

A landscape photograph of a vast green field under a dramatic, cloudy sky. The sky is filled with large, dark, textured clouds, with some lighter patches where the sun might be breaking through. The field is a mix of green and brown, suggesting a natural or agricultural setting. The horizon is flat and distant.

State of the State Presentation

North Dakota

Act Early Summit
Region VIII

Quick Overview of State System

- North Dakota has 635,867 people spread over 68,976 square miles leaving a population density of 9.3 people per square mile. This is considered rural.
- About 37 of 53 counties have fewer than 7.0 people per square mile. These counties are considered frontier. About 47% of ND's population lives in these frontier counties.

Quick Overview of State System

- Early Intervention (Birth to 3) services are coordinated by the ND Department of Human Services, Disability Services Division. ND has had early intervention services since the mid 1980s.
- Early intervention services are coordinated through 8 regional human service centers and accompanying infant development programs.
- State sponsored early intervention services are provided through a parent education model.

Quick Overview of State System

- ND's special education services for children and youth with disabilities (ages 3 – 21) are coordinated by the ND Department of Public Instruction, Special Education Division. There were 13, 825 children enrolled in special education in 2006-2007 and 375 (or 2.7%) had a primary disability label of autism.

Quick Overview of State System

The prevalence of children with a label of autism has risen dramatically in North Dakota. The following data are from US Dept of Education, Office of Special Education Programs.

Table 1-1: IDEA Part B - Children with Autism in North Dakota for 1999-2000 and 2006-2007
(Child Count by Age Group)

	Child Count in 1999-2000	Child Count in 2006-2007
Age 3-5	17	40
Age 6-11	71	154
Age 12-17	38	155
Age 18-21	9	26
Age 6-21	118	335
Age 3-21	135	375

Quick Overview of State System

- The ND Department of Public Instruction has a handbook called *Identifying, Serving, and Educating Children and Youth with Autism* (2003). This set of guidelines describes state accepted procedures for diagnosis and services for school-age students with autism.

Quick Overview of State System

- Existing Statewide Networks for Family Support and Education
 - FamNet
 - Pathfinder Services of North Dakota
 - Autism Society of North Dakota
 - Family Voices of North Dakota

Training Efforts

- State Part C Program: Statewide training efforts for providers including research-based practices
- Global Rural Autism Asperger Information Network (GRAAIN) – Graduate Certificate Program
- North Dakota Center for Persons with Disabilities: Autism Webinar Series
- Anne Carlsen Center for Children: Autism Training Series
- Red River Valley Asperger Network: Direct Teacher Training

Family Support

- Several autonomous family support groups that specialize in serving families of children with ASD operate in ND.
- These groups are collaborating to address policy and legislative initiatives, working with state and private agencies to plan services and consider family input.
- ND has a parent-to-parent program that matches families of people with ASD.

Current Resources

- Private Programs (e.g., AuSome Kids Program)
- Local Support Groups
- Statewide Early Intervention/Identification Programs
- Grant Programs (e.g., Great Plains Autism Spectrum Disorders Treatment Program)

Current Challenges and Gaps

- Few ND physicians follow the AAP recommended guidelines for screening at ages 18 and 24 months
- Lack of services and systems for young and older adults with ASD.
- Lack of qualified personnel, especially in rural areas.
- Lack of data on ASD in ND
- Lack of knowledge of available funding sources for services for children with ASD
- Lack of coordination in care and service delivery
- Lack of consistency in diagnostic methods
- Variability in utilizing DSM-IV (TR) criteria in diagnostics

Current Challenges and Gaps

- Variability in educational categories used by schools in order to access services (e.g., ED vs ASD)
- Outdated DPI guidelines
- Lack of coordination between the medical, mental health and educational communities
- Lack of coordinated statewide training to include medical, educational, and mental health professionals

Challenges and Gaps

- Lack of an infrastructure to provide effective in-home intensive early intervention
- Lack of funding to pay for effective in-home intensive early intervention
- Families are not able to meet the needs of children, youth and adults with ASD.

Looking Toward the Future

- The ND legislature is considering a bill to establish a Task Force on autism, with funds for the group to meet periodically each year.
- The ND legislature is considering the use of an autism waiver for Medicaid.