

# State Government Assistance and Supports for Individuals with Traumatic Brain Injury

by the National Association of State Head Injury Administrators for the

## Administration for Community Living Traumatic Brain Injury State Partnership Workgroup on Waiver and Trust Fund Programs

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### Why is Traumatic Brain Injury (TBI) a Public Concern?

The Centers for Disease Control and Prevention (CDC) estimated that in 2014, there were approximately 2.87 million Americans treated for a traumatic brain injury (TBI) in emergency department visits and hospitals or that resulted in death. As such, TBI is the *leading cause of death and disability in the United States* and can lead to a lifetime of physical, cognitive, emotional and behavioral changes. The overall impact may result in:

- **Unemployment and loss income** – CDC estimates that the lifetime economic cost of TBI, including direct and indirect medical costs, to be approximately \$76.5 billion in 2010 dollars.
- **Homelessness** – In a February 6, 2020, article featured in *Neurology Today*, researchers found the lifetime prevalence of any severity of TBI in homeless and marginally housed individuals was 53.1 percent, and the lifetime prevalence of either moderate or severe TBI was 22.5 percent based on studies conducted and reviewed. The article cited a recent *Lancet Public Health* study that noted that an estimated six million people experience homelessness annually in the U.S. and the European Union and that homeless individuals are more likely to have a host of mental and physical health problems, including depression, drug and alcohol dependence, HIV, and hepatitis C.
- **Incarceration** – CDC, in its review of jail and prison studies, noted that 25-87% of inmates report having experienced a head injury or TBI, as compared to 8.5% in a general population reporting a history of TBI.
- **Institutional and nursing home placement** due to lack of alternatives. The July 2013 study titled, “Medicaid Expenditures for Persons with Traumatic Brain Injury while residing in Maryland Nursing Facilities: A follow-up Study,” conducted by the Hilltop Institute at University of Maryland Baltimore County found that approximately 3,000 Maryland Medicaid beneficiaries with a history of brain injury had nursing facility (NF) stay during the Fiscal Year (FY) 2010 to FY 2012 study period. Medicaid costs for persons with a TBI and/or anoxia diagnosis while residing in a nursing facility were \$16,000 higher per person than those of their non-TBI diagnosed counterparts.

### What are the Challenges to States to Providing Appropriate Services and Supports?

Individuals with TBI are often ineligible for state intellectual/developmental disability (I/DD), mental health and special health care needs programs due to: 1) diagnosis, 2) age at the time of the injury or, in the instance where children and youth with TBI may be eligible for services offered by the Special Health Care Needs, they will no longer be eligible after the age of 21; and 3) financial eligibility due to assets, particularly in instances where a spouse is injured. Services for which they may be eligible may be inappropriate due to the lack of trained and experienced staff; residential setting, such as a nursing home or a group home for individuals I/DD; and lack of provider network to address specialized cognitive, emotional, physical, and behavioral needs. Although individuals with TBI may be eligible for I/DD services, if the injury occurs prior to the age of 22, yet if it occurs one day after that age, the individual is not eligible – creating inequality in access to service delivery among individuals with TBI, simply due to age.

## **Does the Olmstead Decision Apply to Individuals with TBI?**

Yes. In 2008, two lawsuits were settled in favor of plaintiffs seeking community services in lieu of nursing and institutional settings resulting in the Commonwealth of Massachusetts using Money Follows the Person Demonstration Grant and two Medicaid Home and Community-based Services (HCBS) Waivers to transition people with TBI from nursing home and institutional settings. In 2001, a U.S. District Court upheld the rights of several people with disabilities, including an individual with TBI, who lived at Laguna Honda Hospital, who pursued a lawsuit alleging that the City and County of San Francisco violated their civil rights by denying access to community-based long-term care services to avoid unnecessary institutionalization in nursing facilities. The lawsuit cited the Americans with Disabilities Act (ADA), as well as the Olmstead Decision in making its case.

## **Are TBI Services and Supports Cost-effective?**

HCBS Medicaid waiver programs are based on the premise that it is more cost effective to serve individuals in the community versus more intensive residential settings, such as nursing homes. However, other programs and supports that are not waiver funded may also show cost effectiveness. For example, in 2004, the University of Missouri, Department of Health Psychology conducted an evaluation of Missouri's Early Referral Program funded with state funds to assess the effectiveness of service coordination offered early in the course of their rehabilitation (e.g., while an inpatient or outpatient in an acute rehabilitation facility). While the study found that those who participated in the program had better functional outcomes in terms of social/emotional functioning and the ability to return to work, it also found that participants were less likely to access emergency room care reimbursed by Medicaid. In other words, service coordinators arranged for resources, services and supports that addressed their needs, deterring them from more expensive emergency room services which were sought by those not receiving state service coordination.

## **What are the Funding Options for States to Provide Services?**

States have implemented several funding streams, with some states having access to more than one funding stream. These include:

- Half of the states have implemented separate Medicaid HCBS, with three states administering more than one brain injury waiver program.
- Almost half of the states have enacted legislation earmarking fines, fees, surcharges, usually related to traffic fines, which is then available for TBI programs.
- A few states have the benefit of state revenue appropriation specifically for a TBI program that offers services, supports and service coordination (e.g., AK, MA, MO, ND, NC, and VA).
- One state provides services to individuals with TBI with complex needs through the state's Medicaid 1915(k) plan (OR).
- One state bills Medicaid for administrative case management, a State Plan service (MO).
- One state just received approval for the 1915(i) HCBS State Plan that includes individuals with brain injury, in addition to individuals with behavioral health needs (ND).
- 27 states receive federal grants to assist with creating and expanding systems through the U.S. Administration for Community Living (ACL) TBI State Partnership Program.
- At least 4 states (IA, MA, MO and VT) use or have used Money Follows the Person program to transition people with brain injury from nursing homes to community-based programs.
- States have also worked with existing, I/DD, behavior health or mental health, substance use, juvenile justice, education, and vocational rehabilitation to expand and improve services through training, screening, and identifying resources that are available to individuals with TBI.

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