



A Report from the 2008/2009 Work Group on ASD

Recommendations for the ND State Plan on Autism Task Force

Overview

The ND State Plan on Autism Work Group held four meetings in 2008/2009 to discuss the current status of ND's response to increasing incidences of ASD in our state. Members of the work group included representatives from:

Anne Carlson Center for Children	ND Center for Persons with Disabilities
Autism Society of North Dakota	ND Dept. of Human Services, Children's
Blue Cross Blue Shield of ND	ND Association of Community Facilities
Family Voices of ND Inc	ND DHS – Disability Services
FOF for Children's Mental Health	ND Dept. of Public Instruction
Health Insurance Counseling	ND Autism Center, Inc.
Mental Health	ND Department of Health - Children's
Pathfinders Parent Center	Special Health Services
Red River Valley Asperger's Network	ND Autism Connection
Special Education, Dept. of Public Instruction	ND P & A Project
South Valley Special Education	Talk About Curing Autism

After extensive discussion and a general review of several preliminary data sets the work group developed a set of value statements. These statements encompass a range of issues that we hope will be addressed by the newly formed ND State Plan on ASD Task Force that was created in the 2009 Legislative Session. Five primary issues emerged as important to people with ASD, families and the people who provide support to this population. These priority categories are:

- **Services**
- **Service coordination**
- **Assessment**
- **Equity**
- **Workforce Development**

After discussing the meaning of each term and reflecting on the data and our individual and collective experiences, the work group formed a value statement for each priority area. Definitions and related value statements follow.

Value Statements

Services – The term services, implies options for education, treatment, & family support and encompasses a discussion about evidence-based treatments, promising practices and alternative medicine. The work group listened to numerous families who stated repeatedly that services for their children with ASD were often not available in their community and had to be created or cobbled together by families. Families report that they are often unable to obtain those treatments recommended by physicians and most families struggled to learn about what was possible on their own. Young people without access to services, and their families are at risk and will ultimately cost the system more over time. **Recommendations:**

- Promote or develop a continuum of necessary services for people with ASD and their families.
- Locate, obtain, develop and disseminate information on ASD and related treatment options for families, physicians, educators and the general public.
- Support young adults and adults with ASD with the exploration and development of vocational skills and employment acquisition.
- Provide support to families so that their children and teens with ASD can live safely at home

Service coordination – The term service coordination refers to processes of providing information and referral, of brokering services and of helping families and people with ASD understand and navigate the service system. Many people in the work group expressed concerns that the services available to people with ASD and their families are limited throughout ND. Where services do exist, people and families need help to understand and access what is available. **Recommendations:**

- Promote the use of Medical home and effective coordination of services through that model for all people with ASD and their families.
- Provide family-centered, comprehensive, community-based, culturally competent, accessible and affordable services to people with ASD and their families.
- Listen to and involve people with ASD and their families in all aspects of planning and decision making.
- Recognize the intense needs of families of children, youth and adults for support and service coordination when a diagnosis of ASD is given and provide appropriate levels of support across the life-span.

Assessment – The 2009/2010 Work Group recognized the on-going nature of assessment and reviewed preliminary data gathered by the ND Department of Human Services, the Department of Public Instruction, the Department of Health, the state directors of Special Education and Family Voices of ND. This data may be insufficient to guide ongoing decision making. It did

provide the work group with a preliminary grasp of the issues and information that is available. To address these issues we recommend that:

- Make early screening and diagnosis for ASD available to all ND children and be a priority in a planned response to ASD in ND.
- Clarify which services people with ASD and their families need, the extent to which those services are available in ND, and if not available work to develop the needed services.
- Develop necessary systems and policies related to ongoing data collection for evaluation purposes to guide the work of the task force and keep families and providers informed.
- Provide people with ASD, their families and those who support them with access to comprehensive, functional assessment data that can be used to implement appropriate education and care plans.

Equity – The work group discussed the concept of equity in terms of individual and family access to services based on affordability and accessibility regardless of where people live in our state and the age of the person with ASD. Based on this discussion the group recommended: that:

- Assure that ND services to children, youth and adults with ASD and their families are equitable (accessible and affordable) in both small and large ND communities across the life span.

Workforce development – In discussions about workforce development, participants spoke about the need to plan for and coordinate efforts toward the recruitment and training of skilled professionals. They also discussed the need to build the capacity of families to cope with and raise children with ASD. Families are their children’s first teachers. Parents need special skills as children with ASD do not respond to typical teaching or discipline in a predictable manner.

Recommendations:

- Support a workforce capable of meeting the needs of people with ASD and their families.
- Provide quality pre-service and in-service professional and parent development, mentorship and ongoing consultation on the best practices for treating, educating and supporting individuals with ASD.