North Carolina State Action Plan
For
People with Traumatic Brain Injury

Department of Health and Human Services

Division of Mental Health, Developmental

Disabilities and Substance Abuse Services

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Contents

A. Introduction

Acquired Brain Injury (ABI) is an injury to the brain that occurs after birth that can occur suddenly and without warning. A traumatic brain injury (TBI) is one type of ABI. TBI is an injury that disrupts the normal function of the brain. It can be caused by a bump, blow, or jolt to the head or a penetrating head injury.[1] Explosive blasts can also cause TBI, particularly among those who serve in the U.S. military. The number of individuals surviving traumatic brain injury has been rising with advances in trauma care. Many are surviving with more complex and lifelong impairments. There are also a large number of TBI survivors who also have a substance use or behavioral health diagnosis. For example, statistics indicate that a significant number of people with a diagnosis of substance use disorder also have a TBI.[2] With the rise of more survivors of TBI, there is also an increased service need. In addition, individuals that sustained a TBI in the past are now being identified and are seeking services.

Each TBI is unique, as is its impact on an individual's physical, cognitive, behavioral, and social abilities. An injury to the brain can have devastating and lifelong effects. Some are visible, whereas others are not. There can be physical changes including coma, headaches, and seizures. There may be loss of muscle control, balance, weakness, or paralysis. There may even be changes in vision, hearing, smell, and taste. The person's speech and ability to read and write may also be affected. Changes in behavior after a TBI can range from depression, irritability, and impulsiveness to poor judgement, difficulty with problem solving, and even changes in personality. However, some of the most difficult and troubling consequences for individuals and their families are changes in cognition – the ability to think, reason, and learn.

The cause of TBI can be categorized across three levels of severity, mild, moderate, or severe, based on the extent and nature of injury, duration of loss of consciousness, post-traumatic amnesia, and the severity of confusion at initial assessment during the acute phase of the injury.[3] These labels describe the extent of neurological injury to the brain and are not necessarily reflective of the extent of functional deficits or predictive of the recovery from the injury. Service needs for these individuals may span the spectrum of medical, behavioral, cognitive, educational, and vocational services. While the outcome of the injury depends largely on the nature and severity of the injury itself, appropriate treatment is vital in determining the level of recovery. While some individuals may receive intervention in the community, others will require some type of residential setting and/or lifelong assistance.

In 2020, self-inflicted firearm injury was the leading cause of injury (33.1%, N=763) among those who died where TBI was reported as a cause of death on the death certificate alone or in combination with other injuries or conditions, followed by unintentional falls (29.5%, N=681). Unintentional falls were the leading cause of injury (48.8%, N= 3,755) among those who were

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[1] Marr AL, Coronado VG, eds. Central nervous system injury surveillance data submission standards—2002. Atlanta, GA: US Department of Health and Human Services, CDC; 2004.

[2] Ohio Valley Center for Brain Injury Prevention and Rehabilitation. http://www.brainline.org/content/2009/03/substance-abuse-and-traumatic-brain-injury_pageall.html

[3] American Psychiatric Association, DSM-5 Task Force. (2013). Diagnostic and statistical manual of mental disorders: DSM-5™ (5th ed.). Arlington, VA, US: American Psychiatric Publishing, Inc.

hospitalized with a TBI alone or in combination with other injuries or conditions in 2020; unintentional motor vehicle traffic injuries were the second most common cause of injury (28.3%, N=2,191) among TBI hospitalizations. Similarly, unintentional falls and motor vehicle traffic injuries were the leading causes of emergency department visits for TBI alone or in combination with other injuries or conditions (28.7 %, N=6478 and 17.2%, N=3,873, respectively).

The incidence of TBI refers to the number of new cases identified in a specific time period and can be measured by emergency department (ED) visits, hospitalizations, and deaths related to TBI. The prevalence refers to the number of individuals who are living with TBI in a given time period. Every year, at least 1.7 million TBIs occur in the United States (across all age groups), and they are a contributing factor in about a third (30.5%) of all injury-related deaths. Older adolescents (ages 15 to 19 years), older adults (ages 65 years and older), and males across all age groups are most likely to sustain a TBI. [4]

Trends of TBI from 2016 to 2020 varied among deaths, hospitalizations, and ED visits. TBI-related death rates have stated relatively stable over this 5-year time from, increasing by 3% from 21.1 to 21.8 per 100,000 population[5]. Rates of TBI hospitalizations increased by 12% from 65.0 per 100,000 in 2016 to 73.0 per 100,000 in 2020. Alternatively, TBI-related ED visit rates decreased by 21% over the most recent 5 years from 270.7 to 213.0 per 100,000. Although ED visit rates had been decreasing through 2019 (219.0 per 100,000), the additional decrease in TBI-related ED visits observed in 2020 occurred admits and overall decrease in ED utilization; total ED visits for any cause dropped by 18% among NC residents during the pandemic. It is believed that factors, such as automobile safety, seat belt use, helmet use, and better overall treatment for severe TBI in prehospital and hospital settings, while unable to prevent TBIs entirely, have mitigated their severity and thus mortality.

Based on the most recent CDC data:

- Nationally, there were approximately 223,135 TBI-related hospitalizations in 2019* and 64,362 TBI-related deaths in 2020.[1]
    - This represents more than 611 TBI-related hospitalizations and 176 TBI-related deaths per day.
    - These estimates do not include the many TBIs that are only treated in the emergency department, primary care, or urgent care setting, or those that go untreated.

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[4] Faul, M., Xu, L., Wald, M. M., & Coronado, V. G. (2010). Traumatic brain injury in the United States: Emergency department visits, hospitalizations and deaths 2002-2006. Atlanta, GA: Centers for Disease Control and Prevention, National Center for Injury Prevention and Control.

[5] North Carolina State Center for Health Statistics, death certificate data. (2016-2020). Analysis by the NC Injury and Violence Prevention Branch, Epidemiology, Surveillance, and Informatics Unit.

- People ages 75 years and older had the highest numbers and rates of TBI-related hospitalizations* and deaths.[1] This age group accounts for about 32% of TBI-related hospitalizations and 28% of TBI-related deaths.

- Males were nearly two times more likely to be hospitalized (79.9 age-adjusted rate versus 43.7) * and over three times more likely to die[1] from a TBI than females (28.3 versus 8.4 per 100,000).
- Children (birth to 17 years old) experienced 16,070 TBI-related hospitalizations* in 2019 and 2,774 (4.3%) TBI-related deaths[1] in 2020.

This rate was calculated using the weighted number of hospitalizations with a primary diagnosis of injury (ICD-10-CM diagnosis codes S00–S99; T07–T34; T36–T50 with a 6th character of 1, 2, 3, or 4; T36.9, T37.9, T39.9, T41.4, T42.7, T43.9, T45.9, T47.9, or T49.9 with a 5th character of 1, 2, 3, or 4; T51–T76; T79; O9A.2–O9A.5; T84.04; or M97) and an ICD-10-CM diagnosis code for an initial medical encounter of TBI (S02.0. S02.1–, S02.80–S02.82, S02.91, S04.02, S04.03–, S04.04–, S06–, S07.1, T74.4)* in any diagnosis field *and dividing it by the corresponding civilian non-institutionalized population per 100,000.* ***Data source:* Healthcare Cost and Utilization Project's National Inpatient Sample. 2019.

North Carolina's population-wide data on TBIs is limited. Statewide data on TBI-related emergency department (ED) visits were obtained from the North Carolina Disease Event Tracking and Epidemiologic Collection Tool (NCDETECT), an electronic public health surveillance system.[6] TBI surveillance, since 2014, has been affected by the change from ICD9-CM to ICD10-CM coding.

North Carolina Demographic data by TBI Diagnosis who received Behavioral Health Services during State Fiscal Year 2019:

- There was a total of 41,398 individuals with TBI who received behavioral health services. 27,370 (66%) were over 21, 2,400 (5.98%) were between 18 and 21 and 11,628 (28%) were under 18.[7]

- Of the 41,398 individuals with TBI who received behavioral health services, there were approximately 22,066 females at (53%) and 19,332 at (47%) were males.[8]

- Of the 41,398 individuals with TBI who received behavioral health services, there were approximately (1,848) Hispanic/Latino origin at (4.5%), 34,496 at 83% were Non-Hispanic origin and 5,054 unknown ethnicities at (12%).[9]

- North Carolina demographic profile by race is 71% White, 22% Black, and 7% other races.(8) Rates of people with a TBI diagnosis by race who received Behavioral Health

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[6] North Carolina Disease Event Tracking and Epidemiologic Collection Tool, NCDETECT

[7] NC Client Services Data Warehouse, NC Department of Health and Human Services.

[8] Ibid

[9] Ibid

Services were approximately (25,959) at 63% were White, (13,202) at 32% were Black and (1,025) at 2% were other races. [10]

The transformation of our current Medicaid program and the addition of a new TBI Medicaid Waiver are ways in which North Carolina can provide better services and outcomes for individuals living with TBI and their families. Our state will also benefit greatly from emergency department surveillance to monitor the incidence of TBIs for the development of targeted prevention strategies. North Carolina's TBI program and all its stakeholders are committed to making meaningful and progressive change in our state for the benefit of the TBI community.

Some North Carolina children and adults with TBIs are unable to reach optimal physical, cognitive, and psychological functioning following a traumatic brain injury because of smaller provider networks due to lack of funding for, or access to, necessary and appropriate therapeutic services. A misdiagnosis can lead to ineffective medical treatment and a lack of access to treatment and rehabilitative care. As a result of lack of knowledge and misdiagnosis, survivors often do not get referrals to specialized treatment. As such, individuals with TBIs have sometimes been placed in inappropriate institutional settings (i.e., nursing homes, psychiatric in-patient hospitals) or are being sent out of state for residential programs because of the lack of support and appropriate community-based residential services for them in North Carolina.[11]

TBI is an issue for a large number of individuals in the nation and in North Carolina. TBIs are a common cause of emergency department visits in our state.[12] The service system needs to expand to meet the needs of individuals with traumatic brain injuries and their families. For example, the Centers for Medicare and Medicaid Services (CMS) has encouraged states to use more Medicaid funds to keep elderly and physically/mentally disabled beneficiaries at home and in community-based settings as opposed to skilled nursing facilities (SNF), when feasible.

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[10] https://www.osbm.nc.gov/demog/county-projections, North Carolina Office of State Budget and Management.

[11] Ohio Valley Center for Brain Injury Prevention and Rehabilitation. http://www.brainline.org/content/2009/03/substance-abuse-and-traumatic-brain-injury_pageall.html

[12] http://ncdetect.org/fact-sheets/, Carolina Center for Health Informatics, Department of Emergency Medicine, University of North Carolina at Chapel Hill, 2014

B. Goals and Objectives

Below are goals and objectives to assist policy makers and other interested stakeholders in helping to improve access to appropriate specialized services and supports and increase knowledge and awareness about brain injuries among children and adults, their families, and providers.

GOAL 1: DATA COLLECTION

Objective 1. Collect data on the incidence and prevalence of TBI for children under age 5.

Measure/Milestone 1: Establish as baseline of incidence and prevalence by assessing all existing TBI data sources (i.e., service systems and programs) used to identify individuals under age 5 in NC.

Objective 2. Collect data on the incidence and prevalence of TBI for individuals between age 5 and 21.

Measure/Milestone 1: Establish as baseline of incidence and prevalence by assessing all existing TBI data sources (i.e., service systems and programs) used to identify individuals between age 5 and 21 in NC.

Objective 3. Collect data on the incidence and prevalence of TBI for individuals age 22 and older.

Measure/Milestone 1: Establish as baseline of incidence and prevalence by assessing all existing TBI data sources (i.e., service systems and programs) used to identify individuals age 22 and older.

Objective 4: Collect data on usage of state resources for all ages.

Measure/Milestone 1: Identify the individuals with TBIs using existing data sources who are in state developmental centers, state psychiatric hospitals, ADACT's, PRTFs (Psychiatric Residential Treatment Facilities), community ICF's and SNF's.

Measure/Milestone 2: Identify individuals with TBI receiving Medicaid who enter jail or prison systems.

Objective 5: Develop a process to identify individuals with TBIs who are in community settings.

Measure/Milestone 1: Identify the individuals with TBIs using existing data sources who are in community settings.

Medicaid Services
Innovations Waiver
NC TBI Waiver

CAP-DA Waiver
CAP-C Waiver

Medicaid behavioral health services
    (SUD, MH, I/DD)
Future 1915i Waiver services
Standard Plan Care Management
TP Care Management

Measure/Milestone 2: Identify the individuals with TBIs using existing data sources who are in community settings.

Non-Medicaid Services
State Funded Behavioral Health Services
    (SUD, MH, I/DD)
TBI State Funded Services

GOAL 2: COLLABORATION AND DEVELOPMENT

Objective 1: Engage community stakeholders, organizations, and agencies to build broader understanding of brain injury while increasing involvement and opportunities for individuals with lived experience across the state.

Measure/Milestone 1: Streamline current TBI screening efforts to establish a baseline of potential incidence versus total number screened in each LME-MCO graphic area.

Measure/Milestone 2: Explore the integration of TBI screening with standard plans.

Measure/Milestone 3: Maintain TBI screening with tailored plans.

Measure/Milestone 4: Maintain ABI screening at DV pilot(s).

Measure/Milestone 5: Explore the integration of ABI screening with the criminal justice system and homeless population.

Measure/Milestone 6: Identify stakeholders and agencies with seats on the Advisory Council to collaborate with the council to identify brain injury needs and opportunities within their organization or agency.

Measure/Milestone 7: Identify other stakeholders and agencies for collaboration with the council to identify brain injury needs and opportunities within their organization or agency.

Objective 2: Promote active participation among Brain Injury Advisory Council (BIAC) members.

Measure/Milestone 1: Create an orientation and refresher curriculum to promote consistent awareness of the roles and responsibilities of each Council member

Measure/Milestone 2: Develop and conduct a survey within each organization represented on the BIAC to determine level of awareness and organization specific needs.

Measure/Milestone 3: Develop meaningful relationships between Council members and within their represented organizations.

Measure/Milestone 4: Maximize Council member involvement in standing and other ad hoc committees.

Objective 3: Facilitate and initiate brain injury education and training development across the state.

Measure/Milestone 1: Collaborate with provider agencies and organizations in regards to determining brain injury training and education needs.

Measure/Milestone 2: Identify available in-person or online training opportunities related to brain injury throughout the state including but not limited to events, conferences, and webinars.

Measure/Milestone 3: Disseminate current and new training and educational information from sources in state and across the country.

Measure/Milestone 4: Facilitate training and educational opportunities regarding brain injury across the state.

GOAL 3: RESOURCE ACCESS AND ENGAGEMENT

Objective 1. Establish opportunities for advocacy to allow for recommendations related to public policy and legislation.

Measure/Milestone 1: Utilize the results of the needs and resources assessment to identify gaps & needs within the NC service system for individuals living with brain injury to potential barriers, including but not limited to accessing benefits and services, long-term supports, residential options, employment, transportation, care coordination and disparities for historically marginalized populations.

Measure/Milestone 2**:** Identify recurring funding opportunities for individuals living with brain injury to help the brain injury service infrastructure and sustain the continuum of brain injury care.

Objective 2. Facilitate continued education, awareness, participation and collaboration in community-supports for individuals living with brain injury.

Measure/Milestone 1: Explore gaps & needs identified in the pilot of the TBI waiver with input from statewide stakeholders.

Measure/Milestone 2: Explore gaps & needs identified within the Medicaid Managed Care system with input from statewide stakeholders.

Measure/Milestone 3: Increase Council education and awareness regarding service system changes and updates.

Measure/Milestone 4: Expand public awareness of BI.

GOAL 4: PREVENTION

Objective 1. Enhance public awareness for targeted brain injury prevention efforts statewide.

Measure/Milestone 1: Determine highest incidence of brain injury based on existing data.

Measure/Milestone 2: Determine best and promising practices for brain injury prevention efforts based upon highest incidence.

Measure/Milestone 3: Identify potential collaborators for brain injury prevention efforts statewide.

Measure/Milestone 4: Implement best and promising practice strategies with collaborators.

C. TBI Program

C.1. DMH/DD/SAS AS COMMITTED LEAD AGENCY FOR TBI SERVICES.

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS) has been the Lead Agency for TBI since 1996 and has had designated TBI funding since 1993. The DMH/DD/SAS oversees a state system of services and supports designed to assist people with mental illness, intellectual and developmental disabilities, traumatic brain injury and substance use disorders in living full lives of their own choosing. The DMH/DD/SAS, has a dedicated TBI Team with staff who coordinate the direction and support for TBI in the state, including the administration of the TBI state funds program, federal TBI Grant, collaboration with other state agencies, participation in the Brain Injury Advisory Council (BIAC) by providing staff support as well as facilitation of training, education, screening, and data collection initiatives statewide. These initiatives are achieved through collaborative partnerships with both internal and external stakeholders.

The TBI state funds program provides services and supports to individuals with TBI through the six Local Management Entities – Managed Care Organizations (LME-MCO’s) statewide. Lead Agency TBI program staff work with the LME-MCO’s to ensure appropriate expenditures and to ensure that resources are maximized to the fullest extent possible. This is accomplished through monthly phone calls as well as quarterly and annual reports that are reviewed and used in strategic planning and program development. Lead Agency TBI program staff meet regularly with providers of TBI services, other state agencies, the BIAC, and with the Brain Injury Association of North Carolina (BIANC).

State funding also supports two TBI prevention and treatment pilot initiatives.

- The Student Athlete Concussion and Traumatic brain injury prevention and care-to provide concussion education, baseline testing, and post-concussion assessment and care to schools and adolescent athletes in eastern North Carolina in a concussion clinic.

- The Adult and Pediatric Pilot- to address the issue of low compliance, poorer medical outcomes, and unnecessary high medical cost. The software solution is, web based, interactive, real-time, decision and support tool that takes the latest approved TBI treatment guidelines and places them into a 90 second tool for clinicians.

The TBI State Partnership Grant Program (TBI SPP) is administered by the federal Administration for Community Living (ACL). The TBI SPP provides grant funding opportunities to help states increase access to services and supports for individuals with TBI throughout their lifetime. More information about ACL, the Grant and related TBI Act federal legislation can be found at: https://acl.gov/programs/post-injury-support/traumatic-brain-injury-tbi.

The federal TBI Grant awarded to NC by the ACL is administered by the DMH/DD/SAS. Through the grant, the NC TBI program addresses four barriers to needed services including 1) Screening to identify individuals with TBI; 2) Building a trained TBI workforce by providing professional training; 3) Providing information about TBI to families and referrals to appropriate service providers; and 4) Facilitating access to needed services through resource facilitation. In addition to these four primary focus areas, the TBI program also maintains or works to develop the following:

- a statewide TBI advisory council charged with advising and making recommendations on ways to improve the continuum of care for individuals with TBI and their families;
- a lead state agency for TBI responsible for coordination of state TBI activities;
- a statewide assessment of TBI needs and resources completed or updated within the last 5 years;
- a statewide TBI action plan that is updated annually and that provides a comprehensive, community-based system of care that encompasses physical, psychological, educational, vocational, and social aspects of TBI services, data initiatives and addresses the needs of individuals with TBI and their families;
- a TBI registry or some other formal mechanism for tracking individuals with TBI and linking them to needed services and supports.

In addition to these initiatives, NC is a grantee partner state that participates in two national workgroups whose goals are to increase the awareness and competency of professionals in the field of TBI. The workgroups focus include transition and employment and opioid use and mental health needs.

The DMH/DD/SAS collaborates on the development of a systems approach to the coordination of the state's systems of services and supports for individuals with TBI and their families. Some of these collaborations include work with the various state entities and community stakeholders. For example, collaboration with NC Medicaid for implementation and development of the pilot TBI Waiver.

The DMH/DD/SAS is a member of the National Association of State Head Injury Administrators (NASHIA) and interfaces with Disability Rights North Carolina (DRNC), the state's federally mandated protection and advocacy system. The DMH/DD/SAS also participates in the development of TBI resources/products and helps to facilitate their dissemination. Contract agencies develop materials at the DMH/DD/SAS's direction. One example is a website that hosts a variety of online training modules developed by BIANC (accessible at: https://www.biancteach.net/). The DMH/DD/SAS also maintains a TBI specific web page accessible at: http://www.ncdhhs.gov/mhdds as/tbi/index.htm).

Through its contracts, DMH/DD/SAS helps assure:

- An ongoing public awareness campaign regarding the causes and consequences of brain injury;
- Information, referral, and support (including Resource Facilitation) for people with brain injury, families and professionals statewide;
- Development and maintenance of an online TBI Resource Manual
- A strong network of approximately 30 support groups that are available and accessible statewide to meet the needs of people with brain injury and their families;
- Education and training;
- Development and maintenance of online training modules for a variety of partners including medical professionals, first responders, therapists, direct care workforce, families and others;
- Development and implementation of a comprehensive training program based on best practices in traumatic brain injury for providers, professionals, and caregivers; and
- Ensure TBI related best practices are being utilized to increase levels of compliance with TBI treatment guidelines have been independently shown to reduce patient mortality, improve patient level of recovery, and reduce long-term care costs, often paid for through state Medicaid and State funds.

C.2. NORTH CAROLINA BRAIN INJURY ADVISORY COUNCIL

The North Carolina Brain Injury Advisory Council (BIAC) was created by statute in 2003 (General Statute 143B-216.65-66).

The BIAC addresses strategic planning, public policy, and services related to the prevention, rehabilitation, and provision of long-term services and supports for individuals who have sustained brain injuries and their families. The BIAC strives to make it possible for individuals who have survived a brain injury to achieve and maintain the highest level of independence possible in their home and community. To achieve this goal, the BIAC seeks input and collaboration from brain injury survivors, family members, caregivers, community professionals, representatives of appropriate state agencies and other stakeholders.

BIAC members are appointed by the Speaker of the House, the President Pro Tempore of the Senate, the Secretary of the Department of Military and Veterans Affairs, the Governor, the Secretary of the Department of Health and Human Services, the Superintendent of the

Department of Public Instruction, and the Commissioner of Insurance. Terms of appointments are for four years. Council members can be reappointed for a second term. The BIAC is comprised of consumers (i.e., survivors of brain injury, family members, caregivers, and representatives of survivors), licensed healthcare professionals, service providers, individuals not affiliated with any brain injury program, state agency representatives, and relevant subject matter experts. BIAC meetings are open to the public and non-Council member can serve on committees to support the BIAC in reaching its goals.

The primary goals of the BIAC include making recommendations to the Governor, the General Assembly, and the Secretary of the Department of Health and Human Services regarding state - wide efforts promoting prevention of future brain injuries, development, and implementation of a comprehensive statewide service delivery system for those individuals having experienced brain injuries; providing oversight in acquiring and utilizing state and federal funding dedicated to services for individuals with brain injury; and improving the coordination of services. The BIAC also identifies service gaps throughout the state, facilitates collaboration among State agencies, organizations, and other entities that provide services to individuals with brain injury and facilitates community participation in program implementation.

The Council consist of four committees including Public Policy, Prevention, Children and Youth, and Service Delivery System. Council meetings are held quarterly and are open to the public.

D. Additional TBI Resources

D.1. BRAIN INJURY ASSOCIATION OF NORTH CAROLINA (BIANC)

BIANC was established in 1982 by family members of individuals with a brain injury and interested professionals. Since then, BIANC has expanded its centrally-operated brain injury support network to a statewide network of five regional resource centers to carry out its mission. BIANC is a 501(c)3 nonprofit organization that strives to offer help, hope and a voice for individuals living with a brain injury and their families. The five resource centers are located in Raleigh, Greenville, Winston-Salem, Charlotte and Asheville enabling it to reach all 100 counties in the state.

BIANC's mission is to offer help, hope, and a voice for people with a brain injury and their families. Education, support, prevention, and advocacy are the pillars that support this mission. BIANC offers resource facilitation, an online resource guide, assistance to over 30 support groups across the state, a website with educational and resource links (www.bianc.net), online and in person trainings, annual conferences, social media, community and statewide events and publishes a quarterly news magazine, Starting Point.

Collaboration with community groups is essential in addressing topics such as advocacy, awareness and education. BIANC representatives participate in statewide groups and committees to assist with identifying current strengths and gaps in the service system, as well as areas for future program development and expansion. BIANC works closely with Alliance Health Care on the implementation of the TBI Waiver, the Brain Injury Advisory Council

(BIAC), and DMH/DD/SAS to name a few, providing updates and disseminating educational materials in the community.

Each year BIANC's endeavors expand its outreach increasing brain injury awareness for groups vulnerable to TBI (i.e. Military, the homeless, athletes, substance misuse etc.) in the general population to help remove any stigma about brain injury. Many individuals living with brain injury and their families have difficulty navigating the brain injury service system and therefore, they struggle with isolation due to lack of support and knowledge. BIANC strives to provide the support and knowledge - being the bridge to connect individuals to services and also to promote advocacy and involvement in communities across North Carolina.

D.2. DEPARTMENT OF PUBLIC INSTRUCTION (DPI)

The North Carolina Department of Public Instruction, Exceptional Children Division (NC DPI, EC Division) is responsible for programs that address the wide range of learning needs of children up to age 22 in special education programs. After the U.S. Department of Education established the classification of Traumatic Brain Injury (TBI) as a category for special education services in 1990, NC developed an initiative to provide additional training to school psychologists about conducting evaluations of students suspected of requiring special education due to a TBI. A formal training program was developed and includes a didactic component as well as 30 hours of direct supervision with a pediatric neuropsychologist to support best practices in evaluation and identification. As a result, NC has a cadre of school psychologists across the state for building capacity within local schools to identify and address the needs of these students. One hundred seventy-four (174) school psychologists and private psychologists with this specialized training are on the TBI Registry of Approved Providers maintained by the Exceptional Children Division of the NC DPI. One hundred fifty-four (154) of those on the Registry are currently employed within NC public schools.

DPI continues to examine ways to best meet the needs of students who have sustained brain injury. In 2013, the NC DPI EC Division, in collaboration with the Children and Youth Committee of the BIAC, facilitated the development of a revised special education definition of TBI to include all children with various brain injuries (published in Policies Governing Services for Children with Disabilities in October 2013). Most recently, DPI has been involved in developing a concussion monitoring policy (SHLT-001), which was approved by the State Board of Education in October 2015, with implementation required of all public schools by 2016-2017 school year. The BIAC has placed a request with the DPI to conduct an analysis of TBI data on school age children. As a result, the Consultant for Psychological Services with NC DPI Exceptional Children Division provides quarterly updates to the BIAC on special education trend data specific to the Individuals with Disabilities Education Act (IDEA) classification of TBI. Additionally, concussion specific data is now accessible for school age children and shows significant increases in identification and monitoring since the initial implementation of SHLT-001 in July 2016. These two sources are provided to assist the BIAC in examining differences in incidence and educational reporting for this population. DPI is a critical partner and stakeholder in improving the services and infrastructure for students with brain injury in NC.

The child count data from public school units in NC indicate that in April of 2021, 976 children and youth were reported as eligible for special education under the category TBI. This number continues to reflect an increase in identification since the definition change was published in October 2013.

DPI maintains a close working relationship with the Carolina Institute for Developmental Disabilities (CIDD) at the University of North Carolina at Chapel Hill. The DPI has supported the development and maintenance of a statewide, online curriculum that is housed through the CIDD, and serves as the initial training component for school psychologists seeking the additional TBI training. This online training is also offered to the public at no charge. The program equates to approximately 15 hours of self-paced training and includes an assessment component for each subsection. The training covers the following topics through four online modules, which were all updated in 2019: (1) mechanisms, characteristics and issues of TBI, (2) advanced assessment techniques, (3) treatment issues and techniques (4) concussion.

D.3. DISABILITY RIGHTS NORTH CAROLINA (DRNC)

DRNC is North Carolina's designated Protection & Advocacy organization, dedicated to advancing the legal and service rights of people with disabilities, including people with TBI. DRNC utilizes a range of advocacy strategies to achieve its mission, including information and referral, individual and systemic legal representation, monitoring and investigation, outreach and education, coalition and policy work, technical assistance and support for self-advocacy. DRNC develops its priorities in consultation with their constituency, people with all types of disabilities, of all ages, throughout North Carolina.

The Protection and Advocacy for Traumatic Brain Injury (PATBI) grant allows DRNC to provide legal assistance to people with TBI, to ensure they are provided appropriate services and supports to live in the least restrictive setting possible, and for children with TBI to receive a free and appropriate public education. DRNC performs this work irrespective of the age of the beneficiary when they received a TBI. DRNC is a member of the BIAC and actively works with the BIAC and others to assure consistent, dedicated funding for persons with TBI in NC.

D.4. DIVISION OF HEALTH BENEFITS (NORTH CAROLINA MEDICAID)

NC Medicaid (Division of Health Benefits or DHB) manages the state's Medicaid and Health Choice programs. NC Medicaid funds cost effective health services, including the Children's Health Insurance Program, four home and community-based waiver programs, and a wide range of medical and rehabilitation services. Behavioral Health services are provided through enrolled providers and a system of Managed Care Organizations (MCOs). Individuals with Traumatic Brain Injury often access services through:

- NC Innovations Waiver: The NC Innovations Waiver helps individuals with Intellectual and Developmental Disabilities (I/DD) live more independently in their community. Individuals who sustained a brain injury before age 22 who meet IDD ICF level of Care may be eligible for this Medicaid Waiver

- NC TBI Waiver: The NC TBI Waiver serves adults who sustained their traumatic brain injury on or after their 18th birthday.
- CAP-DA: The CAP/DA Program allows elderly and disabled adults, ages 18 and up to receive support services in their own home, as an alternative to nursing home placement.
- CAP-C: The CAP/C Program provides services for medically fragile children under age 21 who are at risk of institutional care.
- Medicaid Personal Care Services.
- Medicaid Behavioral Health Services
- Medicaid Substance Use Services
- Medicaid I/DD Services
- Physical Therapy/Occupational Therapy/Speech and Language Therapy.
- Medicaid 1915(i) Services (anticipated to launch with Tailored Plans 4/1/23)

The NC TBI Waiver serves adults who sustained their traumatic brain injury on or after their 18th birthday. This pilot waiver is managed by Alliance Health and is currently available in the counties they serve. Individuals with a TBI may be eligible to participate in this program if they need specialty hospital care or skilled nursing level of care and are Medicaid eligible. The services are provided in the individuals’ own home and community, or in a group living setting – offering choice and promoting independence.

1915(i) Medicaid services will be available with the launch of Tailored Plans (anticipated launch date Apr. 1, 2023). Services will be available to children and adults with TBI service needs. This marks an exciting milestone that adults with TBI are included in 1915(i) service eligibility. 1915(i) services will include Community Living and Supports; Supported Employment; Respite (if the beneficiary lives with a primary caregiver); and Community Transition.

D.5. DIVISION OF HEALTH SERVICES REGULATION (DHSR)

The DHSR is the licensing and regulatory agency for medical, mental health, and group care facilities, emergency medical services, and local jails across the state. In collaboration with the other involved agencies, the DHSR: promotes mutual outreach efforts between DHSR and DMH/DD/SAS to ensure provider accountability for licensure rules through regular meetings between the divisions; participates in rules review, promulgation, and implementation with DMH/DD/SAS to ensure all consumer needs for safety and treatment are met; analyzes internal compliance data to monitor services to persons with TBI to assure licensed services are provided in compliance with rule; expands provider training to include statewide sessions focused on establishing and maintaining client-focused compliance; and completes annual surveys of all residential treatment facilities in North Carolina.

One section of DHSR is the Office of Emergency Medical Services (OEMS) which ensures that all citizens have access to quality emergency medical care by providing technical assistance, services, and regulatory oversight to all local EMS systems in North Carolina. The office also has oversight of the Trauma System in North Carolina, which includes serving as the designating body for Trauma Centers in the state.

OEMS has opportunities in the following areas to support TBI in our state. These areas are:

1. Support the funding of the NC state trauma system in recognition of its importance to the reduction of morbidity and mortality associated with TBI. Support efforts to determine the financial impact of TBI on the state trauma system.
2. Query the Pre-hospital Medical Information System (PreMIS) to identify patients at risk for TBI to determine injury and residence, county, and disposition of patients to trauma centers versus non-trauma centers. Map incidence by injury and county of residence.
3. Establish an injury prevention coordinator in the Division of Public Health's Injury Prevention Branch to work with the eight trauma Regional Advisory Committees on prevention activities to reduce the morbidity and mortality related to brain injury. This person could then work with the BIAC and on falls prevention, motor vehicle crashes, and other areas that present risks for brain injuries.

DHSR has other areas of interest that pertain to TBI:

1. Licensing: DHSR will assist the BIAC in exploring licensing issues that create challenges for TBI programs, with a goal of ensuring appropriate licensing categories for a comprehensive continuum of residential services for people with TBI.
2. Training: DHSR recognizes the need to expand expertise for survey staff that regulate licensed facilities serving people with TBI. The agency will continue to develop training opportunities for surveyors with emphasis on identifying the needs of persons served in licensed mental health, developmental disabilities, adult care, and long-term care facilities in North Carolina, including those consumers with TBI.
3. Collaboration:
    1. DHSR will promote mutual outreach efforts between DHSR and DMH/DD/SAS to ensure provider accountability for licensure rules through regular meetings between our divisions.
    2. DHSR will participate in rules review, promulgation, and implementation with DMH/DD/SAS to ensure all consumers' needs for safety and treatment are met.
    3. DHSR's O EMS will continue to educate and collaborate with agencies regarding TBI in the trauma system.
4. Services:
    1. DHSR will analyze internal compliance data to monitor services to persons with TBI and other disabilities to assure licensed services are provided in compliance with rule.
    2. DHSR will expand provider training to include statewide sessions focused on establishing and maintaining client focused compliance.

DHSR will continue to focus on the completion of annual surveys of all residential treatment facilities in North Carolina.

D.6. DIVISION OF PUBLIC HEALTH (DPH)

The North Carolina Department of Public Instruction, Exceptional Children Division (NC DPI, EC Division) is responsible for programs that address the wide range of learning needs of children up to age 22 in special education programs. After the U.S. Department of Education established the classification of Traumatic Brain Injury (TBI) as a category for special education services in 1990, NC developed an initiative to provide additional training to school psychologists about conducting evaluations of students suspected of requiring special education due to a TBI. A formal training program was developed and includes a didactic component as well as 30 hours of direct supervision with a pediatric neuropsychologist to support best practices in evaluation and identification. As a result, NC has a cadre of school psychologists across the state for building capacity within local schools to identify and address the needs of these students. One hundred seventy-four (174) school psychologists and private psychologists with this specialized training are on the TBI Registry of Approved Providers maintained by the Exceptional Children Division of the NC DPI. One hundred fifty-four (154) of those on the Registry are currently employed within NC public schools.

DPI continues to examine ways to best meet the needs of students who have sustained brain injury. In 2013, the NC DPI EC Division, in collaboration with the Children and Youth Committee of the BIAC, facilitated the development of a revised special education definition of TBI to include all children with various brain injuries (published in Policies Governing Services for Children with Disabilities in October 2013). Most recently, DPI has been involved in developing a concussion monitoring policy (SHLT-001), which was approved by the State Board of Education in October 2015, with implementation required of all public schools by 2016-2017 school year. The BIAC has placed a request with the DPI to conduct an analysis of TBI data on school age children. As a result, the Consultant for Psychological Services with NC DPI Exceptional Children Division provides quarterly updates to the BIAC on special education trend data specific to the Individuals with Disabilities Education Act (IDEA) classification of TBI. Additionally, concussion specific data is now accessible for school age children and shows significant increases in identification and monitoring since the initial implementation of SHLT-001 in July 2016. These two sources are provided to assist the BIAC in examining differences in incidence and educational reporting for this population. DPI is a critical partner and stakeholder in improving the services and infrastructure for students with brain injury in NC.

The child count data from public school units in NC indicate that in April of 2021, 976 children and youth were reported as eligible for special education under the category TBI. This number continues to reflect an increase in identification since the definition change was published in October 2013.

DPI maintains a close working relationship with the Carolina Institute for Developmental Disabilities (CIDD) at the University of North Carolina at Chapel Hill. The DPI has supported the development and maintenance of a statewide, online curriculum that is housed through the CIDD, and serves as the initial training component for school psychologists seeking the additional TBI training. This online training is also offered to the public at no charge. The program equates to approximately 15 hours of self-paced training and includes an assessment component for each subsection. The training covers the following topics through four online modules, which were all updated in 2019: (1) mechanisms, characteristics and issues of TBI, (2) advanced assessment techniques, (3) treatment issues and techniques (4) concussion.

D.7. DIVISION OF VOCATIONAL REHABILITATION SERVICES (DVRS)

The Division of Vocational Rehabilitation Services (DVRS) assists individuals with disabilities, including TBI survivors, to obtain and maintain employment. In addition, the Independent Living (IL) section of the DVRS assists persons with disabilities to reach the highest possible level of independent functioning in the community as an alternative to living in a nursing home or other facility. The DVRS currently contracts with programs that offer employment-related services, such as cognitive rehabilitation, career exploration and development, and intensive job supports to TBI survivors. Such specialized services are available at four locations across the state as of 2016: Charlotte, Winston-Salem, Raleigh, and Greenville.

These specialized programs provide participants education on the nature of brain injury, instruction on developing compensatory strategies related to concentration and memory, group counseling, social skills and communication training, loan of adaptive equipment, consultation to families, vocational counseling, career exploration activities, job seeking skills training, and guidance about utilizing community resources.

Standard DVRS services are available across the state to individuals with TBI and other neurocognitive impairments. In addition, one vocational rehabilitation (VR) counselor position (in Raleigh) and one IL counselor position (in Greenville) are dedicated to serving individuals with TBI. The DVRS is represented on the BIAC.

D.8. VETERANS

The US Department of Defense data showed North Carolina had the fifth largest military presence in the nation, with more than 100,000 active-duty, and over 43,000 National Guard and Reserve members, as of May 17, 2021. Per the Veterans Administration, 698,000 Veterans live in North Carolina, as of September 30,2020, which is approximately eight percent of the state’s population.

The North Carolina Department of Military and Veterans Affairs (DMVA) is the primary Point of Contact in North Carolina to assist all military service members, Veterans, and their families to meet their needs. This includes a wide range of partnerships. These programs include:

- **DMVA Resource Guide**; over 200 pages of resources for Veterans, Servicemembers and their families. https://files.nc.gov/ncdmva/documents/files/dmva-guide-2019a.pdf
- **NCMAC**: NC Military Affairs Commission works to make North Carolina the most military friendly state in the nation.
- **NCVAC**: North Carolina Veterans Affairs Commission advises the Secretary of Military and Veterans Affairs on matters relating to veterans in North Carolina by reviewing the veteran benefits provided by North Carolina, including state veterans’ cemeteries, nursing homes and scholarships.
- **NCVAC Advisory Committee consists of the leadership of the Congressionally Chartered Veteran Service Organizations with state offices**

The North Carolina Department of Health and Human Services (DHHS) provides treatment options for active duty service members, veterans, and families, which includes those with PTSD or other mental health issues and substance use disorders via the LME/MCO system, and the Division of State-Operated Healthcare Facilities (DSOHF), as well as a partnership with the Steven A Cohen Military Families Clinic at Cape Fear Valley. The DMH/DD/SAS, as noted elsewhere is also the lead agency for TBI in the state. Supportive employment programming and chronically homeless veterans outreach teams further engage Veterans with TBIs.

- **NCServes**: NC's first coordinated network of public, private, and non-profit organizations working together to serve veterans and their families via web-based care coordination. Serving all 100 counties through the Central, Coastal and Western Carolina coordination centers. There are now four (4) NCSERVES regions in NC (Western, Metroland, Central, Eastern). They are also a division of Asheville Buncombe County Christian Ministry with the following mission statement: Veterans Services of the Carolinas is a division of Asheville Buncombe Community Christian Ministry. Our mission is to assist our nation's Veterans and their families by identifying needs and connecting them to community partners across North Carolina. https://nccare360.org/ncserves/

- **Governors Working Group on Veterans, Service Members and their Families**: https://ncgwg.org/ The North Carolina Governor's Working Group [NCGWG] facilitates collaboration and coordination among ALL Federal, state and local agency partners that touch a veteran's life in the state of North Carolina. Monthly meetings, broadcast via social media has over 5,000 views a month.

Some veterans choose not to receive care from the Veterans Administration (VA). In 2018, only 33% of North Carolina Veterans were receiving Veterans Health Administration (VHA) benefits. We are unable to determine the number who seek treatment outside the VA. There are more veterans who may not receive services due to homelessness, incarceration, or distance from a VA facility or are ineligible due to other circumstances. Since 9/11, nearly 20,000 individuals from North Carolina have received Other - Than - Honorable (OTH) discharges for MH/BH reasons, rendering them ineligible for virtually all VA services. These individuals routinely suffer from TBI, PTSD, MST and other Behavioral Health issues. The account for over 12% of Veteran Suicides and makes up a high percentage of Homeless Veterans.

For Veterans in the Veterans Health Administration (VHA) system suffering from TBI, Intrepid Spirit Centers at Camp Lejeune (https://dvbic.dcoe.mil/location/camp-lejeune-nc), and Ft. Bragg (https://dvbic.dcoe.mil/location/fort-bragg-nc) may be able to provide services.

Currently, the VA's Polytrauma System of Care includes four Polytrauma Rehabilitation Centers and 21 Polytrauma Network Sites. None of these are located in North Carolina, the closest being in Richmond, VA. Plans to add Polytrauma Support Clinics, which will provide only outpatient care and post-release follow-up, have been delayed.

D.9. OTHERS

Other critical partners include public and private providers of community-based residential services, vocational and educational services, case management, psychological, neurological and behavioral services and supports, respite care, and recreational/social programs.

E. Needs Assessment

E.1. METHODS FOR CONDUCTING NEEDS AND RESOURCES ASSESSMENT

For the first time, in fiscal year 2017-2018 traumatic brain injury related questions were included in the annual Gaps and Needs assessment conducted by all LME-MCO's statewide for individuals within their service system. These assessments provide DHHS with information about the current service system gaps and needs of individuals with TBI, their families and caregivers, as well as professionals/providers statewide.

The Brain Injury Association of NC (BIANC) conducts a bi-annual gaps and needs assessment which emphasizes assessing the gaps and needs of individuals who do not receive publicly funded services to the greatest extent possible. The overall goal is to get a broad understanding of the needs and gaps of individuals across the spectrum to include publicly funded, privately funded and unfunded individuals living with TBI statewide, their families, caregivers, and professionals. The combined results from the most recent surveys are found below.

E.2. COMMON GAPS

E.2.1. COMMON GAPS IDENTIFIED BY TBI SURVIVORS, FAMILY/CAREGIVERS, AND SERVICE PROVIDERS

1. Service access/assessment of need for non-Medicaid and Medicaid beneficiaries
2. Appropriate services/long-term support/community-based services
3. Funding for services
4. Education/awareness of TBI
5. Transportation
6. Employment opportunities
7. Housing
8. Difficulty with navigating through system
9. Behavioral health training for service providers
10. Lack of specialized services
11. Substance use disorder
12. Limited methods in tracking/collecting data
13. Case management resources

Individuals with TBI, their families and caregivers, as well as professionals/providers indicated a need to improve statewide services in the areas of service delivery and improved funding options for service access. Utilizing this information provided at state and local levels is critical for developing and maintaining effective, viable service systems that balance the current and future needs with capacity and resources.

E.3. ANALYSIS OF ASSESSMENT PROCESS

E.3.1. STRENGTHS

1. TBI is officially included in the annual Needs and Gaps assessment process within each LME-MCO statewide.
2. Needs and gaps for TBI are more prominently highlighted and documented in the statewide service system.
3. Individuals with TBI and their families have a formal mechanism to report challenges and concerns in a consistent, uniform manner.

E.3.2. CHALLENGES

1. LME-MCO's did not ask all suggested questions submitted for consideration to use with the TBI population assessment process although the same focus/topic areas were included within all LME-MCO assessments.
2. Some response categories were not consistent between all LME-MCO's making it challenging to compare some results.
3. Individuals with TBI in the TBI state funds program were the primary focus of the survey. This reduced the ability to capture response information from TBI survivors receiving services in other programs administered by the LME-MCO's that are not TBI specific.
4. Does not capture needs and gaps information from individuals that do not access services through an LME-MCO.

F. Conclusion

The implementation of the TBI State Action plan helps to support the goal of prevention, increasing public awareness, and an expansion of services and supports for survivors and their families. This State Plan provides the foundation for the State of North Carolina, BIANC and other stakeholders to expand and coordinate services and increase education and prevention efforts.