

Testimony
House Bill 1038
Senate Human Services Committee
Monday, March 11, 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 HB 1038.

Section 2 of the bill instructs the North Dakota Department of Health to establish and administer an autism spectrum disorder (ASD) registry 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 also mandates reporting of ASD cases by physicians, psychologists, or other licensed providers who are qualified to make the diagnosis and specifies that new cases reported must include the child's birth date, gender, zip code at birth residence, and specific diagnosis. Name and address of the child are not to be included in the registry and reported children cannot be compelled to submit to medical or health examination or supervision by the department.

If HB 1038 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 registry.

- The department concurs that reporting be mandatory to assure the registry will provide a complete and accurate record of all ASD cases in North Dakota. However, the department has questions and concerns regarding specific reporting requirements included in HB 1038. Clarification is needed on whether the ASD registry is intended to focus on children or if it's meant to include all reported cases of ASD in the state. It would also be helpful to clarify the usefulness of reporting the zip code at birth residence. Although this may tell you where individuals with ASD were born, you won't have a good indication of where cases currently are within the state. ASD is not identifiable at birth. Lastly, names and addresses of children diagnosed with an ASD are required to be excluded from the registry. This conflicts with the

requirement that the registry include information in order to provide services to individuals with ASD. The department recommends that names and addresses be included to assure reported cases can be deduplicated for more accurate statistical reporting and that contact can be made if follow-up is needed to link families to educational opportunities or other services. 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 is expected to establish and administer the registry and complete the epidemiologic surveys conduct analysis and provide services to individuals with ASD? Language in lines 12 through 15 of the bill differs from what was communicated when the Department of Health was initially contacted for information regarding the registry. 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 have a thorough understanding of 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.
- 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. With the additional requirements of HB 1038, this system will need to be customized in order to use it for an ASD database. By the time staff is hired, the autism registry 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.
- The fiscal note for HB 1038 is \$589,464 for the 2013-2015 biennium. Of that amount, \$198,000 is for the Department of Public Instruction to provide training and support to teachers and other school staff. Estimated expenditures for the Department of Health total \$391,464. 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 registry using our current MAVEN system, and \$40,000 for system maintenance and hosting fees (\$20,000 per year).

SB 2193 contains similar instruction to the Department of Health and a similar fiscal note, but has an appropriation of only \$200,648 and authorizes one full-time equivalent position.

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