

# **Support Funding for Millions of Americans Living with Traumatic Brain Injury**

*This is a programmatic request.*

Dear Colleague:

I urge you to join me in sending the attached letter to the Chairman and Ranking Member of the Subcommittee on Labor, Health and Human Services and Education Appropriations requesting funding for programs for traumatic brain injury (TBI) in the Fiscal Year 2020 Labor-HHS-Education Appropriations Bill.

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 in both adults and youth, each day taking the lives of 138 people in our country. The primary source of funding to address this growing population is provided through the TBI Act programs.

The TBI Act, which was originally passed in 1996 and reauthorized in 2008, 2014, and 2018 is the only federal law that specifically addresses the needs of the growing population of TBI survivors. The programs authorized under the TBI Act provide public awareness and education through the CDC and State TBI care capacity-building and protection, legal, referral, and advocacy services at the Administration for Community Living. Furthermore, the TBI Model Systems of Care at the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) represent a vital national network of TBI research and expertise—providing the only source of non-proprietary longitudinal data on TBI experiences and a key source of evidence-based medicine. The letter also requests funding for the CDC to establish and oversee a national surveillance system to accurately determine the incidence of concussions, particularly among the most vulnerable of Americans—our children and youth

If you have any questions or would like to sign on, please contact Carrie Swope in Congressman Pascrell’s office at [carrie.swope@mail.house.gov](mailto:carrie.swope@mail.house.gov).

Sincerely,

Bill Pascrell, Jr.  
Member of Congress

March XX, 2019

The Honorable Rosa DeLauro  
Chairwoman  
Subcommittee on Labor,  
Health and Human Services  
Education and Related Agencies  
Committee on Appropriations  
2358 Rayburn House Office Building  
Washington, DC 20515

The Honorable Tom Cole  
Ranking Member  
Subcommittee on Labor,  
Health and Human Services  
Education and Related Agencies  
Committee on Appropriations  
1016 Longworth House Office Building  
Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro:

As the committee begins consideration of the Fiscal Year (FY) 2020 Labor, Health and Human Services, Education and Related Agencies (Labor HHS) appropriation bill, the undersigned members of the Congressional Brain Injury Task Force, and other members of Congress, respectfully request your support for an increase in funding for programs authorized by the Traumatic Brain Injury (TBI) Act. We also request an increase for the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) TBI Model Systems administered by the Administration for Community Living.

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 in both adults and youth, each day taking the lives of 138 people in our country. The primary source of funding to address this growing population is provided through the TBI Act programs.

The Centers for Disease Control and Prevention’s National Injury Center is responsible for assessing the incidence and prevalence of TBI in the United States. The CDC estimates that 2.5 million TBIs occur each year and 5.3 million Americans live with a life-long disability as a result of TBI. CDC provides states with funding for TBI registries, creates and disseminates public and professional educational materials for families, caregivers and medical personnel, and has recently collaborated with the National Football League and National Hockey League to improve awareness of the incidence of concussion in sports. CDC plays a leading role in standardizing evidence based guidelines for the management of TBI, linking civilian and military populations with TBI services, and educating primary care physicians and educators.

In 2013, the National Academies of Sciences, Engineering, and Medicine (formerly known as the Institute of Medicine, or the IOM) issued a report calling on the CDC to establish a surveillance system that would capture a rich set of data on sports- and recreation-related concussions among 5-21 year olds that is not currently available. In the 2018 Reauthorization of the TBI Act, language was included authorizing CDC to create a National Concussion Surveillance System.

To meet this goal, we respectfully request an increase of \$5,000,000 in the CDC budget to establish and oversee a national surveillance system to accurately determine the incidence of concussions, particularly among the most vulnerable of Americans—our children and youth.

The TBI Act authorizes the Department of Health and Human Services (HHS) to award grants to (1) states, American Indian Consortia and territories to improve access to service delivery and to (2) state Protection and Advocacy (P&A) Systems to expand advocacy services to include individuals with TBI. For the past seventeen years the Federal TBI State Grant Program has supported state efforts to address the needs of persons with brain injury and their families and to expand and improve services to underserved and unserved populations including children and youth; veterans and returning troops; and individuals with co-occurring conditions

In FY2009, the number of state grant awards was reduced to 15, later adding three more states, in order to increase each monetary award from \$118,000 to \$250,000. This means that many states that had participated in the program in past years have now been forced to close down their operations, leaving many unable to access brain injury care.

Increased funding of the program will provide resources necessary to sustain the grants for the 24 states currently receiving funding and to ensure funding for additional states. Steady increases over five years for this program will provide for each state including the District of Columbia and the American Indian Consortium and territories to sustain and expand state service delivery; and to expand the use of the grant funds to pay for such services as Information & Referral (I&R), systems coordination and other necessary services and supports identified by the state. This year, we respectfully request increased funding in the amount of \$12,000,000 for an additional 20 State grants, which would expand the total number of State grants to 44 bringing the total State grant allocation to just over \$19,000,000.

Similarly, the TBI P&A Program currently provides funding to all state P&A systems for purposes of protecting the legal and human rights of individuals with TBI. State P&As provide a wide range of activities including training in self-advocacy, outreach, information & referral and legal assistance to people residing in nursing homes, to returning military seeking veterans benefits, and students who need educational services. We request \$6,000,000 be allocated to the TBI P&A program to allow them to serve more individuals in each state.

Effective Protection and Advocacy services for people with TBI is needed to help reduce government expenditures and increase productivity, independence and community integration. However, advocates must possess specialized skills, and their work is often time-intensive. An increased appropriation in this area would ensure that each P&A can move towards providing a significant PATBI program with appropriate staff time and expertise.

Funding for the TBI Model Systems, funded by NIDILRR in the Administration for Community Living (ACL), is urgently needed to ensure that the nation's valuable TBI research capacity is not diminished, and to maintain and build upon the 16 TBI Model Systems research centers across the country.

The TBI Model Systems of Care program represents an already existing vital national network of expertise and research in the field of TBI, and weakening this program would have resounding effects on both military and civilian populations. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury. They are a key source of evidence-based medicine, and serve as a “proving ground” for future researchers.

In order to address TBI as a chronic condition, Congress should increase funding in FY2020 for NIDILRR's TBI Model Systems of Care program to add one new Collaborative Research Project and increase the number of centers from 16 to 18. In addition, given the national importance of this research program, the TBI Model Systems of Care should receive "line-item" status within the broader NIDILRR budget. Over the next 5 years, the Congressional Brain Injury Task Force requests increased funding by \$15 million to expand the TBI Model Systems program:

- Increase the number of multicenter TBI Model Systems Collaborative Research projects from one to three, each with an annual budget of \$1 million;
- Increase the number of competitively funded centers from 16 to 18 while increasing the per center support by \$200,000; and
- Increase funding for the National Data and Statistical Center by \$100,000 annually to allow all participants to be followed over their lifetime.

We appreciate your consideration of these requests for the CDC, the Federal TBI Program, and the TBI Model Systems Program to further data collection, increase public awareness, improve medical care, assist states in coordinating systems, protect the rights of persons with TBI, and bolster vital research.