ISSUE BRIEF

Traumatic Brain Injury in North Carolina:
The State of the State Today

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This issue brief provides an overview of the "state of the state" for traumatic brain injury (TBI) issues and challenges in North Carolina. A previous issue of the *North Carolina Medical Journal* discussed this topic approximately 14 years ago, and this issue brief showcases changes and advances since that time. Collectively, articles in the current issue highlight the current epidemiology of TBI; the rapidly advancing and critical topic of concussions; special populations where TBI is seen more frequently, such as elderly individuals and veterans; advances in TBI-related treatments; and the all-important family perspective on TBI. Additionally, this issue brief discusses key developments and advances in the state related to a statewide needs assessment; legislative and policy actions, including a new sports concussion awareness act and a significantly revised definition of TBI as it relates to special education classification; and ongoing exploration of evidence-based community services that have the potential to improve our system of care for adults with TBI. Finally, ongoing challenges are detailed with the intention of pushing the state to become one of the nation's leaders in TBI services.

Traumatic brain injury (TBI) affects 1.7 million individuals in the United States per year, with many concussions and other types of mild TBI likely going unreported. The rate of emergency department visits for TBI is highest in young children, followed by teenagers and then young adults [1, 2]. In North Carolina for the year 2012, there were an estimated 76,708 TBIs, with 1,871 fatalities. There were about 6,249 hospitalizations, and about 68,588 people were treated and released from emergency departments [3], with both statistics suggesting the concomitant need for TBI-related services in the community due to associated, and perhaps chronic, morbidity. TBI is thus a major public health concern, a potentially long-term and costly event for individuals and families, and a topic worthy of ongoing educational update.

Approximately 14 years ago, the *North Carolina Medical Journal* devoted an issue to TBI [4]. Articles were devoted to epidemiology, abusive head trauma, TBI training of school personnel, several treatment approaches for community reintegration and primary care, a hospital-based model of coordinated care, falls among elderly individuals, sports-related brain trauma, the economics of TBI in the state, and an overview of the state's status with respect to TBI. As such, these articles represented the state of TBI services in North Carolina in 2001. Interestingly, while there have been significant advances in the broad area of TBI since 2001, including changes in North Carolina, many of these issues continue to be relevant in our current climate and are addressed via the articles in the current issue. To complement these articles, a number of additional advances and changes in the state since 2001 are worth mentioning.

Statewide Needs Assessment

As part of the 2001 issue of the NCMJ, there was mention of the need to conduct a statewide needs assessment. In 2007, the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MH/DD/SAS) orchestrated a preliminary needs assessment to begin to more fully understand the needs of the state's TBI constituency. The results of this needs assessment were published in March 2008. For this preliminary needs assessment, existing TBI databases (eg, from the Division of Vocational Rehabilitation Services and the Department of Public Instruction) were examined, and surveys were developed and distributed to TBI survivors, family and friends, and providers. Across all sources, a multitude of needs were expressed, and some common themes emerged. These themes reflected the need for increased financial support, community-based services, housing, transportation, professional and agency-based knowledge of the available community services, and education of professionals working with individuals who have sustained a TBI. Findings also illustrated a need for better prevalence data, particularly for returning veterans, and a need to better understand the challenges faced by families following a TBI. While many of these challenges continue to be present in the state, there clearly have been improvements in these areas, as will be shown by the articles in the current issue.

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Legislative Actions and Public Policies

Since 2001, there have been significant advances in the state related to public policy. While continued challenges remain (eg, sustainable funding for TBI services), a number of changes have propelled North Carolina into a position among the national leaders on a number of fronts. First, the North Carolina General Assembly passed the Gfeller-Waller Concussion Awareness Act in June of 2011. This act, similar in scope to many of the other concussion laws passed in other states, includes concussion management guidelines for student-athletes in North Carolina public middle schools and high schools, return-to-play guidelines, and concussion education for coaches and other school personnel. Described in detail in the sidebar by Bloom [5], this law represents a significant advance not only in concussion management of student-athletes but also in the implementation of education and prevention strategies.

Second, a major change occurred in the TBI definition used by the North Carolina Department of Public Instruction, Exceptional Children Division, as reflected in the policies governing services for children with disabilities [6]. This revised definition emanated from a collaboration between the Department of Public Instruction and the Children and Youth Committee of the North Carolina Brain Injury Advisory Council, with a comprehensive review of state definitions across all 50 states. While maintaining the basic tenets of the federal definition of TBI, there are key components of the revised North Carolina definition that differ from the federal definition. The current state definition, enacted in October 2013, reflects the idea of acquired brain injury, and it is one of the few definitions in the country that includes birth-related brain injuries in this special education classification:

> Traumatic brain injury means an acquired injury to the brain caused by an external physical force or by an internal occurrence resulting in total or partial functional disability and/or psychosocial impairment that adversely affects a child's educational performance. Causes may include but are not limited to, open or closed head injuries, cerebrovascular accidents (eg, stroke, aneurysm), infections, kidney or heart failure, electric shock, anoxia, tumors, metabolic disorders, toxic substances, or medical or surgical treatments. The brain injury can occur in a single event or can result from a series of events (eg, multiple concussions). Traumatic brain injury also can occur with or without a loss of consciousness at the time of injury. Traumatic brain injury may result in impairments in one or more areas such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. Traumatic brain injury does not apply to brain injuries that are congenital or degenerative, but can include brain injuries induced by birth trauma.

The revised definition increases the range of neurological conditions that can fall under the TBI classification. It resulted in increased consistency of definition across state agencies, and it likely requires providers to have more background knowledge in neurological conditions and associated factors.

Third, there have been longstanding efforts to develop a state trust fund and/or a Medicaid waiver to support intensive services for TBI survivors and their families. Persons suffering from a severe TBI require an array of short- and long-term treatments, rehabilitation, and home and community supports. Many states have developed specific programs and infrastructure to address the needs of these individuals and their families. To date, about 40 states provide intensive TBI services that are funded by Medicaid waivers, trust funds, or a combination of these 2 sources. North Carolina does not have either funding mechanism, and this has created many hardships for TBI survivors and families across the state.

The North Carolina Brain Injury Advisory Council presented a report to the legislature during the 2014 North Carolina legislative session that examined the benefits of establishing a Medicaid waiver for constituents who have sustained a TBI. Legislation in response to this report directed the Joint Legislative Oversight Committee on Health and Human Services to establish a subcommittee on TBI to study the problem and make recommendations.

The following recommendations were approved in December 2014 with the intent that they will be considered in the 2015 legislative session. First, a Medicaid home- and community-based waiver is the preferred approach to provide state-funded services to individuals with TBI. Second, the Department of Health and Human Services (DHHS) needs to provide more support for the efforts of local management entities/managed care organizations (LME/MCOs) as they attempt to identify veterans who are eligible for federally funded TBI services and to coordinate with the US Department of Veterans Affairs. Third, there is a need for valid and reliable data on the incidence rate of TBI in North Carolina and on the need for subsequent acute, rehabilitative, or long-term services. Fourth, DHHS should ensure that LME/MCOs screen, identify, and collect data on individuals in need of TBI treatment and services.

Finally, from a policy perspective, the state has taken steps to enhance the system of care for individuals with TBI, including paying attention to behavioral health needs. For instance, the state facilitated the development of 2 clubhouses to support persons with TBI, as described in the article by Farmer [7]. This structured environment helps integrate the individual back into the community and, ultimately, fosters a support network crucial for positive behavioral health. This model of care also provides respite for caregivers.

Additionally, the state was awarded a Health Resources and Services Administration (HRSA) Traumatic Brain Injury State Implementation Partnership Grant to focus on information and referral, training, screening, and resource facilitation. The TBI program will contract with the Brain Injury

Association of North Carolina to provide an initial access point for TBI survivors and their caregivers. This concept is further enhanced by the use of a resource facilitator to help clients and caregivers navigate the system. The state will work with the LME/MCOs to increase screening to identify individuals with TBIs and connect them to appropriate behavioral health treatment. All of these aspects foster the development of a medical home for those with TBI.

Prevention Activities

In the 2001 issue of the NCMJ, an article by Hooper and Callahan [4] described a number of prevention-related activities in the state (eg, The Injury Prevention Research Center TBI Prevention Handbook). Since that time, prevention activities have gained increased attention at the national level [8, 9] as well as in North Carolina. Over the past 14 years, there has been an increasing number of TBI prevention strategies employed by the state, with many of these activities being coordinated by the MH/DD/SAS TBI Program, the Brain Injury Association of North Carolina, the North Carolina Brain Injury Advisory Council, and the Matthew Gfeller Sport-Related Traumatic Brain Injury Research Center at the University of North Carolina at Chapel Hill. With the increase of evidence-based guidelines for managing all forms of TBI, including concussions (eg, the Centers for Disease Control and Prevention's Heads Up Program), the state has become much more active with respect to the dissemination of TBI-related materials. A major change that puts the state in a leading position nationally is the state's hiring of a full-time TBI manager to develop, coordinate, and administer statewide prevention and intervention initiatives across the lifespan.

The Current Issue

In addition to the updates and advances mentioned above, the current issue of the NCMJ comprises an array of articles dedicated to key issues and advances in TBI, with a major focus being placed on issues relevant to the state of North Carolina. Each of these articles provides insight into a significant advancement with respect to TBI across the lifespan: epidemiology, concussions, special populations, treatments, and family perspectives.

Any issue devoted to TBI would be remiss without an up-to-date appraisal of the epidemiology of this condition. Although these types of data surface across many of the articles in this issue, the Running the Numbers column by Austin and colleagues showcases the most recent numbers with respect to TBI in North Carolina [10].

As noted above, one of the major advances in the field of TBI over the past decade has been the increased public awareness and associated scientific inquiries related to mild brain injuries or concussions. This issue contains several articles that address facets of this condition. Conder and Conder provide a comprehensive overview of concussion in the sports setting, and they describe how various factors contribute to the manifestation of this form of mild brain injury [11]. Additionally, 3 associated sidebars describe selected issues pertinent to concussion in sports. The sidebar by Bloom provides an overview of North Carolina's sports concussion law, the Gfeller-Waller Concussion Awareness Act, which is an important piece of legislation that has changed how concussions are recognized and managed for student-athletes at the middle school and high school levels, particularly with respect to return-to-play practices [5]. Two additional sidebars address key aspects of managing concussions. The sidebar by Newlin and Hooper provides a complement to the Gfeller-Waller Act's return-to-play procedures by describing the return-to-learn protocol for use with all students who have sustained a concussion across the K–12 grade span [12]. A second article, by Guskiewicz, provides empirical findings with respect to concussion prevention [13].

Another area of interest that has emerged over the past decade has been a focus on special populations. The article by Filer and Harris in the current issue is devoted to the occurrence of falls among elderly individuals and how such events are a leading cause of TBIs within this population [14]. Similarly, with the involvement of our country in multiple wars over the past decade, there has been much attention devoted to our returning veterans, many of whom have sustained concussions and other types of brain injuries. The commentary by Hooker and Moore is focused on this special population and showcases the multiple complex needs of injured veterans when they return from the battlefield [15].

The topic of treatment is a major aspect of this issue, and 3 commentaries are devoted to this area of interest. The commentary by Niemeier and colleagues provides an overview of evidence-based treatments and practices [16], while the commentary by Nelson and coauthors describes advances in prehospital care for individuals who have sustained a TBI, with an inside look at practices in North Carolina [17]. A third commentary, by Santopietro and colleagues, addresses behavioral health, which is an often-overlooked aspect of treatment for individuals following a TBI. This third article addresses the current status of such treatment in the state and suggests that policy provisions could facilitate access to behavioral health care for individuals who have sustained a TBI [18]. In regards to treatment, there have also been some advances made with respect to evidence-based community practices, and the Spotlight on the Safety Net column describes one such effort: the clubhouse model [7].

This issue contains one final sidebar that confronts a major issue that crosses over different populations, different ages, and all treatment approaches: families. The family perspective and the active involvement of family members from the moment of injury through the recovery process should never be overlooked. This sidebar by Herbert provides a powerful description of the family perspective, illustrating the challenges and frustrations of navigating a complex and

fragmented care system, and it has important messages for providers and policy makers alike [19].

Conclusions: State of the State

The articles contained within this issue provide keen insights into not only the advances that have occurred in the state of North Carolina over the past 14 years but also the many ongoing challenges faced by TBI survivors, their families, the communities in which they reside, and their provider networks.

On a positive note, there have been efforts to survey the needs of North Carolina constituents with respect to TBI services in the state, and screening and prevention efforts appear to be more coordinated than they were in 2001. One of the largest accomplishments has come through the North Carolina Department of Public Instruction, Exceptional Children Division, with the changing of their definition to align with an acquired brain injury conceptualization. Similarly, concussions have witnessed an explosion of interest at the national level, in large part due to attention arising from the recognition of concussions in professional athletes and veterans. This attention has led to all 50 states developing and passing sports concussion laws. As evidenced by the commentaries and sidebars in this issue, there have been significant advances not only in how to manage concussions, but also in our understanding of how to prevent them from occurring. Finally, while the state has not developed a TBI surveillance system, our counting of various TBIs has advanced; thus, our understanding of the epidemiology of TBI in the state has improved significantly over the past 14 years. These are the types of data that will continue to advance targeted initiatives in the state.

On the state's list of things to do, North Carolina remains challenged with many of the same issues that were present 14 years ago. For example, despite the preliminary needs assessment conducted in 2007, it took another 7 years for the state to complete a more thorough needs assessment, and these results have not yet been analyzed with respect to setting contemporary goals and objectives for TBI endeavors in the state. Further, North Carolina continues to remain fragmented with respect to how individuals with TBI are served across the lifespan, and associated community-based programs struggle to receive sustainable sources of support, particularly those that provide behavioral and mental health care. In that regard, the North Carolina DHHS was asked by the Legislative Oversight Committee for DHHS to begin writing and applying for a Medicaid TBI waiver, after determining that development of a waiver is a viable way to proceed for state constituents. It is understood that this is only a beginning step in stimulating the development of an appropriate continuum of care for all constituents with TBI and that much more will need to be done in the future, but this is a historic first step. The North Carolina Brain Injury Advisory Council is currently working with DHHS to draft the language and select service definitions for this TBI waiver. At present, North Carolina remains 1 of only 10 states that have not enacted some form of financial assistance for this population. As a final item on the state's "to do" list, initial efforts to address screening have begun, but how screening strategies will be implemented across our various state systems remains unknown. These TBI-related issues, amidst a number of others, remain ongoing challenges for the state to tackle in the next decade. NCMJ

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