

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

### Overview

Beginning in the 1980s, States began responding to families calling for services and assistance to address the unique cognitive and behavioral needs of individuals with traumatic brain injury (TBI). 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. States use a combination of funding streams to support an array of services, including State revenue, dedicated funding (trust fund), usually from traffic fines, Vocational Rehabilitation, federal grants, and Medicaid.

Since 1997, Federal Health Resources and Services Administration (HRSA) TBI State Grants have been instrumental in assisting States to develop, expand and improve systems, services and resources. Over the years, States have expanded efforts to address the needs of veterans and returning servicemembers; victims of domestic violence; and children and youth served in education, special health care needs and youth services programs.

Programs may be administered by health, Vocational Rehabilitation, Medicaid, education, social services agencies within the States and in partnership with community organizations, providers and professionals.

### STATE TBI PROGRAMS

#### Map Key:

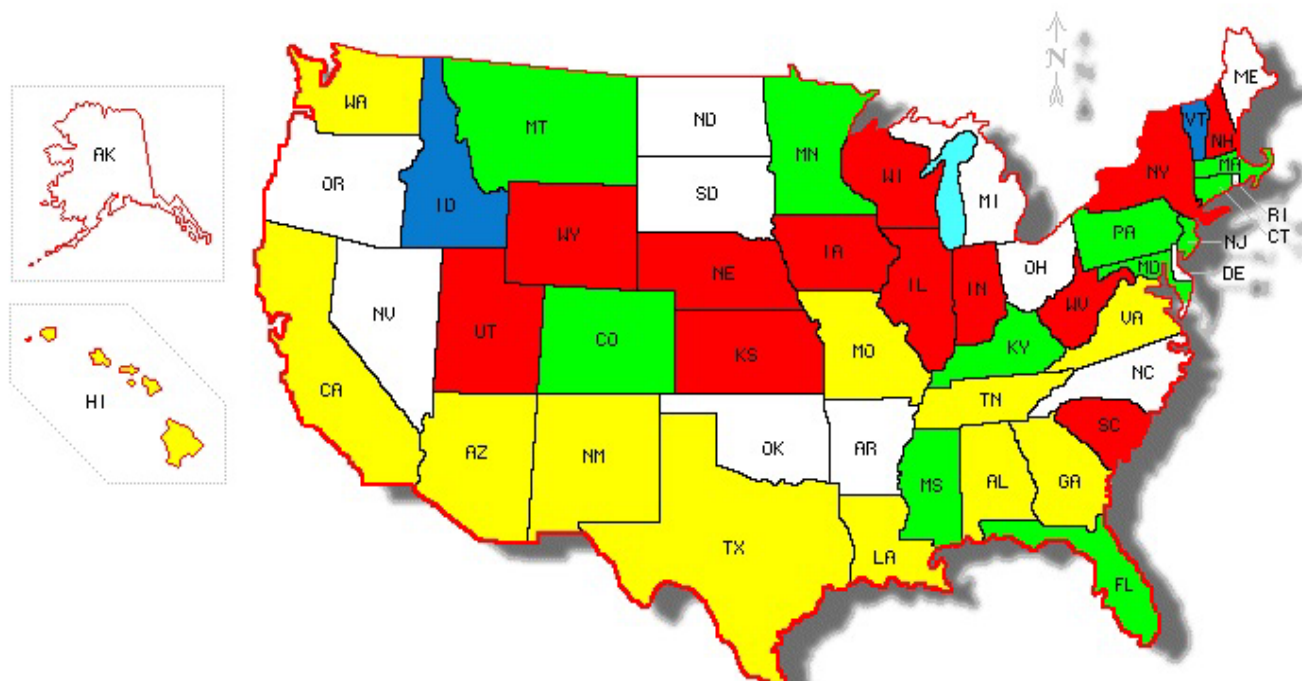
**Trust Fund Programs** (Yellow)

**TBI Medicaid HCBS Waiver Programs** (Red)

**Both Trust Fund and Waiver Programs** (Green).

**Combined their TBI Waiver programs into other HCBS or long-term care waiver programs** (Blue)

**Note:** Many States, including North Dakota and Alaska, receive State appropriated funding for specific TBI services, such as service coordination. Also, Michigan is in the process of submitting a Medicaid HCBS waiver.



## Background

Each State has addressed needs by enacting legislation or Executive Orders to develop service infrastructure necessary to develop and to expand service delivery to fill in the gaps, including:

- 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).
- **Expanding existing systems** developed for individuals with other disabilities or health care needs.
- **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 across the States with regard to the amount generated and how the funds are used. States may use funding to support a registry for determining incidence and prevalence; 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.

## 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 State Plan services to targeted populations or targeted areas of the State who are Medicaid eligible and are at risk for institutional or nursing facility services. Since 1991, almost half of the States have implemented HCBS Waiver programs specifically for TBI.

States also provide HCBS waiver services to individuals with TBI through other waiver programs, such as waiver programs for physical disabilities or intellectual/developmental disabilities. Services covered consists of case management, therapies, in-home supports, personal care, durable medical equipment and in-home 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. States have developed capacity for training and support for educators; special health care needs programs for children; and Vocational Rehabilitation, substance abuse, and mental health providers to better serve individuals with TBI. More recently, States have engaged in 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.

A few State 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 State 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 20 States over a period of five years, ending in the spring of 2014, and which has provided 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; resource facilitation and service coordination; and implementation of State laws pertaining to return to play with regard to sports-related concussions.

The law requires the establishment of State advisory board to develop a strategic plan with recommendations for maximizing and coordinating State and local resources.