WRITTEN TESTIMONY SUBMITTED BY THE

National Association of State Head Injury Administrators

by
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TO THE

SENATE APPROPRIATIONS SUBCOMMITTEE
ON LABOR-HHS-EDUCATION-RELATED AGENCIES

D**IRECTED AT THE DEPARTMENT OF HEALTH AND HUMAN SERVICES**
ADMINISTRATION FOR COMMUNITY LIVING AND
CENTERS FOR DISEASE CONTROL AND PREVENTION

May 31, 2018

Dear Chairman Blunt and Ranking Member Murray:

On behalf of the National Association of State Head Injury Administrators (NASHIA), thank you for the opportunity to submit testimony regarding the fiscal year 2019 appropriations for programs authorized by the Traumatic Brain Injury (TBI) Act administered by the U.S. Department of Health and Human Services' (HHS) Administration for Community Living (ACL) and the Centers for Disease Control and Prevention's National Center for Injury Prevention and Control, as well as funding for the TBI Model Systems administered by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) housed in the ACL

NASHIA thanks the Committee for the additional $2 million for fiscal year 2018 included in the omnibus spending bill passed in March for the ACL TBI Federal Grant Program. These funds should be split between grants for state Protection and Advocacy systems, known as disability rights in some states; and the Federal TBI State Implementation Grant program. The HHS' ACL Federal TBI State Implementation Grant Program is the *only* program that assists states in addressing the complex needs of individuals with TBI and their families.

For fiscal year 2019 NASHIA is requesting: **$11 million total for HHS' ACL TBI State Implementation Grant Program, representing a $5 million increase** for additional state grants to expand and improve service delivery; and **$5 million additional funding** for CDC's National Center for Injury Prevention and Control to establish and oversee a national concussion surveillance system. Furthermore, NASHIA supports **funding for CDC's falls prevention program ($5 million) and the injury control research centers ($9 million)**, both of which the President proposed to eliminate in fiscal year 2019.

In addition, NASHIA recommends **$15 million for the NIDILRR TBI Model Systems** to expand the number of centers and research projects. NASHIA strongly opposes the President's budget recommendation to reduce funding and move NIDILRR from the ACL to the National Institutes of Health (NIH). NIDILRR was formerly located in the Department of Education and, as the result of the Workforce Innovation and Opportunity Act (WIOA) of 2014, was only recently transferred to the ACL.

NASHIA is a nonprofit organization representing states administering TBI services and is comprised of state government agencies and associate members consisting of professionals, consumers, families, providers and others interested in TBI. Our mission is to assist states in promoting partnerships and building systems to meet the needs of individuals with TBI with the goal of all states having resources to assist individuals with TBI to return to home, community, work and school after sustaining a brain injury, as well as assistance to family members who often serve as primary caregivers. The TBI Act programs assist states to achieve this goal.

In 2013, 2.8 million Americans sought treatment for or died from a TBI as the result of a car crash, fall, sporting or recreational injury, an assault. The leading causes of non-fatal TBI are falls (35%), motor vehicle-related injuries (17%), and strikes or blows to the head from or against an object (17%), such as in sports injuries. The leading causes of TBI-related deaths are motor vehicle crashes, suicides, and falls. The CDC estimates, based on data from two states, that 3.2 million -- 5.3 million persons in the United States are living with a TBI-related disability. Children aged 0–4 years, adolescents aged 15–19 years, and adults aged 75 years and older are among the most likely to have a TBI-related emergency department visit or to be hospitalized for a TBI. Adults aged 75 years and older have the highest rates of TBI-related hospitalizations and deaths among all age groups. Individuals who sustain a TBI often have resulting problems with cognition, emotions, language, physical mobility and sensory disabilities that can lead to lifelong problems.

TBI is a *complex disability* that challenges states' ability to provide the *right services at the right time*. Often, several private and public entities may be involved over the course of recovery including, medical and rehabilitative facilities and programs, including emergency departments, hospitals, trauma centers; post-acute rehabilitation programs; education; vocational rehabilitation; therapies to maintain physical and cognitive functioning; and community services and supports to enable the individuals to live as independently as possible. Payors for these type of services may include private health insurance, Workers' Compensation, Medicaid, private pay, and public assistance programs. Navigating this path to recovery is often overwhelming for the individual and their families. Many states have developed service coordination or case management systems supported by Medicaid, state funding or dedicated funding from fines or fees, referred to as trust fund programs to assist with the coordination of rehabilitative care, services and supports..

About half of the states have enacted legislation to establish a trust fund program specifically to fund TBI services; a few state legislatures appropriate general revenue to

fund services; about half of the states have implemented brain injury Medicaid Home and Community-Based Services (HCBS) waiver programs; and some states use a combination of these funding sources to support the array of needs. These services include post-acute rehabilitation; personal care; service coordination or case management; assistance with activities of daily living; in-home accommodations and modifications; transportation; and therapies, including behavioral, cognitive, speech-language and physical therapies. With limited state resources to address these needs, many individuals, particularly those with behavioral issues, addiction problems, and poor judgment, will find themselves homeless or in correctional facilities.

Nineteen (19) States have just finished a four-year Federal TBI State Implementation Grant and, along with other states, are currently awaiting the results of funding for new three-year competitive grants to be determined by the ACL. Over the past four years, state grantees have identified and assisted high risk populations, which included youth and adults with TBI in juvenile justice and criminal justice systems; older adults with fall-related TBIs; and young children in pre-school programs through screening, training, and linking individuals to services. As states wind down these activities, the likelihood of continuing this work is slim without continued support.

Since 2009, all 50 states and the District of Columbia have enacted “return to play” laws following the state of Washington, which was the first state to do so, to address concussion management in youth athletes. States are now beginning to address “return to learn” issues to identify the academic needs of students after a concussion, regardless of cause. The requested $5 million for the CDC’s National Center for Injury Prevention and Control to establish and oversee a national concussion surveillance system will greatly assist states as they target their resources to better meet and understand the needs of individuals who sustain a concussion.

Currently, there are 16 TBI Model Systems Centers which provide comprehensive systems of specialty care from the point of injury through return to the community. They participate in independent and collaborative research projects developing and evaluating medical, rehabilitation, vocational and other services designed to address the physical, cognitive and psychological needs of individuals with TBI and share their findings to healthcare professionals; individuals with TBI; their families, caregivers and friends; and the general public. States benefit from their research and tools to assist with screening, training, and assessing program outcomes.

We are pleased that ACL is beginning to develop a Federal Interagency Coordinating Plan, as called for by the TBI Reauthorization of 2014, to align TBI resources with other federal aging and disability programs to help states maximize and to coordinate federal resources as states primarily incur the burden of TBI for individuals who need on-going, intermittent, or short-term services and supports that are not paid for through private health care insurance plans. The ACL resources include Lifespan Respite Care, Aging and Disability Resource Centers, Independent Living, NIDILRR, and Assistive Technology programs. Other federal resources include the National Institutes of Health (NIH); CDC; Department of Veterans Affairs; Department of Defense; disability benefits

administered by the Social Security Administration; vocational rehabilitation and educational services funded by the Department of Education; children's programs (Title V) administered by HHS' Health Resources and Services Administration (HRSA); Medicaid and Medicare administered by the Centers for Medicare and Medicaid Services (CMS); job training programs through the Department of Labor (DOL); housing programs administered by the Department of Housing and Urban Development (HUD), and transportation programs.

In closing, the TBI State Implementation Grant Program has helped states to leverage other state and federal funds and to bring partners together in order to address the complex needs of individuals with TBI and their families. To continue and expand resources we believe that **all** States should have access to the federal program to address this growing and aging population. Therefore, we ask that you continue to fund and increase appropriations for this important program, as well as to establish the CDC national concussion surveillance system to improve and expand data needed to plan for service delivery; and to increase funding for NIDILRR TBI Model Systems to support research to address this critical issue.

Should you wish additional information, please do not hesitate to contact Rebeccah Wolfkiel, Executive Director, at 202-681-7840 (execdirector@nashia.org). You may also contact Becky Corby, NASHIA Government Relations at 202-480-8902 (rcorby@ridgepolicygroup.com) or Susan L. Vaughn, Director of Public Policy, at 573-636-6946 (publicpolicy@nashia.org). Thank you for your continued support.