

115th Congress – 2017-2018



Public Policy Platform



**National Association of State
Head Injury Administrators**

P.O. Box 878
Waitsfield, Vt. 05673
Phone: 802-498-3349

Washington, D.C.
1140 Connecticut Avenue, NW, Suite 510
Washington, DC 20036

February 2017

ABOUT NASHIA

The National Association of State Head Injury Administrators (NASHIA) is a nonprofit, voluntary membership organization established by State government employees to help States plan, implement and administer public programs and services for individuals with brain injury and their families. Members represent a broad spectrum of State agencies, including health, Vocational Rehabilitation, mental health, Medicaid, social services, intellectual/developmental disabilities and education, as well as other professionals, private providers and organizations, individuals with brain injury and their families. Since 1990, NASHIA has been the source of information and education for State employees and the collective voice of State government on federal policies affecting service delivery for individuals with brain injury and their families. NASHIA provides technical assistance and educational opportunities through a national conference, webinars, resources and materials. For further information, visit www.nashia.org.

MISSION

The mission is to assist State government in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families.

PRINCIPLES

NASHIA:

- Respects the past and embraces the future.
- Values diversity, creativity, innovation and individuality in people and systems.
- Is goal-directed, and strives to learn from others.
- Believes brain injury is a significant public health and disability concern that requires resources for prevention, research and service delivery commensurate with its scope and impact at the local, State and federal level.
- Believes individuals with brain injuries have the right to a life in the mainstream of society with the full range of service and support options necessary to meet individualized needs across the lifespan.
- Believes State service delivery systems should outreach to and support all individuals with brain injuries, including those from culturally and linguistically diverse communities, in setting their own goals, determining their own needs, and choosing their own services and supports in culturally appropriate environments.
- Believes service delivery systems should be accessible, available, acceptable, appropriate, and affordable, and respect the values, knowledge, and history of individuals with brain injury and their families.
- Believes individuals with brain injury, their circle of supports, and their families should be active participants in the planning and implementation of service delivery systems that balance financial responsibility with the dignity of risk.
- Values collaborative approaches across organizations and systems and the contributions of all partners and stakeholders who share NASHIA's goals.

FEDERAL PUBLIC POLICY PLATFORM

NASHIA Public Policy Priorities

Individuals with brain injury and their families seek services from State government when they do not have means to pay for the necessary rehabilitative, community and family short-term and long-term services and supports. This is often due to their health care coverage limiting services, particularly with regard to long-term services and supports. They are most likely to seek public services and assistance from State departments of health, Vocational Rehabilitation, Medicaid, social services, mental health or intellectual/developmental disabilities agencies or a combination of these agencies that together provide the necessary services and supports. State brain injury programs are housed in one of these agencies and strive to work across State and community programs to coordinate resources.

NASHIA's priorities reflect goals for strengthening and building capacity in health, rehabilitation, disability, education and other systems, in addition to State brain injury programs, in order to offer effective and coordinated services. Furthermore, NASHIA supports improved data collection and research to assist with planning and best practices, as well as prevention efforts to reduce the number of brain injury-related disabilities.

The public policy priorities for the 115th Congress were approved by the NASHIA membership during its annual meeting held in September 2016 and are as follows:

- Enhance and expand State capacity to provide services and supports for individuals with brain injury and their families.
- Expand public and professional awareness about brain injury and service delivery.
- Maintain and expand access to health care, rehabilitation, and community-based long-term services and supports and community integration for individuals with brain injury.
- Expand research to promote best practices with regard to brain injury treatment, care, rehabilitation and vocational rehabilitation.
- Expand primary and secondary prevention related initiatives to reduce the number of Traumatic Brain Injury (TBI)-related injuries and to minimize affects.
- Maintain safety net programs for individuals with brain injury.

The NASHIA Public Policy Committee, chaired by William A.B. (Bill) Ditto, MSW, is comprised of both full and associate members. Rebecah Wolfkiel, NASHIA Government Relations, and Susan Vaughn, NASHIA Director of Public Policy, assist the committee in formulating recommendation and the organization in pursuing its public policy agenda. Through coalitions, NASHIA is able to monitor, support or oppose health care, rehabilitation, research and prevention issues that impact brain injury. NASHIA belongs to the American Brain Coalition (ABC), Consortium for Citizens with Disabilities (CCD), the Disability and Rehabilitation Research Coalition (DRRC), the Therapy Cap Coalition and the Injury and Violence Prevention Network (IVPN).

TBI Stakeholders

NASHIA regularly communicates and partners with brain injury stakeholders, including the Brain Injury Association of America (BIAA), U.S. Brain Injury Alliance, the National Disability Rights Network

(NDRN) and the Collaborative on Children's Brain Injury. NASHIA also collaborates with its federal partners, the Administration for Community Living; Centers for Medicare and Medicaid Services (CMS); and Centers for Disease Control and Prevention's (CDC) National Injury Center, with regard to State service delivery for individuals with brain injury and their families.

NASHIA works closely with the Congressional Brain Injury Task Force (CBITF), which was created to promote TBI awareness and education among Members of Congress. Each March, the Task Force sponsors a Brain Injury Awareness Day featuring a Fair that provides an opportunity for national and federal organizations and agencies to showcase information on brain injury research, prevention, programs and initiatives; a briefing on current issues; and a reception in honor of the Task Force and Awareness Day. The CBITF regularly sponsors legislation affecting brain injury. NASHIA also supports other congressional caucuses, such as the Neuroscience Caucus, Safe Kids Caucus and the Bipartisan Disabilities Caucus. These caucuses and the CBITF regularly sponsor briefings and hearings on such topics as sports-related concussions, long-term consequences of brain injury, older adults and fall-related TBIs, and issues relating to women and TBI.

About TBI

The Centers for Disease Control and Prevention (CDC), National Center for Injury Prevention and Control (NCIPC) reported in 2010 at least 2.5 million Americans sustained a traumatic brain injury (TBI) -- either alone or in combination with other injuries. A TBI is caused by a sudden jolt, blow or penetrating injury to the head that disrupts the normal function of the brain. Falls and motor vehicle crashes are the primary cause of injuries with sports, recreational injuries, work-related and war-related injuries also contributing factors. A TBI can happen to anyone at any age at any time. The injury may result in problems with thinking, memory, emotions, behavior, language, physical mobility and sensory that affects how a person is able to live and work independently.

TBI is a *complex disability* that challenges States' response to individual and family needs including access to post-acute rehabilitation, therapies, in-home support, education, employment, and short-term and long-term community and family supports. Individuals may have co-occurring conditions with regard to substance use and mental health. This requires services and funding to be flexible in order to meet the individual needs – and to provide the *right services at the right time*. It also requires professionals, support staff and providers to be knowledgeable with regard to TBI-related disabilities across service systems that may offer services and supports to persons with similar disability and health-related issues.

Federal Programs

The Traumatic Brain Injury (TBI) Act of 1996, as amended in 2014, authorizes appropriations for the *only* federal program specifically addressing public service delivery systems for individuals with brain injury, surveillance, prevention, research and public awareness and education. Other federal programs which may also provide assistance include the Individuals with Disabilities Education Act (IDEA); Maternal and Child Health, Special Health Care Needs (Title V); Title XIX of the Social Security Act (Medicaid), including the Early & Periodic Screening, Diagnosis and Treatment (EPSDT) program; Vocational Rehabilitation, Assistive Technology; Independent Living Centers; Lifespan Respite Care and Aging and Disability Resource Centers authorized by the Old Americans Act; and Medicare, Social Security, and other public assistance programs. These programs are administered by agencies by various federal agencies and implemented across State agencies. In addition, federal research is conducted by the U.S. Department of Health's Administration for Community Living (ACL) National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), the National Institutes of Health (NIH) centers, Department of Defense and the Department of Veterans Affairs research programs.

NASHIA PUBLIC POLICY PRIORITIES

1. Enhance and expand State capacity to provide services and supports to individuals with brain injury and their families

State general revenue, dedicated funding (i.e. trust fund programs), federal funding, and local resources are used for planning, developing and administering long-term and short-term community and family services and supports. State brain injury programs, therefore, collaborate with other State and public programs to provide coordinated services, as individuals with brain injury often seek assistance from several government programs, such as Vocational Rehabilitation, Medicaid, and Independent Living.

The Traumatic Brain Injury (TBI) Act of 1996, as amended in 2014, is the *only* federal legislation designed to assist States in these endeavors. The Act authorizes funding to the U.S. Department of Health and Human Services (HHS) to award State grants to improve access to service delivery and to (2) state Protection and Advocacy (P&A) Systems to expand their advocacy services. In 2016, the Federal TBI Program was transferred from the Health Resources and Services Administration (HRSA) to the HHS' Administration for Community Living (ACL) to help States maximize and coordinate resources available for persons who are elderly and individuals with disabilities across the lifespan.

The Federal TBI State Implementation Grant Program has helped States to leverage assistance through other State and community programs to expand capacity. However, available TBI Act funding limits the number of States which can participate (19) in the TBI State Implementation Grant Program.

NASHIA recommends:

- Increased funding for the ACL TBI State Implementation Grant Program to help more States develop and expand service capacity.
- Federal interagency collaboration and initiatives to support individuals with brain injury and co-occurring conditions relating to mental or behavioral health and substance use.
- Expanded opportunities for home and community long-term services and supports (LTSS), including individuals with TBI and behavioral issues; veterans and returning service members with TBI; and adults with TBI, through Medicaid community initiatives for LTSS.
- Capacity for public schools to provide appropriate and adequate education for students with TBI, including students with concussions, and youth within juvenile justice systems.
- Methods for identifying and coordinating State and federal funding availability for TBI within each State.
- Support for the ACL to provide opportunities for States to maximize and coordinate disability and aging resources across the lifespan in order to support individuals with brain injury and their families (e.g. Aging and Disability Resource Centers, Lifespan Respite Care, Intellectual and Developmental Disabilities, Independent Living, and Assistive Technology programs).

2. Expand public and professional awareness about TBI and service delivery.

Individuals with brain injury are treated and supported by multiple systems, usually starting with professionals in the health care system then, transitioning to rehabilitative services before returning to home, school or work. In some instances, they may not receive a diagnosis or treatment at all should their mild (concussion) brain injury in particular be undiagnosed. Recognizing the link between TBI-

related disabilities and academic performance or on the job performance or ability to interact socially will lead to assessment, diagnosis, treatment and any necessary accommodations in order to address issues associated with brain injury. It is critical that the professionals, paraprofessionals, educators, and family members, who are often the caretakers, recognize the symptoms associated with brain injury, which may not even manifest until later.

NASHIA recommends:

- Expanded professional and paraprofessional educational opportunities through CDC, HRSA, Department of Education, Department of Justice, and other pertinent federal programs.
- Development of an ACL Federal TBI Interagency Coordination Plan and convening the Federal TBI Interagency Work Group to identify and report on current federal activities and resources for purpose of education and better coordination among federal programs.
- Improved reporting by public education systems with regard to TBI (child find or child count) to better understand the extent of TBI among children and youth in academic settings.
- Expanded awareness and education among policy makers, including Congressional briefings on crosscutting issues, and the annual CBITF Awareness Day.

3. Maintain and expand access to health care, rehabilitation, and community-based long-term services and supports and community integration for individuals with brain injury.

The Affordable Care Act of 2010 identified rehabilitation as an essential health care benefit with regard to insurance plans. Medicare and Medicaid are also payers of rehabilitative services. NASHIA opposes any efforts to limit rehabilitation and therapies based on artificial caps and on the premise that providing therapy to maintain functioning is not rehabilitation. NASHIA is also concerned that limiting Medicare coverage for rehabilitation shifts the burden to Medicaid and the States as they pick up the costs in nursing homes or other settings for continued rehabilitation and therapies.

About half of the States administer Medicaid Home and Community-Based Waiver programs for individuals with brain injury and/or may include people with brain injury in other waiver programs. **NASHIA opposes transforming the Medicaid program to a block grant program or setting per capita caps to reduce federal participation.** Revamping Medicaid to shift costs and the administration of the program to States will result in less capacity for long-term services and supports. Populations and special interests groups will be pitted against each other as they compete for available funding as States determine eligibility, services/benefits offered, and eligible providers.

NASHIA recommends:

- That health care insurance plans cover rehabilitation as an essential health care benefit.
- Adequate Medicare reimbursement for therapies to restore and maintain functioning and provided in accordance with appropriate rehabilitation settings.
- Medicaid initiatives designed to expand access, *not restricting access*, to health care and to address long-term chronic health issues related to brain injury.
- Rebalancing initiatives to support community living for individuals with brain injury and that managed care plans for LTSS include individuals with brain injury.
- Better CMS data regarding prevalence of brain injury among HCBS populations.

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- Competitive integrated employment policies for individuals with TBI returning to work or seeking work for the first time within State Workforce Investment and Vocational Rehabilitation (VR) Systems.
 - Expanded federal and State Employment First Initiatives to include individuals with TBI.

4. Expand research to promote best practices with regard to brain injury TBI treatment, care, rehabilitation and vocational rehabilitation.

The National Institutes of Health (NIH) and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) are primary funders of disability and rehabilitation research. NIDILRR currently funds 16 TBI Model Systems and one Rehabilitation and Research Training Center (TR&TC) on TBI. In addition, the Department of Defense and the Department of Veterans Affairs also conduct research with regard to brain injury in coordination with NIH and NIDILRR. NIH leads the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, which is aimed at revolutionizing our understanding of the human brain.

NASHIA recommends:

- Funding to continue and expand the Project BRAIN initiative.
- Increased funding for TBI Model Systems (TBIMS) to expand the number of TBIMS and research projects, particularly with regard to functional assessment tools, employment and community long-term services and supports.
- Funding to improve understanding of concussion treatment, diagnosis and lingering effects.
- Funding for research and dissemination of best practices and models for VR services for youth and adults with TBI and for sustaining employment.
- Expand the TBI Model Systems' concept for research capacity for data collection and systemic approach for serving children and youth.

5. Expand primary and secondary prevention related initiatives to reduce the number of TBI-related injuries and to minimize affects.

The Traumatic Brain Injury (TBI) Act of 1996, as amended in 2014, authorizes funding to the Centers for Disease Control and Prevention (CDC) for surveillance, public education, prevention and research activities. The CDC's National Center for Injury Prevention and Control (NCIPC) programs work to prevent TBI and help people better recognize, respond to, and recover from a TBI if it occurs. Congress has also introduced legislation the past few years to assist States with guidelines and training materials with regard to sports-related concussions. NASHIA supports efforts to provide funding to States to better identify brain injury, its causes and contributing factors through State injury and violence prevention programs.

For over 45 years, the American Trauma Society has advocated for a trauma care system of care to reduce the number of deaths associated with TBI and to minimize resulting disability through organized system of emergency medical services (EMS) and trauma care.

NASHIA recommends:

- A national surveillance system to accurately determine the incidence of sports-related concussions and other causes of TBI.

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- Increased funding for the Centers for Disease Control and Prevention's (CDC) National Injury Center's TBI program and integrate TBI among injury center prevention programs (e.g. injury and violence prevention, motor vehicle injuries, older adult falls, child abuse and neglect); and to increase the number of States receiving injury and violence prevention grants.
 - Legislation to prevent and minimize sports-related injuries.
 - Funding to support the elder-falls prevention initiatives and funding within ACL's Administration on Aging (AoA) and CDC.
 - Expanded State and regional trauma care systems.

6. Maintain health and safety net programs for individuals with brain injury.

Individuals with brain injury and their families may be eligible for benefits and programs offering an array of services, supports and public assistance to individuals with other disabilities or other health care needs, such as housing assistance, food stamps (SNAP), Medicare and disability benefits from the Social Security Administration. Without assistance individuals may end up homeless or in institutional settings, including jails.

In addition, individuals' rights are protected under the Americans with Disabilities Act (ADA), as well as under the Rehabilitation Act, as amended. The ADA inspired the Convention on the Rights of Persons with Disabilities (CRPD) that embraced the rights and dignity of all people with disabilities around the world. Approximately 160 countries have signed on to the treaty, however, the United States is not one of them.

NASHIA recommends:

- Preserving and strengthening Social Security, Medicare, and Medicaid programs.
 - NASHIA opposes per capita caps, block grants, and other significant cuts to the Medicaid program.
 - Continuation of Medicaid expansion to cover uninsured adults
- Ratification of the UN CRPD
- Preserving disability rights laws (i.e. IDEA, ADA, and the Rehab Act).
- Continued funding for the State Children's Health Care Program, which expires Sept. 30, 2017.
- Increasing the age of onset of disability to allow individuals injured after the age of 26 to participate in ABLE accounts.

For further information contact:

Rebecca Wolfkiel, Government Relations Consultant
Phone: (202) 480-8901 or email: rwolfkiel@ridgepolicygroup.com

Susan L. Vaughn, Director of Public Policy
Phone: (573) 636-6946 or email: publicpolicy@nashia.org

William A.B. Ditto, Chair of the Public Policy Committee
Email: WilliamABDitto@aol.com