

Testimony
Senate Bill 2193
House Human Services Committee
Tuesday, March 12, 2013
North Dakota Department of Health

Good afternoon, Chairman Weisz and members of the House 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 research and analysis of the ASD and provide services to individuals with an ASD. It instructs the department to establish criteria, in consultation with experts, on who is qualified to report cases of ASD in the database. It requires the department to include diagnoses from the Diagnostic and Statistical Manual of Mental Disorder, Fifth Edition, in the database in addition to a complete physical evaluation of the reported individual performed by a licensed physician. It requires the State Health Council to adopt rules to provide for established mandatory reporting requirements to the ASD database. Lastly, it addresses confidentiality of identifiable database records, but allows the department to provide the records to other state agencies to carry out the purposes of the database after notifying the receiving agency of the confidential nature of the records. Section 4 of the bill provides an appropriation of \$200,648 from the general fund 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.

- Who is expected to establish and administer the registry and complete the epidemiologic surveys, enable research and analysis, and provide services to individuals with ASD? Language in lines 7 through 12 of the bill differs from what was communicated when the Department of Health was initially

contacted for information regarding the database. At that point, it was communicated that only 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 and complexities of ASD and have a background in public health informatics. Ongoing FTE would be needed to carry out this level of responsibility.

- The bill requires that the database include a complete physical evaluation of the reported individual, performed by a licensed physician. This component adds complexity to registry reporting and may not be useful unless it's autism-specific.
- The department concurs that reporting be mandatory to assure the database will provide a complete and accurate record of all ASD cases in North Dakota and that rules be adopted to address specific reporting requirements.
- 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. The department agrees that having the ability to provide records to other state agencies, as necessary, to effect the purposes of the database is beneficial as it supports coordination across agencies and enables families to be linked to educational opportunities or other services.
- The amount appropriated to the Department of Health in SB 2193 is \$200,648. This figure originated from an estimate provided by the State ASD Task Force to an interim legislative committee and was a proxy estimate based on costs of an Early Hearing Detection and Intervention Tracking System. Upon request of advocates, the Department of Health also 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. With the additional requirements of SB 2193, the Maven 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 to the added staff, additional costs include such things as maintenance costs from the system vendor, staff travel, and educational resources to create awareness for registry reporting.

- In the fiscal note, estimated expenditures for the Department of Health total \$391,464, which requires an additional appropriation of \$190,816 in general funds from what is included in the bill. This includes two full-time equivalent positions at \$291,464 and associated operating expenses at \$100,000, which are comprised of \$30,000 in general operating expenses associated with the FTE, \$30,000 for the purchase and license of a new module for the autism database using our current Maven system, and \$40,000 for system maintenance and hosting fees (\$20,000 per year).

HB1038 contains similar instruction to the Department of Health and a similar fiscal note, but includes no appropriation or full-time equivalent positions.

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