

**Testimony
Education Interim Committee
Autism Spectrum Disorder Task Force
Representative David Monson, Chairman
October 12, 2010**

Chairman Monson and members of the Education Committee, I am JoAnne Hoesel, Director, Division of Mental Health & Substance Abuse Services. I am here today, in my role as chairperson of the Task Force, to present the statutorily required report regarding the work of the Autism Spectrum Disorder Task Force (Section 10-06-32).

Senate Bill 2174 established the autism spectrum disorder (ASD) task force during the 2009, 61st Legislative Assembly. One of the requirements was to develop a state autism spectrum disorder plan and present the plan to the governor and the legislative council before July 1, 2010. A copy of this initial state plan is provided to each of you. In addition, the ASD resource book developed by the Department of Health is also provided.

About ASD

On page two of the report, the definition of ASD is provided. Five diagnosis are referred to in the spectrum:

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

ASD in North Dakota

There is no registry of the numbers of individuals with ASD in North Dakota. National prevalence data indicates that Autism occurs in 1 out of 91 children.

What we do know about ASD in North Dakota can be seen in information from several state agencies. The Department of Public Instruction (DPI) has seen a dramatic increase in the numbers of children with Autism. In DPI's April 2, 2009 report on ASD disorders in the public school system, of the 12,059 students with a diagnosed disability who were being served in special education, 4.5% possessed Autism as their primary diagnosis. In DPI's report, "1999-2008 North Dakota - Special Education Child Count Related to Autism", shows the change in incidents of Autism compared to the change in other disabilities. (Attachment A)

In the Department of Human Services (DHS), for the time period of 7/1/2007 to 6/30/2008, 91 individuals had a diagnosis of Aspergers, 99 individuals had a diagnosis of PDD-NOS, and 46 individuals had a diagnosis of Autism and were seen in non-DD services. 446 individuals with Autism were served in the Developmental Disabilities system. In child welfare, 65 individuals with a diagnosis of ASD had a plan of care through county social services.

The Initial ASD Plan

The members of the ASD task force are listed on page 10 of the report. The group is diverse and brings many perspectives to the table. Carolyn Fogerty, a parent member on the task force, is in attendance today. The group met eight (8) times since July 2009, studied plans from other states, worked with the Minot State – North Dakota Center for Persons with Disabilities, and formed five workgroups. A survey was developed and distributed to gain a point- in- time view of attitudes and perspectives regarding ASD issues in North Dakota.

Results of those completing the survey felt current ASD services inadequate, information scarce, and training is needed for both parents and professionals. More qualified individuals are needed to provide evidence-based services and people need to know how to access the services.

The report contains seven (7) categories of recommendations each with a vision, listing of current barriers, and a list of recommendations. The categories are:

1. Early Identification and screening
2. Appropriate and effective practices
3. Quality providers
4. Funding Issues
5. Information Access
6. Family Support
7. Accountability

Gains made

While the challenges are formidable, it is important to note a few gains made in this area. Teachers across the state have access to an on-line certification course provided by UND in ASD, an ASD Medicaid waiver was funded by the last legislative session for 30 children from birth through age 4 which is expected to be approved for implementation in November 2010, NDCPD has a wealth of knowledge and expertise in ASD, and in collaboration between the ASD task force and NDCPD, a web site is in the works which will provide a focal point for ASD information.

Next Steps

The ASD Task Force held its most recent meeting in late September and has begun identifying next steps to put action to the initial plan. The need for

ASD action reaches far beyond the task force. When considering what might be important options to consider for North Dakota, the following list of ideas was developed by the task force.

1. Funding for the task force be continued. \$3,000 was appropriated this biennium in the DHS budget.
2. Fund and hold a statewide conference on the state of ASD in ND.
3. Hold a meeting of current professionals who screen young children. The current screeners are physicians, public health units, Health Tracks, and Right Track agency staff. The goal would be to review the need for both developmental AND autism screenings, achieve coordination and avoid duplication.
4. Fund training through existing venues/conferences across disciplines (health, education, family support, therapy) to address statewide need to build awareness, capacity building and coordination of services.
5. Fund a dedicated ASD coordinator with the authority and funds to direct and coordinate cross-agency training and implement the strategic plan. This issue is not 'owned' by any one agency from a statewide, collaborative, and 30,000 foot view. This would provide a focused attention on ASD, heighten awareness and organize the varied pieces tied to ASD. Coordinate and manage with a dedicated eye.
6. Fund training through already existing venues across agencies and disciplines (including training for families) to build awareness and capacity for the implementation of evidence-based practice for persons with ASD
7. Fund a second ASD Medicaid waiver or other Medicaid funding mechanism to serve ages 14 through 26 in the second year of the biennium. This would be logical next step following the birth through age 4 Medicaid waiver funded last session.

It should be noted that there has been activity in the employee benefit committee where a bill draft has been heard that would require insurance companies to reimburse services for ASD conditions.

I would be happy to answer any questions.