
Next Steps

A Guide for Families New to Autism Spectrum Disorders



This booklet outlines the educational verification process, services and supports for autism spectrum disorders and provides helpful information and statewide resources for Nebraska families.



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National Resources

Autism Society of America

The Autism Society exists to improve the lives of all affected by autism. ASA does this by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals, and providing the latest information regarding treatment, education, research and advocacy.
www.autism-society.org Phone 1.800.328.8476

Autism Speaks

Autism Speaks is one of the nation's largest autism advocacy organizations. Autism Speaks has produced many excellent resources aimed at increasing awareness of ASDs; supporting families new to ASDs; and advocating for the needs of individuals with autism and their families.
www.autismspeaks.org

OASIS and MAAP Website

The Online Asperger Syndrome Information and Support (OASIS) center has joined with MAAP Services for Autism and Asperger Syndrome to create a single resource for families, individuals, and medical professionals who deal with the challenges of Asperger Syndrome, Autism and related disabilities.
www.aspergersyndrome.org

Centers for Disease Control & Prevention

The Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD), in collaboration with a number of national partners, launched a public awareness campaign called "Learn the Signs. Act Early."
www.cdcinfo@cdc.gov Phone 1.800.232.4636

Autism Internet Modules

Autism Internet Modules (AIM): The NE ASD Network has partnered with the Ohio Center for Autism, and several other organizations to support the development of a variety of user friendly, free, web-training modules on issues related to autism spectrum disorders.
www.autisminternetmodules.org

Long before their child receives a school verification or a medical 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?

This "Next Steps" booklet provides some general information about autism spectrum disorders, an overview of the various intervention options and a summary of the services available in the state of Nebraska. It was designed to be helpful to everyone affected by autism spectrum disorders including:

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

Trying to find appropriate information, treatment and supports for a family affected by autism can be challenging. Collaboration among agencies and providers is crucial for effectively supporting individuals on the autism spectrum.

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Autism Society of Nebraska

Public Relations Subcommittee (Subcommittee of the ASD State Standing Committee)

A special thanks to the Nebraska families who generously shared their children's pictures for use in this brochure.

What is an Autism Spectrum Disorder?



Autism is a complex developmental disability affecting individuals in the areas of social interaction and communication. Autism spectrum disorders (ASDs) are estimated to occur in about 1 in 88 children (Center for Disease Control's Autism and Developmental Disabilities Monitoring Network, 2012). Autism is referred to as a spectrum disorder, meaning the symptoms can occur in any combination and with varying degrees of severity.

Autism spectrum disorders affect individuals in every country and region of the world and know no racial, ethnic, or economic boundaries. ASDs begin before the age of 3 and last throughout a person's life, although symptoms may improve over time.

Some children with an ASD show signs of autism within the first few months of life. In others, symptoms might not show up until 24 months or later. Some children with an ASD seem to develop normally until around 18 to 24 months of age and then stop gaining new skills, or lose skills acquired earlier.

Nebraska Resources

Nebraska ASD Network
UNL
253F Barkley Center
Lincoln, NE 68583-0738
Phone: 402.472.4194
Website: www.unl.edu.asdnetwork/

Autism Society of Nebraska
PO Box 83559
Lincoln, NE 68501-3559
www.autismnebraska.org
Phone: 800.580.9279

Autism Action Partnership
14301 First National Bank Parkway
Suite 115 Omaha, NE 68154
Phone: 877.ASD.AAP1 (Resource Line)
Website: www.autismaction.org

Easter Seals
Easter Seals Nebraska
638 N 109th Plaza
Omaha, NE 68154
Phone: 800.650.9880
402.345.2200 ext. 1112
Website: www.ne.easterseals.com

Parent Training and Information Center (PTI)
3135 North 93rd Street
Omaha, Nebraska 68134
Phone: 402.346.0525 or 800.284.8520
Website: www.pti-nebraska.org

The ARC of Nebraska
3601 Calvert Street, Suite #25,
Lincoln, NE 68506
Phone: 402.475.4407
Website: www.arc-nebraska.org

Autism Family Network
Phone: 402.617.2093
Email: AFNLincoln@aol.com
Website: www.autismaction.org

Developmental Disabilities Services
Nebraska Department of Health and Human Services
P.O. box 98925
Lincoln, NE 68509-8925
Phone: 402.479.5247

Nebraska Respite Network VR
P.O. Box 94987
Lincoln, NE 68509
Phone: 402.471.3644
877.637.3422
Website: www.respitenetwork.org

Munroe-Meyer Institute for Genetics and Rehabilitation
985450 Nebraska Medical Center
Omaha, NE 68198-5450
Phone: 402.559.8863
Website: www.unmc.edu/mmi

Health and Human Services
P.O. Box 95044
Lincoln, NE 68509-5044
Phone: 402.471.2306

Nebraska ChildFind and Assistive Technology Partnership
3901 N. 27th Street, Suite 5
Lincoln, NE 68521
Phone: 402.471-2447
888.806.6287

Where do I go for More Information?

The Nebraska ASD Network:

Education and Training: The Nebraska ASD Network is committed to providing up-to-date information and training on autism spectrum disorders. Workshops are scheduled throughout the state on a variety of topics relevant to ASD. Additionally the ASD Network hosts an annual state conference where educators, family members, and community providers come together to learn and network.

School Consultations: Upon request, the regional ASD Network Coordinators are available to provide training and support to school districts to help ensure the development of appropriate, individualized programs for students with autism.

Website: The Nebraska ASD Network has compiled local and national online resources that offer a wealth of information related to autism spectrum disorders. Visit our website to learn more about autism spectrum disorders, find state and national resources and find out more about services provided by the NE ASD Network.

Nebraska ASD Network
www.unl.edu/asdnetwork

Autism Society of Nebraska:

The Autism Society of Nebraska provides a wealth of information about available activities, services and community supports. Communication and support from family and friends can benefit parents as they prepare to take the next steps to help their child. While parents are their child's best advocates, they are not alone. For information on area support groups contact the Autism Society of Nebraska at 800.580.9279 or by visiting the website below.

Autism Society of Nebraska
www.autismnebraska.org

Some of the Terms You Might Hear associated with Autism

Autism is a general term used to describe a group of complex developmental brain disorders known as Pervasive Developmental Disorders (PDD). The other pervasive developmental disorders are

- PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified)
- Asperger's Syndrome
- Rett Syndrome
- Childhood Disintegrative Disorder

Many professionals refer to this group as Autism Spectrum Disorders.

The medical community uses the above mentioned terminology to provide families with a specific diagnosis. Schools use the verification category of autism when determining if a child is eligible for special education services. School teams do not diagnose students with a specific autism spectrum disorder.

What causes autism?

At this time there is no known single cause for autism. It is generally accepted by experts in the field that it is caused by abnormalities in brain structure or function. Brain scans show differences in the shape and structure of the brains of children with autism when compared to those of children who do not have autism.

Currently researchers are investigating a number of theories, including the link between heredity, genetics and medical problems. In many families, there appears to be an increased prevalence of autism or similar disabilities, which has added support to the hypothesis that there is a genetic basis to autism spectrum disorders.

Educational Verification of Autism

In Nebraska, each school district is 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 services the school district must evaluate them through a multidisciplinary team process (MDT) in order to determine their educational and developmental abilities and challenges.



What is the Difference Between an Educational Verification and Medical Diagnosis?

An educational verification is a process conducted by a school district to determine if a student has a disability and to plan appropriate special education services based on individual needs. An educational verification should reflect assessments done by a multidisciplinary team.

A medical diagnosis is usually given by a doctor or clinical psychologist. Diagnosing autism spectrum disorders (ASDs) can be difficult, since there is no medical test, like a blood test, to diagnose the disorder. Doctors look at the child's behavior and development to make a diagnosis. Families may choose to pursue a medical diagnosis of an autism spectrum disorder for their child but it is not required to receive school special education services.

What to Expect in the Future?

Much has been learned about ASD from research and experience. With appropriate education and support, individuals with autism can be active and participating members in their communities. Each individual with autism is unique and may require individualized supports to ensure success.

Regardless of each person's strengths and struggles, there are certain areas to consider when deciding the most appropriate level of support. It is important to consider the following questions as an individual is young, moves into adolescence, and reaches adulthood.

- Is there support in place to ensure success in their environment?
- Is the team measuring progress on this individual's acquisition of necessary skills?
- Is this individual placed in the least restrictive environment possible to facilitate success?
- What changes are coming in this individual's life? What is needed to support a smooth transition?
- What types of recreational and social activities does this individual enjoy?
- Is the team working together to support independence across settings?
- Are special interests being encouraged to support the development of functional skills and, when possible, future employment opportunities?

Remember each person is different. What works for one person on the autism spectrum may not work for another. However, it is important to remember that all individuals can learn new skills and be successful in a variety of environments.

Resources for Transition Planning



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 site below:

Nebraska Department of Education, Transition Project

<http://ndetransition.site.esu9.org/>

Nebraska VR Offices

www.vocrehab.state.ne.us

Developmental Disabilities Services

<http://www.hhs.state.ne.us/dip/ded/dedindex.htm>

Special Education Services for Young Children

For children ages birth to three years of age: A Services Coordinator with the Early Development Network will support the family through the evaluation process. Once a child is determined to be eligible for special education services, the Services Coordinator will assist in identifying the child and family's priorities for supports and resources and will facilitate the development of an Individual Family Service Plan (IFSP).

For children ages 3 – 21, an Individualized Education Program (IEP) will be developed to guide the child's educational program. Parents and guardians are members of the child's IFSP or IEP team that will determine what supports and services are needed to provide appropriate learning opportunities for the child.

Children with autism display many different learning characteristics. The child's individualized plan (IFSP and IEP) will be developed based upon the child's and the family'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

Once a child has been verified with autism, an IEP will be developed and reviewed, at least annually, to determine progress and to reflect his/her current level of performance by the IEP team. This team consists of parents or guardians, educators and/or related service professionals. Older students may also be a part of the IEP team, when appropriate. An educator who is a member of the 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.

Transition

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

It is important for teams to think about emphasizing skills that will help individuals on the autism spectrum become more independent in everyday life. Adolescents with autism and their transition team members may want to consider the following practical suggestions when planning for the future:

People learn best:

- in the places where they happen – like buying things at a store or shaving in the bathroom.
- when they use the real item- like using real money when learning to count.
- when they do activities at the time they are usually done - like brushing teeth after a meal or before going to bed.
- from other people- like learning how to work in places where other people work.
- when the things that they learn are useful – like using the telephone or taking the bus or writing a check.

From the Resource: It's My Choice by the Minnesota Governor's Council on Developmental Disabilities, p. 40

To view the entire handbook visit: www.mnddc.org/extra/publications/choice/Its_My_Choice.pdf

Recently many excellent resources have been developed in the area of transition, self advocacy, and ASD. For more information on these resources please visit our website at:

www.unl.edu/asdnetwork



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 upon income, age, or disability. There are various waiver programs such 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.



What Is the Most Effective Intervention?

Currently there is no cure for autism. However, continued research has provided a clearer understanding of the disorder leading to better interventions and therapies. Early and appropriate interventions can significantly improve the quality of life for individuals with autism.

Parents and educators should work together to investigate interventions thoroughly, as there is no single approach proven effective for all children with ASD. Therefore, intervention programs should incorporate a variety of effective practices tailored to meet the specific needs of the 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.

The National Research Council Report

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 interventions are summarized below and on the following page.

Features of Effective Programs for Young Children on the Autism Spectrum:

- Early entry into intervention
- Active engagement in intensive instruction for at least 25 hours a week, 12 months per year
- Repeated, planned teaching opportunities with sufficient individualized attention on a daily basis
- Systematically planned developmentally appropriate activities aimed toward identified objectives
- Highly supportive environments which include a structured physical environment, trained and consistent staff and on-going monitoring of progress, with programming adjustments as needed

The National Research Council Report Cont.

The National Research Council committee also 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
- 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 on 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
- Interventions that address problem behaviors should focus on positive, proactive approaches; utilizing a 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 abilities and needs of the child should be taught

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

In summary, to accommodate the diverse needs of individuals with ASD, effective approaches should be functional, focus on parent participation, and occur within the natural environment to promote generalization. The child's team should monitor progress on a regular basis in order to evaluate current strategies and determine next steps.

National Standards Report

Following a rigorous and thorough review of the educational and behavioral literature on effective interventions for individuals with autism spectrum disorders, the National Autism Center, published the National Standards Report in the fall of 2010.

*In the National Standard Report the word treatment is used to describe and categorize effective approaches and interventions. In the educational setting we typically refer to these approaches as interventions.

The findings of the National Standards Report include the identification of:

Eleven “Established” Treatments: this group refers to interventions that were proven to produce beneficial outcomes and therefore are known to be effective for individuals on the autism spectrum. The overwhelming majority of these interventions were developed in the behavioral literature (e.g., applied behavior analysis, behavioral psychology, and positive behavior support).

Twenty Two “Emerging” Treatments: this category includes a variety of interventions that showed some evidence of effectiveness, but not enough to substantiate that they are absolutely effective.

Five “Unestablished” Treatments: treatments for which the committee did not find documented evidence of effectiveness.

The National Standards Report recommends that parents, educators, and service providers use this information as they make decisions about programming. It encourages teams to consider other factors in addition to these findings, including the judgment and data-based recommendations of qualified professional(s), the values and preferences of the family and individual with ASD, as well as the capacity of the local school, or other agency to implement the interventions/program.

National Standards Report:, 2009

To read the entire report please visit:

<http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf> or the state ASD website to download a copy.