

Testimony
Human Services Committee
October 29, 2013
North Dakota Department of Health

Good afternoon Chairman Damschen and members of the Human Services committee. My name is Diana Read, and I am the Injury and Violence Prevention Program Director for the Division of Injury Prevention and Control at the North Dakota Department of Health. I am going to provide information about the history of the traumatic brain injury registry. Most of the people that were involved with the Traumatic Brain Injury Registry are no longer employed at the Department of Health. The information that I was able to gather came from reports and files of the person who was responsible for the registry back in the 1990's.

During the 1987 Legislative Session, two bills were introduced and passed at the request of the North Dakota Head Injury Association, which mandated Traumatic Brain Injury (TBI) as a reportable condition and required the Department of Health (the Department) to set up and maintain a TBI registry. There was no appropriation attached to this bill to fund the administrative costs associated with the registry. Within this mandate there was a requirement for physicians and hospitals to report TBIs to the Department within 7 days of occurrence.

To initiate and implement the registry, letters were sent to all hospitals in the state explaining the purpose of the registry and informing the facilities that TBI was a mandated reportable condition in N.D. An informational campaign was initiated by the Department, which included visiting or calling each hospital's medical records director to assist in establishing a reporting system. Most facilities reported TBIs either through their Emergency Departments or medical records. Participating facilities were asked to report TBIs on an injury report card.

This manual reporting system was somewhat effective in providing statewide information on TBIs for a time following the initial implementation. At one point in time, 42 of 48 hospitals were reporting TBIs through this mechanism. However, even then, reporting from the participating hospitals was sporadic. If facilities were not reminded of the reporting requirements, reporting dropped off significantly. When facilities were contacted as to why they had ceased to report TBIs, reasons cited were: manual system of completing the injury card was burdensome and too time consuming; not a high priority due to increased workload within the facility; and there were too many reportable conditions. The chief complaint was the

department had created another report card to another condition. The TBI registry as a manual reporting system had significant shortfalls. It was time consuming, required a dedicated position and even then, hospitals did not want to do a manual reporting card.

During the 1993 Legislative Session, another bill was introduced and passed at the request of the North Dakota Head Injury Association. This bill designated the Department of Human Services as the lead agency in N.D. for traumatic brain injuries. Along with this designation, the bill stipulated that the Department of Health would periodically forward the TBI registry to the Department of Human Services. The Department of Human Services was then required to notify individuals whose names appeared on the registry of services in the state that the TBI individual(s) may be eligible for. The Departments of Health and Human Services and the N.D. Head Injury Association jointly developed a pamphlet outlining programs and services that TBI individuals may require or be eligible for. In late 1993, the Department began forwarding a listing of names from the TBI registry to Human Services and they began sending out the pamphlet. Again there was no appropriation attached to this bill to cover administrative costs for the Department of Human Services or the Department of Health to adhere to this statute.

From 1990 through December 1997, the TBI surveillance and the registry were maintained within the department's Injury Prevention Program, Division of Disease Control. The funding source was a grant from the Centers for Disease Control and Prevention (CDC), which funded two full-time equivalents. The CDC funding ended in September 1994. TBI surveillance and the registry were part of a number of injury prevention activities that were undertaken during this time period. When the CDC funding ceased in September 1994, the Injury Prevention Program was allocated an in-house ½ FTE to continue to assist with injury program activities. One of the continued duties of this ½ FTE position was to maintain the TBI registry. In July 1996, the ½ FTE position was shifted out of the Injury Program into other division areas.

It was determined that the Injury Program could not maintain the TBI registry utilizing a manual reporting system. The manual reporting system required regular intervention to keep hospitals reporting and even with that effort, reporting was still inconsistent. Hospitals continued to report TBIs, but at a diminished rate. Much discussion was held throughout the following months to determine future options for the TBI registry to become a viable referral source. Several options were offered, which included: a) allocating resources to develop and maintain a

reporting system, b) repeal the statute which mandated reporting and the registry, and c) explore the possibility of an electronic/computerized reporting system and determine the resource requirements necessary to support this approach.

After reviewing existing data sources (option c) it was determined the only data source which appeared compatible with the need to identify TBI cases and place them in a registry was the department's Emergency Health Services division's State Trauma Registry. Meetings were held with that division to review the Trauma Registry structure, reporting system, data elements, level of participation by hospitals and possible data transfer snags. For this option to work, the Department needed the backing of all participants involved in the Trauma Registry. One of the anticipated problems was releasing names from the Trauma Registry and the participating hospitals were firm on their decision not to divulge that information. Discussion then followed where many of the partners, such as the local trauma coordinators and the State Trauma Advisory Committee, felt things could be worked out and the Trauma Registry should be where the TBI Registry is housed.

There is gap in the information about what happened next. However, in January of 1999 legislation was introduced and passed to remove the mandatory TBI reporting requirement.

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

Reference:

23-01-20 contained the definition of traumatic head injury.

23-01-21 required the state department of health and consolidated laboratories to establish and maintain a central registry of persons who sustain traumatic brain injury in order to facilitate the provision of appropriate treatment and rehabilitative service to those persons by the division or other providers. Attending physicians in the state shall report to the department within seven days after identification of any person sustaining a traumatic brain injury. The report must contain the name, age, residence, and diagnosis of the injured person and any additional information determined to be necessary by the department. A report submitted pursuant to this section and all information contained in the report is confidential, but the state department of health and consolidated laboratories shall furnish a copy of the report to the department of human services. The department of human services shall use the information contained in the report to carry out the purposes of sections 23-01-20 and 23-01-21 and shall notify the attending physician and the injured person or immediate family of the rehabilitative services for persons sustaining traumatic head injuries.

In 1995 legislation was passed to shorten the department of health and consolidated laboratories to just the department of health.

These two codes were repealed by S.L. in 1999.