

Autism Spectrum Disorder in North Dakota
Next Steps for 2013 Legislative Session

Chairman Wieland, members of the committee, my name is Kristen Wallman. I am the President of the Autism Society of North Dakota and an elected member of the Board of Education in Fargo. I'm speaking today on behalf of the Autism Society.

We would foremost like to thank the Department of Human Services Interim Committee for keeping Autism Spectrum Disorders as one of the areas being addressed in the interim session.

We would like to thank the Autism Task Force for their years of work leading up to their recent recommendations to this committee. The ASD Task Force recommendations are thorough and underscore the complex needs of the hundreds of families impacted by Autism Spectrum Disorder in our state.

We would also like to thank the non-profit Family Voices of North Dakota for all their work distributing surveys, helping families navigate disparate services in different regions of the state, and for offering one on one help directly to parents. They continue to be critical in the state for families trying to piece together needed services in our local communities.

Without the collaboration of many people across the state we aren't able to help those impacted by autism, living in often hopeless and desperate circumstances.

The Autism Society of North Dakota (Autism ND) has been working with stakeholders around the state to pinpoint what next steps would be best as efforts to address ASD in our state move ahead. With the ASD Task Force work as a foundation, we have identified three areas that are critical for the development of state initiatives for Autism Spectrum Disorders in North Dakota.

First, accurate data about individuals on the autism spectrum is needed in order to attach responsible appropriations to ASD initiatives.

1. ASD Registry: The proposal is for state lawmakers to mandate the development of an Autism Spectrum Disorder registry to be maintained in the Department of Health.

- The state currently has analogous processes and infrastructure in place. The Dept. of Health already uses similar processes such as the state registry for vaccinations.
- Through the processes already in place, information can be shared appropriately and safely so that we can provide consistent information to coordinate existing services among agencies including DPI, DHS, and the Dept. of Health

- The ASD Task Force estimated a state registry would cost approximately \$200,000.

Second, in order to have accurate diagnoses by qualified individuals, the establishment of best-practice standards to be used throughout the state is necessary.

2. BEST-PRACTICE STANDARDS: The proposal is for a mandated, temporary Ad Hoc Committee. The committee will be made up of stakeholders from around the state including, but not limited to, professionals qualified to diagnose Autism Spectrum Disorders, consistently using evidenced based, best-practice screening and assessment tools and protocol.

- Stakeholders will come to together to document the protocol for the registry and establish the means by which qualified providers are identified. Well-established registries in other states could be used in this process.
- Guidelines from the Centers for Disease Control will be used to direct the standard for North Dakota's protocol from screening to assessment.
- A public/private partnership will be used to identify current providers who utilize evidence-based assessments and provide training for professionals in regions of the state where there is not currently access to qualified providers.
- Providers, both public and private, qualified to diagnose autism spectrum disorders, would report to the registry the incidence of individuals who are on the autism spectrum.
- To convene such a stakeholder working group for 4-6 months would cost an estimated \$6,000 for meeting space with technology and support such as telephone call-in costs, and coordination and meeting planning.

Third, a system of vouchers to be used for services and support from qualified providers throughout the state, both public and private, streamlining appropriate service delivery.

3. SERVICE AND SUPPORT: The proposal is for a contract for programs and services (using evidence based and best-practice guidelines as put forth by the Centers for Disease Control and National Autism Center), for interventions using a voucher system with a private-public partnership. This will allow for addressing the entire spectrum of Autism, will allow everyone in the state to access services where they are available, and at all ages.

- Based on the cost of the traditional Developmental Disability Waiver, which the ASD Task Force estimated at \$27,239 per person, per year.
- A waiver for 150 individuals who do not meet the criteria of Intellectual Disability, and are diagnosed with ASD.
- Estimated cost \$4,085,850 per year.

Proposal	Estimated Cost	Source
ASD Registry	\$ 200,646	ASD Task Force Estimate
Development of Best Practice Standards	\$ 6,000	Ad Hoc, 4-6 month committee operating budget
Service and Support	\$ 4,085,850	Based on the cost of the traditional DD waiver (\$27,239 per person) for 150 individuals
Total	\$ 4,292,496	

On behalf of everyone whose lives are impacted by Autism I thank you for hearing this testimony and proposal.