



TESTIMONY SUBMITTED BY THE
National Association of State Head Injury Administrators

to the

SENATE SPECIAL COMMITTEE ON AGING
“State of Play: Brain Injuries and Diseases of Aging”

June 25, 2014

On behalf of the National Association of State Head Injury Administrators (NASHIA), thank you for the opportunity to submit testimony regarding issues affecting individuals who are aging with a traumatic brain injury (TBI) as the result of a sports-related injury. We welcome the discussion on the long-term consequences of TBI that may affect an individual's ability to lead an independent, productive life, as well as the impact on the family who is usually the caregiver. NASHIA is a non-profit organization representing and assisting 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.

As sports-related injuries (concussions) are a contributing factor to TBI, all 50 states and the District of Columbia have enacted legislation calling for schools to develop “return to play” guidelines with regard to student athletes to prevent further injury. Most state laws include provisions for education and training for coaches and athletic trainers, as well as information for parents. Many states use materials (Heads Up) developed by the Centers for Disease Control and Prevention's National Injury Center, which has been a leader in developing resources for states and school districts. Two states this spring enacted additional legislation to address “return to learn” guidelines in recognition that sports-related concussions may impact a student's cognitive, emotional and behavioral functioning affecting academic performance.

There have been few prospective studies to ascertain the needs of individuals over a life time after a TBI. In some respects, the concerns of individuals with TBI may be similar to that of all individuals who age -- will they experience a decline in mental or cognitive abilities; encounter progressive health, physical, sensory or mobility problems; will they have opportunities to make choices as to how they wish to live, who to

socialize with, work or volunteer; and who will be there to provide assistance when needed.

While states tend to address prevention measures, it has been difficult to develop sufficient state capacity to address life long assistance after a TBI. Over the past thirty years, states have developed capacity for information and referral services, service coordination, rehabilitation, in-home support, personal care, counseling, transportation, housing, vocational rehabilitation services, respite care for families and other assistance. However, services vary in scope across the country and even within a state.

To pay for public services and supports, states use a variety of funding mechanisms. Some states have developed services using state appropriations for such purposes. Since 1985, twenty-four States have enacted legislation to assess fines or surcharges to traffic related offenses or other criminal offenses and/or assessed additional fees to motor vehicle registration or drivers license to generate funding for TBI programs and services, generally referred to as trust fund programs.

Twenty-one States have implemented TBI Home and Community-Based Medicaid Waiver Programs to provide community-based services to individuals with TBI who are Medicaid eligible and are at risk of institutionalization or nursing facility level of care. Several states provide services with funds from all of these sources – state, dedicated funding (trust fund), and Medicaid. Within a state, these services may be administered by the state public health, Vocational Rehabilitation, mental health, Medicaid, intellectual disabilities, education or social services agency. Direct care services are then carried out by community providers and professionals.

State TBI programs work with other state agencies to coordinate resources in order to develop capacity within programs which may not be housed in the same agency, such as Medicaid; Vocational Rehabilitation; and aging and disability resource centers funded by the U.S. Administration for Aging. The result is often a patchwork of programs and systems in order to provide the array of rehabilitative and long-term community and family services and supports.

In 1996, Congress passed the TBI Act which authorized funding to the Centers for Disease Control and Prevention to assist with obtaining data to determine the incidence and prevalence of TBI; prevention; public education and other activities. The federal law also authorized funding to the U.S. Department of Health and Human Services, Resources and Services Administration (HRSA) for grants to states to improve and expand access to rehabilitation and community services. (The program is due for reauthorization, and a bill is progressing in the U.S. House of Representatives.)

Since 1997, HRSA has awarded grants to 48 States, District of Columbia and one Territory, although not concurrently, 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. Five 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 to 21 -- *less than half of the states and territories receive funding.*

Over the course of the grant program, states have developed state plans and implemented initiatives 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 conducted public awareness and educational activities that have helped states to leverage and coordinate funding in order to maximize resources within states to the benefit of individuals with TBI. And, in some states, federal grant funds were used to assist in developing educational materials and training to implement their sports-concussion laws.

NASHIA has long advocated for the U.S. Department of Health and Human Services to develop a national plan to identify and coordinate federal resources, much like states do, in order to maximize resources and to streamline services for families and individuals with TBI who need an array of short-term and long-term supports. We have also recommended that a federal interagency entity be established to promote collaboration among federal agencies, state government, providers, consumers and other partners involved in TBI services over the lifespan and to take the lead for developing a plan. While HRSA has created an interagency TBI working group, this group has not involved or communicated with TBI stakeholders or solicited input from families and individuals with TBI. Furthermore, NASHIA recommends:

- 1) **Reauthorization of the TBI Act** – the *only* federal program providing assistance to states to improve services for individuals with TBI.
- 2) **Transferring the HRSA TBI State Grant Program to the Administration for Community Living to maximize resources to support the array of services and supports needed following a brain injury and to:**
 - Integrate TBI into the U.S. Department of Health and Human Services (HHS) long-term services initiatives, which also rely on Aging and Disability Resource Centers (ADRCs) as the entry point into these systems;
 - Promote collaboration with the Administration on Aging (AoA) on falls-related TBIs among older adults;
 - Include TBI in the Office of Disability and Aging Policy's Office of Integrated Policy initiatives (i.e. Lifespan Respite Care Program, Participant Direction Program, Evidenced-Based Care Transitions, and Transportation Research and Demonstration Program); and.
 - Coordinate with the Independent Living program and the National Institute of Disability and Rehabilitation Research (NIDRR), which funds the TBI Model

Systems, should those programs move to the ACL as called for in the Workforce Innovation and Opportunity Act (WIOA) moving through Congress.

- 3) Fund research to study community living service needs over the long-term for both individuals with TBI and their families or other caregivers.
- 4) Provide funding for coordinated education and training among professionals and providers to better identify TBI as an underlying condition as people age who may access medical, aging or other health care systems to prevent misdiagnosis and to better address an individual's needs.
- 5) Provide funding for respite services and training for family caregivers.

Thank you again for this opportunity. Should you wish additional information, please do not hesitate to contact Rebecca Wolfkiel, Governmental Consultant, at 202-480-8901 (office) or 717-250-6796 (cell) or email: 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.