

April 25, 2008

**Testimony of William A.B. Ditto, President
National Association of State Head Injury Administrators,**

4330 East West Highway, Suite 301, Bethesda, MD 20814, 301-656-3500, www.nashia.org

**Submitted to the Senate Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies**

**In Support of Funding the Federal Traumatic Brain Injury Grant Program
in the Health Resources and Services Administration
U.S. Department of Health and Human Services, Health**

Mr. Chairman, on behalf of the National Association of State Head Injury Administrators (NASHIA), I am submitting this testimony in support of funding the Federal Traumatic Brain Injury (TBI) Grant Program at \$15 million for Fiscal Year 2009. The members of NASHIA also thank you for your support of the reauthorization of the TBI Act, which is expected to be signed into law within the next few days.

This year marks the eleventh year that grants have been available to States to develop and expand service delivery systems to better serve those with TBI and their families. Congress originally authorized the Federal TBI Program under the TBI Act of 1996, and the most recent reauthorization bill is currently awaiting the President's signature. The Act authorizes funding to the Department of Health and Human Services, Health Resources and Services Administration (HRSA) for grants to States, the District of Columbia and Territories to improve access and increase service delivery for individuals with TBI and their families. The Act also authorizes funding to HRSA for Protection & Advocacy Services (P&A) for individuals with TBI and their families and to the Centers for Disease Control and Prevention (CDC) for injury surveillance, prevention and public education.

The HRSA Federal TBI State Grant Program began as a very small program, yet it remains the only source of Federal funding that spurs States to develop, expand and improve service delivery for individuals with TBI and their families. For the past four years, the Administration has zeroed out funding for the program as a result of a poor PART score by the Office of Management and Budget (OMB). This was unfortunate for persons with TBI and their families because the PART evaluation was flawed as it measured health outcomes for individuals and this program was not designed nor intended to provide direct health services.

In order to better evaluate the program, the Institute of Medicine (IOM) conducted a study and issued a report on its findings in 2006. The report commended state activities, particularly in leveraging other resources, but was less complimentary of program management due to lack of staff (there has been only one staff person) and agency commitment. IOM recommended that an advisory board be established as soon as possible to assist HRSA in setting a national agenda, coordinating with sister federal agencies and to develop evaluation procedures for the program.

The IOM found that the "Federal Program has demonstrated beneficial change in State organizational infrastructure and increased the visibility of TBI – both essential conditions for improving TBI service systems." Further, the IOM noted that "States are now at a critical stage

and will need continued Federal support if they are to build an effective, durable service system for meeting the needs of individuals with TBI and their families.” Federal funding, however, has declined.

To address IOM’s recommendations and the emerging issues, such as returning troops with misdiagnosed or undiagnosed TBIs, we respectfully request \$15 million for the HRSA Federal TBI State Grant Program. This would allow each State to be funded in the amount of \$250,000, which is closer to the amount initially awarded to States in 1997 for Implementation Grants. Over time, HRSA lowered the grant award amounts to \$100,000 in an effort to bring more States into the program, with the Territories receiving \$70,000. While this approach may have helped to bring attention to TBI in more States, fewer dollars to each State made it more difficult to make important systems change and to sustain efforts.

As the result of the large number of returning troops from Iraq and Afghanistan who have TBI and related conditions, States are facing an increased demand for information, community resources, assistance and family supports. Almost half of the States legislatures, Governors and/or department directors have initiated State agency coordination among TBI, mental health, State Veteran’s Commissions and National Guard or have elected to only focus on either TBI or Post Traumatic Stress Disorder (PTSD) in some capacity to address these concerns. This puts more pressure on TBI systems that are already woefully underfunded.

Given that the origin of these TBIs is a result of service to our country, this has resulted in a federal action that ultimately imposes an additional burden on the States. A \$100,000 grant is inadequate for States to develop and sustain efforts previously initiated, let alone increase service delivery each year to meet the growing number of individuals with TBI and their families, including returning servicemembers.

NASHIA also supports **\$9 million for CDC** data surveillance, prevention and public education programs, and **\$6 million for the HRSA P&A Services Grant Program** to expand their client advocacy to include individuals with TBI. These programs augment States’ abilities to better plan for service delivery, as the result of CDC data, and the P&A grants help individuals to access these often confusing and complicated systems.

Families are the primary caretakers of individuals with TBI, and these families are aging as well. The CDC has just released its informational packet, “Help Seniors Live Better, Longer: Prevent Brain Injury Initiative” as the result of its finding that people ages 75 and older have the highest rates of TBI-related hospitalizations and death – another emerging issue. States have limited resources to provide the long-term care and supports needed for those who may not have families any longer to protect and support them. They are faced with decreased State revenue, cut backs in Medicaid and other Federal resources.

Despite all these challenges, States have been able to leverage and maximize other resources to address unmet needs. Some of these examples include:

Veterans and Returning Troops

The beauty of the HRSA Federal TBI Grant program is that it directs States to develop necessary infrastructure for service delivery, and promotes coordination of State programs and policies through the advisory boards and by the lead TBI agency. As such, those States that have had strong leadership and commitment for TBI services, are poised to help their sister State agencies and returning troops to access services. A few States (MA, VT and NY) have already been at the forefront of collaborating with other State and local agencies to better coordinate public education, outreach, information & referral and resources to returning troops with TBI or for those who may be misdiagnosed and undiagnosed.

Children

The CDC estimates that 37,000 children and youth receive brain injuries severe enough to require hospitalization each year. According to the most recent U.S. Department of Education numbers, the total number of students served in special education under the TBI category is 14,844. This discrepancy in numbers illustrates that the majority of students with traumatic brain injury are either misclassified or not identified at all as having a brain injury and will not receive needed services.

As the result of these findings, States (OR, TN, AL, PA, HI, OH) have used their Federal grant funding to screen children for TBI in public educational settings to improve identification; developed resources for educators to help with developing Individual Education Programs (IEPs) and appropriate educational and behavioral strategies to improve learning; and/or resource teams to provide consultative services.

Unserved/Underserved

Several States have used their Federal funds to provide outreach to Native Americans (MT, OH, ND, AZ) and other cultures, such as African Americans, Hispanics and Asians (MA, NJ, IL, CT, FL, MN), to access TBI, needed services and supports to live and work in the community.

TBI Technical Assistance Center (TAC)

Another important component of the HRSA Federal TBI Program is the TBI TAC which is administered by NASHIA in order to help State grantees and non-grantees to:

- Develop Service delivery infrastructure
- Develop effective programs that improve access to health and other TBI services
- Develop plans for sustainability after federal funding ends
- Develop plan, implement and evaluate TBI related initiatives
- Identify resources, develop strategies, and implement programs for children and youth and ensure that activities are appropriately family centered and culturally competent.
- Develop and submit grantee proposal applications

The TBI TAC also develops and conducts the annual Federal TBI Program Grantee Meetings, offers peer mentoring to encourage the transfer of knowledge among the States and Territories, and disseminates materials and resources.

Responding to National Needs

The TBI TAC responds to emerging issues through webcast trainings and informational packets on state and community initiatives. These educational packets include information on returning troops with TBI; TBI trust funds to support rehabilitation services and supports; educational services for children, screening tools, and training programs for direct support personnel and other professionals. Webcasts have been conducted on a variety of issues including services provided by the Veterans Administration, housing, substance abuse, employment, TBI trust funds, domestic violence, children's services, educational services and neurobehavioral health.

The TBI TAC also maintains a data base known as the Traumatic Brain Injury Collaboration Space (TBICS). The TBICS is a clearinghouse of all products and materials available for improving state service delivery. The TBI TAC also operates a listserv for approximately 1000 subscribers to disseminate information and for subscribers to submit questions and share "best practices."

Still Work to Do

While the IOM acknowledged these and other State efforts, it still noted that the quality and coordination of post-acute TBI service systems remains inadequate. Individuals with TBI, their families, caregivers and others report substantial problems in getting basic services, including housing, vocational services, neurobehavioral services, transportation and respite for caregivers. Service coordination, which is offered in some States, is not uniformly offered in all States to all age groups. Families still report the need for information and assistance at the time of hospitalization, and help with resulting behavioral problems that often are too burdensome to the family. States report difficulty in finding and paying for qualified and experienced providers, professionals and direct care workers. Training and education are needed across the board for individuals, families, professionals, providers and policy makers to understand the complexity of the disability and resulting problems.

In conclusion, while the Federal TBI Act Programs have impacted State and local service delivery significantly, it is the *only* Federal funding available to help States develop, improve and expand service delivery to meet the growing, yet differing needs of individuals of all ages, all cultures and regardless of cause of injury – motor vehicle, falls, sporting, or occupational, including war-related injuries. This burden on the States is significant, complex and requires additional funding resources. For States to continue their efforts, let alone increase their capacity for the growing numbers of individuals with TBI needing community and long-term care and supports, will take significant federal support. **We, therefore, urge you to increase funding for HRSA Federal TBI State Grant Program to \$15 million, as well as appropriate \$9 million to CDC and \$6 million to the HRSA TBI P&A Grant Programs.**

Thank you for your continued support for the millions of individuals with TBI and those who serve them.