

**April 22, 2025**

The Honorable Robert F. Kennedy  
Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

**Re: Urgent Meeting Request to Discuss the Future of Brain Injury Programs at HHS**

Dear Secretary Kennedy,

On behalf of the 64 million Americans who have experienced a traumatic brain injury<sup>1</sup> and the millions more who have experienced non-traumatic brain injuries, ***I am writing to respectfully request a meeting*** to discuss the proposed elimination, restructuring, and funding cuts of brain injury programs within the Department of Health and Human Services (HHS).

Brain injury doesn't have an end date and neither should federal funding. Current funding levels are already too low, with federal funding for TBI research amounting to only \$3.03 per person with TBI.<sup>2</sup> The proposed elimination of brain injury programs under the National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention (CDC) and the potential elimination of programs previously within the Administration for Community Living (ACL) is unacceptable and would roll back decades of progress that America has made towards treatment and prevention of this largely invisible epidemic.

For many people, brain injury can develop into a lifelong chronic health condition that requires ongoing management and care. Prior brain injury and head trauma has been linked to the development of neurodegenerative diseases and other conditions, including Parkinson's disease, ischemic stroke, Alzheimer's disease, chronic traumatic encephalopathy, chronic pain, and depression. These proposed changes pose an urgent threat to the continuity of prevention, care coordination, and long-term support that people with brain injury rely upon.

Cutting support for brain injury programs now will also mean that we will be paying more in the future. More than half of adults who survived a moderate or severe TBI are no longer employed within five years of their injury,<sup>3</sup> which puts a greater strain on public and private resources. By pulling resources, many people with brain injury will be abandoned. HHS has long been a leader in advancing injury prevention, addressing disability that results from brain injury and other injuries and illnesses, and evidence-based medical rehabilitation. However, the priorities outlined in the apparently leaked Office of Management

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<sup>1</sup> Daugherty J, Peterson A, Black L, Waltzman D. Summary of the Centers for Disease Control and Prevention's Self-reported Traumatic Brain Injury Survey Efforts. J Head Trauma Rehabil. 2025 Jan-Feb 01;40(1):E1-E12. doi: 10.1097/HTR.0000000000000975. Epub 2024 Jul 22. PMID: 39038104; PMCID: PMC11693486. (<https://pubmed.ncbi.nlm.nih.gov/39038104/>)

<sup>2</sup> <https://report.nih.gov/funding/categorical-spending#/>

<sup>3</sup> Centers for Disease Control and Prevention (U.S.). National Center for Injury Prevention and Control (NCIPC). Division of Injury Prevention. (2021). Moderate to Severe Traumatic Brain Injury is a Lifelong Condition.

and Budget “pass back” proposal reflect a stark departure from HHS’s long-standing commitment to these national priorities

We urge HHS to restore its commitment to people with brain injury and others with disabling conditions by preserving the following programs and maintaining essential funding.

- The CDC’s **Core State Injury Prevention Program (Core SIPP)** builds injury prevention capacity at the state level. For the brain injury community, it supports TBI surveillance, funds local prevention efforts, trains frontline responders, and connects EMS, hospitals, schools, and Medicaid. Cutting Core SIPP would dismantle this infrastructure, severely limit early intervention, and leave more people with brain injury undiagnosed and unsupported. Cutting this program will place additional burden on state systems and Medicaid.
- The CDC’s **HEADS UP** initiative is a cornerstone of concussion education and prevention. It delivers free, evidence-based tools to healthcare providers, schools, coaches, and families. HEADS UP improves early recognition of symptoms, supports safe return-to-learn and return-to-play protocols, and equips professionals with continuing education. Eliminating this program would strip thousands of communities of the only national concussion guidance for youth. We urge HHS to maintain this program internally or fund its continuation externally.
- The CDC’s **National Center for Injury Prevention and Control** is the federal government’s only entity solely focused on reducing injuries, one of the top causes of death and disability nationwide. Its elimination would undermine national efforts to prevent, track, and respond to traumatic brain injuries (TBI), halting vital research, surveillance, and public education. Without this center, the brain injury community will face immediate setbacks in awareness, prevention, and data-informed policymaking.
- The CDC’s **National Concussion Surveillance System (NCSS)** is the only ongoing federal system tracking the incidence of concussion and brain injury across age groups. This data guides policy, research, clinical protocols, and local resource allocation. Preliminary findings already show significant underreporting: adults are 30 times and youth are 17 times more likely to experience concussions than previously thought<sup>4</sup>. Eliminating NCSS would cut off essential data and paralyze effective responses. We strongly urge HHS to preserve this system or, at a minimum, enable its continuation through public-private partnerships or external grants.

We are equally alarmed by the proposed elimination or restructuring of the Administration for Community Living (ACL), which administers the **TBI State Partnership Program** and **Protection and Advocacy (P&A) Services**—critical initiatives that provide care coordination, provider training, and access to essential supports. Fragmenting or relocating these programs outside of HHS would unravel decades of progress toward a unified, community-based support system for individuals with brain injuries. Any reassignment must be approached with extreme care and ensure that these programs receive the structure, funding, and policy alignment needed to maintain their effectiveness and stability.

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<sup>4</sup> Centers for Disease Control and Prevention National Concussion Surveillance System Pilot Summary

Further, the proposed elimination of the **National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)** is catastrophic. NIDILRR is the nation's leading source of brain injury rehabilitation research, assistive technology innovation, and return-to-work program development. Its removal would strip survivors of essential federal support for independent living, community reintegration following injury, and recovery.

NIDILRR also funds the **TBI Model Systems**, a network of 16 centers that provide cutting-edge rehabilitation and conduct the nation's only long-term studies on moderate to severe TBI outcomes. These centers manage the largest and longest-running TBI database in the world, tracking critical recovery metrics like employment, mental health, and cognition. Eliminating funding for the Model Systems would collapse this research infrastructure, reduce access to specialized care, and deprive the field of the evidence base that informs clinical practice and national policy. It would also waste valuable resources that have been expended for many years to maintain a comprehensive, intact, longitudinal database that will be impossible to replicate in the near term.

While we understand the importance of modernizing federal systems, these decisions must be made transparently and with stakeholder input so these efforts do not create more waste than they propose to eliminate. The elimination or reorganization of these programs would devastate brain injury survivors, their families, and the professionals and systems that support them. If implemented, these reductions will result in more concussions, injuries, disability and deaths.

We strongly urge you to meet with us and ensure that HHS remains a strong federal partner in brain injury prevention, rehabilitation, community living, and data-driven decision-making. Thank you for your time and leadership. We look forward to working together to protect and strengthen the programs millions of Americans depend on.

Sincerely,

A handwritten signature in black ink that reads "Rick Willis". The signature is written in a cursive, flowing style.

Rick Willis  
President and CEO  
Brain Injury Association of America