

Traumatic Brain Injuries



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Introduction

A traumatic brain injury [TBI] is a disruption in the normal functioning of the brain as a result of a bump, blow, or jolt to the head, or as a result of a penetrating head injury. Each year, TBIs contribute to a substantial number of deaths and cases of permanent disability. The 2019 Surveillance Report published by the Centers for Disease Control and Prevention, estimates that, in 2014, there were approximately 2.8 million TBIs in the United States, nearly 30 percent of which were sustained by individuals under the age of 18. Of those, 288,000 resulted in hospitalizations and 56,800 resulted in death. Eight percent of the patients who were hospitalized and 4.5 percent of the patients who died were under the age of 18.

Causes of Traumatic Brain Injuries

In 2014, the leading cause of TBIs was falls. Falls accounted for 48 percent of all TBI-related emergency department visits. Nearly half of all individuals under the age of 18 who presented at an emergency department with a TBI were there because of a fall and 81 percent of those over the age of 65 who presented at an emergency department with a TBI were there because of a fall.

Seventeen percent of all TBI-related emergency department visits occurred as a result of an individual being struck by or striking an object. In the case of individuals under the age of 18, the rate was 28 percent. In terms of TBI-related hospitalization, falls accounted for 52 percent and motor vehicle accidents accounted for 20 percent.

Thirty-three percent of all TBI-related deaths occurred as a result of intentional self-harm. The leading cause of TBI-related deaths was not consistent among the various age groups. For those age 65 and older, the leading cause of TBI-related death was falls. For those in the 45-64 age bracket, the leading cause of TBI-related death was intentional self-harm. Motor vehicle accidents were the leading cause of TBI-related death for individuals between 15 and 34, and homicide was the leading cause of TBI-related death for children under five.

Statistical Limitations

The Centers for Disease Control and Prevention acknowledge that the estimates cited in the 2019 Surveillance Report come from a period prior to the change in the International Classification of Diseases diagnosis codes. The centers also acknowledge that the estimates cited in the report do not include individuals who sought care for a TBI in a setting outside of a hospital – e.g. a primary care, urgent care, or specialty clinic.

National Concussion Surveillance System - Authorization

This dearth of accurate and timely information was noted by Congress and therefore, in the Traumatic Brain Injury Program Reauthorization Act of 2018, Congress directed the Centers for Disease Control and Prevention to implement a National Concussion Surveillance System. In the fall of 2018, the Centers began efforts to pilot-test a survey that they believe will assist in refining their plans for the surveillance system and ultimately:

- Create true national estimates regarding the number of individuals living with a disability caused by a traumatic brain injury;
- Provide the first national estimates of sports-related concussions among youth, and indicate whether those occurred inside or outside of organized sports;

- Provide information about the most common causes of concussion, including motor vehicle crashes, falls, and self-harm;
- Monitor trends to understand whether the number of concussions is increasing or decreasing, and subsequently assess whether prevention efforts are working; and
- Offer insight to healthcare providers, including hospitals, about where patients seek care for concussions and their recovery needs.

Effects of a Traumatic Brain Injury

The effects of a TBI can vary significantly, depending on the individual and the severity of the injury. Mild TBIs generally result only in short-term symptoms, whereas a moderate to severe injury can take a toll similar to that of a chronic disease. A TBI may lead to a wide range of short-term or longer term issues that affect:

- Cognitive function – attention and memory;
- Motor function – extremity weakness, impaired coordination, and balance;
- Sensation – hearing, vision, impaired perception, and touch; and
- Behavior – emotional regulation, depression, anxiety, aggression, impairments in behavioral control, and personality changes.

A severe TBI may lead to a patient's death, a reduced lifespan, or time spent in a coma or needing to address amnesia. Often, a severe TBI will affect many aspects of a patient's life, including relationships with family and friends, the ability to progress at school or perform at work, and the ability to care for oneself through the performance of basic household tasks, as well as the ability to drive and participate in other daily activities.

Traumatic Brain Injuries in South Dakota

In 2008, the South Dakota Legislature enacted SB 200, which directed that the Department of Health, in conjunction with the Department of Public Safety, "develop, implement, and administer a trauma care system including a statewide trauma registry that involves all hospitals and emergency medical services within the state." The bill also directed the Department of Health to promulgate rules that set forth "[r]equirements for the collection and release of trauma registry data." The bill was subsequently codified as SDCL §§ 34-12-52 through 34-12-55.

By 2009, the Department of Health had established a trauma registry that required hospitals to report any patient who:

[M]eets the local hospital criteria for trauma team activation, or any patient that [sic] has a hospital admission of greater than 48 hours with at least one injury, an International Classification of Diseases, 9th revision ICD-9 diagnosis code between 800.00 and 959.9, including 940-949 (burns), excluding 905-909 (late effects of injuries), 910-924 (blisters, contusions, abrasions, and insect bites), 930-939 (foreign bodies), and isolated hip fractures resulting from a same level fall unrelated to a traumatic event, and also meet [sic] at least one of the following criteria:

- (1) The patient's outcome was death due to trauma;
- (2) The patient was admitted to the intensive care unit and/or operating room; or
- (3) The patient was transferred either into or out of the hospital.

According to information provided by the South Dakota Trauma System staff, the registry uses more than 200 diagnostic codes that are related to TBIs to reflect the "mechanism" of injury and its severity, among other factors. In 2017, 936 patients received a TBI. In 2018, the number was 935. This "raw" data does not include patients who were seen in an emergency department then sent home or patients seen at Indian Health Services facilities.



The South Dakota Department of Social Services, likewise, does not collect data regarding the number of residents who have a TBI, the level of service that such individuals require, whether they are obtaining the services, or where they are obtaining services. The department becomes aware of such individuals only if they are Medicaid eligible and seek services from the department.

If an individual under the age of 22 meets certain statutorily defined criteria, that individual is deemed eligible for services through the Division of Developmental Disabilities. In accordance with SDCL 27B-1-18, eligibility is based on the individual having a severe, chronic disability that:

- Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- Is manifested before the person attains age 22;
- Is likely to continue indefinitely;
- Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and
- Reflects the person's need for an array of generic services, met through a system of individualized planning and supports over an extended time, including those of a life-long duration.

If the TBI is sustained after age 22, the individual is generally limited to assisted living arrangements or nursing homes. These options are, however, inherently incompatible with a resident's desire to pursue independent living and employment opportunities.

With respect to Medicaid funding, in 1996, the Department of Human Services adopted rules to implement a program under which certain TBI-related services were funded. Those services were defined as:

[C]omprehensive rehabilitation services which are provided in a residential setting or in a community rehabilitation program on a short-term basis, usually not more than 24 months, which are delivered to eligible individuals who no longer demonstrate the need for acute medical care or intensive rehabilitation and whose rehabilitation service plan substantiates the continuing benefit of and the need for specialized services, and which are designed to assist a client to acquire or improve cognition, perception, language, physical, social-emotional, vocational, and independent living skills necessary to function independently at home, on the job, and in the community . . . [See, ARSD 67:54:07:01(9)]

Covered services included cognitive training – i.e. "[S]ervices provided in a face-to-face encounter with the client which provide instruction and training in perception, judgment, and language and physical, social-emotional, vocation, and independent living skills" and case management services – i.e. "[S]ervices which are provided on behalf of a client; which are provided by professional staff, such as a case manager, psychologist, or nurse; and which are designed to move the client towards the goals specified in the client's TBI rehabilitation service plan . . . " [See, ARSD 67:54:07:01(1) and (2)]

Department of Human Services staff were unable to verify whether funding was made available for the "array" of TBI services defined in the 1996 rules. They were able to verify that funding was eliminated in 2011. They indicated that services are still provided through the Division of Rehabilitation Services, in order to help eligible individuals reach their employment goals.

If individuals with TBIs reside in nursing homes, they are eligible for "add-on payments" to address their extraordinary care costs. Individuals with TBIs who are in assisted living or other residential environments are eligible to receive home and community based services made available through the Home and Community-Based Options and Person Centered Excellence [HOPE] waiver program, authorized by §1915(c) of the Social Security Act. While this waiver does not provide for TBI-specific rehabilitation services, it does provide for services that are designed to support deficits in daily living activities.



South Dakota does have a long-term rehabilitative care facility that provides specialized treatment for eight individuals who have a TBI. While at Sunrise Villa/Avera Health in Irene, SD, the individuals reside in their own apartments and have vocational services made available to them. Until recently, those services were provided through the Ability Building Services Program, a not-for-profit community support provider in Yankton, SD. The current contractor is the Southeast South Dakota Activity Center (SESDAC) in Vermillion, SD.

Sunrise Villa receives occasional calls from healthcare facilities or providers who are seeking placement for a qualified patient. Although the names are retained on a waiting list, when an opening does occur, Sunrise Villa is often unable to make contact with the individual to find out if there is still an interest in the placement. Openings at Sunrise Villa are also fairly limited because a patient's discharge must be contingent upon Sunrise Villa finding an appropriate step-down arrangement for the patient.

A number of individuals with TBIs are sent out of state for services each year. These individuals generally have complex medical issues along with their other challenges. State facilities are not able to provide the requisite care for these individuals at this time. The number of individuals who have been sent out of state for services has varied between 10 and 13 since FY 2012 and the total annual expenditures have varied from a low of \$1.08 million to a high of \$1.9 million in FY 2017. A patient's requisite length of stay is the primary determinant of the amount expended for his or her care.

Federal Legislation

Recognizing the large number of individuals and families struggling to access appropriate and community-based services, Congress authorized the Federal TBI Program in the TBI Act of 1996 [PL 104-166.] The TBI Act of 1996 launched an effort to conduct expanded studies and to establish innovative programs for TBI. The Act gave the Health Resources and Services Administration authority . . . to establish a grant program for States to assist it in addressing the needs of individuals with TBI and their families. The TBI Act also delegated responsibilities in research to the National Institutes of Health, and prevention and surveillance to the Centers for Disease Control and Prevention. [See, <https://acl.gov/about-acl/authorizing-statutes>]

The 1996 Act was amended in 2000 [PL 106-310—Title XIII of the Children's Health Act] to add protection and advocacy services and in 2008, the programs were reauthorized in the Traumatic Brain Injury Act of 2008 [PL 110-206]. During that evolution, the Health Resources and Services Administration was authorized to award grants to federally mandated state protection and advocacy systems.

Following passage of the TBI Reauthorization Act of 2014 [PL 113-196], the Department of Health and Human Services transitioned the TBI program from the Health Resources and Services Administration to the Administration for Community Living. The current authorizing legislation, the *Traumatic Brain Injury Program Reauthorization Act of 2018* [PL 115-377], raised the authorization levels for the TBI State Partnership Program and TBI Protection and Advocacy and officially designated the Administration for Community Living as the administering agency for both programs. In addition, the Act's new provision for partners at the Centers for Disease Control will allow for the collection and analysis of concussion prevalence and incidence data, thereby filling a longstanding data gap that will bolster all TBI programs.

The aforementioned federal legislation also created the TBI State Partnership Grant Program. The goal of the program was to strengthen the system of services and supports so that individuals with TBIs could maximize their independence, well-being, and health, throughout their lives, and to similarly help their family members and caregivers. Over the years, federal funding has been provided to state agencies to develop and enhance services, systems, and infrastructure that serve people with TBIs. At times, the program provided small grants to many states. More recently, the program has provided larger grants to fewer states. These larger grants have allowed recipient states to maintain well-developed infrastructure, while states that did not receive the grants have found it more challenging to create and sustain the infrastructure necessary to serve and support individuals with TBIs.



The design of the program, in conjunction with protection and advocacy efforts, is to:

- Assist states in expanding and improving state and local capabilities so that individuals with TBIs and their families can have improved access to comprehensive and coordinated services;
- Generate support from local and private sources for sustainability of funded projects after the federal support is terminated; and
- Encourage systemic changes so that individual states can continuously evaluate their structures and policies and improve their systems to better meet the needs of individuals with TBIs and their families.

Participating states have to address barriers to needed services by:

- Screening to identify individuals with a TBI;
- Utilizing professional training to build a trained TBI workforce;
- Providing information about TBIs to families and referrals of patients to appropriate service providers; and
- Facilitating access to needed services through resource facilitation.

TBI State Partnership Program grants cannot be used to support primary injury-prevention initiatives, research initiatives, or the provision of direct services.

The twenty-four current grantees are: Alaska, Arkansas, California, Colorado, Georgia, Idaho, Iowa, Indiana, Kansas, Kentucky, Maryland, Massachusetts, Minnesota, Missouri, Nebraska, North Carolina, Oregon, Pennsylvania, Rhode Island, Tennessee, Utah, Vermont, Virginia, and West Virginia.

In mid-2019, funding was made available for two states that do not currently have a TBI State Partnership Program grant. In order to qualify, a state had to meet the criteria set forth below.

- Commit \$1 for every \$2 provided by the grant.
- Support a TBI advisory board.
The board is to consist of the appropriate state agencies, public and private nonprofit health-related organizations, disability advisory or planning groups, members of an organization or foundation representing individuals with TBI, representatives of injury control programs, individuals with a TBI or their family members, and TBI survivors.
- Provide at least one dedicated staff person at a 50 percent FTE.
- Create an annual TBI state plan.
The plan is to be developed through the state TBI advisory board and include the involvement of other underserved and inappropriately served individuals. The plan development assumes a comprehensive review and analysis of the services, support, and other assistance available to individuals with TBIs, as well as the extent of the unmet needs. The plan is also to include goals for addressing the unmet needs and objectives for any projects to be undertaken with the grant dollars.
- Create a TBI registry or expand an existing TBI registry.
The registry must focus on data collection, the identification of individuals with TBIs through personal identifiers and the maintenance of contact information, and the linking individuals to available services.
- Work independently with one or more mentor state grantees for the purpose of expanding and strengthening the Partner State capacity to provide access to comprehensive and coordinated services for individuals with TBIs and their families.
The grantee must participate in at least two workshops that focus on particular areas of need. These include survivor engagement; criminal and juvenile justice; opioid use, substance use, and mental health; Return-to-Learn and Return-to-Play; sustainable partnerships [between lead state agencies and



stakeholders]; transition and employment; underserved populations; using data to connect people to services; and waivers and trust funds.

- Plan for Project sustainability.

This involves developing a plan under which the state's capacity to serve individuals with TBIs can continue, even after the period of federal funding concludes.

The award "ceiling" was listed at \$150,000. The "floor" was listed at \$75,000.

TBI Trust Funds

Trust funds are accounts established by law and earmarked for specific purposes. As state revenue sources became more difficult to obtain, some states turned to trust funds as a way to offer additional services to individuals who have sustained a TBI.

The earliest TBI trust fund legislation occurred in 1985, in Pennsylvania. Today, more than half the states utilize trust funds for the benefit of individuals with TBIs. Some also extend the funds for the benefit of individuals with spinal cord injuries. Those having such legislation include Alabama, Arizona, California, Colorado, Connecticut, Florida, Georgia, Hawaii, Kentucky, Louisiana, Maine, Massachusetts, Minnesota, Mississippi, Missouri, Montana, New Jersey, New Mexico, Oklahoma, Rhode Island, Tennessee, Texas, Utah, Vermont, Virginia, Washington, and West Virginia.

While all the programs are not specifically called "trust funds," they do share these similarities:

- They are established by legislation and dedicated for activities benefitting individuals with brain injuries;
- They are supported by revenues from fees, fines, or surcharges; and
- The revenue is placed in an interest-bearing, non-reverting account.

The sources of revenue are most often tied to traffic-related issues or offenses such as:

- Penalty assessments on DUI, speeding, reckless driving, and accidents causing bodily injury or death;
- Assessments on violations of child safety restraint laws or helmet laws;
- Surcharges on motorcycle or motor vehicle license tag fees;
- Surcharges on vehicle registration fees or driver license reinstatement fees; and
- Penalty assessments on criminal or civil infractions.

Some of the state programs provide funding for individual consumer needs, while others devote funds to projects selected through a grant-award process. The purposes to which the funds are dedicated include acute care, rehabilitation, community-based services, case management, resource facilitation, information and referral, registry, research, education and training, public awareness, prevention, advisory council supports, etc.

Department of Justice Complaint

In 2016, following a United States Department of Justice Civil Rights Division investigation regarding the "system of care for individuals with disabilities who receive services and supports in nursing facilities," this state was notified "of the steps it must take to meet the obligations under Title II of the ADA." With respect to individual's living with TBIs, the investigation pointed out the following:

Many individuals are segregated in South Dakota's nursing facilities because they require care or assistance due to mental illnesses, intellectual and developmental disabilities, and traumatic brain injuries. Some of these people are further segregated based on their specific disability in designated nursing facilities or units. Many of these individuals can receive services in integrated settings.



For example, in 2008, the Department of Social Services, in conjunction with a private nursing facility, opened a nursing facility unit in Irene, South Dakota, to provide specialized care for individuals with traumatic brain injuries. This traumatic brain injury unit was created to allow several South Dakotans to return home to the State, having previously only been able to access adequate care elsewhere. But the State has not developed alternative, community-based services for South Dakotans who require services due to traumatic brain injuries. Rather, it has cut services that once existed and has declined to pursue federal funding that could help create a home- and community-based services program for people with brain injuries. Instead, the State funds the placement of approximately 80 people with traumatic brain injuries in the Irene facility and other nursing facilities across South Dakota.

The Department of Human Services has indicated its disagreement with many of the findings and has communicated the same to the Department of Justice. It has taken the position that South Dakota has made considerable progress in expanding the awareness, availability, and support for home and community-based services throughout the entire state, and that the State continues to work closely with stakeholders and disability advocacy organizations to enhance and expand the home and community-based services available to individuals with disabilities.

Conclusion

While some TBIs result in only short-term, relatively minor symptoms for the recipient, others harken the beginning of a lifelong disability that entails a lifetime of needs and reliance on services. TBIs often engender significant financial and interpersonal impacts on families and on society.

Initial care requirements, through emergency departments and acute hospitalization, are generally assumed and understood. Post-initial treatment needs, including acute rehabilitation, post-acute rehabilitation, outpatient rehabilitation, and appropriate residential arrangements, are as varied as the injured individuals.

Anecdotally, service gaps exist. However, without a robust surveillance system or registry, it is not possible to accurately determine how many South Dakotans sustain a TBI each year, nor how many South Dakotans live with a TBI-related disability. The lack of empirical data also limits discussions about the range of services that might be necessary and how and where those services can be effectively and efficiently delivered. The lack of empirical data likewise limits the state's ability to pursue any available federal funding or accurately assess existing needs for purposes of increasing or redirecting state funds.

This issue memorandum was written by L. Anita Thomas, Principal Legislative Attorney, on November 18, 2019 for the Legislative Research Council. It is designed to provide background information on the subject and is not a policy statement made by the Legislative Research Council.

