April 26, 2021

The Honorable Sherrod Brown  
U.S. Senate  
Washington, DC 20510

The Honorable Bob Casey  
U.S. Senate  
Washington, DC 20510

The Honorable Maggie Hassan  
U.S. Senate  
Washington, DC 20510

The Honorable Debbie Dingell  
U.S. House of Representatives  
Washington, DC 20515

Dear Senators Brown, Casey, Hassan, and Representative Dingell:

On behalf of the National Association of State Head Injury Administrators (NASHIA), thank you for your efforts to expand home and community-based services (HCBS) for people with disabilities and older adults. Our organization represents state governmental agencies that provide an array of rehabilitation and community-based services through state and trust funded programs and Medicaid waiver programs designed specifically for individuals with brain injury. It is through this lens that we are responding to this opportunity to comment on the discussion draft of the HCBS Access Act (HAA).

Currently, 21 states administer 1915(c) brain injury HCBS waiver programs with three of these states offering multiple brain injury waivers. Oregon includes individuals with brain injury with complex issues in the state’s 1915(k) Community First Choice Option and North Dakota recently implemented 1915(i) HCBS State Plan benefits that includes individuals with brain injury. Three other states have combined their brain injury waiver programs into their Section 1115 Demonstration Waivers. Of course, in some states, individuals with brain injury may receive services from other waiver programs, such as Intellectual/Developmental Disabilities and physical disability waiver programs.

States vary considerably in terms of their target populations and the size of the waiver. States may offer services for individuals with traumatic brain injury (TBI) only, while other states include individuals with non-traumatic injuries or acquired brain injury (ABI), such as strokes, anoxic and hypoxic brain injuries and aneurisms. A few states may only serve 20 participants, while in other states, the number may be closer to 1,000 or more. Half of the states do not have separate HCBS options for individuals with brain injury.

Barriers have resulted in this patchwork of services across the country. First, in some states, the level of care requirements for HCBS waiver programs favor individuals who need hands on care to carry out activities of daily living (ADLs) and instrumental activities of daily living (IADLs) in lieu of accommodations and cueing needed due to memory and other cognitive problems necessary to perform such activities. In states that have adopted functional assessment or level of care tools to assess needs across populations, we have concerns that the tools will not be accommodating to individuals with brain injury.
Secondly, the 1915(c) waivers required states to demonstrate cost neutrality. Most states with waiver programs have used nursing facility rates as cost offset, which is usually a lower rate than an ICF-I/DD rate, and thus rates have been insufficient to cover the extent of services needed by people who have extensive needs in order to live in the community. Third, lack of state match has kept states from expanding their HCBS to include individuals with brain injury.

We believe your proposal will address these barriers. However, we are concerned that particularly in states that have not included individuals with brain injury in HCBS waiver programs, they will not be included in the proposal to mandate HCBS, unless it is clear that individuals with brain injury who meet Medicaid eligibility and need HCBS are included. Therefore, we recommend the following.

Page 5-6 – Personal assistance
Lines 1-3, add: “and assistance with accommodations, cueing, and training individuals to perform personal care activities.”

Page 7 -- Listing of services and benefits
Add: rehabilitative and therapy services, including cognitive and behavioral therapy, necessary to support recovery and maintain functioning after a brain injury.

Page 8 – Advisory Panel
Composition (aa)
Add individuals with brain injury to the listing of individuals who may be represented on the proposed Advisory Panel.

(bb) – Add the “National Association of State Head Injury Administrators” to the listing of organizations.

Our organization participates on monthly calls with the other national state organizations listed and the Centers for Medicare and Medicaid Services (CMS) to discuss HCBS issues.

Page 11-12 – Eligibility; Functional Impairment
Clarify that functional impairment includes individuals needing accommodations by adding on page 12, line 3; after “perform, without assistance,” or accommodations, such as cueing…

Page 12 – Health Care Provider and Assessment
To ensure that the state will consider health care providers that have experience in assessing needs of individuals with brain injury, we recommend adding at the end of that sentence (line 15), “which may include provider requirements to ensure that the health care provider has experience in assessing individuals with brain injury and other conditions.”
Thank you for your consideration. Please do not hesitate to reach out if we can be of further assistance.

Sincerely,

[Signature]
Rebecca Wolfkiel
Executive Director