Next Steps

A GUIDE FOR FAMILIES NEW TO
AUTISM SPECTRUM DISORDERS

This booklet outlines the diagnosis and verification of autism spectrum disorders and provides helpful information and statewide resources for Nebraska families.

Nebraska Autism Spectrum Disorders
N • E • T • W • O • R • K

First Edition 2004-2005

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References

American Psychiatric Association. (1994). *Diagnostic and Statistical Manual for Mental Disorders, (DSM-IV). 4th ed. Washington, DC: American Psychiatric Association.*

Autism Society of America. (1999). *Shaping our Future: Educating Children with Autism,* pp.8-9.

Autism Society of Wisconsin. (2000). *Autism Resources*. Retrieved 01/25/05 from www.asaw4autism.org

Center for Disease Control and Prevention. (2005) *What is the Prevalence of ASDs?* Retrieved 04/05/05 from www.cdc.gov/ncbddd/autism

National Research Council (2001). *Educating Children with Autism.* Committee on Educational Interventions for Children with Autism. Catherine Lord and James P. McGee, eds. Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.

Nebraska Department of Education. (October 03, 2004). *Nebraska Administrative Code* (92 NAC 51, Title 92) (Rev. ed.).

Special Education Advisory Council Ad Hoc Committee on Autism Spectrum Disorders. (May 2000). *Special Education Verification and Effective Instructional Practices for Children with Autism Spectrum Disorders (ASD).* Lincoln, NE: Nebraska Department of Education.

Storms, J.; O'Leary, E.; & Williams, J. (2000). *The Individuals with Disabilities Education Act of 1997 Transition Requirements: A Guide for States, Districts, Schools, Universities and Families*. Minneapolis, MN: Institute on Community Integration (UAP), National Transition Network, University of Minnesota.

National Resources

Autism Society of America
7910 Woodmont Ave, Suite 300
Bethesda, MD 20814-3067
www.autims-society.org
800-3AUTISM

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

Office of Special Education & Rehabilitative Services
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 Street SW
Washington, DC 20202
www.ed.giv/offices/OSERS

Administration for Families & Children: Administration on Developmental Disabilities
Programs, policies, and activities for 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, SW
Washington, DC 20447
(202) 690-6590
www.acf.dhhs.gov/programs/add

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

Long before their child receives the diagnosis of Autism Spectrum Disorder (ASD), parents may 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 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 Nebraska. It was designed to be helpful to everyone affected by autism, including:

*** Parents** *** Doctors** *** Therapists**

*** Family Members** *** Caregivers** *** Educators**

Trying to find the appropriate treatment and education for someone affected by autism can be challenging. We encourage you to help educate others affected by autism by making this booklet available in schools, offices, hospitals and other community places.

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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 166 individuals (Centers for Disease Control and Prevention, 2005).

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 autism spectrum disorders (ASD) may or may not be apparent in infancy (18-24 months), but usually become obvious during early childhood (24 months – 6 years). ASD affects individuals in every country and region of the world and knows no racial, ethnic, or economic boundaries.

Nebraska Resources

Nebraska ASD Network
Nebraska Department of Education, Special Populations
301 Centennial Mall South
Lincoln, NE 68509
402-471-2471
www.nde.state.ne.us/autism

Autism Society of Nebraska
www.autismnebraska.org
877-375-0120

Health & Human Services
P.O. Box 95044
Lincoln, NE 68509-5044
(402) 471-2306
www.hhs.state.ne.us

Asperger's Support Group
Carolyn May
mays0000@inetnebr.com
(402) 421-8994
nncf.unl.edu/family/sharing/aspergersgroup.html

Nebraska ChildFind
3135 North 93 Street
Omaha, NE 68134-4717
Phone: (402) 346-0525
(866) 806-6287
FAX: (402) 934-1479

Office of Early Childhood
Nebraska Department of Education
301 Centennial Mall South
Lincoln, NE 68509
(402) 471-3184
Fax: (402) 471-0117

Nebraska Educational Assistive Technology (NEAT) Center
1910 Meridian Avenue
Cozad, NE 69130-1159
(308) 784-4525
www.neatinfo.net
neat@esu10.org

Developmental Disabilities Services
Nebraska Department of Health & Human Services
P.O. Box 98925
Lincoln, NE 68509-8925
Phone: (402) 479-5247

Vocational Rehabilitation
P.O. Box 94987
Lincoln, NE 68509
(402) 471-3644
(877) 637-3422

Nebraska Respite Network
www.respitenetwork.org
(866) 737-7483

This booklet was developed through the collaborative efforts of the following organizations:

Nebraska ASD Network

The Nebraska ASD Network provides information, training and technical assistance to education personnel and families throughout the state related to educational verification and program planning for students with autism spectrum disorders. The ASD Network is funded by the Nebraska Department of Education through set-aside dollars made available through Part B of the Individuals with Disabilities Education Act (IDEA).

Autism Society of Nebraska (ASN)

The mission of the Nebraska Chapter of the Autism Society of America is to support and advocate for individuals with autism and their families through increasing education and awareness, fundraising, and facilitating community involvement for persons with autism spectrum disorders to achieve their potential by becoming a productive, accepted, and integral part of society.

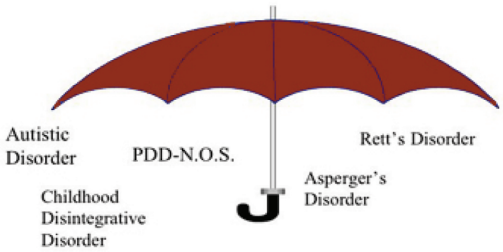
Autism Society of America

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 29814-3067
800-3AUTISM
www.autism-society.org

What are Pervasive Developmental Disorders?

Pervasive Developmental Disorders (PDD) 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 specified PDD but exhibit related symptoms.



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. While these findings are substantial, they require further study.

How can autism be treated?

Currently, there is no cure for autism. However, continued research has provided a clearer understanding of the disorder and has led to better treatments and therapies. Early and appropriate interventions can significantly improve the quality of life for individuals with autism. 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, individualized and systematic 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 treatments thoroughly as there is no single treatment proven effective for all children with ASD. Therefore, intervention programs should incorporate a variety of effective practices tailored to meet the specific needs of your child. Considerations when selecting treatments should include a variety of factors, including how the intervention will affect the child, as well as the entire family.

At the request of the U.S. Department of Education's Office of Special Education Programs, the National Research Council appointed a committee to analyze available scientific evidence related to educational intervention for young children with ASD. The committee developed a report that outlines recommendations for educational programming for children with ASD. Their recommendations for educational intervention are summarized on the following page.

The Future

Much has been learned about ASD 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:

- Many children with ASD are learning in regular education classrooms with their peers.
- Students with ASD may choose to 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.

These 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 Nebraska includes fostering such groups through local chapters. Contact the Autism Society of Nebraska (ASN) for more information on chapters, parent support groups, respite care, Family Support Program, or any other questions or concerns that you may have.

Autism Society of Nebraska
www.autismnebraska.org

The Nebraska ASD Network is also an excellent source for information and materials. Visit the ASD Network website to learn more about autism spectrum disorders, find state and national resources and find resources that are available for checkout from the Network's five regional resource libraries.

Nebraska ASD Network
www.nde.state.ne.us/autism

Sharing the Next Steps Booklet

Trying to find the appropriate treatment and education for someone with autism can be challenging. We encourage you to help educate others affected by autism by making this booklet available in schools, offices, hospitals and other community places.

Priorities for Developing Effective Programs

Following an analysis of scientific evidence related to the effects of early educational intervention for young children with autism spectrum disorders, a National Research Council committee on autism recommended that six types of educational interventions should have priority. Their recommendations are summarized below:

- Functional, spontaneous communication should be the primary focus of early education. For very young children, programming should be based on the assumption that most children can learn to speak. Effective teaching techniques for both verbal language and alternative modes of functional communication, drawn from the empirical and theoretical literature, should be vigorously applied across settings.
- Social instruction should be delivered throughout the day in various settings, using specific activities and interventions planned to meet age-appropriate, individualized social goals.
- The teaching of play skills should focus on play with peers, with additional instruction in appropriate use of toys and other materials.
- Other instruction aimed at goals for cognitive development should also be carried out in the natural context, with generalization and maintenance being as important as the acquisition of new skills. And methods of introducing and documenting new skills may differ from strategies to support generalization and maintenance.
- Intervention strategies that address problem behaviors should incorporate information about the contexts in which the behaviors occur; positive, proactive approaches; and the range of techniques that have empirical support (e.g., functional assessment, functional communication training, reinforcement of alternative behaviors).
- Functional academic skills should be taught when appropriate to the skills and needs of a child.

Summary from NRC (2001).
Chapter 16, Conclusions & Recommendations

Insurance and Medical Assistance

Insurance

The family's insurance plan or Medical Assistance may cover services such as speech, physical, and occupational therapy. Parents should check with their insurance provider(s) to find out what services are covered.

Medical Assistance

There are several types of Medical Assistance, sometimes referred to as Title 19, available to parents. Acquiring assistance may depend on income, age, or disability. There are various waiver programs, as well as the Katie Beckett Program, which may allow individuals under the age of 18 to obtain Medical Assistance funding regardless of family income or resources. Medical Assistance may cover expenses related to various therapies as well as other medical benefits. For information on Medical Assistance, contact the Nebraska Department of Health and Human Services (HHS) office in your area. Office locations may be found on the HHS website (www.hhs.state.ne.us) or by calling 402-471-2306.

It is important for families to plan for adult services years before the individual reaches the age of 21. For more information on transition in Nebraska, visit the sites below:

Nebraska Department of Education, Transition Project
http://sites.esu9.org/NDEtransition

Vocational Rehabilitation Offices
www.vocrehab.state.ne.us

Developmental Disabilities Services
http://www.hhs.state.ne.us/dip/ded/dedindex.htm

Parent and Family Support

Communication and support from family and friends can benefit parents as they prepare to take the next steps to help 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.

Transition

One of the most critical times for individuals with ASD and their families comes when planning to leave public school services into adult living. Transition planning must be included in the child's individual education program (IEP), beginning at age 16. The concept of transition generally has three major components:

1) Coach every student, along with his or her family, to think about goals for life after high school and to develop a long-range plan to get there.
2) Design the high school experience to ensure that the student gains the skills and competencies needed to achieve his or her desired post-school goals.
3) Identify and link student and families to any needed post-school services, supports or programs before the student exits the school system.

Successful transition plans for students with ASD take into account individual communicative, social, behavioral and sensory needs, together with the student's personal interests and strengths.

Transition Requirements: A Guide for States, Districts, Schools, Universities and Families, (Storms, O'Leary and Williams, 2000).

Students with ASD and their families need time and opportunities to plan for successful transition. Important areas to address include community experiences, the development of employment and other post-school living objectives, and the acquisition of daily living skills and functional vocational evaluation, if appropriate.

Each of these should be considered with the long-term outcome of assuming an active and productive role in the community. Parents, school officials and agency personnel work together to make the transition as smooth as possible for the student.

Verification in Nebraska Schools

In Nebraska, school districts are responsible for providing special education and/or related services to all eligible children in their district, birth to age 21, who have been verified with a disability according to Nebraska Department of Education Rule 51. One of the disability categories under Rule 51 is autism. In order for a child to be eligible for special education and/or related services, the school district must evaluate your child through a multidisciplinary team process (MDT) to determine the educational and developmental abilities and needs of your child.

The purpose of the evaluation is to determine, or verify, whether a disability exists that affects educational performance, not to make a medical diagnosis.

Once a child is determined to be eligible for special education services, an Individualized Family Service Plan (for children birth to age 3), and a services coordinator with the Early Development Network is available to assist you in identifying your family's priorities for supports and resources. For children ages 3-21, an Individualized Education Program (IEP) will be developed to guide your child's educational program. You will be a member of your child's IFSP or IEP team that will determine what supports and services are needed to provide appropriate learning opportunities for your child.

Birth-Age 5 Programs

Children with autism display many different learning characteristics. Your child's individualized plan (IFSP and IEP) will be developed based upon your child's specific needs.

To the maximum extent possible, early services and supports for children from birth to age five should be provided in natural and inclusive (least restrictive) environments where typically developing children spend their time. Settings that are natural for the preschool child's peers include community preschools, homes, childcare centers, Head Start Programs and other community settings.

Special Education for School-Aged Children

Your child's IEP will be reviewed to determine progress and updated to reflect his/her current level of performance by the IEP team, which consists of parents or guardians, educators and/or related service professionals. The student may also be a part of the IEP team, when appropriate. An educator who is a member of your child's IEP team will serve as the IEP manager and facilitate the planning and review process.

Children with autism may display a variety of symptoms, ranging from mild to severe. While there is no proven curriculum that provides positive outcomes for all children and youth with autism, a successful program will include an individualized combination of strategies and interventions based on scientifically supported and/or promising practices for children with autism spectrum disorders. The educational program should build upon the interests of the child and include specific strategies to meet the child's needs. When appropriate, related services, such as speech or occupational therapy, are included to address communication, motor and sensory issues.