

**Testimony to the Interim Long-Term Care Committee
Study of the Impact of Individuals with Traumatic Brain Injury
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Good morning Chairman Kreidt, Vice Chair Uglem, and other members of the Committee. My name is Rebecca Quinn. I am currently the TBI Program Director at the Center for Rural Health, UND School of Medicine and Health Sciences.

The brain injuries we see on the evening news (e.g., injured celebrities or soldiers returning from war with grievous wounds) are clearly evident: this is *known* traumatic brain injury, or TBI. However, these visible TBIs only tell a part of the story. The remaining brain injuries are hidden and often remain unrecognized--causing brain injury to be called the "silent epidemic." These are the individuals and families who have to pick up the pieces and move on from a horrible injury and often now face a life time of unknowns.

According to the Centers for Disease Control and Prevention (CDC), each year, at least 1.7 million Americans sustain a traumatic brain injury (TBI). A TBI can happen to people of every age, race, gender, and socioeconomic status at any time. Brain injuries are caused by falls, motor vehicle crashes, assaults, sports/recreation accidents, and most recently, blasts from improvised explosive devices. The CDC numbers underestimate the true prevalence of TBI, since only individuals treated in hospitals, those seen in ERs and those who die are counted. Not included are those who receive care outside of hospitals (e.g., in medical offices) or who do not receive medical attention at all (e.g., people injured in assaults, domestic violence, falls and the like). Research suggests that for every person hospitalized with a brain injury, three to five others are injured but do not receive any care.^{1 2}

Brain injuries are often misunderstood by society and do not fit well into any one particular system. Care and treatment often involves the need to access multiple public and private systems, as well as overlapping use of both the medical community and the human services field. Individuals are unprepared for how best to coordinate services and often do not know what services are available in their area.

Across the lifespan, TBI can lead to a wide range of functional changes affecting thinking, language, learning, emotions, behavior, and sensation. TBI can also cause epilepsy and increase the risk for conditions such as Alzheimer's disease, Parkinson's disease, and other brain disorders that become more prevalent with age.^{3 4} Even so called "mild" injuries can have devastating consequences that require intensive treatment and long-term care. It is estimated that at least 3.17 million Americans currently have a long-term or lifelong need for help to perform activities of daily living as a result of a TBI.⁵

According to a study done by Mt. Sinai TBI Model System, about 40% of those hospitalized with a TBI had at least one unmet need for services one year after their injury. The most frequent unmet needs were:

- Improving memory and problem solving;

- Managing stress and emotional upsets;
- Controlling one's temper; and
- Improving one's job skills.⁶

Across the lifespan, perhaps the biggest challenge when it comes to addressing brain injury is the fact that the brain is infinitely more complex than any other organ or organ system in the human body. Add to that the fact that every brain and every brain injury are unique, and it is easy to understand why it is often said that "there is much more that is unknown about the brain (and, accordingly, brain injury) than is known."

Of significant concern is the impact of TBI on children. **The highest prevalence of brain injuries occur during the ages of 0 to 4 and 15 to 19 and nationally TBI is the leading cause of death and disability in children and young adults.**⁷ For many years it has been believed that children are more resilient and bounce back from brain injury quickly. In fact, often children who sustain a brain injury early in life may look "well" at that moment in time, but as the child gets older more serious cognitive and behavioral problems emerge. For example, frontal lobe functions develop relatively late in a child's growth, so an injury to the frontal lobes may not become apparent until the child reaches adolescence. Since the frontal lobes control our social interactions and interpersonal skills, damage from the brain injury may not manifest until such frontal lobe related skills are called into play later in development⁸.

Schools are the single largest provider of services to students with brain injury. However, it is estimated that of the more than 500,000 children impacted by TBI each year only 2% will be referred for special education services⁹. In North Dakota, in 2002 only 35 students were receiving services through Department of Public Instruction for TBI. Nationally brain injury is often over looked by education systems because of limited knowledge about TBI and improper diagnosis. In North Dakota children with brain injury are also serviced by the Anne Carlsen Center in Jamestown, N.D through both residential and community programs. Community programs are available in Grand Forks, Jamestown, Fargo and surrounding counties.

Among current available services is a lack of recognition and services for milder injuries. Services are available for severely disabled children with TBI; however services do not exist to address the subtler impact of brain injury. Children with TBI are at increased risk for social failure as they mature into adulthood. TBI in children is associated with poor academic performance,¹⁰ as well as problem behaviors.¹¹ Many studies have looked at the connection between early brain injury and social problems. It is estimated that the prevalence of TBI within the prison population ranges from 42 percent to 87 percent;^{12 13 14} for most, the brain injury preceded the start of criminal activity. TBI is also common in inpatient psychiatric and substance abuse populations, and, similarly, the injury often precedes onset of psychiatric symptoms^{15 16} or substance abuse. Most of these brain injuries had gone unidentified prior to the respective studies. TBI is associated with high levels of co-occurring depression and anxiety.^{17 18}

**North Dakota Department of Instruction 2002
Special Education Enrollment**

Disability Category	Enrollment
Learning Disabilities	5,247
Speech Language	4,262
Mental Retardation	1,169
Emotional Disturbance	1,123
Other Health Impairment	960
Autism	197
Orthopedic Impairment	158
Hearing Impairment	106
Vision Impairment	61
Traumatic Brain Injury	35
Deaf blind	2

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