



# **Texas Brain Injury Advisory Council Report**

**As Required By  
Texas Administrative Code, Title 1, Part 15, §351.825(d)(2)  
and Texas Government Code §531.012**

**Health and Human Services Commission  
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## **1. What is the Texas Brain Injury Advisory Council?**

The Council was established as the Texas Traumatic Brain Injury Advisory Board in 1997 by former Governor George Bush to give brain injury survivors, their families, caregivers, service providers, and state agencies a voice in identifying and meeting the needs of people with brain injuries. In 2003, the Council was established in statute by the 78th Texas Legislature. In 2015, the 84th Texas Legislature removed most health and human services advisory councils from statute and authorized the Health and Human Services Commission (HHSC) to reestablish the Council in rule. Through advocacy, the Council's scope was expanded to include all acquired brain injuries (ABIs) and, accordingly, the name was changed to the Texas Brain Injury Advisory Council (TBIAC).

TBIAC advises HHSC and state leaders on the prevention of brain injury, as well as improving the quality of life of individuals who have survived brain injuries, their families, and caregivers by:

- Informing state leadership (the Office of the Governor and Legislature) of the needs of people with brain injuries and their families
- Recommending policies and practices to meet those needs
- Encouraging research into the causes, prevention, and treatment of brain injuries
- Providing long-term services and supports for people with a brain injuries
- Promoting brain injury prevention and awareness throughout the state
- Facilitating the development and implementation of sustainable supports and services to meet the complex needs of persons who have survived a brain injury

Historically, TBIAC has advocated for or supported:

- Full funding for the Comprehensive Rehabilitation Service (CRS) program, a Texas program which funds rehabilitation for individuals with traumatic brain injury (TBI) or spinal cord injury (SCI)
- The creation of and funding for the Office of Acquired Brain Injury (OABI)
- Implementation and improvement of the TBI Registry by the Department of State Health Services (DSHS)
- Providing training of 2-1-1 staff in ABI needs and resources
- Requiring insurers to provide acute and post-acute rehabilitation services to individuals with ABIs, including cognitive rehabilitation therapy
- Adding cognitive rehabilitation therapy to the services available under Texas' Medicaid home and community based services waiver programs
- Requiring children to wear helmets when bicycling or participating in bull riding and other rodeo events
- Educating school personnel regarding sports concussions
- Educating law enforcement personnel in effectively interacting with individuals with brain injuries
- Identifying youth in the Juvenile Justice System with brain injuries and implementing approaches to improve management of, and outcomes for, juvenile offenders with brain injuries
- Educating the public through brochures, public service announcements, appearing on media broadcasts, and speaking at community events

TBIAC will continue to advocate for persons with brain injury and their families with input from all persons experiencing brain injury or involved with brain injury care and treatment.

## **2. What is an Acquired Brain Injury?**

An ABI is defined as, “Damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease. These impairments may be temporary or permanent and cause partial or functional disability or psychosocial maladjustment” (World Health Organization –Geneva 1996).

An ABI may occur from a traumatic injury or a non-traumatic injury or disease and affects individuals of all ages. The Center for Disease Control and Prevention (CDC) reports individuals from birth to 5 years old and above 65 years old have the highest number of ABIs from falls, while individuals ages 16-25 years old have the highest number of ABIs from motor vehicle crashes (cdc.gov). Strokes generally occur among older people, however, recently 34 percent of individuals hospitalized from a stroke are younger than 65(cdc.gov). A non-traumatic brain injury or disease may be caused by strokes, infections of the brain (such as viral encephalitis), brain tumors, loss of oxygen to the brain due to heart attack or other causes, choking, near drowning, drug overdose, or other anoxic or hypoxic conditions.

The CDC defines a TBI as, “a disruption in the normal function of the brain that can be caused by a bump, blow or jolt to the head or a penetrating injury” (CDC, 2015 Report to Congress). Traumatic forces to the brain may be caused by car crashes, falls, sports injuries, explosive blasts, gunshot wounds to the head, objects falling on the head, and sharp objects penetrating the skull. TBI severity is generally classified by duration of symptoms. A mild TBI is a brief change in mental status or consciousness, while a severe TBI is an extended period of unconsciousness or post traumatic amnesia (traumaticbraininjury.com; cdc.gov).

## **3. How Does an Acquired Brain Injury Impact an Individual?**

Just as no two individuals are alike, no two brains are alike. Brain injury may cause the person to have impaired functional abilities in some or all areas listed below. Not all symptoms are likely to be present at once, and the degree of impairment may range from minimal to severe. Impairments may be short lived or may last a lifetime.

**Physical impairments** may include problems walking; motor weakness or paralysis; loss of coordination; tremors; poor balance; chronic pain; headaches; dizziness; mental or physical fatigue; loss of sensation; difficulty swallowing; unclear speech and inability to speak words.

**Cognitive/Communication impairments** may include disorientation in regards to time, place, or situation; difficulty processing information; shortened attention span; impaired decision making and problem solving abilities; difficulty understanding abstract concepts or following directions with multiple steps; memory loss; difficulty understanding others; and difficulty or inability to express thoughts.

**Perceptual impairments** may include a change in any of the senses; however, vision, taste, and smell are the most often affected.

**Behavioral/Emotional impairments** may include irritability; impatience; lack of initiative; impulsiveness; denial of impairments; reduced tolerance for stress; inflexibility; flattened or heightened emotional response and reactions; and loss of impulse control that may result in physical aggression, verbal aggression, or inappropriate sexual behavior.

Research indicates that a brain injury is not an “event”, it is a disease condition that causes the development of other diseases. Individuals with a brain injury are at an increased risk of developing other neurological, neurodegenerative and neuroendocrine disorders, psychological and psychiatric diseases, and non-neurological disease (Masel et al, 2010).

#### **4. Acquired Brain Injury Incidence and Facts**

Data on ABI incidence and related disability are limited for the United States (U.S.) and Texas. The 2015 CDC Report on TBI to the U.S. Congress made several recommendations related to improved incidence estimates. One recommendation is to include data on individuals with TBI who are not receiving medical care and identify non-hospital incidence data. Another recommendation is to generate state specific TBI estimates through the collection and compilation of health care administrative data in all states.

At a national level, incidence of persons living with TBI disability is estimated to be between 3.2 million and 5.3 million. The 2015 CDC Report to Congress on TBI stated that these estimates are based on extrapolations of state-level data from South Carolina and Colorado (cdc.gov).

The American Stroke Association (ASA) reported that stroke is the fifth leading cause of death (nearly 130,000 per year). Stroke is a leading cause of disability and the leading preventable cause of disability (americanstrokeassociation.org).

The Brain Injury Association of America reports the total annual national incidence of ABI is 2,617,000. The table below breaks down non-traumatic brain injury incidence by diagnosis. Anoxia/hypoxia is unknown and not included in the chart (biaa.org).

**Table 1. National Incidence of ABI**

<b>Traumatic Brain Injury</b>	<b>Non-Traumatic Brain Injury</b>
917,000	1,700,00

**Table 2. Type and Incidence of TBI**

<b>Type of Traumatic Brain Injury</b>	<b>Estimated Annual Incidence</b>
Stroke	795,000
Tumor	64,530

Type of Traumatic Brain Injury	Estimated Annual Incidence
Aneurysm	27,000
Viral Encephalitis	20,000
Multiple Sclerosis	10,400

The following data is provided by the Texas Emergency Medical Services (EMS) Trauma Registry and is generated by hospital patient records submitted as of August 1, 2014. About 59 percent of hospitals reported to the registry, with a total of 22,635 reported TBIs in Texas.

**Table 3. Top Five Causes of Injury Resulting in a TBI, Texas 2013**

Rank	External Cause of Injury	# of Hospitalizations	Case Fatality
1	Fall	11,696	4.7%
2	Motor vehicle/ traffic	7,285	9.1%
3	Struck by, against	2,748	2%
4	Transport, other	1,201	3.1%
5	Unspecified	500	5.4%

**5. Impact of Acquired Brain Injury**

The cognitive, emotional, physical, behavioral, and perceptual changes after an ABI may impact an individual's ability to work, drive, read, write, manage their finances, take care of their children, live independently, or participate in community and social activities. Improvements may come as a result of hard work and rehabilitation. Recovery is dependent upon the nature of the injury or disease, the individual, family support, the availability of resources, and access to appropriate rehabilitation at the appropriate time and for the appropriate amount of time.

Texans with ABI are fortunate to have access to a large number of acute and post-acute rehabilitation providers throughout the state. Texas is the only state to require insurance companies to provide coverage for the spectrum of rehabilitation services needed after a brain injury, including cognitive rehabilitation and post-acute brain injury rehabilitation. Because of the ABI law, Texans have greater access to acute and post-acute rehabilitation than any other state. In addition, Texas partially fills a rehabilitation gap by providing CRS program services to individuals with TBI or SCI who do not have adequate insurance.

While Texas leads the way in these two key areas, it does not currently offer programs and funding to help meet the long-term needs of individuals living with brain injury. Other states

have long term brain injury residential programs, structured brain injury day activity programs, and more robust brain injury vocational rehabilitation programs. Access to all of these programs helps individuals with brain injuries increase their ability to return to work and reduces their disability and medical complications.

The estimated national economic cost of TBI in 2010, including direct and indirect medical costs, is estimated to be approximately \$76.5 billion. Additionally, approximately 90 percent of the total TBI medical costs are from fatal TBIs and TBIs requiring hospitalization, many of which are severe (cdc.gov).

According to the CDC, acute care and rehabilitation of brain injury patients in the U.S. costs about \$9 billion to \$10 billion per year. This does not include indirect costs to society or families, including costs associated with lost earnings, work time, and productivity. The costs linked to providing social services are also not included. Although the long term costs of a TBI vary according to many factors such as the severity of the injury and associated impairments, it is estimated that the cost of caring for a survivor of severe TBI is between \$600,000 and over \$1.8 million over a lifetime (brainandspinalcord.org).

## **6. Recommendations of the Texas Brain Injury Advisory Council**

### **Legislative Recommendations**

#### *1. Adequately fund the Office of Acquired Brain Injury*

The OABI provides guidance, referrals, and service coordination for survivors of brain injuries and their families, including returning combat veterans, by arranging a comprehensive system of care through federal, state, and local resources. Full funding will enable the OABI to carry out its mission, including supporting the TBIAC with:

- Addition of three full-time employees
- Travel reimbursement for TBIAC consumer members for council meetings, outreach, education, and other activities to prevent brain injuries and improve lives (HHSC Legislative Appropriations Request, Rider Revisions and Additions Request, 3C Page 15)

#### *2. Add other acquired brain injuries, such as stroke, to the traumatic brain injury registry maintained by Department of State Health Services*

DSHS has maintained a traumatic brain injury registry since 1998. Texas needs a registry of all ABIs to better inform policy making.

#### *3. Fully fund the Comprehensive Rehabilitation Service program*

The CRS program provides services needed to help Texans with TBIs or SCIs live independently in their homes and communities. The program focuses on three primary areas that affect function and quality of life: mobility, self-care, and communication skills. Services may be provided in various settings to maximize effectiveness. Settings include the home, hospital, residential facility, outpatient clinic, or a combination of these settings. CRS services include inpatient comprehensive medical rehabilitation services, post-acute brain injury rehabilitation services, and outpatient therapies. The services are time-limited and designed to assist the individual with

daily living skills and prevent secondary medical conditions, thereby increasing the ability to function independently and reduce the need for ongoing state services (HHSC LAR 3.A. Page 229 of 491).

The CRS program was first funded in 1991 with dedicated funding to aid the recovery process of Texans experiencing TBIs and/or traumatic SCIs. Part of the funding for the program comes from surcharges on convictions of felonies and misdemeanors. Other money comes from general revenue funds allocated to the program by the Texas Legislature.

Full funding for the program will restore the 4 percent of funding previously cut (Item 13 on HHSC LAR Exceptional Item), and eliminate the CRS wait list (Item 17 on HHSC LAR Exceptional Item) for individuals with TBIs or SCIs.

The base request for CRS is \$50,169,740. Restoring the 4 percent previously cut will increase this amount by \$574,626 per year. The wait list elimination amount is \$6,938,148 for fiscal year 2018 and \$229,740 for fiscal year 2019.

#### *4. Add cognitive rehabilitation therapy as a state plan service in Texas Medicaid*

Currently, the Texas Medicaid state plan does not cover cognitive rehabilitation therapy. It is common for individuals with brain injury to have cognitive deficits which impact their ability to make choices, understand, remember, and use information. Cognitive deficits may affect attention, concentration, memory, communication, planning, organizing, reasoning, problem solving, decision making, judgment, impulse control, and processing and understanding information.

Cognitive rehabilitation has been proven an effective treatment to address cognitive deficits resulting from brain injury. The Cognitive Rehabilitation Task Force of the American Congress of Rehabilitation Medicine reviewed 370 studies and concluded there is sufficient evidence for the effectiveness of cognitive rehabilitation clinical protocols in addressing cognitive deficits resulting from TBI or stroke. Early intervention yields improved vocational/productivity outcomes, social integration, and independence.

Texas added cognitive rehabilitation therapy to the Star+Plus, Home and Community-based Services, and Community Living Assistance and Support Services Medicaid waiver programs in 2014 through Rider 66. This is an improvement for waiver participants with brain injuries. However, a significant number of individuals with brain injuries do not have timely access to these waivers. Additionally, many individuals with ABIs cannot access services because they do not meet the disability-onset age or medical condition requirements.

Texas passed legislation requiring insurance companies to cover cognitive rehabilitation under Texas Insurance Code Chapter 1352, which was established in 2001 when the 77th Legislature passed House Bill (H.B.) 1676, effective September 1, 2002. Rules to implement the statute (28 Texas Administrative Code §§ 21.3101-21.3107) were adopted August 26, 2002.

*5. Amend the Natasha's law, H.B. 2038, 82nd Legislature, Regular Session, 2011, to include neuropsychologist as part of the team to help determine return to play decision*

A concussion is an injury to the brain that can be caused by a blow to a person's body or head. Because a concussion may not result in loss of consciousness, physical, cognitive, emotional, sleep-related, and other symptoms can be missed without proper training. The medical consequences for failing to recognize and appropriately treat a concussion can be severe, sometimes causing brain swelling and death. Athletes who sustain concussions are sometimes more susceptible to repeat injury, and recent studies have shown that younger patients may recover from concussions more slowly than adults, making young athletes particularly vulnerable. Though increased media attention has called attention to the seriousness of concussions, many concussions sustained by student athletes go unrecognized or unreported.

Natasha's Law, enacted in 2011, requires the governing body of applicable schools and school districts to appoint or approve a concussion oversight team to establish a return-to-play protocol for student athletes believed to have sustained a concussion during a practice or competition. While Natasha's law authorizes physicians and other health providers to remove players with suspected concussion from play, only a physician can authorize their return to play. TBIAC's proposed amendment to Natasha's Law would add neuropsychologists as healthcare providers able to authorize return to play. Neuropsychologists specialize in evaluating and treating persons with acquired brain injuries.

All 50 states have a concussion law and the majority allow for multiple different healthcare providers with proper training and experience to clear student-athletes to return to sports after a concussion. Neuropsychologists have organizations dedicated to sports concussion care and are adequately qualified to assess and detect the presence of concussion and determine when an athlete has fully recovered. Neuropsychologists are leaders in sport concussion research and developed the most widely used tool for return-to-play decision making after a concussion, known as the ImPACT – Immediate Post Concussion and Cognitive Assessment Tool. Therefore sport neuropsychologists who are properly trained and skilled should have this authority as well.

*6. Support legislation for stop-loss regulation of self-funded employee health benefit plans or allow the Texas Department of Insurance rule making authority to establish criteria for a stop-loss insurance policy*

Employers with self-funded employee health benefit plans are excluded from all state mandates, including Texas Insurance Code 1352, which applies to benefit coverage for brain injury rehabilitation. A self-insured employer may assume full or partial responsibility for all medical claims. The employer may reduce their risk for large claims by purchasing stop-loss insurance coverage. If the aggregate losses get above a certain attachment point, the stop-loss insurance kicks in and starts to pay benefits for the employer.

It is not widely recognized that stop-loss insurance policies covering self-funded health plans are subject to state insurance laws, as pointed out in an article by Rhonda D. Orin, managing partner for a Washington, D.C. law firm. Also little known is that, “employers - not Employee Retirement Income Security Act (ERISA) beneficiaries - are insured by stop-loss policies and therefore fall outside of ERISA” (andersonkill.com).

The Employee Benefit Research Institute (EBRI) noted that stop-loss insurance is a direct insurance and states are permitted to regulate (ebri.org). Many states, such as Louisiana and Minnesota, have passed legislation that all stop-loss policies are regulated by the state department of insurance as a direct insurance (andersonkill.com). Similarly, in a Texas Court Case, the Texas Supreme Court ruled in favor of stop-loss reinsurance as a direct insurance (caselaw.findlaw.com).

Some self-funded plans which have low attachment points enable employers to take advantage of ERISA law and gain exclusion from state mandates and patient and provider protection. Some states are addressing the issue of a low attachment points, even though the carrier takes all the risks for loss and the plan acts like a regular health insurance.

In Texas, stop-loss insurance is unregulated and, due to such innovations as low attachment products, the self-funded market has grown to be much larger than the regulated insurance market. As a result, federal law is largely preempting application of important patient and provider protections enacted by the Legislature. The insurance department should be directed to regulate stop-loss insurance, protect employers purchasing the coverage, and protect the group health insurance market by ensuring that self-funded plans truly are self-funded, not insured.

## **Non-Legislative Recommendations**

### *1. Develop a demonstration program for an Acquired Brain Injury Family Navigator*

Families often are too overwhelmed at the time of the brain injury or event to understand its impact and may not be aware of helpful resources and information throughout the course of recovery. Valuable recovery time may be lost because of family uncertainty about how to move forward.

Families feel lost as to what resources are available as changes occur over the recovery path. The proposed Acquired Brain Injury Family Navigator program will provide families with education, support, and connections to resources at appropriate times following the brain injury or event. Recommendations for the program include:

- Partner with non-profit organizations and targeted hospital systems in key locations throughout Texas to develop and implement the program
- Identify funding sources and submit grant applications with partners
- Develop a training program and criteria for individuals serving as family navigators on behalf of the program
- Develop a process to ensure the family navigator is contacted by the hospital system within 72 hours of the ABI
- Implement the program in selected sites with partners
- Analyze the effectiveness of the program to determine outcome improvement and value added for individuals, their families, caregivers, hospitals, and the state

### *2. Develop fact sheets for education*

Develop educational fact sheets to include topics such as:

- What to expect after a brain injury

- Traumatic Brain Injury
- Stroke
- Aneurysm
- Anoxia
- Diffuse Axonal Injury
- Preventing brain injuries
- Resources for treating brain injuries and rehabilitation

### 3. *Build a network of brain injury focused social media sites and contacts to promote education and prevention*

Promote TBI and Stroke awareness months through television, radio and social media, including YouTube.

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