

Campaign 2018: Brain Injury Issues A Guide for Meeting with Candidates and Office Holders

Introduction

November 6 is election day for all members of the U.S. House of Representatives (435 seats) and one-third of the U.S. Senate (35 seats). In addition, 36 State and 3 Territory gubernatorial elections will be held on that day, as well as elections for state legislators and other statewide elected officials. This guide is to present information on priority legislation and federal funding that the National Association of State Head Injury Administrators (NASHIA) adopted for the 116th Congressional Session during its Membership Meeting held September 26, 2018. While these are national and federal priorities, these priorities may also apply to State laws and policies. Feel free to use these materials as you see fit.



In this document, you will find:

- Pointers for meeting with your elected officials/candidates;
- Talking points for discussing brain injury legislation and funding;
- Sample letters/email messages for soliciting support for the Traumatic Brain Injury (TBI) Act Reauthorization and to invite members to join the Congressional Brain Injury Task Force;
- Advocacy Resources; and
- NASHIA's public policy priorities for the 116th Congress (2019-2020).

Meeting with Your Elected Officials and Candidates

During the campaign season is an excellent time to meet with candidates. They may be visible at city/county events and available in their home district offices. If you do not know who the candidates are in your state, you may contact your Secretary of State or local election office (county) or click here: <https://www.usa.gov/election-office>. Below are ways that you may be able to connect with candidates to discuss brain injury issues:



- Call or email your lawmaker's U.S. district office or candidate's campaign office and ask for appointment with your U.S. Representative/Senators while they are home and/or candidates who may not be elected officials, but are running for office.
- The same is true for State lawmakers/candidates who are running for State offices and other elected officials in terms of contacting their local campaign offices or in-district office.
- Attend a town hall meeting or public forum.
- Connect with them at public events such as a county fair, parade, festival, etc.
- Invite them to a rehab or community program to see first hand services that may be provided in the district. If you are staff/administrator, perhaps arrange for a picture they can use in their campaign materials and local newspapers.
- Submit an op-ed to your local paper with regard to needs of individuals with brain injury.
- Attend candidate forums that may be organized by League of Women Voters, Chamber of Commerce, local radio/television stations/newspapers, universities, or other organizations in your community.
- Use Facebook or Twitter to engage your members of Congress and other elected officials.

General Pointers

- Do your homework. Check out the background/interests of the elected official/candidate. If currently elected, check Congressional or State websites to see if serving on a committee that may be responsible for the issues you are proposing. Check out their positions so you know how to tailor your remarks to be of interest to them.
- When setting up an appointment or calling to discuss an issue, identify yourself as a constituent.
- When you do meet or talk with him/her, get straight to the point - tell what you want him/her to do and why it is important to you and your State.
- If you are writing or emailing, please include your name and contact information.
- Be prepared to explain traumatic brain injury (TBI), the extent of TBI in your State and/or nationally, and services and supports needed concisely.
- Tell how TBI may affect you personally or if you are staff to a program, what your program does – how you are involved.
- Explain that without coordinated resources to improve access to care and community living and supports, individuals with brain injury end up homeless, in our jails/correctional facilities, institutions and nursing homes. While much work has been done in developing service delivery, there are still gaps in service delivery that present hardships on individuals with TBI and the family that make it difficult for individuals to live and work in the community without supports.
- Give them materials on brain injury, resources and needs.

Quick Talking Points About TBI

In comparison to other disability populations, TBI is significantly underfunded in terms of number of individuals each year who incur a TBI-related disability. The Centers for Disease Control and Prevention (CDC), National Center for Injury Prevention and Control (NCIPC) reported in 2013, at least 2.8 million Americans visited an emergency department, hospital, or physician office as the result of a 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.

The TBI Act, first passed in 1996, is the only federal law focused on issues faced by individuals with TBI and their families; and is the only law authorizing federal funding to assist States to address these unique and complex service needs.

Specific requests:

- Increase funding to the U.S. Department of Health and Human Services' (HHS) Administration for Community Living (ACL) for fiscal year 2020 in order to expand the number of TBI State Partnership Grant Program to all states, as currently only 24 states are participating. (Currently, \$11,321,000, which is combined funding, is appropriated to support both the Protection & Advocacy and State grant programs.)
- Support reauthorization of the TBI Act, which authorizes appropriations for the:
 - Centers for Disease Control and Prevention (CDC) to conduct prevention, surveillance/data, public and professional education and awareness, and special reports, such as TBI among veterans and returning servicemembers and guidelines for management of mild TBI among children.
 - ACL TBI State Partnership Grant Program and the Protection and Advocacy TBI Grant Program.
 - National Institutes of Health (NIH) to conduct research.
- A sample letter/message is included below for you to use to solicit support and co-sponsorship from current Representative for H.R. 6615, which has been introduced this session ending in December.
- Support funding and authorization, through the TBI Act, for CDC to conduct a National Concussion Surveillance System.

- Invite them to join the bi-partisan Congressional Brain Injury Task Force, if elected, which works to increase awareness of brain injury, supports rehabilitation and treatment research initiatives for both the civilian and military populations. Current co-chairs are Rep. Bill Pascrell, Jr. (D-NJ) and Rep. Tom Rooney (R-FL), who is retiring after this year. A sample letter/message is included below for you to use to solicit membership to the Congressional Brain Injury Task Force.

Sample Letters/Message

Due to security issues, it is strongly recommended that individuals e-mail U.S. Representative and Senators in lieu of writing letters (snail mail). State employees may need to use personal e-mail accounts outside of office hours and use personal stationery, if you attach a document to an e-mail. You may ask your advisory board/council members and other partners (e.g., state brain injury alliance/association, developmental disability state councils, statewide independent living council, and others) to join in this efforts.



There is no central listing of member office public e-mail addresses. Each member of Congress establishes their office's policy related to the processing and management of e-mail. Generally, if a member has a public e-mail address, it can be found on the Member's website. You may find your Representative here: <https://www.house.gov/representatives/find-your-Representative>.

TBI Reauthorization

Dear Congressman(woman) X:

I am writing to you to respectfully request your support for reauthorization of the Traumatic Brain Injury (TBI) Act (H.R. 6615). This legislation will reauthorize the only federal programs dedicated to supporting civilians with TBI.

As you may know, TBI is a leading cause of death and disability in the United States. Falls and motor vehicle accidents are the leading causes of TBI, impacting children ages 0-14 and older adults over age 65 disproportionately. The Centers for Disease Control and Prevention (CDC) estimates that 2.8 million TBIs occur each year and 5.3 million Americans live with a lifelong disability as a result of TBI.

Please insert a paragraph explaining your program that serves individuals with brain injury and their families, or your personal story.

First signed into law in 1996, the TBI Act provides funding for States to serve unserved populations with brain injury, such as returning servicemembers, children and older adults, through the TBI State Partnership Program and the TBI Protection and Advocacy Program at the U.S. Department of Health and Human Services' Administration for Community Living (ACL). These programs fund State systems of supports for individuals living with TBI and their families. The TBI Act also funds the CDC's TBI Program that provides educational materials for diverse audiences about the prevalence and impacts of brain injury nationally.

Please join Congressmen Bill Pascrell and Tom Rooney in cosponsoring H.R. 6651 and continuing to ensure that individuals with TBI have access to resources and supports in the communities. Thank you for your consideration.

Sincerely,

Your Name
Contact Information

Congressional Brain Injury Task Force

Dear Congressman (woman) X:

I am writing to you to respectfully request you join the bicameral, bipartisan Congressional Brain Injury Task Force. Task Force, which promotes awareness of traumatic brain injury (TBI) in the United States, supports research initiatives for rehabilitation and potential cures; and strives to address the effects such injuries have on families, children and adults with TBI, education, and the workforce. The Task Force annually calls attention to these issues through an Awareness Day in March that features a Fair consisting of federal and national organizations and agencies addressing TBI; a briefing on current issues; and a reception to celebrate March Awareness Month.

Known as the “silent epidemic,” TBI was dubbed the signature injury of the wars in Iraq and Afghanistan. Meanwhile, incidence continues to increase here at home among our nation’s civilian population. From the battlefield to the football field, TBI remains a leading cause of death and disability among adults and youth. The Centers for Disease Control and Prevention (CDC) reports that 2.8 million Americans sustain a TBI each year requiring treatment in physician’s offices, emergency departments, and hospitals. An estimated 5.3 million Americans are living with long-term disabilities impacting cognitive, behavior, emotional, and physical functioning, which affect an individual’s ability to return to school, work and home to live independently. Brain injuries affect the whole family and often result in medical and rehabilitation expenses not otherwise covered by private health care insurance.

Please insert a paragraph explaining your interest in brain injury.

I ask that you strongly consider joining Congressmen Bill Pascrell and Tom Rooney in raising awareness about brain injury through the Congressional Brain Injury Task Force. Thank you for your consideration.

Sincerely,

Your Name

Contact Information

Advocacy Resources:

- How to Advocate as a State Employee: http://www.nashia.org/pdf/how_advocate_state_employee_2011.pdf
- How to Write to Members of Congress: http://www.nashia.org/pdf/contacting_members_congress.pdf
- NASHIA’s webpage on Key Issues (2017-2018): <http://www.nashia.org/KeyIssues.asp>

NASHIA Priorities (2019-2020)

Background

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.

The National Association of State Head Injury Administrators (NASHIA) supports legislative and Administrative issues impacting individuals with brain injury and their families -- including prevention, research, short-term and long-term rehabilitation and community services and supports. NASHIA works closely with the Congressional Brain Injury Task Force (CBITF), which was created to promote TBI awareness and education among Members of Congress, and other TBI stakeholders. The CBITF regularly sponsors legislation impacting brain injury. NASHIA also collaborates with other Congressional caucuses, including the Neuroscience Caucus, Safe Kids Caucus and the Bipartisan Disabilities Caucus.

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. Federal agencies, which are tasked with these issues include: the Departments of Health and Human Services (HHS), Education, HUD, Labor, Justice, Social Security, Transportation, Defense (DoD), and Veterans Affairs (VA).

To assist with its advocacy work, 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, Preserve Rehabilitation Coalition, and the Injury and Violence Prevention Network (IVPN).

Primary Support

1. Enhance and expand state capacity to provide services and supports:

- Increase funding for the Administration for Community Living (ACL) TBI State Partnership Grant Program.
- Reauthorization of the TBI Act (reauthorizing CDC, State Grant, P&A Grant programs).
- Expand data capacity for determining national and state incidence and prevalence:
 - Funding for National Injury Surveillance Pilot Project.
 - Funding to support state surveillance initiatives (CDC)
 - Expand data capacity for identifying individuals with TBI in institutional and nursing facility settings (CDC, Centers for Medicare and Medicaid Services -- CMS).
- Promote 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 Vocational Rehabilitation supported employment program.
 - Expand capacity of ACL programs to better address TBI (e.g., Aging and Disability Resource Centers, Assistive Technology, Independent Living Centers).
- Appropriate and adequate education for students with TBI.
 - Full funding for IDEA and reauthorization.
 - Return to Learn legislation.
 - Improved reporting of TBI in Child Find.
 - Training for educators.
- Underserved/Unidentified populations
 - Violence Against Women Reauthorization (include TBI screening, training, accommodations/strategies, 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 adults with TBI (e.g., screening, education and training for caregivers).

- Funding and policies for addressing homelessness among individuals with brain injury, including veterans.

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

- Promote and support the development of the ACL Federal TBI Interagency Coordination Plan and the Federal TBI Interagency Work Group to identify and report on current federal activities and resources for purpose of education and better coordination.
- Advocate for methods to collect state programmatic data on TBI served in state programs, including Medicaid, to provide a national perspective and to track trends in federal, state, and local government spending for services and income maintenance for persons with brain injury and their families.

Secondary Support

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

- Increase access to health care insurance plans that provide necessary rehabilitation and therapies.
- Support Medicare/Medicaid reimbursement methods that support comprehensive post-acute rehabilitation, cognitive and behavioral therapies.
- Support initiatives to support treatment for pain, but avoid dependence or overuse of opioids.
- Oppose measures to block grant, cut and transfer the Medicaid program to the states.
- Support Trauma-Informed Care for Children and Families Act.
- Support legislation to improve EMS and trauma systems.
 - Military Injury Surgical Systems Integrated Operationally Nationwide to Achieve ZERO Preventable Deaths Act or MISSION ZERO Act, HHS to award grants to certain trauma centers to enable military trauma care providers and trauma teams to provide trauma care and related acute care at those trauma centers. Funds may be used to train and incorporate military trauma care providers into the trauma center, including expenditures for malpractice insurance, office space, information technology, specialty education and supervision, trauma programs, and state license fees. (passed the House, in Senate HELP).
- Support Emergency Medical Services for Children program administered by Health Resources and Services Administration (HRSA).

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

- Support funding to continue and expand Project BRAIN research.
- Increase funding for the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) funded TBI Model Systems (TBIMS) to expand the number of TBIMS and research projects. NIDILRR is housed in the Administration for Community Living.
- Support research to improve understanding of concussion treatment, diagnosis and lingering affects.
- Support 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

- Oppose work requirements which may present a hardship for individuals with brain injury or their caregivers with regard to such programs as housing assistance, Medicaid, Supplemental Nutrition Assistance Program -- SNAP (food stamps).
- Support continued funding for SSI/Social Security, SNAP, housing assistance, Temporary Assistance for Needy Families (TANF) and other benefits necessary for individuals to survive and reside in the community.
- Support the Medicaid Buy-In program, an optional state Medicaid benefit group for workers with disabilities who have earnings in excess of traditional Medicaid rules.

- Support the ABLE Age Adjustment Act to extend eligibility 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 and secondary prevention related initiatives to reduce the number of TBI-related injuries and to minimize affects:

- 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, child abuse and neglect).
- Support legislation to prevent and minimize sports-related concussions
- Support elder-falls prevention initiatives and funding within ACL's Administration on Aging (AoA) and CDC.

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.

*Assisting state government in promoting partnerships and building systems
to meet the needs of individuals with brain injury and their families.*

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