

Testimony
Senate Bill 2198 – Department Human Services
Senate Human Services Committee
Senator Lee, Chairman
January 21, 2009

Senator Lee and members of the Senate Human Services Committee, I am Susan Wagner, LSW, Human Services Program Administrator, with the Division of Mental Health and Substance Abuse Services, for the Department of Human Services (DHS).

On behalf of the Department, I am here to provide testimony about the history of services and activities related to individuals who have sustained a traumatic brain injury (TBI) in North Dakota.

Efforts to address the problem of TBI in North Dakota began in the 1980s with the formation of the Head Injury Association of North Dakota (HIAND). The Association's board of directors consisted of representatives from a mix of public and private entities whose concerns and interests spanned the spectrum of TBI from prevention to treatment and rehabilitation. The organization did obtain federal IRS 501c3 status and began accepting charitable donations. A grant from the Rocky Mountain Brain Injury Center further strengthened the organization and increased visibility.

In 1987, the HIAND introduced legislation that established TBI as a mandated reportable medical condition and required the North Dakota Department of Health (DoH) to establish a TBI registry. The legislation passed, mandating TBI as a reportable condition by a physician or medical facility, and required the DoH to establish and maintain the registry. There was no fiscal note attached to establish and maintain the

registry. DoH received a Center for Disease Control (CDC) surveillance and prevention capacity building grant that was used to establish the registry. A significant drawback to the system was the reliance on participating medical facilities to voluntarily complete the injury report card and forward to DoH. In most instances, the report cards were completed by emergency room departments and reflected only preliminary diagnoses, no treatment or discharge information.

In 1989, the HIAND introduced legislation that established the Department as lead agency in North Dakota for the delivery of TBI services. This legislation also required DoH to provide DHS with names and addresses of individuals who were listed in the registry. DHS was then to forward to these individuals information on medical, rehabilitation, and social services that were available in North Dakota. A joint effort between DoH and DHS produced a brochure with service-related information.

The DoH maintained the registry until 1994, when the CDC funding ended. Due to the reliance on voluntary submission of the report cards, reporting compliance fell off significantly. In 1999, the TBI reporting and registry statute was repealed by the legislature at the request of DoH. During this same time, grant funding for the HIAND ended and the association became inactive.

The Indigenous People's Brain Injury Association (IPBIA) was established in 1994. The IPBIA was established for the benefit of all tribes in North Dakota and is comprised of individuals who have sustained a TBI, family members, and service providers. The IPBIA has become a recognized leader in the field of Native American TBI issues and has hosted a

national conference. The organization continues to exist today and hosts an annual conference.

On April 1, 1994, North Dakota received approval for a Medicaid waiver for TBI that enabled eligible individuals to choose between receiving care in an institutional care setting or in their home with the assistance of various community-based services. The TBI waiver was merged with the Aged and Disabled Waiver which was renamed the Home and Community-Based Services waiver. This was effective on March 31, 2006.

More than 5.3 million Americans live with a disability as a result of a TBI. Many of these individuals and their families are confronted with inadequate or unavailable TBI services and supports. Passage of the Traumatic Brain Injury Act of 1996 (PL104-166) signaled a national recognition of the need to improve state TBI service systems. The Act authorized the Health Resources and Services Administration to award grants to states and territories for the purpose of planning and implementing needed health and related service systems changes.

North Dakota received a TBI planning grant in April 2003. The DoH selected the University of North Dakota School of Medicine's Center for Rural Health as a contractor to form the TBI Advisory Committee, conduct a statewide TBI needs assessment, and write a plan of action to address the needs of North Dakotans with TBI and their families. The advisory committee met regularly, the needs assessment was completed, and an action plan was developed. The action plan, designed to be executed during the three-year implementation phase of the TBI federal grant

program, set forth a number of intended outcomes and steps for achievement. Those outcomes are:

- TBI will have a presence in the state with accessible, available, appropriate, and affordable services and supports for individuals with TBI and their families.
- Individuals with TBI, family members, significant others, and providers of support and services to have timely information, resources, and education regarding TBI.
- Ensure a coordinated system for individuals with brain injuries and their families to access and receive services and supports.
- Increased quality and availability of key supports for individuals with TBI and their families.
- Native American individuals with TBI and their families to have access to culturally appropriate TBI information, services, and supports.

In partnership with the University of North Dakota's School of Medicine Center for Rural Health, the Department applied for and was awarded a TBI Implementation Partnership Grant in April 2007. This is a three-year grant in the amount of \$118,000 each year. The action plan developed as a result of the TBI planning grant laid the groundwork for this implementation grant. The goals of the grant are:

- To build a formal presence and infrastructure for the advancement of TBI focused issues
- To provide timely information, resources, and education regarding TBI to individuals with TBI, family members, other caregivers, and service and support providers.
- To ensure a coordinated system to access and receive services and support for individuals with brain injuries and their families.

- To improve access for American Indian individuals with TBI and their families to culturally appropriate information, services, and supports.

Progress on the goals is as follows:

- The Advisory Committee is established and active in planning and sustainability efforts.
- Partnerships have been developed with military support organizations in an ongoing effort to assess their needs. The project coordinator and state TBI program administrator serve on the Interagency Family Assistance Committee.
- Research has been completed on peer mentoring with Native American individuals who have sustained a TBI and preliminary discussion has been had about the most effective way to develop a project on each reservation in North Dakota.
- Seven educational presentations on TBI at various statewide conferences have been conducted. Plans are in place for presentations at the eight regional human service centers and the North Dakota State Hospital.
- A strategic plan for state government funding was developed.
- Resource packets for individuals who have sustained a TBI and their family members are in the development stage.
- Two spots on Good Health TV provide education and prevention of TBI to Native American individuals who are in the waiting room areas of the Indian Health Services clinics and hospitals in North Dakota.
- A resource library is in the development phase and will be operated out of the Prevention Resource Center, which is part of the Division of Mental Health and Substance Abuse Services.

- The state program administrator is working on a project to implement a screening tool at the regional human services.

Please see the attached [FACT SHEET](#).

That concludes my testimony. I will answer any questions you have at this time. Thank you.