

117th Congress – 2021-2022



**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

NASHIA's 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 Brain Injury

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 traumatic brain injury (TBI) in 2014 -- 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.

Brain injury 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 brain injury-related disabilities across service systems that may offer services and supports to persons with similar disability and health-related issues.

No doubt the coronavirus pandemic (COVID-19) has impacted the way services are delivered to individuals with brain injury and their families with States relying more on technology to determine eligibility and to provide oversight, while realizing that many individuals may not have the resources or need further assistance with technology due to cognitive related disabilities. The pandemic has also impacted ability to employ direct care workers, private duty nurses and other staff necessary to carry out services.

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 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 117^h Congress were approved by the NASHIA membership and address funding, legislation, and policies to:

- Enhance and expand State capacity to provide services and supports.
- Improve services for individuals with brain injury who are underserved (e.g., co-occurring conditions; older adults; who experience domestic violence).
- Improve outcomes for individuals in juvenile and criminal justice systems.
- Ensure availability of public assistance and safety net programs.
- Improve service delivery for children and youth with brain injury.
- Maintain and expand access to health care, trauma care and rehabilitation.
- Reduce the number of TBI-related injuries, minimize effects and optimize outcomes (primary, secondary and tertiary prevention).

The NASHIA Public Policy Committee is comprised of both full and associate members. Jennifer Braun (MO) is chair and Becky Corby, NASHIA Government Relations, and Susan L. 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 an array of issues that impact individuals with brain injury and service delivery. NASHIA belongs to the 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.

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 legislative and policy issues.

NASHIA works closely with the Congressional Brain Injury Task Force (CBITF), which was created to promote brain injury 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 impacting 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 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), authorized 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 education. The U.S. Department of Health and Human Services (HHS), Administration for Community Living (ACL) administers the TBI State Partnership Program and the Protection & Advocacy TBI program authorized by the TBI Act. The TBI Act authorizes funding for the Centers for Disease Control and Prevention to carry out prevention activities, surveillance, and public education. The 2018 reauthorization also authorized \$5 million to establish a CDC National Concussion Surveillance System. The Supporting Older Americans Act of 2020 included provisions relating to TBI-related falls with regard to screening and health promotion. The Individuals with Education Act (IDEA) 1990 added TBI as a disability that may be eligible for special education and related services.

Federal programs which may also provide assistance include the 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 Supporting Older Americans Act; 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 capacity for service delivery refers to funding and staff necessary to offer and/or contract for resources, services and supports for individuals with brain injury and their families across the lifespan, such as State staffing for administering funding and/or contracts, monitoring services, supervising staff, such as case managers/service coordinators; interagency coordination; and collecting and reporting data with regard to individuals served, costs, and outcomes. Capacity also includes the ability to access data to assist with assessing needs and to develop a State plan for addressing gaps in service delivery, involving stakeholder in all aspects of planning and service delivery. Challenges to offering services include workforce shortages, turnover of direct care staff, low wages for direct care staff; lack of provider capacity; and lack of funding for direct services and resources and to support staff and infrastructure needed to administer assistance, services, and supports.

NASHIA recommends:

- Increased funding to the Administration for Community Living (ACL) TBI State Partnership Program to increase the number of State grantees to address the needs in their States.
- Funding to expand data capacity for determining national and State incidence and prevalence for purposes of State planning:
 - Funding for CDC National Concussion Surveillance System, as authorized by the TBI Program Reauthorization Act of 2018.
 - Policies to ensure that federal data collection efforts include critical disability status information to inform the federal pandemic response, as well as to inform State government, as to the impact on access to health, rehabilitation and services and supports.
- Expanded capacity for home and community long-term services and supports:
 - Passage of COVID HCBS Relief Act to provide dedicated funding and/or targeted Federal Medical Assistance Percentage (FMAP) enhancement to sustain HCBS services that may be at risk due to declining budget revenues.
 - Passage of the Disability Integration Act to end the institutional bias and people with brain injury home and community-based services (HCBS) as an alternative to institutionalization.
 - Legislation to support grants for recruitment, retention and advancement of direct care workers.
 - Funding for supported employment program.
 - Maximization of ACL programs to include brain injury (e.g., Aging and Disability Resource Centers (ADRCs), Assistive Technology, Independent Living Centers (ILCs).

2. Improve services for underserved populations.

Co-occurring conditions

Co-occurring mental health and substance abuse are common among persons who sustain a TBI. Between 30-50% of people with TBI are injured while they intoxicated by alcohol and about one-third were under the influence of other drugs. Depression, anxiety, substance abuse, chronic pain, and psychosocial conditions are contributing factors to relationship problems with family, often resulting in burn out by family, employers and friends. The Substance Abuse and Mental Health Services Administration (SAMHSA) is the primary federal funder of State prevention and treatment services for individuals with behavioral and substance use disorders.

NASHIA recommends:

- SAMHSA policies and funding to support individuals with brain injury seeking treatment and services through State agencies and programs funded by SAMHSA for:
 - Individuals with brain injury and neurobehavioral issues and
 - Individuals with brain injury and substance use issues.
- Funding and legislation to address substance abuse and misuse, including the opioid epidemic, among individuals with brain injury.

Domestic Violence

Individuals who experience intimate partner or domestic violence, often incur a brain injury. Offenders may strike, strangle and/or severely shake their partner, often multiple times, that impact cognitive and behavioral functioning. A 2017 retrospective study of 115 patient files, reviewed by the Barrow Neurological Institute, and reported in the *Journal of Neurotrauma*, indicated that 88% of individuals who experience domestic violence self-reported more than one injury and 81% reported a history of loss of consciousness associated with their injuries as the result of domestic violence. Only 21% sought medical help at the time of injury. A common cause of brain injury in women is domestic and intimate partner violence.

NASHIA recommends:

- Passage of the Violence Against Women Reauthorization to include brain injury screening, training, accommodations/strategies, and resource collaboration.
- Funding and policies to support collaboration and coordination among domestic violence providers and organizations and brain injury programs.
- Public education regarding domestic violence and brain injury-related injuries, symptoms, treatment and resources.
- Education and training among healthcare providers, physicians, and educators to identify, treat, and provide needed accommodations to assist with education and activities of daily living.

Older Adults

Recognizing that older Americans are a high risk group for a TBI due to a fall, the Supporting Older Americans Act of 2020 included provisions to promote education and awareness of TBI and to allow federal funding for state aging programs to be used to screen for TBI after a fall. To implement these provisions,

NASHIA recommends:

- Federal funding to implement the screening and health promotion provisions pertaining to TBI-related falls in the Supporting Older Americans Act of 2020.

3. Improve outcomes for individuals with brain injury in juvenile and correctional justice systems.

Individuals with brain injury may be overrepresented in juvenile and criminal justice systems, due to poor judgement, inappropriate behavior, poor impulse control and other brain injury-related disabilities that impact overall educational and employment outcomes. However, individuals in these systems may not be recognized or diagnosed nor receive accommodations and strategies to address cognitive and behavioral issues associated with their brain injury that would assist with day to day functioning within these systems and successful community re-entry once released.

NASHIA recommends:

- Juvenile justice and corrections reauthorizing legislation to support TBI screening, training, accommodations/strategies, resources to support community re-entry.
- The Traumatic Brain Injury and Post-Traumatic Stress Disorder Law Enforcement Training Act” or the “TBI and PTSD Law Enforcement Training Act.

Secondary Support

4) Ensure availability of 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.

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 Supplemental Nutrition Assistance Program (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.

5) Improved service delivery for children and youth with brain injury

Children and youth with brain injury generally do not have many resources following initial treatment, other than returning to school. The Health Services and Resource Administration (HRSA) administers the Title V Maternal and Child Health Services (MCH) Block Grant program which is a major funder for State programs offering services to children and youth with special health care needs. The Medicaid Early Periodic Screening, Diagnosis, and Treatment (EPSDT) is a mandated health program for children under the age of 21. TBI is also one of the disabilities eligible for special education and related services under the Individuals with Disabilities Education Act (IDEA). Children with brain injury may also be eligible for accommodations under Section 504 that prohibits discrimination against individuals with disabilities.

NASHIA recommends:

- The Title V Children with Special Health Care Needs program to prioritize case management and other services needed by children with brain injury and to collect data accordingly.
- Primary care providers participating in the EPSDT program to better identify, diagnose, and treat children and youth with brain injury.
- Increased funding to support the Emergency Medical Services and Emergency Medical Services for Children (EMSC) program.
- Appropriate and adequate education to address educational needs of students with brain injury.
 - Full funding for IDEA and reauthorization.
 - Return to Learn legislation.

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- Improved reporting of TBI in IDEA's Child Find.
 - Training for educators.

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

The Affordable Care Act of 2010 identified rehabilitation as an essential health care benefit with regard to insurance plans. NASHIA is concerned that the previous 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.

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.

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.
- Ensure the rights of individuals with brain injury access to COVID-19 vaccine and hospitalization for COVID-19 treatment.
- Mission Zero Act" legislation that would assist civilian trauma centers in partnering with military trauma professionals to establish a pathway to provide patients with the highest quality of trauma care in times of peace and war.

7) Expand research for promising practices for treatment, rehabilitation and community services and supports.

The National Institutes of Health (NIH), the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Department of Veterans Affairs (VA) and the Department of Defense (DoD) 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 DoD and VA also conduct collaborates 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 employment.
- Research to build knowledge on COVID-19 brain injuries.

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- Targeted research on the inequitable impact of COVID-19 on people with disabilities.

8) Expand primary, secondary and tertiary prevention programs directed at reducing the number of TBI-related injuries, minimizing effect and optimizing outcomes.

NASHIA supports CDC's National Injury Center's efforts to prevent and minimize the effects of TBI through public education and other initiatives that help people better recognize, respond to, and recover from a TBI. NASHIA has supported CDC's efforts to develop guidelines to better manage the treatment of TBI for targeted groups, such as children and youth.

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).
- NASHIA supports the Injury Center to direct resources to secondary and tertiary prevention efforts.
- Funding for research related to preventing firearm injury and death.
- Funding to support falls prevention among older adults.

For further information visit NASHIA's website: www.nashia.org or contact NASHIA: publicpolicy@nashia.org

