

# History of the Traumatic Brain Injury (TBI) Act

# Background

In 1996, Congress passed the Traumatic Brain Injury Act of 1996 (P.L. 104-166) and the bill was signed by President Bill Clinton on July 29, 1996. This is the first and only legislation passed specifically to address needs of civilians with brain injury. Subsequent reauthorizing legislation passed as part of the Children's Health Act of 2000, and is referred to as the Traumatic Brain Injury Amendments of 2000 (P.L. 106-310). In 2008, President George W. Bush signed the TBI Reauthorization Act on April 28. On November 26, 2014, President Obama signed into law the Traumatic Brain Injury Reauthorization Act of 2014 (P.L. 113-196). President Donald Trump signed the Traumatic Brain Injury Program Reauthorization Act of 2018 on December 22, 2018.

The overall purpose of the legislation is to assist States in expanding and improving access to service delivery for individuals living with traumatic brain injury (TBI); provide protection and advocacy services to individuals living with a TBI; obtain data with regard to incidence and prevalence; conduct public education and awareness; and conduct research for primary, secondary and tertiary prevention. These activities are directed to three federal agencies within the U.S. Department of Health and Human Services (HHS): Administration for Community Living (ACL); Centers for Disease Control and Prevention (CDC); and the National Institutes of Health (NIH).

The following is a summary of the TBI Act of 1996 and subsequent reauthorizing legislation:

# TBI Act of 1996 (P.L. 104-166)

- Defined traumatic brain injury (TBI).
- Authorized funding to the Department of Health and Human Services' (HHS) Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), and Health Resources and Services Administration (HRSA) to conduct TBI studies and to improve access to service delivery.
- Authorized studies and innovative program through NIH.
  - Directed NIH to conduct a national consensus conference on managing TBI and related rehabilitation outcomes, which was conducted by the National Center for Medical Rehabilitation Research within the National Institute for Child Health and Human Development and held in 1998.
- Authorized CDC to carry out projects to reduce the incidence of TBI 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.
- Authorized funding to the Health Resources and Services Administration (HRSA) for State demonstration grants to expand access to health and other services
  - o Required State match.
  - o Required advisory board.
- Authorized programs from fiscal year1997 through fiscal year1999

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

- Extended the TBI Act programs from 3 to 5 years.
- Authorized CDC to conducted a national education and awareness campaign in conjunction with the *Healthy People* goals Section 1301), including
  - The national dissemination of information on incidence and prevalence; and information relating to TBI and the sequelae of secondary conditions arising from TBI 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.
- Added new CDC section (393B) on registries to expand state surveillance, including incidence and prevalence of TBI in institutional settings and mild brain injury, and to expand education, and prevention programs. 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.
- Authorized 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.
- Authorized HRSA to make capacity building grants to improve access to health and other services, removing the term "demonstration," which was in the initial law.
- Added language recognizing self-determination and consumer direction of services and supports, and the use of funds was expanded to include an array of services and supports, including consumer education and service coordination.
- Allowed to use "in-kind" match in lieu of State dollar match.
- 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.
  Added new section on Protection & Advocacy Grants to be administered by HRSA.
- P&A Services include: information, referrals, and advice; individual and family advocacy; legal representation; and specific assistance in self-advocacy.
- Provided a mechanism to automatically fund each State and territory contingent on sufficient appropriations to allow formula funding.

#### Reauthorization of the TBI Act of 2008 (P.L. 110-206)

- Authorized appropriations to HHS through FY 2012.
- Made minor changes to reflect current language used with regard to CDC public education and data collection; and re-designated sections relating to CDC.
  - Added "surveillance" to the National Program for Traumatic Brain Injury Registries title, Section 393C.
  - Expanded registry and surveillance programs to include linking individuals with TBI to services and supports.
  - Directed CDC to 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.
  - Directed CDC to report on national trends in TBI; and report any study relating to incidence and prevalence to Congress not later than three years after the enactment of the Act.

- 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
- Added American Indian Consortium as an eligible entity for grant funds awarded by the HRSA Federal TBI State Grant Program.
- Changed "health" to "rehabilitation" as the purpose of the State grant program, "improving access to rehabilitation and other services regarding TBI."
- 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 technical assistance (TA) to P&A Systems.

### TBI Reauthorization Act of 2014 (Public Law 113-196)

- Directed CDC, in consultation with NIH, to conduct a study of scientific evidence research related to brain injury management in children and identify opportunities for research.
- Removed Health Resources and Services Administration (HRSA) from the sections authorizing the State and the P&A grant programs, leaving the administration of these program to be determined by the Secretary of HHS.
- Directed HHS to develop a plan for the improved coordination of federal activities.
- Authorized funding for TBI programs through fiscal year 2019.

#### Traumatic Brain Injury Program Reauthorization Act of 2018 (Public Law 115-377)

- Authorized CDC to collect and analyze data regarding the national prevalence and incidence of concussions.
- Designated the HHS' Administration for Community Living as the agency to administer the TBI State and P&A grant programs.
- Reauthorized funding through 2024.
- Required HHS to submit to two House Committees and the Senate describing the findings and results of the programs established for State grant and P&A grant programs, including measures of outcomes and consumer and surrogate satisfaction.

This summary was prepared by Susan L. Vaughn, NASHIA Director of Public Policy. Visit NASHIA's website for additional information on TBI and public policy: <u>www.nashia.org</u>. May 2022.