.

The most effective programs share an emphasis on early, appropriate, and intensive interventions. 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 subscribing to any particular treatment.

The following are some of the most common approaches for treating autism:¹

¹This 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. For more information on specific treatments, contact the Autism Society of Wisconsin at 888-4AUTISM.

EDUCATIONAL OPTIONS

- Structured Teaching (TEACCH)
- Social Stories
- Picture Exchange Communication System (PECS) for expressive communication
- Sensory Integration Strategies
- Visual Support for Receptive Communication
- Speech-Language Therapy
- Occupational Therapy
- Specialized/Adaptive Physical Education
- Floortime

MEDICAL TREATMENT OPTIONS

BIOLOGICAL

- Diet
- Vitamins
- Medication (e.g., to reduce aggression, self-injury, hyperactivity, mood disorders, etc.)

SENSORY

- Occupational Therapy
- Sensory Integration Therapy
- Auditory Integration Training
- Developmental Optometry

COMMUNICATION

- Speech-Language Therapy
- Picture Exchange Communication System (PECS)
- Auditory Processing Strategies (e.g. Fast Forward)
- Augmentative Communication Strategies using Assistive Technology (e.g. voice output devices)
- Facilitated Communication

HOME-BASED TREATMENT OPTIONS

- Applied Behavioral Analysis (ABA) Therapy; (e.g. Lovaas Therapy, Discrete Trial Teaching, Intensive Behavioral Intervention)

INSURANCE AND MEDICAL ASSISTANCE

Insurance

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) to find out what services are covered.

Medical Assistance

There are several types of Medical Assistance (MA), sometimes referred to as Title 19, available to parents. Acquiring assistance may depend on income, age, or disability. Many families of individuals with autism have used the *Katie Beckett Program*. This program 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. Currently in Wisconsin, MA covers the cost of intensive treatment in the home. For information on Medical Assistance, contact the Wisconsin Department of Health and Social Services at (800) 362-3002.



Early Intervention Services: Birth to 3

The Birth to 3 Program provides developmental and other supportive services to children with developmental disabilities from birth up to age three. The program is available in all 72 counties in Wisconsin.

To be eligible for this program, a child must be between birth and 36 months of age, have a diagnosed developmental disability, or be significantly delayed in one or more areas of development. Families concerned about their child's development can contact the Birth to 3 Program in their county. A team of professionals will come to the home, evaluate the child, and provide necessary services through a state-mandated cost share system.

For the Birth to 3 Program in your area contact:

Wisconsin First Step

Hotline providing statewide information and referrals to assist professionals and families who have a child with special needs.
(800) 642-STEP



EARLY CHILDHOOD PROGRAMS

Once a child reaches the age of three, the Birth to 3 program 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 three, families should contact their local or county special education program to enroll their child in the Early Childhood Program.

The Early Childhood Program typically serves children ages 3 to 6. Programs are typically two and one-half hours per day, four days a week.

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. Day care agencies in some communities will accept children with ASD.

EDUCATING CHILDREN WITH AUTISM

All public schools in Wisconsin 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 autism 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 autism 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.

Children with autism may be educated in partially or fully-integrated classrooms with typical peers, in specialized classrooms within the regular school, or in a specialized school for children with special needs. Higher-functioning individuals may be *mainstreamed* (including peers without autism) for all or a portion of their school day. Others may require placement in a special education setting to receive an appropriate education.

For more information regarding educational services, contact:

Wisconsin Department of Public Instruction

125 South Webster Street
Madison, WI 53707-7841
(608) 266-3390
Toll Free: (800) 441-4563
www.dpi.state.wi.us/dpi/dlse/cen/



HOME SCHOOLING

Some families choose to educate their child at home, especially if the child is receiving intensive in-home treatment for autism. For general information, contact:

Wisconsin Parents Association

P.O. Box 2502
Madison, WI 53701-2502
(608) 283-3131
www.homeschooling-wpa.org

TRANSITION

One of the critical times comes when individuals with ASD and their families 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 educational program, beginning at age 14.

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.

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.

Adult services are available in Wisconsin in some communities. Generally, these services tend to be much less specific to autism and are often limited in the services provided.

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. For more information on transition contact:

Wisconsin FACETS : Family Assistance Center for Education, Training and Support

2714 Martin Luther King Drive, Suite E

Milwaukee, WI 53212

(414) 374-4645

(877) 374-4677

www.wifacets.org

Vocational Centers

Wisconsin Department of Workforce Development

201 East Washington Avenue (GEF-1)

Madison, WI 53702

(800) 362-1290 (Wisconsin Only)

www.dwd.state.wi.us

State Independent Living Council

P.O. Box 7851

Madison, WI 53707-7851

(608) 261-8397

Toll Free: (888) 947-7452

PARENT AND FAMILY SUPPORT

Raising a child with autism 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.

The groups are a vital resource for parents looking for answers to their many questions. Part of the mission of the Autism Society of America and the Autism Society of Wisconsin includes fostering such groups through local chapters. Your state agencies can also provide you with information on financial assistance, education, and respite.

To find out about agencies in your area contact Wisconsin First Step at 800-642-STEP (available 24 hours a day, 7 days a week). You may contact the Autism Society of Wisconsin for more information on chapters, parent support groups, respite care, Family Support Program, or any other questions or concerns that you may have.



THE FUTURE

Much has been learned about autism spectrum disorder in the last ten years. Now, with appropriate treatment, many people with autism are 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.
- More people with ASD are living in a home or community of their own rather than institutions.
- 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 the challenges of this disability by publishing articles and books and by appearing on television specials about their lives and their disabilities.

WHERE CAN I GET MORE INFORMATION?

The Autism Society of Wisconsin

103 West College Avenue, Suite 709

Appleton, WI 54911-5744

(920) 993-0279 Toll Free: 888-4AUTISM

www.asw4autism.org



The ASW Web site includes extensive and up-to-date information on Wisconsin resources, recommended books, publications, treatment options, local chapters, conferences and workshops, general autism information, and links to many helpful Web sites. ASW also maintains an e-mail list for members of the autism community to communicate with each other.

The **ASA's bookstores** are among the largest bookstores specializing in titles on autism. You may contact the bookstores directly to receive a catalog or to place an order:

Autism Society of North Carolina

505 Oberlin Road, Suite 230

Raleigh, NC 27605-1345

(919) 743-0204

www.autismsociety-nc.org

Autism Society of Michigan

6035 Executive Drive, Suite 109

Lansing, MI 48911

(800) 223-6722

www.autism-mi.org



WISCONSIN RESOURCES

Autism Society of Wisconsin

103 West College Ave., Suite 709
Appleton, WI 54911-3744
(920) 993-0279
Toll Free: (888) 4-AUTISM
www.asw4autism.org

Wisconsin First Step

Hotline providing statewide information and referrals to assist professionals and families who have a child with special needs.
(800) 642-STEP

Child and Family Services

Wisconsin Department of Health and Family Services
1 W. Wilson Street
Madison, WI 53702
(608) 266-1865
TTY: (608) 267-7371
www.dhfs.state.wi.us

Insurance

State of Wisconsin Office of the Commissioner of Insurance
121 East Wilson Street
Madison, WI 53702
(608) 266-3585
Toll Free: (800) 947-3529
TDD: (608) 266-3586
http://badger.state.wi.us/agencies/oci/oci_home.htm

Vocational Centers

Wisconsin Department of Workforce Development
201 East Washington Avenue
(GEF-1)
Madison, WI 53702
(800) 362-1290
www.dwd.state.wi.us

Developmental Disabilities Council

Wisconsin Council on Developmental Disabilities
600 Williamson Street
Madison, WI 53707-7851
(608) 266-7826
TTY: (608) 266-6660

Special Education

Wisconsin Department of Public Instruction
125 South Webster Street
Madison, WI 53707-7841
(608) 266-3390
Toll Free: (800) 441-4563
www.dpi.state.wi.us/dpi/dlsea/een

Parent Training & Information Center

Wisconsin FACETS
2714 N. Dr. Martin Luther King Dr.
Milwaukee, WI 53212
(414) 374-4645
Toll Free: (877) 374-4677
TDD: (414) 374-4635
www.wifacets.org

NATIONAL RESOURCES

Autism Society of America

7910 Woodmont Ave, Suite 300
Bethesda, MD 20814-3067
www.autism-society.org
800-3AUTISM

ERIC Clearinghouse on Disabilities and Gifted Children

One of 16 federally-funded ERIC (Educational Resources Information Center) clearinghouses sponsored by the U.S. Department of Education.

NICHCY

National Information Center for Children and Youth with Disabilities
PO Box 1492
Washington, DC 20013-1492
(202) 884-8200
Toll Free: (800) 695-0285
www.nichcy.org

Office of Special Education & Rehabilitative Services

OSERS supports programs that assist in educating children with special needs, provides for the rehabilitation of youth and adults with disabilities, and supports research to improve the lives of individuals with disabilities.
U.S. Department of Education
330 C St., S.W.
Washington, DC 20202
www.ed.gov/offices/OSERS

Administration for Families and Children: Administration on Developmental Disabilities

Provides information on programs, policies, and activities related to partnerships with state governments, local communities, and the private sector that are assigned to help assist people with developmental disabilities.
U.S. Department of Health and Human Services
370 L'Enfant Promenade, S.W.
Washington, DC 20447
(202) 690-6590
www.acf.dhhs.gov/programs/add

Americans with Disabilities Act (ADA) Information Line

The ADA prohibits discrimination on the basis of disability in employment, programs and services provided by state and local governments, goods and services provided by private companies, and in commercial facilities.
Disability Rights Section
Civil Rights Division
U.S. Department of Justice
PO Box 66738
Washington, DC 20035-6738

Council for Exceptional Children

1920 Association Drive
Reston, VA 20191-1589
(800) 328-0272
www.eric.org

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asa

Autism Society of America

the voice and resource of the autism community

Founded in 1965, the mission of the ASA is to promote lifelong access and opportunities for all individuals within the autism spectrum and their families, to be fully included, participating members of their communities. Education, advocacy, public awareness efforts and the promotion of research form the cornerstones of the ASA's activities. Through its varied benefits and services, the ASA continues to be *the voice and resource of the autism community*.

Autism Society of America

7910 Woodmont Avenue, Suite 300

Bethesda MD 20814-3067

800-3AUTISM

www.autism-society.org

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