NATIONAL ASSOCIATION OF STATE HEAD INJURY ADMINISTRATORS

January 7, 2021

President-Elect Joseph Biden
Vice President-Elect Kamala Harris
Presidential Transition Team
1401 Constitution Ave. NW
Washington, DC 20230

Recommendations to Coordinate and Maximize Services for Persons with Brain Injury Provided by the U.S. Department of Health and Human Services

Submitted to the Biden-Harris Transition Team January 2021

Dear President-Elect Biden and Vice President-Elect Harris:

On behalf of the undersigned organizations, thank you for this opportunity to submit recommendations to coordinate policy and resources within the U.S. Department of Health and Human Services (HHS) for purposes of improving outcomes and functioning for persons with brain injury in order to live as independently and be as productive as possible. Our organizations represent individuals with brain injury and their families, as well as state government brain injury programs. Collectively, our organizations offer a range of services and supports funded by state revenue; dedicated funding known as trust fund programs, usually from revenue generated from traffic related fines; and federal sources of funding, including Medicaid. In addition, state brain injury programs may benefit from the federal TBI State Partnership Programs grants, administered by the U.S. Department of Health and Human Services' (HHS) Administration for Community Living (ACL), which are offered on a competitive basis to improve access to service delivery as called for by the Traumatic Brain Injury (TBI) Program Reauthorization Act of 2018.

Each year, a substantial number of Americans are injured due to motor vehicle crashes, falls, industrial injuries, sports-related injuries and other injuries that cause cognitive, emotional, physical, sensory and health-related problems. The resulting symptoms may result in unemployment and loss income; homelessness; incarceration; and institutional and nursing home placement due to lack of community alternatives. Recent trends have pointed to the increasing numbers of Americans with TBI-related disabilities attributed to the number of older adults who are at high risk due to falls and athletes who are at risk of sports-related injuries. Yet, new causes continue to emerge that call for research with regard to identification and treatment.

For example, the COVID-19 pandemic is raising alarms regarding those who are infected who may experience hypoxia due to the deprivation of oxygen, resulting in brain damage that may necessitate the need for rehabilitation to regain functioning and ongoing supports should functioning not be restored. Additionally, we are learning that sonic waves are resulting in

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symptoms similar to a mild TBI (concussions), referred to as the "Havana syndrome," although similar symptoms have been documented by U.S. government employees in other places abroad.

Since the passage of the TBI Act of 1996, there have been federal accomplishments to further improve service delivery, including transferring the Federal TBI State Grant and Protection & Advocacy grant programs from the Health Resources and Services Administration (HRSA) to the ACL in order to coordinate and maximize resources with other disability and aging programs. These ACL programs include respite care, long-term care and supports, aging and disability resource centers, independent living, and assistive technology. ACL also collaborates with the Centers for Medicare and Medicaid Services (CMS) and the Veterans Administration to improve and expand home and community-services (HCBS) options for individuals with disabilities, veterans and Americans who are aging.

However, brain injury is a complex disability that challenges states' ability to respond in a timely and coordinated manner to meet individual and family needs, including access to post-acute rehabilitation, therapies, in-home support, education, employment, and short-term and long-term community and family supports. States that offer brain injury services and resources may be housed in differing agencies throughout the country and most often are located in health, vocational rehabilitation, Medicaid, education, behavioral health and developmental disabilities agencies, which have sources of federal funding in addition to the TBI Act funding that they may receive.

While federal programs are critical for a variety of populations with similar needs, the funding often result in institutional barriers, or silos, within state systems. Families and individuals with brain injury find it difficult to navigate the myriad of programs only to find they are ineligible due to their diagnosis, income or age; or that services offered are not appropriate; or are offered by providers who do not have expertise in brain injury treatment, rehabilitation, and community supports.

We therefore offer these recommendations to further the goal of increased resources and coordinated state systems through federal interagency collaboration and maximization of resources both within the ACL and other HHS' agencies in order to address barriers to services.

Coordination and collaboration among HHS' ACL programs

We believe that HHS can help overcome some of the barriers to services through their grant guidance for disability and aging programs by promoting brain injury awareness, training and coordination of resources, while keeping with the intent of the federal law governing the program. Earlier this year, the Support Older Americans Act of 2020 included provisions to promote education and awareness of TBI and to allow federal funding for state aging programs to be used to screen for TBI after a fall, recognizing that older Americans are a high risk group for a TBI. This provides an opportunity for ACL to allow state aging agencies to include TBI in their state plans and funding to be used accordingly. Another example is the Lifespan Respite Care Program authorized by under Title XXIX of the Public Health Service Act to coordinate state systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs. Very few of these projects involve families who are caregivers of their family members with brain injury.

We recommend:

- That where appropriate, federal ACL grants to states should encourage state agencies to collaborate and coordinate activities that would benefit persons with brain injury and their families across systems. This could be accomplished by requiring the grantee to include a letter of support from state brain injury programs/associations or alliances, families and individuals with brain injury; involving individuals with brain injury in the grantee's projects; and, where appropriate, further demonstrate how collaboration and coordination of resources will take place.
- That ACL involve state brain injury programs, individuals and family members, and/or other persons offering expertise in their other state aging/disabilities grantees meetings and webinars to educate them about brain injury and resources that may be available. ACL currently involves other federal agency representatives in the Federal ACL TBI State Partnership grantees meeting.

Increase funding and support for the ACL TBI State Grant and P&A Grant programs
The ACL Federal TBI State Grant Partnership Program and the Protection & Advocacy (P&A) TBI Program, authorized by the TBI Program Reauthorization of 2018, have been woefully underfunded since first implemented. While 27 states currently have grant funding, this funding ranges from $150,000 -- $300,000 and will end this year. These grants will be competitively awarded in the next fiscal year (FY 2021). Over the years, the competitive process has resulted in states discontinuing their efforts once funds are no longer available to support their work. Continuity and allowing funds to build on prior work allows states to expand and improve their systems to better assist families and individuals with brain injury without interruptions. Similarly, the P&A programs have only received bare minimums to support even a full time employee to be available to assist individuals and their families in accessing services.

- We recommend that HHS support additional funding for the TBI State Grant Partnership Program to expand the number of state grants and additional funding to increase the amount of the P&A grant awards to support necessary staff to assist persons with brain injury.

Increase prevention and treatment options for individuals with co-occurring conditions
Co-occurring mental health and substance use are common among persons who sustain a TBI. In a 2017 publication of the *Journal on Head Trauma Rehabilitation*, The Ohio State University reported on a study of 295 people with co-occurring mental health and substance use disorders enrolled in a prospective study of integrated treatment of substance abuse found eighty percent screened positive for TBI, and 25% reported at least 1 moderate or severe TBI. TBI was associated with current alcohol use and psychiatric symptom severity and with lifetime institutionalization and homelessness. Another 2017 article in the same *Journal* by different authors reported that individuals with milder injuries return to alcohol use earlier than those with more severe injuries, which may alter their course to recovery. Between 30-50% of people with TBI are injured while they were drunk and about one-third were under the influence of other drugs (Model Systems Knowledge Translation).

Depression, anxiety, substance abuse, chronic pain, and psychosocial conditions impact relationship problems, unemployment or underemployment, intimate partner violence (IPV), homelessness, and incarceration. Furthermore, there is concerning evidence that people with brain injury may be at increased risk for suicide, calling for the need for clinicians to be able to assess those at risk and to treat accordingly.

To address these issues we encourage the Substance Abuse and Mental Health Services Administration (SAMHSA), the primary federal funder of state prevention and treatment services for individuals with behavioral and substance use disorders, to work with state behavioral health and substance use agencies to identify brain injury among individuals seeking treatment and services through their agencies and to offer treatment that will accommodate their associated disabilities. Further, we recommend that:

- SAMHSA add individuals with brain injury and co-occurring conditions to the list of target populations as part of the Substance Abuse Prevention and Treatment Block Grants awarded to states.
- SAMHSA add individuals with brain injury and co-occurring conditions to priority populations as part Community Mental Health Services Block Grant (MHBG) program.
- SAMHSA acknowledge TBI as a co-occurring condition and integrate brain injury into its national online registry of interventions supporting mental health promotion and treatment and substance abuse prevention and treatment to include interventions that address cognitive and behavioral issues as the result of a brain injury; collaborate with other federal programs involved in TBI service delivery (ACL, VA, DoD); and acknowledge TBI as a co-occurring condition in its priorities for Community Mental Health Services Block Grant and Substance Abuse Prevention & Treatment Block Grant funding to states, especially with regard to “trauma,” which SAMHSA has identified as a priority.
- SAMHSA add resources and assessment guidelines for individuals with brain injury who may be at risk of suicide.

Expand service delivery for children and youth with brain injury

Children and youth with brain injury generally do not have many resources following initial treatment, other than returning to school. The Health Services and Resource Administration administers the Title V Maternal and Child Health Services (MCH) Block Grant program, which includes children and youth with special health care needs (CYSHCN) defined as those who "have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and also require health and related services of a type or amount beyond that required by children generally.” Although a few states provide case management and other assistance to children and youth with brain injury, not all states do. As a federal leader, HRSA should play a key role to (1) assist states to create systems change for children and youth that would include children with brain injury; (2) assist states to build data systems that capture children and youth with brain injury; and (3) provide information on best practices for screening, diagnosis and care coordination for children and youth with brain injury.

Furthermore, the Title V and the Medicaid program are required under federal law to coordinate activities, using coordination agreements and partnerships between state Medicaid agencies and

Title V MCH program grantees to improve access to services for children, including the Medicaid Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit which is required to provide comprehensive health coverage for all children under age 21 who are enrolled in Medicaid. Since 1967, every state finances a wide array of appropriate and necessary pediatric services under the EPSDT program. This benefit requirement includes children enrolled in a state's Children's Health Insurance Program (CHIP) through Medicaid Expansion CHIP, but not those in separate, private CHIP health plans.

As states are required to provide comprehensive services and furnish all Medicaid coverable, appropriate, and medically necessary services needed to correct and ameliorate health conditions, children and youth with brain injury who are Medicaid eligible should be able to access EPSDT benefits. HRSA could ensure that this takes place by partnering with the Centers for Medicare and Medicaid Services (CMS) to inform primary care and other health providers, as well as state Medicaid directors, of this important program that could benefit children and youth with brain injury who may need ongoing cognitive rehabilitation, physical therapy, behavioral therapy, and speech and language therapy that may be above and beyond what is provided in public school settings. We recommend that:

- HRSA encourage the Title V Children with Special Health Care Needs program to prioritize case management and other services needed by children with brain injury and to collect data accordingly.
- HRSA collaborate with CMS to assist primary care providers participating in the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program in identifying, diagnosing, and treating children and youth with brain injury.
- HRSA support increased funding to support the Emergency Medical Services and Emergency Medical Services for Children (EMSC) program, which is the only federal grant program specifically focused on addressing the distinct needs of children in pre-hospital and hospital emergency medical systems.

Increase home and community-based services (HCBS) options

Largely due to decreases in insurance coverage for inpatient rehabilitation following a brain injury over the past two decades, individuals who sustain a brain injury are increasingly likely to receive much of their rehabilitation in skilled nursing facilities with non-specialized therapy teams. This poorly impacts outcomes and increases the likelihood that individuals will continue in these facilities for long term care rather than returning to their home or to the community.

Only about half of the states administer a Medicaid Brain Injury Home and Community-based Services (HCBS) 1915(c) waiver program; at least one state provides HCBS to persons with complex needs through its 1915(k) Community First Choice State Plan benefit; and another state has included persons with brain injury under its new 1915(i) HCBS State Plan option. A few states have folded their HCBS waiver program for brain injury into a 1115 waiver. And, some states include individuals with brain injury in other waiver programs, such as intellectual/developmental disabilities (I/DD), physical disabilities and private duty nursing waiver programs. However, data is not available as to the numbers of individuals with brain injury who may be served through these various Medicaid programs. We do know that there is considerable differences among the 1915(c) waiver programs with some states serving as few as

20 and others who may serve closer to 1,000 – far smaller than I/DD and aging HCBS waiver programs.

Individuals with brain injury who are injured after the age of 22 and reside in nursing or institutional level of care facilities are not afforded the same options as those who are injured prior to age 22 or who have mental illness. That is, they are not included in the Preadmission Screening and Resident Review (PSRR) process, a federal requirement designed to help ensure that individuals with serious mental illness or intellectual disability (ID) are not inappropriately placed in nursing homes for long term care. While CMS considered a specific alternative regarding the inclusion of brain injury, their belief was that it did not have the authority for those who are injured after the age of 22.

One promising program is the Money Follows the Person (MFP) Demonstration Program, which a few state brain injury programs have partnered with their state Medicaid agency to identify individuals with brain injury in nursing facilities and transitioned them to more appropriate community alternatives. This program has allowed states to transition people out of nursing facilities regardless of age of onset of injury.

Finally, the ACL and Veterans Health Administration. (VHA) established the Veteran-Directed Home & Community Based Services (VD-HCBS) Program in 2008 to help veterans with disabilities of all ages and their families to receive needed services in their own homes and communities. The VD-HCBS Program is offered through the Aging & Disability Network which collaborates and coordinates with the local Area Agency on Aging (AAA), Aging & Disability Resource Center (ADRC) or Center for Independent Living. As a substantial number of returning service members and veterans have also sustained a TBI, we believe that the state brain injury programs should also be involved to help with locating community resources and assistance, especially with regard to rural areas.

To assist states to increase capacity for HCBS programs for persons with brain injury, we recommend:

- That HHS integrate brain injury into their long-term services initiatives, which also rely on Aging and Disability Resource Centers as the entry point into these systems;
- Include TBI in the veterans initiatives between ACL and Department of Veterans Affairs (VA) to support home and community-based services for veterans and returning service members with TBI;
- That CMS collect data from all HCBS waivers and State Plan options with regard to the numbers of persons with brain injury served to better understand options and needs within the states;
- That CMS inform Medicaid, Aging, and I/DD state directors about state and community resources for individuals with brain injury who are identified by the PSRR process.
- HHS support the continuation of the Money Follows the Person Demonstration Program and how this resource can assist states in identifying individuals with brain injury in nursing level of care and arranging community services accordingly.
- That CMS work with state Medicaid agencies on level of care assessments which recognize the individual's cognitive disabilities and need for verbal assistance, physical

cueing, prompting, accommodations, and supervision in order to carry out activities of daily living (ADLs). Many states assessment tools are designed for people who need hands on care (e.g., bathing, feeding), rather than accommodating the need for cueing or other accommodations in order to engage in ADLs.

Expand data collection

States rely on data to assist with planning for service delivery and national organizations rely on data to assist with identifying appropriate federal policies. The last estimate for TBI was provided by the Centers for Disease Control and Prevention (CDC) in 2014, which estimated there were approximately 2.87 million Americans treated for a TBI in emergency department visits and hospitals or that resulted in death. In addition to the need for more recent incidence and prevalence data to assist with identification and determining service delivery needs, data is needed from federal programs to identify funding streams which may support individuals , as well as to be able to identify gaps in service delivery.

The Government t Accountability Office (GAO) issued the Report to Congress, "Domestic Violence: Improved Data Needed to Identify the Prevalence of Brain Injuries among Victims," June 2020. Based on its review of the literature, as well as interviews with HHS officials and other non-federal stakeholders, GAO found that data on the overall prevalence of brain injuries resulting from intimate partner violence are limited and that such data is needed to better understand the problem and to ensure that resources are targeted appropriately to address these issues. In addition to the TBI program, the CDC's National Center on Injury and Prevention also administers funding for domestic and intimate violence programs. This presents the opportunity for these programs to coordinate and collaborate to address the GAO's concerns.

We recommend:

- Funding for the Injury Center to implement a National Concussion Surveillance System, as authorized by the TBI Program Reauthorization Act of 2018.
- Funding to support states in determining the incidence and prevalence of brain injury and the clinical aspects of the disability in all age groups and racial and ethnic minority groups in the general population of the United States, including institutional settings, such as nursing homes, correctional facilities, psychiatric hospitals, child care facilities, and residential institutions for people with developmental disabilities.
- That the CDC Injury Center's Brain Injury Program and Violence Prevention Programs collaborate to address the GAO's recommendation to improve data collection with regard to victims of domestic and intimate violence who sustain a brain injury-related disability.

In closing, a new Administration offers the opportunity to consider how federal resources may be best utilized and produce good outcomes. We believe this is an opportunity to examine and to improve data capabilities across federal programs that may serve or impact individuals with brain injury and their families in order to have a basis for planning and improving the delivery of services; to consider the coordination and maximization of federal grant programs to states to ensure that service delivery is not further fragmented, but coordinated; and to identify gaps whereby individuals with brain injury may need additional resources that are not already available.

Thank you for this opportunity. We look forward to working with you. Please do not hesitate to contact us if we may be of further assistance.

Sincerely,

National Association of State Head Injury Administrators (NASHIA)
Brain Injury Association of America (BIAA)
Friends of TBI Model System
United State Brain Injury Alliance (USBIA)

Alabama Head Injury Foundation
Brain Injury Alliance Colorado
Brain Injury Alliance of Iowa
Brain Injury Alliance of Nebraska
Brain Injury Alliance of New Jersey
Brain Injury Alliance of Utah
Brain Injury Alliance of Wisconsin
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