

Testimony
Human Services Interim Committee
Department of Human Services
Representative Alon Wieland, Chairman
August 2, 2011

Chairman Wieland and members of the Human Services Interim Committee, I am JoAnne Hoesel, Director, Division of Mental Health & Substance Abuse Services, for the Department of Human Services. I am here today to provide comments regarding the committee's study of the autism spectrum disorder (ASD).

My comments focus on four areas: 1) background information on the autism spectrum disorder, 2) information on the developmental disability (DD) system and the mental health system and their interactions with individuals with disorders on the spectrum, 3) the ASD Task Force of which I am chairperson, and 4) general issues for consideration.

Background information on ASD

In order to provide context to my comments, I will describe the conditions that fall on the ASD spectrum and define commonly used terms.

- **Intellectual disability (previously referred to as mental retardation)** is characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities. Intellectual disability is sometimes referred to as a cognitive disability or mental retardation.

- **Developmental disabilities** are a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living.
- **Autism Spectrum Disorders** are a group of developmental disabilities that can cause significant social, communication, and behavioral challenges.

The diagnoses that are on the ASD spectrum are:

- Autism
- Asperger's Syndrome
- Rett's Syndrome
- Pervasive Developmental Disabilities, Not Otherwise Specified
- Childhood Disintegrative Disorder

The Center for Disease Control estimates a range between about 1 in 80 and 1 in 240, with an average of 1 in 110 children in the United States have an ASD.

There is currently no cure for ASDs. However, research shows that early intervention treatment services can greatly improve a child's development. Early intervention services help children from birth to three years old learn important skills. Services can include therapy to help the child talk, walk, and interact with others.

We do not know all of the causes of ASDs. However, we have learned that there are likely many causes for multiple types of ASDs. There may be many different factors that make a child more likely to have an ASD including environmental, biologic, and genetic factors.

- Most scientists agree that genes are one of the risk factors that can make a person more likely to develop an ASD.
- Children who have a sibling or parent with an ASD are at a higher risk of also having an ASD.
- ASDs tend to occur more often in people who have certain other medical conditions. About 10 percent of children with an ASD have an identifiable genetic disorder, such as Fragile X syndrome, tuberous sclerosis, Down syndrome, and other chromosomal disorders.
- Some harmful drugs taken during pregnancy have been linked with a higher risk of ASDs, for example, the prescription drugs thalidomide and valproic acid.
- We know that the once common belief that poor parenting practices cause ASDs is not true.
- There is some evidence that the critical period for developing ASDs occurs before birth.

Services for individuals with ASD are provided by varied sources both public and private: education, mental health, primary health care, developmental disabilities, advocacy organizations, and vocational rehabilitation.

The Department of Human Services administers the early intervention programs in North Dakota for children birth through three years old. This program, referred to as Infant Development, is contracted to private agencies. Children are served by the education system after early intervention services end.

The regional human service centers provide services to individuals through the DD system, the vocational rehabilitation system, and the mental health system.

In the DD system, individuals need to have a developmental or intellectual disability, must be in need of institutional level of care, and diagnosed with mental retardation. Services are delivered through a Medicaid waiver in the community or through Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IDs). For those who are not eligible for the DD system and/or have a mental health condition, individual, group, or family therapy are provided in addition to care coordination, residential, medication therapy and psychiatric and psychological services. The regional human service centers do not provide specific ASD services nor does the Department consider this a core service even though we do have professionals skilled in this area. Many individual professionals in the mental health system have received additional specific training for ASD and provide appropriate care, but this must be determined by the professional and not by the profession. The majority of specific ASD therapies are provided by private providers in the state. The term Applied Behavior Analysis (ABA) is one therapy method often referred to in a discussion about ASD.

Depending on the individual, severity of condition, and diagnosis, services are delivered in varied settings. It can be confusing and frustrating to access services due to the eligibility criteria of a program, level of training of the professional, and availability of trained providers. We are aware of young children discharged from their daycare services due to behaviors associated with ASD.

ASD Waiver

The Department of Human Services was appropriated funds during the 2009 Legislative Session to develop and implement a specific Medicaid waiver for children ages birth through four years of age who have ASD or have significant delays in the areas affected by ASD. The intent of this waiver is to provide interventions early to mitigate the effects of these conditions. The waiver has a capacity for 30 children and there have been 14 children served since services began in November 2010. The waiver includes the following services: intervention coordination, in-home supports, equipment & supplies, and environmental modifications. Early detection and early diagnosis do lead to better outcomes according to the Center for Disease Control. Minot State Center for Persons with Disabilities serves as the evaluation and consultation team for this waiver. The 2011 Legislature continued the funding for the waiver.

ASD Task Force

The ASD Task Force was formed in 2009 but was preceded by the work of a Minot State University-led work group formed in 2008. The ASD Task Force distributed a survey in the spring of 2010 which provided insight into the current status of ASD services and support. Responders confirmed what task force members had suspected in that they felt services are lacking, there are limited comprehensive services, there is a need for training, and they recommended earlier identification. An initial plan was written and the Task Force continues work on the plan's recommendations.

Issues to Consider

- 1) Consistent service delivery, provider expertise, and public awareness options,
- 2) Methods to increase access to services,

- 3) Financial impact on families receiving effective services,
- 4) Potential incentives for individuals to encourage the pursuit of educational degrees and certifications to address the lack of well trained workforce,
- 5) Include all age groups in the scope of the study, and
- 6) Public policy needs to support an effective and comprehensive service delivery system for individuals in need of support.

We are pleased that a comprehensive review of the needs of individuals with ASD is occurring, and we look forward being involved and being a resources to achieve a successful study result.

I am available to answer any questions you may have.