



National Association of State Head Injury Administrators

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Mary Lazare, Acting Administrator
Administration for Community Living
330 C St. SW
Washington, DC 20201

Dear Ms. Lazare:

Thank you for the opportunity to respond to the proposed design and principles of the PIII program combining federal funding for the Developmental Disabilities (DD) State Councils, Statewide Independent Living Councils and the Traumatic Brain Injury (TBI) State Grant program into one program called the Partners in Partnerships for Innovation, Inclusion, and Independence. The National Association of State Head Injury Administrators (NASHIA) has advocated for the TBI Act of 1996, and the resulting Federal State Grant Program in order to obtain federal funding to assist states in meeting the unique needs of individuals with TBI and their families. We have long supported funding to assist states for the reasons outlined in this letter and **oppose any attempt to repeal the TBI Act and replace it with a cross disability council in lieu of separate funding for TBI service delivery.**

While this approach may eliminate duplicative administrative functions within the ACL, it will not eliminate duplication at the state level. TBI advisory boards have been established for purposes other than the Federal TBI State Grant Program and specific TBI-related services have been established due to the lack of appropriate services and expertise in existing disability programs.

Since the 1980s, states have collaborated with individuals with TBI and their families to develop services and resources specific to their needs as they were unable to access assistance from existing state disability systems due to:

- Diagnosis
- Age of onset of TBI, which excluded individuals from DD systems
- Age at the time of injury, which excluded them from children's systems
- Financial eligibility requirements
- Inappropriate or nonexistent services being offered due to lack of expertise in TBI-related rehabilitation and community supports for cognitive and behavioral challenges
- Lack of private insurance provisions for TBI
- Lack of identification, services and supports particular to children and youth with TBI

Initially, states created advisory boards to assist with creating a comprehensive TBI service delivery system. These boards also created state TBI programs with dedicated funding from traffic-related fines or other state resources. The state advisory boards provide oversight for program priorities and expenditures. However, there is great diversity across state services and supports due to the nature of TBI and the variation of state agencies and programs. TBI state programs are not located in the same state agency; they may be housed within public health, vocational rehabilitation, mental health, education, Medicaid or social services programs. Often, programs are located in more than one agency. For example, a TBI HCBS Medicaid waiver program is housed in one department, while the advisory board and/or state funded program is housed in another agency.

The TBI Act of 1996, as amended, and the subsequent administration by the federal designated agency, the Health Resources and Services Administration (HRSA), incorporated these varied state approaches for developing services into the Federal TBI State Grant Program. The federal law requires a state receiving a federal grant to have an appointed advisory board in order to carry out activities designed to improve service delivery. The law, which authorizes appropriations for the program, **was not designed to fund advisory boards nor are state advisory boards the sole purpose of the law.**

If the federal TBI State Grant Program is swept up into a program with the federal DD state council and ILC grant programs, **the current customized rehabilitative and support needs for individuals with TBI will not be met.** TBI is still considered to be a new disability due to improved trauma care, resulting in lives being saved. The population continues to increase due to the military-related TBIs, recently recognized symptoms of sports-related concussions; and an aging population. Research is just now documenting the long-term chronic health problems emerging over time. Yet, extensive data, evidence-based practices, program outcome measures, and overall systems framework have yet to be determined or adopted.

States are challenged to offer a comprehensive system for individuals with TBI that may be available to individuals with other disabilities, generally due to budget constraints, range of needs and the complexity of TBI-related disabilities. NASHIA's experience has been that when states engaged in initiatives to combine cross-disability services and supports, individuals with brain injury are left out of recommendations and programs. The Federal TBI State Grant Program has been the one carrot distinctly for TBI that specifies support within states for the needs of individuals with TBI and their families.

In summary, NASHIA is greatly concerned that the focus of the new grant program is on TBI advisory boards, rather than systems change designed to create, improve and expand service delivery specific to the needs of individuals with TBI as identified by the state. We are further concerned that considerations will not be given to treatment and rehabilitative services, including services that address behavior, co-occurring conditions and executive functioning, that are necessary for individuals to return to home, school, work and community living after a brain injury.

ACL Questions for written submission:

i. What is the unique role of the DD Council/SILC/TBIAC (select the one that applies to you or your program), and how can that be incorporated into the PIII design?

The TBI Advisory Boards focus on systems planning from treatment at the scene of injury to community integration, and as such, advisory boards/councils will have professional and clinical members who will not be the type of professionals serving on other councils. The brain injury community recognizes research which shows upfront care and treatment will minimize the resulting disabilities associated with brain injury, as well as to save lives. States have sought to improve early care and treatment and to help families and individuals with TBI to transition from medical care and rehabilitation to home and community. Families, including spouses, are also usually involved in the board/council deliberations, as well, as they are generally the primary caregivers.

ii. What principles would you want to have incorporated in PIII?

Recognition and understanding that no two brain injuries are alike as many factors, both pre-injury and post-injury, impact resulting disabilities. This requires systems to be flexible and responsive to individual needs which may be short-term, intermittent or long-term. Services and supports need to be provided at the *right time* or *just in time* to prevent further deterioration and inappropriate institutionalization, including nursing homes, correctional facilities; and homelessness. Person centered planning process is one way to assist individuals in developing short-term and long-term goals to improve their own independence.

iii. How would you address funding from these programs that is currently going to service or demonstration activities?

Federal funding needs to support systems change and filling in the service gaps with regard to services to meet the needs of individuals with brain injury. This may include screening; assessment; service coordination; training professionals, providers, educators; family education and supports; rehabilitative services and treatment for individuals with dual diagnosis (e.g. TBI/mental health) and co-occurring conditions (e.g. TBI/substance use); and the array of home and community services and supports, including vocational and employment. The TBI service delivery system is lacking across the country and, in most states, throughout the state.

At the national level, the TBI community could benefit from national outcome and performance measures to assist states in assessing their state programs funded with state revenue or through trust funds or Medicaid or a combination of these funding streams and programs. The measures need to be collected nationally in order to present data to better understand the role of state and federal government; how funding streams are of benefit; and what gaps exist. In addition, comprehensive data is needed for the TBI population. Some of that is available through hospital discharge data; TBI registries and other sources, but not in a comprehensive fashion.

iv. What single feature or function drives the purpose of the DD Council/SILC/TBIAC (select the one that applies to you or your program) , and if lost negatively impacts the purpose?

As stated above, **current TBI grant funding does not support the TBI Advisory Board nor is the intent of the law to fund advisory boards.** The purpose of current funding is to identify and to address gaps in service delivery specific to the needs of individuals with TBI across the life-span. As TBI is a newly sustained disability, the service delivery system starts with treatment at the time of injury and progresses through recovery, involving EMS/trauma care, rehabilitation, transition to home/community, education, employment, and community living. Each service component accommodates the unique cognitive and behavioral issues associated with TBI. While the disability community as a whole has similar needs -- such as transportation, housing, employment -- individuals with TBI will have difficulty accessing these services/supports as their needs vary widely based on time since injury, severity, age and a multitude of other factors. Without cognitive and behavioral accommodations through adequate funding, needs are not met.

v. The DD Council/SILC/TBIAC (select the one that applies to you or your program) has membership requirements, including requirements to include people with disabilities. How can this representational role be incorporated in PIII?

Again, **current TBI grant funding does not support the TBI Advisory Board.** States ensure advisory board representation of individuals with TBI; family members; TBI professionals, such as neuropsychologists and rehabilitation providers; and other caregivers and advocates. As some states have implemented state registries for purposes of data collection and/or linking individuals to services, it may be useful for some state advisory boards to include epidemiologists or public health staff. Many state advisory councils/boards also include individuals involved in injury prevention, which also helps with public awareness and education. The federal law provides flexibility for advisory board composition and most state laws specify board or council representation.

vi. What are the operational challenges of the DD Council/SILC/TBIAC (select the one that applies to you or your program) that can be addressed? What are the challenges that can be addressed?

- Which state agency would the proposed cross-disability advisory board be housed in? TBI advisory boards/councils and programs vary across the country, while DD Councils generally focus on DD systems, which are similar across the country, and SILCs focus on ILcs. TBI services/programs may not be in the same agencies that the DD Councils and SILCs are associated with and funding/support for the TBI Advisory Boards generally comes from the state.
- Which state agency would be eligible for grant funding?

- Would states that have a state legislatively established TBI advisory council associated with a TBI program be eligible for federal funding since they already have an advisory council. If so, that would be duplication to have the proposed cross disability council – which, in some states, there already is a Governor’s Council on Disability – a potential duplication – as well as the TBI advisory council associated with the TBI program.
- What would be the staff requirements, background and expertise?

vii. *What requirements are important for Board/Governance and Representation as well as Appointment Process?*

Equal representation among the three programs. TBI professionals are an important component, as well as consumer representation. However, each person with a TBI will have a different experience and different needs, depending on severity of injury; age at the time of injury; co-occurring conditions; and resources available in his or her state. In most instances, one person cannot speak on behalf of all people with brain injury.

viii. *What is a fair and equitable priority setting process for the Council?*

There isn’t one. The TBI Act was enacted because states did not offer rehabilitative and community services and supports for individuals with TBI and their families. The purpose of the federal TBI program is to provide federal resources to assist states in addressing service delivery gaps that vary in each state. While there may be common needs, such as transportation, housing, employment, how they are delivered with regard to necessary supports will differ, plus state disability programs differ considerably in terms of funding and resources. TBI programs are woefully underfunded.

ix. *How could PIII be phased in?*

Congress will probably determine this since they annually appropriate funding for these distinctive programs.

x. *What are your recommendations for how funds are distributed under this program? For example, do you recommend a formula be used to award grants?*

Formula grants are generally based on population and/or federal poverty guidelines for the states. However, these criteria do not necessarily take into the account the progress of a state in developing service delivery, resources, and assistance. Grants need to be continued to address TBI issues specifically. These grants have been previously awarded to state agencies delivering services, not to state advisory boards/councils. State agencies should continue to have the opportunity to develop, improve, expand services to address identified needs in their states.

Thank you again for soliciting our input. If we can be of further assistance, please do not hesitate to contact us.

Sincerely,

Lorraine Wargo

Lorraine Wargo
Executive Director

Susan L. Vaughn

Susan L. Vaughn
Director of Public Policy

cc Melissa Ortiz
Bob Williams