

# **TRAUMATIC BRAIN INJURY WAIVER REPORT**



**Session Law 2014-100, Section 12H.6**

**State of North Carolina**

**Department of Health and Human Services  
Division of Medical Assistance  
Division of Mental Health, Developmental Disabilities,  
and Substance Abuse Services**

**February 1, 2015**

**Division of Medical Assistance  
Division of Mental Health, Developmental Disabilities and Substance Abuse  
Services**

**Development of Traumatic Brain Injury Home and Community Based Services Waiver  
Report to the General Assembly**

**Table of Contents**

Executive Summary .....	1
Recommendations if NC Pursues a TBI Waiver .....	1
Waiver Purpose .....	2
Demographics .....	2
Target Population.....	2
Proposed Service Array .....	3
Assistive Technology Equipment and Supplies .....	3
Day Supports .....	3
Respite Care .....	3
In-Home Supports .....	3
Residential Supports .....	4
Home Modifications .....	4
Family and Caregiver Training.....	4
Vehicle Modifications .....	4
Supported Employment .....	4
Supported Living .....	5
Personal Care .....	5
Extended Clinical Services .....	5
Medical Day .....	5
Neurobehavioral Programming .....	5
Transportation .....	5
Providers .....	6
Estimated Cost .....	6
Total Population that may need Long Term Care.....	6
North Carolina compared to New York.....	7
North Carolina compared to Minnesota.....	7
5 year Project with 122 Participants .....	7
Assumptions .....	8
Cost Limitations / Requirements .....	8
Recommendation Regarding Pursuit of Waiver .....	9
Next Steps.....	9
Appendix A: Session Law 2014-100.....	10
Appendix B: States Surveyed.....	11

## **EXECUTIVE SUMMARY**

Session Law 2014-100, SECTION 12H.6 instructed the Department of Health and Human Services, Division of Medical Assistance, and Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, in conjunction with the North Carolina Advisory Council, to design and draft a 1915(c) waiver to add a new service package for Medicaid beneficiaries with traumatic brain injury (TBI). At this time, there are no appropriations to fund the Traumatic Brain Injury Medicaid Waiver.

North Carolina's capacity to serve survivors of traumatic brain injury with long-term needs in communities must grow. Although it is well known that social isolation is often a negative factor impacting TBI survivors, there are only three day programs in the State that are designed for people with brain injuries. Also, services that are available are often designed for people with other disabilities. A waiver would help the State achieve expected outcomes for this population so that individuals with TBI would be able to both choose where and with whom they live and to live self-satisfying lives.

## **RECOMMENDATIONS**

If the decision is made to pursue a TBI Waiver, and the Division of Medical Assistance is appropriated additional funding to cover the state share of all expenditures, DHHS recommends that the TBI Waiver begin with a smaller number of beneficiaries with TBI and allow the program to expand over time. It is estimated that from initial planning and waiver preparation, submission, provider eligibility and enrollment of the waiver, operation of the waiver would be nine to twelve months from legislative approval of waiver submission.

## **WAIVER PURPOSE**

The waiver is designed to provide community alternatives for individuals with traumatic brain injuries who are currently in nursing facilities, chronic hospitals, or specialty rehabilitation hospitals or who are in the community and at risk for placement in nursing facilities, chronic hospitals or specialized rehabilitation hospitals. The objective of the waiver is to integrate and maintain the individual in the community utilizing services that are specifically targeted for this population.

## **DEMOGRAPHICS**

Using the federal Centers for Disease Control and Prevention (CDC) prevalence data of 2 percent, there are approximately 190,000 survivors of traumatic brain injury in North Carolina; it is further estimated that up to one-third of those persons may need long-term care. Therefore, the estimated North Carolina population of individuals functioning with a TBI and who may need varying levels of long term support is 63,333. Although data on traumatic brain injuries is not systemically tracked, based on various claims data at least 30,000 individuals with traumatic brain injury received Medicaid funding in 2010. In 2012, 76,708 North Carolina citizens sustained a traumatic brain injury.<sup>1</sup>

## **TARGET POPULATION**

Medicaid beneficiaries who:

1. Reside in the State of North Carolina;
2. Have a traumatic brain injury which occurred on or after their 22<sup>nd</sup> birthday;
3. Require a need for a combination and sequence of special interdisciplinary, or general care, treatment, or other services which are of a lifelong or extended duration and are individually planned and coordinated which is likely to continue indefinitely;
4. Meet placement criteria for placement in nursing facilities, chronic hospital or specialty rehabilitation hospital;
5. Are not more appropriately serviced by any other 1915(c) waiver; and
6. Exhibit medical, emotional, behavioral and cognitive deficits.

The target waiver population is adults with cognitive, behavioral, and physical deficits who require supervised and supportive care. Most targeted individuals have either completed a course of intensive rehabilitation and need a less intensive rehabilitative schedule or are in need of long-term services and supports. A small portion of the individuals on this waiver would benefit from a more intensive course of rehabilitation.

---

<sup>1</sup> NC Disease Event Tracking & Epidemiologic Collection Tool (NC DETECT), analysis conducted by the Injury & Violence Prevention Branch, NC Division of Public Health.

## PROPOSED SERVICE ARRAY

Some of the proposed waiver services are similar to services found under the NC Innovations waiver for individuals with intellectual disabilities. However, under a TBI Waiver the service array is expanded to include a rehabilitation element which differentiates these services from those found under NC Innovations. The following waiver services are proposed in conjunction with any Medicaid State Plan services for which the beneficiary is eligible.

<b>COMPARABLE NC INNOVATIONS WAIVER SERVICES</b>	
<b>SERVICE</b>	<b>DESCRIPTION</b>
Assistive Technology Equipment and Supplies	Necessary for the proper functioning of items and systems, whether acquired commercially, modified, or customized, that are used to increase, maintain, or improve functional capabilities of beneficiaries. This service covers purchases, leasing, shipping costs, and as necessary, repair of equipment required to enable beneficiaries to increase, maintain or improve their functional capacity to perform daily life tasks that would not be possible otherwise. All items must meet applicable standards of manufacture, design, and installation.
Day Supports	Paid, continuous, onsite-supervised, community activity. Day programming is an individual or group service that provides assistance to the beneficiary with acquisition, retention, regaining or improvement in self-help, socialization and adaptive skills. Day Supports are furnished in a non-residential setting, separate from the home or facility where the beneficiary resides. Day Supports focuses on enabling the beneficiary to attain, regain, or maintain his or her maximum functional level and is coordinated with any physical, occupational, or speech therapies listed in the Individual Support Plan.
Respite Care (in-home or at a facility)	Provides periodic support and relief to the primary caregiver(s) from the responsibility and stress of caring for the beneficiary. This service enables the primary caregiver to meet or participate in planned or emergency events, and to have planned time for him/her and/or family members. Respite may include in and out-of-home services, inclusive of overnight, weekend care, or emergency care (family emergency based, not to include out of home crisis). The primary caregiver is the person principally responsible for the care and supervision of the beneficiary and must maintain his/her primary residence at the same address as the beneficiary.
In-Home Supports	Personal care/assistance, medication administration, chore services, night supervision, companion services, and homemaker services. For beneficiaries living alone or with families, services are unbundled and offered according to a plan determined by the care coordinator, the participant and/or their designated representative(s).

<b>COMPARABLE NC INNOVATIONS WAIVER SERVICES</b>	
<b>SERVICE</b>	<b>DESCRIPTION</b>
Residential Supports	Personal care/assistance, medication administration, chore services, night supervision, companion services and homemaker services. For individuals living in a residential setting, services are unbundled and offered according to a plan determined by the care coordinator, the participant and/or their designated representative(s).
Home Modifications	Physical modifications to a private residence that are necessary to ensure the health, welfare, and safety of the beneficiary or to enhance the beneficiary's level of independence. A private residence is a home owned by the beneficiary or his/her family (natural, adoptive, or foster family). Items that are portable may be purchased for use by a beneficiary who lives in a residence rented by the beneficiary or his/her family. The service would be limited to expenditures of \$20,000 over the duration of the waiver which is consistent with the highest limit in any of the State's other 1915(c) waivers.
Family and Caregiver Training	Provides training to families and the beneficiary's natural support network in order to enhance the decision making capacity of the natural support network, provide orientation regarding the nature and impact of the TBI on the beneficiary, provide education and training on intervention/strategies, and provide education and training in the use of specialized equipment and supplies.
Vehicle Modifications	Alterations to a vehicle to accommodate a person. This includes devices, service or controls that enable beneficiaries to increase their independence or physical safety by enabling their safe transport in and around the community. The service would be limited to expenditures of \$20,000 over the duration of the waiver which is consistent with the highest limit in any of the State's other 1915(c) waivers.
Supported Employment	Provides assistance with choosing, acquiring, and maintaining a job when competitive employment has not been achieved and /or has been interrupted or intermittent. This includes pre job training, coaching, and long term follow along.
Supported Living	Provides individualized services and support to enable individuals to reside in a home that is under the control and responsibility of the individual. The service includes direct assistance as needed with activities of daily living, household chores essential to the health and safety of the individual/s, budget management, attending appointments, and interpersonal and social skills building to enable the individual to live in a home in the community. Training

<b>COMPARABLE NC INNOVATIONS WAIVER SERVICES</b>	
<b>SERVICE</b>	<b>DESCRIPTION</b>
	activities, supervision, and assistance may be provided to allow the person to participate in home life or community activities. Other activities include assistance with monitoring health status and physical condition, and assistance with transferring, ambulation and use of special mobility devices. Transportation is an inclusive component of Supported Living to achieve goals and objectives related to these activities with the exception of transportation to and from medical services covered through the Medicaid State Plan.
Personal Care	Includes support, supervision and engaging participation with eating, bathing, dressing, personal hygiene and other activities of daily living. Support and engaging the beneficiary describes the flexibility of activities that may encourage the beneficiary to maintain skills gained during rehabilitation while also providing supervision for independent activities. This includes cueing support.

<b>TBI-SPECIFIC WAIVER SERVICES</b>	
<b>SERVICE</b>	<b>DESCRIPTION</b>
Extended Clinical Services	Physical therapy, occupational therapy, neurobehavioral and cognitive behavioral interventions, cognitive rehabilitation, mental health and substance abuse services, speech and language services, and similar services performed by credentialed professionals at a level higher or not otherwise covered under the State Plan.
Medical Day	Medically supervised, health-related services provided in an ambulatory setting to medically involved adults who, due to their degree of impairment, need health maintenance and restorative services supportive to their community living.
Neurobehavioral Programming	Assists the individual to change behavior, replacing maladaptive, badly adjusted, or self-destructing behaviors by learning new, more beneficial behaviors. Common neurobehavioral issues for people with TBI include behavioral/personality changes, cognitive (intellectual) deficits, mood disorders, sleep disorders, post traumatic epilepsy or seizures and chronic pain such as headaches. This service is provided by a psychologist, behavioral analyst, mental health counselor, clinical social worker, or a marriage and family counselor.
Transportation	Provides transportation to community activities and/or other waiver services when transportation is not included in another service rate.

<b>TBI-SPECIFIC WAIVER SERVICES</b>	
<b>SERVICE</b>	<b>DESCRIPTION</b>
Resource Facilitation	Partners with the individual to be served to assist with information regarding community access and partnership building to allow the individual to make appropriate choices for a full life.

## **PROVIDERS**

All service providers must be licensed, certified, or accredited as appropriate and have experience/training in serving individuals with traumatic brain injury.

## **ESTIMATED WAIVER COST**

To estimate the overall cost of the waiver, DHHS looked at the overall prevalence of TBI in North Carolina, and examined other states currently operating TBI waivers to develop a range of waiver costs. Based on other states' experience, DHHS assumes the average cost per beneficiary in North Carolina would be \$85,000 per year (State and federal funds). The range of potential waiver cost is expansive – from \$167 million annually using New York State's waiver criteria to \$5.4 billion annually, serving every potentially-eligible TBI beneficiary needing long term support.

### **Estimated Cost: Total TBI Population**

The chart below shows the total cost if North Carolina provided care to the estimated 63,333 total beneficiaries with TBI who need long term support.

#### **DMA COSTS – SERVICES**

<b># Beneficiaries</b>	63,333
<b>Average annual cost/beneficiary</b>	\$85,000
<b>Total Costs</b>	<b>\$ 5,383,305,000</b>

### **Estimated Cost: North Carolina using New York Eligibility Criteria**

New York operates and serves the most beneficiaries on a TBI Waiver, 3,939 beneficiaries. Since North Carolina has roughly half the population of New York State — 9.84 million (NC) compared to 19.65 million (NY) — DHHS assumes that half the number of individuals would be eligible for a TBI waiver in NC if DHHS were to use the same eligibility criteria, resulting in the following cost estimation.



### **DMA COSTS – SERVICES**

<b># Beneficiaries</b>	1,969
<b>Average annual cost/beneficiary</b>	\$85,000
<b>Total Costs</b>	<b>\$167,365,000</b>

**Estimated Cost: North Carolina compared to Minnesota Eligibility Criteria and Service Array**  
Minnesota has a robust TBI Waiver that includes both Skilled Nursing Facilities and Neurobehavioral Hospital Levels of Care. The Minnesota TBI waiver serves 2,008 beneficiaries. North Carolina has roughly 1.8 times the population of Minnesota, so assuming a proportionate number of individuals would be eligible in NC results in the following cost estimate.

### **DMA COSTS – SERVICES**

<b># Beneficiaries</b>	3,614
<b>Average annual cost/beneficiary</b>	\$85,000
<b>Total Costs</b>	<b>\$307,190,000</b>

### **Estimated Cost: North Carolina 5-year Projection**

In order to support survivors of traumatic brain injury with long-term needs, North Carolina's TBI provider capacity must grow. DHHS would recommends a starting point of 122 beneficiaries in order to develop a phased waiver in a targeted area of the State. The waiver could expand to other regions after evaluation, needed programmatic changes, and the development of trained community providers.

### DMA COSTS – SERVICES

	SFY2015	SFY2016	SFY2017	SFY2018	SFY2019
# Beneficiaries	74	76	98	110	122
Average annual cost/Beneficiary	\$85,000	\$85,000	\$85,000	\$85,000	\$85,000
<b>Total Costs</b>	<b>\$6,290,000</b>	<b>\$6,460,000</b>	<b>\$8,330,000</b>	<b>\$9,350,000</b>	<b>\$10,370,000</b>
<b>Federal Share</b>	<b>\$4,143,852</b>	<b>\$4,279,104</b>	<b>\$5,517,792</b>	<b>\$6,193,440</b>	<b>\$6,869,088</b>
<b>State Appropriation</b>	<b>\$2,146,148</b>	<b>\$2,180,896</b>	<b>\$2,812,208</b>	<b>\$3,156,560</b>	<b>\$3,500,912</b>

### DHHS COSTS – STAFF (3)

	SFY2015	SFY2016	SFY2017	SFY2018	SFY2019
<b>Total Costs</b>	<b>\$256,305</b>	<b>\$256,305</b>	<b>\$256,305</b>	<b>\$256,305</b>	<b>\$256,305</b>
<b>Federal Share</b>	<b>\$168,854</b>	<b>\$169,776</b>	<b>\$169,776</b>	<b>\$169,776</b>	<b>\$169,776</b>
<b>State Appropriation</b>	<b>\$87,451</b>	<b>\$86,529</b>	<b>\$86,529</b>	<b>\$86,529</b>	<b>\$86,529</b>
<b>FMAP</b>	<b>0.6588</b>	<b>0.6624</b>	<b>0.6624</b>	<b>0.6624</b>	<b>0.6624</b>

#### Assumptions

1. A maximum of 122 people will be served. The full amount will not be served in the first year.
2. The maximum annual cost will be less than the average institutional cost. On average, there is an annual cost of \$85,000 per beneficiary.
3. The staff position is assumed at a 50/50 administrative match.
4. The Federal Medical Assistance Percentages (FMAPs) applied above (for services) are at the normal shares.
5. For each year, the majority of individuals will be served at the Skilled Nursing Level of Care. A smaller group will be served at the Chronic Hospitalization or Rehabilitation level of Care. The assumption is that many of the individuals receiving the Chronic Hospitalization or Rehabilitation Level of Care will transition over to the Skilled Nursing Level of Care. See the chart below for information:

	Individuals	Hospital LOC	Nursing LOC
Year 1	74	10	64
Year 2	86	12	74
Year 3	98	13	85
Year 4	110	15	95
Year 5	122	17	105

#### Cost Limitations / Requirements

Total program costs are limited by the number of community care slots used each year and by costs per beneficiary. Each individual's service package must be no more than the cost of institutional care, determined at a projected weighted cost of institutional care. There will be no retroactive reimbursement of waiver services provided prior to program enrollment.

## **RECOMMENDATIONS**

**If the decision is made to move forward with a TBI Waiver, DHHS would recommend it be implemented as follows:**

1. Initially serve 122 to 200 individuals and allow the population served to expand over time.
2. Initially serve adults. During future evaluation, DHHS will determine if it is appropriate to expand the Target Population to include injuries sustained prior to the 22nd birthday.
3. Develop a trained and competent provider network that is able to support the TBI population as the waiver expands.
4. Assess the TBI waiver at regular intervals to ensure it is meeting the needs of participants, is cost neutral, and sustainable.
5. In order for a TBI Waiver to be pursued, a State appropriation would need to be made available to fund the state match.
  - a. The present TBI State specialty funds will continue to be used for those who do not qualify for Medicaid but demonstrate need
  - b. The combination of a TBI specific Waiver and specialty TBI State funds will increase the service capacity for this underserved population

## **NEXT STEPS**

1. Continue to work with Stakeholder groups and in conjunction with the North Carolina Brain Injury Advisory Council for feedback and to ensure the waiver will meet the needs of the TBI community.
2. Work with states with successful TBI programs to isolate learning lessons and opportunities.
3. Determine ways to ensure cost neutrality, contain costs, and establish an upper limit to the waiver benefit.
4. Investigate starting the TBI Waiver as a pilot program and expanding the waiver to the entirety of the State after evaluating the program and making changes based on lessons learned.
5. Develop a working relationship between the Veterans Administration and the LME/MCOs to ease the transition burden for our Veterans from program to program.
6. Choose or develop an appropriate assessment tool.
7. Establish TBI Waiver eligibility requirements.

## **Appendix A: Session Law 2014-100**

From **SUBPART XII-H. DIVISION OF MEDICAL ASSISTANCE (MEDICAID)**

### **TRAUMATIC BRAIN INJURY WAIVER**

**SECTION 12H.6.** The Department of Health and Human Services, Division of Medical Assistance, and Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, in conjunction with the North Carolina Traumatic Brain Injury Advisory Council, shall design and draft a 1915(c) waiver to add a new service package for Medicaid eligibles with traumatic brain injury (TBI). This draft waiver may be based on an update to the 2010 report on a waiver to serve individuals with traumatic brain injury. The Department shall report the draft waiver, other findings, and any additional options to provide Medicaid services to those suffering from TBI to the House Appropriations Subcommittee on Health and Human Services and the Senate Appropriations Committee on Health and Human Services by February 1, 2015. The Department may submit drafts of the waiver to the Centers for Medicare and Medicaid Services (CMS) to solicit feedback but shall not submit the waiver for CMS approval until authorized by the General Assembly.

## Appendix B: States Surveyed

### TBI Waivers in Other States:

Currently, 23 states have a Home and Community Based Waiver that serves individuals with TBI.

STATES	Level of Care	#'s Served	Waiver Cost (Factor D)	Total Medicaid Costs
Colorado	Hospital & SNF	345	54,773.91	60,876.91
Florida	SNF	410	28,474.31	45,651.40
Illinois	SNF	4905	6,396.45	19,908.45
Indiana	SNF & ICF-IID	200 (146 SNF + 54 ICFIID)	31,407.46	65,279.36
Iowa	SNF & ICF-IID	1625 (1577 SNF + 48 ICFIID)	23,055.71	42,749.71
Kansas	(Hospital) Traumatic Brain Injury Rehabilitation Facility	804	22,998.02	33,362.02
Maryland	SNF & Hospital (Rehabilitative, Chronic, Specialty)	112	87,050.00	93,723.62
Massachusetts (3)	Hospital and SNF	100	107,302.28	143,821.08
Minnesota	Hospital (Neurobehavioral hospital) and SNF (services to support people with brain injury who have significant cognitive and behavioral needs)	2008 (542 Hospital + 1466 SNF)	76,955.02	93,008.02
Mississippi (TBI/SP)	SNF	3600	42,883.10	54,718.10
Nebraska	SNF	40	38,222.48	41,685.61
New York	SNF	3939	53,975.53	72,545.53
Pennsylvania	SNF	729	49,490.38	57,421.38
South Carolina (TBI/SP)	SNF & ICFIDD	1395 (1360 SNF +35 ICFIID)	41,820.70	53,808.70

**States that have TBI services integrated within a waivers with broader levels of care:**

Connecticut ( Acquired Brain Injury Waiver)
Delaware (Under the Medicaid Waiver for the Elderly and Disabled)
Kentucky (Acquired Brain Injury Waiver)
New Hampshire (Acquired Brain Injury Waiver)
New Jersey (Transitioned to Comprehensive Medicaid Waiver)
Utah ( Acquired Brain Injury Waiver)
Wisconsin (Expired transitioned to the Family Care Program)
Wyoming (Acquired Brain Injury)