

Testimony
Senate Bill 2241
Senate Human Services Committee
Wednesday, February 8, 2017
North Dakota Department of Health

Good morning, Chairman Lee and members of the Senate Human Services Committee. My name is Kodi Pinks and I am the Autism Database Administrator in the Division of Children's Special Health Services, which is located in the North Dakota Department of Health (NDDoH). I am here to provide information regarding SB 2241.

The NDDoH was charged with establishing an autism spectrum disorder (ASD) database during the 2013 legislative session. An ASD expert panel that was convened in 2014 determined that language used in the original bill was too restrictive and might hinder reporting. These issues were subsequently addressed in SB 2176 during the 2015 legislative session.

The NDDoH uses the disease surveillance system known as MAVEN for several mandatory reportable conditions such as Influenza and HIV. The ASD database is a module contained within the MAVEN system and was first implemented in February 2016.

The ASD database has been progressively fine-tuned based on recommendations from an expert panel, input from mandatory reporters, public comment through the administrative rule-making process, and implementation experience to date. The NDDoH plans to convene an ASD Database Advisory Group this spring to continue engagement efforts and address changes to the ASD Report Form (SFN 60804 is available electronically on-line or as a fillable PDF at <http://www.ndhealth.gov/cshs/autism.htm>).

The NDDoH would like to provide information regarding the following sections of SB 2241:

Section 1, Part 3c – The NDDoH has concerns in this area because of issues with confidentiality, data quality, and security access and management. This section requires the database to be searchable and would allow a reporter to update or amend the diagnosis or status of a previously reported case of ASD. There are three main reasons why this section is problematic.

1. Confidentiality is a concern if mandatory reporters are allowed to access the database. First of all, there is no way to audit reasons why reporters or their

designees are accessing an individual's information. Secondly, there is no way to monitor whether or not reporters or their designees are sharing their usernames and passwords with others.

2. The quality of the data could be affected if mandatory reporters or their designees are allowed to update or amend a diagnosis or the status of a reported case of ASD if they are not familiar or trained on how to use the database. For example, a reporter could enter information incorrectly or inconsistently, or override a previous entry.
3. Security access and management of the database is also a concern. Based on the number of licensed mandatory reporters practicing in the state, there are potentially 4,800 external users. All of these users would require a secure user name, password, and supportive services or help desk functions. However, out of the 4,800 potential users, the NDDoH estimates 912 will be active users based on the number of licensed physicians and psychologists in the state. These two professions are currently the majority of database reporters.

NDCC Chapter 23-07 also addresses reportable diseases and the collection of public health information by the NDDoH. Reportable diseases are to be disclosed only to the extent necessary to protect the health or life of an individual.

Section 1, Part 4a – This section allows a reporter to decline to provide mandatory reportable data if the reporter files an articulable rationale. By giving reporters the option of selective reporting, the integrity of the data could be compromised by reporting bias. Reporting bias is the reluctance to report based on attitudes, beliefs, and perceptions which can lead to underreporting. Another concern arises when reporters are given the opportunity to opt-out of reporting. It sets an undesirable precedent for other mandatory reportable conditions in North Dakota. Lastly, the term articulable rationale is ambiguous. Acceptable reasons for not reporting would need to be determined.

Section 1, Part 4c – Although section 23-01-41 4.c states that a provider who violates this subsection may be subject to a civil fee, not to exceed one hundred dollars per occurrence, the NDDoH is unable to determine the providers who may be violating this subsection or the number of violations that might occur.

There is a fiscal note attached to this bill totaling \$64,149. The NDDoH anticipates additional costs to allow users to access the system, ITD server costs, security

configuration costs, and increased staff time to assist users. Estimated expenditures are as follows:

- ITD user costs for mandatory reporters to access MAVEN - $\$1.35 \times 912 \text{ users} \times 24 \text{ months} = \$29,549$
- ITD server costs – 1 additional server at $\$400/\text{month} \times 24 \text{ months} = \$9,600$
- Security configuration costs (e.g., estimate for user account set-up for an autism reporter group through Conduent) – 100 per hour “bucket” at $\$130/\text{hour} = \$13,000$
- Temporary salary costs to handle “help-desk” like functions for new MAVEN users - $\$25/\text{hour} \times 20 \text{ hours/month} \times 24 \text{ months} = \$12,000$

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