# REAUTHORIZE AND FULLY FUND THE TBI ACT 

NASHIA Brain Injury Alliance -

## IMPROVE AND EXPAND THE TBI ACT

The Administration for Community Living (ACL) administers the TBI Act funding. It is used for the TBI State Partnership Grant Program, which helps states increase access to services and supports for individuals with TBI throughout their lifespan. It is also used for the Protection and Advocacy (P\&A) TBI Grant Program, which helps states provide advocacy services for people with brain injury. Currently 31 states receive TBI State grants, and they are severely underfunded, as are all the P\&A grants.

## BIAA urges Congress to:

- Expand the eligibility criteria for programs to include hypoxic and other acquired brain injuries;
- Ease the state match requirement from $50 \%$ to $25 \%$;
- Allow P\&A access into VA facilities and federal prisons;
- Require the Heath and Human Services Secretary to examine the evidence base of brain injury as a chronic condition.
- Increase funding for the TBI Act to $\$ 25$ million, and appropriate
- \$19 million to the State Grant Program so all states can participate (an increase of $\$ 11$ million), and
- $\$ 6$ million to the P\&A Grant Program (an increase of $\$ 3.5$ million).


## FULLY FUND THE CDC TBI PROGRAM

The TBI Act authorizes the Centers for Disease Control and Prevention (CDC) to collect data and conduct public education and research. The TBI Program Reauthorization Act of 2018 further authorized the establishment of a National Concussion Surveillance System; a pilot indicated much higher levels of brain injury than have been reported from other large, national datasets. Their work needs to be fully funded to truly grasp the scope of the issue and continue its vitally important work in this area.

BIAA urges Congress to reauthorize $\$ 11.75$ million in CDC TBI Programs funding, and appropriate:

- $\$ 6.72$ million for the TBI program within the CDC's National Center for Injury Prevention and Control (NCIPC), and
- $\$ 5$ million for the National Concussion Surveillance System.

BRAIN INJURYIS A CHRONIC CONDITION

Every year, at least 2.8 million Americans sustain a traumatic brain injury. While most of them fall into the "mild" category, they can cause temporary and permanent neurological impairment. There are more than 5 million people living with a permanent brain injuryrelated disability - one in 60 Americans.

Brain injury is viewed by healthcare systems and the public as a one-time event, rather than the beginning of what can be persistent medical, physical cognitive and behavioral effects. The idea that brain injury can permanently change a person - their capabilities, their personality, their ability to work and socialize as they once did - is not something most people can understand.

Extensive research has demonstrated brain injury is not just an acute injury, but a chronic condition that affects far more than the brain; it may cause associated conditions that can increase health care costs and complicate recovery. The chronic, long-term effects of brain injury are wide-ranging, and can include fatigue, sensitivity to noise and light, memory loss, mobility issues, chronic migraines, trouble with focus and executive functioning, depression, and anxiety.

Having brain injury recognized as a chronic condition would mean more services and supports across the lifespan; it would open new avenues to treatment and research; and it would go a long way toward educating the public and correcting misconceptions about a condition that impacts millions of Americans.

> Sign up for BIAA's free enewsletter, Policy Corner! www.biausa.org/get-involved

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## FULLY FUND TBI MODEL SYSTEMS OF CARE

The TBI Model Systems are a collection of 16 research centers providing a multidisciplinary continuum of care that includes emergency and acute medical, rehabilitative, and post-acute services to improve recovery for people with TBI.

In addition to providing direct services, these centers play a pivotal role in building national capacity for high-quality treatment and research for persons with TBI, their families, and the communities in which they reside.

The TBI Model Systems are the only source of long-term data on what happens to people with brain injury across the lifespan, and their findings are critical to identifying and designing future improvements in brain injury treatment. They are a critical source of evidence-based brain injury medicine, and often serve as a "launching pad" for future researchers.

The Model Systems receive grants administered by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) in the Administration for Community Living at the Department of Health and Human Services. In 2008, the Department of Veterans Affairs partnered with NIDILRR to establish VA-TBI Model Systems to investigate recovery and outcomes in the 5 VA Polytrauma Rehabilitation Centers (PRCs).

BIAA urges Congress to increase funding for the TBI Model Systems by at least $\$ 15$ million over the next 5 years to:

- Increase the number of multicenter TBI Model Systems Collaborative Research projects from one to three, each with $\$ 1$ million budget;
- Increase the number of competitively funded centers from 16 to 18 while increasing per center support; and
- Increase funding for the National Data and Statistical Center for tracking participants over their lifetime


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## JOIN THE CONGRESSIONAL BRAIN INJURY TASK FORCE

NASHIA
Brain Injury Alliance -

The mission of the Congressional Brain Injury Task Force is to further education and awareness of brain injury and support funding for basic and applied research, brain injury rehabilitation, and development of a cure. Please join the Task Force to help make life better for individuals with brain injury and their families. To sign up, contact the office of a co-chair: the Hon. Bill Pascrell, Jr. or the Hon. Don Bacon.

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Bill Pascrell (D) NJ-9
Tammy Baldwin (D)
Andy Barr (R) KY-6
Joyce Beatty (D) OH-3
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# Building a Better Future for Brain Injury 

## Understanding the Brain Injury Challenge

- Brain injuries are considered a significant public health issue in the United States and the leadingcause of death and disability_in both older adults and youth.
- 2.5 million brain injuries occur each year and 5.3 million Americans live with a life-long disability as a result of brain injury. This is likely an underestimation of the true prevalence.
- Approximately 200 Americans die each day due to a traumatic brain injury.
- Approximately $15 \%$ of high school youth in the United States report one or more sports or recreationrelated concussions annually.
- Individuals with brain injury have high co-occurrence with behavioral health and substance misuse challenges and are significantly over-represented within the criminal justice system and among the intimate partner violence and unhoused communities.
- These data combined underscore the significant prevalence and growing complex challenges related to brain injury.


## Key Priorities for Fiscal Year 2025 Funding

Because of the significant needs associated with supporting individuals with brain injury, the Traumatic Brain Injury Act authorizes:

- The Administration for Community Living (ACL) to award grants to states, tribes, and territories to improve access to service delivery through a discretionary grant called the Traumatic Brain Injury State Partnership Program. The Act also authorizes The Traumatic Brain Injury Protection and Advocacy Program for all states to help protect the legal and human rights of people with brain injury.
- The Centers for Disease Control and Prevention's (CDC) TBI Program is responsible for assessing and reporting on the incidence and prevalence of TBI in the United States. The CDC's National Concussion Surveillance System is the most comprehensive mechanism available for collecting national data on the number of Americans who have experienced a brain injury.

In addition to the Traumatic Brain Injury Act authorized programs, we also support funding for:

- National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) TBI Model Systems, which is authorized under Title II of the Rehabilitation Act. The TBI Model Systems is comprised of a network of 16 research institutions across the country that research best practices for rehabilitation and community integration for individuals with brain injury.

FY25 Brain Injury Community Funding Requests

| Program | FY25 Funding Request | FY23 Funding Level |
| :--- | :--- | :--- |
| State Partnership <br> Program and Protection <br> \& Advocacy Grants | $\$ 25$ Million | $\$ 13.1$ Million |
| TBI Model Systems | $\$ 15$ Million | $\$ 7.1$ Million |
| TBI Program and the <br> National Concussion <br> Surveillance System <br> (NCSS) | $\$ 11.75$ Million with $\$ 5$ million <br> specifically allocated for the <br> NCSS | $\$ 8.25$ Million with $\$ 1$ million allocated for <br> the NCSS |

## Empowering States is Vital for Brain Injury Support

Current funding for the TBI State Partnership Program Grant provides funding for just more than 30 states. More funding is needed to ensure that every state is able to receive dedicated brain injury funding. Research shows that individuals with brain injury who live in states with TBI State Partnership Program funding have better longterm outcomes than individuals living in states without the grant. States use TBI State Partnership Program funds to:

Expand and Improve State Capacity, including:

## Ensuring Dedicated Staff

Connecting Individuals to
Community Resources

Creating Resource Networks

Providing Training to Community
Professionals

Collaborate with Other State Agencies who Serve People with Brain Injury, such as:

Criminal and Juvenile Justice and Law Enforcement

Aging

Behavioral Health

Veterans

## Maintain State Brain Injury

 Advisory Boards to:
## Develop State Plans on Brain

 Injury
## Promote Awareness

Identify Areas of Needed Focus and Resources

Amplify the Voice of Individuals with Lived Experience to Impact Service Delivery

## Data Needed to Drive Change

Existing national data underestimate the prevalence of brain injury across the country with most estimates coming solely from emergency department data. This data is not reflective of the many individuals who do not seek care, seek care outside of emergency departments, or those who are not reported. With internal funding, CDC was able to conduct a pilot of the National Concussion Surveillance System, which found significantly higher levels of brain injury.


30 times as many TBIs in Adults 17 times as many TBIs in Children

The CDC needs $\$ 5$ million annually to fully fund the National Concussion Surveillance System, in order to get a more accurate understanding of the incidence and prevalence of brain injury.

