

116th Congress – 2019-2020

nashia

giving states a voice

National Association of State Head Injury Administrators

Public Policy Platform



National Association of State Head Injury Administrators

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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

About TBI

The Centers for Disease Control and Prevention (CDC), National Center for Injury Prevention and Control (NCIPC) reported that at least 2.8 million Americans sustained a TBI in 2013 -- 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.

NASHIA's 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 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 116^h Congress were approved by the NASHIA membership during its annual meeting held in September 2018 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.
- Maintain and expand access to health care, trauma care and rehabilitation.
- Expand research to promote best practices with regard to brain injury treatment, rehabilitation and vocational rehabilitation.
- Support public assistance and safety net programs.

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- Expand primary, secondary and tertiary prevention related initiatives to prevent traumatic brain injury, minimize affects after a brain injury, and to improve the quality of life and life expectancy for those who have incurred a brain injury.

The NASHIA Public Policy Committee is comprised of both full and associate members. Judy Dettmer (CO) is chair and Becky Corby, NASHIA Government Relations, and Susan Vaughn, NASHIA Director of Public Policy, assist the committee and the organization in formulating recommendations and in pursuing its public policy agenda. Through coalitions, NASHIA is able to monitor, support or oppose research, prevention, health care, rehabilitation, and long-term care and services that impact brain injury. NASHIA belongs to the Administration for Community Living (ACL) Disability Network, American Brain Coalition (ABC), Coalition to Preserve Rehabilitation (CPR), Consortium for Citizens with Disabilities (CCD), the Disability and Rehabilitation Research Coalition (DRRC), Injury and Violence Prevention Network (IVPN), National Violence Prevention Network, and the Therapy Cap Coalition.

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 ACL; 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 collaborates with 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.

Federal Programs

The Traumatic Brain Injury (TBI) Program Reauthorization Act of 2018 (P.L. 115-377), authorizes appropriations for the *only* federal programs specifically addressing public service delivery systems for individuals with brain injury, including surveillance, prevention, research, public awareness 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 public assistance programs. These programs are administered by various federal agencies and are implemented across State agencies. In addition, federal research is conducted by ACL's National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), the National Institutes of Health (NIH), Department of Defense and the Department of Veterans Affairs.

NASHIA PUBLIC POLICY PRIORITIES

NASHIA's priorities are influenced by emerging issues and dictated by the amount of organizational resources that are available to carry out the work. NASHIA offers primary support for legislation, funding or regulatory initiatives that directly and exclusively impact service delivery for individuals with brain injury and their families. This includes researching or drafting legislative language or funding proposals; educating legislators and other public policymakers; and coalescing with stakeholders to support brain injury initiatives. It also includes advocating for inclusion of brain injury in reauthorizing legislation for other programs. NASHIA also supports or opposes, and monitors federal legislation, funding, and Administrative proposals, rules and regulations that pertain to broader health care, disability related and public assistance issues that are primary priorities of other organizations. These issues are listed under secondary support, which NASHIA is able to impact through organizational sign on letters, *Action Alerts* and Congressional briefings in concert with other coalitions and organizations. For further information contact: Becky Corby, Government Relations Consultant; rcorby@ridgepolicygroup.com; Susan L. Vaughn, Director of Public Policy, publicpolicy@nashia.org or Rebecca Wolfkiel, Executive Director, execdirector@nashia.org.

Primary Support

1. Enhance and expand State capacity to provide services and supports.

State general revenue, dedicated funding (i.e. trust fund programs), federal funding, and local resources are used for planning, developing and administering rehabilitation and long-term and short-term community and family services and supports. State brain injury programs may fund or contract for service coordinators to coordinate services and assistance provided by private organizations/agencies and governmental programs, such as Vocational Rehabilitation, Medicaid, and Social Security Administration. However, not all States have developed services specifically for people with brain injury and those that have, may not have a robust delivery system throughout the State. Consumers may find few options to address their needs. Families are likely to be the primary caregiver.

The Traumatic Brain Injury (TBI) Program Reauthorization Act of 2018 (P.L. 115-377), is the *only* federal legislation designed to assist States in addressing the specific needs of individuals with brain injury. The Act authorizes funding to the U.S. Department of Health and Human Services' (HHS) Administration for Community Living (ACL) to award grants to States to improve access to service delivery and to (2) state Protection and Advocacy (P&A) Systems to expand their advocacy services. The ACL TBI State Partnership Grant Program has helped States to leverage assistance through other State and community programs to expand capacity. However, the funding limits the number of States which can participate (24) in the TBI State Partnership Grant Program.

The 2018 reauthorizing legislation included a provision for the Centers for Disease Control and Prevention (CDC) to establish and carry out a national concussion surveillance program to help determine the number of Americans who have incurred a mild TBI. This data is needed to help States to better plan and address needs associated with a mild TBI.

About half of the States administer Medicaid Home and Community-Based Services (HCBS) Waiver programs for individuals with brain injury and some States may include people with brain injury in other waiver programs. These programs differ significantly across States and within States. Data is lacking with regard to the number of individuals with brain injury served in these waiver programs, as well as expenditures and outcomes. Federal policies should help States to increase access to HCBS for individuals with brain injury who are often excluded, in part, due to nursing level of care assessment tools which may not be sensitive to assessing cognitive and behavioral disabilities associated with brain injury. As HCBS are optional services under the Medicaid programs, States may not prioritize individuals with brain injury as needing HCBS services, resulting in inequities across populations receiving HCBS. Federal policies should help to

address these inequities, perhaps by focusing more on the needs of individuals, rather than the target population (e.g., aging, physical disabilities, developmental disabilities).

NASHIA recommends:

- Increased funding for the ACL TBI State Partnership Grant Program to increase the number of grantees.
- Expanded data capacity for determining national and State incidence and prevalence:
 - Funding for National Injury Surveillance Project (CDC).
 - Funding to support State surveillance initiatives (CDC).
 - Program priorities to identify individuals with TBI in institutional and nursing facility settings (CDC, CMS).
- Opportunities for home and community long-term services and supports:
 - Money Follows the Person Program Legislation.
 - Disability Integration Act.
 - Lifespan Respite Care Reauthorization.
 - Funding for VR supported employment program.
 - Expand capacity of ACL programs to better address TBI (e.g., ADRCs, Assistive Technology, ILCs, I/DD).
 - Medicaid policies to encourage States to serve individuals with brain injury in HCBS programs.
- Appropriate and adequate education for students with TBI.
 - Full funding for IDEA and reauthorization.
 - Return to Learn legislation.
 - Improved reporting of TBI in IDEA's Child Find.
 - Training for educators.
- Funding opportunities to address crosscutting issues:
 - Violence Against Women Reauthorization (include TBI screening, training, accommodations/strategies, and resource collaboration).
 - Juvenile justice and corrections legislation/funding (TBI screening, training, accommodations/strategies, resources to support community re-entry).
 - Individuals with TBI and co-occurring conditions (e.g., screening, best practice, professional training).
 - Individuals with TBI and neurobehavioral issues (e.g., best practice models, professional training, payment such as Medicaid/insurance).
 - Older Americans Act programs (e.g., aging and disability resource centers, falls prevention, and lifespan respite care).
 - Funding and policies for addressing homelessness, including veterans with a TBI.

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, individuals may not receive a diagnosis or treatment at all should a mild (concussion) brain injury occur. 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 professionals, paraprofessionals, educators, and family members, who are often the caretakers, recognize the symptoms associated with brain injury, which may not manifest until later.

NASHIA recommends:

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- Finalization of the ACL Federal TBI Interagency Coordination Plan report to identify and report on current federal activities and resources for purpose of education and better coordination across federal programs.
 - Support and participation in the annual Congressional Brain Injury Task Force (CBITF) Awareness Day to inform policymakers about TBI and State service delivery.
 - Congressional briefings in collaboration with the CBITF and stakeholders on crosscutting issues, such as TBI and domestic violence, sports-related concussions, juvenile justice and corrections.
 - Federal policies to support State programmatic data on individuals with brain injury served by federal programs.

Secondary Support

3) Maintain and expand access to health care, trauma care and rehabilitation.

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. Not all States have implemented a statewide and regionalized system of care. In recent years, following 9/11 and other catastrophic events, the medical community and the Department Defense, as well as the National Academies of Sciences, Engineering and Medicine, NIH, National Highway Traffic Safety Administration (NHTSA) have worked collaboratively and issued a 2017 report calling for a national trauma care system that integrates civilian and military trauma systems. Since then, legislation was introduced in the previous Congress.

The Affordable Care Act of 2010 identified rehabilitation as an essential health care benefit with regard to insurance plans. NASHIA is concerned that the Administration's push for cheap, stripped down health insurance plans do not cover extensive rehabilitation coverage that individuals with brain injury need. 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 to the States, as they pick up the costs in nursing homes or other settings for continued rehabilitation and therapies.

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:

- Health care insurance plans that provide necessary rehabilitation and therapies.
- Medicare/Medicaid reimbursement methods that support comprehensive post-acute rehabilitation, cognitive and behavioral therapies.
- Initiatives to support treatment for pain, but avoid dependence or overuse of opioids.
- Medicaid initiatives that support comprehensive and coordinated rehabilitation to assist individuals to return to and live in the community. NASHIA oppose measures to block grant, cut and transfer the Medicaid program to the States.
- Legislation to improve EMS and trauma systems.

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

The National Institutes of Health (NIH), the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Department of Veterans Affairs and the Department Defense are primary federal funders of disability and rehabilitation research. NIDILRR currently funds 16 TBI Model Systems and one Rehabilitation and Research Training Center (TR&TC) on TBI. The Departments of Defense and 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:

- Continued funding to support and expand the Project BRAIN research.
- Funding to increase the number of TBI Model Systems (TBIMS) and research projects.
- Research 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 employments.

5) Support public assistance and safety net programs.

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, Supplemental Nutrition Assistance Program (SNAP), known as food stamps, 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. 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:

- Sufficient funding for public assistance programs. NASHIA opposes work requirements which may present a hardship for individuals with brain injury or their caregivers with regard to such programs as housing assistance, Medicaid, and SNAP.
- Funding for the Medicaid Buy-In program, an optional State Medicaid benefit group for workers with disabilities who have earnings in excess of traditional Medicaid rules.
- ABLE Age Adjustment Act legislation to extend eligibility for individuals with brain injury to participate in the savings program from age of onset of disability from age 26 to age 46, in order to set aside money for future needs and still be eligible for public assistance.

6) Expand primary, secondary and tertiary prevention to reduce the number of TBI-related injuries and to minimize affects.

NASHIA supports CDC's National Injury Center's efforts to better TBI, its causes and contributing factors and other initiatives that help people better recognize, respond to, and recover from a TBI.

NASHIA recommends:

- Increase funding for the CDC's 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, and child abuse and neglect).