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The Honorable Richard Shelby
Chairman
Senate Appropriations Committee
Washington, DC 20510

The Honorable Patrick Leahy
Vice Chairman
Senate Appropriations Committee
Washington, DC 20510

The Honorable Roy Blunt
Chairman
Senate Appropriations Subcommittee on
Labor, Health and Human Services,
Education, and Related Agencies
Washington, DC 20510

The Honorable Patty Murray
Ranking Member
Senate Appropriations Subcommittee on
Labor, Health and Human Services,
Education, and Related Agencies
Washington, DC 20150

Dear Chairman Shelby, Vice Chairman Leahy, Chairman Blunt, and Ranking Member Murray,

As you prepare the Fiscal Year (FY) 2021 Labor, Health and Human Services, Education and Related Agencies (Labor HHS) appropriations bill, we 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 called the signature injury of the wars in Iraq and Afghanistan, with service members at high risk for TBI from blasts and other combat operations. The Defense and Veterans Brain Injury Center (DVBIC) reported more than 408,000 TBIs among U.S. service members worldwide between 2000 and early 2019.¹ Many veterans who have sustained a brain injury while in theatre return home in need of resources and support. Meanwhile, incidence continues to increase here at home among our nation’s civilian population, mainly due to assaults, falls, automobile accidents, or sports injuries. From the battlefield to the football field, TBI remains a leading cause of death and disability in both adults and youth, taking the lives of an average of 155 people each day in the U.S.² The primary source of funding to address the growing population affected by TBI comes through the TBI Act programs.

Centers for Disease Prevention and Control (CDC) National Concussion Surveillance System

The CDC National Center for Injury Prevention and Control is responsible for assessing the national incidence and prevalence of TBI. According to CDC, 2.5 million TBIs occur each year,

¹ Defense and Veterans Brain Injury Center (2019). https://dvbic.dcoe.mil/sites/default/files/tbi-numbers/DVBIC_WorldwideTotal_2000-2019_Q3.pdf

² Centers for Disease Control and Prevention (2019). *TBI: Get the Facts*. https://www.cdc.gov/traumaticbraininjury/get_the_facts.html

and 5.3 million Americans live with a lifelong disability because of TBI.³ CDC plays a leading role in standardizing evidence-based guidelines for the management of TBI, as well as linking civilian and military populations with TBI services. CDC also provides state funding for TBI registries, creates and disseminates 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.

In 2013, the National Academies of Sciences, Engineering, and Medicine 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 to 21-year-olds that is currently unavailable. The 2018 Reauthorization of the TBI Act included language that authorized the CDC to establish 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 Federal TBI Program

The TBI Act authorizes the Department of Health and Human Services (HHS) to award grants through two key programs. The TBI State Partnership Grant Program funds states, American Indian Consortia, and territories to improve access to TBI services and supports. The Protection and Advocacy (P&A) TBI Program (PATBI) supports state Protection and Advocacy (P&A) Systems to empower and advocate on behalf of individuals with TBI.

For more than two decades, the federal TBI State Partnership Grant Program has supported state efforts to address the needs of individuals with brain injury and their families. This has included expanding and improving services to underserved and unserved populations, such as children and youth, veterans and returning troops, and individuals with co-occurring conditions.

Increased funding of the program will provide the necessary resources to sustain the grants for the 24 current state grantees and ensure funding for additional states. Steady increases over 5 years for this program will enable each state – including the District of Columbia, the American Indian Consortium, and territories – to sustain and expand capacity to include services like Information & Referral (I&R), systems coordination, and any other necessary activities identified by the state. This year, we respectfully request an increase of \$12,000,000 for an additional 20 State grants. This would expand the total number of State grants to 44, bringing the total State grant allocation to just over \$19,000,000.

Similarly, the Protection and Advocacy (P&A) TBI Program (PATBI) currently funds all state P&A systems with the goal of protecting the civil rights of individuals with TBI. State P&As provide a wide range of services, including self-advocacy training, information and referrals, and legal assistance to people residing in nursing homes, returning military seeking veterans' benefits, and students in need of educational services.

³ Centers for Disease Control and Prevention. (2015). Report to Congress on Traumatic Brain Injury in the United States: Epidemiology and Rehabilitation.

https://www.cdc.gov/traumaticbraininjury/pdf/tbi_report_to_congress_epi_and_rehab-a.pdf

Effective P&A services for people with TBI play a crucial role in increasing their productivity, independence, and community integration. However, their advocates must possess specialized skills and often carry out time-intensive work. An increased appropriation in this area would ensure that each P&A could build a more robust PATBI program to serve more individuals with appropriate staff time and expertise. To that end, we request \$6,000,000 for the TBI P&A program.

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) TBI Model Systems

The TBI Model Systems (TBIMS) program, which is funded by the NIDILRR at the ACL, urgently needs funding to maintain the nation's valuable TBI research capacity and build upon the 16 TBI Model Systems research centers across the country. This program represents a 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 the experiences of individuals with brain injury. As a key source of evidence-based medicine, such systems serve as "proving ground" for future researchers.

To better address TBI as a chronic condition, we request an additional \$6.6 million for NIDILRR in FY2021 for the expansion of its TBI Model Systems program. This new funding would:

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

Thank you for your leadership and consideration of these requests for the CDC, the Federal TBI Program, and the TBI Model Systems Program. Investing in these programs will collectively 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.

Sincerely,