Traumatic Brain Injury Act: Overview

Background
On July 29, 1996, President Bill Clinton signed the Traumatic Brain Injury (TBI) Act of 1996 (P.L. 104-166) authorizing funding to the US Department of Health and Human Services (DHHS) for prevention, education, research and grants to States to increase access to services for individuals with TBI and their families. Reauthorizing legislation passed as part of the Children’s Health Act of 2000 (P.L. 106-310), and included authorization for grants for state Protection and Advocacy Systems to expand their services to include TBI. In 2008, legislation reauthorized programs through FY 2012.

Since 1997, Federal funds have been awarded to 48 States, District of Columbia, and two Territories through a competitive grant process for purposes of developing, expanding and improving access to service delivery for individuals with TBI and their families. Funds have also been appropriated to the Centers for Disease Control and Prevention (CDC) for injury surveillance, prevention and public education programs, of which, some of these funds have been awarded to State health departments to carry out these projects. Through these projects, CDC determines incidence and prevalence of TBI, causes of injuries and costs associated with treatment and care. CDC has produced studies on mild TBI, TBI among inmates of correctional facilities, and more recently, concussions due to sports-related injuries.

TBI Act of 1996 (P.L. 104-166)
The bill authorized funding for prevention, surveillance, research and State grant programs to improve service delivery and access for individuals with TBI. The bill defined the term “traumatic brain injury” as “an acquired injury to the brain. Such term does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma, but may include brain injuries caused by anoxia due to near drowning.”

Section 1 authorized $3 million for each fiscal year from 1997 through 1999 for CDC to carry out projects to reduce the incidence of traumatic brain injury either directly or through awards of grants or contracts to public or nonprofit private entities.

Section 2 authorized the National Institutes of Health (NIH) to award grants or contracts to public or nonprofit private entities for the conduct of basic and applied research.

Section 3 authorized the $5 million for each fiscal year from 1997 through 1999 for HRSA to make grants to States for purpose of carrying out demonstration projects to improve access to health and other services. This section also:

- Required States to establish an advisory board within the appropriate health department or within another department as designated by the chief executive officer to the State to advise and make recommendations to the State on ways to improve services coordination regarding TBI.
- Required States to match Federal dollars in the amount that is not less than $1 for each $2 Federal funds provided under the grant.
- Required DHHS to coordinate activities under this section with other Public Health service agencies.
Section 4 required DHHS through appropriate agencies to conduct a study for the purposes of determining the incidence and prevalence of TBI and developing a uniform reporting system of TBI; to identify common therapeutic interventions which are used for the rehabilitation of individuals with TBI, including the effectiveness of such interventions and the adequacy of existing outcome measures; and to develop practice guidelines for the rehabilitation of TBI at such time as appropriate scientific research becomes available.

- Required the National Center for Medical Rehabilitation Research within the National Institute for Child Health and Human Development to conduct a national consensus conference on managing TBI and related rehabilitation outcomes.

TBI Amendments of 2000 (P.L. 106-310)

On October 17, 2000, President Bill Clinton signed the TBI Act Amendments of 2000 as part of the Title XIII of the Children’s Health Act of 2000 (P.L. 106-310). The law extended the authorization of the TBI Act for five years and authorized “sums as may be necessary” to carry out programs in lieu of a designated amount. The law also changed the definition of TBI by replacing the phrase “anoxia due to near drowning” with “anoxia due to trauma”, except for the section pertaining to data collection for determining incidence and prevalence. Other changes include:

Section 1301 established the National Education and Awareness Campaign regarding injury in conjunction with the goals set forth in Healthy People 2010, including:

- The national dissemination of information on incidence and prevalence; and information relating to traumatic brain injury and the sequelaes of secondary conditions arising from traumatic brain injury upon discharge from hospitals and trauma centers and
- The provision of information in primary care settings, including emergency rooms and trauma centers, concerning the availability of State level services and resources.

Section 393B added a new subsection regarding TBI registries and authorized CDC to expand State TBI surveillance, education and prevention programs. Provided for registries to collect data concerning:

- Demographic information;
- Information about the circumstances surround the injury;
- Administrative information about the source of the collected information, dates of hospitalization and treatment, and the date of injury; and
- Information characterizing the clinical aspects of the TBI, including the severity of the injury, outcomes, types of treatments received, and types of services used.

Section 1302 expanded the study of incidence and prevalence of TBI to specifically include individuals in institutional settings and individuals with mild brain injury, and to report findings on mild brain injury to Congress.

Section 1303 authorized the NIH to carry out applied research related to cognitive disorders and neurobehavioral consequences, including the development, modification, and evaluation of therapies and programs of rehabilitation toward reaching or restoring normal capabilities in areas such as reading, comprehension, speech, reasoning, and deduction.

Section 1304 reauthorized HRSA to make capacity building grants to States to improve access to health and other services for individuals with TBI and their families. The 2000 Amendments removed the term “demonstration” to denote the type of projects to be awarded. The law added a new section to
allow States that had received grants prior to the enactment of the 2000 Amendments to apply for funds under a new category. The 2000 Amendments also:

- Added language that recognizes self-determination, and consumer direction of services and supports.
- Allowed States to (directly or through awards of contracts to nonprofit private entities) to use amounts received under a grant to develop, change, or enhance community-based service delivery systems that include timely access to comprehensive appropriate services and supports.
- Expanded the type and range of projects that could be funded, from consumer education to service coordination systems to improved data sets coordinated across systems.
- Allowed States to use “in-kind” matches, in lieu of State dollar match.
- Required the State agency responsible for administering amounts received under the grant to be able to demonstrate that it has knowledge and expertise of traumatic brain injury and the unique needs associated with TBI.
- Required State services and supports to reflect best practices in the field of traumatic brain injury and to be in compliance with Title II of the Americans with Disabilities Act of 1990.
- Promoted full participation by individuals with brain injury and their families in decision making regarding the services and supports.
- Allowed use of funds for contracts to be awarded to nonprofit entities for consumer or family service access training, consumer support, peer mentoring, and parent to parent programs.
- Allowed use of funds to develop individual and family service coordination or case management systems.
- Recognized that existing State systems could be tailored or expanded to accommodate the needs of individuals with TBI, including State agencies that administer health, mental health, labor/employment, education, developmental disabilities, transportation, and correctional systems.

Section 1305 adds new section authorizing HRSA to make grants to State P&A systems for advocacy services for individuals with TBI to include:

- Information, referrals, and advice
- Individual and family advocacy
- Legal representation
- Specific assistance in self-advocacy

The section provides a mechanism to automatically provide funds to each state and territory P&A System contingent on sufficient appropriations to allow formula funding.

**Traumatic Brain Injury Act of 2008 (P.L. 110-206)**

On April 28, 2008, President George Bush signed the Reauthorization of the TBI of 2008, extending reauthorization of programs through FY 2012 (P.L. 110-206). The bill made minor changes to reflect current language used with regard to CDC public education and data collection; re-designated sections relating to CDC, and added American Indian Consortium as an eligible entity for grant funds awarded by the HRSA Federal TBI State Grant Program.

Section 393B(b)(3)(A) amended language relating to dissemination of information to individuals after discharge from hospitals and trauma centers by striking the term “trauma centers” and inserting “emergency departments”.

Section 393C added “Surveillance” to the National Program for Traumatic Brain Injury Registries title and expanded registry and surveillance programs to include linking individuals with traumatic brain injury to services and supports. The section directs CDC to (1) determine incidence and prevalence of
brain injury related disability and the clinical aspects of the disability in all age groups and racial and ethnic minority groups in the general population of the United States, including institutional settings, such as nursing homes, correctional facilities, psychiatric hospitals, child care facilities, and residential institutes for people with developmental disabilities; (2) report on national trends in TBI; and (3) report any study relating to incidence and prevalence to Congress not later than three years after the enactment of the Act.

Congress also added a new subsection to require CDC and NIH in consultation with the Department of Defense and the Department of Veterans Affairs to submit a report to Congress on methods for collecting and disseminating compatible epidemiological studies on the incidence and prevalence of TBI in the military and veterans’ populations that return to civilian life.

Section 1252 added American Indian Consortium as defined by the Developmental Disabilities (DD) Act as eligible for funding from the HRSA TBI Federal State Grant Program. The DD Act defines American Indian Consortium as:

Any confederation of 2 or more recognized American Indian tribes, created through the official action of each participating tribe that has a combined total resident population of 150,000 enrolled tribal members and a contiguous territory of Indian lands in 2 or more States.

The purpose of the grant program was amended to improving access to “rehabilitation” and other services, instead of health and other services.

Section 1253 requires HRSA to pay any P&A System in compliance not later than October 1 the total amount of the grant for such system, unless the system provides otherwise for such payment. The law requires HRSA and the Administration on Developmental Disabilities to enter into an agreement to coordinate the collection of data with regard to P&A services. Included a new provision for Training and Technical Assistance by the National Disability Rights Network when the amount for the HRSA TBI P&A Grant Program is $6 million or greater. HRSA shall use 2 percent of such amount for TA to state P&A Systems.

The law also allows P&A Systems to have access to TBI records as necessary to carry out functions authorized under this Act.

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