

Testimony
Department of Human Services
Human Services Interim Committee
Representative Chuck Damschen, Chairman
April 9, 2014

Chairman Damschen, members of the Human Services Interim Committee, I am Susan Wagner, Program Administrator, with the Department of Human Services (DHS), Division of Mental Health and Substance Abuse Services. I oversee DHS efforts related to traumatic brain injury (TBI) and I appear before you to provide information as requested by the committee.

Definition of Acquired Brain Injury

According to the Brain Injury Association of America, acquired brain injury is defined as an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma. An acquired brain injury (ABI) is an injury to the brain that has occurred after birth. By definition, any traumatic brain injury (TBI) could be considered an ABI. In the field of brain injury, ABIs are typically considered any injury that is non-traumatic. Some common examples of an ABI include stroke, near drowning, hypoxic or anoxic brain injury, tumor, neurotoxins, electric shock or lightning strike.

Estimated cost of expanding TBI services to those with ABI

DHS is currently unable to provide an estimate of the cost of expanding TBI services to individuals with ABIs because we do not have access to more complete data on the number of individuals with ABI in North Dakota. We do suspect the number is significant given the definition and

common examples mentioned above. We were able to obtain the following data:

- According to the Trauma Registry, 1,698 TBI's occurred between October 1, 2012 – September 30, 2013.
- According to the Medill Justice Project, there have been 13 cases of shaken baby syndrome in our state in the past 25 years.
- According to the infectious disease division of the Department of Health (DoH), there were the following cases reported for the years 2009-2013 that caused brain injury or trauma:
 - 9 Meningococcal Disease
 - 2 Creutzfeldt-Jakob Disease suspect
 - 46 Encephalitis
 - 43 Meningitis
 - 17 Meningoencephalitis

We will continue efforts as best we can with the assistance of the DoH to gather more data and report that at the next committee meeting.

Status of the North Dakota Brain Injury Network (NDBIN)

The NDBIN was established August 1, 2013, by the University of North Dakota – Center for Rural Health to serve as a hub of information about TBI in North Dakota. Its purpose is to provide information and support to individuals with brain injury and family members, assist them with navigating the service system, and provide peer support and resource facilitation services; and provide ongoing public awareness and education about TBI.

- NDBIN is staffed with a program director and three resource facilitators. The resource facilitators are based in Towner, Grand Forks, and Bismarck and provide services statewide.

- A marketing plan is in place to inform medical, social, human service, and behavioral healthcare providers, military and veteran service organizations, and the general public about the work of the NDBIN. The NDBIN staff is in the process of contacting various providers across the state to promote services and encourage referrals. They are also partnering with current providers of TBI services to streamline the referral process and lessen the number of calls and inquiries an individual and or family member need to make in order to get connected to services.
- Staff is currently providing services to 18 individuals with TBI. To date, they have provided services to 35 individuals. The NDBIN received 10 new referrals in March.
- The NDBIN has an established website, www.ndbin.com and a toll-free number, 1-855-866-1884.
- Since August 1, 2013, 20 presentations or training sessions have been conducted across the state to various agencies. A series of six training sessions with Home and Community-Based Services case managers is scheduled for the month of June.
- NDBIN staff partnered with Community Options for Residential and Employment Services, Inc. to host four open houses (Minot, Bismarck, Grand Forks, and Fargo) for Brain Injury Awareness Month during the month of March 2014.
- NDBIN staff partnered with Freedom Resource Center to host an open house on brain injury awareness in Wahpeton on April 1, 2014.
- NDBIN project director is co-leading the planning efforts for the third annual Mind Matters Conference to be held in Fargo on June 24-25, 2014.

Flex Fund Program

The primary benefit to establishing a flex fund program for individuals with TBI is that a fund would exist to assist them with a way to request assistance with day-to-day needs that are not covered by any other source. It could provide the opportunity to receive a service not otherwise covered by Medicaid, insurance, or personal earnings, pay essential bills or obtain personal necessities they are unable to purchase because they do not have the financial means to do so. Such a fund would provide support, increase independence, and increase self-determination to become and remain as self-sufficient as possible. Considerations for implementing a flex fund would be developing needs-based criteria for individuals to receive funds, adequate staff resources for the day-to-day management of the fund, and establishing and monitoring payment processes. DHS does have some experience in implementing and managing flex funds. For example, each regional human service center manages a flex fund for the Partnerships and Transition to Independence case management program. In the West Central region, the human service center contracts with Dakota Foundation to be the fiscal agent. The Partnerships/TIP supervisor receives and approves all requests for funds then forwards the approved requests to the Dakota Foundation for payment.

TBI Registry

I met with three representatives from the DoH and the project director with the NDBIN to prepare the following information for the committee. We took into consideration the legislation of the autism registry that was authorized last session in regards to budget and development of the registry. We would propose, that if a registry was created, that the development and maintenance of a TBI registry would be a joint effort

between the DoH, NDBIN, and DHS. The registry would be maintained by the DoH. It may be possible to add a module for a TBI registry to the current infectious disease registry similar to what is being done with the autism registry. The DoH would require an FTE, most likely an epidemiologist, to develop the module and perform all the necessary work with the registry.

All three entities could work together to develop the required list of data elements to include in the registry as well as the ongoing maintenance of the registry. DHS and NDBIN could develop the registry form and conduct all marketing, training, and informational meetings with medical providers regarding the registry. Packets of information could be developed detailing all necessary information for the medical providers. If created, it's recommended that all hospital emergency rooms and acute care departments, inpatient rehabilitation facilities, and outpatient clinic practitioners such as physicians, nurse practitioners, and physician assistants be mandated to report to the registry.

The purpose of the registry would be twofold: serve as a connection to the NDBIN for individuals with TBI and a means to gather data on the number of individuals with TBI in North Dakota for the purposes of ongoing service development as well as a more accurate understanding of the number of individuals in North Dakota with a TBI. It will be critical for each individual to have staff from the NDBIN personally contact them as reports are received into the registry. The initial contact with each individual would determine the extent of the need for assistance from the NDBIN.

The following outlines anticipated costs to implement and maintain the registry within the DoH for a total of \$251,083:

- \$60,000 registry model and license (one-time cost)
- \$20,000 annual maintenance of registry (estimate one year due to timing of start-up)
- \$12,517 software and other computer related costs
- \$1,050 computer costs
- \$500 other equipment costs
- \$11,000 DoH staff travel to reporting sites to discuss and monitor data entry
- \$5,000 printing registry forms and manuals
- \$137,798/biennium (\$94,980 salary and \$42,818 fringe) for DoH staff, epidemiologist
- \$2,218 IT data processing and telephone
- \$1,000 professional development

Estimated costs related to DHS efforts totals \$20,000. It's possible DHS would contract with the NDBIN for this work.

- \$20,000 marketing, training, and registry information (start-up cost, may need to consider the need to fund ongoing training efforts if revisions occur)
- TOTAL BIENNIUM ESTIMATED COSTS for DoH and DHS: \$271,083 for the 2015-17 biennium

TBI Statewide Advisory Committee

Since the study language included wanting input from the statewide TBI Advisory Committee, I want to inform you that the committee has taken time to review the information presented to the interim committee. The TBI Advisory Committee was revitalized in 2007. The committee consists of individuals with TBI, family members and caregivers, private providers,

and representatives from DoH, Department of Public Instruction, Protection and Advocacy, Veterans Administration, Department of Corrections and Rehabilitation, and DHS. The advisory committee recognizes the need for a comprehensive system of services and support for individuals with TBI and their family members. To date, the members of the committee have discussed the need for the development of prevention messaging and activities; a TBI registry; increasing the newly established service of resource facilitation to have a resource facilitator in each of the eight regions of the state; substance abuse treatment services specific for those individuals with TBI; flexible funding; increased community-based support services such as supported employment and day supports; and an increase in the variety of levels of supported living and residential options.

This concludes my testimony. I am happy to answer any questions you might have.