

Human Services Interim Committee
August 30, 2012

Autism Spectrum Disorder Proposal
Kris Wallman
701-412-3843

Mr. Chairman and Members of the Committee,

My name is Kris Wallman. I'm the President of the Autism Society of North Dakota, a member of the Board of Education in Fargo, and along with my husband, am the parent of two children, one with an autism spectrum disorder.

As you may remember, members of family support groups, autism organizations and direct service providers, both public and private, gave input for a proposal we brought to you the last time this committee met.

In fine-tuning the proposal we took into account testimony from the individuals on the autism spectrum who you've heard from during this interim session, from parents and grandparents, and from service providers who all testified to the needs and, often, dire circumstances of families in North Dakota impacted by autism.

We considered the thorough recommendations of the Autism Task Force that were presented to this committee. We sought input from staff in the Department of Public Instruction (DPI) who received endorsements from their regional directors, specifically for the training component of this proposal. We sought input from the Department of Health and are awaiting estimates for resources regarding the Autism Registry within the next several weeks. This proposal is not comprehensive. We have chosen to prioritize things that are widely agreed on and are basic necessities.

Thank you to Roxanne Woeste for compiling a summary of the proposals. We appreciate her work. We apologize for not getting this information to her earlier. In conversations with our stakeholders it became clear that the proposal needed a component to address educational needs. We have added this to the proposal.

The proposal contains three main items. They are: 1) Development of an Autism Registry; 2) Development of a System to Reimburse Necessary Services Not Covered by Insurance; and 3) Educational Training and Support.

Our hope is that you will take this proposal and have a bill draft crafted to vote on at your next meeting. I am handing out copies of the full proposal, which fleshes out the summary that we emailed to you earlier in the week.

We would like to thank everyone who provided input and guidance in this process. We would especially like to thank this committee for your time and efforts. I am open to answer your questions.

**COLLABORATIVE PLAN FOR AUTISM SERVICES FOR PRESENTATION TO THE
HUMAN SERVICES INTERIM COMMITTEE
August 30, 2012**

Autism refers to a group of complex developmental brain differences that are collectively referred to as autism spectrum disorders (ASDs) that can cause a wide range of symptoms which can include social, communication, and behavioral difficulties as well as executive skills deficits.

In the current Diagnostic and Statistical Manual IV TR (DSM IV TR) autism spectrum disorders are referred to as pervasive developmental disorders and include subcategories of classic autism with ranges from high functioning to low functioning autism, Asperger's syndrome, and pervasive developmental disorder not otherwise specified, as well as Rhett Syndrome and Child Disintegrative Disorder. This proposal excludes Rhett Syndrome and Child Disintegrative Disorder. According to the DSM IV TR, pervasive developmental disorders are characterized by qualitative impairments and verbal and nonverbal communication, qualitative impairments in social interactions, and a combination of restricted repetitive stereotyped behaviors, interest, and activities. It is also understood that individuals with autism have impairments in sensory integration.

Autism is identified in an estimated one in 88 children by age 8 and one in 54 boys. Boys are five times more likely than girls to be identified with autism.

An estimated 1,500,000 individuals in the United States are affected by autism.

More children will be diagnosed with autism this year than with AIDS, diabetes, and cancer combined.

Autism is considered to be the fastest-growing serious developmental disability in the United States.

Autism costs the United States over \$35 million per year, a figure expected to significantly increase in the next decade.

There is currently no medical cure for autism, but there are evidence-based and emerging interventions proving to be effective in improving outcomes for individuals with autism. There are also evidence-based assessments that are proven to accurately identify individuals with autism in a majority of cases.

In order to better serve North Dakota individuals with an autism spectrum disorder and their families the following is proposed.

1. DEVELOPMENT OF AN AUTISM REGISTRY

There is currently no system to track the number of individuals with autism in the state of North Dakota.

The State of North Dakota currently registers a number of other conditions, including influenza, cancer and certain birth defects, that are reported and maintained in a central registry through the Department of Health. We are proposing that a similar registry for reporting diagnoses of autism spectrum disorders and maintaining a tracking of that information is needed to improve current knowledge and understanding of autism, to conduct thorough and complete epidemiologic surveys of the disorder, to enable analysis of this problem, and to plan for and provide services to children and adults with autism spectrum disorders and their families.

A physician or any other health care professional independently licensed in the state of North Dakota who is qualified by training to make the diagnosis of autism and who then makes the diagnosis that a child is affected with autism shall report this diagnosis to the Department of Health in a form and manner prescribed by the Director of the North Dakota Department of Health.

The reporting of data to the registry and information dissemination will follow all privacy mandates as established by The Health Insurance Portability and Accountability Act of 1996 (HIPAA) Federal Regulation 45 CFR Parts 160 and 164 list Privacy Rule Standards for Privacy of Individually Identifiable Health Information.

The Department of Health shall maintain an up-to-date registry which shall include a record of: all reported cases of autism that occur in North Dakota; each reported case of autism that occurs in North Dakota in which the initial diagnosis is changed, lost, or considered misdiagnosed; and any other information it deems relevant and appropriate in order to conduct thorough and complete epidemiologic surveys of autism, to enable analysis of this problem and to plan for and provide services to children with autism and their families.

Estimated cost for biennium (2013-2015): (We contacted Arvy Smith, DOH, and she will calculate the costs)

2. DEVELOP A SYSTEM TO REIMBURSE NECESSARY SERVICES NOT COVERED BY INSURANCE

A voucher system will include an individualized plan of supports and services designed to meet the needs and goals of a consumer with an autism spectrum disorder. The plan is based on the preferences, interests, talents, attributes and needs of each consumer.

These vouchers will enable individuals on the autism spectrum and their families to access goods and services to cover a range of home and community-based services (HCBS) that will benefit the individual with autism to function successfully in their home, school, employment, and community.

Administering Agency: The Department of Human Services* through existing case management programs will administer the voucher program. At least one case manager from the current Developmental Disability Case Management system or The Partnership Care Coordinator program in each Regional Human Service Center will be identified and appropriately trained to understand the needs of individuals with an autism spectrum disorder and how to effectively work with them and their family, caregiver, or guardian. Adequate financial support will be given to train and provide resources to these staff persons.

*Since autism is not a core service of DHS another administering agency could be considered.

Age Range: There will be two distinct voucher programs:

Plan 1:	0 – 26 years old
Plan 2:	26 – end of life

Financial limits: Each individual will be allocated up to \$30,000 annually to access necessary services available under the voucher.

Services for Plan 1: Services to children will include but not be limited to assessments, medical care, mental health services, occupational therapy and equipment, speech and language services, assistive technology, case management, transportation, educational supports, respite care, executive and social skills training programs, and development and implementation of behavioral intervention plans.

Services for Plan 2: Services to adults will include but not be limited to assessments, medical care, mental health services, occupational therapy and equipment, educational and employment services, housing, transportation, medical care, and independent living services.

Number of slots available: 150 for the 2013- 2015 (100 for Plan 1: Children and 50 for Plan 2: Adults)

Eligibility: Individuals on the Autism Spectrum who are at or below 300% of the federal poverty level are eligible. Individuals must have been a resident of North Dakota for a minimum of six months.

The process for the voucher will begin with a diagnostic evaluation that meets these requirements:

- A qualified clinician must complete the evaluation. The clinician's evaluation must state that the individual has a diagnosis of Autism, Asperger's Syndrome, or Pervasive Developmental Disorder not otherwise specified (PDD-NOS).
- The evaluation must have been completed no more than one year prior to application for Autism Voucher funding for services.
- The evaluation must include supporting documentation that includes a DSM-IV-TR diagnosis and identification of the testing tools.
- The tests used must be considered valid for the age of the individual and the diagnosis given.
- The evaluation must support that the individual is a candidate for this treatment methodology.

A Plan of Care will be developed with the individual with an autism spectrum disorder and/or their family, care-giver or guardian. The Plan of Care must contain the following information:

- the services to be provided, utilizing evidence based services as appropriate
- the frequency of each service
- who will provide each service
- the cost of each service

Consumer Rights: If a plan or service is denied there will be an appeal process. All consumers will be able to request a change to their support plan based on a change in needs or health status. Service plans must be reviewed annually by the case manager, or whenever necessary due to a change in a consumer's needs or health status. A consumer may discontinue participation in the voucher program at any time and may re-apply should services be requested at a later date.

Provider qualifications: Provider qualifications and provider selection will be completed through an application process similar to current ND Medicaid provider requirements.

Dissemination of information: Details regarding the voucher program including general information and application processes will be on the Department of Human Services Website, Regional Human Service Center websites, and brochures will be distributed to stakeholders. Information will be given to autism and advocacy organizations in the state for giving out of information to potential participants.

Oversight: A detailed summary of the services and related costs of the program will be given to the Director of the Department of Human Services for report to the interim Human Services Legislative Committee. Yearly regional meetings to include staff and stakeholders will be held to gather input.

Cost of voucher for biennium (2013 – 2015): \$4,500,000

3. EDUCATIONAL TRAINING AND SUPPORT

School can be especially challenging for students on the autism spectrum. The educational environment is socially complex, constantly changing and often unpredictable. Students are required to cope with changing environmental stimuli; adapting to situational expectations; complex social interaction with adults, same age peers and students of other ages; the academic challenges of each day; their own mood and state of mind and are they expected to behave appropriately at all times. This can be a challenge for all children but for those with autism spectrum disorders, it can, unless properly, managed be almost insurmountable. Only by having properly trained administrators, teachers, and school staff who have a desire to work with children with an autism spectrum disorder can they reach their highest level for success.

Many students with autism spectrum disorders are of average or above average intelligence and as they mature, they become aware of their differences and despite wanting to communicate effectively or fit in don't know how to. This can lead to intense frustration which may either result in outbursts of verbal and/or physical violence or withdrawal into themselves. The quiet, well behaved student is often the most at risk because the problem issues are unseen and thus unaddressed. These children are very vulnerable to bullying situations that further exacerbate emotional and behavioral difficulties.

Also, many students may have a "reputation that precedes them" for both other students and staff. This will impact how they are perceived and treated. Some students may have low self esteem and an expectation of failure both academically and behaviorally.

Contingent on available funding through the general fund or other funding sources to the North Dakota Department of Public Instruction, to be administered by the North Dakota Department of Health, the following activities will be provided to prekindergarten through grade 12 public educators.

School administrators, general education and many special education classroom teachers and school staff (including but not limited to counselors, paraprofessionals, recess monitors, maintenance, and dietary staff) often currently are not adequately trained to work effectively with students with autism spectrum disorders. Such skills may be attained through qualified training programs and could be implemented in school settings.

Training general education classroom teachers and other school staff to implement evidence-based practices for educating and providing services for students with autism spectrum disorder with accuracy and fidelity will help provide for the best possible outcome not only for the students with autism, but also for other students in the classroom. Training can be provided by nationally known experts in the field of both education and autism. These trainings could be provided regionally throughout the state.

This training on providing effective support includes but is not limited to academic support, behavioral support, communication support, social emotional support, and facilitating positive peer interactions. Furthermore, learning and implementing strategies to effectively include and involve parents and caregivers of students with autism spectrum disorders in this process is essential.

A strategy to recruit and retain skilled personnel participating in the education of autism spectrum disorders will be established.

An effective educational program will, at the least, be based on the students' strengths and build on them to give them a feeling of achievement and thus improve their confidence. It will also identify the challenge areas and provide strategies to deal with behaviors, strategies to teach both academic and social concepts which start with building executive skills at the student's pace. Overall the program will not just teach 'academics' but teach strategies and skills that will assist future academic, independence, and life skills.

Estimated cost for educational training and support for biennium (2013-2015):

3 nationally recognized speakers with expertise in education and autism to address multiple aspects of educating/managing students with an ASD (includes speaker fee, travel, lodging, food)	\$84,000
Lodging for participants	\$78,000
Venue fees and food (two lunches each conference)	\$36,000
Total expenditure	\$198,000

It is requested that a motion be made to prepare a bill draft to be available for the next interim Human Service Committee meeting to address the three priority services for individuals with an autism spectrum disorder including development of a registry, a voucher system for provision of services, and educational training and supports as presented today.