

**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

2017

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A. Introduction

The number of individuals surviving traumatic brain injury (TBI) has been rising with advances in trauma care. Many are surviving with more complex and lifelong impairments or disabilities. There is also a large number of individuals with dual diagnoses. For example, statistics indicate that a significant number of people with a diagnosis of substance use disorder also have a TBI¹. Not only are there more survivors, but also newly identified needs for services are increasing. In addition, through advances in science, individuals that sustained a TBI in the past are now being identified.

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.

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 role in determining the level of recovery.

The Centers for Disease Control and Prevention (CDC) report that TBI contributes to a substantial number of deaths and cases of permanent disability annually. According to the CDC, each year an estimated 1.7 million people nationwide sustain a TBI. Of those individuals, 52,000 die from their injuries, 275,000 are hospitalized, and 1.365 million, nearly 80 percent, are treated and released from an emergency department². In 2012 in North Carolina, there were a reported 1,871 deaths related to brain injury, 6,249 hospitalizations, 68,588 emergency department admissions, and an unknown number of outpatient or medically unattended TBIs³.

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 system⁴. In 2010-2011 there were 140,234 TBI-related ED visits in North Carolina, which yields a rate of 7.3 visits per 1,000 individuals.

¹ http://www.brainline.org/content/2009/03/substance-abuse-and-traumatic-brain-injury_pageall.html

² http://www.cdc.gov/traumaticbraininjury/pdf/BlueBook_factsheet-a.pdf

³ <http://www.ncmedicaljournal.com/content/76/2/84.full>

⁴ <http://www.ncmedicaljournal.com/content/75/1/8.short>

The following chart provides some detail for the 2010-2011 data:

Category	Rate
Men	7.9 visits per 1,000
Women	6.8 visits per 1,000
Aged 0-4	13.1 visits per 1,000
Aged 15-19	10.6 visits per 1,000
Aged 75-79	11.3 visits per 1,000
Aged 80-84	17.9 visits per 1,000
Aged 85 and older	30.6 visits per 1,000

TBI-related ED visits were principally the result of falls (39.0%), being struck by a person or object (17.6%), or motor vehicle-traffic related crashes (14.1%)⁵. The average length of stay for a TBI-related hospitalization was 7.5 days per admission, but the average cost of admission per day rose from \$3,805.00 in 2003 to \$4861.60 in 2006. The total cost for TBI-related hospitalizations in 2006 was \$535,686,944.00.

According to the CDC, falls are the leading cause of TBI and recent data shows that the number of fall-related TBIs among children aged 0-4 years and in adults aged 75 years or older is increasing. Among all age groups, motor vehicle crashes and traffic-related incidents result in the largest percentage of TBI-related deaths (31.8%). Adults aged 65 years old and older have the highest rates of TBI-related hospitalizations and death. Shaken Baby Syndrome (SBS), a form of abusive head trauma (AHT) and inflicted traumatic brain injury (ITBI), is a leading cause of child maltreatment deaths in the United States⁶.

TBI in North Carolina is defined as a developmental disability by statute NCGS §122C-3(12a) as follows:

"Developmental disability" means a severe, chronic disability of a person which:

- a. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- b. Is manifested before the person attains age 22, **unless the disability is caused by a traumatic head injury and is manifested after age 22;**
- c. Is likely to continue indefinitely;
- d. Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, capacity for independent living, learning, mobility, self-direction and economic self-sufficiency; and
- e. Reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of a lifelong or extended duration and are individually planned and coordinated; or
- f. When applied to children from birth through four years of age, may be evidenced as a developmental delay.

⁵ <http://www.ncmedicaljournal.com/content/75/1/8.short>

⁶ http://www.cdc.gov/traumaticbraininjury/get_the_facts.html

The Brain Injury Advisory Council (BIAC) and stakeholders will be advocating for a more accurate, comprehensive definition of TBI for adults above the age of 22. They will be requesting that the following definition of TBI for adults be formally adopted by the General Assembly in statute:

“Traumatic brain injury (TBI) means an insult to the brain from an outside physical force that may or may not have produced a diminished or altered state of consciousness. The term applies to open or closed head injuries resulting in an impairment of cognitive ability and/or physical functions but not necessarily both. Impairments in one or more areas including but not limited to: cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory; perceptual, and motor abilities; psychosocial behavior, physical function, information process and speech. Impairments may be either temporary or permanent and may cause partial or total functional disability and/or psychosocial disorientation.”

TBI is an issue for a growing number of individuals in the nation and in North Carolina. TBIs are a common cause of emergency department visits in our state⁷. 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.

According to the Kaiser Family Foundation, in 2015, the median cost for one year of home health aide services was less than \$46,000 compared to the median annual cost for a nursing facility at \$91,250⁸. The expansion of our current Medicaid program is only one way 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 prevention strategies. North Carolina’s TBI program and all of its stakeholders are committed to making meaningful and progressive change in our state for the benefit of the TBI community.

B. Goals and Objectives

Many North Carolina children and adults with TBIs are unable to reach optimal physical, cognitive, and psychological functioning following a traumatic brain injury because of the lack of funding for or access to necessary and appropriate therapeutic services. People with brain injuries are often misdiagnosed, lack proper medical treatment, rehabilitative care and habilitative supports, or do not get referrals to appropriate, specialized services because of a lack of knowledge of TBI among medical and rehabilitation personnel. As such, individuals with TBIs have historically 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.

⁷ <http://ncdetect.org/fact-sheets/>

⁸ <http://www.modernhealthcare.com/article/20160803/news/160809955?template=print>

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 TO SUPPORT PLANNING EFFORTS

Develop a systematic data collection process with stakeholder input to demonstrate the incidence of TBI and the need for specific habilitative and rehabilitative interventions using evidenced-based outcome data in North Carolina:

Objective 1. Increase awareness and education among key stakeholders of incidence, needs, and specialized service models for North Carolinians living with TBIs.

Measure 1: Implement an education campaign targeted towards elected officials and state agencies that increases awareness and understanding of the continuum of TBI across the lifespan of people with such injuries, their families, and communities.

Measure 2: Engage interested stakeholders and advocacy groups for education and collaboration.

Measure 3: Educate key stakeholders on best practices for the continuum of care for people with TBIs.

Measure 4: Educate key stakeholders on the need for increased funding for best practices throughout the continuum of care.

Objective 2. Collect data on the incidence and prevalence of TBI for all ages and levels of severity to inform legislative and other stakeholder initiatives.

Measure 1: Provide data and funding recommendations to North Carolina policy-makers and other stakeholders/interested parties.

Measure 2: Establish system(s) to track incidence and prevalence of all levels of TBI in North Carolina.

Measure 3: Identify providers and gaps throughout the continuum of care that serve individuals with TBI.

Objective 3. Advocate for funding to ensure coverage of necessary and appropriate services and supports.

Measure 1: Review policies of existing Medicaid Home and Community-Based Settings (HCBS) Waivers to identify necessary revisions to enable appropriate support for people with brain injuries.

Measure 2: Advocate for revisions/modifications to existing waiver(s) to provide increased community-based care.

Measure 3: Advocate for revisions/modifications to existing service provision for people who do not qualify for Medicaid HCBS Waivers and do not have private means of insurance, to obtain services.

Measure 4: Identify people with TBIs who have been unable to obtain services through the state system of services.

Measure 5: Meet with representatives of Medicaid HCBS Waiver programs to discuss specialized TBI training/services and competitive reimbursement rates.

Objective 4. Develop a system to identify and provide community-based supports for people with TBIs who are in long-term services and supports, prisons, or are homeless.

Measure 1: Identify the individuals with TBIs who are in long-term service and support settings, prisons, or are homeless.

Measure 2: Advocate for the development of, and work with stakeholders and professionals to develop, individualized plans to transition people with TBIs through the continuum of care.

Measure 3: Educate people with TBIs, their families, and advocates on data regarding outcomes and funding recommendations.

GOAL 2: COLLABORATION AND COALITION BUILDING

Identify and partner with governmental, non-governmental, and advocacy agencies involved in providing or supporting TBI services in order to increase awareness, knowledge, and support of TBI, to reinforce existing stakeholder collaborations, to expand new community partnerships, and to provide a robust provider network of TBI services in North Carolina.

Objective 1. Collaborate with and make recommendations to community stakeholders/agencies to increase opportunities for all individuals with TBIs, particularly those who live in rural areas and do not have access to specialized TBI rehabilitative care and habilitative supports to reach optimal physical, cognitive, and psychological functioning through increased access to high-quality, age-appropriate rehabilitative care and habilitative supports.

Measure 1: Ensure that appropriate training and consultation is provided to local rehabilitative and habilitative agencies, hospitals and centers that do not specialize in TBI rehabilitation and care.

Measure 2: Assist appropriate agencies in the development of detailed action plans for priorities related to specialized services for individuals living with TBIs.

Measure 3: Advocate for mobile resource and consultation teams at the state and local levels, as well as telemedical and telerehab programs, to provide training in TBI rehabilitative care and habilitative supports.

Measure 4: Explore the merits of developing and maintaining a centralized database of service providers and caregivers with specialized training in TBI, including accredited rehabilitative care and habilitative support programs.

Objective 2. Collaborate with and make recommendations to community stakeholders to implement best practices for all individuals with TBIs across the continuum of care.

Measure 1: Increase the number of service providers and caregivers with specialized training in TBI, including gender, age, and cultural competencies.

Measure 2: Increase awareness about all levels of severity of TBI among healthcare providers and emergency medical personnel.

Measure 3: Increase TBI expertise of health care providers and emergency medical personnel.

Objective 3. Collaborate with and make recommendations to community stakeholders to increase unity and opportunities for networking, communication and peer support among people with TBIs and their families.

Measure 1: Enhance the ability of people with TBIs and their family members to become self-advocates by providing information and training on advocacy, best practices and trends, clinical trials, available resources, personal responsibility for care, school re-entry services, and assessments, etc.

Measure 2: Educate the TBI community and stakeholders about the spectrum of TBIs and the range of needs among individuals with TBIs and their families.

Measure 3: Educate the TBI community, families, and stakeholders about available resources, best practices and self-advocacy.

Measure 4: Educate and support individuals with TBIs and their families in choosing high quality, age-appropriate, TBI rehabilitative care and habilitative supports.

Objective 4. Develop TBI-specific competencies to ensure that individuals with TBIs who require services receive appropriate, effective, and high-quality treatment in community-based residential settings.

Measure 1: Develop and/or make recommendations for the development and implementation of specific competencies to direct the functioning of rehabilitative care and habilitative community-based residential programs.

Measure 2: Develop and/or make recommendation for the development and implementation of specific competencies for lifelong care of people with severe TBIs and/or high intensity needs.

Measure 3: Develop and/or make recommendations for the development and implementation of competencies to ensure consistency of treatment across providers and settings.

GOAL 3: RESOURCE DEVELOPMENT AND SUSTAINABILITY

Secure adequate and specialized funding to meet the needs of North Carolinians with TBIs and seek to increase/modify existing funding programs to provide for the continuum of care.

Objective 1. Advocate for and make recommendations to state legislators and/or other funders for sufficient financial support to cover the costs of community-based care.

Measure 1: Meet with legislators and/or other funders to discuss the need to develop and monitor reimbursement rates.

Measure 2: Develop a service model that meets the cognitive, behavioral, physical, and medical needs of people with TBIs across each phase of their lifespan based on best practices and encouraging innovative approaches.

Measure 3: Identify and evaluate successful models for providing community-based residential settings for people with TBIs in North Carolina and make recommendations for funding the models that best meet the needs for individuals living with TBIs.

Measure 4: Advocate for sustainable state dollars to start up and to increase TBI service infrastructure and expansion of the TBI Waiver to include increased capacity to meet the level of services needed in the state, as well as state-wide inclusiveness and increased care coordination.

Measure 5: Educate funders, educators, federal and state agencies, and other stakeholders and partners regarding the need for funding for TBI rehabilitative care and habilitative supports.

Objective 3. Advocate for and make recommendations to state legislators and/or other funders for increased funding for *post-acute* rehabilitative care, habilitative supports and other community support services.

Measure 1: Develop specialized, community-based neurobehavioral/neuromedical program(s) in North Carolina for individuals with TBIs that combine cognitive, behavioral, and pharmacological treatments.

Measure 2: Develop specialized, community-based residential programs for individuals with TBIs who have complex *medical* needs.

Measure 3: Develop specialized, community-based residential programs that can work effectively with individuals living with TBI who are in need of a residential support program.

Measure 4: Develop residential settings that have a home-like, rather than institutional, setting.

GOAL 4: PREVENTION

Identify and build prevention strategies through public health injury prevention programs and initiatives to reduce injuries that are associated with TBI among North Carolinians and assure widespread adoption of effective prevention strategies.

Objective 1. Increase public awareness about injury risks and the effectiveness of prevention strategies to reduce the incidence of TBI in North Carolina.

Measure 1: Create a network of available professional spokespeople and safety advocates who can deliver compelling, evidence-based messages to the media.

Measure 2: Identify and collaborate with local businesses that value safety for injury prevention events and distribution sites of public awareness information.

Measure 3: Encourage hospitals and other health care facilities to use their communication channels to share safety information (i.e., television messages in waiting rooms).

Measure 4: Engage community-based organizations, volunteer groups, non-governmental organizations, and local merchants in sponsoring injury prevention events to raise awareness about a specific cause that relates to safety and prevention (i.e., attending a bike-a-thon to raise awareness about helmet safety).

Objective 2. Educate key stakeholders about injury risks and effective strategies to prevent TBI in North Carolina.

Measure 1: Educate policy-makers about the cost burden of TBI as well as the effectiveness of prevention strategies, cost savings potential, and overall public health benefit.

Measure 2: Strengthen the knowledge base of injury and prevention information by strengthening collaborations between people working in injury prevention and those working directly with the public.

Measure 3: Integrate injury prevention education into broader promotion efforts such as schools, hospitals, early childhood programs, and violence prevention agencies.

Measure 4: Incorporate injury prevention information in health, education, and safety professional trainings by offering continuing education credits.

Measure 5: Include injury prevention into minimum standards for competency for credentialing, licensing, and certification of residential programs.

Objective 3. Support and advocate for any new prevention legislation and strengthen existing prevention policies.

Measure 1: Collect and analyze injury data to inform prioritization of prevention efforts.

Measure 2: Support the use of statewide data to evaluate local prevention efforts for the purpose of advocating for changes in prevention policies when necessary.

Measure 3: Develop a state TBI registry and to use this registry for surveillance to better understand TBI outcomes and risks, to inform prevention strategies, and to connect individuals with TBI to specialized continuum of care community-based services.

Measure 4: Assist in the promotion of prevention legislation and support statewide efforts to reduce child abuse, domestic violence, and non-accidental injuries.

C. TBI Program Core Components

The NC TBI Program uses the Health Resources and Services Administration (HRSA) four core components as its program infrastructure model. Although the federal TBI Grant program has moved from HRSA to the Administration for Community Living (ACL), these four components are still recognized by ACL. They are also found in federal statute. As a result, the NC TBI program will continue to use these core components.

The components are: 1) a statewide TBI advisory council charged with advising and making recommendations on ways to improve coordination of TBI services; 2) a lead state agency for TBI responsible for coordination of state TBI activities; 3) a statewide assessment of TBI needs and resources completed or updated within the last 5 years and including the full spectrum of care and services from initial acute treatment through community reintegration for individuals of all ages having TBI; and 4) a statewide TBI action plan to provide a culturally competent, comprehensive, community-based system of

care that encompasses physical, psychological, educational, vocational, and social aspects of TBI services and addresses the needs of individuals with TBI, as well as family members.

North Carolina has developed all of these components: 1) There is an active legislatively mandated Advisory Council; 2) The North Carolina Department of Health and Human Services, Division of Mental Health, Developmental Disabilities and Substance Abuse (DMH/DD/SAS) is the designated lead agency with TBI Program specific staff; 3) A statewide assessment of TBI needs and resources was completed in 2015; and, 4) As demonstrated by this document, a statewide TBI action plan has been updated.

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, 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 relationships with both internal and external stakeholders.

The TBI state funds program provides services and supports to individuals with TBI through the 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).

The federal TBI Grant awarded by the Administration for Community Living (ACL) is administered by the DMH/DD/SAS. The grant has five core components which include 1) updating the TBI Needs and Resources Assessment, 2) development and implementation of a statewide information and referral system, 3) conducting TBI screening, 4) providing Neuro-Resource facilitation, and 5) providing education, training, and outreach. Many of these grant deliverables are contracted to the BIANC. TBI grant funding is currently focused on a TBI Medicaid Waiver pilot. However, the DMH/DD/SAS has expanded and sustained several of the grant deliverables statewide.

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 Division of Public Health (DPH), Department of Public Instruction (DPI), and Division of Medical Assistance (DMA). The collaboration with DMA is primarily focused on the development and implementation of the TBI Medicaid Waiver pilot.

The DMH/DD/SAS is committed to providing proactive leadership for maintaining and strengthening the core components of a systems approach to identifying needs and resources, strategic planning to meet those needs, and developing a process that is responsive to constituency initiatives as well as State and Federal policies. Some initiatives include statewide TBI screening through the LME/MCO's using the Ohio State TBI Screening Method, collaborating with DMH/DD/SAS Quality Management Section to

conduct claims data reviews to determine the number of individuals with TBI accessing public service systems, and implementing a statewide education and outreach initiative.

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, through the BIAC and workgroups. 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 an online introduction to TBI (accessible at: <http://www.nctbitraining.org/>). The DMH/DD/SAS also maintains a TBI-related web presence (accessible at: <http://www.ncdhhs.gov/mhddsas/tbi/index.htm>)

The TBI State Action Plan is the primary tool used to help guide strategic planning and provides the direction needed to achieve long-term goals and objectives. The DMH/DD/SAS provides administrative oversight and policy direction to the agencies that deliver public TBI services and supports. The DMH/DD/SAS maintains an awareness of federal policies that impact the development and delivery of the state's services and supports through listserv membership, grantee meetings, and NASHIA membership. The DMH/DD/SAS also collaborates with state partners to incorporate federal policies and programs into state policy and service delivery systems.

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 Neuro-Resource Facilitation) for people with brain injury, families and professionals in the community;
- Development and maintenance of an online TBI Resource Manual
- A strong network of over 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 of online training modules for a variety of including medical professionals, therapists, direct care workforce, families and others; and
- Development and implementation of a comprehensive training program based on best practices in traumatic brain injury for providers, professionals, and caregivers.

C.2. NORTH CAROLINA BRAIN INJURY ADVISORY COUNCIL

Senator John Kerr from Goldsboro, NC introduced legislation (Senate Bill 704) in 2003 calling for the establishment of the North Carolina Traumatic Brain Injury Advisory Council (NCBIAC). The bill was ratified on May 22, 2003 and may now be found in General Statute 143B-216.65-66. In 2009, legislation required a name change to North Carolina Brain Injury Advisory Council and charged the Council to review traumatic and other acquired brain injuries in North Carolina.

The BIAC addresses strategic planning, policy rules, 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 a high quality of life by accessing the services and supports they need as they heal and return to their homes and function in their communities. To achieve this goal, the BIAC seeks input from brain injury survivors, family members, caregivers, community professionals, and other stakeholders.

BIAC members are appointed by members of the General Assembly, the Governor, the Secretary of the Department of Health and Human Services, the Superintendent of the Department of Public Instruction,

the Commissioner of Insurance, and the Secretary of the Department of Administration. Terms of appointments are four years. The BIAC is also 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 other *ad hoc* advisory members. In addition to the appointed members of the BIAC, non-council members can participate in meetings and 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 the planning, development, and implementation of a comprehensive statewide service delivery system; providing oversight in acquiring and utilizing state and federal funding dedicated to services for individuals with brain injury; building provider capacity and provider training to address the needs of individuals with brain injury; and improving the coordination of services. The BIAC also investigates the needs of individuals with TBI to help identify service gaps throughout the state, to facilitate collaboration among State agencies, organizations, and other entities that provide services to individuals with brain injury, and encourage and facilitate community participation in program implementation.

D. Coordinating Services for Individuals with TBI and Their Families

Individuals with TBI most often access and navigate among service systems with the assistance of family or other natural supports. Individuals that receive services from one of the Medicaid Waivers do receive care coordination services, which provides assistance in linking with other needed resources. The following are state agencies and other organizations that provide a variety of services and supports to individuals with TBI.

D.1. DIVISION OF VOCATIONAL REHABILITATION SERVICES (DVRS)

The 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. 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.2. DIVISION OF PUBLIC HEALTH (DPH)

The DPH covers a range of programs aimed at protecting and improving the health of North Carolinians. Of the five sections within DPH, two sections have been directly involved in activities that prevent TBI or improve the health of persons with TBI. They are the Chronic Disease and Injury Section and the Women's and Children's Health Section (formerly known as Maternal and Child Health). The State Health Director appoints the DPH representative to the BIAC. Epidemiologists and injury prevention specialists from the Injury and Violence Prevention Branch may serve on the Prevention Committee and provide technical expertise to the BIAC and to the DMH/DD/SAS. Much of the BIAC's work requires TBI surveillance data. The Injury and Violence Prevention Branch facilitates access to data from the state's centralized vital statistics, emergency department, and hospital discharge databases. The branch prepares "The Burden of Traumatic Brain Injury (TBI) in North Carolina" disseminates the report and posts the report on the branch website <http://www.injuryfreenc.ncdhhs.gov/resources/docs/BurdenofTBI2014.pdf>. The report describes fatal, hospitalized, and emergency department visits and provides demographics, external cause of injury, and discharge disposition for the TBI's in North Carolina. The DPH also generates special reports and investigations upon request into specific causes of TBI such as motor vehicle, suicide, falls, and other mechanisms of injury.

The DPH and the BIAC have collaborated on policies to prevent injury that results in TBI's. Since 2011, this collaboration has been key in educating and informing partners on the value and benefits in retain North Carolina's universal motorcycle helmet law during a time when a well-organized campaign was under way to repeal the law. The DPH coordinates with a wide network of partners, including the BIAC and DMH/DD/SAS staff, to develop a new state suicide prevention plan. The DPH also coordinated with a wide network of partners to address the medication and drug overdose epidemic. This effort resulted in the enactment of state laws that strengthened the Controlled Substances Reporting System (CSRS) to include automated alerts and proactive reporting of patients at risk for excessive opioid prescription behavior and suspicious prescriber behavior. A series of state laws were also passed to provide limited immunity from prosecution for dispensing and using the opioid antigen naloxone in 2013. Following the enactment of the laws, North Carolina has implemented one of the largest state-wide naloxone distribution programs in the country with over 28,000 overdose rescue kits distributed at the community level, 3,400 confirmed overdose reversals, over 1,000 pharmacies across the state offering naloxone for sale under a new state-wide standing order, and 95 law enforcement agencies in that with officers trained and carrying naloxone.

Both sections have been responsible for initiatives that teach communities about child and adult safety, and prevention of injury, secondary disabilities and fatalities, and advance supportive policies for TBI prevention. The Women's and Children's Health Section contributed matching funds and ongoing technical assistance in the management of previously funded HRSA projects and continues as a partner in all TBI initiatives.

Presently the DPH, in partnership with the Division of Aging and Adult Services (DAAS), the University of North Carolina (UNC) Institute on Aging, and the Carolina Geriatric Education Center at UNC, initiated the NC Falls Prevention Coalition to reduce the number of falls, fall-related injuries, and the seriousness of injuries resulting from falls. This multidisciplinary group has been meeting since April 2008 to assist with falls among older adults and all others in the State. The DMH/DD/SAS serves in this coalition. In 2014, the DAAS received a falls prevention grant to implement a hub to disseminate and share falls prevention information and services to partners statewide.

In 2016, the Injury and Violence Prevention Branch received funding from CDC to extend the hub system and incorporate the STEDI falls prevention program in North Carolina. The CDC grant also provided funding to address youth sports concussions. The DPH will partner with the North Carolina Sports

Athletic Association to develop and implement CDC's "Heads Up" concussion education and awareness program in middle schools in the state.

D.3. DIVISION OF MEDICAL ASSISTANCE (DMA)

The DMA manages the state's Medicaid and Health Choice programs. It funds cost effective health services, including the Children's Health Insurance Program, three home and community based waiver programs, and a wide range of medical and rehabilitation services through enrolled providers and Managed Care Organizations (MCOs) to eligible persons across the state. Individuals with TBI 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.
- 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.
- Physical Therapy/Occupational Therapy/Speech and Language Therapy.

The DMA, working collaboratively with DMH/DD/SAS and the BIANC, have submitted an application to CMS for the NC TBI Waiver. The NC TBI Waiver will serve adults who survived their TBI on or after their 22nd birthday.

The DMA is represented on the BIAC.

D.4. 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. 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.

The Office of Emergency Medical Services (OEMS) 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:
 - 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.
 - 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.5. 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 TBI as a category for special education services in 1990, NC developed an initiative to train school psychologists to conduct extended evaluations of students suspected of requiring special education due to 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 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 eighty-nine (189) school psychologists with this specialized training are on the registry maintained by the Exceptional Children Division of the NC DPI. One hundred sixty-three (163) of those on the registry work in the 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 ([HRS-E-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 School Psychology with NC DPI provides quarterly updates to the BIAC on special education trend data specific to the Individuals with Disabilities Education Act (IDEA) classification of TBI. Additionally, because of the concussion monitoring policy, it is expected that concussion specific data will be accessible in the near future, and will be more accurate in reflecting the incidence rate of this TBI across all school-age children. These two sources will help the BIAC examine 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 TBI in NC.

The child count data from the 119 school systems in NC and 159 charter schools reveal that in April of 2016, 620 children and youth were reported as eligible for special education under the category TBI. This number reflects an increase in identification from 420 within this special education classification in April 2014. Although the revised definition has appeared to improve accuracy in identification, other children and youth with a TBI may still exist among the 75,214 reported as eligible under specific learning disability, the 28,511 reported as speech-language impaired, the 820 reported as orthopedically impaired, the 35,964 found eligible under the “Other Health Impairment” category, or the 5,520 reported as eligible due to serious emotional disability.

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 didactic training program 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: (1) mechanisms, characteristics and issues of TBI, (2) advanced assessment techniques, and (3) treatment issues and techniques.

D.6. DISABILITY RIGHTS NORTH CAROLINA (DRNC)

DRNC works with and for all people with disabilities to protect and advance their legal rights, their dignity, and opportunity to make choices. DRNC is the federally mandated protection and advocacy program (P&A) for persons with disabilities in NC. As the P&A, DRNC investigates complaints, pursues legal remedies for protection of individual’s rights, reviews and recommends changes in laws, and provides legal back up to local advocacy programs. DRNC provides legal representation to people with disabilities consistent with the annual priorities adopted by its Board of Directors.

The Protection and Advocacy Traumatic Brain Injury (PATBI) grant allows DRNC to provide services for people with TBI, ensuring 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 is an active member of the BIAC and actively works with the BIAC and others to assure consistent, dedicated funding for persons with TBI in NC.

D.7. BRAIN INJURY ASSOCIATION OF NORTH CAROLINA (BIANC)

The BIANC was established in 1982 by family members of individuals with brain injury and interested professionals. In 1994, BIANC expanded the TBI support network statewide from a one-person, centrally-operated network to a central resource center and four regional resource centers. All of the resource centers provide information and resource referrals; neuro-resource facilitation; training and education; professional online training module development, public awareness and prevention; advocacy; and peer and family support largely through contracts with DMH/DD/SAS. The administrative office for BIANC is located in the central Raleigh Resource Center. The other four resource centers include the Greenville Resource Center; the Triad Resource Center in Winston-Salem (office space donated by Wake Forest Baptist Health); the Charlotte Resource Center (office space donated by Carolina's Rehabilitation); and the Asheville Resource Center (office space donated by CarePartners Rehabilitation Hospital).

All of the resource centers provide organizational support and assistance with more than 30 support groups statewide, including groups that support returning military service members and their families. BIANC manages a comprehensive website, which provides online education and training; a resource book; family helpline; and contact information about the brain injury support groups in NC. BIANC conducts annual conferences for individuals with brain injury, family members, and service providers. Wellness and recreational activities are sponsored by BIANC regularly and numerous public awareness events, fund raising activities, as well as face-to-face training, education, and advocacy for individuals with brain injury and their families.

BIANC publishes a quarterly news magazine, *Starting Point*, which provides information related to brain injury to over 2,000 individuals. BIANC's website, on average, has over 4,000 visitors per month. The website provides information and resource referrals to over 3,000 families and professionals each year. Additionally, in coordination with the DMH/DD/SAS, BIANC provides neuro-resource facilitation and training to the public, specifically to Alliance Behavioral Healthcare (LME/MCO) and their provider network in preparation for the implementation of the TBI Waiver pilot.

Legislation for the Brain Injury Advisory Council (BIAC) specifies that there will be one representative from BIANC, which is the executive director and one representative from BIANC's board of directors, which is the Chairperson. With this representation, BIANC has a strong voice in the implementation and development of services and supports for individuals with TBI, their families, and professionals. BIANC works closely with BIAC and DMH/DD/SAS. BIANC provides quarterly reports to DMH/DD/SAS that provide quantitative and qualitative analyses of reported needs based on calls and inquiries to BIANC's resource centers. This information assists with identifying current strengths, gaps in the service system, and identifies areas for future program development and expansion.

BIANC utilizes information and educational materials from national and local sources to respond to inquiry calls to its regional offices. It disseminates materials developed by the CDC, NASHIA, BIAA, the NC Injury and Prevention Program, the Governor's Advocacy and Protection Council, and other expert sources that provide the most accurate information.

D.8. Veterans

The US Department of Defense data showed North Carolina had the third largest total of active duty and reserve members of the military as of May 2016. At that time, NC had 129,049 military service members. Per the Veterans Administration, 773,000 veterans live in North Carolina, in the year 2015⁹.

North Carolina has continually worked to improve collaboration among federal and state agencies, universities, independent organizations, Veterans groups, and many others to improve services and supports for active duty, reserves and Veterans across the state.

The North Carolina Department of Military and Veterans Affairs leads the way 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:

- NC4VETS: Connects Veterans, Active Military and their families with information and over 2500 points of service regarding employment, healthcare, benefits, housing, personal services, education and events; 844-NC4-VETS (844-624-8387); www.NC4Vets.com
- NC4ME: North Carolina 4 Military Employment educates employers on the advantages of hiring Veterans; www.NC4ME.org
- NCWorks: Offers the complete set of employment tools for Veteran job seekers, with specialized Local Veteran and Disabled Veterans Outreach Professionals www.ncworks.gov
- NCMAC: NC Military Affairs Commission works to make North Carolina the most military friendly state in the nation.
- NCVAC: North Carolina Veterans Affairs Commission works to make North Carolina the most Veteran-friendly state in the nation.
- NCServes: NC's first coordinated network of public, private, and non-profit organizations working together to serve veterans and their families. Currently locations in:
 - Charlotte-Metrolina
 - Triangle-Fayetteville
 - Coastal NC
- Governors Working Group on Veterans, Service Members and their Families: Intergovernmental working group focused on job creation, workforce enrichment, health and wellness, legal and financial services and benefits for veterans.

The DMH/DD/SAS works closely with the Governors Working Group on Veterans, Service Members and their Families and provides treatment options for active duty service members or veterans with PTSD or other mental health issues as well as for those with substance use disorders. The DMH/DD/SAS, as noted elsewhere is also the lead agency for TBI in the state.

⁹ <http://www.governing.com/gov-data/military-civilian-active-duty-employee-workforce-numbers-by-state.html>

With offices throughout the state active duty service members or veterans may seek services in their home community if they desire.

Countless governmental agencies, private companies, non-profits, colleges and universities, and many more work together in NC to improve treatment options, housing, employment, counseling and many other areas important to our service members and veterans. Every office has both a point of contact for veterans and for TBI.

Some veterans choose not to receive care from the Veterans Administration (VA). 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. Treatment for TBI may be unavailable in some areas as well. Many people across the state are working to develop more solutions for these men and women who have proudly served their country.

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

A North Carolina TBI Needs and Resources Assessment was conducted by Carolina's Healthcare/TBI Project Star in the fall of 2014. The final report was completed and approved in the summer of 2015. The purpose of the Needs and Resources Assessment was to provide the DMH/DD/SAS with current information about the current needs and resources of individuals with TBI, their families and caregivers, as well as professionals/providers statewide.

There were four primary objectives:

1. Develop a project team to conduct discussion groups in five (5) catchment areas including Asheville, Charlotte, Winston-Salem, Raleigh, and Greenville.
2. Develop and facilitate discussion groups including individuals and families affected by TBI in NC, as well as provider discussion groups, to assist in identifying service gaps.
3. Develop an electronic online questionnaire for each targeted population to collect input about needed services. The three targeted participant groups include:
 - a. Individuals with TBI,
 - b. Families/caregivers of individuals with TBI, and
 - c. Community service providers (including hospital discharge planners).
4. Compile final report and present findings as requested by the DMH/DD/SAS.

A total of 115 individuals participated in face to face discussion groups across NC. 67 participants (58.3%) were individuals living with TBI, 35 family members/caregivers (30.4%) participated and 13 professional service providers (11.3%) joined in the discussion group meetings. A separate questionnaire was sent to individuals in the TBI Registry that includes over 1,500 individuals. The survey was also sent to a service provider list and support group leader list. The questionnaires were created to direct the

respondent to the correct categorized questionnaire. The questionnaire was available online for individuals to complete for one week. 81 individuals living with TBI (25.7%), 118 families/caregivers (37.7%) and 115 professionals (36.5%) participated in the electronic online questionnaire, for a total of 314 participants.

E.2. COMMON GAPS

E.2.1. Common Gaps Identified by people with a TBI

1. Service access/assessment of need
2. Appropriate services/long term support/community-based services
3. Funding for services
4. Concerns that TBI is defined as an Intellectual/Developmental Disability by the state
5. Concerns that Intellectual/Developmental Disability is not an appropriate access point in the for TBI services
6. Education/awareness of TBI
7. Social opportunities
8. Empathy/support/professionals listening
9. Assistive Technology Access
10. Financial stress
11. Loss of independence
12. Transportation
13. Loss of employment
14. Difficulty navigating the NC social service systems
15. Frustration with discharge diagnoses or instructions that did not include brain injury or other useful follow-up information about brain injury recovery.

E.2.2. Common Gaps Identified by family/caregivers

1. Frustration with systems of care and support
2. Isolation
3. Financial burden/reduction in income
4. Unable to provide adequate supervision
5. Service Access/Assessment of Need
6. TBI specialized service providers/TBI provider training
7. Appropriate services/community-based services
8. Communication between providers
9. Awareness of established services
10. Statewide service availability-especially in rural areas
11. Funding for services
12. Family support/counseling
13. Residential Options
14. Transportation Needs

E.2.3. Common Gaps Identified by service providers

1. Lack of financial resources for services
2. Service delivery challenges/appropriate services/number of service options
3. Few housing options
4. Lack of TBI trained professionals
5. Lack of vocational support services

All three respondent categories indicated a need to improve statewide services in the areas of service delivery, the provision of appropriate services for individuals with TBI, and improved funding options for service access. Both families/caregivers and providers identified TBI education for providers specializing in TBI and housing/residential support options as critical needs. There were also several references to increased community inclusion opportunities with a focus on social involvement.

F. Statewide TBI Action Plan

The numbers of people with TBI will continue to expand as improved emergency medical services and trauma treatment have resulted in increased survival rates in NC and nationally. As a result, more individuals with TBI are living with disabilities that will require lifelong services and supports. Currently, there are excellent hospitals in North Carolina for the care and rehabilitation of people with TBI. However, there are not adequate community-based services to support people in living full lives integrated in their communities. A comprehensive state plan for brain injury services and supports is essential to maximize access to services and to provide adequate funding sources. General components of this plan are described below.

F.1. INCREASE SERVICE CAPACITY

The most persistent needs for individuals with traumatic brain injury over their lifetimes are for assistance with cognitive changes (difficulties with attention, memory, judgment and reasoning) and assistance with behavioral challenges (impulsivity, agitation and a variety of emotions). Many individuals also require personal care/assistance to remain in the community. There are unmet needs for funds and programs to provide crisis assessment and intervention, family support, caregiver and professional training, neuro-behavioral programs, cognitive rehabilitation, residential services and other community-based programs. Without these services, individuals with brain injuries are at greater risk for admission to psychiatric hospitals, criminal charges, incarceration, and/or homelessness.

The DMH/DD/SAS has implemented a carefully monitored allocation process for the statewide TBI state-fund service program, which has led to a marked decrease in unspent money left at the end of the fiscal year. The DMH/DD/SAS is developing ways to train professionals within the existing public mental health, developmental disabilities and substance abuse system of services. It is focusing on protocols and training for screening and assessment and training for psychiatrists and other licensed professionals as well as paraprofessionals and other direct care staff. It is also seeking to enhance the ability of state facilities to appropriately treat TBI consumers with neurobehavioral issues.

Through its four-year competitive ACL grant, the DMH/DD/SAS is overseeing the provision of Neuro-Resource Facilitation, Training and Outreach, online training module development for professionals, and TBI screening at an LME/MCO. All of these grant activities have expanded beyond the pilot area to include statewide implementation.

F.2. MAINTAIN AND ENHANCE TRAINING/EDUCATIONAL OPPORTUNITIES

One of the primary goals of DMH/DD/SAS's TBI Program is to provide training and education opportunities to professionals, families and caregivers, individuals with TBI, and the general public throughout NC. This is partly accomplished by DMH/DD/SAS staff who provide training to a variety of professional and public audiences at conferences, workshops, provider agencies, and other venues. The DMH/DD/SAS also contracts with BIANC to provide a variety of TBI training opportunities statewide.

The DMHDDSAS contracts with BIANC to provide education, outreach, and training activities through their five resource centers across the state. BIANC has a full time Resource and Training Coordinator who is responsible for the development and implementation of a statewide training plan and who serves as the point person for all BIANC training activity statewide. The training plan was updated and implemented during the first quarter of SFY 2015-2016. The Resource and Training Coordinator also completed a review of all existing BIANC training curricula and developed a training library for use by all BIANC staff statewide. This training library will be expanded as new training tools and resources are identified or developed.

BIANC also collaborates with the DMH/DD/SAS to develop online training modules for professionals, family members, caregivers, and others in NC. This includes the development of new training modules as well as tailoring existing modules for audiences in NC. Many of these online trainings will offer continuing education credits as well. Both in-person and online training modules will support opportunities to increase knowledge and skill in the field of brain injury in different training formats that appeal to diverse audiences. The online training modules will be hosted by an Area Health Education Center (AHEC) who will maintain a repository of online TBI training opportunities.

Training is the primary means to increase awareness of TBI and to increase the skill and competency of professionals throughout the state working with individuals who have TBI in various service systems. As service capacity increases in the future, it will be vital to maintain and increase training opportunities to ensure competent and effective service delivery to individuals with TBI statewide.

F.3. DATA COLLECTION

The General Assembly requested data on the number of individuals with TBI statewide. In response, the DMH/DD/SAS has implemented TBI Screening among all LME/MCO's using the Ohio State University TBI Identification Method Tool. This tool is a nationally recognized method for identifying the potential for TBI among individuals participating in the screening. The screening was implemented with one LME/MCO during SFY 2014-2015 as part of the ACL grant. Those results indicated that 210 individuals within their catchment area that participated in the screening likely sustained a TBI. During the first half of SFY 2015-2016, this TBI screening was implemented at all LME/MCO's.

The DMH/DD/SAS Quality Management Section has also initiated TBI claims data reviews to determine the number of individuals with a diagnosed TBI that have accessed Medicaid physical health or behavioral health services. Preliminary results indicate that 99,720 individuals with a diagnosed TBI accessed Medicaid or state behavioral health services between July 1, 2013 and October 1, 2015. In SFY 2014-2015, data revealed that 20,224 individuals with a diagnosed TBI accessed at least one behavioral health service.

The DMH/DD/SAS will continue both the TBI screening through the LME/MCO's statewide and the claims data reviews. This data will help inform the General Assembly regarding the numbers of individuals with TBI throughout NC and for use in other education and outreach initiatives. It will also serve to compliment the data received from the CDC regarding the incidence of TBI in NC.

F.4. PROVIDE ADEQUATE RECURRING FUNDING

Approximately 160,000 North Carolinians with TBI will have long-term needs.¹⁰ Estimating that 40 percent or approximately 62,000 will need some form of public services, current state appropriations for TBI funding through DMH/DD/SAS equals roughly \$37 per person annually. Based on these data, the current levels of funding for the TBI state funds program and the TBI Waiver pilot will likely not be adequate to serve the needs of the TBI population in NC.

F.5. COMMUNITY BASED WAIVER FOR TRAUMATIC BRAIN INJURY

The General Assembly approved a TBI Medicaid Waiver pilot with a \$2 million appropriation in Session Law 2015, House Bill 97, Section 12H.6. Subsequent to the passage of this legislation, the DMA and DMH/DD/SAS, in collaboration with stakeholders, wrote a TBI Waiver application to CMS to implement a pilot Waiver program. It is anticipated that the TBI Waiver pilot will be implemented in the Alliance Behavioral Healthcare catchment area during SFY 2015-2016.

Collaborative efforts between the DMH/DD/SAS, DMA, BIANC, and Alliance Behavioral Healthcare are occurring in support of the TBI Waiver pilot implementation.

F.6. CHANGE TBI RESIDENTIAL LICENSURE

In 2009, NC NCGS §122C was amended and directed the DMH/DD/SAS to:
“Adopt rules providing for the licensure and accreditation of residential treatment facilities that provide services to persons with traumatic brain injury.”

The goal was to write licensure rules that better correspond to the needs of TBI consumers and their families. The DMH/DD/SAS, DHSR, and representatives of the BIAC are collaborating on this process. Further discussion will occur to determine if legislative changes are recommended.

F.7. IMPLEMENT STATEWIDE PREVENTION PLAN

Prevention of TBI in the State of North Carolina requires a unified effort by many state agencies, private providers, advocacy groups, and survivors of TBI and their families. There is no cure for TBI, so prevention is the key. Although not all TBIs can be prevented, their incidence can be reduced through education and awareness. A State TBI Prevention Plan allows all stakeholders to have a blueprint for intervening to reduce the number of brain injuries to the fullest extent possible. Prevention of TBI reduces medical and educational costs as well as lost productivity and wages in our state. It also reduces the immeasurable cost to individuals and families who live with this "silent epidemic". A prevention plan is part of a comprehensive system of supports and services for TBI across the state.

F.7.1 Partners with the DMH/DD/SAS:

- DPH: Injury and Violence Prevention Branch – a primary partner for prevention plans and strategies.
- DPI: Safe and Drug Free Schools Division and Exceptional Children Division
- Injury Research Prevention Center at UNC
- NC Safe Kids: Injury prevention in the ages 0-14 population

¹⁰ CDC reports that 1.7% of the US population will have long-term needs as a result of their TBI (5,300,000 of 307,035,000). This translates to 156,781 of North Carolina’s 9,222,444 population.

- DHSR
- DAAS
- DSOHF
- US Department Veterans Affairs and the Veterans Administration
- NC Falls Prevention Coalition

F.7.2. Build prevention capacity

F.7.2.1. Universal strategies that address the entire population

- The DMH/DD/SAS contracts with organizations that provide public information and education opportunities around the state. The BIANC consists of five Regional Resource Centers across the state and is the primary information and advocacy organization for TBI in North Carolina. It disseminates information throughout the state to individuals, families and providers to educate about TBI. All offices maintain a resource library of TBI information.
- Nationally, TBI Awareness Month is March, and a variety of activities occur throughout the state, including a Governor’s proclamation, races and walks and other activities to raise the awareness of brain injury and its consequences.

F.7.2.2. Selective strategies that target groups of people determined to be at risk

Presentations at:

- Mental Health Conference
- Social Workers Conference
- Social Services Conference
- Intellectual and Developmental Disabilities Conference
- Safe Schools and Character Education Conference
- NC Conference on Aging
- NC Tide
- Student Athlete Training Institutes
- Athletic Director’s Workshop

F.7.2.3. Indicated strategies that target those at highest risk:

- The DMH/DD/SAS and BIANC participation in the Falls Prevention Coalition jointly lead by DPH, the Center for Aging & Health, UNC Institute on Aging, DAAS, and the Carolina Geriatric Education Center.
- The program’s ACL grant includes a variety of educational and informational activities to train the Primary Healthcare community about TBI. Additionally, the grant supports one Neuro-Resource Facilitator who works with Medical Professionals and others to identify resources needed for the TBI population.
- BIANC offers an annual weekend camp for TBI survivors and regional events that provide wellness activities and health information for prevention of secondary problems.

F.7.3. Implement effective community prevention programs, policies and practices:

Groups within regional communities will be approached to help expand current activities and develop additional intervention strategies to include TBI. Partners and strategies will differ from community to community based on needs, participating partners, and available resources.

F.7.3.1. Universal strategies that address the entire population:

- The *Safe Kids* Program works with the child population from 0-14 years, and has many effective injury prevention programs such as Risk Watch and Buckle Bear.
- The *Period of PURPLE Crying* is a Shaken Baby Prevention initiative that is being implemented through the Injury Research Prevention Center at UNC.
- *Walk Safe* (www.walksafe.us), a pedestrian safety program, is often implemented through Police Departments.
- *Remembering When*, a fire and fall safety program for seniors is being implemented through the Office of the State Fire Marshal.
- *Sports Safety Clinics* provide concussion education for 6th graders in North Carolina Public Schools and is being implemented by BIANC and Injury Prevention Programs.
- *BrainMinders* puppet show provides brain safety education for children 0-6 years. It is a program sponsored by the NC Pilot Club and implemented by BIANC.
- BIANC assists in programs offered through regional Falls Prevention Coalitions.

F.7.3.2. Selective strategies that target those at risk:

- UNC-CH is leading research in the area of concussion management with athletes.
- ImPACT is a user-friendly computer based testing program specifically designed for the management of sports-related concussion. The instrument has been designed after approximately 10-years of University-based, grant-supported research. ImPACT is currently the most widely utilized computerized concussion program in the world and is implemented effectively across high school, collegiate, and professional levels of sport participation. Participants in North Carolina include seven universities and colleges, and at least seven high schools use this system of preventing complications from a head injury.

F.7.4. Evaluate efforts for outcomes:

Evaluation of effectiveness is an integral part of prevention strategy. Ongoing work in this area will vary depending on strategies employed and areas targeted.

The general process includes:

- Collect ongoing data throughout the process and reviewing it.
- Provide ongoing monitoring and evaluation of activities
- Provide training and technical assistance to communities regarding evaluation and performance measurement
- Assess program effectiveness
- Identify successes
- Encourage needed improvement
- Promote sustainability of effective policies, programs, and practices
- Adjust implementation plans based on monitoring/evaluation activities

G. Conclusion

Contemporary advanced medical technologies and improved trauma systems are leading to more and more long-term survivability for people with TBI. Unlike many diseases, however, an injury to the brain often has lifelong consequences, with too few individuals experiencing a complete recovery. The number of survivors is going to continue to increase and will likely require some type of long-term resources.

In order to address these needs, the State of North Carolina needs to expand and coordinate services for these individuals, and coordinate education and prevention efforts. This State Plan provides the structure for those activities.