

Testimony
Senate Bill 2193
Senate Human Services Committee
Tuesday, January 22, 2013
North Dakota Department of Health

Good morning, Chairman Lee and members of the Senate Human Services Committee. My name is Tamara Gallup-Millner and I am Director of the Division of Children's Special Health Services for the North Dakota Department of Health. I am here to provide information regarding SB 2193.

Section 1 of the bill instructs the North Dakota Department of Health to establish and administer an autism spectrum disorder (ASD) database that includes a record of all reported cases of ASD in the state and any other information deemed relevant and appropriate by the department in order to complete epidemiologic surveys of the ASD, enable analysis of the ASD and provide services to individuals with an ASD. Section 2 provides an appropriation of \$200,648 in general funds to the Department of Health for the purpose of establishing and administering the ASD database and authorizes one full-time equivalent position for this purpose.

If SB 2193 is adopted, the Department of Health requests clarification on a number of items bulleted below in order to ensure we establish and administer a successful database or registry.

- Is reporting into the database to be voluntary or mandatory? Based on past experience with other voluntary reportable conditions, it is the department's recommendation that reporting be mandatory to assure the database will provide a complete and accurate record of all ASD cases in North Dakota. As with other registries maintained in the Department of Health (e.g., HIV), confidentiality would be maintained and the data kept in a secure system.
- Who determines an individual has an ASD and from whom should the department accept a valid report for the database? Who actually reports the ASD may affect the validity of the data. Self-reporting is different than data obtained from individuals qualified to make medical diagnoses based on established criteria. ASD is not a simple diagnosis. The Division of Children's Special Health Services currently provides contract funding for

five ASD diagnostic clinics per biennium, using a team approach for the diagnostic process.

- Who is expected to complete the epidemiologic surveys, analysis and provide services to individuals with ASD? Is it the Department of Health, the Department of Human Services, or some other entity? Language in lines 11 through 13 of the bill differs from what was communicated when the Department of Health was initially contacted for information regarding the database or registry. At that point, it was communicated that an accurate number of individuals with ASD was needed. To carry out the responsibilities as currently written in the bill, individuals would need to understand the intricacies of ASD and have a background in public health informatics. Ongoing FTE would be needed to carry out this level of responsibility.
- Upon request of advocates, the Department of Health provided an initial cost estimate for a simple autism registry. With that option, ASD was to be added to an existing system, the ND Electronic Disease Surveillance System, also known as Maven. This system will need to be customized in order to use it for an ASD database. By the time staff is hired, the autism database is operational, and reporting initiated, it's realistic to anticipate a two-year time frame before the system is fully functional. In addition, costs are likely more than originally expected. Items that were not initially included in the department's estimate include such things as maintenance costs from the system vendor, staff travel, and educational resources to create awareness for registry reporting.

There is a bill in the House (House Bill 1038) that contains similar instruction to the Department of Health. In that bill, the term "registry" is used rather than "database" and the appropriation is \$148,132 rather than \$200,648.

This concludes my testimony. I would be happy to answer any questions you may have.