



National Association of State Head Injury Administrators

# State Programs and Services for Individuals with Traumatic Brain Injury (TBI) and Their Families

## Overview

Beginning in the 1980s, States began responding to families requesting services and assistance to address the unique cognitive and behavioral needs of individuals with traumatic brain injury (TBI) or acquired brain injury (ABI). Often, these individuals found that their insurance coverage was insufficient to cover the array of short-term and long-term rehabilitation care and community supports. States began developing infrastructure and capacity for addressing these complex, unique needs associated with TBI-related disabilities. To pay for services and supports, States use a combination of funding streams, including State revenue; dedicated funding, usually from traffic fines (generally referred to as a trust fund); Vocational Rehabilitation; Title V Special Health Care Needs; and Medicaid.

State programs may be administered by health, Vocational Rehabilitation, Medicaid, education, social services agencies in partnership with community organizations, providers and professionals.

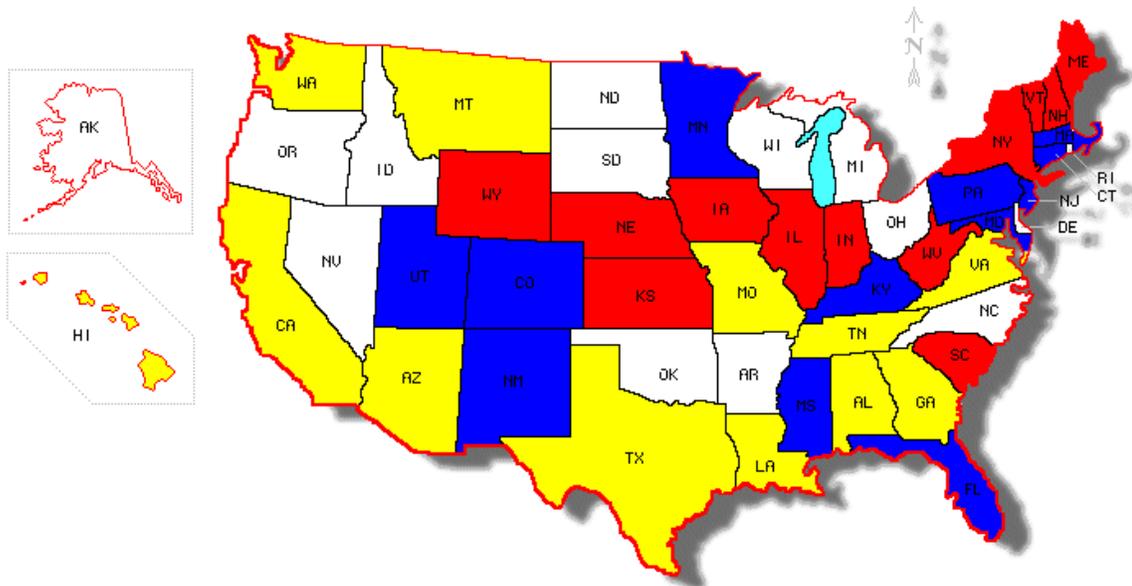
The TBI Act of 1996 authorized funding to assist States in developing and expanding capacity for rehabilitation and services. Since 1997, the U.S. Department of Health and Human Services (HHS) has administered time-limited grants, which have helped State to develop infrastructure to expand service capacity to include underserved and unserved populations (i.e. veterans and returning servicemembers; victims of domestic violence; and children and youth).

## STATE TBI PROGRAMS

### Map Key:

- Yellow** -- Trust Fund Program/dedicated funding only
- Red** – TBI/ABI Medicaid HCBS Waiver Program or 1115 Demonstration Program only
- Blue** – Both trust fund/dedicated funding and Medicaid HCBS Waiver/1115 Demonstration Program

**Note:** Some States receive State revenue (general revenue) for specific TBI services in addition to the sources below or may receive State revenue only to support TBI specific services (i.e. ND, OH and AK). States may also serve individuals with TBI/ABI under other HCBS waiver programs, disability programs and through other federal programs.



## Background

Each State has addressed needs by enacting legislation or Executive Orders to develop service infrastructure necessary to develop and to expand service delivery. These efforts include establishing or designating:

- An **advisory body** (council/board/task force) charged with responsibility for planning and recommending policies to address gaps in services, including coordinated systems of care.
- A **brain injury registry** and/or trauma registry to obtain data, and in some States, to link individuals to services.
- A **State agency** responsible for an array of community services and supports.
- **Funding** mechanisms to pay for services and supports (i.e. State, Trust Fund, Medicaid).

In addition, States have:

- **Expanded existing systems** developed for individuals with other disabilities or health care needs to include TBI, where appropriate.
- **Provided training opportunities** to expand the knowledge among health, rehabilitation and disability professionals.

## TBI Trust Fund Programs

Twenty-three (23) States have enacted legislation designating funding, usually associated with traffic fines and/or surcharges to vehicle registration and motor vehicle licenses, for an array of programs and services for individuals with TBI and their families. The revenue is usually collected by county clerks and forwarded to the State treasurer to be placed in a non-reverting account. The legislation designates a State agency to administer the funds. Most States established an advisory body to provide input and oversee the fund.

There is variability with regard to the amount generated and how the funds are used. States may use funding to support a registry; public education and awareness; prevention; rehabilitation; case management or service coordination; family education; and an array of rehabilitation and community services and supports. A few States with similar funding mechanisms do not refer to the program as a "trust fund", as such. And, at least two States do not have a fund generator.

## HCBS Medicaid Waivers

Section 1915(c) of the Social Security Act allows States to provide an array of home and community-based services (HCBS) that are in addition to Medicaid State Plan services for individuals who are Medicaid eligible and are at risk for institutional or nursing facility services. Almost half of the States have implemented TBI/ABI HCBS Waiver programs.

States also provide HCBS waiver services to individuals with TBI through other waiver programs for individuals with disabilities and/or through 1115 Demonstration waivers providing managed care for long-term services and supports (LTSS). Services covered consists of case management, therapies, in-home supports, personal care, durable medical equipment and in-home/vehicle modifications.

## Maximizing Existing Systems and Resources

States have expanded existing disability, health and children's programs to meet the needs of people with brain injury, where possible. These efforts include training and support for educators; special health care needs programs; Vocational Rehabilitation, substance abuse, and mental health providers to better serve individuals with TBI.

A few States have enacted laws to expand the definition of intellectual/developmental disabilities to include TBI as a developmental disability. Some States have also expanded existing State rehabilitation or health facilities to include rehabilitative services for TBI.

## Federal HRSA TBI Grants

Since 1997, the Federal TBI State Grant Program has supported States' efforts to expand and improve services to underserved and unserved populations, including children and youth; veterans and returning troops; victims of domestic violence; and individuals with co-occurring conditions. These grants have varied in amount of funding and duration of the grant. More recently, the federal program has awarded grants to 19 States over a period of four years, providing roughly \$250,000 annually to assist States in changing systems and developing partnerships to sustain activities.

Over the years, a total of 48 States, Territories, and District of Columbia have participated in the program. States have developed systems for early referral from hospital to home and community services; training to improve the workforce; information & referral services; and establishing resource facilitation and service coordination. More recently, States have used funding for screening and training in youth services programs, correctional facilities and victims of domestic violence programs. And, States have partnered with State Veterans Affairs, National Guard/Reserve and military associations to provide outreach to returning servicemembers with TBI.

The federal law requires the establishment of a State advisory board. The grant program has required the development of a strategic plan with recommendations for maximizing and coordinating State and local resources.

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