

## History of the TBI Act

### ***Background***

The Traumatic Brain Injury Act Amendments of 2000 is the reauthorization legislation of the TBI Act of 1996, which was passed in response to the advocacy efforts of the Brain Injury Association of America. TBI legislation was filed initially by Senator Edward Kennedy in 1991 and re-introduced in 1992, (S. 2949 and H.R. 5907) 1993 (S. 725 and H.R. 3121), 1994 (S. 725) 1995 (S. 96 and H.R. 248), and 1996. The earlier proposals focused on prevention, proposed marketing standards, practice guidelines, and outcome studies. These proposals provided for State grants for purposes of developing an extensive program of advocacy and service system coordination. In the early versions direct services were authorized.

In February 1994, Kennedy introduced S. 725 that contained substantial amendments to the earlier proposals. In this legislation:

- HRSA was specifically designated as the granting agency for State programs
- Most of the prescriptive language for the grant program was removed
- A State cash match requirement was introduced: \$1 State for every \$2 Federal

In 1995, Senator Hatch and Senator Kennedy introduced S. 96, which was a significantly watered-down version of earlier proposals. Representatives Greenwood and Pallone introduced the same legislation, H.R. 248, in the House. Neither bills passed that year. However, the house version passed in 1996 as the Traumatic Brain Injury Act of 1996. The Act was reauthorized in 2000 as Title XIII of the Children's Health Act of 2000 (P.L. 106-310). The law is up for reauthorization in 2005.

### ***Traumatic Brain Injury Act of 1996 (PL 104-66)***

In 1996, Congress passed H.R. 248, the Traumatic Brain Injury Act of TBI Act of 1996. Senators Kennedy and Hatch introduced similar legislation in the Senate, S. 96. The bill was signed by President Clinton on July 29, 1996 and became P.L. 10-166. The law amended the Public Health Services Act to provide for the conduct of expanded studies and the establishment of innovative programs with respect to traumatic brain injury, and for other purposes. In summary:

In general, the bill authorized funding for prevention, surveillance, research and State grant programs to improve service delivery and access for individuals with traumatic brain injury. 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 -- Programs of Centers for Disease Control and Prevention**

Section 1 authorized the Centers for Disease Control and Prevention (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. Activities authorized included the implementation of public information and education programs for the prevention of injuries, as well as promoting public awareness concerning the public health consequences of such injuries. The bill required CDC to coordinate activities under this section with other agencies of the Public Health Services responsible for activities regarding TBI.

## **Section 2 -- Programs of National Institutes of Health.**

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 -- Programs of the Health Resources and Services Administration**

Section 3 authorized the US Department of Health and Human Services (DHHS), Health Resources and Services Administration (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 that the advisory board be comprised of representatives of appropriate State agencies, public and nonprofit private health related organizations, other disability advisory or planning groups, members of an organization representing individuals with TBI, injury control programs, and a substantial number of individuals with TBI or the family members of such individuals.
- 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 -- Programs of the Department of Health and Human Services**

Section 4 required the DHHS 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.

### ***Traumatic Brain Injury Amendments of 2000 (P.L. 106-310), as part of the Children's Health Act of 2000)***

On October 17, 2000, President Bill Clinton signed the TBI Act Amendments of 2000 as Title XIII of the Children's Health Act of 2000. The Children's Health Act of 2000 (P.L. 106-310) is a compilation of many different bills, both new and existing, that amended the Public Health Service Act with respect to children's health. The Children's Health Act, H.R. 4365, was sponsored by Representative Mike Bilirakis (R-FL). It authorized expanded research and services for a range of childhood and prenatal health problems, including autism, diabetes, asthma, hearing loss, epilepsy and traumatic brain injury.

The TBI Act Amendments of 2000 was introduced by Senator Hatch (S. 3081) initially in a separate bill that was later folded into H.R. 4365. The law extended the authorization of the TBI Act from three to five years. The law also changed the definition of TBI by replacing the phrase “anoxia due to near drowning” with “anoxia due to trauma.” Other changes include:

### **Section 1301 – Programs of Centers for Disease Control and Prevention**

Added the implementation of a 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 sequelae of secondary conditions arising from traumatic brain injury upon discharge from hospitals and trauma centers;
- 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 traumatic brain injury registries.

Authorized CDC to expand State surveillance, education and prevention programs for TBI.

Authorized CDC to make grants to States or their designees to operate the State’s TBI registry, and to academic institutions to conduct applied research that will support the development of such 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 traumatic brain injury 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 – Programs of National Institutes of Health.**

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 – Programs of Health Resources and Services Administration**

Authorized HRSA to make capacity building grants to States to improve access to health and other services for individuals with traumatic brain injury 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.

- 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.
- 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 -- State Grants for Protection and Advocacy Services**

Adds new section authorizing HRSA to make grants to State P&A systems for advocacy services for individuals with TBI. Services 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 contingent on sufficient appropriations to allow formula funding.

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