



TESTIMONY SUBMITTED BY THE

National Association of State Head Injury Administrators

TO THE

HOUSE COMMITTEE ON ENERGY AND COMMERCE

SUBCOMMITTEE ON HEALTH

March 19, 2012

Dear Chairman Joe Pitts and Ranking Member Frank Pallone:

Thank you for this opportunity to testify before the Committee regarding federal programs that serve individuals impacted by traumatic brain injury (TBI). My name is William A.B. Ditto, and I recently retired as the Director of the New Jersey Division of Disability Services. I currently serve as the Chairman of the Public Policy Committee for the National Association of State Head Injury Administrators (NASHIA), which is a non-profit organization representing State governmental officials, who administer an array of short-term and long-term rehabilitation and community services for individuals with TBI and their families.

I am pleased to be here today to talk about issues affecting State government in terms of serving individuals with TBI and their families, and how the Federal HRSA TBI Program assists States to be able to do so. As no two individuals with TBI are the same, no two States are the same with regard to the extent to which they are able to assist individuals and their families.

In the 1980's, families began advocating for States to provide rehabilitation and other assistance not otherwise covered by insurance or by existing State systems for individuals with disabilities. In order to expand services to individuals with TBI, States needed to determine which State agency or agencies should be responsible for providing or overseeing services; what type of services or assistance should be provided; how should the services be paid for; and to determine the eligibility criteria for those needing services.

Since individuals may be injured at any age, have differing needs due to severity of injury, have different resources available to them, and their needs change over time, States have generally taken multiple approaches to address these variables. Some

States expanded systems designed for individuals with developmental disabilities, mental health, special health care needs and vocational rehabilitation to also serve TBI; other States have created dedicated funding streams for TBI services; others have expanded Medicaid to cover those who are Medicaid eligible; and many States use a combination of these funds.

Most State programs identify a point of contact, which may be a case manager or service coordinator, who then will work with the individual to assess their needs and develop a plan for services and outcomes. The TBI program may be administered by the State public health, Vocational Rehabilitation, mental health, Medicaid, developmental disabilities, education or social services agencies. Most states have also created advisory councils or boards to promote interagency coordination and to obtain input from consumers and others with regard to developing a State plan.

Currently, almost half of all States have enacted laws to create State accounts dedicated to serving the needs of individuals with TBI. Usually these accounts, or trust funds, are financed through traffic violation fines, and are appropriated for such purposes as TBI prevention, public education, research, TBI registries, provider training and other related services.

About 20 States administer Medicaid Brain Injury Home and Community-Based (HCBS) Waiver programs offering an array of services for those who are Medicaid eligible. A Waiver program is designed to maintain a person in the home and community, in lieu of more expensive institutional or nursing home programs. Individuals with TBI may be also served in other State waiver programs designed for individuals with physical disabilities, developmental disabilities, seniors and other populations. These waiver programs vary greatly across the States both in terms of numbers served and the level of care the State defines for eligibility purposes.

Why have States developed services and supports for this population, especially with State budgets so austere? Without appropriate services and supports, individuals with TBI may become homeless, or inappropriately placed in more costly institutional settings. Some individuals are placed in expensive residential programs and some end up in correctional facilities due to their cognitive and behavioral impairments. A report issued by the Centers for Disease Control and Prevention (CDC) indicated that 25-87% of inmates report having experienced a TBI; this is a stark contrast compared to the 8.5% of the general population that has experienced a TBI. States are also obligated to provide care for this population as mandated by the Americans with Disabilities (ADA) Act which requires States to provide services in integrated community settings.

In more recent years, returning servicemembers and veterans with TBI have turned to the States for help in locating family supports and community services. Some States have used their Federal HRSA TBI State Grant and/or other State resources to address these issues, often in collaboration with the State Veterans agency, National Guard, and state and local veterans' organizations. Members of the National Guard and Reserve generally return to their own home after deployment, and are apt to look for resources within the community. These members may not be eligible for TRICARE insurance, once they are deactivated or leave duty. Some members also elect to maintain insurance provided by their employer.

While the number of Americans who sustain a TBI is increasing, especially among senior and veterans populations, States are experiencing significant budget cuts impacting rehabilitation and community services available for individuals with TBI. Some States do not have a funding stream specific to the needs of individuals with TBI. The HRSA Federal TBI Grant Program assists such States to develop and leverage State/federal resources to build identification and service delivery systems.

NASHIA strongly supports the reauthorization of the federal Traumatic Brain Injury (TBI) Act, and recommends that changes be made to give stability to State TBI efforts, and to ensure that all States may participate in the program. NASHIA recommends:

- 1) That grant awards be shifted away from a short-term project focus to allow States to maintain and expand activities initiated through the grant funds.
- 2) That States are given additional flexibility to use funds for case management and other services, allowing those States that have a solid infrastructure to provide critical services.
- 3) That States target their grant requests on populations that they identify as underserved or unserved, such as children, victims of domestic violence, veterans and returning servicemembers.
- 4) That the program move from a competitive grant program to a formula funded approach, contingent upon availability of federal funds, to allow each State to receive a predictable amount of funding for use to build upon existing programs. In a 2010 NASHIA survey of States that administered federal TBI grants, 9 States reported that once they no longer received federal grant funding, activities previously conducted diminished in scope, particularly with regard to planning, capacity to expand services, and training to providers, professionals and caretakers. The grant funding provided necessary resources to keep the State focused on systems change.

Finally, just as States are required to coordinate and maximize State and federal programs and resources, NASHIA supports the Federal Interagency Task Force that HRSA has created to promote federal coordination of resources. We look forward to when the Task Force will invite stakeholders, such as NASHIA, Brain Injury Association of America (BIAA), National Disability Rights Network (NDRN), as well as individuals with TBI and their families to provide input as they develop a national plan and priorities for TBI.

In closing, thank you for your support for addressing the issues affecting Americans with TBI. Please do not hesitate to contact us if we can be of further assistance.