



Testimony Submitted by the

**Brain Injury Association of America
National Association of State Head Injury Administrators
National Disability Rights Network**

**To the House Committee on Energy and Commerce
Subcommittee on Health**

November 20, 2013

Chairman Pitts, Ranking Member Pallone, and members of the Health Subcommittee, thank you for giving me the opportunity to testify about the reauthorization of Traumatic Brain Injury Act, H.R. 1098.

My name is Dr. Drew Nagele. I am employed as executive director of Beechwood NeuroRehab, which is based in Langhorne and serves clients primarily from Pennsylvania, New Jersey and Delaware. As a licensed psychologist with training and experience in neuropsychology, I have been working with individuals who have brain injury and their families for over 30 years.

I serve on the Board of Directors of the Brain Injury Association of America and as the elected leader of BIAA's chartered state affiliates, 11 of which receive funding to assist their state agencies in carrying out TBI Act initiatives. I am also testifying on behalf of the National Association of State Head Injury Administrators and the National Disability Rights Network in support of reauthorizing the TBI Act.

According to the Centers for Disease Control and Prevention, there were 2.4 million emergency department visits, hospitalizations, or deaths associated with TBI in the US in 2009. Brain Injury is a leading cause of death and disability that affects persons of all ages, races, and income levels. Any injury to the brain – regardless of type, cause or severity – can change the way a person moves, talks, thinks, feels and acts. TBI can cause epilepsy and increase the risk for Alzheimer's disease, Parkinson's disease and other brain disorders that become more prevalent with age.

The TBI Act of 1996, as amended and reauthorized in 2000 and 2008, is a comprehensive law combining research, data collection, prevention, public awareness, consumer advocacy and service system coordination for this vulnerable and growing population.

The law authorizes the National Institutes of Health to conduct basic and applied research and the CDC to conduct surveillance, prevention and public education programs to prevent TBI and help people better recognize, respond, and recover if an injury occurs. For example, the CDC

has produced a number of reports and guidelines relating to Veterans with TBI, sports concussions, and for educators.

The TBI Act also authorizes the Health Resources and Services Administration (HRSA) to make competitive grants to States and Territories to develop or expand service system capacity to address the unique needs of their citizens as determined by statewide needs and resource assessments.

Currently, 20 States and Territories are receiving grant funds. Many states are working to **strengthen screening and identification methods**, particularly among un-served or under-served portions of the TBI population. For example, starting July 2014, all new admissions to domestic violence shelters in Pennsylvania will be screened for TBI as part of our state's grant project. In Pennsylvania, we're also piloting a program to screen inmates for TBI and to connect those who are leaving prison with brain injury services and supports. Minnesota has instituted a similar program, and Virginia is working in partnership with Virginia Commonwealth University to administer screening in its juvenile justice system.

Several states use grant funds for **TBI-specific training and professional development** for educators, substance abuse and mental health service programs, child care providers and other professionals. For example, in New Jersey, state grant funds were used to train members of the clergy.

Grant funds allow states to **coordinate and streamline service systems** such as improving linkages between hospitals and schools as has been done in Pennsylvania and Tennessee and to improve referral mechanisms to existing brain injury resources as is the case in Alabama.

Additionally, state grants have helped **leverage resources in other federal and state programs and nonprofit organizations**. For example, Michigan and West Virginia have both used grant funds to evaluate Medicaid utilization, leading to successful proposals for Home and Community-Based Services Waivers and other funding mechanisms that are tailored to the needs of individuals with brain injury and are more cost-effective for the state.

By far, the most common use of state grants is to **assist persons with brain injury and their families** through outreach, information, education, service coordination, and resource facilitation. After a life-altering, often devastating, injury, individuals and families need considerable help in navigating the complex maze that makes up state service systems. Grant funding in Arizona, Colorado, Idaho, Iowa, Indiana, Massachusetts, Michigan, Missouri, Nebraska, New York, Virginia, West Virginia, and Texas has supported outreach to children and youth, active duty military and Veterans, Native Americans, older adults, multi-cultural families and the thousands of civilians who fall through the cracks because of TBI.

The TBI Act also authorizes HRSA to make formula-funded grants to Protection and Advocacy organizations to ensure that people with TBI live full and independent lives free from abuse, neglect, and financial exploitation. Known as Protection and Advocacy for Traumatic Brain

Injury, the PATBI program helps people with brain injury navigate complex service systems within their state and investigates instances of abuse and neglect that, unfortunately, occur far too often in this population.

Recently, the Disability Rights Network of Pennsylvania, which is the designated protection and advocacy organization in my state, represented a client who has a TBI as a result of domestic violence and was being denied appropriate services by her service coordinator. Our P&A helped her change to a new service coordinator, and now she is getting the services she needs and is being treated with dignity and respect.

In this reauthorization, the Brain Injury Association of America, the National Association of State Head Injury Administrators, and the National Disability Rights Network recommend the committee elevate the State Grant Program and the PATBI Program within the Department of Health and Human Services.

We believe that by elevating these programs within HHS, preferably to the Administration for Community Living, individuals with brain injury would be better integrated into the department's aging and disability initiatives. For example, moving the State and P&A grant programs would:

- Promote collaboration on fall-related TBIs among older adults,
- Support collaborations between HHS and the Department of Veterans Affairs in developing and implementing home and community-based service and support initiatives,
- Assure that families who are primary caregivers are included in the Lifespan Respite Care Program; and
- Coordinate and strengthen services for individuals with TBI of all ages who may also be eligible for services provided through other disability systems.

We're specifically recommending the state grant and protection and advocacy grant programs authorized by the TBI Act be moved to the ACL because that agency was created to address needs of individuals with disabilities across the lifespan by combining and coordinating services and resources within the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and the Office of Disabilities.

Now more than ever, it is imperative that we foster collaboration and eliminate potential for duplication in order to maximize the limited resources at both the state and federal levels. This can only be achieved if we work hand-in-hand with other aging and disability populations. The TBI Stakeholders believe the best way to increase effectiveness and efficient is to elevate the state and protection and advocacy grant programs to the Administration for Community Living.

With your help, advocates, state agency administrators, researchers and clinicians can continue to work together to improve the lives of individuals with brain injury. Thank you for giving me the opportunity to testify today. I am happy to answer any questions you may have.