



TESTIMONY SUBMITTED BY THE

National Association of State Head Injury Administrators

TO THE

SENATE APPROPRIATIONS SUBCOMMITTEE

ON LABOR-HHS-EDUCATION-RELATED AGENCIES

APRIL 18, 2011

Dear Chairman Tom Harkin and Ranking Member Richard Shelby:

Thank you for this opportunity to submit testimony regarding the fiscal year 2012 budget as it pertains to funding for programs authorized by the Traumatic Brain Injury (TBI) Act of 1996, as amended in 2008. The TBI Act authorizes funding to the US Department of Health and Human Services (HHS) to carry out the intent of the Act through the (1) Centers for Disease Control and Prevention (CDC) for purposes of brain injury surveillance, prevention and education; and the (2) Health Resources and Services Administration (HRSA) for grants to State governmental agencies and to Protection and Advocacy Systems to improve and increase access to rehabilitation services and community services and supports for individuals with TBI and their families.

NASHIA is a non-profit organization representing State governmental officials who administer an array of short-term and long-term rehabilitation and community services and supports for individuals with TBI and their families. These services are generally financed through an array of federal, State and dedicated funds (State trust funds) with the HRSA Federal TBI grants used to support and improve the necessary infrastructure to support these service systems. While NASHIA is well aware that federal funds are becoming increasingly difficult to obtain, NASHIA is recommending increased funding for the federal TBI Act programs because:

- The number of Americans who sustain a TBI is increasing, especially among the elderly and young children, and among our men and women in uniform as a result of the wars in Iraq and Afghanistan, while at the same time,
- States are experiencing significant budget cuts impacting rehabilitation and community services and supports for individuals with TBI, yet

- The number of States receiving grants has been *reduced* from 49 to 21 due to recent changes in HRSA policy and the level of appropriations to support State grant activities.

These factors, as well as the overall economy, are creating a strain on State TBI systems. As the TBI Act program is the *only* federal funding to help States to better serve individuals with TBI, NASHIA recommends:

- \$10 million for the CDC programs to support TBI registries and surveillance; to develop Brain Injury Acute Care Guidelines, and to expand prevention and public education regarding injury prevention, including sports-related concussions (mild TBI)
- \$ 8 million for the HRSA Federal TBI State Grant Program to increase the number of grants to States
- \$ 4 million for the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program to increase the amount of grant awards

HRSA FEDERAL TBI STATE GRANT PROGRAM

Since 1997, HRSA has awarded grants to 48 States, District of Columbia and one Territory to develop and improve services and systems to address the short-term and long-term needs. These grants have been time limited and are relatively small. Two years ago, HRSA increased the amount of the award from approximately \$100,000 to \$250,000 to make it more feasible for States to carry out their grant goals and the legislative intent. While this increased amount is more attractive to States, this change reduced the number of grantees from 49 to 21 -- less than half of the States and Territories. As a result, States that do not have federal funding are finding it increasingly more difficult to sustain their previous efforts, let alone expand and improve, due to other budget constraints in their States.

Over the course of the grant program, States, depending on individual State needs, have developed State plans for improving service delivery; information & referral systems; service coordination systems; outreach and screening among unidentified populations such as children, victims of domestic violence, and veterans; and training programs for direct care workers and other staff. States have also conducted public awareness and educational activities that have helped States to leverage and coordinate funding in order to maximize resources to the benefit of individuals with TBI.

In keeping with the HRSA Federal TBI State Grant Program most States have identified a lead State agency responsible for providing and coordinating services and an advisory board to plan and coordinate public policies to better serve individuals who frequently needs assistance from multiple agencies and funding streams in order to address the complexity of their needs.

STATE COLLABORATIVE EFFORTS TO ADDRESS THE NEEDS OF VETERANS

The HRSA grant funding has been used to address the needs of returning service members and veterans with TBI and their families. Since service members and veterans first began to return from Iraq and Afghanistan, States have been contacted by families

and returning servicemembers, especially those who served in the National Guard and Reserves, to obtain community resources in order to return to work, home and community.

NASHIA and some individual States have reached out to US Department of Veterans Affairs (VA), particularly staff from individual Polytrauma Centers, to promote collaboration in order to better understand VA benefits for veterans that may be seeking State services, and for VA to understand what is available in the communities. In addition, some States have added representatives from VA, National Guard and Reserves, State Veterans Affairs, and/or veterans organizations to serve on their State advisory board in order to improve communications and policies across these programs.

THE INCIDENCE AND PREVALENCE OF TBI IS ON THE RISE

CDC released new data last year showing that the incidence and prevalence of TBI in the United States is on the rise. CDC reported that each year, an estimated 1.7 million people sustain a TBI. Of that amount: 52,000 die; 275,000 are hospitalized; and 1.365 million (nearly 80%) are treated and released from an emergency department. TBI is a contributing factor to a third (30.5%) of all injury-related deaths in the United States. About 75% of TBIs that occur each year are concussions or other forms of mild TBI. The number of people with TBI who are not seen in an emergency department or who receive no care is unknown.” (www.cdc.gov/TraumaticBrainInjury/statistics.html)

The data collected by CDC relies heavily on State data, gathered through State registries and hospital discharge data. These numbers do not include the veterans who sustained TBIs in Iraq or Afghanistan and now use private or State funded resources for care, or undiagnosed TBIs.

ABOUT STATE RESOURCES AND SERVICES

Since the 1980s, States have developed services and supports largely in response to families who often seek help in crisis situations, such as loss of job due to TBI; or out of control behaviors or substance abuse that may result in family violence or dangerous situations to self and others; and the need for overall help in providing care to their family members who have extensive medical, behavioral and cognitive problems. A critical service that States provide is service coordination to help coordinate and maximize resources and supports for individuals with TBI and their families.

Over the past 25 years, States have developed service delivery systems that generally offer information and referral, service coordination, rehabilitation, in-home support, personal care, counseling, transportation, housing, vocational and other support services for persons with TBI and their families. These services are funded by State appropriations, designated funding (trust funds), Medicaid and Rehabilitation Act programs and are administered by programs located in the State public health, Vocational Rehabilitation, mental health, Medicaid, developmental disabilities, education or social services agencies.

Approximately half of all States have a dedicated funding mechanism, mainly through traffic related fines, and about half of all States also administer a Medicaid Home and

Community-Based Services (HCBS) Waiver for individuals with brain injury who are Medicaid eligible. Individuals with TBI are also served in other State waiver programs designed for physical disabilities, developmental disabilities, elderly and other populations. Some States have the advantage of both waiver and trust fund programs, in addition to other State and federal resources.

As private insurance generally does not provide for extended rehabilitation and long-term care, supports and services, most long-term services and supports for persons with TBI are administered by the States. These programs are funded mainly through the shared federal/State Medicaid Home and Community-based Services Waivers (HCBS) program and Medicaid State Plan services, such as personal assistance, nursing homes and in-home care.

Medicaid HCBS Waivers for Individuals with TBI have grown significantly in recent years, doubling from 5,400 individuals served in 2002 to 11,214 in 2006, at a cost of \$155 million in 2002 to \$327 million in 2006 (Kaiser Commission on Medicaid and the Uninsured (2007, December); Medicaid Home and Community-Based Service Programs: Data Update, The Henry J. Kaiser Family Foundation, Washington DC).

Without appropriate services and supports, individuals with TBI may become homeless, or inappropriately placed in institutional settings or end up in State or local Correctional facilities due to their cognitive and behavioral disabilities. A recent report issued by the Centers for Disease Control and Prevention (CDC) cited other jail and prison studies indicating that 25-87% of inmates report having experienced a TBI as compared to 8.5% in a general population reporting a history of TBI.

ABOUT NASHIA

The mission of NASHIA is to assist State government in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families. Since 1990, NASHIA has held an annual State-of-the-States conference, and has served as a resource to State TBI program managers. NASHIA also maintains a website (www.nashia.org) containing State program contacts and other resources. NASHIA members include State officials administering public TBI programs and services, and associate members who are professionals, provider agencies, state affiliates of the Brain Injury Association of America (BIAA), family members and individuals with brain injury.

Should you wish additional information on State services and resources, or other information, please do not hesitate to contact Rebeccah Wolfkiel, Governmental Consultant at 202-480-8901 (office) or 202-603-9686 (cell) or rwolfkiel@ridgepolicygroup.com. You may also contact Susan L. Vaughn, Director of Public Policy, at 573-636-6946 or publicpolicy@nashia.org or William A.B. Ditto, Chair of the Public Policy Committee, at williamabditto@aol.com.

Thank you.