

**Report of the Texas Traumatic Brain Injury Advisory Council  
Presented to the Governor, Lieutenant Governor,  
and Speaker of the Texas House of Representatives  
October 2007**

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.

# Traumatic Brain Injury in Texas

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## **A Note About Terminology**

Traumatic brain injury (TBI) is an insult to the brain, not of a degenerative or congenital nature, caused by an external physical force that may produce a diminished or altered state of consciousness resulting in an impairment of cognitive abilities or physical functioning. Profound disturbances of cognitive, emotional, and behavior functioning after TBI may produce permanent impairments that result in partial or total functional disability and psychosocial maladjustment.

There are three generally acknowledged levels of severity of TBI:

**Mild traumatic brain injury** is a trauma to the head that results in a confused state or a loss of consciousness of less than 30 minutes, the initial Glasgow Coma Scale of 13 - 15, and posttraumatic amnesia lasts less than 24 hours.

**Moderate traumatic brain injury** is a trauma to the head that results in a loss of consciousness of 30 minutes to 24 hours, an initial Glasgow Coma Scale of 9 - 12. Posttraumatic amnesia can last 24 hours to seven days.

**Severe traumatic brain injury** is a trauma to the head that results in a loss of consciousness of greater than 24 hours, an initial Glasgow Coma Scale of 3 - 8, and a posttraumatic amnesia period of greater than seven days.

Definition of Brain Injury

(<http://www.neuroskills.com/edu/ceuoverview2.shtml>)

## Executive Summary

By the year 2020, brain injury is expected to be the number one public health problem in the world. Due to the life saving techniques of modern medicine, there is a large and growing population of individuals with brain injury. It is estimated that over five million Americans currently have a long-term or life-long need for help in performing activities of daily living as a result of traumatic brain injury (TBI), the most common cause of brain injury. In Texas it is estimated that 144,000 individuals sustain a TBI each year, and as of 2007, approximately 479,000 Texans were living with TBI-related disabilities.

The lifetime medical and work loss costs associated with TBI-related hospitalizations are astronomical. In Texas these costs exceed one billion dollars each year. The annual medical costs and lost productivity costs of TBI in the U.S. total an estimated \$60 billion.

While the current situation seems overwhelming, there is good news for Texas. Through the collaboration of the Traumatic Brain Injury Advisory Council (TBIAC) members, a number of educational products have been developed and printed through grants received from the Health Resources and Services Administration (HRSA). In particular, the TBIAC *Concussion Cards* provide important information on procedures to follow when an adult or child has a concussion. The Council has also produced a number of papers (available on the website) including one on veterans' issues entitled, *Report to the Deputy Commissioner, Texas Health and Human Services Commission: Traumatic Brain Injury and Operations Iraqi and Enduring Freedom: Implications for Healthcare in Texas* dated January 2007.

One of the major objectives of the current TBI grant awarded to the Department of State Health Services (DSHS) from HRSA is the development and distribution of an electronic training module entitled "Meeting the Special Needs of Individuals with Brain Injury" for the front-line staff of 2-1-1 Texas, the state-wide information and referral network for health and human services. The training, developed by the TBIAC, includes a section that addresses the special needs of veterans with TBI, and will be available in digital video disc (DVD) format and on the website. The training will be distributed in late 2007. The training module may also be used to inform other health care professionals, educators, policy makers, family members, friends and brain injury survivors.

Another significant accomplishment for the TBIAC was the passage of House Bill 1919 (HB 1919) during the 80<sup>th</sup> Texas Legislature, 2007. The bill, effective September 1, 2007, expanded the covered population to include state employees and requires that insurers send written notification of the mandated cognitive rehabilitation benefit to those insured.

In 2007, the Legislature also authorized the establishment of an Office of Brain Injury to assist and coordinate services for persons with acquired brain injury (ABI), including TBI. It is expected that the office will be set up in 2008.

Further good news for Texas was announced in September 2007. The Department of Veterans Affairs plans to build a trauma facility designed to help patients with multiple serious injuries in San Antonio.

While the activities and accomplishments of the TBIAC during 2006-2007, with the help of DSHS and many other partners, provide hope for the future of Texans with brain injury, there remain multiple challenges that must be addressed.

A primary unmet need for persons with brain injury is for information about necessary services and how to access them. In Texas there are many gaps in the public services available to individuals with brain injury. In many cases the services and supports needed are unavailable, unidentified, or non-existent. Exacerbating the problem of scarce resources is the fact that there is no central system available to make appropriate referrals for individuals with brain injury.

Receiving the appropriate cognitive rehabilitation services at the right time in recovery can make the difference between a person returning to a functional life in the community or becoming dependent on others or the state. The goal for each individual with TBI is to return to independent living to work, to school, and/or to care for their family. In reality, only five percent of persons with TBI receive the rehabilitation services necessary for maximum recovery.

Utilizing a dedicated trust fund for brain and spinal cord injury rehabilitation totaling approximately \$10 million per year, the Department of Assistive and Rehabilitative Services (DARS) provides short-term (six months) comprehensive rehabilitation services (CRS). While the CRS program provides needed support, six months is grossly inadequate for individuals with severe brain injuries who may need years of rehabilitation. An additional issue is that once persons are discharged from the CRS program there is no follow-up case management or systematic way to link the individual or their families with other services. In addition, the CRS program serves fewer than 500 individuals each year.

Another issue is the lack of Medicaid waiver services in Texas for individuals who were injured as adults. The current care option is a nursing home. With waiver services, such individuals would be able to live in the community with supports. Medicaid waivers for brain injury programs are currently expanding in other states, a trend that will hopefully continue as policymakers become more aware of the utility and cost-effectiveness of long-term community-based care. Also, funding is typically not available to provide the structured settings and professional supports needed to properly manage brain injury patients with behavioral problems.

There are growing concerns about our brain-injured troops and those with undiagnosed TBIs. The influx of returning servicemen and women and veterans with TBI will only add to the demands on an already overburdened system. If current trends continue, over half of all injured soldiers will have a brain-related injury. The problem is further compounded by the added components of poly-trauma (amputations and other coexisting traumatic injuries), post-traumatic stress disorder, and/or misdiagnosis. Given the large number of Texans who are in the military (1 in 4 enlistees are from Texas), these findings pose a significant concern regarding accessibility to limited state and Veterans Administration (VA) health services.

The TBIAC recommends that Medicaid waiver programs, along with eligibility requirements, both be amended to meet the wide array of needs of individuals with brain injury. If federal waiver rules preclude amending current waivers, the addition of a brain injury waiver should be considered. Furthermore, sufficient funds must be allocated to accommodate interest lists for services. A pilot study of group homes for individuals with brain injury is also needed. Such a pilot should be based on the concept of least restrictive environment and should seek to maximize the independence of the residents, as well as meet their social needs.

Many other issues identified by the TBIAC need to be addressed, such as: prevention; meeting the needs of children with brain injury; the relationship of brain injury to homelessness; jail diversion for inmates and veterans with brain injury; involving family and care givers in rehabilitation; providing support for family members and care givers and appropriate training on brain injury for health and human service professionals.

In summary, Texas is making progress toward the goal of recognizing brain injury as a major public health problem; however, multiple challenges remain.

# Traumatic Brain Injury in Texas

## Introduction

By the year 2020, traumatic brain injury (TBI), the most common cause of brain injury, is expected to be the number one public health problem in the world.<sup>1</sup> As emphasized in the 2006 report of the Texas Traumatic Brain Injury Advisory Council (TBIAC), 35 years ago 50 percent of all people who sustained a TBI died. That number has been greatly reduced due to the life saving techniques of modern medicine resulting in a large and growing population of TBI survivors, many facing life-long needs for support.

According to the Centers for Disease Control and Prevention (CDC), an estimated 1.4 million people sustain a TBI each year in the United States. Of those, 50,000 die, 235,000 are hospitalized, and 1.1 million are treated and released from an emergency department. Of the 235,000 hospitalizations for TBI in the U.S. each year, it is estimated that 62,000 (26 percent) occur among children and youth aged 0-19 years (J. Langlois, personal communication, February 6, 2006).<sup>2</sup> In fact, TBI is the leading cause of death and disability in children and young adults.<sup>3</sup> Studies indicate that brain injuries are far more frequent among men than women. By age 16, about 4 out of every 100 boys and 2.5 out of every 100 girls have sustained a TBI.<sup>4</sup>

Following is a comparison of the annual incidence of TBI and other leading injuries or diseases.<sup>5</sup>

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<sup>1</sup> Zitnay, George (2007). *Survive, Thrive, & Alive! Understanding Traumatic Brain Injury, Revised* (DVD). Office of Education Programs, Defense and Veterans Brain Injury Center. DVBIC Headquarters, Walter Reed Army Medical Center, Washington, D.C.: Group Pictures.

<sup>2</sup> Extrapolated by Centers for Disease Control and Prevention based on data from Langlois, J.A., Rutland-Brown, W. & Thomas, K.E. (2004). Traumatic brain injury in the United States: Emergency department visits, hospitalizations, and death. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; Kegler, S., Coronado, V., Anest, J. & Thurman, D. (2003) Estimating nonfatal traumatic brain injury hospitalizations using an urban/rural index. *Journal of Head Trauma Rehabilitation*, 18(6), 469-78; Pacific Institute for Research and Evaluation (2004). Unpublished data.

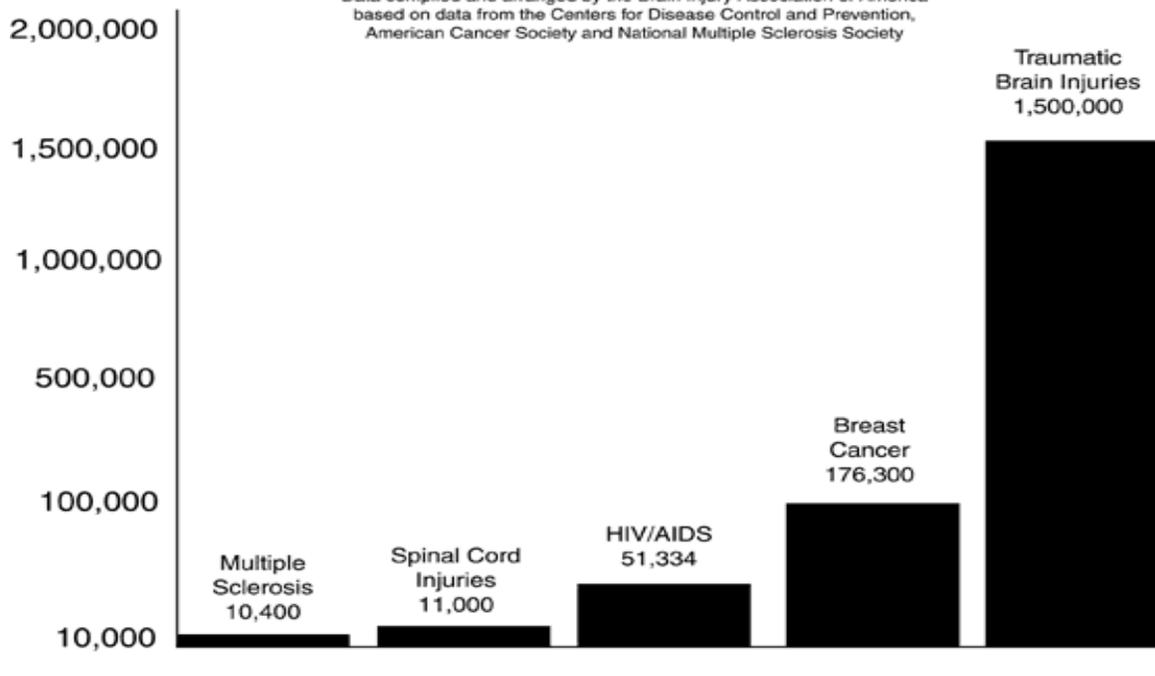
<sup>3</sup> Centers for Disease Control and Prevention, National Center for Injury Prevention and Control (1999, December). *Traumatic Brain Injury in the United States: A Report to Congress*. Retrieved October 3, 2007, from the Centers for Disease Control and Prevention website at [http://www.cdc.gov/80/ncipc/tbi/tbi\\_congress/01\\_executive\\_summary.htm](http://www.cdc.gov/80/ncipc/tbi/tbi_congress/01_executive_summary.htm)

<sup>4</sup> Christensen, JR. *What is Traumatic Brain Injury?* in *Children with Traumatic Brain Injury: A Parent's Guide*, Schoenbrodt, L. (Ed). New York: Woodbine House, 2001

<sup>5</sup> Brain Injury Association of America (2001, March). *TBI Incidence*. Retrieved September 17, 2007, from the Brain Injury Association of America website at <http://www.biausa.org/word.files.to.pdf/good.pdfs/2002.Fact.Sheet.tbi.incidence.pdf>

## Comparison of Annual Incidence

Data compiled and arranged by the Brain Injury Association of America based on data from the Centers for Disease Control and Prevention, American Cancer Society and National Multiple Sclerosis Society



In 1999 the CDC reported to Congress that 2 percent of the nation's population was living with TBI-related *disabilities*.<sup>6</sup> In 2000, the total number of new disabilities from brain injuries was approximately 98,560, a rate of 35 per 100,000 population.<sup>7</sup>

### Effects of Brain Injury

The consequences of brain injury are myriad. Subsequent to an injury to the brain, an individual may experience problems in multiple domains: physical (e.g., mobility, vision, sleep, etc.), language (e.g., speaking and/or understanding language), cognitive (e.g., memory, problem solving, organization, attention, etc.), behavioral-emotional (e.g., control of impulses, initiating activity, controlling mood, controlling temper/handling frustration, paranoia, etc.), or psychosocial (e.g., getting along with others, inhibiting inappropriate sexual behavior, social judgment, inhibiting impulses to steal, compliment, and insult. See Appendix I). Changes may vary from one person to the next depending upon the nature of the injury or the part of the brain that was damaged. Some may recover physically and may look normal. However, cognitive and emotional/behavioral or psychosocial changes may severely impact the individual's ability to perform

<sup>6</sup> Thurman, D.J., Alverson, C., Browne, D. et al. (1999/2005). *Traumatic brain injury in the United States: A report to Congress*. Centers for Disease Control and Prevention. Information obtained from J.M. Silver, T.W. McAllister, & S.C. Yudofsky (Eds.) *Textbook of traumatic brain injury* (p.7). Washington, D.C.: American Psychiatric Publishing, Inc.

<sup>7</sup> Kraus, J.F., Chu, L.D. (2005). Epidemiology. In J.M. Silver, T.W. McAllister, & S.C. Yudofsky (Eds.) *Textbook of traumatic brain injury*. Washington, D.C.: American Psychiatric Publishing, Inc.

activities of daily living, return to work, and function in the community. As might be expected, many frequent the psychiatric hospital setting at a high expense, as well as other state-funded institutions. Many, who could be healthy and productive given the appropriate level of care, accrue unnecessary medical costs.

While the injury may be mild, moderate or severe, the impact is often associated with exorbitant costs and is felt within the family, the school, the workplace, and the community (including the healthcare and criminal justice systems).

The CDC estimates that at least 5.3 million Americans currently have a long-term or life-long need for help in performing activities of daily living as a result of TBI.<sup>8</sup> TBI can also cause epilepsy and increase the risk for conditions such as Alzheimer's disease, Parkinson's disease, and other brain disorders that become more prevalent with age.<sup>9</sup>

## **Economic Impact**

The economic impact of brain injury and TBI extends far beyond the survivor and family, into the workplace, the community, the healthcare system, and the criminal justice system. The direct and indirect costs (such as medical costs and cost of lost productivity due to TBI in the U.S.) totaled an estimated \$60 billion annually.<sup>10</sup>

The following information was compiled by the Family Caregiver Alliance:<sup>11</sup>

- According to the National Institute of Neurological Disorders and Stroke (1989), the lifetime costs for one individual surviving a TBI can reach \$4 million.
- Survivor costs account for \$31.7 billion and fatal brain injuries cost another \$16.6 billion (1991 dollars) (Lewin-ICF, 1992).
- One study showed that supported employment for helping TBI survivors return to work costs an average of \$10,198 for the first year of service (Wehman, Kregel, West, & Cifu, 1994).

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<sup>8</sup> Centers for Disease Control and Prevention, National Center for Injury Prevention and Control (2005, August). *Facts about traumatic brain injury*. Retrieved September 17, 2007, from the Brain Injury Association of America website at <http://www.biausa.org/word.files.to.pdf/factsaboutBI.8.29.05.pdf>

<sup>9</sup> National Institute of Neurological Disorders and Stroke. *Traumatic brain injury: hope through research*. Bethesda (MD): National Institutes of Health; 2002 Feb. NIH Publication No.: 02-158. Retrieved from Centers for Disease Control's National Center for Injury Prevention and Control's web site: <http://www.cdc.gov/ncipc/tbi/Outcomes.htm>

<sup>10</sup> Finkelstein, E., Corso, P, Miller, T. *The Incidence and Economic Burden of Injuries in the United States*. New York: Oxford University Press; 2006.

<sup>11</sup> Family Caregiver Alliance (n.d.) *Selected traumatic brain injury statistics*. Retrieved September 13, 2007, from Family Caregiver Alliance website: [http://www.caregiver.org/jsp/content\\_node.jsp?nodeid=441](http://www.caregiver.org/jsp/content_node.jsp?nodeid=441)

**The current lifetime medical and work loss costs associated with TBI hospitalizations among Texans total approximately \$1.08 billion each year** (J. Langlois, personal communication, February 21, 2006).<sup>12</sup> These estimates do not include the costs of loss of work and loss of benefits for caretakers who leave the workforce to care for their loved ones. The current crisis is compounded by escalating volume as increasing numbers of servicemen and women return from the conflicts in Iraq and Afghanistan with a TBI.

## **Incidence and Prevalence of TBI in Texas**

The CDC estimates that 144,000 Texans sustain a TBI each year. Of these people, 4,200 will die and over 5,700 will have a permanent disability from the brain injury. This estimate of disability only includes individuals who were hospitalized and does not include those who were seen in the emergency department and released. Based upon the 2007-estimated population for Texas, approximately 479,000 Texans were living with TBI-related disabilities.<sup>13</sup>

Data from the Texas Emergency Medical Services (EMS)/Trauma Registry shows that in 2003 and 2004 over thirty percent of those hospitalized for TBI were children ages 0 -19.<sup>14</sup> The data do not include those who were treated in emergency rooms (ERs) and not hospitalized, or those who did not seek treatment in hospitals or ERs.

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<sup>12</sup> See Extrapolation by Centers for Disease Control and Prevention above.

<sup>13</sup> Reference Thurman, D.J., Alverson, C., Browne, D. et al. (1999/2005). *Traumatic brain injury in the United States: A report to Congress*. Centers for Disease Control and Prevention. Information obtained from J.M. Silver, T.W. McAllister, & S.C. Yudofsky (Eds.) *Textbook of traumatic brain injury* (p.7). Washington, D.C.: American Psychiatric Publishing, Inc.

<sup>14</sup> Texas Department of State Health Services (January 2007). *Traumatic brain injuries in children ages 0-21years and Traumatic brain injury in adults ages 22 and over*. Unpublished data.

## Challenges for Texans with Brain Injury

### Accessibility to Information and Services

**“The primary unmet need after TBI (particularly in the first year) is the need for information about services that may be available and how to access them”** (E. Pickelsimer, personal communication, December 15, 2005).<sup>15</sup> People who know what to expect after a brain injury are much more likely to recover successfully and prevent further injury. Yet, in reality, individuals are frequently discharged to home from the acute care setting with little to no information regarding the long-term consequences of the injury, treatment options, service options, and the expected course of improvement.

Results of the 1999 TBIAC Needs Assessment indicated that 60 percent of Texans with TBI did not receive information about brain injury at the time of their injury and 55 percent did not receive information about supports and services. Thirty-six percent (36 percent) of the families did not receive information about brain injury and 52 percent did not receive information about resources for their family member.<sup>16</sup>

There may be many reasons for the lack of information provided to patients with TBI and their families. During the weeks following the trauma, family members experience high levels of emotional strain and may only be able to absorb or process a limited amount of information at any one time. As described above, after the patient is discharged to the home setting, the family has limited access to informational support. Additionally, recommendations that were given in the hospital may no longer be effective or no longer apply. The primary goal of ER personnel is to save lives: a doctor may communicate to a family member that their loved one is going to be ‘okay,’ meaning, that their loved one is going to live, but fail to specify that the quality of life and need for support may change dramatically.

Unfortunately, the problem may also be attributed, at least in part, to lack of knowledge and experience of health care professionals (depending upon the area of practice) regarding the long-term needs of the individual with TBI. An experienced neurotrauma intensive care unit nurse stated: “[until my own husband, a policeman, was injured] my perception was that we stabilized them [medically in the neurotrauma unit] ...they went to rehab, they woke up and everything was okay. My perception has totally changed.”<sup>17</sup>

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<sup>15</sup> Picklesimer, E., personal communication (December 15, 2005). Based upon information from states’ needs assessments reported in proposals submitted for the 2006 HRSA TBI Implementation Grants.

<sup>16</sup> Texas Traumatic Brain Injury Advisory Council (1999, March). *Needs assessment report*. Austin, TX: Texas Department of Health.

<sup>17</sup> Baylor Institute for Rehabilitation (Producer). (n.d.) *Journeys of a lifetime: Personal perspectives of brain injury survivors* [Video]. Dallas, TX: Baylor.

Compounding the problem are situations where the injury may be mild or moderate, with no 'visible' consequences or apparent lesions to neural tissue on imaging studies (magnetic resonance imaging, computed tomography). An individual may be discharged from the ER without adequate information or may not seek ongoing medical attention. The individual may have little knowledge or preparation for subsequent problems that may be encountered: problems functioning at work or school, with family relationships, physical, cognitive and emotional functioning, or even problems with the law.

Texans in search of critical services often do not know where to begin. Looking for help means, locating dozens of phone numbers and/or websites, and searching through a complex and ever-growing maze of agencies and services to make the right connection. During public meetings held in Texas in the spring of 1998, attendees frequently stated "once they or their family members were discharged from the hospital they were on their own and had no idea of where to turn to get help. ***The common thread of need expressed at all the public meetings, was for a service coordinator or personal advocate to help with identifying, accessing, and coordinating services.***"<sup>18</sup>

Information and referral (I&R) services are available from the Brain Injury Association of Texas (BIATX), the Brain Injury Resource and Information Network (BRAIN), and the Texas TBIAC). While BIATX maintains an 800 number, volunteers have been unable to respond on a consistent basis over the course of 20 years. BRAIN restricts its activities to the Dallas/Ft. Worth Metroplex, and also depends upon volunteers. Staff members of the TBIAC's lead agency, the Department of State Health Services (DSHS), may respond to calls for assistance with support and guidance from the members of the TBIAC, however TBIAC members' time is donated.

## **Insurance Coverage in Texas**

There is compelling evidence that structured, goal-oriented individualized multidisciplinary cognitive rehabilitation improves mobility, personal care, and independence in performing activities of daily living of persons with acquired brain injury (ABI). Receiving the appropriate cognitive rehabilitation services at the right time in recovery can make the difference between a person returning to a functional life in the community or becoming dependent on others or the state. The goal for each individual with acquired brain injury is to return to independent living to work, to school, and/or to care for their family.<sup>19</sup>

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<sup>18</sup> Texas Traumatic Brain Injury Advisory Council (1999, March). *A policy analysis of the Texas health and human service delivery system*. Austin, TX: Texas Department of Health.

<sup>19</sup> Texas Traumatic Brain Injury Advisory Council (n.d.) *Position statement of the Texas traumatic brain injury advisory council concerning house bill 1676 – chapter 1352, brain injury of the Texas insurance code cognitive rehabilitation services*. Austin, TX: Texas Department of State Health Services.

The following letter in support of adding Article 21.530 to Chapter 21E, of the Texas Insurance Code, describes conditions for survivors of brain injury and their families:

*Texans who have suffered traumatic brain injuries receive very inconsistent treatment for these injuries due to the fact that insurance carriers have no legal requirements to provide their insureds treatment for traumatic brain injury and acquired other brain impairment (due to brain illnesses). Although many policies cover rehabilitative services for traumatic brain injury, there is extreme variability from carrier to carrier as to which services are covered and how much therapy is allowed under their plans. Also, the degree to which services are considered medically necessary is highly variable from one insurance carrier to another.*

**...When insurance carriers pass the costs of rehabilitative services to State agencies (via the Texas Rehabilitation Commission [currently, Department of Assistive and Rehabilitative Services]) while maximizing profits, not only does the State suffer, but the individual insureds and their employers who pay health insurance premiums pay an undue cost while the insurance carriers reap profit from their neglect of this issue.<sup>20</sup>**

The wife of a survivor describes the experience:

*...It takes a toll on you as a couple, your family life, emotionally, mentally, financially. I had to take a second job [in addition to my job as a registered nurse], and hire a nanny (my daughter needed care since she had been in the wreck with my husband). There was virtually no insurance coverage for rehabilitation [for my husband who was a police officer], and we were forced to be 'charity patients,' if you will. ...We have had to pay out of pocket or find programs that needed 'guinea pigs' and that helped.<sup>21</sup>*

The following are the candid observations of a professional in the field of brain injury rehabilitation:

*Public funding brings to mind funds for the indigent. It's truly not that way. People do not understand, at least until they are injured. I didn't understand until I was in the business. But most everyone is only their 401K, IRA, thirty-day hospital stay, and sixty-certed (sic) rehab days away from public funding.*

*The average length of stay for...a severely injured person [with TBI] in acute rehab is about 55 days. Approximately 20% of survivors of severe TBI remain unresponsive for at least [30 days]. So by discharge time, you are barely getting started. ...The average insurance purchaser has no*

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<sup>20</sup> Excerpts from a letter dated February 12, 2001 in support of Article 21.530 [Texas Insurance Code] by Fulbright, O'Krent, Fulbright, Lurie, Smernoff, Thompson, & Nelson.

<sup>21</sup> See Baylor above.

*comprehension of what is in store for him/her if the unimaginable happens.*<sup>22</sup>

The 77<sup>th</sup> Texas Legislature, 2001 passed House Bill 1676 (HB 1676) prohibiting health benefit insurance plans from excluding certain insurance benefits for rehabilitative testing and treatment related to ABI. Subsequently, the Texas Department of Insurance (TDI) adopted rules to implement the law. However, conditions changed minimally in most parts of the state, due to a failure to educate those it affected. The benefit was not being used statewide because in most regions of the state, family members and providers were unaware that the benefit existed. For providers and family members who were aware of the benefit, access became progressively more difficult due to limitations imposed by the health benefit plan and a lack of education of many health benefit plan utilization reviewers.

In 2006, the Sunset Advisory Commission (SAC) reviewed the effectiveness of the benefit provided by HB 1676 and reported to the Legislature the extent to which covered health insurance enrollees used the mandated benefit and the associated costs to the health benefit plan. The SAC Staff Report, dated November 2006, found that the costs associated with the brain injury mandated benefit were very small - less than one-fifth of one percent of total claims paid by insurers in 2005.<sup>23</sup>

### **Public Support for Rehabilitation in Texas**

Failure to obtain effective and timely rehabilitation results in lost productivity, increased costs for education, increased crime, increased costs for criminal justice, and other direct and indirect costs to the community and state. In reality, only five percent of the victims of TBI receive the rehabilitation services that they need to reach their “maximum potential for recovery.”<sup>24</sup>

The Department of Assistive and Rehabilitative Services (DARS) provides short-term (six months) comprehensive rehabilitation services (CRS) utilizing a trust fund dedicated to brain and spinal cord injury rehabilitation. Created by the 72<sup>nd</sup> Texas Legislature, 1991, the fund is supported by a percentage of court costs collected on misdemeanor and felony convictions that total approximately \$10 million per year. In addition, DARS also provides vocational rehabilitation services through its Divisions of Rehabilitation Services and Blind Services.

The CRS program provides needed support to many, however, for individuals with severe brain injuries who may need years of rehabilitation, six months is grossly inadequate. While an individual with a TBI may make significant gains as

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<sup>22</sup> Watkins, K. (Spring, 2005). Willie, dancing and rehab. *Premier Outlook*, 5(1), p.67-68

<sup>23</sup> Sunset Advisory Commission Staff Report (November 2006). *Study of Health Benefit Plan Coverage for Brain Injuries*. Austin: Texas Sunset Advisory Commission.

<sup>24</sup> Winslade, W.J. (1998). *Confronting traumatic brain injury: Devastation, hope and healing*. Binghamton, NY: Vail Ballou Press.

a result of the CRS program, afterwards there is no case management or systematic way to link the individual or their families with other services. In cases where state services are unavailable (which is most often the case), there is no mechanism to ensure that the person transitions successfully from the rehabilitative setting into the home and community settings where supports are extremely limited, unidentified, or nonexistent. Historically, the CRS program funds have been exhausted during the first half of every state fiscal year, resulting in a long interest list (up to nine months).

## Long-Term Care

There is an urgent need to consider the impact of the lack of long-term services for acquired brain injury on the individual and the community. Frequently, there is no second income in the family (e.g., single parent homes) or the primary caretakers are elderly or will become so. These conditions prevent a family member from providing adequate support when there are physical, cognitive and emotional/behavioral/psychosocial consequences of brain injury. Therefore, the family and their loved one experience significant setbacks, including threats to safety, financial ruin, unbearable emotional strain, disintegration of the family, and homelessness.

*[He] was not eligible [for assistance] because he was 25 when he was injured. Whenever I learn about a program...they all require that he be injured before age 22 or 18...What's the magic in those two ages? Mother, Richardson, Texas*<sup>25</sup>

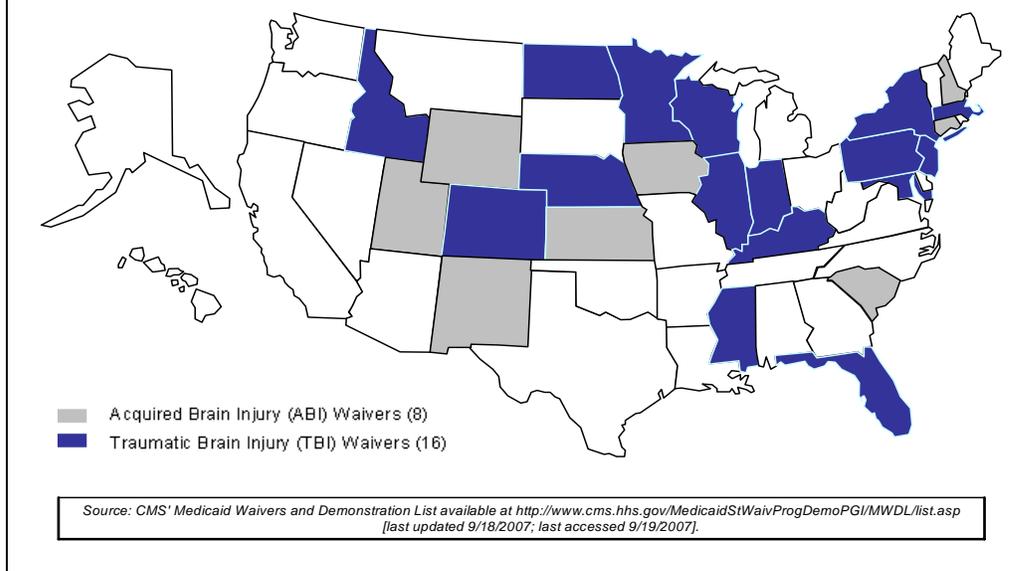
In the state of Texas, unlike in many other states, there is no TBI Medicaid waiver. The Texas Department of Aging and Disability Services (DADS) offer Home and Community Based Services (HCBS) waiver programs for Medicaid, Medicaid waiver, and state-funded long-term care services. However, Medicaid waiver programs are available only for persons injured prior to age 22, or for those who have a medical condition requiring skilled nursing care. Additionally, stringent requirements regarding community living preclude group home living, which may be more appropriate for some who need regular supervision. Facilities that provide 24-hour supervision are usually designed for those with mental retardation or the elderly. Unfortunately, many with TBI are inappropriately institutionalized in nursing homes at great cost. Finally, there is currently a ten-year interest list for services.

The figure on page 16 illustrates the states that currently have a Medicaid waiver program for ABI and TBI (a subset of ABI).

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<sup>25</sup> Texas Traumatic Brain Injury Advisory Council (2001). Traumatic brain injury in Texas: The silent epidemic: Putting the pieces together. Austin: TBIAC

## ABI and TBI HCBS Waivers



There are presently 24 states with ABI/TBI waivers. Other states have non-ABI/TBI-specific waivers that serve individuals with brain injury. These are not included on this map. For instance, Michigan's Choice waiver and Vermont's Long-term Care waiver serve individuals with brain injury and other disabilities. New Mexico's Mi Via Plan also serves individuals with TBI and other populations, but is included on the map as it specifies individuals with brain injury.<sup>26</sup> Many state programs favor those with *physical* disabilities and are not equipped to recognize or deal with individuals who have subtle but often incapacitating behavioral problems and cognitive dysfunction. Advocates or case managers are often needed to negotiate social service systems, especially for individuals with cognitive impairments. Finally, programs tend to exclude patients with problematic or aggressive behavior. Funding is typically not available to provide the structured settings and professional supports needed to properly manage TBI patients with behavioral problems. Medicaid waivers for TBI are currently expanding in other states, a trend that will hopefully continue, as policymakers are made more aware of the utility and cost-effectiveness of long-term community-based care for TBI.<sup>27</sup>

<sup>26</sup> Centers for Medicare and Medicaid Services Medicaid Waivers and Demonstration List updated by National Association of State Head Injury Administrators (NASHA), personal communication, September 2007.

<sup>27</sup> Hornstein, A. (2005). Social issues. In J.M. Silver, T.W. McAllister, and S.C. Yudofsky (Eds.), *Textbook of Traumatic Brain Injury*. Washington, D.C.: American Psychiatric Publishing, Inc.

Some states serve persons with brain injury and spinal cord injury within the same waiver, making it difficult to obtain an exact count of persons with brain injury who are being served in waiver programs. Since it is possible for one individual to access Medicaid waiver services during part of a year and another individual to access services the remainder of the year, the National Association of State Head Injury Administrators (NASHIA) estimates that more than 8,000 persons were served by TBI waivers in 2004.<sup>28</sup>

While 2 percent of the population lives with a disability from TBI, the number of individuals who are served by brain injury waivers is considerably lower: the number of beneficiaries in any one state rarely exceeds 1,000. Reasons may include problems with accessibility or lack of needed services (limited service array). Additionally, as a consequence of the injury, there may be a lack of insight into one's limitations or impairments. For example, unless a substitute decision maker has been appointed by the courts, the individual with brain injury may insist that there is "nothing wrong" with them and struggle with demands of daily living rather than seek or accept services. For these reasons, it is difficult to estimate the numbers who might utilize services in Texas if eligibility requirements are expanded.

The type of service/support environment and duration of services will vary greatly depending upon the functional level, specific programming needs, and preferences of the individual with brain injury. Furthermore, the individual's need for a less restrictive environment will change over time as they make progress and acquire skills. Some will graduate out of a program and become self-supporting. A continuum of care is recommended with service coordination/case management support throughout the course of care to ensure that the individual is most appropriately placed from the outset, is receiving needed supports, and transitions to a less restrictive environment as soon as possible (including graduating out of services). The precepts of person-centered planning and self-determination must be incorporated (including dignity of risk and discovery). Additionally, flexibility is required to graduate and to later move back into services as needs arise. Direct care staff must have training in brain injury, behavioral management strategies, and crisis prevention intervention.<sup>29</sup>

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<sup>28</sup> National Association of State Head Injury Administrators (n.d.). Medicaid waivers. Retrieved June 16, 2006 from the National Association of State Head Injury Administrators website at <http://www.nashia.org/issues/medicaid.html>

<sup>29</sup> See TBIAC above.

## Special Populations

### Texas Veterans with TBI

Blast injuries, typically caused by a variety of military munitions containing explosives, land mines, car bombs, and improvised explosive devices frequently result in TBI when the brain moves violently inside the skull. In addition, soldiers and marines have received TBIs as a result of falls, motor vehicle accidents, and gunshot wounds to the head and neck. Nearly two-thirds of injured U.S. soldiers sent from Iraq to Walter Reed Army Medical Center have been diagnosed with TBIs. If current trends continue, over half of all injured soldiers will have a brain related injury.<sup>30</sup>

While the Pentagon has yet to release hard numbers on troops with brain injury, brain injury professionals express concern about the incidence reported from other military-related sources like the Defense and Veterans Brain Injury Center (DVBIC), the Department of Defense, and the Department of Veterans Affairs. One expert from the Veterans Administration (VA) estimates the number of *undiagnosed* TBIs at over 7,500. Nearly 2,000 soldiers with brain injury have already received some level of care, but more continue to return from the current conflicts with TBI.<sup>31</sup>

The need for appropriate services for civilians with brain injury in Texas has been identified as a significant problem.<sup>32 33</sup> The problem is compounded by volume and complexity as increasing numbers of servicemen and women with TBI return from the war with the added components of polytrauma (amputations and other coexisting traumatic injuries), post-traumatic stress disorder, and/or misdiagnosis. Many may choose not to utilize the VA services because of the perceived stigma associated with brain injury and because the VA facilities specializing in brain injury services are located outside of the State of Texas.

Given the large number of Texans who are in the military (1 in 4 enlistees are from Texas), these findings pose a significant concern regarding accessibility to state and VA health services. Previously there were no specialized inpatient facilities providing acute TBI evaluation and treatment in the Texas VA system. The Department of Veteran Affairs recently announced that it would build a trauma facility designed to help patients with multiple serious injuries in San Antonio. However, limited post-acute care is available.

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<sup>30</sup> U.S. Department of Health and Human Services (2005, October). *America's soldiers paying the cost of survival: A look at the new faces of traumatic brain injury*.

<sup>31</sup> Mason, Michael (2007). *Dead men walking: what sort of future do brain-injured Iraq veterans face?* Retrieved September 14, 2007 from the Discover website at <http://discovermagazine.com/2007/mar/dead-men-walking/>

<sup>32</sup> Traumatic Brain Injury Advisory Council (1999, March). *Needs assessment report*. Retrieved November, 2005, from <http://www.dshs.state.tx.us/braininjury>

<sup>33</sup> Traumatic Brain Injury Advisory Council (2002, Fall). *Improving the quality of life of Texans with traumatic brain injury*. Report to the Texas Health and Human Services Commissioner.

Another concern is the reality that the wars in Iraq and Afghanistan have relied heavily upon National Guard and Reserve soldiers who have a different class of health benefits and training from their active duty counterparts.<sup>34</sup>

Since a serious brain injury often presents lifetime disabilities, it is expected that servicemen and women with TBI will eventually require services from DARS and DADS, both of which historically have extensive interest lists for services. The current Texas healthcare service delivery system is not capable of addressing the myriad chronic disability issues related to TBI for the current civilian population. The additional influx of returning veterans will only add to the demands on an already overburdened system.

### **Children and Youth with TBI**

TBI in children and adolescents is, undeniably, a major public health problem. In Texas, over 5,500 children aged 0 to 19 are hospitalized each year due to TBI.<sup>35</sup> Of those, approximately one-third results in a long-term or lifelong disability. This estimate of disability is based only on the number of children who are hospitalized, and does not include those who are treated in the emergency department and released. Finally, the CDC estimates that the lifetime medical and work loss costs associated with TBI-related hospitalizations among Texas children aged 0 to 19 years total approximately \$268 million each year (J. Langlois, personal communication, February 14, 2006).<sup>36</sup>

While approximately 1,650 Texas children are permanently disabled by TBI each year, special education departments in public schools have not identified the vast majority of these children. According to the Texas Education Agency (TEA), during the 2006-2007 school year only 1,350 Texas students received special education services as traumatically brain injured (TEA, Division of Individuals with Disabilities Education Act (IDEA) Coordination, personal communication, October 10, 2007).<sup>37</sup>

The remaining unidentified students may be classified incorrectly (e.g., emotionally disturbed, learning disabled, etc.) resulting in inappropriate intervention and poor outcomes, or they may struggle alone with the consequences of their injury. Many will quit school or will be removed from school by their parents due to frustration.

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<sup>34</sup> U.S. Department of Health and Human Services (2005, October). *America's soldiers paying the cost of survival: A look at the new faces of traumatic brain injury*. Draft publication of the Health Resources and Resources and Services Administration, Maternal and Child Health Bureau. Forwarded November, 15, 2005, by National Association of State Head Injury Administrators.

<sup>35</sup> See Texas Department of State Health Services, January 2007 above.

<sup>36</sup> See extrapolation by Centers for Disease Control & Prevention above.

<sup>37</sup> Division of IDEA Coordination (2007, October 10). Age by primary disability for special education students statewide without duplicate student ID and including age less than or equal to 22, based on PEIMS Fall snapshot data 2006-2007. Austin, TX: Texas Education Agency.

## Health Disparities and TBI

“Health disparities are the ‘differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States.’ Common characteristics of these populations include race, culture, gender, age, economic status, and geographic distribution.”<sup>38</sup>

Groups at risk for TBI, identified by the CDC are as follows:

- males, who are about twice as likely as females to sustain a TBI;
- age groups 0 to 4 years old and 15 to 19 years old;<sup>39</sup>
- adults age 75 years or older;<sup>40</sup>
- African Americans, who have the highest death rate from TBI;<sup>41</sup> and,
- African Americans and American Indians/Alaska Natives (AI/AN), who have the highest TBI hospitalization rates.<sup>42</sup>

Regarding *falls and TBI*, gender, race, and age are highly influential criteria for associated risk of mortality and morbidity according to the CDC.<sup>43</sup>

## Brain Injury in the Criminal Justice System

While some of the individuals who sustain a brain injury each year in the U.S. are able to function with no apparent deficits, for many others life after a brain injury has been associated with an increased risk for irritability, temper outbursts, and decreased self-control, in addition to cognitive problems such as attention and memory deficits. One study revealed that five years after a severe brain injury, 64 percent of the individuals were described as having a bad temper, and 54

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<sup>38</sup> Texas Department of State Health Services (2006, February 21). National Institutes of Health as cited in draft text of the Texas Health and Human Services System Strategic Plan for fiscal years 2007-2011. Retrieved March 30, 2006 from the Department of State Health Services website at <http://www.dshs.state.tx.us/council/agendas/030206/2StrategicPlanChapIX.pdf>

<sup>39</sup> Langlois JA, Rutland-Brown W, Thomas KE. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2006.

<sup>40</sup> See Centers for Disease Control and Prevention above.

<sup>41</sup> See Centers for Disease Control and Prevention above.

<sup>42</sup> Langlois J.A., Kegler S.R., Butler J.A., et al. Traumatic brain injury-related hospital discharges: results from a fourteen state surveillance system, 1997. *Morbidity and Mortality Weekly Reports* 2003; 52,SS-04: 1–18.

<sup>43</sup> Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, Division of Unintentional Injury Prevention. Cost of falls among older adults: how big is the problem? Retrieved September 20, 2007 from <http://www.cdc.gov/ncipc/factsheets/fallcost.htm>

percent threatened violence.<sup>44</sup> Brain injury was also found to increase the risk for psychiatric disorders and substance use disorders. Individuals with brain injury who are not treated with medical (pharmaceutical) and psychological (behavioral) interventions may pose a threat to others and themselves, and be at risk for incarceration.

About 2 percent of the general population is arrested annually. In contrast, in a study of survivors five years after severe brain injury, researchers found that 31 percent had been in trouble with the law one or more times.<sup>45</sup> A similar rate of arrest (33.3 percent) was found in a community sample of children and adolescents with TBI.<sup>46</sup>

In a 1986 study of 15 death row inmates in the U.S., researchers found evidence of brain impairment in 100 percent of the cases.<sup>47</sup> Similar results were found in a subsequent study of 14 juveniles: again, 100 percent had histories of head injury with associated signs of neurological dysfunction.<sup>48</sup> In a case-study analysis conducted in 2000 with 16 men on death row, other researchers found a history of organic brain impairment/mental illness in all cases (12 had a history of TBI).<sup>49</sup>

There is an urgent need to consider the impact of the lack of services for brain injury on the individual and the community. While widespread services are available for other disability conditions in the community, treatment services for ongoing cognitive/behavioral problems associated with brain injury are usually excluded from community support services. At a minimum, the findings above have important implications for long-term care and ongoing case management past the acute/post-acute stages of rehabilitation, particularly when individuals with brain injury return to the community setting and when inmates in correctional institutions are released to the community.

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<sup>44</sup> Brooks, N., Campsie, L., Symington, C., et al. (1988). The five year outcome of severe blunt head injury: A relative's view. *Journal of Neurology, Neurosurgery, and Psychiatry*, 49, 764-770.

<sup>45</sup> See Brooks et al., 1988 above.

<sup>46</sup> Luiselli, J. K., Arons, M., Marchese, N., Potoczny-Gray, A., & Rossi, E. (2000). Incidence of law-violating behavior in a community sample of children and adolescents with traumatic brain injury. *International Journal of Offender Therapy and Comparative Criminology*, 44(6), 647-656.

<sup>47</sup> Lewis, D. O., Pincus, J. H., Feldman, M., Jackson, L., & Bard, B. (1986). Psychiatric, neurological, and psychoeducational characteristics of 15 death row inmates in the United States. *American Journal of Psychiatry*, 143(7), 838-845.

<sup>48</sup> Lewis, D. O., Pincus, J. H., Bard, B., Richardson, E., Pritchep, L. S., Feldman, M., & Yeager, C. (1988). Neuropsychiatric, psychoeducational, and family characteristics of 14 juveniles condemned to death in the United States. *American Journal of Psychiatry*, 145(5), 584-589.

<sup>49</sup> Freedman, D., & Hemenway, D. (2000). Precursors to lethal violence: A death row sample. *Social Science & Medicine*, 50, 1757-1770.

## **Texas Traumatic Brain Injury Advisory Council (TBIAC)**

### **History**

The mission of the TBIAC is to:

- Educate and inform consumers, providers, policy makers, and the public;
- Promote prevention efforts in Texas;
- Inform the Executive Commissioner of the Health and Human Services Commission (HHSC), of the needs of persons with brain injuries and their families; and
- Recommend to the Executive Commissioner of HHSC, policies and practices to meet those needs.

The TBI Act (PL 104-166), passed by Congress in 1996 and re-authorized in 2000, signaled national recognition of the need to improve state TBI service systems. The TBI Act authorizes the federal government to award grants to states for the purpose of TBI related planning and systems change.

Since August 2000, the TBIAC's activities related to systems changes have been made possible by grants issued by the Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB) to DSHS, the coordinating office for state brain injury activities.

The TBIAC has published eight reports which can be viewed on the TBIAC website at [www.dshs.state.tx.us/braininjury](http://www.dshs.state.tx.us/braininjury):

- *A Policy Analysis of the Texas Health and Human Services Delivery System*;
- *Needs Assessment Report*;
- *A Summary of the Gaps in Services in the Texas Health and Human Services*;
- *Statewide Action Plan of Supports and Services for Persons with Traumatic Brain Injury and Their Families*;
- *TBI: The Silent Epidemic-Putting the Pieces Together, An Executive Summary of the Findings*;
- *TBI in Texas, Report to the Governor*;
- *Acquired Brain Injury and Long-term Care in Texas*; and
- *Traumatic Brain Injury and Operations Iraqi and Enduring Freedom: Implications for Healthcare in Texas*.

### **Meetings of the Texas TBIAC**

The TBIAC and its predecessor, the Texas TBIAC Board, have never failed to achieve a quorum at its regular quarterly meetings and, since 1998, have complied with the legislative mandate to meet at least quarterly. The TBIAC met

on January 27, April 7, August 8, and October 20 of 2006; and January 19, April 9, July 20, and October 19 of 2007. Minutes of meetings may be viewed on the TBIAC website at [www.dshs.state.tx.us/braininjury](http://www.dshs.state.tx.us/braininjury).

### **Texas TBIAC Membership**

The TBIAC is composed of 22 members, including eight public consumer members (three must have a brain injury, three must be related to a person with a brain injury, and two may be a person with a brain injury or a relative of a person with a brain injury). Six are professional members having special training and interest in the care, treatment, or rehabilitation of individuals with brain injury. All of eight state agency representatives hold policy and programmatic responsibilities within their respective agencies and several have personal experience with brain injury.

The TBIAC has three standing committees: Identification, Resources, and Education. An ad hoc Strategic Planning Committee works on sustainability; the Legislative and Policy Committee prepares position papers and provides resource information as requested; the Funding Committee responds to requests for funding proposals; and the Nominations Committee prepares a slate of officer candidates, supervises election of TBIAC officers, and recruits prospective applicants for the TBIAC to recommend to the Executive Commissioner of HHSC for appointment. In addition, other ad hoc committees are established as needed to address emerging issues such as servicemen/women and veterans with brain injury.

In addition to the statutorily prescribed membership, the TBIAC consistently requests participation from other stakeholder state agencies and groups, former members, and staff who provide valuable input and support.

A list of the TBIAC members appears on the following page.

## **Texas TBIAC Members**

By designated category, members include:

### **Eight Public Consumer Members**

*Three Persons Related to Individuals with TBI*

- Sonia Quintero, Edinburg
- Joe Shockley, Montgomery
- Elaine Parker Adams, Ph.D., Houston\*

*Three Persons with a TBI*

- Catherine Rich, Dallas (member of BIATX)
- Jason Ferguson, Houston (Board of Directors, BIATx)
- Erroll Smith, Edinburg

*Two Public Members*

- David Seaton, Austin
- J. Charles Haynes, Houston

### **Six Professional Members**

- Mary Z. Adams, South Plains Community Action Association, Inc., Lubbock (Community Based Services)
- Timothy Atchison, Ph.D., West Texas A&M University, Canyon (Faculty of Institution of Higher Education)
- Mary Carlile, M.D., Baylor Institute for Rehabilitation, Dallas [National Institute on Disability and Rehabilitation Research (NIDRR) TBI Model Systems]
- Cynthia Cavazos-Gonzalez, Ph.D., Pinkerman & Gonzalez Psychological Association, Edinburg (Provider of Cognitive Rehabilitation)
- Todd Maxson, M.D., FACS, Dell Children's Medical Center, Austin (Acute Hospital Trauma Unit)
- Joanne McGee, Ph.D., ResCare Premier, San Marcos (Provider of Cognitive Rehabilitation)\*\*

### **Seven State Agencies**

- Margaret Lazaretti, TDI
- Barbara Kaatz, TEA
- Tom Valentine, HHSC
- Lesa Walker, M.D., M.P.H., Children with Special Health Care Needs (CSHCN), DSHS
- Les Young, DARS (formerly Board of Directors, BIATx)
- Angela Lello, Texas Council for Developmental Disabilities (TCDD)
- Maxcine Tomlinson, MSW, DADS

\*Assistant Presiding Officer

\*\*Presiding Officer

## Texas TBIAC: 2007 Initiatives

### 2-1-1 Texas Project

Based upon a statewide needs assessment conducted in 1998, families and individuals with brain injury reported being alone in searching out brain injury supports and services.<sup>50</sup> In response, the TBI/2-1-1 Project was initiated by the TBIAC and was funded through a HRSA grant awarded in April 2004.

2-1-1 Texas is a free, easy to remember phone number connecting callers with health and human services in their community, as well as state benefits. Callers may also report waste, fraud, and abuse. Information and referral is available 24 hours a day, seven days a week throughout the year. Information can be provided in over 90 different languages. A network of 26 Area Information Centers (AICs) is linked together to provide information about health and human service resources throughout Texas.

The project has begun to expand the state's capacity to serve individuals with brain injury and their families by augmenting the database of regional and local supports and services (including public and private support, as well as volunteer). The project also began improving responsiveness of the 2-1-1 system for brain injury needs through education and training of I&R professionals and *Promotores* (community health workers). Training for *Promotores* was conducted in Spanish. Texas TBI/2-1-1 initially involved a pilot project in 27 Texas counties (Ft. Worth, the Permian Basin, and Lower Rio Grande Valley areas).

In March 2006, DSHS was awarded another grant to begin funding the expansion of the TBI/2-1-1 Project in the remaining Texas counties. The project includes the development, production and distribution of an electronic training module or DVD, entitled "Meeting the Special Needs of Individuals with Brain Injury." The electronic training module was created for the purpose of statewide training for 2-1-1 specialists. The module may also be used to train health and human services agency staff and staff at Texas VA Centers about brain injury issues. Other health care professionals, educators, policy makers, family members, friends, and brain injury survivors may also benefit from this program. The training will be available in DVD format and on the website and will be distributed in late 2007.

The curriculum includes sections relating to how the brain functions, needs of and interventions for individuals with brain injury, and information concerning VA and other services and resources for brain injury. A professional video production company filmed the training, with assistance from the media services division at DARS. Two licensed neuropsychologists and a physician from the Michael E. DeBakey VA Medical Center contributed to this project by making

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<sup>50</sup> Texas Traumatic Brain Injury Advisory Council (1999, March). *Needs assessment report*. Austin, Texas: Texas Department of Health.

professional presentations. Also, members of the TBIAC and its Education Committee have generously volunteered their time, talents, and services in the making of this training module.

The TBIAC has worked to build a collaborative relationship with staff of 2-1-1 Texas and its 26 AICs. When fully implemented statewide, the project will facilitate access for individuals of all ages with brain injury and their families to culturally competent statewide and local resources and family- and person-directed supports. The value of the Texas TBI/2-1-1 Project has been recognized by the BIAA, CDC, AIRS, the National Association of State Units on Aging (NASUA), and the National Association of State Head Injury Administrators (NASHIA), as well as Texas legislators and U.S. senators and representatives.

### **Distribution of Educational Information**

Through the collaboration of TBIAC members, a number of educational products have been developed and printed through prior HRSA grants (see Appendix III). In particular, the TBIAC *Concussion Cards* provide important information and procedures to follow when an adult or child has a concussion. The cards are printed in English and Spanish and have been used by public school nurses and coaches, 2-1-1 Texas information specialists, EMS providers, hospitals, and physicians' offices. The concussion cards have been reproduced by other states as well.

The *Important First Steps* brochure is published in English and Spanish and provides information on resources that can be accessed after an individual has sustained a brain injury. The *Important First Steps* brochure is used widely and is distributed through hospital ERs/trauma units, acute care hospitals, state agencies, and the BIATX. In addition, other states have adapted and distributed the brochure. However, due to limited funding and support, the brochures have not been distributed in all settings in Texas where they are needed, nor have they been distributed in all geographic regions of the state. These publications are free and may be ordered through the DSHS website at <http://webds.dshs.state.tx.us/mamd/litcat/default.asp>. These publications may also be downloaded from the TBIAC website at [http://www.dshs.state.tx.us/braininjury/tbi\\_pub.shtm](http://www.dshs.state.tx.us/braininjury/tbi_pub.shtm).

### **Partnership of TBIAC and U.S. Department of Veterans Affairs**

The TBIAC's ad hoc Committee on Veterans Affairs has been attended by members of the TBIAC, representatives from the VA, the Department of Defense (DOD), and the Texas Veteran's Commission. The ad hoc Committee meets in conjunction with the TBIAC's quarterly meetings and when necessary via conference call. The Committee prepared a white paper entitled, *Report to the Deputy Commissioner, Texas Health and Human Services Commission: Traumatic Brain Injury and Operations Iraqi and Enduring Freedom: Implications*

for *Healthcare in Texas* dated January 2007, that may be found on the TBIAC website at [www.dshs.state.tx.us/braininjury/docs/veterantbiwp.pdf](http://www.dshs.state.tx.us/braininjury/docs/veterantbiwp.pdf).

The United States Department of Veterans Affairs has collaborated with the TBIAC and HHSC on the TBI/2-1-1 project to enhance access to services for veterans of the Iraq and Afghanistan conflicts who have sustained TBI and their families. The VA has agreed to identify a specific 2-1-1 (AIC) as the "VA Call Center." In the VA Call Center, 2-1-1 resource coordinators, in collaboration with VA staff, will maintain a current resource database with links to VA services for veterans with brain injury. Additionally, the 2-1-1 training program that the Council is expanding statewide includes important information for veterans with brain injury and their families. The training will be available in DVD format and will be distributed in late 2007.

### **Legislative and Policy Initiatives of the TBIAC**

During the past year, the TBIAC prepared four position statements for the purpose of urging state lawmakers to:

- 1) establish an Office of Brain Injury (OBI);
- 2) strengthen the motorcycle helmet law and prevent TBIs;
- 3) clarify the Texas Insurance Code regarding the mandate requiring health benefit plan coverage for cognitive rehabilitation after brain injury; and
- 4) evaluate the adequacy of the current health and human services delivery system as it relates to Texans with brain injury.

These position statements may be viewed on the TBIAC website at [www.dshs.state.tx.us/braininjury/positions.shtm](http://www.dshs.state.tx.us/braininjury/positions.shtm). Other policy initiatives are also described below.

### **Office of Brain Injury**

The TBIAC is composed of volunteer appointees who have full-time jobs and donate their time to Council activities. The TBIAC and its efforts have been totally funded by HRSA grants for the past six years. Although the TBIAC members are dedicated to the Council goals, they often cannot devote sufficient time and resources to adequately tend to the daily business of the Council.

Lack of administrative capacity has severely limited the capability of the TBIAC to influence Texas state policies and services for individuals with brain injury and their families. For example, a brain injury training program was developed by TBIAC and the offer to provide the training to staff members/administrators of state health programs was well received. However, coordination is needed to provide the training on an *ongoing* basis. Additionally, as valuable products are developed by TBIAC and other states, support is needed to ensure that the information is disseminated and that programs are implemented as directed.

In 2006, the TBIAC recommended that HHSC include the establishment of an OBI in its Legislative Appropriations Request. The 2007 Legislature approved the request, including 1.5 full time employees. The plans and process for creating the office and the job duties of its employees were underway as of the date of this report.<sup>51</sup> The TBIAC recommended the following job duties:

- Respond to callers requesting information on brain injury and services (professionals, survivors, and family members);
- Provide service and care coordination;
- Liaison with state agencies that provide services for brain injury survivors;
- Publish and distribute educational/informational materials regarding brain injury prevention, awareness, and services;
- Assist veterans with brain injury and their families seeking services;
- Collaborate with other organizations and agencies that provide services or information for brain injury survivors, veterans, retired and active military personnel and their families;
- Collect and disseminate relevant data and information that can be used for policy and legislative decisions;
- Search for and apply for grants or other funding to support its mission; and
- Be a voice for brain injury survivors.

### **Insurance Coverage of Cognitive Rehabilitation After Brain Injury**

In the fall of 2006, long after the passage of HB 1676 in 2001, the TBIAC issued a position statement concerning the problems that Texans still have in accessing the benefit for cognitive rehabilitation after brain injury. The 80<sup>th</sup> Texas Legislature, 2007 passed HB 1919, authored by Representative Todd Smith, which addressed the barriers and problems Texans face in accessing the benefits provided by HB 1676. Effective September 1, 2007, the new bill also expands the covered population to include state employees and requires that insurers send written notification of the mandated cognitive rehabilitation benefit to those insured. The TBIAC's Education Committee has been charged with developing a flyer describing the mandated brain injury benefit. The flyers will be distributed to hospital case managers, family members of individuals with brain injury, social workers, advocacy groups, rehabilitation centers and schools.

In addition, an educational program with detailed information regarding the requirements of the law, barriers in accessing the benefit, and procedures for referring a patient for rehabilitation services after brain injury is being piloted and presented to groups that would benefit or groups whose patients would benefit, including the Texas Trauma Coordinators Forum. If approved by the TBIAC, an electronic version of the program may be added to the TBIAC website in an effort to educate brain injury survivors, their families, healthcare providers, and other stakeholders.

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<sup>51</sup> Valentine, Tom (September 17, 2007). Personal communication.

Furthermore, the presiding officer of the TBIAC is working with the BIAA to draft similar legislation to apply to voluntarily established health plans in private industry that are governed by the Employee Retirement Income Security Act of 1974 and federally controlled health plans.

### **Motorcycle Helmet Legislation**

The TBIAC reviewed results of a study conducted by Baylor Institute for Rehabilitation concerning prevention of TBIs by strengthening the motorcycle helmet law. The study highlighted significant problems in relation to brain injury after the legislature repealed the mandatory motorcycle helmet law in 1997. The injury and death rates both tripled the first year after the law was repealed. The study noted that hospital and related health care costs for uninsured and unhelmeted riders were being absorbed by hospitals and the state (primarily Medicaid and CRS). Recognizing that helmets prevent traumatic brain injuries and reduce demands on our health care providers and state-funded health care programs, the TBIAC supported legislation that would not only encourage helmet use, but also require the unhelmeted rider to carry adequate health insurance to cover acute medical costs in case of a brain injury. In a Senate Transportation Committee hearing, members identified complications in enforcement of proposed Senate Bill 1368 and unfortunately, the bill did not move forward.

### **Support of Texas EMS/Trauma Registry to Identify the Incidence and Prevalence of Brain Injury in Texas**

To provide Texas with the data needed to make informed and responsive policy and funding decisions regarding appropriate and sufficient services for Texans with brain injury, a thorough identification of the needs of this population throughout the state is required. An emphasis must be placed on reaching children and adults who are not receiving services. Additionally, data is needed to make informed decisions regarding prevention efforts as well as policy initiatives.

Given the nature of brain injury in terms of diversity of outcomes and a varied but unremitting course, it is necessary to track outcomes over time to define the needs of the population. The DSHS currently maintains the EMS/Trauma Registry. However, due to funding limitations, the Registry is incomplete and the data inadequate for reporting purposes within the State of Texas or for reporting to CDC. The CDC has recommended that each entry (each person injured) have a unique identifier (e.g., driver's license number or social security number) to track persons with brain injury from acute care, through inpatient rehabilitation, post-acute rehabilitation, and social services. Currently, hospitals have the option of using "unknown" for this important element in the Registry, which renders the entry unusable. Unfortunately, some entities send data that is predominantly composed of "unknowns." Rehabilitation hospitals are required to report; however, there is no enforcement mechanism in place and no funding to

make this happen. Additionally, there are restrictions on linking hospital discharge data collected by DSHS with other data sets.

One member of the TBIAC is also a member of the Governor's EMS and Trauma Advisory Council (GETAC). In the future, TBIAC members will work with the data informatics group of GETAC to evaluate the possibility of utilizing the EMS/Trauma Registry to track outcomes for individuals with brain injury. The TBIAC and GETAC advocate for and support the EMS/Trauma Registry and recognize its importance for brain injury issues.

### **Long-Term Care**

The TBIAC and staff have met with representatives from DADS to explore how a brain injury waiver could be added or how currently existing waivers could be adapted for brain injury. Because of concerns about the gaps in services for brain injury, the TBIAC compiled a report entitled, *Acquired brain injury and long term care in Texas*. The report appears on the TBIAC website at <http://www.dshs.state.tx.us/braininjury/docs/braininjurylongtermcare.pdf>. During 2007, the TBIAC presiding officer and staff members, along with many other stakeholder groups, participated in a series of waiver optimization meetings held by DADS. However, no substantive progress has yet been made concerning a brain injury waiver or waiver optimization for individuals with brain injury.

### **Children and Brain Injury in Texas: TBIAC Needs Assessment**

In an effort to learn more about what happens to children who sustain a brain injury and how they may or may not be connected to appropriate educational services, the TBIAC, as part of its partnership grant from HRSA, is undertaking a needs and resources assessment for children with brain injury in the state. The project, which is expected to be completed in November 2008, will consist of two parts:

1. Issues with incidence data, especially for children - a description of what currently exists, a discussion of the problems and issues with the data, and recommendations on how better/more complete data might be gathered. A discussion of TBI registries in other states would also be relevant, especially as they pertain to children and how they work. In light of what is uncovered, should Texas set up a TBI Registry? Can it be incorporated into the EMS/Trauma Registry? If not, how should it be set up? Either way, what is the estimated cost? Would additional personnel be required? How would it work? What would the benefits be?
2. An analysis of the situation with respect to children who sustain a brain injury and how they are referred to needed services in their schools. Also an identification of the "disconnect," an estimate of the percent of children who incur a brain injury and the typical resolution – this should be broken down by severe, moderate and mild, if possible. A discussion is needed on the topic of best

practices, as well as recommendations for improving the process of referral between health care providers and schools. This discussion should also take into consideration the varied geography of the state (e.g., urban, rural, frontier) as well as race/ethnicity and the identification of any disparities.

### **Special Populations and Brain Injury in Texas**

The TBIAC is concerned about the impact of brain injury on the population as a whole and in special populations that are at higher risk. To that end, the TBIAC has invited representatives of the Office for the Elimination of Health Disparities (OEHD) to attend and participate in Council and committee meetings. Likewise, TBIAC members or staff members may attend OEHD meetings and functions to take advantage of opportunities to share information or collaborate. The TBIAC considers the OEHD to be a partner and a stakeholder in prevention of brain injury and meeting the special needs of individuals with brain injury.

The TBIAC has discussed the need for Council and committee membership from under-represented groups such as Hispanics, African-Americans and Native Americans with the OEHD staff. The TBIAC membership application form and solicitation letter were sent to the OEHD for distribution to its stakeholders. The letter and the application form appear on the TBIAC's website at [www.dshs.state.tx.us/braininjury/tbi\\_adv.shtm](http://www.dshs.state.tx.us/braininjury/tbi_adv.shtm).

The Council has also been active in building collaborations with groups that are concerned about brain injury and its prevalence in the population housed in the nation's criminal justice institutions. The TBIAC presiding officer is a member of and participates in the Texas Jail Diversion/Incarcerated Vets Committee, hosted by the National Alliance on Mental Illness (NAMI) and consisting of representatives from the Veterans Administration, DSHS, Texas Department of Criminal Justice (TDCJ), and NAMI. The purpose of the Texas Jail Diversion/Incarcerated Vets Committee is to provide a forum for collaboration of Veterans Administration and Texas agencies in identifying individuals incarcerated with mental illness and brain injury in order to provide treatment and services. As a result, a memorandum of understanding was developed to promote discharge planning and continuity of care for incarcerated veterans upon release from TDCJ.

In May 2007 the TBIAC presiding officer gave a presentation to the committee on a police training program that was developed in Maryland concerning methods for improving outcomes of police interactions with individuals with brain injury. The Committee was very interested in additional representation from brain injury advocates.

### **Future Initiatives**

The TBIAC's legislative authority includes promotion of research, education, treatment, and support of activities related to persons with brain injury. Routine

business activities include coordination and management, reporting for grants and donations, and distribution of TBIAC products. To ensure that Texans have access to information regarding the TBIAC's activities, as well as products and web links that may be of use, it is essential to maintain and update the TBIAC website at [www.dshs.state.tx.us/braininjury/](http://www.dshs.state.tx.us/braininjury/).

Work on updating the TBIAC's strategic plan will continue. The TBIAC is looking forward to receiving applications for Council membership that reflect the state's geographic, ethnic, and cultural diversity and working with enthusiastic Council members who are new or are returning for a second term.

The TBIAC will most certainly be involved in the development of position statements for the 81<sup>st</sup> Texas Legislature in 2009. Considerations for the future include education of the public, policymakers, and motorcycle riders about brain injury prevention and the need for a universal helmet law in Texas. Current and future concerns also include the need to collect and compile data and information regarding brain injury for use in policy and legislative decisions.

The TBIAC will continue its efforts to fund and establish a Brain Injury Registry in Texas.

The TBIAC will collaborate with TDI in the development of a written notice about the availability of cognitive rehabilitation services as required by HB 1919.

The TBIAC will continue to review and study options, in collaboration with DADS, for long-term care for persons with brain injury in Texas, including a brain injury waiver and/or the fine-tuning of existing waivers.

The TBIAC and staff will develop a strong partnership with the OBI and provide expertise, as the OBI materializes.

The TBIAC will consider developing and delivering training on managing students with brain injury to appropriate school personnel throughout the state.

## **Texas TBIAC Recommendations**

### **Improve Services and Access to Services**

The TBIAC recommends that:

- Broader access to existing systems be facilitated by expanding the eligibility criteria of the state's health and human service systems to assure the inclusion of persons with brain injury (no matter what age the injury occurred) and their families.
- All Texans who require acute medical care for a brain injury be ensured the necessary care regardless of ability to pay.
- Community-based "Care or Service Coordination" be funded as a means to identify community supports and resources; to assist with service access and coordination; and to advocate for persons with brain injury and their families.
- Distribution of brain injury materials be continued in acute care settings, to EMS providers, to schools, promoters, etc.
- "One-stop shopping" for accessing brain injury services be provided by developing local regional service centers that have case managers who can assist in providing a seamless continuum of services.
- Application and eligibility processes be streamlined for brain injury services.
- Service options be increased and service duplication be avoided.

### **Improve Education to Providers**

The TBIAC recommends that:

- Information on brain injury be provided to educators (including higher education for teachers, healthcare workers, counselors, psychologists, speech pathologists, and those in the legal and public service fields), 2-1-1 specialists, EMS providers, emergency room and hospital healthcare workers, police, and professionals in the court and prison system.
- Statewide implementation of the Texas TBI/2-1-1 Project be improved, increasing access to state services and local community supports for individuals with brain injury and their families.
- Education and training on the needs of people with brain injury and their families be provided to providers of services at all levels of care.

## **Resolve Problems with Identification of Brain Injury**

While the CDC estimates that 144,000 Texans sustain a brain injury each year and that 410,000 Texans are living with permanent disabilities as a result of a brain injury, it is unknown where they live, what their current conditions are, what services they may be receiving, and what needs they and their families have for services and supports. In order to make informed and responsive policy and funding decisions, a thorough identification must be made of the needs of Texans with brain injury and their families.

The DSHS EMS/Trauma Registry should collect names and other data needed for the EMS/Trauma Registry to conform to the recommendations of the CDC. Collection of these data will improve the ability to accurately identify individuals with brain injuries and determine what acute medical and rehabilitation services are being accessed by persons with brain injury, and will help provide a more accurate picture of the issues for Texans with brain injury.

The TBIAC recommends that:

- Sufficient appropriations be made available for DSHS to better conduct public health surveillance of brain injury through the EMS/Trauma Registry.
- State agency staff and contractors receive periodic training regarding the special needs of individuals with brain injury, and knowledgeable case managers/service coordinators should be assigned to brain injury clients. State agencies providing services for persons with brain injury may not know that their clients' disabilities result, in whole or in part, from brain injury. As a result, people with brain injury are not identified and services and supports may be inappropriate.
- The Texas health and human services agencies using consensus International Classification of Diseases codes be required to identify people with brain injuries who are currently receiving services from the agencies; and provide annually, to the TBIAC, within 90 days after the end of the state fiscal year, an aggregate report of the demographics and magnitude of the population being served.
- The TEA assist school districts in developing and implementing methods to identify students who may have sustained a brain injury, especially those receiving special education or 504<sup>52</sup> services; and provide annually, to the TBIAC, within 90 days after the end of the school year, an aggregate report of the demographics and magnitude of the population being served.

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<sup>52</sup> Section 504 of the Rehabilitation Act prohibits discrimination on the basis of disability. It includes handicapping conditions that may not qualify a student for special education.

- Individuals facing legal charges, particularly veterans with TBI, be screened for brain injury, in conjunction with issues and procedures identified by the Texas Jail Diversion/Incarcerated Veterans Committee.

### **Reduce Preventable Brain Injuries in Texas**

Up to 95 percent of the 144,000 brain injuries sustained in Texas each year may be preventable. The primary causes are motor vehicle crashes, falls, violence, and sports injuries. The use of safety devices, enactment and enforcement of traffic safety and other safety legislation, along with safety education and can reduce the number and severity of brain injuries that are sustained each year in Texas.

The TBIAC recommendations regarding prevention of brain injury are as follows.

- Promote coordination of local and regional injury prevention programs with state, public, and private injury prevention programs.
- Foster the implementation of evidence-based programs designed to lead to a reduction of brain injuries in both English and Spanish.
- Implement mandatory school prevention programs (e.g., *Think First*, an educational prevention program designed to prevent brain and spinal cord injuries).
- Provide childcare education to junior high /middle school students to prevent child abuse, especially shaken baby syndrome.
- Adopt laws that would require fencing, gates and locks around swimming pools everywhere.

The positive association between blood alcohol concentration and risk of injury has been well established.<sup>53</sup> Studies show that between 29 percent and 52 percent of individuals treated in the hospital for brain injury tested positive for blood alcohol.<sup>54</sup> In Texas, of all traffic fatalities in one year, 47 percent were alcohol-related. Additionally, Texas law does not require helmet use for motorcycle riders. The TBIAC recommends that:

- Additional and ongoing public education regarding the consequences of substance use prior to or while driving be made available, as well as consistent application of effective deterrents to such behavior in state traffic laws.

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<sup>53</sup> Smith, G. S., & Kraus, J. F. (1988). Alcohol and residential, recreational and occupational injuries: A review of the epidemiologic evidence. *American Journal of Public Health*, 79, 99-121.

<sup>54</sup> Miller, N. S., & Adams, J. (2005). Alcohol and drug disorders. In eds. Silver, J. M., McAllister, T.W., & Yudofsky, S. C. *Textbook of Traumatic Brain Injury*, p. 509. Washington, D.C.: American Psychiatric Publishing, Inc.

- The legislature consider passing and implementing state laws that require the use of helmets when driving or riding on a motorcycle.

## **Rehabilitation**

Adequate rehabilitation services are generally not available to individuals disabled by brain injury. Nationally, it is estimated that fewer than one in twenty individuals receive the rehabilitation needed to recover from a brain injury. Failure to provide effective, timely rehabilitation can result in lost productivity, increased medical costs, increased costs for education, increased crime, increased costs for criminal justice, and other direct and indirect costs to the community and state.

The TBIAC recommends that:

- The requirements of HB 1676 and HB 1919 be applied to health insurance plans for city and county employees, the Children's Health Insurance Program, and the State Kids Insurance Program benefit plans, as well as other health insurers.
- The requirements of HB 1676 and HB 1919 be applied to out-of-state insurance companies covering Texas beneficiaries.
- Funds be allocated at a sufficient level to accommodate all waiting/interest lists for Comprehensive Rehabilitation Services.

## **Community-Based Long-Term Care and Care Coordination**

As currently established, Medicaid services and Medicaid waiver services generally do not provide adequate services and supports for individuals with cognitive and/or emotional/behavioral and psychosocial impairments. There is a lack of care coordination and there are long interest lists for services.

- The TBIAC recommends that DADS amend the eligibility requirements (regardless of age of onset) and service array of Medicaid waiver programs to include:
  1. Service for individuals (including residential long-term care) who have incapacitating cognitive/emotional-behavioral/psychosocial dysfunction regardless of accompanying physical disabilities, and
  2. Provision of functionally based support, behavioral management, community integration services, medication management, family training, as well as intensive support if needed.
- The TBIAC recommends that a pilot study be conducted that would

1. Designate 10-15 group homes for individuals with brain injury who have cognitive, emotional/behavioral, psychosocial, and/or physical impairments ensuring geographical representation in the south and west Texas regions, as well as urban areas. The group homes should be based on the concept of the least restrictive environment and should maximize the independence of the residents.
  2. Evaluate the effectiveness of the program after one and two years.
- The TBIAC recommends that a jail diversion program for veterans with brain injury in the criminal justice system be developed and implemented after collaborations with representatives from health and human services, the criminal justice system and the VA. In addition, it should be determined whether parallel processes for other adults and juveniles with brain injury could be beneficial.

Failure to address the needs of brain injury survivors' neurobehavioral issues increases the risk of job loss, underemployment or unemployment, social isolation, homelessness, substance use disorders, inappropriate institutionalization, incarceration, and in some cases, further injury, or even death. These situations often result in a high cost to society. However, with appropriate and timely treatment; effective interventions and supports; these problems often are manageable or can be minimized.

## Conclusion

Persons with brain injury who do not receive appropriate and timely treatment experience problems that are life changing. Problems associated with employment, relationships, and activities of daily living often result in serious secondary issues such as substance use disorders, violence/abuse, criminal activity, incarceration, termination of marriages and parental rights, homelessness, and even death. The public health implications are far-reaching.

Important issues that are at the forefront for the TBIAC include:

- identification of persons with brain injury;
- identification of brain injury providers and services;
- timely and appropriate treatment;
- public and legislative awareness of the extent of the problems and issues;
- prevention, long-term care/intervention;
- collaboration with partners, teachers, and service providers; and
- education; and the special needs of children with brain injury.

The past success of the TBIAC has been greatly determined by the knowledge; experiences; enthusiasm; and unique relationships its membership brings to the table, and the series of brain injury grants awarded to DSHS. Since its inception, the TBIAC has made great strides in identifying needs of persons with brain injury and collaborating with partners to implement system changes. Still, there are multiple challenges that need to be addressed for the large and ever-growing population of those with brain injury, their family members, and society at large.

## Appendix I

### POSSIBLE CHANGES AFTER BRAIN INJURY

<i>Physical</i>	<i>Cognitive</i>	<i>Emotional/Behavioral</i>
<ul style="list-style-type: none"> <li>• Seizures</li> <li>• Spasticity</li> <li>• Tremors</li> <li>• Changes in sensual perception</li> <li>• Double vision</li> <li>• Visual field cuts</li> <li>• Hearing loss</li> <li>• Fatigue</li> <li>• Ataxia (problems with balance or coordination)</li> <li>• Dysphagia (problems swallowing)</li> <li>• Dysarthria (problems with articulation)</li> <li>• Autonomic dysfunction (disregulation of the stress reaction)</li> <li>• Hemiplegia or hemiparesis (paralysis or weakness of one side of the body)</li> <li>• Apraxia (inability to carry out purposeful movement)</li> </ul>	<ul style="list-style-type: none"> <li>• Level of consciousness</li> <li>• Attention/concentration</li> <li>• Memory</li> <li>• Planning</li> <li>• Organizing</li> <li>• Problem solving</li> <li>• Mental processing speed</li> <li>• Academic skills</li> <li>• Right-left orientation</li> <li>• Expressive language (spoken or written)</li> <li>• Receptive language (understanding what is said or written)</li> <li>• Constructional ability (ability to copy 2-D or 3-D designs)</li> <li>• Abstract thought</li> <li>• Insight</li> <li>• Generalization</li> <li>• Flexibility</li> <li>• Orientation (knowing who, what, when, where &amp; why)</li> </ul>	<ul style="list-style-type: none"> <li>• Impulsivity</li> <li>• Agitation (excessive restlessness)</li> <li>• Disinhibition</li> <li>• Lack of cooperation</li> <li>• Aggression, anger, hostility</li> <li>• Low frustration tolerance</li> <li>• Decreased social skills</li> <li>• Loose associations</li> <li>• Emotional lability (inappropriate fluctuations in mood)</li> <li>• Distortions of reality</li> <li>• Obsessions/compulsions</li> <li>• Tangentiality (answers to questions are obliquely related or unrelated)</li> <li>• Egocentrism</li> <li>• Lack of initiation/motivation</li> <li>• Perseveration (repeating an idea or action over and over)</li> </ul>

## Appendix II

### Council Members' Biographical Information

**Elaine Adams, Ph.D.** – is the mother of a TBI survivor and is a retired psychology professor of the Houston Community College District (HCCD). She has also served the District as Vice Chancellor for Educational Development, as Interim President of HCC-Central, and as the Founding President of HCC-Northeast. Prior to her work for HCCD, she held administrative posts at the Texas Higher Education Coordinating Board and at Prairie View A&M University. Her degrees are from Xavier University of Louisiana (B.A.), Louisiana State University (M.S.), the University of Houston-Clear Lake (M.A.), and the University of Southern California (Ph.D.).

Dr. Adams is the Assistant Presiding Officer of the TBIAC and serves on the Education Committee. She also serves as a member of the board of Advocacy, Inc., an organization supporting the rights of individuals with disabilities, and volunteers in her local community. She is the primary advocate for her son who was critically injured in an automobile accident at age 16 and spent months recovering in the Texas Institute for Rehabilitation and Research (TIRR). Now 32 years old, he is raising a family and working part-time in customer services.

**Mary Z. Adams, R.D., L.D.** – is the Director of the Division of Health Services with South Plains Community Action Association, Inc. in Levelland, Texas. She has fifteen years experience managing community based long-term care services for individuals with developmental disabilities, and currently oversees three home and community support services agencies. She serves as a provider representative on several state agency workgroups and was instrumental in developing the Texas HHSC's Consumer Directed Services program. Ms. Adams obtained her undergraduate degree from Cornell University in Ithaca, New York and completed a dietetic internship at Yale New Haven Hospital in New Haven, Connecticut. Ms. Adams is chair of TBIAC's Resources Committee and the By-Laws Committee.

**Timothy Atchison, Ph.D.** – is currently a professor of psychology at West Texas A&M University and is chair of the Institutional Review Board for the Protection of Human Subjects. Dr. Atchison is part of a committee developing an interdisciplinary neuroscience initiative and his current research is in recovery of function after brain injury. In addition, he has a collaborative grant project underway with the Brain Injury Research Center to explore training family members as paraprofessionals in cognitive rehabilitation using distance learning techniques and tools. This is important as many individuals in rural areas have a difficult time accessing services in rehabilitation. Funding for this project is provided by the NIDRR.

Dr. Atchison holds a Ph.D. in clinical psychology from the University of Houston in the neuropsychology track. Dr. Atchison trained at the Houston Medical Center and the Houston VA Hospital (now the Michael E. DeBakey VA Medical Center) rehabilitation unit. Additional training sites included the neuro-oncology section at M.D. Anderson Cancer Center, Baylor Neurology Department, and the Brain Injury Research Center. Dr. Atchison has also conducted assessments and provided treatment on brain injury in private practice settings. Dr. Atchison serves on the TBIAC's Identification Committee.

**Mary Carlile, M.D.** – is the Medical Director of TBI Services at Baylor Institute for Rehabilitation in Dallas. She is a Diplomate of the American Board of Physical Medicine and Rehabilitation and a Fellow in the American Academy of Physical Medicine and Rehabilitation. Dr. Carlile is active in the Texas and American Medical Associations. She is president of the Texas Physical Medicine and Rehabilitation Society.

Dr. Carlile is an advocate for survivors of TBI and their families and received the 2002 Professional Contribution Award from the BIA of Texas. In 2003, she received a Lifetime Achievement Award from the BIA. She chaired the founding Texas Traumatic Brain Injury Advisory Board and currently sits on the Texas TBIAC, working with state agencies and the government of Texas to improve supports and services for survivors of TBI. Dr. Carlile is active in teaching and research. She is assistant professor at the University of Texas Southwestern Medical School and attending physician at Baylor University Medical Center. Dr. Carlile is co-principal investigator of the North TBI Model System. Dr. Carlile is Chair of the TBIAC's Legislative and Policy Committee.

**Cynthia Cavazos-Gonzalez, Ph.D.** – is a licensed neuropsychologist in private practice in Edinburg, Texas. Formerly, Dr. Cavazos-Gonzalez was the clinical director of the Neurocognitive Rehabilitation Center (NRC) in Edinburg, Texas. Her areas of specialty include neurophysiology, rehabilitation psychology, bilingual assessments, and behavioral-health consultation in medical settings. She is also affiliated with several acute rehabilitation hospitals in the Hidalgo County area. Dr. Gonzalez is Co-Chair of the TBIAC's Education Committee.

**Jason E. Ferguson** – is employed as a research technician in a federally funded research grant at the Brain Injury and Stroke Program at Memorial Hermann/The Institute for Rehabilitation and Research (TIRR). The program maximizes a patient's outcome by providing specialized medical management, nursing, and therapy services in a hospital setting. Individual therapy, group treatment, and community outings address the patient's functional abilities. He serves as a member of the TIRR research team on two projects: one on substance use disorders following TBI and one on peer mentoring of social integration skills after TBI. Mr. Ferguson serves on the TBIAC's Legislation and Policy Committee.

Mr. Ferguson survived a severe traumatic brain injury in a motor vehicle accident in December 2002. He has an outstanding commitment to improving the lives of

others with TBI. He volunteered for two years as an assistant on the Quentin Mease inpatient rehabilitation unit at TIRR and also serves as an advisor for the TIRR and Training Center on Community Integration in Persons with TBI.

Mr. Ferguson was awarded the 2004 Survivor of the Year Award from the BIATX and the 2004 Volunteer of the Year Award from Harris County Hospital District. He is currently on the board of directors of BIATX.

**J. Charles Haynes** – has served as a consumer member on the TBIAC since 2005 and currently co-chairs the TBIAC ad hoc Veteran’s Affairs Committee. In 1979 Mr. Haynes’s sister sustained a TBI, an event that precipitated years of dedication in advocacy for individuals with TBI and their family members. His history and experience as a publisher of materials related to TBI, as well as an executive in advocacy organizations for brain injury and other disabilities demonstrate his interest in extending personal scientific knowledge in the field. He serves as the Executive Director of the North American Brain Injury Society, Alexandria, Virginia; the Executive Director of the Society for Neuro-Oncology, Houston, Texas, a multidisciplinary association of medical professionals working in the field of neuro-oncology; the secretariat of the International Brain Injury Association, Alexandria, Virginia, with primary responsibility for the administration and coordination of the biennial World Congress on Brain Injury, scheduled for April 2008, in Lisbon, Portugal; and supervises all communications and membership functions of the National Spinal Cord Injury Association, Rockville, Maryland, a national advocacy organization with over 14,000 active members. Mr. Haynes holds a doctorate of jurisprudence from South Texas College of Law, Houston, Texas, and a bachelor of arts from the University of Texas at Austin. Mr. Haynes serves on the TBIAC’s Education Committee.

**Barbara Kaatz** – is a special education teacher who works for TEA as a program specialist with IDEA Coordination. Ms. Kaatz works with the Policy and Texas Continuous Improvement Process Teams and came to TEA after teaching for 31 years. Ms. Katz serves on the TBIAC’s Identification Committee.

**Margaret Lazaretti** – is the deputy commissioner in charge of the Health & Workers’ Compensation Network Certification and Quality Assurance Division of the Life, Health and Licensing Program at TDI. Prior to assuming this position, she served several years in the quality assurance section of the Health Maintenance Organization Division, and in general management for the Life, Health and Licensing Program at TDI. In addition, Ms. Lazaretti has seven years of experience in the managed care industry and has held a number of clinical nursing positions. She received her undergraduate degree in nursing from the University of Texas at Austin, and earned her J.D. degree from Loyola University School of Law in New Orleans. Ms. Lazaretti serves on the Legislation and Policy Committee.

**Angela Lello** – has over eight years of professional experience in issues related to policies, services, and supports for persons with disabilities across all age

groups. She currently serves as the public policy director for the Texas Council for Developmental Disabilities, where she has been responsible for a variety of policy analysis, strategic planning, and public awareness activities, including coordinating with various interagency and external stakeholder groups concerning policy matters. Formerly, she worked as policy analyst with DADS and for the Austin Resource Center for Independent Living. Ms. Lello is also a family member of a person with a traumatic brain injury. Ms. Lello serves on the TBIAC's Resources Committee.

**R. Todd Maxson, M.D., FACS** – is the medical director of trauma services at Dell Children's Hospital of Austin. His primary research interests are brain injury and resuscitation of injured children. He is an active child safety advocate and lecturer. Dr. Maxson came to Dell Children's Hospital in 2006 from Children's Texas Children's Hospital in Dallas. Prior to his appointment there, he was at Ben Taub General Hospital in Houston where he was chief of pediatric surgery. Prior to that appointment he was the medical director of the Pediatric Trauma Program at Brackenridge Children's Hospital in Austin, Texas.

Dr. Maxson received his undergraduate degree in biochemistry from Texas A&M University and received his MD degree from the University of Texas Medical Branch at Galveston. He interned and did his Surgical Residency at the University of Arkansas, Arkansas Children's Hospital and completed his Pediatric Surgical Fellowship at Baylor College of Medicine, Texas Children's Hospital, Houston, Texas. Dr. Maxson serves on the Legislation and Policy Committee.

**Sonia Quintero** – is a Deafness Resource Specialist in Edinburg, Texas with funding provided by the Office for Deaf and Hard of Hearing Services (DHHS) of the Department of Assistive and Rehabilitative Services (DARS). She works with consumers with hearing loss, their families, and state, local and federal agencies and is responsible for addressing attitudinal and cultural barriers of the populations. She was formerly the case manager/outreach coordinator at Neurocognitive Rehabilitation Center (NRC) in Edinburg, TX. Throughout her career she has demonstrated an abiding commitment in working with brain injury survivors and their families to promote their self-determination, independence, productivity, integration, and inclusion in the community. As a family member of a survivor of brain injury she has attended hundreds of support groups; helping people to understand the impact of a brain injury. Ms. Quintero has been working in the field of brain injury rehabilitation since 1989. She has translated into Spanish brochures, materials, documents and resource information on brain injury and disability for the BIA of America and for other state organizations. She has been invited to give international presentations regarding the needs of people with brain injury. Currently, Ms. Quintero is co-chair of the TBIAC's Education Committee.

**Catherine A. Rich, J.D.** – is legal counsel with the Department of Veterans Affairs, Dallas VA Medical Center, Dallas, Texas. She is advisor to the administration and medical staff of the medical center and represents the medical

center in legal issues involving medical treatment of veterans and procurement. She is also legal advisor to the medical center in the areas of research, employee ethics and medical ethics. Prior to law school, Ms. Rich obtained her B.S. and M.S. degrees at Southern Methodist University in speech and language pathology and was employed with the Dallas Independent School District and the Visiting Nursing Association. She also maintains her license in this field. Ms. Rich is a survivor of a TBI. Ms. Rich is chair of the TBIAC's Nominations Committee.

**David Seaton** – is owner and chief executive officer of Live Oak Long-term Living Programs in Austin, Texas. He has more than 25 years experience working in brain injury rehabilitation and long-term care. He is a graduate of The University of Texas and completed his graduate studies in rehabilitation counseling. He is the president of the Seaton Foundation, which provides brain injury education and training programs for families and professionals on issues related to long-term planning. Mr. Seaton serves on the Texas TBIAC, on the Board of Directors of the North America Brain Injury Society, and is chairman of the Texas Brain Injury Society. Mr. Seaton serves on the TBIAC's Resources Committee.

**Joe C. Shockley** – resides in Montgomery, Texas and retired June 6, 2005, after 44 years of service with Centerpoint Energy as the construction supervisor for the south district. Mr. Shockley serves on the TBIAC's Education and Nominations Committees. His biographical statement is as follows:

“On February 1, 1995 my life was forever changed. My only son, a senior honor student at Texas A&M University, was involved in a bus/bicycle accident on the campus. The accident left him in a coma for two and a half months. In addition to the traumatic brain injury the dual rear wheels of the eighteen-ton bus crushed both legs. The accident also broke his jaw and crushed his right rib cage, puncturing his lung. For two months he was not expected to live. He was 26 years old at the time of the accident and was no longer on my employers' policy. After three months of fighting to get him the help he desperately needed, the Transitional Learning Center (TLC) stepped in giving him the help he needed. After three months in critical care he went to TIRR for six months and then to (TLC) in Galveston for nine months. He came home in June 1996 and continued in outpatient rehab for three years; during this time he learned to walk again. After another six years of trying to get his vision corrected, he was able to return to A&M where he graduated with honors in December 2003.”

Mr. Shockley continues his story and that of his son, Trevor. “His goal before the accident was to be a veterinarian. He is now a graduate student at the University of North Texas working on his masters in rehabilitation counseling. His goal is to help and encourage others going through what he experienced. Trevor and all who love him will forever be grateful to God and all who helped and are still helping him. Along with two other parents of children with TBI we started a camp for people with TBI called Higher Ground in September 1997. This camp is held each May at Camp for All at Burton, Texas. The camp is now under the direction

of the Pilot Club of Texas. For as long as God allows me to live I will forever be an advocate for people with TBI and those who care for and support them.”

**Erroll Jacob Smith** – from Edinburg, Texas, is a survivor of TBI. His biographical statement is as follows:

“My life was looking very bright up until my accident. I'd just graduated college where I had played basketball and was in great physical condition, but when driving to a summer job as a camp counselor I was involved in a horrendous accident. I was blessed, as an off duty Emergency Medical Technician stopped to help at the accident site and I began my second life's journey. I'd have to develop every human ability over again, both mentally and physically. My great support team (family and friends) is a huge reason I'm where I am today. I feel a survivor's environment influences the recovery of the victim so much that it's a huge predictor of the final outcome of the recovery. I've been very blessed at who all my wonderful family and friends are, and this along with hard work has gotten me to where I am today, a certified elementary physical education teacher who is about to finish his first year teaching triumphantly. It was never easy, but it all paid off.”

“I graduated from Southwestern University in Georgetown. I worked at Camp Champions as a camp counselor one exactly year after my injury. It was a rough job that year, but if I hadn't done it then I wouldn't have been able to work as well the following four summers at camp. I used to substitute teach for Edinburg Independent School District, but with the help of the Lord, I received my certification and now teach in the McAllen (Texas) School District. I'm currently a physical education teacher at Milam Elementary in McAllen.”

Mr. Smith serves on the TBIAC's Education Committee.

**Maxcine Tomlinson** – has a master's degree in social work with an emphasis in mental retardation and developmental disabilities from the University of Kentucky-Lexington. She has worked with persons with mental retardation, developmental disabilities, and the aging from August 1983 to November 1998 in: alternate placement in the community and state school; survey and certification in Intermediate Care Facilities for Persons with Mental Retardation (ICFMR); consumer assessment and quality assurance in ICFMR group homes and nursing facilities; and policy writing and analysis in various long term care programs. Ms. Tomlinson was responsible for policy, rules, and compliance in the Texas Medicaid Hospice Program from November 1998 through September 2006. Currently, she works in the Stakeholder Relations Unit, Center for Consumer and External Affairs at DADS. Ms. Tomlinson is responsible for responding to constituent issues and complaints and requests for information from legislators and their staff. This requires extensive knowledge in program in the aging and disability arenas and other enterprise agencies. Ms. Tomlinson serves on the TBIAC's Nominations Committee.

**Tom Valentine** – began his public service career as a special education teacher at the Callier Center for Communication Disorders in Dallas, Texas. Mr. Valentine has been a special education teacher at the Texas School for the Blind, and a special education consultant at TEA. In 1981 Mr. Valentine joined the staff of the Legislative Budget Board (LBB) where he was the senior analyst and team leader for the health and human service function. Mr. Valentine left the LBB in 1993 and became the deputy director for management at the Department of Protective and Regulatory Services. Three years later he joined the staff of the Texas State Auditor, where he was the manager for health and human services audits. Mr. Valentine rejoined the staff of the LBB as the special assistant to the director assigned to the Office of State and Federal Relations in Washington D.C. in 1997. In 1999 Mr. Valentine assumed the position of chief of staff for the congressman from the 13<sup>th</sup> Congressional District. Following this position, Mr. Valentine joined the staff of the National Mental Health Association as the chief operating officer. In late 2003, he returned to Texas as the senior policy advisor for health services at HHSC. He is a graduate of Southern Methodist University and a father of two grown children. Mr. Valentine serves on the TBIAC's Resource Committee.

**Lesa R. Walker, M.D., M.P.H.** – is the Texas Title V CSHCN director and the systems development manager in the Purchased Health Services Unit of DSHS. Dr. Walker oversees the planning and implementation of the Title V CSHCN initiatives and services to improve the quality of care for CSHCN and their families in Texas. She has served in a leadership role in the CSHCN Services Program for 19 years, representing the program on many state and federal committees and authoring numerous program policies and rules. She was a contributing author to Healthy People 2010, Chapter 6, relating to people with disabilities. Dr. Walker received her M.D. in 1980 from Baylor College of Medicine in Houston, Texas and her M.P.H. in 1982 from the University of Texas School of Public Health, also in Houston. She completed her preventive medicine/public health residency at the University of Michigan School of Public Health in Ann Arbor, Michigan. She is board certified in general preventive medicine/public health.

**Les Young** – has a B.A. in English and provides technical support to vocational counselors serving consumers with any neurological disorder and is the comprehensive rehabilitation services program specialist for DARS. He has worked for DARS for nine years; serving clients in the Vocational Rehabilitation program and Comprehensive Rehabilitation Services program. He has worked in the field of human services for more than thirty years in a variety of settings. In the past fourteen years Mr. Young has worked with clients with brain injury in rehabilitation hospitals, community vocational rehabilitation programs, sheltered workshops, and for the legacy Division for Rehabilitation Services and DARS. He has also served as an administrator of services to homeless families. He has developed many training programs for DARS regarding the needs of people with brain injury and spinal cord injury. Mr. Young serves on the TBIAC's Identification Committee.