



Traumatic Brain Injury Waiver: Vision for Statewide Expansion

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Overview

North Carolina's Department of Health and Human Services (DHHS) is working with its community partners to increase access to care for North Carolinians with brain injuries by improving the fragmented and expensive systems of care they face. The Brain Injury Association of North Carolina estimates that roughly 78,775 North Carolinians experience a traumatic brain injury (TBI)¹ annually, and more than 200,000 currently live with a long-term disability related to TBI.² A portion of individuals with TBI need intensive rehabilitative treatment to strengthen or regain injury-related loss of functions, develop compensatory strategies, and live as independently as possible. Historically, North Carolina has funded TBI-related education and supports with limited state funds. In 2018, North Carolina piloted the 1915(c) Medicaid TBI waiver in select counties to provide community-based rehabilitation services to individuals with TBI at risk of living in facilities long-term (e.g., at a nursing facility or specialty rehabilitation hospital).

The General Assembly, DHHS, self- and family-advocates, and other partners recognize the critical need to expand home and community-based supports available to North Carolinians with TBI. Expanding the waiver would increase statewide access to specialized rehabilitative services that support the greatest extent of recovery possible for individuals with TBI who are at risk of hospitalization and long-lasting functional decline. The [October 2023 Appropriations Act](#) (HB 259, Section 9E.16.(d) of Session Law 2023-134) signaled that, "It is the intent of the General Assembly that the Medicaid Traumatic Brain Injury waiver be expanded throughout the State. Within 60 days after the effective date of this act, DHHS shall 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."³ However, the Appropriations Act did not provide the funding required to implement this expansion.

Since this Act's establishment, DHHS has engaged its community partners to improve access to waiver services for beneficiaries, met with the Centers for Medicare and Medicaid Services

¹ Defined by [North Carolina General Statutes §122C-3 \(38a\)](#) as "An injury to the brain caused by an external physical force resulting in total or partial functional disability, psychosocial impairment, or both, and meets all of the following criteria:

- a. Involves an open or closed head injury.
- b. Resulted from a single event, or resulted from a series of events which may include multiple concussions.
- c. Occurs with or without a loss of consciousness at the time of injury.
- d. Results in impairments in one or more areas of the following functions: cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech.
- e. Does not include brain injuries that are congenital or degenerative."

² Brain Injury Association of North Carolina. The Need in North Carolina. Available at: <https://www.bianc.net/>.

³ North Carolina General Assembly. House Bill 259 / SL 2023-134. Available at: <https://www.ncleg.gov/BillLookup/2023/H259>.

(CMS), and worked with its actuary to understand projected expansion costs.⁴ **DHHS is committed to continuing to work with partners including but not limited to the General Assembly, self- and family-advocates, local management entities/managed care organizations (LME/MCOs) (now Tailored Plans), and providers to expand the TBI waiver statewide.**

Background on North Carolina's Traumatic Brain Injury Waiver

History

DHHS previously worked with TBI self- and family-advocates, providers, and other partners to design the TBI waiver pilot, which launched in 2018 and was renewed for a five-year period in April 2022. CMS approved the waiver's enrollment capacity of up to 107 eligible Medicaid beneficiaries at a given time in seven counties: Cumberland, Durham, Harnett, Johnston, Mecklenburg, Orange, and Wake. Since 2018, Alliance Health, an LME/MCO, has managed the TBI waiver.

Eligibility

As of December 2024, approximately 79 Medicaid beneficiaries are currently enrolled in the TBI waiver. To be eligible, individuals must:

- Have experienced a TBI on or after their 18th birthday;
- Show they can benefit from rehabilitative services and supports to help regain skills and decrease or prevent regression or readmission to a facility;
- 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;⁵ and
- Have incomes that do not exceed 300% of the Federal Poverty Level (FPL).⁶

Individuals are reassessed each year to determine their continued eligibility for the waiver. Waiver beneficiaries can receive clinically indicated covered services within an annual cost limit of \$135,000.⁷

TBI Waiver Design

Goals of North Carolina's 1915(c) TBI waiver include maximizing self-determination, self-advocacy, and self-sufficiency, increasing community integration through work, life-long learning, and socialization, and supporting independent living and community engagement.

TBI waiver design aligns with national best or promising practices for supporting rehabilitation for individuals with brain injuries who may require a range of specialized rehabilitative and

⁴ See [Appendix](#) for an overview of estimated TBI costs per new waiver beneficiary.

⁵ See [Appendix](#) for a detailed explanation of the skilled nursing facility (SNF) and specialty rehabilitation hospital level of care requirements.

⁶ Estimated annual income of \$46,950 for an individual in 2025. Office of the Assistant Secretary for Planning and Evaluation (ASPE). Poverty Guidelines API. Available at: <https://aspe.hhs.gov/topics/poverty-economic-mobility/poverty-guidelines>.

⁷ North Carolina Department of Health and Human Services. Application for a §1915(c) Home and Community-Based Services Waiver. Available at: <https://medicaid.ncdhhs.gov/1915c-tbi-waiver-amendment-waiver-approved-march-1-2024/open>.

transitional supports. These may include compensatory strategies to reacquire skills and/or activities of daily living (ADLs) and home and vehicle modifications (e.g., ramps, chair lifts, or door openers) to support the greatest level of independence possible.⁸

TBI waiver services support individualized needs and promote physical and cognitive rehabilitation. The TBI waiver offers beneficiaries a range of services, including personal care, physical, occupational, and speech therapies,⁹ in-home intensive supports, residential supports, life skills training, cognitive rehabilitation, employment support, caregiver respite, and community networking. Specially trained Tailored Care Managers develop an individual support plan that is customized to address the unique needs of each waiver beneficiary. The person-centered individual support plan directs the beneficiary's access to waiver services delivered by providers who are educated and trained on effective strategies for supporting individuals with TBI.¹⁰

Waiver Improvements

Throughout its pilot phase, the TBI waiver has provided access to a range of community-based rehabilitative services to help waiver beneficiaries regain skills or develop compensatory strategies, improve their quality of life, and achieve the highest level of independence possible. To that end, DHHS remains committed to incorporating feedback from advocates, providers, and other stakeholders to continuously improve the TBI waiver and, in response, has made several changes to the waiver. To enhance beneficiary care, DHHS added supported living and remote support services to the waiver's benefit package. To extend the reach of the TBI waiver, DHHS also expanded eligibility to individuals whose TBI occurred at or after age 18 (previously age 22) and to those with incomes up to 300% FPL (previously 100%). With 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.¹¹ Since its inception in 2018, the waiver has served approximately 107 individuals with TBI.

Statewide Traumatic Brain Injury Waiver Expansion

Need for Waiver Expansion

Statewide waiver expansion would allow DHHS to provide medically necessary, specialized services to a greater number of North Carolinians with TBI, improving their health outcomes, reducing risks of permanent disability and/or long-term facility-based care, and potentially resulting in cost savings. Studies have shown that best practice rehabilitative care for TBI like the home and community-based services included in the TBI waiver can lead to cost savings by

⁸ Brain Injury Association of America. Brain Injury Treatment. Available at: <https://www.biausa.org/brain-injury/about-brain-injury/treatment>.

⁹ The scope of these services is beyond what is offered under the Medicaid State Plan.

¹⁰ North Carolina Department of Health and Human Services. Application for a §1915(c) Home and Community-Based Services Waiver. Available at: <https://medicaid.ncdhhs.gov/1915c-tbi-waiver-amendment-waiver-approved-march-1-2024/open>.

¹¹ North Carolina Department of Health and Human Services. NC Medicaid Behavioral Health Services Rate Increases. Available at: <https://medicaid.ncdhhs.gov/blog/2023/11/15/nc-medicare-behavioral-health-services-rate-increases>.

avoiding long-term facility-based care, loss of work and disability, emergency department visits, and hospital stays, among other indicators.¹²

Currently, only individuals who reside in one of the seven counties served by Alliance Health can access the TBI waiver and receive its set of specialized services to support their recovery and ability to live as independently as possible. However, Medicaid beneficiaries with TBI residing outside of the TBI waiver's seven-county catchment area must navigate a fragmented and complicated system of care that does not offer adequate, TBI-specific support. Some individuals with TBI may even have to leave the state to receive needed services. Others are enrolled in different Medicaid waivers, such as the 1915(c) Community Alternatives Program for Disabled Adults (CAP/DA) waiver and 1915(c) Innovations waiver or use North Carolina's 1915(i) State Plan home and community-based services—all of which offer a diverse set of community-based services that are not uniquely specialized for TBI needs. Additionally, some individuals with TBI may receive limited services through the TBI State Funded program. Individuals with the most acute needs may reside in skilled nursing facilities or have extended stays in specialized rehabilitation hospitals to receive needed care. Expanding the TBI waiver statewide would provide a more coordinated, TBI-specific care pathway for those in need of rehabilitative treatment. It would also encourage more investment in and growth of the specialized TBI provider network to meet the needs of a larger number of waiver beneficiaries.

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. For example, if DHHS were to enroll 300 additional Medicaid beneficiaries in the TBI waiver, annual costs would total roughly \$18,000,000, with the federal government covering about \$11,700,000, and North Carolina covering the remaining \$6,300,000 of Medicaid costs.

Future State of Brain Injury Care in North Carolina

DHHS recognizes that a large number of North Carolinians experience traumatic and non-traumatic brain injuries that lead to diverse rehabilitative needs. Based on feedback from community partners, to meet the needs of more North Carolinians living with brain injuries, DHHS is considering widening waiver eligibility and services to conditions beyond TBI over the longer term to include adults with acquired brain injuries (ABIs)¹³ or non-traumatic brain injuries who meet current waiver income and level of care requirements (i.e., criteria for admission to a nursing facility or specialty rehabilitation hospital with capacity to benefit from rehabilitative services). This expansion may extend services to individuals who sustained brain

¹² National Academies of Sciences, Engineering, and Medicine. Traumatic Brain Injury: A Roadmap for Accelerating Progress (2022). Available at: <https://nap.nationalacademies.org/catalog/25394/traumatic-brain-injury-a-roadmap-for-accelerating-progress>.

¹³ Defined by Utah's ABI waiver, for example, as "as being injury related and neurological in nature and may include cerebral vascular accident and brain injuries that have occurred after birth. Acquired brain injury does not include individuals whose functional limitations are due solely to mental illness, substance abuse, personality disorder, hearing impairment, visual impairment, learning disabilities, behavior disorders, aging process, or individuals with deteriorating diseases such as multiple sclerosis, muscular dystrophy, Huntington's chorea, ataxia, or cancer." Utah Acquired Brain Injury Waiver Application (July 2024). Available at: <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/83331>.

damage due to internal factors, such as a lack of oxygen, heart attack, stroke, infectious disease, or pressure from a tumor.¹⁴ Individuals living with ABI may require additional care beyond the TBI waiver's current benefit package to manage the underlying condition or illness causing the brain injury. DHHS continues to engage a broad range of community partners to assess the need for this expansion and other potential reforms to the TBI waiver.

Conclusion

Navigating the return home and path forward following a brain injury can be complicated and overwhelming. Many individuals with TBI and their families require community-based, specialized rehabilitative services to support their recovery and highest level of independence possible. In line with the U.S. Supreme Court's *Olmstead* decision in 1999, North Carolinians with TBI should have equitable access to condition-related services and supports in their homes and communities so that they are not subject to avoidable facility stays.¹⁵ **To achieve this goal, DHHS seeks to expand the TBI waiver beyond its seven-county catchment area to avert long-term facility-based care, support community-based living, and provide high-quality care for individuals living with TBI statewide.**

¹⁴ Brain Injury Association of America. What is the difference between an acquired brain injury and a traumatic brain injury? Available at: <https://www.biausa.org/brain-injury/about-brain-injury/nbiic/what-is-the-difference-between-an-acquired-brain-injury-and-a-traumatic-brain-injury>.

¹⁵ U.S. Department of Health and Human Services, Community Living and Olmstead. Available at: <https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html>.

Appendix: Level of Care Parameters

Below are the parameters for TBI waiver applicants to meet the required SNF level of care.

1. Modified Rancho Los Amigos © Level of Cognitive Functioning Level IV through VIII.
2. Cognitive support needs – One impairment in Awareness, Communication, Judgement, Memory, Planning, Problems Solving skills AND one other cognitive skill OR Impairment in three or more cognitive functions with at least two of the three functions requiring “Present / Requires frequent support” or “Present and severe, requires availability of “24-hour support” or monitoring level of intensity.
3. Behavior Assessment Grid indicates impairment in two or more of the following areas: Agitation, Impulsivity, Intrusiveness, Legal history after brain injury, Pica, socially offensive behavior, Susceptibility to victimization, Verbal aggression, Wandering/ Elopement, Withdrawal, Damage to Property, Inappropriate sexual activity, Injury to others, Injury to self and/or Physical Aggression,
4. Behavioral Support at one of the following levels:
 - a. Needs and receives occasional staff intervention in the form of cues because the person is anxious, irritable, lethargic, or demanding. Person responds to cues. “Occasional” is defined as less than 4 times per week.
 - b. Needs and receives regular staff intervention in the form of redirection because the person has episodes of disorientation, hallucinates, wanders, is withdrawn or exhibits similar behaviors. Person may be resistive but responds to redirection. “Regular” is defined as 4 or more times per week.
 - c. Needs and receives behavior management and staff intervention because person exhibits disruptive behavior such as verbally abusing others, wandering into private areas, removing, or destroying property, or
 - d. Needs and receives behavior management and staff intervention because person is physically abusive to self and others. Person may physically resist redirection.
5. Requires level of specialized cognitive and behavioral support(s) available in a nursing facility that provided brain injury services. A person does not have to be a resident of a nursing facility to require this level of care.

Below are the parameters for TBI waiver applicants to meet the required specialty rehabilitation hospital level of care.

1. Behavior Assessment Grid indicates impairment that is present and severe AND requires the availability of intensive behavior intervention in two or more of the following areas:
 - a. Damage to property,
 - b. Inappropriate sexual activity,
 - c. Injury to others, Injury to self,
 - d. Physical aggression
2. Behavioral Support at one of the following levels:

- a. Needs and receives occasional staff intervention in the form of cues because the person is anxious, irritable, lethargic, or demanding. Person responds to cues. “Occasional” is defined as less than 4 times per week and needs and receives regular staff intervention in the form of redirection because the person has episodes of disorientation, hallucinates, wanders, is withdrawn or exhibits similar behaviors. Person may be resistive but responds to redirection. “Regular” is defined as 4 or more times per week.
 - b. Needs and receives behavior management and staff intervention because person exhibits disruptive behavior such as verbally abusing others, wandering into private areas, removing, or destroying property, or acting in a sexually aggressive manner. Person may be resistant to redirection.
 - c. Needs and receives behavior management and staff intervention because person is physically abusive to self and others. Person may physically resist redirection.
- 3. Requires services and/or supports that exceed services in TBIW-NF.
 - 4. Requires a 24-hour plan of care that includes a formal behavioral support plan.
 - 5. Requires level of care and behavioral support available in a neurobehavioral hospital; available intensive behavior intervention. A person does not have to be a resident of a neurobehavioral hospital to require this level of care.