NC BRAIN INJURY ADVISORY COUNCIL

March 5, 2025

Dr. David Clapp, Deputy Director, Behavioral Health/IDD
NC Medicaid, Division of Health Benefits
NC Department of Health and Human Services
2001 Mail Service Center Raleigh, NC 27699-2000
101 Blair Drive Raleigh NC 27603

RE: TBI Waiver Expansion Concept Paper

Dear Dr. Clapp:

Thank you for the opportunity to provide feedback on the NC Department of Health and Human Services (NCDHHS or Department) Division of Health Benefits proposed "TBI Waiver Expansion Concept Paper," dated February 6, 2025. This feedback is provided on behalf of the North Carolina Brain Injury Advisory Council (BIAC), the statutory body appointed in accordance with N.C. Gen. Stat. § 143B-216.66 that is responsible for making "recommendations to the Governor, the General Assembly, and the Secretary of Health and Human Services regarding the planning, development, funding, and implementation of a comprehensive statewide service delivery system." However, due to the time constraints, the full Council did not vote on this feedback, and it is provided by consensus.

First and foremost, we appreciate the Department's attention to the need for specialized services for individuals with brain injuries and your advocacy for additional funding to support the Traumatic Brain Injury (TBI) Waiver, although we are concerned with the delay in the Department's compliance with the 2023 Appropriations Act (HB 259, Section 9E.16.(d) of Session Law 2023-134), which required "that the Medicaid Traumatic Brain Injury waiver be expanded throughout the State" and directed that NCDHHS "submit an amended waiver application to expand the Traumatic Brain Injury waiver statewide by January 1, 2025, or any later date approved by the Centers for Medicare and Medicaid Services."

We support the Department's recommendation to expand the TBI Waiver statewide, although we recognize this may be impacted by proposed federal funding cuts to the Medicaid program. We also support consideration of inclusion of all individuals with an acquired brain injury (ABI) regardless of cause of injury, as a future covered group, so as not to exclude individuals based solely on the cause of injury[1]. This is based on previous BIAC

[1] Note that the BIAC uses the following definitions of ABI and TBI: Acquired brain injury encompasses both traumatic and nontraumatic brain injuries acquired after birth. A TBI is an acquired brain injury sustained due to a blow to the head from an outside source. A non-traumatic brain injury (NTBI) is an ABI resulting from an assault to the brain from an internal injury (e.g., poisoning, drug use, carbon monoxide, anoxia, hypoxia, virus/bacterial infection, stroke, etc.).

conversations, the prevalence of ABIs, and the lower than anticipated utilization of Waiver services in the pilot catchment area by individuals with TBI.

Below is a list of comments and questions a subgroup of the BIAC identified. We look forward to your response on these items at our next BIAC meeting:

1) To the best of our knowledge, despite serving as the statutory body responsible for advising the Governor and General Assembly on brain injury services, the BIAC has never been provided with any data on the outcomes of the TBI Waiver pilot since it was launched in 2018. We would recommend adding language to strengthen the need for statewide expansion by including demonstrated benefits of participation, if any have been identified. The top of page 4 cites a study that references the benefits of services like those offered in the TBI Waiver. Has the Department or Alliance Health completed any data analysis of cost savings with the pilot population and has it shown results that align with the studies that are cited? The pilot has provided a lengthy period to assess issues related to eligibility, enrollment, participation in services, and efficiencies that could benefit expansion implementation. Are there examples of meaningful outcomes for individuals served that could be used to offer a compelling case for additional funding and statewide expansion?
2) Can the Department provide the data supporting this statement: "Based on DHHS estimates, enrolling a new waiver beneficiary would cost about $60,000 per year in total federal and state Medicaid dollars, with the state paying approximately 35% of the cost."
3) There are currently over 18,000 individuals on the waitlist for the Department's 1915(c) Innovations Waiver. Given that the need for TBI services far exceeds the number of slots currently available under the pilot or likely to be available under the proposed statewide expansion, can you describe the Department's plan for the TBI Waiver waitlist? For example, would individuals on the TBI Waiver waitlist who are eligible for Medicaid be eligible for services under the 1915(i) benefit? What services would be available for individuals on the waitlist who are not eligible for Medicaid?
4) What process is the Department proposing for determining who receives the initial expansion slots? For example, we are aware that some individuals on the Innovations Waiver waitlist may in fact have an TBI or NTBI rather than an intellectual or developmental disability; would those individuals be given priority for TBI Waiver expansion slots?
5) Will the TBI Waiver eligibility criteria mirror the Innovations Waiver criteria allowing for "household of one" eligibility that only looks at the income of the person with the disability when determining Medicaid eligibility and/or whether they "have incomes that do not exceed 300% of the Federal Poverty Level (FPL)"?
6) Is there a standardized functional assessment that must be completed that determines an individual's ability to "benefit from rehabilitative services and supports to help regain skills and decrease or prevent regression or readmission to a facility" per the proposed eligibility criteria? Will that be part of a prior authorization process or the process for being added to the anticipated waitlist?
7) The concept paper cites data indicating that over 200,000 people in North Carolina currently live with a long-term disability related to a TBI. Does the Department have any data estimating what percentage of these individuals are enrolled in the NC Medicaid program or meet NC Medicaid eligibility criteria? Does the Department have any data estimating what percentage of these individuals "meet admission criteria for placement in a nursing facility (at minimum) or specialty rehabilitation hospital due to lost cognitive, behavioral, or physical functioning resulting from the TBI" per your proposed eligibility criteria? For

example, is there any data about the percentage of individuals institutionalized at a state facility who have a TBI or NTBI diagnosis?

8) Does the term "nursing facility" in the criteria refer to an Adult Care Home or Intermediate Care Facility or is this limited to only a Skilled Nursing Facility (SNF)?
9) We are concerned that due to widespread misunderstanding about brain injuries, both within the medical community and in the general population, that individuals with a TBI may have been misdiagnosed as having an NTBI or other condition, or their medical records do not accurately reflect sufficient information that would allow them to qualify for the TBI Waiver under the proposed criteria. For example, the Department lists the potential to expand services to "individuals who sustained brain damage due to internal factors, such as a lack of oxygen." Would the Department consider someone who suffered anoxia because of a violent or traumatic act (e.g., strangulation or drowning) as a qualifying TBI for purposes of the TBI Waiver?
10) Is there a plan to provide greater education and clinical training to help ensure that people with a brain injury needing services and supports can access the Waiver if it is expanded statewide? Will the Department provide technical assistance and support for someone who needs help demonstrating they meet the eligibility criteria?
11) Regarding the annual cost limit of $135,000:
    a. Is the Department considering increasing this to match the Innovations Waiver budget limit of $184,000? Unfortunately, due to increased provider costs and inflation, the proposed maximum budget cap is likely not sustainable if the participant needs a residential service. For example, at least one LME/MCO has data showing that residential supports for individuals with a TBI typically range higher than that of Innovations Waiver participants (e.g., certain TBI members require $400+/day in residential supports only). If the annual cost limit remains capped at $135,000, this may negatively impact the ability to offer residential supports to this population.
    b. Conversely, would the Department consider a tiered budget approach based on severity of need? This might help ensure that individuals whose primary support need is less severe (e.g., caregiver respite) could receive services, rather than targeting all funding to only the most severely impacted.
    c. Does the annual cost limit include all services and supports billed to Medicaid or only specific services within the TBI Waiver?
    d. Does the annual cost limit include supported living services?
    e. Does the annual cost limit include home and vehicle modifications? Is there a proposed cap for either of these services, like the Innovations Waiver?
12) The concept paper references Tailored Care Management (TCM). Are these TBI Care Managers all plan-based or are provider-based TCM agencies permitted to provide this service?
13) The concept paper references employment support. Would this employment service be similar to the I/DD Supported Employment (SE) service or the MH/SU Individual Placement and Support (IPS) model? If the IPS-SE model is used, will the Department require a fidelity review along with coordination with the individual's treatment team? Is the NCDHHS Division of Employment and Independence for People with Disabilities (formerly Vocational Rehabilitation) equipped to support individuals with TBI? Do they have additional trained providers for TBI supports?
14) The concept paper states that "[w]ith General Assembly funding, DHHS also required standard rate increases for providers for a number of TBI services, which allowed Alliance Health to grow and support

its specialized provider network during the pilot." Has this resulted in any provider incentive to deliver TBI Waiver services over Innovations Waiver services?

15) What is the Department's plan to increase the number of TBI specialized providers? What would signify a specialized TBI provider? Would there be an accreditation requirement, mandatory training, or certifications that are required to get this designation? Will the Department fund or offer provider trainings (e.g., through AHEC, like the trainings that were offered to new TCM providers) for community-based TBI services as well as residential services?
16) What is the Department's plan to address the impact that statewide expansion may have on direct support professional availability?
17) The concept paper states that "[s]ince its inception in 2018, the waiver has served approximately 107 individuals with TBI." It also states that "[a]s of December 2024, approximately 79 Medicaid beneficiaries are currently enrolled in the TBI waiver." Is there data identifying the reason(s) that approximately 28 individuals are no longer enrolled? How were individuals disenrolled from the Waiver? For example, will the disenrollment process mirror the process for the Innovations Waiver?
18) The Appendix for the Level of Care Parameters focuses around cognitive/behavioral deficits and needs, but not physical and/or functional needs. Is there a reason for this focus?
19) In the Level of Care Appendix, each of the "Behavioral Support" areas states that "staff" are providing services and completing the assessment. What is the Department's proposal for how to address individuals with a TBI who are cared for by family?
20) What is the specific Behavior Assessment tool/Grid that will be utilized?
21) Will the statewide TBI Waiver allow for Relatives as Direct Support Employees (RADSE) to provide services to their family members in their homes?
22) Please confirm the acronym "TBIW-NF" stands for Traumatic Brain Injury Waiver-Nursing Facility. The acronym is only used once and is unclear.
23) The eligibility parameters in the Level of Care Appendix include a reference requiring "a 24-hour plan of care that includes a formal behavioral support plan." Does this mean that 24-hour services are required to be eligible for the TBI Waiver? Would this include provider supervision time? Is any unsupervised time allowed?

Again, we appreciate the opportunity to provide feedback. Moving forward, we hope that DHB will provide more ongoing data and information to the BIAC in real time about the TBI Waiver so we can be better informed and able to fulfill our statutory mandate. We look forward to our next meeting with DHB representatives.

Sincerely,

Members of the North Carolina Brain Injury Advisory Council
Kristen L. Barboza, PT, MBA, FACHE, Director of Rehabilitation Services, Atrium Health
Leila Hicks, JD, Attorney, Henson Fuerst
Tracy Hayes, JD, CHC, Vaya Health Area Director and CEO
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cc: Jay Ludlam, Deputy Secretary, NC Medicaid
Kelly Crosbie, Director, NC DMHDDSUS