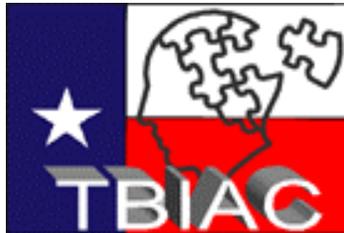


Recommendations for Improving the Lives of Individuals With Traumatic Brain Injury, 2014



2014

**Report of the Texas Traumatic Brain Injury Advisory Council
Presented to the Governor of Texas, the Lieutenant Governor,
The Speaker of the Texas House of Representatives, and
The Texas Legislature**

http://www.hhsc.state.tx.us/hhsc_projects/abj/Council.shtml

This report is submitted in compliance with the provisions of the HEALTH & SAFETY CODE, CHAPTER 92. INJURY PREVENTION AND CONTROL, SUBCHAPTER B. Sec. 92.061 that requires the Texas Traumatic Brain Injury Advisory Council to submit to the Governor, Legislature, and other appropriate state and federal authorities periodic reports on the Council's responsibilities and performance.

DISCLAIMER

This Texas Traumatic Brain Injury Advisory Council report, *Recommendations for Improving the Lives of Individuals with Traumatic Brain Injury, 2014*, reflects the views and opinions of a majority of the Council's membership. The views and opinions expressed in this report do not necessarily reflect the policy of HHSC or any state agency represented on the Council.

Texas TBI Statistics (2010 CDC Data)

- 146,000 Texans sustain a TBI every year (80% are mild, and 20% are moderate to severe)
- 10,000 Texans are permanently disabled every year from TBI
- 500,000 Texans live with a disability caused by TBI, most have limited options for long-term supports and services
- Every 4 minutes a Texan sustains a TBI
- Every 30 minutes a Texan is hospitalized with a TBI
- Every 80 minutes a Texan is permanently disabled by a TBI

Texans at Greatest Risk

- Ages 0-4; ages 15-44; and over age 65
- Abused Children (Shaken Baby Syndrome)
- Individuals with Unidentified Brain Injuries
- Individuals with Mental Health and Substance Abuse Disorders

- Military and National Guard
- Victims of Domestic Violence
- Individuals who have sustained a TBI (Occurs 2 times more in males than females)
- Individuals Incarcerated
- Participants in Sports

Potential Impact of a Brain Injury

- Problems with balance, motor skills, mobility
- Sensory losses
- Problems with alcohol and drugs
- Cognitive deficits
- Communication deficits
- Impaired mobility
- Loss of social and intimate relationships
- Impaired ability to perform activities of daily living

- Behavioral issues
- Fatigue and headaches
- Epilepsy and seizures
- Respiratory, circulatory, digestive and neurological diseases
- Alzheimer's and Parkinson's disease
- Loss of independence
- Loss of previous levels of functioning
- Loss of jobs & professions

Executive Summary

Traumatic brain injury (TBI) is a leading cause of death and disability in the United States, according to Víctor G. Coronado, MD, of the Centers for Disease Control and Prevention (CDC).¹ Texas is part of this national epidemic with an estimated 146,000 individuals sustaining a TBI every year (one every four minutes). Around 500,000 Texans live with disabilities caused by TBI. These include shaken babies, wounded warriors, elders who have fallen, young adults in car crashes, participants in sports, and others.

Texas has been a national leader in addressing the TBI epidemic. Texas established: the Comprehensive Rehabilitation Service program to rehabilitate Texans with traumatic brain or spinal cord injury; the Texas Traumatic Brain Injury Advisory Council (TBIAC); the TBI registry; and the Office of Acquired Brain Injury (OABI). Texas was the first state to require insurers to provide services to Texans with acquired brain injury (ABI), and Texas has made cognitive rehabilitation therapy available through the Medicaid home and community based services waivers to Texans with ABI. Texas has pioneered identifying TBI among youth in the Juvenile Justice System and testing approaches to improving management of, and outcomes for, juvenile offenders with TBI. Texas has helped connect individuals with ABI and their families with supports and services through the 2-1-1 system by providing ABI training to 2-1-1 information specialists and working with the United States Department of Veterans Affairs (VA). Texas has made significant strides in preventing TBIs through requiring helmets for children riding bicycles or participating in some rodeo events; educating school personnel regarding sports concussions; providing for primary enforcement of seat belt laws; and providing for protection of child motor-vehicle passengers through mandatory use of child seats, boosters and seat belts.

And yet, most Texans with brain injury still fall through the cracks. The TBI Registry captures only individuals who arrive at the hospital in an ambulance or individuals admitted to the hospital for at least 48 hours. Individuals taken to the emergency room or doctor's office by private vehicle are not counted. Many Texans are served by state agencies that do not know which of their consumers have had TBIs. The types of services and the means of delivery may be more effective and efficient if their brain injuries are known. In Individuals, including veterans, often don't know what their needs are, or how to get them met. Long term services, including residential, are largely unavailable to many Texans disabled by brain injury. Law enforcement personnel may mistake individuals with brain injury for individuals under the influence of alcohol or other substance, especially in conjunction with traffic stops. We have much work to do.

TBIAC makes the following recommendations to facilitate full participation of our fellow Texans living with brain injury. Acting on these recommendations will provide them with opportunities to contribute to the future of Texas through jobs and by other means.

TBIAC Policy and Program Recommendations

1. Adequately fund the Office of Acquired Brain Injury (OABI) to carry out its mission including support of the Texas Traumatic Brain Injury Advisory Council (TBIAC). Funding will support
 - 3.5 full time employees (FTEs).
 - An additional 5 FTEs to serve as the Texas Brain Injury Resource Facilitator (RF)/Case Manager (CM), and work with Texas 2-1-1 and Texas Department of Information Resources (DIR) Veterans Portal, to direct resources to individuals with brain injury.
 - Travel reimbursement funds for TBIAC members for council meetings, outreach and education activities, and other activities to prevent brain injuries and improve lives.
2. Adequately fund the TBI registry operated by the Department of State Health Services (DSHS).
3. Establish structure and oversight for the Department of Assistive and Rehabilitative Services (DARS) Comprehensive Rehabilitation Services (CRS) program. Fully fund the CRS to ensure that all available funds are used to serve individuals with traumatic brain injury (TBI) or spinal cord injury. Use all the program outcome data collected by DARS for the CRS program to measure program effectiveness and efficiency.
4. Assess the effectiveness of the DARS Vocational Rehabilitation (VR) programs in identifying and serving individuals with brain injury. The assessment will be done by the Health and Human Services Commission (HHSC) in collaboration with OABI and TBIAC.
5. Add Cognitive Rehabilitation Therapy (CRT) to the Medicaid state plan so that individuals with ABI, have access to the services and supports needed to restore normal functioning or to compensate for cognitive deficits.
6. Develop a common screening and assessment system to identify individuals with a brain injury who are receiving state services. Under leadership of HHSC Strategic System Support, state agencies including HHSC, DARS, DSHS, Department of Aging and Disability Services (DADS), Department of Family and Protective Services (DFPS), Texas Department of Criminal Justice (TDCJ), and Texas Department of Insurance Workers' Compensation and Health Division (TDI/WC), will
 - Develop, in conjunction with the OABI and the TBIAC, the identification tools, assessment protocols, and reporting system to begin in FY 2016.
 - Identify incoming consumers with brain injury and provide data to HHSC Strategic System Support.
 - Implement the identification system for existing consumers to begin in FY 2018.
7. Require the Medicaid agencies to create a plan to meet the unique long-term needs of individuals with acquired brain injury. Under the leadership of HHSC and in collaboration with the OABI and the TBIAC, this plan will include, but not be limited to, long-term residential care, day habilitation, supported living, and supported work, and will ensure that the providers have the necessary knowledge and skills to meet the unique needs of this population. The plan will be submitted to the legislature by September 1, 2016.
8. Expand the scope of the TBIAC to include acquired brain injury (of which traumatic brain injury is a subset) and change the name to the Texas Brain Injury Advisory Council. Add to the membership of the TBIAC a representative of Department of Family and Protective Services appointed by the DFPS Commissioner.
9. Require Texas Department of Public Safety (DPS), in collaboration with OABI and TBIAC to develop and certify an identification card to be used by individuals with ABI. Require DPS, in collaboration with OABI and TBIAC, to sponsor training for law enforcement officers, first responders and members of the judiciary in working with individuals with ABI.

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Introduction

Every year in the US, more than 125,000 individuals become disabled due to a Traumatic Brain Injury (TBI). The Centers for Disease Control and Prevention (CDC) estimates of over 3 million individuals in the US live with a TBI. ² The CDC, in its 2010 report to Congress, stated that TBI will be the number one health issue by the year 2020. The World Health Organization (WHO) goes further claiming that TBI will be the number one cause of death and disability in the world.

The CDC estimates the annual cost of TBI in the US is **\$6.8 billion**. This estimate includes the cost of initial medical care, lost earnings of the survivor, and death. This number **does not** include lost earnings of caretakers, uncompensated medical and non-medical costs, publicly funded programs such as Medicaid, school programs or criminal justice costs.

Recent research reveals that TBI fits the WHO definition of a chronic disease. Dr. Brent Masel, a Texas neurologist, and medical director for the Brain Injury Association of America (BIAA), and President of the Transitional Learning Center in Galveston, co-authored a journal article reviewing 25-years of scientific data, and concluded that “TBI is the beginning of an ongoing disease process, rather than a final outcome.” ³ It is clear from this article that TBI is neither acute or chronic. TBI is a static process-- it impacts multiple organs and life expectancy, and is disease causative and disease accelerative. TBI is strongly associated with the following diseases:

- Neurological disorders that may reduce life expectancy, like epilepsy and obstructive sleep apnea, which can be associated with reduced cognition and severe cardiac arrhythmias during sleep.
- Neurodegenerative disorders that are known to lead to a decline in cognitive function after a TBI including Alzheimer's dementia, Parkinson's disease, and chronic traumatic encephalopathy. Chronic encephalopathy is also referred to as "punch drunk" because it is characterized by disturbed coordination, gait, slurred speech and tremors.
- Neuroendocrine disorders that lead to acute and/or chronic post-traumatic hypopituitarism, and result in several related conditions, including growth hormone deficiency and hypothyroidism.
- Psychiatric and psychological diseases, arguably some of the most disabling consequences of traumatic brain injury. Many individuals with TBI are left with significant long-term neurobehavioral conditions. These range from aggression, confusion and agitation to obsessive-compulsive disorders, anxiety/mood/ psychotic disorders, major depression and substance abuse, and high rates of suicide.
- Non-cognitive disorders, may be seen in individuals who have incontinence issues, musculoskeletal dysfunction, or spasticity that results in abnormal motor patterns that may limit mobility and independence. Individuals with a TBI may also develop metabolic dysfunction, which is critically important in brain function, as brain injury appears to impact the way the body absorbs, uses and converts amino acids. In addition, a high rate of sexual dysfunction, affects 40-60% of individuals with TBI.

It's important that we begin to advocate for TBI to be viewed and managed as a “chronic disease” to ensure that brain injury is treated as a medical disease and workers' compensation and health insurance provides coverage similar to other injury and disease processes, and appropriate long- term services and supports are provided for individuals with TBI. It is also

important for identification purposes which is often related to research and discovering therapies to interrupt the disease process.

In addition to trauma, brain injuries can be caused by many non-traumatic factors including strokes; and oxygen deprivation from heart attacks, near drownings, and other causes. Non-traumatic brain injury can also occur from chemicals such as chemotherapy, poisoning, drug overdose, and diseases such as meningitis, encephalitis, tumors, etc. Traumatic and non-traumatic brain injuries after birth are referred to as acquired brain injury (ABI). Individuals with brain injury from these causes often have many of the same disabling conditions.

While disabling ABIs may not be cured, they can be effectively treated and managed if the individuals receive the right rehabilitation treatment at the right time and for the right duration; and the appropriate on going supports and services they need.

The Texas Traumatic Brain Injury Advisory Council

The State of Texas has been actively involved with brain injury rehabilitation, prevention, awareness and advocacy for individuals with brain injury since the inception of the CRS program in 1986. The Texas Traumatic Brain Injury Advisory Council (TBIAC) was established in 1997 by former Governor George Bush in response to the Federal Traumatic Brain Injury Act of 1996 which authorized the United States Department of Health and Human Services to make grants to states for the purpose of improving access to health and other services for individuals who sustain a traumatic brain injury. The TBIAC was established in statute September 1, 2003, by the 78th Texas Legislature.⁴

The TBIAC consistently participates and collaborates with stakeholder state agencies, the Brain Injury Association Texas Division, the Texas Brain Injury Alliance, Disability Rights Texas, the legal protection and advocacy agency, for individuals with disabilities, the Department of Veterans Affairs (VA), and other organizations.

The TBIAC is composed of volunteer appointees who donate their time to Council activities. The TBIAC and its efforts have been funded by federal grants and general revenue.

The mission of the TBIAC is to:

- Educate and inform state leadership of the needs of people with brain injuries and their families.
- Recommend policies and practices to meet those needs.
- Encourage research into the cause, prevention and treatment of traumatic brain injury and care of people with a traumatic brain injury.
- Promote brain injury prevention and awareness throughout the state.
- Identify people with traumatic brain injuries, their family members and caregivers, and to improve their access to supports and services.

Texas Office of Acquired Brain Injury

In 2006, the TBIAC recommended that HHSC include the establishment of the Office of Acquired Brain Injury (OABI) in its Legislative Appropriations Request (LAR). In 2007 the 80th Legislature approved the request, which included 1.5 full time employees.

OABI serves as the lead agency in Texas providing guidance, consultation, referral and service coordination for individuals with acquired brain injuries, including veterans and their families to ensure a comprehensive system of care through federal, state and local resources. The OABI also provides administrative support to the TBIAC.⁵

TBIAC and OABI: Highlights and Accomplishments

Continuing Education: Web-Based Training Courses

- “Making a Difference: Meeting the Needs of Individuals with Brain Injury,”
 - A10-part web-based course, through the Department of State Health Services (DSHS)
 - Provides vital information about brain injury, how to recognize signs and symptoms of brain injury and necessary communication skills to work with a brain injury survivor, family member or caregiver.
 - More than 700 individuals have received certification
 - Six other states are using the course
 - Available in Spanish
 - More than 8,400 English and 3,100 Spanish DVDs have been distributed throughout the United States and in eight foreign countries.
 - More than 800 CEU certificates issued for both courses
 - Required training for all 2-1-1 Texas call center specialists⁶
 - 2-1-1 Information and Referral Network uses the course in a number of states⁷
- “Brain Injury – The Silent Epidemic” is the second OABI approved web-based course.⁸
- “Re-entry of students with TBI to the school setting”
 - The 2008 Needs and Resource Assessment Report was developed through the TBIAC Resource Committee in collaboration with the Texas Education Agency (TEA), Region 12 Education Services Centers and a statewide stakeholder group of education professionals including representatives of Texas Juvenile Justice Department (TJJD) to assist professionals and families in creating a successful education program for every student with TBI.
 - The committee identified a need to improve the transition of students with brain injuries from their hospitalization and rehabilitation programs or juvenile justice setting into their schools.
 - TEA collaborated with the OABI to develop guidelines for school re-entry, including information for teachers, intervention strategies and resources.
 - The target audience included teachers, evaluators, counselors, coaches, school administrators, nurses, security personnel and parents.
 - Course content included education of services and resources available to students, brain injury facts, and the potential impact of a brain injury on the students’ behavior and ability to learn.
 - An approved course available on the OABI, TEA and TJJD websites.
 - A questionnaire was developed to address problems with identification of TBI in schools.

Texas Juvenile Justice Screening Project

- The US Health Resources and Services Administration (HRSA) Federal TBI Program, awarded a grant specifically to the OABI in 2009 to partner with the TJJD for the purpose of:
 - Screening to identify the presence of TBI among the 106,000 youth in the juvenile justice system to determine the presence of brain injury, and whether a brain injury may have contributed to their misbehavior/criminality; and
 - Offering referral for treatment and services to reduce recidivism, improve functioning for adolescents served, and improve access to community supports.
- Wayne Gordon, Ph.D., director of the Mount Sinai Brain Injury Research Center is Principal Investigator. The Brain Injury Screening Questionnaire (BISQ), developed by Dr. Gordon was used as the screening instrument to identify potential brain injury.
- More than 300 professionals who work in juvenile justice, have been trained about TBI and how to use the BISQ.
- Dr. Gordon has led a series of training seminars for juvenile justice staff on the impact of brain injury specific to the juvenile population and recommended treatment approaches.
- A specialized treatment center for TBI and behavioral issues was developed at the Corsicana State School for all youth.
- A specialized “pilot within the pilot” cognitive rehabilitation therapy (CRT) program was developed by Dr. Gordon, to train youth offenders in the three El Paso County Justice Department programs, for offenders with the most serious offenses and highest recidivism rates.
- Preliminary results indicated that offenders who participated in the pilot project have had more than a 75% decrease in referrals to security by self or staff and in injury to self or others.
- Approximately 80% have demonstrated utilization of the therapy and have reduced recidivism rates.
- The grant ends in 2014.

TBI Registry

- The Texas TBI registry was established in 1997 by the 75th Legislature. This statute contains the first statutory reference to the TBIAC.
- Data collection from acute care hospitals began in 1998.
- As of September 2012 and with funding from Texas Department of Transportation, DSHS has been building a new Emergency Medical Services (EMS)/Trauma Registry, a previously unfunded mandate.
- With stakeholder input and based on CDC recommendations, data elements were added for TBI and spinal cord injury patients.
- Long term acute care and rehabilitation facilities were scheduled to report data for individuals with TBI and spinal cord injury (SCI) beginning March 2013.

Brain Injury Manual for Disaster and Emergency Response Management

- Manuals were developed and provided to all 23 statewide Regional Advisory Councils (components of the state’s emergency response system).

- A program was developed from the manual and has been taught at three annual Texas Department of Emergency Management conferences, at the Health and Human Services Commission (HHSC) Disaster and Emergency Council, and the HHSC Business Continuity Council.
- The program is available on the OABI website.

Texas Brain Injury Resources and Services Directory

- The OABI developed a state directory of public and private brain injury resources and services available to assist in the provision of consumer and constituent service coordination and referral for individuals, family members and others.
- The OABI regularly responds to requests from state and national elected officials for information, referrals and service coordination for constituents.
- Since its inception the OABI has responded to about 1,500 consumer calls for information and service referral and coordination. Referrals and coordination are based on each individual's needs, some requiring a significant amount of time.

Veteran Tactical Response – A Law Enforcement Guide to Working with Veterans with TBI, PTSD, and Homelessness

- The Austin Police Department (APD) recognized the large population of Texas military forces in the Austin area and expressed a need for training in responding to veterans with TBI, Post-Traumatic Stress Disorder (PTSD) and who may be homeless.
- The OABI, in partnership with multiple veterans' organizations and APD, developed a train-the-trainer program with instruction manuals and two DVDs.
- The program includes methods of communication and engagement that have proven to be life-saving.
- More than 450 law enforcement officers have received Veteran Tactical Response training, including all special agents in the Firearms Division of the Bureau of Alcohol, Tobacco and Firearms.
- The Texas Department of Public Safety (DPS) has requested information.
- Program development was funded by HRSA, Federal TBI Program grant.

Wallet Identification Cards

- Families with loved ones who have sustained a brain injury made the Council aware of instances where the loved one had been falsely arrested, or experienced negative encounters with authorities because of their loved one's response to law enforcement, airport security personnel or other authorities. Stressful situations may exacerbate behavioral outbursts, increase use of inappropriate language, and decrease the ability to communicate clearly.
- Identification cards were developed to distribute to individuals with brain injury, including veterans. These cards include a place for the individual's name, and emergency contact information. The reverse side of the card contains signs and symptoms of TBI and a message stating communication may be difficult especially during stressful situations.

Informing Policy and Programs

The TBIAC receives statewide input from the public and private sectors to ensure an ongoing process of assessing the needs of people with brain injuries and their families. The Council informs, educates and makes recommendations to state leadership on policies and programs that will promote prevention of TBI and address the needs individuals with TBI, and their families. The Council has written position papers and provided public testimony in support of the following initiatives.

Brain Injury Insurance Coverage

Texas is the only state to have addressed the issue of insurance companies, health benefit plans and issuers regularly denying coverage for the spectrum of rehabilitation services needed after a brain injury, including cognitive rehabilitation and post-acute brain injury rehabilitation. The Council lead efforts to address these issues. Texas Insurance Code Chapter 1352 was established in 2001 when the 77th Legislature passed House Bill (HB) 1676, effective September 1, 2002. Rules to implement the statute (28 Texas Administrative Code §§ 21.3101-21.3107) were adopted August 26, 2002. This legislation was amended in 2007 when the 80th Legislature passed HB 1919, effective September 1, 2007; and in 2013 when the 83rd Legislature passed HB 2929 in response to insurance companies continuing denial of services outlined in the original and amended legislation.

The 2006 Texas Sunset report concluded claims cost for the 2001 mandate are considered minimal at one-fifth of one percent of total claim cost and, an estimated premium cost of only an additional \$1.37 per policy issued for an individual policy plan and \$4.94 per policy issued for employee only for employer sponsored plans.

Many other states are attempting to develop similar legislation as Texas, in response to the same issues Texas faced prior to 2002.

Texas legislation for ABI:

- Requires fully insured health plans to:
 - Provide benefits for cognitive rehabilitation therapy, cognitive communication therapy, neurocognitive therapy & rehabilitation, neurobehavioral, neurophysiological, neuropsychological, and psychophysiological testing and treatment, neuro-feedback therapy, and remediation; post-acute transition services, community reintegration services, including outpatient day-treatment services, or other post-acute care treatment services.
 - Provide the same coverage (limitations, co-insurance, deductibles, co-payment, and co-insurance) as other “medical” conditions.
 - Ensure that an adequate number of brain injury specialty programs licensed as an Assisted Living Facility (ALF), are made available to the insured.
 - Cover reasonable costs for periodic re-evaluation.
 - Provide appropriately trained staff in ABI who conduct authorization and utilization review of ABI services.
 - Provide qualified physicians to conduct medical necessity reviews.
 - Provided a telephonic response within three business days to requests for pre-authorization or appeals to adverse determination.
- Prohibits fully insured health plans from:
 - Requiring hospitalization to receive the benefit.

- Placing annual or lifetime limitations on days for post-acute and acute treatment covered.
- Limiting the number of days of covered post-acute care, which might include therapy, treatment, rehabilitation, testing, remediation or other services, or the number of days covered inpatient care, as long as services are considered medically necessary.
- Denying treatment solely because a provider is licensed as an ALF, or refuse to contract with a provider because it is licensed as an ALF, as long as the services provided by the facility are within the scope of their licensure and the facility is accredited as a brain injury program by the Commission on Accreditation of Rehabilitation Facilities (CARF).
- Regarding as custodial care, when treatment is provided in a specialty brain injury program licensed as an ALF.

Additional requirements:

- The TDI commissioner may require CARF brain injury specialty accreditation.
- The insurance plan must notify the insured annually about ABI benefit coverage.

Support for the Department of Assistive and Rehabilitative Services (DARS) Comprehensive Rehabilitation Services (CRS)

- As it now exists, CRS began in 1991 with \$1 million serving consumers with TBI and SCI.
- Current funding is based on surcharges on convictions of all misdemeanors and felonies.
- Current funding is more than \$24 million per year and served 908 TBI consumers in fiscal year (FY) 2013 and 938 in FY 2014.
- 75% of consumers were referred from hospitals and other institutions.
- An estimated 80% of consumers who have completed the CRS program live in their own home or their families' homes, many of whom were living in a nursing home prior to CRS services.

Support for Cognitive Rehabilitation Therapy

In 2009, the 81st Legislative Session, directed the OABI by to conduct a feasibility study regarding the need for a system of community support and residential services for individuals with acquired brain injury. A multi-agency work group of subject-matter experts worked to provide research, recommendations and options for an ABI Medicaid waiver pilot.

The results of the nine-month study, the "Feasibility Study for Providing Community Support and Residential Services for Individuals with Acquired Brain Injury" was prepared by the OABI and submitted to the Governor, Lieutenant Governor, Speaker of the House and other state leadership. HHSC included an exceptional item in the 2012-13 LAR to fund a pilot ABI Medicaid home and community based services waiver. Although a new waiver was not funded, funding was approved to add cognitive rehabilitation therapy (CRT) to the Community Living Assistance and Support Services (CLASS), Star+Plus, and Home and Community-based Services (HCS) waiver programs. These services allow individuals with brain injury to remain in the community with increased independence.

Support of the Office of Acquired Brain Injury

- The 82nd Legislature in 2011 did not appropriate funding for OABI from general revenue, due to a shortfall of \$27 billion.
- The federal grant was able to sustain the office until the 83rd Legislature in 2013 restored the general revenue funding for the OABI.
- The Council supports general revenue appropriation of the OABI.

Additional OABI Accomplishments

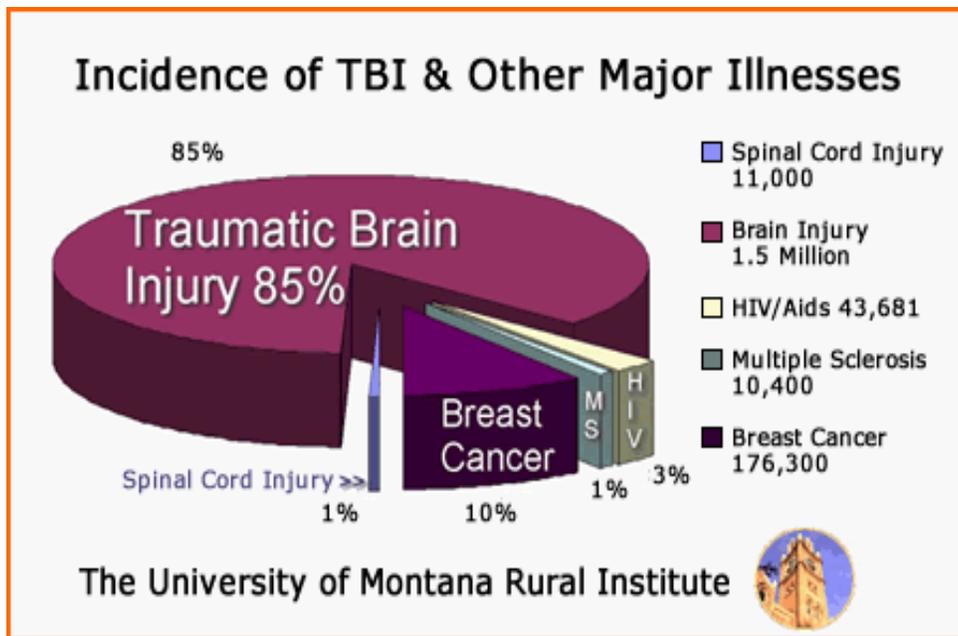
- Presentations made by OABI staff at 62 state, national and international conferences.
- Participation of OABI staff on advisory councils/boards including
 - Defense Centers of Excellence in Psychological Health and TBI and the National Intrepid Center of Excellence, and
 - Texas Coordinating Council for Veterans Services and the Substance Abuse Mental Health Services Administration/Texas Policy Council for Service Members, Veterans and Families.
- Recognition of the OABI by the U.S. Department of Health and Human Services, Health Resources and Services Administration in 2009, as a national model for its robust, innovative programs and its unprecedented development of a multi-systemic national and statewide network of partners providing service referral coordination, education and outreach, connecting civilians as well as veterans to an appropriate array of care.
- The U.S. Department of Health and Human Services, Health Resources and Services Administration recognized the OABI with the 2013 Leadership Award for its achievements and contributions.
- The OABI serves on the Texas Coordinating Council for Veteran Services, which was established by the 82nd Legislature in 2011 to coordinate the activities of state agencies that assist veterans, service members, and their families; coordinate outreach efforts that ensure that veterans, service members, and their families are made aware of services; and facilitate collaborative relationships among state, federal, and local agencies and private organizations to identify issues affecting this population.
- The OABI and the Texas Athletic Trainers' Association began the Texas Sports Concussion Partnership, in 2011. The Texas Institute for Brain Injury and Repair at UT Southwestern Medical School under the direction of Dr. Hunt Batjer, became a third partner in 2012. The partnership focus is education about concussion and return to play, and prevention of future TBIs.

Acquired Brain Injury Data

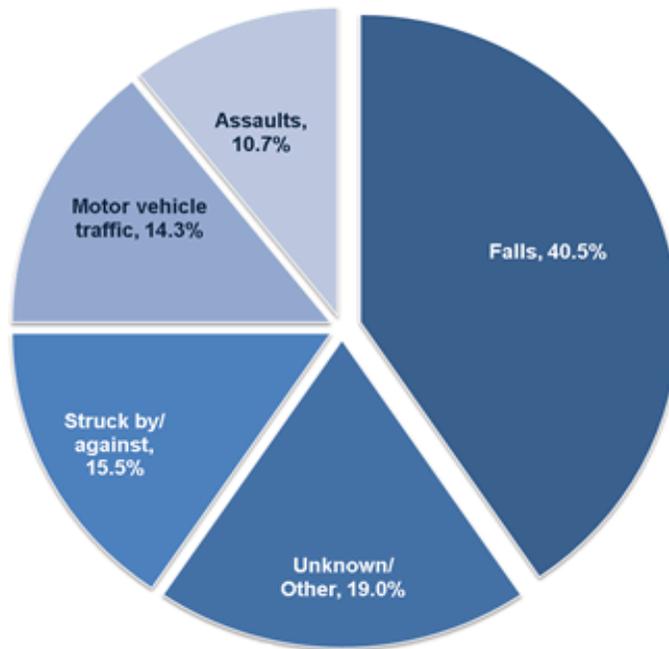
An ABI is an injury to the brain that occurs after birth, and prevents normal function of the brain. A TBI is one type of ABI and may be caused by an external bump, blow, or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. TBI severity is generally classified from mild or a brief change in mental status or consciousness, to severe or an extended period of unconsciousness or memory loss.

National Brain Injury Data

TBI is the nation’s leading cause of death and disability in persons under 45 years old, occurring more frequently than breast cancer, human immunodeficiency virus/acquired immunodeficiency virus (HIV/AIDS), multiple sclerosis, and spinal cord injury combined.

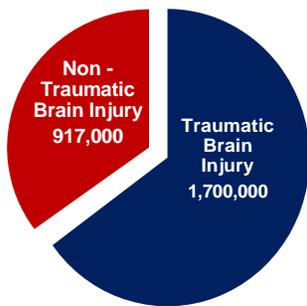


Leading Causes of TBI



Source: CDC - 2006-2010

National Incidence of Traumatic and Non-Traumatic Brain Injury



Type of non-traumatic brain injury	Estimated annual incidence
Stroke	795,000
Tumor	64,530
Aneurysm	27,000
Viral Encephalitis	20,000
Multiple Sclerosis	10,400
Anoxic/Hypoxic	No National Data Available

Non-traumatic brain injuries and diseases are other types of ABI, and may include stroke; infections of the brain; tumors; loss of oxygen to the brain; injury which may be caused by a heart attack; choking; near drowning or other anoxic/hypoxic conditions.

Texas Brain Injury Data

The State of Texas Health and Human Services Enterprise has a variety of rich databases available to help identify the incidence and prevalence of brain injury within the state; however, it is difficult to access and use this data. The accuracy and inclusiveness of this type of data is critical when applying for grants, conducting research, demonstrating program efficacy,

developing program improvement plans, identifying service gaps, developing prevention campaigns and formulating future policies or programs.

DSHS EMS Trauma Registry has data representing Texas residents transported by EMS or discharged from Texas hospitals that has been collected and has been available since 1998. Approximately 50 to 60% of Texas hospitals reported in 2012 and 2013. This percentage estimate of hospitals reporting is considered to be fairly consistent over the years.

However, individuals with brain injury who go to the emergency department (ED) of a hospital and are released often go unidentified. If the individual is transported by EMS the diagnosis is recorded. Individuals with a concussion who are transported by a family member or friend in a personal vehicle are not recorded. These “unidentified” cases are not tracked and as a group, individuals with unidentified brain injuries are at high risk for many complications later in life.

The Texas Cardiovascular Disease (CVD) Stroke Plan references data obtained through DSHS Surveillance Systems, Center for Health Statistics regarding Stroke and CVD. Additional information may be available regarding other types of brain injury in Texas through DSHS, Surveillance Systems and Center for Health Statistics.

DARS has data regarding access and outcomes of the CRS and Vocational Rehabilitation Programs.

DADS provided data regarding individuals with brain injury who were enrolled in a DADS program at the time. Data is included in this report from a Feasibility Study for Providing Community Support and Residential Services for Individuals with ABI, conducted by the OABI in 2009.

TEA faces many obstacles in its attempt to screen and identify children with TBI in Texas schools. Although initiatives such as Child First, and portable patient health records are used to help identify children with TBI, it is difficult to enforce and develop accurate data. Unfortunately, parents may fear their child being labeled as having a TBI, which may be in the form of a concussion or mild TBI. It may be difficult to find a physician who will sign the appropriate paperwork required to identify an individual with a TBI. Often parents may not be aware of the opportunities available to help their child, and the consequences that may occur to their child later in life when their TBI goes unidentified.

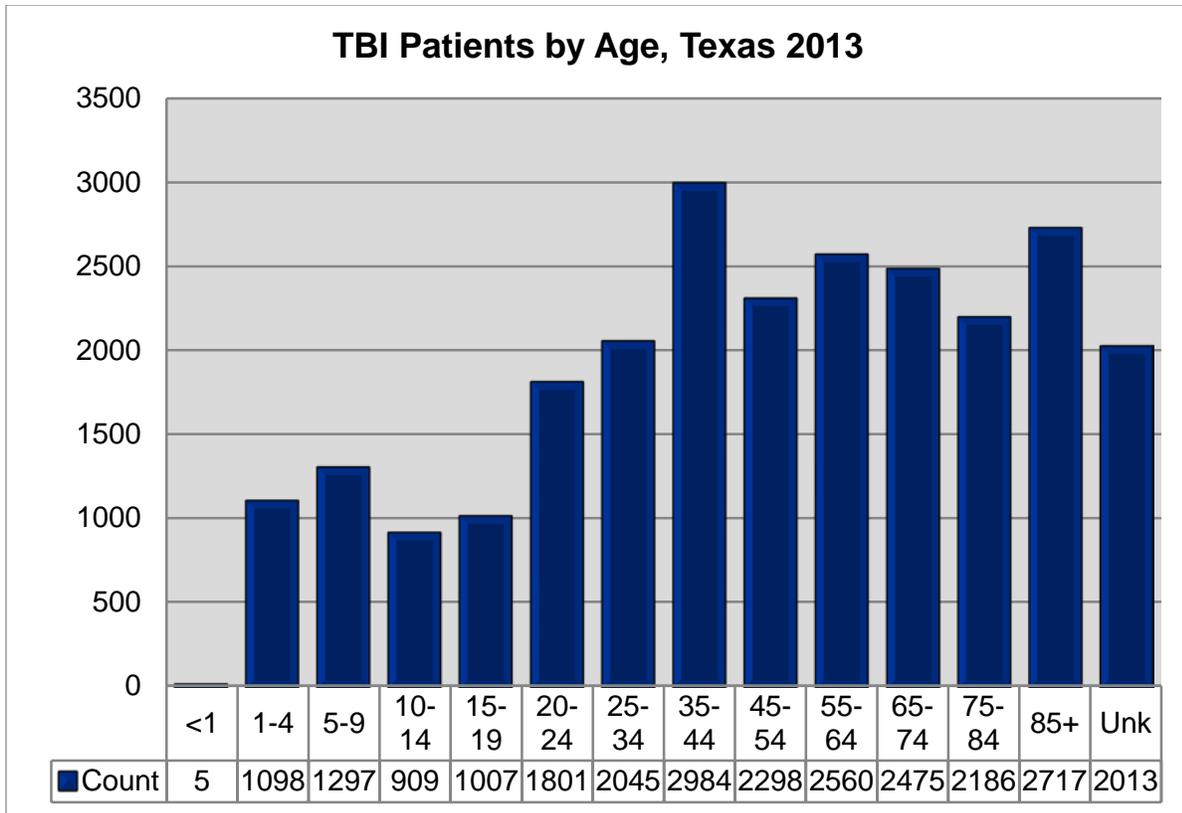
Next Steps

- Fully fund the Texas EMS Trauma Registry.
- Have all state agencies identify those with ABI whom they serve.

CDC National and Texas-based TBI Incidence Data

	Annual ED visits	Annual hospitalizations	Individuals living with TBI-related disability
National	2.2 million; increasing over time	280,000	5.3 million
Texas	212,500	25,000	500,000

The following data is provided by the EMS Trauma Registry and is generated by hospital patient records submitted as of 8/1/2014. As of this date about 59% of the hospitals had reported to the registry.



TBI Hospitalizations by Gender, 2013		
Gender	Frequency	Percent
Female	9,195	36%
Male	16,198	64%
Unknown	2	<1%
Total	25,395	100%

TBI and Stroke-related Cost Data in Texas

CORE Health Foundation estimated the following costs of TBI and Stroke in Texas in a 2010 White Paper.⁹

Annual hospital charges for stroke	>\$2.7 billion
Annual cost of TBI-related ED visits	\$740 million
Annual cost of TBI-related hospitalizations	\$623 million
Annual cost of TBI	\$680 million
Estimated lifetime per person costs associated with severe TBI	up to \$4 million
Average inpatient rehabilitation per person costs associated with severe TBI	\$110,891

High Risk Individuals With Brain Injury

The following section of the report addresses the issues and concerns of high risk populations, opportunities to decrease the impact and decrease the financial burdens on the state of Texas, the individuals living with brain injury, their families and their communities.

Military/Veterans

The VA Office of the Actuary estimated in a 2009 report that the total number of Texas Veterans is 1,701,675. This is the second largest population of veterans in the United States, of which the U.S. Census reported in 2011 that nearly 300,000 have served since 2001. About 40% of these military service members, including Active Duty, National Guard and Reserve, have been deployed multiple times as part of Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF), some as many as 7–10 times. The average age of a combat service member is 19, and the brain is not fully developed until age 25. Multiple studies show that each deployment and exposure to blasts, vehicle accidents, direct hits or continued concussive incidents significantly raise the risk that a veteran will return with TBI, PTSD, or a co-occurring condition.

The Defense Centers of Excellence in Psychological Health and TBI reported that as many as 22 – 25% of warriors may have a TBI that could lead to depression, self-isolation, anxiety, irritability, impulsivity, drug and alcohol abuse, depression, suicidality, and other cognitive, physical, and functional impairments associated with TBI. Although it is clear that many returning veterans have significant health needs, a review of the available literature shows that only 53% of service members and veterans with probable TBI/PTSD or major depression sought help within a 12-month period, and only 43% of those with probable TBI had been evaluated by a physician for a brain injury.¹⁰ The VA reported in June 2009 that the number of Texas veterans from the conflicts in Iraq and Afghanistan seeking treatment in 2008 was 26,248.

Many barriers prevent military personnel, including members of the National Guard, and their family members from seeking appropriate treatment for mental health related conditions. Many fear that seeking such services will jeopardize their career or cause stigmatism among their peers, families and others. Others are reluctant to expose their vulnerabilities to providers who are often military personnel themselves – given the military culture's emphasis on strength, confidence, self-sufficiency and bravery. In order to assist veterans in recognizing that the problems they are experiencing post-deployment are often very amenable to treatment, DSHS has created a peer-to-peer program that involves veterans facilitating groups of their peers in a model that was created in Texas and has been supported by the Texas Veterans' Commission.

According to the VA projections for 2011, approximately 90% of Texas veterans are male and 69% are Anglo. Twenty-five percent are 17-44 years of age, 40% are 45-64 years of age, and 34% are 65-85+ years of age. The Texas Army National Guard has 19,350 members, and the Texas Air National Guard is 3,100 strong. Army and Air National Guard members and their families number approximately 53,000. While many live near military and VA medical and rehabilitation facilities, a vast number reside in rural Texas where such services don't exist and health care providers may not be fully aware of an individual's medical or psychological condition due to TBI and /or PTSD. Over the years, federal and state agencies, as well as other partner organizations and stakeholders have worked to ensure that services are readily accessible and that mechanisms are in place to appropriately respond to the needs of Texas military service members, veterans, and their families.

Accordingly, 64.2% of Texas veterans live within 30 miles and 92.8% live within 100 miles of a large VA or military hospital. Additionally, 87.1% of veterans live within 75 miles of a DRS rehabilitation facility. The State of Texas has made great strides to develop a coordinated infrastructure of collaborative referral, services, and support for veterans. As an example, a Memorandum of Agreement (MOA) between DARS and the VA, Vocational Rehabilitation and Employment Service (VA-VRE) focuses on the coordination of services to Veterans with TBI and traumatic spinal cord injury. The MOA provides a clear understanding of services provided by each agency, methodology for making referrals and sharing information between agencies, and a system for coordinating services available from each agency. It is important to track and trend the outcome of these coordinated

Next Steps

- Fund a pilot program with 5 FTEs to provide Brain Injury Resource Facilitation through the Office of Acquired Brain injury to coordinate with Texas 2-1-1, Texas Information and Referral Network and the Texas Department of Information Resources (DIR), Veterans Portal. Resource Facilitation to be available to all Texan who need it.
- Ensure adequate resources are available for appropriate response time to Texas 2-1-1 callers.
- Expand current collaborative and partnership efforts, to increase veteran access to needed brain injury programs and services, and decrease duplication of services, through greater utilization of Texas brain injury providers in the private sector.

Children With Traumatic Brain Injury

TBI is the leading cause of death and disability in children in the USA, according to CDC epidemiology studies. The U.S. is not alone in this regard. TBI in children is a world-wide epidemic.

The National Center for Shaken Baby Syndrome (SBS) and the CDC reported SBS is the leading cause of death in abusive head trauma (AHT) cases. Further, babies (newborn to 4 months) are at greatest risk of injury from shaking. The primary trigger for SBS is inconsolable crying. An estimated 1,200 to 1,400 children are injured or killed by shaking every year in the United States. Approximately 25 percent of all SBS/AHT victims die as a result of their injuries. Of those who survive 80% suffer permanent disability such as severe brain damage, cerebral palsy, intellectual disability, behavioral disorders and impaired motor and cognitive skills. The medical costs associated with initial and long-term care for children with SBS can range from \$300,000 to more than \$1,000,000.

The American Academy of Pediatrics reported children who still require cardiopulmonary resuscitation (CPR) from drowning at the time they arrive at the emergency department have a poor prognosis, with at least half of survivors suffering significant neurologic impairment.

The National Safety Council estimated 5,000 children ages 14 and under are hospitalized due to unintentional drowning-related incidents each year; 15 percent die in the hospital and as many as 20 percent suffer severe, permanent neurological disability.

We know from the CDC research that the vast majority (at least 75%) of TBIs fall into the mild range (often called by the lay term concussion). This percentage is widely believed to be a gross underestimate since many mild TBI patients go unrecognized, never making it to EDs where the CDC data was collected. Despite the epidemic proportions of mild TBI, the general population and even the medical culture itself have been very slow to embrace the impact of these injuries. This is starting to change, thanks mainly to recent media attention on football

players in the National Football League. It has taken the sacrifice of our quarterbacks to make America stop ignoring this problem affecting so many of our children daily.

The CDC studies also showed us that TBI is disproportionately a pediatric problem, affecting a far greater percentage of children than adults. Unfortunately, research funding, medical training, insurance coverage and even the availability of pediatric TBI specialists and treatment facilities do not reflect this at all. Perhaps one cause is the common misbelief (called the “Kennard Principle”) that children recover better than adults after TBI because they are young and “plastic.” However, research has repeatedly shown that this is not true. The most vulnerable of brains are those of infants and children before preschool age. Injury at these stages impact critical stages of development and even mild TBIs can cause long-term cognitive and socio-behavioral problems for the rest of the child’s life. Children often do not show signs or symptoms of TBI until later in life, it is said kids “grow into” their brain injury because the damage caused by TBI in a “developing” brain is not seen until a child is much older. Most physicians are not even trained to recognize this. An infant who sustains a TBI often has a faulty “foundation” in cognition and behavioral development that appear normal at two years of age but are problematic as a teenager. Many of these children are labeled as “problem children” or diagnosed with attention deficit hyperactivity disorder (ADHD) after their history of TBI is long forgotten.

Currently there is no reliable way of tracking prior diagnoses of TBI. Often times there is no connection between a blow to the head and the child’s school record. Often parents are uneducated on the signs, symptoms and consequences of a mild TBI and may believe the child has fully recovered. Another issue may be when a child changes grade levels or goes to a new school, the teachers may be unaware of a prior TBI and may not offer accommodations to which they are entitled. The history of TBI is often forgotten or minimized when children are passing through the foster care system from one home to another. It may also be that there are financial pressures on our education system associated with TBI screening and identification. This can result in high rates of misdiagnosis, and greater consequences later in life. Just because it looks like a learning disability or an attention deficit disorder doesn’t always mean it is. There is strong evidence that a high percentage of youth in prison have a history of TBI. Such injuries can contribute to impulsivity, difficulty controlling anger and inability to anticipate the consequences of one’s actions. These injuries often cause difficulty reading the facial expressions of other people and failure to understand when one is “crossing the line” in social settings, both of which may lead to confrontation.

Texas continues to be a leader in our nation in recognizing and addressing TBI, but there is so much more that can be done. Texas has passed “return to play” legislation to protect our adolescent athletes participating in school-sponsored sports programs; however, younger children participating in youth-league programs and those who compete in non-school sports like rodeo, continue to fall through the cracks. The efforts to protect our athletes is a step in the right direction, but 70% of mild TBIs have nothing to do with sports. These children do not benefit at all from recent legislation, nor are there adequate guidelines compelling physicians to evaluate them or treat them in any certain way. Busy ED physicians are focused on detecting emergency head bleeds and may refer the child back to a pediatrician with little to no training in properly treating a concussion or advocating for the child in school.

We need a fundamental change in education about this diagnosis starting in medical school and including the thousands of existing physicians that come in contact with these children daily. The focus needs to shift from adolescents and “return to play” to the young majority of injured children and adolescents and “return to learn” guidelines. Not only do physicians need more education about this, but our school teachers, nurses and physical education teachers need

systematic training in recognizing concussive or TBI symptoms and dealing with these children when they return to class.

The TEA carries out much of its work through 20 regional Education Service Centers. This year largely due to the efforts of the TEA representative to the TBIAC, one of the regions will be dedicated to providing expertise about pediatric TBI which affects more public school children than any other single diagnosis. However, due to the problems associated with identification mentioned previously, only 1,300 children have been identified with TBI in our schools. This is believed to be a gross underestimate.

We must deal with the obstacle of research funding that prioritizes basic science research (focusing on animal models). Our knowledge base in TBI, especially milder forms, is just not yet at that level and research on animals cannot shed much light on the higher level of cognition and behavioral development of a human child. We also need to recognize that research on adults cannot simply be applied to the brains of young children. Research funding needs to be directed at each stage of early development of a child's brain. It is difficult to support the need for research when so many TBIs go unidentified in children.

We need insurance companies to comply with Texas Brain Injury Insurance Code, Chapter 1352, to cover the continuum of brain injury services they are required to provide by law. We need employers choosing self-insured, or partially self-insured benefit plans to understand that these brain injury benefits are available at nominal cost. Compliance and education regarding these benefits will help save the State of Texas considerable dollars, including potentially reducing some of the long-term effects of brain injury on these children.

Texas has many specialty brain injury providers offering intensive post-acute brain injury programs, licensed as ALF, with specialty brain injury CARF Accreditation. However, many children in Texas with a brain injury have Medicaid and cannot access services through these facilities.

Finally, we must focus on prevention of this problem – real penalties for failing to properly restrain children in cars, helmet laws and campaigns to protect our children, real penalties for child abuse and widespread educational campaigns for preventing shaken-baby syndrome.

Not a single state has taken the forefront in all the areas of this complex medical problem so Texas has an opportunity to be the first and lead the nation.

Next Steps

- Develop appropriate transition from acute hospital, from inpatient rehabilitation, and from post-acute rehabilitation into the school setting, including coordination to provide appropriate supports and services.
- Establish collaboration between the OABI/TBIAC and other states which have model brain injury programs addressing the needs of children with brain injury. This may be accomplished by collaborating with participants from the Summit on Childhood Brain Injury held in August of 2011. Participating states and organizations included: Oregon, Nebraska, Ohio, Pennsylvania, Tennessee, Kansas, District of Columbia, HRSA, National Institute of Disability Research, BIAA and the U.S. Brain Injury Alliance.
- Explore whether any of the Texas Specialty Post-Acute Brain Injury Programs might accept Medicaid, and whether there are any possibilities to include these programs and providers under Medicaid Managed Care Plans.

Sports Injuries

The U.S. Consumer Product Safety Commission (CPSC) tracks product-related injuries through its National Electronic Injury Surveillance System (NEISS). According to the American Association of Neurological Surgeons (AANS) study utilizing CPSC data, there were an estimated 446,788 sports-related head injuries treated at U.S. hospital emergency rooms in 2009.

This number represents an increase of nearly 95,000 sports-related injuries from the prior year. The CDC reports the proportion of these concussions that are repeat injuries is unknown; however, there is an increased risk for subsequent TBI among persons who have had at least one previous TBI.

We know that repeated mild traumatic brain injuries occurring over an extended period (i.e., months or years) can result in cumulative neurologic and cognitive deficits, but repeated mild traumatic brain injuries occurring within a short period (i.e., hours, days, or weeks) can be catastrophic or fatal.

Next Steps

Extend recent concussion laws to include injuries that occur while playing sports outside the school, in community and city leagues.

Unidentified Brain Injuries

CDC estimates that the 3 million to 5 million TBIs reported as ED visits are a significant understatement. Dr. Wayne Gordon, Ph.D, said on BrainLine.org that we need to also consider the 7% to 8% of non-disabled individuals who have experienced a mild TBI with persistent symptoms, and the 7% of 5,800 interviewed in the New Haven catchment area study who reported a loss of consciousness.^{11 12} Dr. Gordon suggests, extrapolation of these percentages to the U.S. population yields up to 21 million people who live with persistent TBI symptoms. This number includes the 5.3 million known plus the 15.7 million unknown. Dr. Gordon further stated that, “these individuals with unknown TBI get lost or are never found in the first place.”

Some 425,000 of these are treated by medical doctors (MDs) in the physician’s office. Another 90,000 are treated in other types of outpatient settings, and as previously discussed in this report, an estimated 320,000 soldiers with TBI, will not speak up (brainline.org). Individuals with brain injury may not speak up because they have been injured in a car accident and think they are fine, they may be injured in a sports event, or they may be a victim of unreported violence. Sometimes they may not seek help because they do not have immediate symptoms; they may feel “dazed” but not exhibit physical injuries.

Children may not have been observed to have been injured, or the responsible adult may be fearful of disclosing the injury. Too often concussions go unnoticed, and they are neither reported nor followed up on appropriately.

Lack of follow-up for those with unidentified TBIs is a significant issue that often leads to long-term society issues. This results in devastating consequences which may include misdiagnosis and prescribing wrong medications. Individuals with TBI are often sent home without follow up. This might include lack of follow up from the ED, school, sporting events, acute-care hospitalization, acute and post-acute rehabilitation, or soldiers may be sent home from war, often with an unidentified brain injury, combined with other injuries. When any of these circumstances happen individuals are often not told what to expect; therefore, they do not connect any changes in function to their TBI. They do not seek TBI rehabilitation services, and often do not let their family or co-workers know about the changes, because they feel they are “going crazy” and do not want to call attention to themselves.

Identification and screening of individuals with TBI is important for several reasons including: prevention and education efforts; reduced burden to society; appropriate treatment at the right time, fewer incarcerations; and fewer incidents of domestic violence. Early identification can prevent long-term failures and can be helped through improved baseline screening and all State Agencies tracking individuals with brain injury using State services and programs, including individuals who have a co-occurring TBI and mental or behavioral health disorders.

Next Steps

- Improve baseline screening by state agencies for brain injury for individuals using services and programs, including assessment for co-occurring TBI and mental or behavioral health disorders.
- TBI is undercounted and increased awareness campaigns may raise awareness among the general public. To date, 1 in 3 individuals are not familiar with the term “brain injury.” Undercounting of TBIs may result in fewer research dollars.

Mental Health and Substance Abuse

Research has shown that almost 50% of individuals with a history of TBI also have some type of psychiatric disorder, including mood disorders, anxiety disorders and substance abuse. Some studies show individuals with a TBI have two-thirds more emotional difficulties, are two-thirds more likely to receive disability payments, and are four times more likely to attempt suicide. Other studies show an increase in criminal behavior, violence and homelessness following a TBI.

Depression is the most frequent and ranges from 33% to 42% during the first year to as high as 51% within the first seven years, to as high as 60% at some point after injury.^{13,14} In addition, those who suffer from TBI are more likely to also suffer from chronic or neurotic depression, and bipolar disorder. Anxiety disorders also occur with a great frequency compared to the general population, impacting about 29%. PTSD is another common co-occurring disorder after a TBI, studies vary ranging from estimates of 1% to 50% across studies.¹⁵

Studies reviewed on the Model System Knowledge Translation Center web site (MSKTC) showed that between 20-50% of adults with TBI were injured while they were intoxicated and about one-third were under the influence of other drugs. We know that the use of drugs and/or alcohol is often the cause of accidents that result in a TBI.

Continuing to drink alcohol or engaging in drug use has a negative impact on the individual with a brain injury. Studies greatly vary regarding the continued use of alcohol and drugs, and indicate that about 25% abused alcohol and/or marijuana at some time after their injury (brainline.org). Other studies report about 50% of those who have a TBI cut down on drinking or stop altogether after their injury. Some studies report that only about 10% drink or use drugs 10 years post injury. In addition, some studies have indicated that between 10% and 20% of persons with traumatic brain injury develop a substance abuse problem for the first time after their injury.^{16, 17} In a quote on brainline.org, John Corrigan, Ph.D. stated, “substance abuse is a risk factor for having a traumatic brain injury and traumatic brain injury is a risk factor for developing a substance abuse problem.”

Alcohol and drug use slows the recovery from a brain injury, further damages the injured brain, increases the frequency of sexual issues, aggressive behaviors and other antisocial behaviors, interferes with thinking, and increases the likelihood of failures at work, school, and parenting. The use of alcohol may increase the onset and/or frequency of seizures and of having multiple TBIs.

Next Steps

- Add a reporting requirement of local mental health authorities for individuals assessed and served who have co-occurring TBI and mental or behavioral health disorders.
- Ensure that any assessment protocols used in the Star+Plus system fairly evaluate the needs of a person with a TBI and/or co-occurring mental or behavioral health disorders and implement protocols to ensure equity in the services approved for individuals with similar needs, like those with TBI or Intellectual and Developmental Disabilities (IDD).

Criminal Justice System

Studies have indicated that 82% to 87% of those incarcerated had experienced a prior TBI, and 65% of those with a loss of consciousness (brainline.org). Dr. Dorothy Lewis reported that, 15 inmates on death row had experienced one or more TBIs.¹⁸ There is also high frequency of frontal and temporal lobe and/or organic damage among juvenile delinquents. Offenders with an acquired brain injury or brain dysfunction, often had a frequent and prolonged history of physical and sexual abuse (brainline.org).

Evidence suggests that the frontal and temporal lobe damage from a TBI is associated with increased potential for aggressive, violent and criminal behavior. This may be attributed to frontal lobe damage and short attention spans, difficulty regulating emotions and inhibiting impulses, difficulty switching behavior, inability to fully recognize the impact of their behavior on others and reduced ability to self-correct, learn and think flexibly.¹⁹ Thus, they are more likely to repeat inappropriate, aggressive and/or criminal behaviors. The person often becomes more frustrated because of their inability to control their emotions and receive the desired response from others. This behavior may result in assault, petty theft, and other offending behavior.²⁰ People regularly report their brain injury is misinterpreted as being drunk, on drugs, or as the effects of a mental illness, which can lead to inappropriate police involvement. Strategies used to communicate with people who are drunk or under the influence of illegal drugs may not be effective for individuals with TBI. Impulsivity, impaired anger-management skills, short-term memory loss, susceptibility to suggestion and impaired social skills may result in a person being charged, convicted and sentenced.

Our prisons are not set up to correct the behavior of someone with a brain injury. Our criminal justice systems operate on the assumption of responsibility for ones' own action, it's a consequence for wrongful actions, meant to act as a warning to stop future wrongful actions. This may be irrelevant to people with a cognitive disability, who have lack of insight, impaired self- control, and impulsivity issues.²¹ Individuals in prison with a brain injury may not understand contracts; their attention deficits may create mental confusion and be misinterpreted for defiance. Memory deficits may make it difficult to follow rules and/or directions, or they may misinterpret directions as threatening or unjust. Impulsivity and anger management may lead to conflict with other prisoners, which may lead to disciplinary action, physical altercation, or further injury.

Next Steps

- Require DPS and first responders in collaboration with OABI and TBIAC, to sponsor training for law enforcement officers and members of the judiciary in working with individuals with ABI.
- Develop special units within the prison system to work with individuals with TBI.

- Explore the expansion of the Jail Diversion and Trauma Recovery program model to all individuals with TBI in the criminal justice system.

Aging and Brain Injury

Many studies indicate a key to preservation of health as one ages is associated with physical activity, social engagement, nutrition and sense of purpose. The CDC reports, “safe and well-designed community environments support healthful behaviors that help prevent chronic conditions and unintentional injuries and enable older adults to be active and engaged in community life for as long as possible.”²² Both of these facts hold true for individuals with brain injuries. It is critical to address the issues of aging with brain injury through the provision of and access to, specialized brain injury long-term services and supports, in order to mitigate risks and concerns discussed below.

The impact of aging is greater on individuals with an ABI. Studies indicate concerns associated with aging and brain injury are: loss of skills over time that may have been gained during rehabilitation, increased risk for injury from falls and other impact injuries, increased medical needs, decreased endurance and range of motion, increased social isolation and decreased independent living skills.

The risk of falls increases because of poor balance, and poor judgment. Sensory systems and acuity diminishes with age; however, the person with a brain injury may not be able to accurately ask for help about hearing, double vision or other perceptual problems.

Aging with a TBI or stroke creates a greater risk for additional disease or injury. Aging creates a stress on cardiac, peripheral vascular and other systems. The individual with a brain injury is less likely to report the development of new medical issues due to increased memory problems and decreased organizational skills. To date we do not have adequate follow up systems in place to address these issues.

Family caregivers are concerned about what will happen to their loved one with the brain injury after the family caregiver(s) pass away, or becomes unable to physically or mentally take care of their loved one any longer. Families know that their loved one is at greater risk for social isolation, and decreased independent living skills. Perhaps the greatest caregiving fear is having to place their loved one in a facility where staff training and staff ratios are not adequate to safely provide care for their loved one, or opportunities to engage in quality-of-life activities.

Next Steps

Address the long-term issues associated with aging and brain injury through appropriate long-term services and supports. This will help individuals engage in vocational and quality-of-life activities to maintain their health, and their cognitive, physical, and independent living skills. This would decrease costly emergency room visits and hospital admissions.

Continuum of Services for Individuals With Brain Injury

The TBI Medical Treatment Guidelines (Colorado Guidelines, 4th Ed), in use since 1996, and endorsed by the BIAA establish the spectrum of services an individual with a brain injury needs to have access to in order to maximize recovery, and/or engage in quality living.

The diagram following illustrates the TBI spectrum of care that may be required for an individual who have sustained a TBI. The definitions of services are provided in Appendix IV. Texans are fortunate to have the availability of many of the services listed through legislation and the efforts of HHSC; however, gaps do exist and will be discussed in the following section.

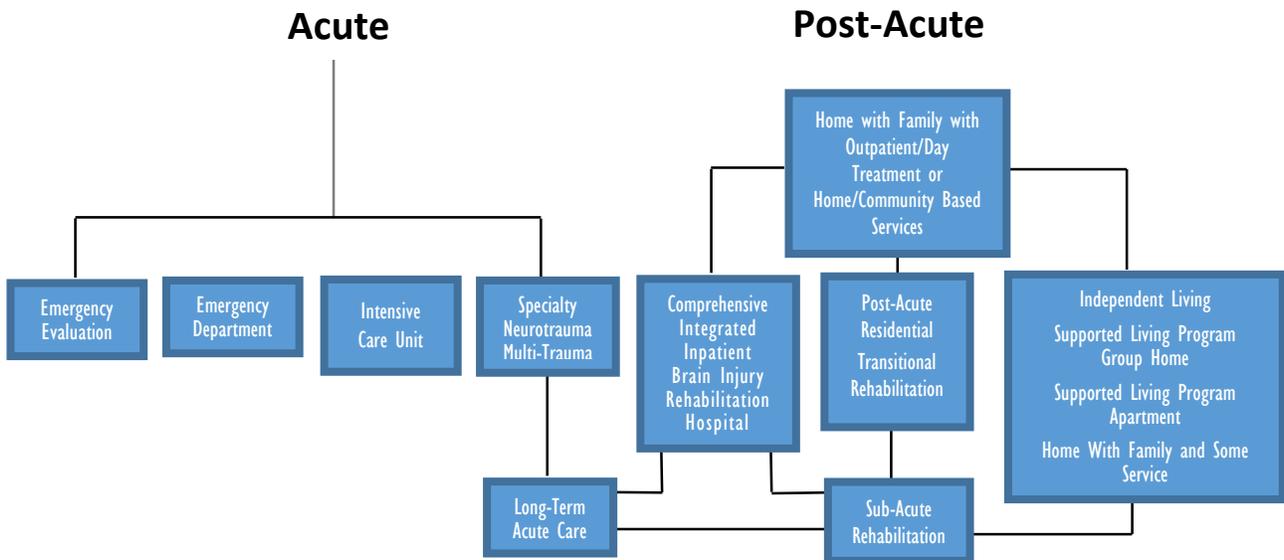
Next Steps

Adoption of these guidelines by the HHSC and TDI/WC.

The BIAA has endorsed the TBI Model System of Continuum of Care schematic below depicting a continuum of care for individuals with moderate to severe TBI. The spectrum of programs and services that may be required are based on the individual's unique needs and condition to maximize their recovery and/or engage in the greatest quality of life.

Definition of services in the diagram below are provided in Appendix IV of this report.

TBI Model System of Continuum of Care



Adopted from the Rocky Mountain Regional Brain Injury System, 1991

Gaps in Service Provision for Brain Injury

Community Participation

Individuals with TBI have decreased community participation (CP) in key roles, including independent living, work/productive activity, and social and leisure activities. For example, TBI negatively impacts household activities, parenting, mobility in the community, productivity, and social relationships. Approximately 60% of individuals hospitalized with TBI remain unable to return to work at one year post-injury.²³ In the first year after TBI, estimates suggest \$642 million in lost wages, \$96 million in lost income taxes, and \$353 million in increased public assistance.²⁴ Notably, the indirect costs of TBI (e.g., lost earnings) exceed the direct costs of TBI (e.g., physician and hospital charges).²⁵

Rehabilitation is effective for improving CP for persons with TBI.²⁶ Early intervention yields improved vocational/productivity outcomes, social integration, and independence.^{27 28} Cognitive rehabilitation and vocational rehabilitation were recently identified as high priorities for knowledge translation by an international workshop of TBI experts.²⁹ Unfortunately, many barriers to successful use of post-TBI resources and services exist. Lack of access to existing services to improve CP after TBI contributes to increased indirect costs and greater dependence on the state and society through reliance on public assistance and state and federally sponsored programs. Additionally, caregiving responsibilities sometimes force family members of persons with TBI to discontinue working, leading to lower tax contributions and increased reliance on public-support programs.

Data documenting the problem of access, referral and utilization of available services comes from nationally based empirical research, published reports of the TBIAC, and research conducted in Texas. In a published review of several statewide needs assessments conducted across the U.S. lack of easy and timely access to services emerged as one of the most prominent challenges to satisfying the needs of persons with TBI.³⁰ In a peer reviewed study of persons with TBI, 59% reported having one or more unmet service needs during the first year after injury, and 40% continued to report at least one unmet need in the second year post-injury.³¹ Other researchers have reported that the most frequently reported unmet need is “receiving information about services,” and the most frequently identified barrier to accessing needed services and achieving full CP is lack of awareness about available services.³² Lack of accessed services after TBI is associated with negative impact on quality of life ratings.³³

Our review of 10 statewide TBI needs assessments (conducted from 2007-2012) indicated that 80% identified lack of awareness of services or difficulty finding information as prominent barriers to service utilization. For example, the TBI Needs and Asset Assessment Report of the Arizona Governor’s Council on Spinal and Head Injuries noted, “A resource is only as good as the capacity of the individual to access and use it.”³⁴ As reported in the 2011 Missouri TBI Needs Assessment Report, information and referral was the greatest service need, and difficulty finding information was rated as a major barrier to service utilization.³⁵ Similarly, the 2009-2010 Kansas TBI Needs Assessment indicated that information and resources represent the greatest need for both persons with TBI and their caregivers.³⁶ The 2010 North Carolina TBI Needs Assessment concluded that, “Services clearly are available in the state, but these need to be more visible and better delineated for professionals, families and survivors...”³⁷

Resources Facilitation (Case Management Services)

Unfortunately, Texas has long faced similar problems with gaps in service provision due to a variety of factors: access due to lack of funding, lack of knowledge and referral to existing

services. In 1998 the TBIAC conducted a needs assessment survey and held statewide public meetings attended by persons with TBI and caregivers. The resulting 1999 “Needs Assessment Report” indicated that 55% of persons with TBI reported having received no information at all about supports and services. The report noted, “Repeatedly, comments were made that the families and individuals were alone in searching out information and resources. They indicated a case manager or personal advocate is a service that is needed for linking them with information and supports and services.” In a 1999 report entitled, “A Summary of the Gaps in Services in the Texas Health and Human Service Delivery System,” the TBIAC identified a strong need for a central entry and referral system involving care coordination. The TBIAC also produced a 1999 report entitled, “A Policy Analysis of the Texas Health and Human Service Delivery System” in which a primary conclusion was that, “Service coordination is absolutely necessary to assist people with TBI and their families in their search and obtaining the needed supports and services.” The same recommendation appeared in the TBIAC’s 1999 “Statewide Action Plan of Supports and Services” report. In the TBIAC’s 2007 “Report to the Governor, Lieutenant Governor, and Speaker of the Texas House of Representatives,” a recommendation was made to develop “one-stop shopping” for accessing services through case managers charged with linking individuals with TBI with a continuum of services.

Texas-based data on gaps in service provision have also been obtained through three focus group meetings of persons with TBI and caregivers conducted at TIRR Memorial Hermann in Houston, ranked third in the nation among rehabilitation hospitals and a recipient of numerous federally funded TBI research grants. Participants identified the Internet as their primary source of information about post-TBI services. They noted that information was often too general, outdated, or otherwise inaccurate. They also described difficulty in following up on information and many reported giving up on attempting to access certain services because the process was too confusing. They identified the biggest barrier as, “not knowing where to start.” Their comments are consistent with the findings of Sample and colleagues.³⁸ Both persons with brain injury and their family members struggle constantly with learning about, finding, and accessing services. This process is ongoing and often frustrating for all involved.”

Resource Facilitation (RF) has demonstrated effectiveness for improving *CP, access to available acute and post-acute services, long-term services and other medical, behavioral services* following TBI. RF can also help identify gaps that may exist in service through a centralized data base. RF is defined as “a partnership that helps people and communities choose, get, and keep information, services, and supports to make informed choices and meet their goals.”³⁹ RF can also be referred to as case management, case coordination, service coordination, or resource coordination. RF seeks to improve outcomes by eliminating barriers to accessing existing resources/services. Participation in RF programs results in improved ability to make informed choices when accessing community and state resources. Moreover, early RF is advantageous and consumers desire to receive information about TBI-related services early after injury.⁴⁰

As of 2000, RF programs for individuals with brain injuries had been implemented in 16 states. By 2008, the number of RF programs had risen dramatically to 40 states, reflecting widespread recognition of the need for RF and its benefits. Funding sources for RF programs vary across states, but the most common source of funding is state general revenue funds.⁴¹

The need for long-term proactive RF was highlighted by national TBI experts at the 2012 Galveston Brain Injury Conference, consistent with recent emphasis on the perspective of TBI as a chronic condition requiring individualized services throughout the lifespan.⁴² Furthermore, empirical studies have demonstrated the effectiveness of RF for improving CP.^{13, 43} Trexler and colleagues found a greater rate of return to work and a higher level of CP in the group of participants with brain injuries who received RF for six months as compared to a control group,

in a prospective randomized controlled trial of RF in Indiana. In a separate report, the provision of RF in Indiana yielded conservatively estimated figures of \$22.5 - \$31 million annually in recaptured earnings.⁴⁴

The development of an RF program in Texas has been a documented goal of the TBIAC since 1999 aimed at filling the gap of underutilization of existing services. In the intervening years, empirical research has identified its effectiveness at improving CP after TBI and RF programs have been established in at least 40 states, funded primarily through state general revenue monies. Given that RF focuses on improving awareness of and access to existing services, it can be implemented at relatively low cost. As underscored by the beneficial economic impact of RF services in Indiana, its operational costs are expected to be outweighed by cost savings to the state over the long-term through recaptured earnings and reduced reliance on public assistance programs.

Next Steps

Establish RF program in Texas provided by dedicated full time employee(s) and/or case managers in the Office of Acquired Brain Injury. This will address Texas' longstanding gap in service provision stemming from lack of awareness and underutilization of services by persons with TBI and their family members.

Access to Post-Acute Transitional Rehabilitation Services

Post-Acute Transitional Rehabilitation Services are most often provided under Texas licensed Assisted Living Facilities (ALF), accredited as Brain Injury Specialty Programs by the Commission on Accreditation of Rehabilitation Facilities (CARF). These programs provide intensive medical coordination and management, and rehabilitation services to help the individual return to the highest level of function. Texans have access to this level of care through DARS CRS and VR programs, private insurance, and Texas Workers' Compensation Insurance.

The brain injury insurance statute does not include the State of Texas Employees, County, and Federal Government Employees, leaving these individuals at risk should they experience a brain injury. In addition, all issuers of insurance are not consistently compliant with this statute and coverage at this level of care. The Texas Workers' Compensation Official Disability Guidelines (ODG) do not include this level of care and often an individual who is injured on the job may not have access to Post Acute Transitional Residential Services. Individuals with a brain injury who may have an opportunity to return to some level of employment are often refused service by DARS VR, or there are limited providers who offer these services due to low reimbursement rates for supported employment and the high intensity of professionals required for success.

Next Steps

- Ensure compliance with the Brain Injury Insurance Statute.
- Evaluate the provision of DARS VR services to individuals with brain injury to determine opportunities to improve access.
- Provide evidence based support of Post-Acute Transitional Residential Rehabilitation to the ODG.

Medicaid Managed Care and Long-Term Services and Supports

Texas has added CRT to the Star+Plus, Home and Community-based Services (HCS), and Community Living Assistance and Support Services (CLASS) Medicaid waiver programs in

2014. This is an improvement for waiver participants with brain injuries; however, a significant number of individuals with brain injuries may not have timely access to these waivers. Additionally, many individuals with a TBI cannot access services because they do not meet the disability-onset age requirements, or medical condition requirements.

The 83rd Texas Legislature passed SB 7 to: improve the coordination of Medicaid long-term services and supports with acute-care services; redesign the long-term-care services and supports system to more efficiently serve individuals with intellectual and developmental disabilities (IDD); and expand on quality-based payment initiatives to promote high-quality, efficient care throughout Medicaid. Some parts of the law already apply to all Texans served in Star+Plus, not just people with IDD. Since the full redesign and roll out of SB7 will happen gradually through 2020, Texas will have the opportunity to evaluate and adjust for the inclusion of children and adults with TBI.

SB 7 requires the development of new outcome measures and incentives to improve the quality of services and reduce “potentially preventable events,” such as institutionalization or hospitalization. Local mental health authorities (LMHAs) were given permission to expand their services to include those with conditions not currently covered, such as depression, anxiety and post-traumatic stress. These disorders and others occur frequently after a TBI.⁴⁵ Access to community mental health services will help address potentially preventable events in individuals with brain injury.

Experts say that adults with TBI who walk, talk, and look “normal” are refused services even though they cannot maintain themselves in the community without help.⁴⁶ These individuals frequently do not qualify for Medicaid waiver services under programs for individuals with physical disabilities because they have little to no difficulty in bathing, dressing, eating, or other activities of daily living (ADLs) used to assess disability. The ADLs that people with a TBI need support with more often fall into executive function and behavioral supports. We can effectively support TBI survivors to live in their communities with specially trained providers, as we do for other complex disabilities.

Another concern is individuals with brain injury who might have the opportunity to have necessary supports to maintain a job, often do not because they are fearful their earnings will disqualify them for Social Security Income (SSI).

Families of individuals with TBI seek housing supports that are not currently available to them. SB7 includes a requirement to explore flexible, low-cost housing options for individuals with all types of disabilities in rural and urban areas that will provide the continuum of integration from most to least restrictive appropriate to the individual’s needs and preferences. SB7 requires DADS, in cooperation with Texas Department of Housing and Community Affairs and Texas State Affordable Housing Corporation to develop a process to receive input from statewide stakeholders to ensure the most comprehensive review of the opportunities and options available. Texas needs to make sure the brain injury community has a seat at the table in exploration of housing and all other areas of evaluation and implementation of SB7.

Finally, a new opportunity for Texas in long-term services and supports is the “Community First Choice Option” that will allow us to provide home and community-based attendant and habilitation services to Medicaid enrollees with disabilities under our Medicaid State Plan instead of having to rely solely on Medicaid waivers. People with traumatic brain injuries should have access to this tremendous opportunity.

Next Steps

- Add CRT to the Medicaid state plan so that all individuals on Medicaid with a brain injury, can have access to the cognitive support needed to achieve maximum independence.
 - Implement a Medicaid LTSS provider specialization for traumatic brain injury in long-term services and supports coupled with a quality-based rate incentive. Consideration might be given to CARF Brain Injury Specialty Accreditation.
 - Add individuals with and family members of an individual with a TBI to the Medical Care Advisory Committee.
 - Ensure that any assessment protocols approved for use in the Star+Plus system are designed to fairly evaluate the needs of a person with a TBI or co-occurring mental or behavioral health disorders to implement protocols to ensure equity in the services approved for individuals with similar needs, like those with TBI or IDD.

How One Dallas Family Struggled 6 Years Against a Broken Provider System Seeking TBI Care for Cody

The following true story is an example of the difficulty many families face after their loved one sustains an Acquired Brain Injury (ABI). It illustrates lack of compliance by insurance companies to the ABI law, the struggles families face to find needed resources, the need for long-term services and supports for individuals with brain injury to include special ABI brain injury training and accreditation by any service provider who works with individuals with ABI, and appropriate provider reimbursement rates to ensure the safety and health of patients.

This is a story of great family courage, and advocacy to help their son live with the greatest quality of life possible, and the extreme toll placed on families that have primary responsibility for care over a long period of time.

Joe and Cindy Derrick's son, Cody, 32, suffered a severe Traumatic Brain Injury (TBI) November 19, 2006, resulting from an automobile accident in Houston, Texas.

Cody lay in a coma for 30 days, and endured a complicated medical recovery that included intubation, shunt, tube, and bifrontal craniotomy. Cody presented with significant cognitive, physical, and behavioral impairments, and minimal ability to complete basic activities of daily living. Cody was discharged from Ben Taub Hospital and admitted to Life Care Hospital in Plano in early January, 2007, where he remained for a month. Cody was next admitted to the Baylor Institute for Rehabilitation, an Inpatient Acute Rehabilitation Hospital in Dallas in February, 2007, followed by admission in March, 2007, to Pate Rehabilitation, a post-acute brain injury rehabilitation facility in Anna, Texas.

Even though state law, enacted through House Bill 1676 with an effective date of January, 2002, requires health insurance to provide benefits for cognitive rehabilitation, Cody was denied insurance benefits for continued treatment within a few weeks of admission to Pate. The insurance company informed Joe and Cindy that Cody had used his 60 benefit days for rehabilitation and that he was not making adequate progress, even though the physician and the rehabilitation team documented medical necessity and progress.

The Derricks filed a complaint with the Texas Department of Insurance, based on lack of compliance with Chapter 1352, Brain Injury Insurance Code. Joe Derrick wrote letters advocating for Cody's continued rehabilitation to President George Bush and First Lady Laura Bush, Vice President Richard Cheney, Lynne Cheney, U.S. Cabinet Members, U.S. senators and representatives, media executives, Governor Rick Perry and Texas senators and representative, including Senator Chris Harris, who contacted Senator Todd Smith, and Representative Burt Solomons, who contacted TDI on behalf of the family. In spite of their efforts, the insurance decision stood, and in April 2007, Cody was discharged from the post-acute brain injury rehabilitation facility where he was making slow but steady gains.

Upon discharge, Cody was admitted to a nursing home. The Derricks stated they did not want to place Cody in a nursing home but at the time of his forced discharge from the rehabilitation facility, Cody was not at a level where they could care for him at home. They also learned that to

qualify for Medicaid, Cody would need to stay in a nursing home for six months. Cody no longer had insurance and the family was grateful for the possibility of Medicaid to help Cody. They had a few bad experiences in and out of nursing homes; however, after a considerable search Cody was admitted to a nursing home that he ultimately was able to stay for six months. Joe stated that the home was “fancy on the outside” but they quickly learned that that did not equate to quality care and a safe living environment.

Joe and Cindy said, “This is when we first began to understand the dangers of placing Cody in a level of care where staff were not equipped to address the special needs of someone with a brain injury and the high staff-to-patient ratios made it impossible for Cody to receive the 1-to-1 attention he needed to be safe.”

When Cody was discharged from Pate, his medications were regulated and Cody was alert. Cody’s TBI had caused him to exhibit aggressive behavior, inappropriate sexual behavior, impulsivity, problems with memory, judgment, problem-solving, visual problems and problems sleeping through the night. Cody would wake up and wander into other patients’ rooms in the nursing home. The nursing home director contacted the Derricks to advise them he could not allow Cody to wander into other patients’ rooms and that he would have to increase Cody’s medication. The Derricks were sympathetic to the fear that Cody’s wandering created for the other patients. Unfortunately, they did not foresee the negative impact the dosage change would have on Cody. Joe reported, “Cody became barely responsive, often times with his head lying on his plate when we would visit at dinner time.” The Derricks had bought Cody a bed alarm and a wheelchair alarm at the time of admission; however, there were not enough staff to check on Cody if the alarm went off, nor were staff trained to help redirect Cody. As a result, staff did not use the alarms. The Derricks realized early on they would need to be heavily involved at the nursing home for Cody to stay safe. They then committed to visiting him once or twice daily.

Cody was on a modified soft diet and they knew if this diet was not followed Cody could choke to death. They visited him at meal time and always found Cody sitting alone, typically with his head in a plate of food that he was not allowed to eat, such as chicken, bread and crackers. The Derricks would talk to dietary staff. Even though staff was aware of his special diet needs, they did not follow it. There weren’t enough staff to assist Cody with eating. Other times his parents would visit and find Cody sitting in urine. The Derricks took on the task of regularly bathing him to ensure he was clean and thereby decrease the chance of skin breakdown.

Cody remained in the nursing home for six months thereby qualifying for Medicaid.

Following Cody’s discharge from the nursing facility, in September, 2008, he moved to an ALF. Even though the Derricks hoped for the best, they knew it would be difficult for Cody to receive appropriate care at the ALF. The facility had only two staff for 14 clients, and staff responsibilities included laundry and meal preparation. The Derricks talked to the staff to try to educate them about TBI and help them understand how to best take care of Cody. They discovered that the other individuals were more independent than Cody, could follow instructions and eat on their own. For example Cindy said, “Staff would tell the other residents to get in the shower and staff could come back later to check on them.” The other residents could follow staff instructions and be okay. When left on his own in the shower, Cindy said “Cody

would drink the shampoo.” Although, the ALF was about an hour away, the Derricks went several times a week to ensure Cody’s safety.

Several weeks after Cody moved to the ALF, Joe received a phone call in the middle of the night from police. The police, who had been called by facility staff, gave Joe and Cindy the option to have Cody go to jail or to be admitted to Parkland Psychiatric Emergency Room. The Derricks’ requested the police to take Cody to Parkland Psychiatric Emergency Department. The staff at Parkland, told the Derricks that Cody had a traumatic brain injury and was not appropriate for services through “MHMR.”

Following his discharge from Parkland at the end of September, 2008, the Derricks returned home with Cody where he stayed for the next four years.

During that time, Cody received services through the Department of Aging and Disability Services (DADS). The Derricks stated, “we don’t know how we would have survived without DADS assistance”. Through DADS, Cody qualified for 50 hours per week of personal attendant services from a home health agency but the journey continued to be difficult. Attendants did not have special training in brain injury. They did not know how to approach Cody to help him engage in meaningful activities. The Derricks also had issues with attendants falsifying records, stealing, arriving late and leaving early. Although the agency would respond by sending a different attendant, these factors caused the Derricks to fear for Cody’s safety.

Despite the growing list of obstacles on Cody’s journey, 2012 proved to be yet another pivotal point. Cindy was experiencing burn out and Joe’s health was deteriorating. Joe’s doctor told Joe they had to stop caring for Cody on a full time basis. They feared the only option for permanent placement would be a nursing home with a locked unit to keep Cody from leaving. They found an Alzheimer’s nursing home facility that accepted Medicaid. But Joe stated they didn’t want Cody to go there because, “a nursing home is a place where old people go to die.” They also still had bad memories from their previous nursing home experiences.

In 2012, during a visit by the DADS case manager who likely saw the extreme stress the Derricks were under, the case manager suggested they access respite care. The Derricks said they were not aware that respite was an option. They felt great relief in learning it was available to them, but at the same time wondered whether their lives would have deteriorated so much had they known about option for respite years earlier.

At this point, Cody was cooperative, and his medications were being regulated by a neurologist, but the family continued to struggle to find a neurologist or primary care physician, who would accept Medicaid. Cody continued to exhibit severe cognitive impairments with memory, problem solving, judgment, vision and impulsivity. He also had problems sleeping through the night, and when he would wake, if unsupervised, he would wander.

The respite provider wanted to send a nurse to their home for the weekend; however, the Derricks wanted some time at home alone. It was difficult to find a setting that would take Cody for a respite weekend; however, they did find an ALF in Grand Prairie. Joe and Cindy were hopeful because the owner of the facility was a physical therapist. The Derricks placed Cody

there initially for respite care over two weekends. Although Joe and Cindy had some reservations, in November 2012, they moved Cody to the ALF where he had received respite.

After Cody was admitted, the nightmare unfolded. The Derricks feared for Cody's safety and once again took it upon themselves to make daily visits to try to help with some of the issues they saw at the facility. Joe said that Cody developed skin problems because of the inadequate number of trained staff, preventing appropriate care for Cody and poor nutrition. Cindy added, "There was very little food in the home. The residents' main source of nutrition came from sandwiches. They never had any fresh vegetables or fruits." There was only one staff available per shift. The Derricks noted the appliances were old and did not work well. When they visited they found dishes piled up and the residents often did not have clean clothes to wear. When Joe and Cindy visited on one particular Friday, Joe recalled the refrigerator had gone out and the owner had instructed the staff that they would have to do without one. Joe bought a refrigerator and had it delivered the same day.

Joe and Cindy were also concerned that Cody was unable to engage in any quality-of-life activities. After Cody first moved to the ALF, he received physical and speech therapy visits from an onsite home health agency but those stopped soon after. The Derricks agreed, "The staff used the television as a babysitter for Cody. He spent never ending days sitting in front of the TV."

On August 19, 2013, Joe and Cindy's life changed forever. Joe received a phone call from staff at the ALF that Cody had been missing for eight hours. There was no real explanation of how or why Cody wandered off at about 2 a.m., or why the Derricks had not been contacted sooner.

The police were notified and they searched for Cody until the next morning.

Joe explained to the police that Cody had a TBI. Joe was able to get the police to use search dogs. Meanwhile, Cindy stayed at home, preparing clothes to go to the hospital. She believed Cody would be found, taken to the hospital and that she would need to be with him.

Cody was not found until September 21, 2013, when by chance someone came upon his body. The Derricks find some peace in the belief that perhaps Cody had a seizure and died peacefully in his sleep.

Grand Prairie police looking for 38-year-old man who walked away from group home

By Bill Miller

wmiller@star-telegram.com

Authorities resumed their search Thursday morning for a missing 38-year-old man who has a brain injury and walked away from a group home in Grand Prairie early Wednesday.

Police were called to the home in the 2900 block of Volturno Drive at 1:30 a.m. Wednesday. The neighborhood is near the west shore of Joe Pool Lake.

They were told that Cody Derrick walked away in his pajamas and had not returned, said Detective Lyle Gensler, a police spokesman.

"Mr. Derrick is a resident at the group home due to a brain injury from an accident," Gensler said. "He suffers memory loss and has unsteady balance."



Cody Derrick

Derrick is white with black hair and brown eyes. He is 5 feet 10 inches tall and weighs 170 pounds.

"He was last seen wearing a yellow shirt and blue-and-white pajama pants," Gensler said.

Anyone who sees him should call police at 972-237-8877, Gensler said.

Bill Miller, 817-390-7684 Twitter: @Bill_MillerST

Appendix I - Texas Brain Injury Advisory Council

The TBIAC membership includes 22 persons located throughout the state of Texas and consisting of the following:

- 8 public consumers (including at least 3 persons with TBI and 3 family members of persons with TBI)
- 6 professional members (acute trauma, acute or post-acute rehabilitation, NIDRR TBI Model System, community based services, higher education, and provider of OT/PT or cognitive rehabilitation.)
- 8 Representatives from Texas State Agencies including:
 - DSHS
 - DADS
 - DARS
 - HHSC
 - TEA
 - TCDD
 - TDI

Public Consumer Members as of September 2014			
Position	Name	Hometown	Term Expiration
Survivor	Sean Carter	Dallas	2017
Survivor	Tam Harwell	Conroe	2015
Survivor	Cheryl Kempf	Bulverde	2017
Family Member	Rose Pelzel	San Angelo	2017
Family Member	Sonia Quintero	Edinburg	2015
Family Member	William (Bill) Roof	Round Rock	2019
Family Member	Bennie Jo (BJ) Wagner	Liberty Hill	2019
Family Member	Larry Swift	Austin	2017

Professional Members			
Company	Name	Hometown	Term Expiration
Community-Based Services	Regina Blye	Austin	2019
Provider	Jane Boutte, M.A.	Dallas	2019
NIDDR TBI Model Systems	Lynne C. Davis, Ph.D.	Houston	2017
Acute Hospital Trauma Unit	Nilda M. Garcia, M.D., FACS	Austin	2015
Acute Rehabilitation Facilities	Wendy Goodwin, M.D.	Dallas	2017
**Faculties of Institutions of Higher Education	Open for Applications/Nominations		2015

State Agency Members			
Agency	Name	Hometown	Term Expiration
Texas Council for Developmental Disabilities	Belinda Carlton	Austin	*
Texas Department of Insurance	Debra Diaz-Lara	Austin	*
Texas Department of Aging and Disability Services (DADS)	Corliss Powell	Austin	*
Texas Education Agency	Barbara Kaatz	Austin	*
Texas Department of State Health Services (DSHS)	John Villanacci, Ph.D.	Austin	*
Texas Health and Human Services Commission	Nancy Walker	Austin	*

*State agency members' terms have no set expiration

Appendix II - TBIAC and OABI Initiatives And Publications

1999

- A Policy Analysis
- Needs Assessment Report
- A Summary of the Gaps in Services
- Statewide Action Plan of Supports & Services

2001

- White Paper: Putting the Pieces Together

2003

- Concussion Cards for Adults and Concussion Cards for Children (**English and Spanish**).

2005

- General Pamphlet # 6-320 August 2005 "Important First Steps in Supporting a Loved One with a Brain Injury" (**English and Spanish**).

2006

- Report to the Governor
- White Paper: Acquired Brain Injury & long-term Care in Texas
- Sunset Advisory Commission: Study of Health Benefit Plan Coverage for Brain Injuries
- HB1919 Brochure: Insurance Coverage Requirements for Post-Acute Care and Cognitive Rehabilitation (**English and Spanish**)

2007

- Report to the Governor
- DVD – Making a Difference: Meeting the Special Needs of Individuals with Brain Injury.

2008

- Needs and Resources Assessment Report

2009

- Feasibility Study for Providing Community Support & Residential Services for Individuals With Acquired Brain Injury
- DVD – Una Fuerza Positiva: Como Satisfacer Las Necesidades Especiales de Personas con Lesión Cerebral
- Texas Juvenile Screening Project

2010

- Brain Injury Survivor Wallet ID Card (**English and Spanish**)
- Brain Injury Handbook for Disaster, Preparedness and Response Management Teams and Brain Injury Survivors, Family Members and Caregivers.

2011

- The OABI and the Texas State Athletic Trainers' Association began the Texas Sports Concussion Partnership

2012

- Traumatic Brain Injury Resource Document: Re-Entry of Students with a TBI to the School Setting

2013

- Veteran Tactical Response: Keeping Police Officers and Veterans Safe. A Law Enforcement and First Responder Guide to Working with Veterans with TBI, PTSD and Homelessness (developed through the Office of Acquired Brain Injury)
- Addition of CRT to existing Medicaid Waiver
- Brain Injury Educational Summit

Appendix III - Acronyms

AANS–	American Association of Neurological Surgeons
ABI–	Acquired Brain Injury
ADL–	Activities of Daily Living
ADHD –	Attention Deficit Hyperactivity Disorder
AIDS –	Acquired Immunodeficiency Syndrome
ALF –	Assisted Living Facility
APD –	Austin Police Department
AHT –	Abusive Head Trauma
BI –	Brain Injury
BIAA –	Brain Injury Association of America
BISQ –	Brain Injury Screening Questionnaire
CARF –	Commission on Accreditation of Rehabilitation Facilities
CDC –	Center for Disease Control
CLASS –	Community Living Assistance and Support Services
CM –	Case Manager
CP –	Community Participation
CPR –	Cardiopulmonary Resuscitation
CPSC-US –	United States Consumer Product Safety Commission
CRT –	Cognitive Rehabilitation Treatment
CVD –	Cardiovascular Disease
DADS –	Department of Aging and Disability Services
DARS –	Department of Assistive and Rehabilitative Services
DIR -	Texas Department of Information Resources
DPS –	Department of Public Safety
DSHS –	Department of State Health Services
ED –	Emergency Department
EMS –	Emergency Medical Services
FTE-	Full Time Employee
FY –	Fiscal Year
HCS –	Home and Community-based Services
HHSC –	Health and Human Services
HIV –	Human Immunodeficiency Virus
HRSA –	Health Resources Services Administration
LAR –	Legislative Appropriations Request
LTAC –	Long-Term Acute Care
LMHA –	Local Mental Health Authorities

MD –	Medical Doctor
MSKTC –	Model System Knowledge Translation Center
MOA –	Memorandum of Agreement
NEISS –	National Electronic Injury Surveillance System
NIDRR –	National Institute on Disability and Rehabilitation Research
OABI –	Office of Acquired Brain Injury
ODG –	Official Disability Guidelines
OEF –	Operation Enduring Freedom
OIF –	Operation Iraqi Freedom
PE –	Physical Education
PTSD –	Post Traumatic Stress Disorder
RF –	Resource Facilitation
SCI –	Spinal Cord Injury
SBS –	Shaken Baby Syndrome
SSI –	Social Security Income
TBI –	Traumatic Brain Injury
TBIAC –	Texas Brain Injury Advisory Council
TCDD –	Texas Council for Developmental Disabilities
TDI –	Texas Department of Insurance
TEA –	Texas Education Agency
TJJJ –	Texas Juvenile Justice Division
TWCC –	Texas Workers' Compensation Commission
US –	United States
VA –	US Department of Veterans' Affairs
VA/VRI –	US Department of Veterans' Affairs Vocational Rehabilitation
WHO –	World Health Organization

Appendix IV – Continuum of Care Definitions

ACUTE CARE

The health system components, or medical management and intervention delivery platforms used to treat individuals with brain injury.

Includes: Emergency Evaluation, Emergency Department, Intensive Care Unit, and Medical Care Hospital Unit: Specialty Neurotrauma, Multi-Trauma.

Comprehensive Inpatient Acute Rehabilitation or Acute Rehabilitation

As individuals with brain injury become medical stable they are often transferred to a hospital or a hospital unit which provides comprehensive integrated rehabilitation therapies and medical services. Patients require a physician or nursing oversight 24 hours per day, seven days per week. Patients must be able to participate 1 to 3 hours of rehabilitation per day and must show continued signs of improvement.

Long Term Acute Care (LTAC)

Individuals with brain injury who are unable to participate in intensive acute or post-acute rehabilitation may require specialized-care service including skilled-nursing to manage medical conditions and progress toward full rehabilitation. Average length of stay is generally 25 days.

POST-ACUTE REHABILITATION

This describes an array of programs typically accessed by individuals with brain injury after they have completed acute rehabilitation. Post-acute rehabilitation programs are described below.

Residential Transitional Rehabilitation

This level of care is utilized for medically, cognitively, or behaviorally complex patients, or in cases where the patient's safety is at risk. Post-acute residential transitional rehabilitation provides intensive medical rehabilitation treatment and disease management services following brain injury and delivered 24-hours per day, seven days per week.

Admission may follow acute hospitalization, acute rehabilitation, psychiatric hospitalization, skilled nursing, nursing home, long-term acute care, or home.

The needs of the patient determine the interdisciplinary team of specialists which may include: behavioral psychology, behavioral analysis, case management, physical therapy, occupational therapy, speech-language pathology, educational therapy, counseling, clinical psychology, neuropsychology, social work, nursing, neurology, neurosurgery, physiatry, psychiatry, ophthalmology, neuro-ophthalmology, optometry, orthopedics, endocrinology, internal medicine, family practice, recreational, psychological, neurobehavioral and vocational therapy. These services are necessary to normalize medical function, minimize or prevent medical complications and re-hospitalization, restore independent living skills function, maximize disability reduction, and enable return to work or school.

Day Neuro Treatment/ Day Treatment

Day Treatment provides 4 to 6 hours, five days per week, of allied health services for medical treatment, medical rehabilitation and disease management following brain injury. Day treatment typically follows transitional residential rehabilitation.

Patients receive a decreased intensity of services than while participating in post-acute transitional residential level of care; however, the complexity and integration of the highly specialized treatment team often remains similar to that required at the transitional residential level. However, the program does not provide the intense coordination of medical services, and the same level of endurance building, monitoring and assistance to insure compliance, and the ability to evaluate the impact of fatigue on cognitive ability, behavioral control, and functional performance.

Outpatient Rehabilitation

Outpatient Treatment, is more traditional therapy often used with orthopedic injuries, and some ongoing neurological injuries. Brain injury outpatient services provides the least intensive treatment at 1 to 3 hours per day, one to five days per week. Outpatient Treatment usually follows the continuum of Post-Acute Transitional Residential Rehabilitation or Day Treatment. Typically, outpatient treatment requires one or more of the following disciplines: physical therapy, occupational therapy, speech/language therapy, neuropsychology, medicine, and case management.

Home and Community Based Programs

These services, also referred to as Community Integration Programs are provided in an individual's home and/or community settings and may be delivered as a separate service or in conjunction with post-acute residential transitional rehabilitation. Home and community-based services are designed to maximize the transition and generalization of skills and behaviors from facility settings to application and assimilation in the community.

Commission for Accreditation of Rehabilitation Facilities (CARF) provides a specialty brain injury accreditation for such programs, however these programs are not readily available for individuals with brain injury in Texas due to lack of funding.

Home Health Care

Services provided to assist the patient in their home. The skilled services are brief, usually not more than 3 to 4 hours a day, and intermittent, and may include such services as nursing, aids, physical therapy, speech therapy, occupational therapy.

Long-Term Residential Programs

Individuals with moderate/severe TBI may require long-term residential care due to behavioral, physical, or cognitive issues impacting their ability to be safe in a less restricted environment. Other factors further post injury that may necessitate the need for a long-term residential program may include the aging process, loss of a caregiver, becoming unsafe in their environment or other similar changes. Such programs provide necessary supervisory support and quality of life engagement activities to safely maintain his/her maximum level of function with the least restrictive environment possible.

These specialty programs are typically offered in Texas at CARF-accredited Specialty Brain Injury ALFs. Unfortunately, individuals with ABI have limited access in Texas to such programs, due to funding issues. These programs may be covered on a case-by-case basis through Workers' Compensation; however, this level of care is not listed in the Texas Workers' Comp Official Disability Guidelines.

Supported Living Programs

These programs provide comprehensive habilitation services designed to support individuals with brain injury in their communities. Individuals receive support in their own home to help them remain as independent as possible. Supports may range in hours and intensity, and minimal services such as home checks to ensure safe appropriate medication administration to supported employment. Supported employment programs may require a licensed vocational counselor, or certified vocational specialist to provide assistance as needed in the workplace.

Day Habilitation Programs

Comprehensive structured day activities and community integration provide up to 8 hours per day.

Sub-acute/Skilled Nursing Facility (SNF)

Individuals appropriate for SNF require nursing care or are judged not to be able to benefit from more intense rehabilitation. A skilled nursing facility is also referred to as a “nursing home” recognized as a facility to meet the long-term health care needs for individuals who have the potential to function independently after a limited period of care.

Subacute Rehabilitation Program

Specialty licensed units of a hospital or nursing home. Individuals typically are medically stable, require skilled nursing care, and have either completed comprehensive inpatient rehabilitation, or are judged to not be able to benefit from inpatient rehabilitation.

Endnotes

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