

MARYLAND

Traumatic Brain Injury Advisory Board



2019

Annual Report

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This year we are partnering with the Brain Injury Association of Maryland (BIAMD) to highlight the Marylanders with brain injuries this board was created to represent. As part of BIAMD’s Unmasking Brain Injury 2.0 project, Marylanders with brain injuries and their caregivers were asked to create masks to help us put a face on this “invisible epidemic”. BIAMD then asked them to tell their story and describe their mask.

Throughout this report, you will find photos of masks and a QR code which you can scan with any smartphone or tablet camera app which will take you to a short video to let the individual personally tell you their story and describe their mask.



Laurie E.
Motor Vehicle Accident



PREFACE

The views in this report reflect those of an independent group of experts with a broad range of personal and professional experience both in Maryland and nationally. To examine traumatic brain injury, the State Traumatic Brain Injury Advisory Board (TBIAB) was established in 2005 by Senate Bill 395, Chapter 306 of the Laws of Maryland. The TBIAB consists of 36 voting members including individuals who have experienced a brain injury, family members and caregivers, advocates, professionals in the field of brain injury prevention and rehabilitation, and state agency representatives.¹ Board members review available data and publications as well as promising practices from other states. The board values the input of individuals who are living with a traumatic brain injury (or TBI) related disability and family members who are caring for individuals with TBI. The information and recommendations in this report are intended to educate policy makers and influence state policy and does not necessarily reflect the current views of the state agencies involved.

The TBIAB is charged with investigating the needs of citizens with TBI, identifying gaps in services to citizens with traumatic brain injuries, facilitating collaboration among Maryland agencies that provide services to individuals with traumatic brain injuries, facilitating collaboration among organizations and entities that provide services to individuals with traumatic brain injuries, and encouraging and facilitating community participation in program implementation.

The Maryland Annotated Code's Health-General Article (HG) § 13–2105(6) requires the TBIAB to submit an annual report summarizing the actions of the TBIAB and containing recommendations for:

1. providing oversight in acquiring and utilizing state and federal funding dedicated to services for individuals with traumatic brain injuries;
2. building provider-capacity and provider-training that address the needs of individuals with traumatic brain injuries; and
3. improving the coordination of services for individuals with traumatic brain injuries.

HG § 13–2105(6) also requires the TBIAB to include information concerning the services and the number of individuals served in the preceding fiscal year, which is discussed in the Maryland Department of Health's (Department) report on the state Brain Injury Trust Fund under HG § 13–21A–02.

EXECUTIVE SUMMARY

Brain injury is a preventable public health issue. It is the leading cause of injury-related death and disability in the United States. Brain Injury may occur from a traumatic injury or a non-traumatic injury or disease and affects individuals of all ages.

¹ See *infra*, pp. 19–20.

Maryland has an array of services available to individuals with disabilities; however, few are specialized for the needs of individuals living with brain injury. Service gaps in Maryland largely revolve around the lack of coordination of available services and supports, limited access to case management and home and community based supports, misdiagnosis or under-identification of brain injury by educators and human service professionals, and inadequate clinical services to support individuals who experience neurobehavioral issues following a brain injury.

The TBIAB's recommendations for Maryland are intended to address these service gaps and reduce the public health burden of brain injury through appropriate resource linkage, training, effective screening practices, and availability of specialized services.

- I. Appropriately identify children and youth with brain injuries.
- II. Implement brain injury screening protocols and offer treatment accommodations to individuals receiving behavioral health services and those incarcerated in jails and prisons.
- III. Expand and improve services offered through the Maryland Brain Injury Waiver.
- IV. Increase funding to allow implementation of the Maryland Brain Injury Trust Fund program.
- V. Establish a central registry of individuals living with a disability as a result of a brain injury and ensure that these individuals and their families are provided information about appropriate resources and assistance.



Cheryl
Drunk Driving Motor
Vehicle Accident



UNDERSTANDING BRAIN INJURY

WHAT IS AN ACQUIRED BRAIN INJURY?

An acquired brain injury (ABI) is defined as: “Damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease. These impairments may be temporary or permanent and cause partial or functional disability or psychosocial maladjustment.”²

An ABI may occur from a traumatic injury or a non-traumatic injury or disease and affects individuals of all ages. A non-TBI or disease may be caused by strokes, infections of the brain such as viral encephalitis, brain tumors, and loss of oxygen to the brain which may be caused from a heart attack, choking, near drowning, drug overdose, carbon monoxide poisoning or other anoxic or hypoxic conditions.

WHAT IS A TRAUMATIC BRAIN INJURY?

A TBI is caused by external forces to the brain including motor vehicle crashes, motorcycle and scooter crashes, falls, assaults, sports injuries, explosive blasts, gunshot wounds to the head, objects falling on the head, and sharp objects penetrating the skull.

SEVERITY AND SYMPTOMS

Brain injury may be classified as mild, moderate, or severe depending on the patient’s neurologic signs and symptoms. Everyone experiences brain injury differently. Brain injury can impair mobility, coordination, dexterity, memory, learning, attention, sleep, and sense of sight, hearing, vision, taste and or smell. A brain injury can also cause headaches, fatigue, mood disorders, post-traumatic epilepsy, and increased risk of dementia and substance use disorders. Exposure to brain injury is associated with employment problems, onset of mental illness, and early death. Caregivers of people with brain injury may also experience negative health effects, including stress-related disorders and depression.

PREVENTING TRAUMATIC BRAIN INJURY

The TBIAB exists to ensure effective treatment and rehabilitative services for those affected by TBI. However, it is equally as important from a public health perspective, to identify and decrease risks factors to prevent TBI and its associated disability. Prevention strategies to reduce the likelihood of sustaining a brain injury include, but are not limited to: wear a seatbelt when driving or riding in a motor vehicle, secure children ages zero to eight in a child safety seat, wear a helmet or appropriate headgear when playing contact sports, biking, motorcycling, snowmobiling or riding a scooter. Additionally, older adults should talk with their physician about evaluating their risk for falling, assess their home for fall-related hazards, have regular eye exams and have their pharmacist review their medications for fall risk. For young children, it is important to ensure play areas are safe for children, install window guards to keep young

² World Health Organization—Geneva 1996.

children from falling out of windows, use safety gates at the top and bottom of stairs, and choose playgrounds with soft material underneath. For more information on preventing TBI please visit the Centers for Disease Control and Prevention (CDC) website.³

UNMASKING BRAIN INJURY

The mission of Unmasking Brain Injury, a nonprofit organization based out of North Carolina, is to promote awareness of the prevalence of brain injury; to give survivors a voice and the means to educate others of what it's like to live with a brain injury; to show others that persons living with a disability due to their brain injury are like anyone else, deserving of dignity, respect, compassion and the opportunity to prove their value as citizens in their respective communities. In the spring of 2018, members of the TBIAB in association with the Brain Injury Association of Maryland participated in the national Unmasking Brain Injury initiative by providing masks and craft supplies to individuals with brain injuries to tell their stories and express their feelings about brain injury through art. Since then, the Brain Injury Association of Maryland has assisted 68 Marylanders with brain injury to create a mask that tells their story. These masks are incredibly powerful. The stories behind them demonstrate hardship, pain, strength, determination, resilience and joy. The TBIAB strongly encourages the readers of this report to visit this site and learn about Brain Injury from the perspective of Marylanders with firsthand experience of this life altering injury.⁴



Steve S.
Bicycle Accident



BRAIN INJURY INCIDENCE DATA AND RESEARCH

NATIONAL INCIDENCE DATA

Brain injury is a preventable public health issue. It is the leading cause of injury-related death and disability in the United States.

According to the Center for Disease Control and Prevention:

³ CDC Traumatic Brain Injury & Concussion, Prevention (last reviewed Mar. 4, 2019), online at <https://www.cdc.gov/traumaticbraininjury/prevention.html>, (all Internet materials as last visited Oct. 15, 2019).

⁴ Brain Injury Association of Maryland, Unmasking Brain Injury, online at <https://www.biamd.org/unmasking-brain-injury-20.html>.

- J In 2014, about 2.87 million emergency department (ED) visits, hospitalizations, or deaths were related to TBI, including over 837,000 of these health events among children.
- J TBI contributed to the deaths of 56,800 people, including 2,529 deaths among children. These consisted of TBI alone or TBI in combination with other injuries.
- J In 2014, an estimated 812,000 children (age 17 or younger) were treated in U.S. hospital ED for concussion or TBI alone, or in combination with other injuries.
- J Between 2006 and 2014, while age-adjusted rates of TBI related ED visits increased by 54%, hospitalization rates decreased by 8% and death rates decreased by 6%.
- J The total cost of ED visits, hospitalizations, and deaths related to TBI, either alone or in combination with other injuries, exceeds \$82 billion annually—this includes medical and work loss costs.⁵

MARYLAND INCIDENCE DATA⁶

According to the Department, Center for Sexual Assault and Injury Prevention, in Maryland in 2015, there were:

- J More than 600 TBI related deaths;
- J 4,422 TBI related hospitalizations; and
- J Almost 40,000 TBI related ED visits.

UNCAPTURED DATA

Many people who experience a mild brain injury, such as a concussion, receive medical care from a physician's office, urgent care center, or perhaps receive no medical attention at all. These data are underrepresented and not reflected above because reporting is not required for TBI treated in settings other than hospitals.

Also, missing from these data are other acquired causes of brain injury that do not fall under the TBI diagnosis. These other causes include near drowning, suffocation, strokes, and opioid-related overdoses and other unintentional poisonings.

⁵ CDC Traumatic Brain Injury & Concussion, Get the Facts, online at https://www.cdc.gov/traumaticbraininjury/get_the_facts.html.

⁶ Akinyemi, Maryland Department of Health Center for Injury Epidemiology, Traumatic Brain Injury (TBI)-related Emergency Department (ED) visits, Hospitalizations and Deaths: Maryland 2012–2015 (Sep. 14, 2017), online at https://phpa.health.maryland.gov/ohpetup/Documents/TBI_AdvisoryBoard_data_Sept2017_Final.pdf.

The interplay between opiate use and brain injury is significant. Individuals who have sustained a brain injury are at increased risk accidental poisoning, such as an opiate overdose. Anoxic and hypoxic brain injuries are on the rise due to the high use of opioids. Opiate use depresses the nervous system and affects breathing. In a drug overdose, the brain is deprived of oxygen resulting in brain damage or death.

An overdose is an injury to the body (poisoning) that happens when a drug is taken in excessive amounts. An overdose can be fatal or nonfatal. Opioid overdose induces respiratory depression that can lead to an anoxic/hypoxic brain injury (NASHIA Fact sheet 2018).

LATEST BRAIN INJURY RESEARCH

Mild TBI and risk of mental health issues—A new study reveals that approximately one in five individuals may experience mental health symptoms up to six months after mild traumatic brain injury (mTBI), suggesting the importance of follow-up care for these individuals. Scientists also identified factors that may increase the risk of developing post-traumatic stress disorder (PTSD) and/or major depressive disorder following mild mTBI; these include: lower levels of education, self-identifying as African-American, and having a history of mental illness. In addition, if the head injury was caused by an assault or other violent attack, that increased the risk of developing PTSD, but not major depressive disorder. Risk of mental health symptoms was not associated with other injury-related occurrences such as duration of loss of consciousness or posttraumatic amnesia. The study was supported by the National Institute of Neurological Disorders and Stroke, part of the National Institutes of Health. The findings were published in *JAMA Psychiatry*.⁷

TBI and Adverse Childhood Experiences—Adverse childhood experiences (ACEs) are significant risk factors for physical and mental illnesses in adulthood. Traumatic brain injury/concussion is a challenging condition where pre-injury factors may affect recovery. Based on literature reviews, a positive association between adverse childhood experiences and TBI occurrence was identified. The review highlights the importance of screening and treatment of ACEs. Exposure to ACEs is associated with increased risk of TBI. Specific types of adverse childhood experiences associated with risk of TBI include childhood physical abuse, psychological abuse, household member incarceration, and household member drug abuse. Clinicians and researchers should screen for a history of about adverse childhood experiences in all people with TBI as pre-injury health conditions can affect recovery.⁸

⁷ Murray B. Stein et al. Risk of Posttraumatic Stress Disorder and Major Depression in Civilian Patients After Mild Traumatic Brain Injury A TRACK-TBI Study. *JAMA Psychiatry*, 2019 DOI: [10.1001/jamapsychiatry.2018.4288](https://doi.org/10.1001/jamapsychiatry.2018.4288).

⁸ Zechen Ma, Mark T. Bayley, Laure Perrier, Priya Dhir, Lana Dépatie, Paul Comper, Lesley Ruttan, Christine Lay & Sarah E. P. Munce (2019) The association between adverse childhood experiences and adult traumatic brain injury/concussion: a scoping review, *Disability and Rehabilitation*, 41:11, 1360-1366, DOI: [10.1080/09638288.2018.1424957](https://doi.org/10.1080/09638288.2018.1424957).

TBI and Substance Use Related Disorders—TBI is common among people who have a substance use related disorder. Over 20% of non-institutionalized adults in the United States have had at least one TBI with a loss of consciousness, and this estimate more than doubles among people with a substance use related disorder. Individuals with co-occurring substance use related disorders and mental health problems are even more likely to have a history of TBI. The increased vulnerability for misuse and addiction to other substances (*e.g.*, alcohol) among people with TBI suggests the same may be true with opioids.⁹



Chuck C.
Motorcycle Accident



SERVICES, SUPPORTS, AND GAPS IN MARYLAND¹⁰

Maryland has an array of services available to individuals with disabilities; however, few are specialized for the needs of individuals living with brain injury.

-) Services and supports that are currently available to Marylanders who sustain a brain injury include: trauma and emergency services, inpatient and outpatient rehabilitation, long-term services and supports (both institutional services such as home- and community-based services and nursing facilities), special education services and educational accommodations for students, behavioral health services, case management, and active advocacy organizations.
-) The gaps in Maryland largely revolve around the absence of available services within many geographic areas in the state and lack of coordination and specialization of these services and supports. Further complicating these issues are: limited access to case management and home- and community-based supports, misdiagnosis or under-identification of brain injury by educators and human service professionals, and inadequate clinical services to support individuals who experience neurobehavioral issues following a brain injury.

⁹ Brandeis University, Heller School for Social Policy and Management, Publications and Products, online at <https://heller.brandeis.edu/ibh/research/inroads/publications-products.html>.

¹⁰ See Appendix A, *infra* pp. 22–23, for more details about Maryland services and service gaps.

MARYLAND ACCOMPLISHMENTS¹¹

Since the establishment of the TBIAB, progress has been made to improve the system of services and supports available to Marylanders with brain injury. Through active participation in a multitude of committees, workgroups and task forces, the TBIAB has successfully advocated for policy changes, including the creation of the State Dedicated Brain Injury Trust Fund, the concussion bill, meaningful changes to the Brain Injury Waiver, implementation of brain injury screening protocol for certain public behavioral health services, and ongoing protections for Maryland's motorcycle safety laws.



George O.
Caregiver



SCAN ME



Sandra B.
Skiing Accident



SCAN ME

RECOMMENDATIONS FOR MARYLAND

The TBIAB's recommendations for Maryland have not changed from the 2017 TBIAB annual report.

The recommendations in this report are intended to reduce the public health burden of brain injury through appropriate resource linkage, training, effective screening practices, and availability of specialized services.

I. Appropriately identify children and youth with brain injuries.

The State of Maryland shall improve identification of students with brain injuries by:

-) requiring local education agencies to add three questions, designed to capture incidence of brain injury or loss of consciousness suffered at any time by the student, to existing annual school health forms; and
-) requiring local education agencies to add three questions, designed to capture incidence of brain injury or loss of consciousness suffered at any time by the student, to the special education identification process; and

¹¹ See Appendix B for more information about Maryland Brain Injury accomplishments.

- J) increasing dissemination of concussion prevention, awareness materials, and brain injury training to: school psychologists, pupil personnel works, counselors, teachers, administrators, specialists, health room staff, athletic departments, coaches, trainers, students, parents, and any other stakeholders.

Progress made since last report

In 2019, legislation designed to study identifying practices was introduced in the Maryland House of Delegates, where it passed unanimously. The proposed legislation did not make it out of committee in the Senate.¹²

Analysis

Brain injury often has a significant impact on the development and functioning of an individual. This is especially true in the developing brains of children and adolescents. Difficulties with problem solving, impulsivity, memory, new learning, and self-regulation are some of the common sequelae of brain injury and represent just some of the serious and potential lifelong consequences of TBI. The CDC 2018 Report to Congress¹³ includes information and tools for healthcare providers, educators, parents, and students to assist with acute medical management of the injury in children as well as recommendations for long-term monitoring and transition to school. The report demonstrates increasing evidence of the relationship between long-term disability and behavioral health conditions that impact functional achievements in adulthood, highlighting the importance of timely, appropriate intervention with children.

Recently, the under identification of students with lasting TBI sequelae is gaining more attention nationally and several states are considering how to best address this problem. According to the Department in 2017 alone there were 4,794 ED visits and 210 hospitalizations for Marylanders ages 0–18 years old with a diagnosis of TBI. This total does not capture the full extent of brain injury among this age population, as it does not include those seen by private practitioners, in urgent care facilities, or not seen at all. It also most likely does not capture most incidences of “mild” and “moderate” brain injury, even though the effects from these types of brain injuries can be devastating and can have long term impacts on an individual’s cognition and functioning. Yet, despite the large number of severe brain injuries reported among school-aged children, there are currently only 221 Maryland students, according to the Maryland State Department of Education’s 2017 Special Education Census, ages birth through 18, receiving special education

¹² See General Assembly of Maryland, HB0708, online at <http://mgaleg.maryland.gov/webmga/frmMain.aspx?pid=billpage&stab=01&id=hb0708&tab=subject3&ys=2019RS> (House Bill 708, Education—Identification of Students with Traumatic Brain Injury—Study and Report, received a favorable vote (138–0) on the House Floor); General Assembly of Maryland SB0778, online at <http://mgaleg.maryland.gov/webmga/frmMain.aspx?pid=billpage&stab=01&id=sb0778&tab=subject3&ys=2019rs>. (Senate Bill 778 received an unfavorable report by the Education, Health, and Environmental Affairs Committee).

¹³ CDC National Center for Injury Prevention and Control, Division of Unintentional Injury Prevention, Report to Congress: The Management of Traumatic Brain Injury in Children (2018), online at <https://www.cdc.gov/traumaticbraininjury/pdf/reportstocongress/managementoftbiinchildren/TBI-ReporttoCongress-508.pdf>.

services with their primary disability¹⁴ determined to be TBI. This is 0.2% of the total population of students currently receiving special education services in Maryland schools.

Under-identification of brain injury may occur because TBI symptoms can be misinterpreted as other disabilities, such as emotional disability and learning disability which may lead to inappropriate individualized education plans with goals and objectives that do not fully address the student's actual needs. The results from improved brain injury identification will help: (1) the identification of students who were not previously identified as having a brain injury and who may need further assessments to determine their need for additional services, supports, and accommodations; (2) increase the likelihood that students with TBI will be appropriately identified by creating and using the screening as evidence for further exploration; and (3) identify appropriate assessments and services for a student based on their history of TBI.

According to a 2017 study published by that National Institutes of Health the effects of TBI on cognition, emotional functioning, and behavior are well known but even professionals sometimes fail to connect learning and other problems to a TBI. This delayed recognition of TBI may "lead to unnecessary chronic and disruptive problems in activities and participation" including learning and school.¹⁵

Effective TBI identification is a crucial and inexpensive tool that can be used to avoid delayed diagnosis and treatment of children who have incurred a TBI. Early diagnosis leads to early treatment and often reduces or eliminates the need for longer term treatment and the associated costs. This is especially true when discussing the child's educational performance. Additionally, by providing appropriate interventions and supports the child with TBI is more likely to have better performance in school, decreased negative behaviors, and overall more positive long-term outcomes.

II. Implement brain injury screening protocols and offer treatment accommodations to individuals receiving public behavioral health services and those incarcerated in jails and prisons.

The Department should:

- J Convert the TBI screening questions that are currently built into the authorization process for two mental health services to mandatory responses (they are currently optional questions); and
- J Expand these questions to additional public behavioral health service authorization workflows.

¹⁴ Primary disability is determined under the federal Individuals with Disabilities Education Act, 104 Stat. 1142.

¹⁵ Van Heigten, Renault, and Resch, The role of early intervention in improving the level of activities and participation in youths after mild traumatic brain injury: a scoping review, *Concussion*, 2017 Nov; 2(3): CNC38. Published online 2017 Aug. 10. DOI: [10.2217/cnc-2016-0030](https://doi.org/10.2217/cnc-2016-0030).

Progress made since the Last Report

The Behavioral Health Administration (BHA) implemented a brief brain injury screening into the online authorization process for certain behavioral health services, *e.g.*, psychiatric rehab and mobile treatment, in early 2017. The screening questions are based on the Ohio State University TBI Identification Method (OSU TBI-ID) quick screen.

<p><u>OSU TBI-ID Quick Screen Questions:</u></p> <p>Ever knocked out or lost consciousness? <i>Yes, No, Not screened</i></p> <p>Longest time knocked out? <i>Less than 30 minutes, 30 minutes–24 hours, > 24 hours</i></p> <p>Age (1–99) when first knocked out or lost consciousness? ____</p>
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For mobile treatment services, in FY17, 2,863 people received a mobile treatment service. Forty-seven percent of those individuals were administered the brief screen. Of those, five percent screened positive for a history of brain injury. In FY18, 3,764 people received mobile treatment services. Forty-two percent of those individuals were administered the brief screen and three percent screened positive for a history of brain injury.

For Psychiatric Rehabilitation services, in FY17, 10,830 people received the service. Fifty-seven percent of those individuals were administered the brief screen and five percent of those screened positive for a history of brain injury. In FY18, 17,272 received the service. Sixty-one percent were administered the brief screen and four percent screened positive for a history of brain injury.

Training is being provided statewide to behavioral health providers on brain injury screening and accommodations to behavioral health treatment. BHA intends to mandate the TBI quick screen in the next phase of implementation within the next couple of years as part of a newly-awarded federal grant that is focused on improving behavioral health care and access for individuals with TBI. Currently most individuals are not screened and the responses may not be reliable.

Why is this important?

Individuals who sustain a brain injury have increased risk of developing a mental illness, a substance use disorder, become incarcerated, and or to experience homelessness. Most individuals who sustain a brain injury in Maryland will not receive services from a specialized brain injury program or provider. Most will either receive no services or receive services from systems or programs that are designed for other diagnosis or disabilities. The unique deficits that result from a brain injury are often misinterpreted as malingering or non-compliance when in fact the individual receiving services may be struggling with cognitive, physical or behavioral

challenges that require a knowledgeable provider to make accommodation to treatment to ensure the service recipient can participate effectively.

The best practice to ensure individuals with brain injury are successful in these settings is to screen for a history of brain and learn how to provide basic treatment accommodations. Several screening tools exist. One tool, the Ohio State University TBI Identification Method, is currently being used by some Maryland behavioral health providers. The tool and the training materials are free to the public.¹⁶

Brain injury is often not a visible disability, and yet a history of a brain injury can result in significant disability that can impact clinical outcomes, social functioning, employment, and mental health. Many individuals who have sustained brain injury are often not aware of the impact of their injuries and may not know the importance of reporting their brain injury or seeking aftercare or supports.

Facilitating brain injury informed awareness among human service providers and agencies, along with implementation of TBI screening measures is critical to providing comprehensive, person centered care. BHA has taken the initiative to implement both brain injury screening and accommodations training for certain mental health services and providers. It is important to expand these efforts to other behavioral health services as well as services provided to individuals experiencing homelessness, victims of domestic violence, and recipients of all home- and community-based services.



Teth
Motor Vehicle Accident



III. Expand and improve services offered through the Maryland Brain Injury Waiver¹⁷

The Department should improve the quality and quantity of resources for people with complex needs resulting from brain injury by:

¹⁶ Wexner Medical Center, Ohio State University TBI Identification Method, online at <https://wexnermedical.osu.edu/neurological-institute/departments-and-centers/research-centers/ohio-valley-center-for-brain-injury-prevention-and-rehabilitation/osu-tbi-id>.

¹⁷ Maryland's Home and Community Based Services Waiver for Individuals with Brain Injury is a Medicaid program that provides community-based services to individuals with brain injury as an alternative to care in an institutional setting such as a nursing facility or chronic hospital.

-) changing the eligibility for the Brain Injury Waiver to a neurobehavioral-needs-based set of criteria rather than facility-based access; and
-) revising individual support service descriptions and rate to ensure that the individual support service rates promote success in independent housing.

Progress made since the Last Report

BHA, Western Maryland Hospital Center (WMHC), and the Brain Injury Association of Maryland implanted weekly meetings to review referrals and facilitate admission to WMHC's Brain Injury unit, one of the facilities currently included in the facility based eligibility criteria, for rehabilitation services as well as to facilitate access to the brain injury waiver program. A neurobehavioral needs-based set of criteria has been developed for this purpose.

In 2018, changes were made to the individual support services related to increment of time. Originally an hourly service, individual support services may now be provided in 15-minute increments, increasing flexibility for the provision for the service. BHA has created a workgroup consisting of waiver participants who have or are interested in transitioning to independent housing, families, waiver case managers, and providers to examine and or develop assessment tools, independent living skills groups and supports, and housing referral protocol.

Why is this important?

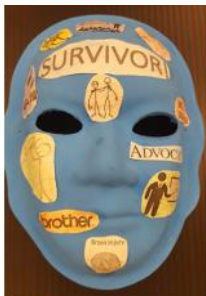
Most individuals with brain injury will not receive services designed for their needs. Approximately 3,000 Medicaid beneficiaries with brain injury receive services in a Maryland nursing facility each year.¹⁸ Fewer than 800 of those beneficiaries are enrolled in Medicaid home- and community-based services. Since 2015, 316 people have inquired about brain injury waiver services, according to available reports generated through the web-based waiver administrative system called Long Term Services and Supports Maryland. Of those individuals, 133 have received brain injury waiver services, while 18 people were denied services. A total of 183 individuals who inquired were not served by the brain injury waiver. Some of these individual have been served through other home and community-based programs.

Despite the prevalence of brain injury among Medicaid beneficiaries who require long-term care services, there are only a limited number of slots in the Brain Injury Waiver. Narrow technical eligibility further limits access to this program. The Brain Injury Waiver is currently based on facility-based access, meaning that it is limited to individuals transitioning out of four state-operated chronic hospital or nursing facility settings and five state psychiatric hospital settings. However, access to the Brain Injury Waiver should be based on the actual neurobehavioral needs of people who have experienced brain injuries. The Brain Injury Waiver Program is designed to support individuals with significant behavioral and cognitive issues that result from their injury and who have identifiable, practical goals focusing on independent living, supervised living, work readiness, and recovery from mental illness or substance-related disorders. However, only individuals in certain hospital settings meet technical eligibility for the program. Individuals living in the community or nursing facilities who are struggling with these issues are not eligible.

¹⁸ The Hilltop Institute, 2013.

Expanding access to this valuable program can reduce rates of institutionalization, incarceration, hospitalizations, and overall costs to the state for individuals in need of these specialized services.

Historically, brain injury waiver service utilization has been highest for residential services and day habilitation, costly services with limited provider capacity. Affordable housing initiatives—such as Bridge Subsidy, HUD 811, and Weinberg and Mainstream Housing—have become increasingly available since the implementation of Maryland’s Money Follows the Person Demonstration. Five years ago, the waitlist for these programs was years long but now waiver participants are able to access these programs within months. This has resulted in a positive change in service utilization for the brain injury waiver. At the time of this report, 14 waiver participants (13% of the waiver population) is living in independent housing with waiver support services. Twenty-five additional brain injury waiver participants are currently on the wait list for the subsidized housing programs. Overall costs to the State for participants who have transitioned to independent housing is on average less than half of that for participants living in a provider owned or controlled residential setting. Brain injury providers however have expressed concern about the inadequacy of the rates and uncompensated services they are providing to participants to ensure health and welfare. Evidence suggests that housing and employment drive recovery and have positive impacts on self-report of quality of life. A large number of waiver participants indicate an interest in living independently during the annual participant experience survey. This convergence of participant needs and preferences with affordable housing opportunities has created a priority for the Department to address in terms of rate and service adequacy.



Martin K.
Hit by a Car



Terrence W.
Motorcycle Accident



IV. Increase funding to allow implementation of the Maryland Brain Injury Trust Fund.

The State should support a system of coordinated case management and support services for people with brain injury who are not eligible for Maryland’s Brain Injury Waiver Program by:

-) allocating appropriate state general funds to the Trust Fund;
-) increasing revenue generated through the voluntary donation program for vehicle registrations by increasing donation demonization options; and

) Implementing a system to provide services set forth in statute.

Progress made since the Last Report

The TBIAB is very appreciative of the efforts of legislators and state leaders at the Maryland Department of Transportation and the Maryland Department of Health for the creation of a revenue source for Maryland's Brain Injury Trust fund. The Maryland Department of Transportation created a voluntary donation option for vehicle registration transactions completed via kiosk or online. Donations are transferred to Maryland's Brain Injury Trust fund, managed by BHA. Revenues are not yet sufficient to support the types of services identified in the law.



Why is this important?

Pursuant to HG § 13–21A–02(i), the Department is required to submit a report on the State Brain Injury Trust Fund, including the number of individuals served and the services provided in the preceding fiscal year using the fund. Since the passage of Senate Bill 632, Chapter 511 of the Acts of 2013, the Department has accrued \$8,332 through the voluntary vehicle registration donation program at time of this report. The Department is unable to provide services to any individuals with a brain injury through this fund since its inception. The Department did establish an account (PSA Code M258S) for this purpose and has the capacity to allocate funding for services once adequate monies are received.

The Department has established a Trust Fund Advisory Committee to advise and assist with developing list of covered services, service descriptions, provider requirements, and conditions for participant participation. This committee projects that a general fund allocation is needed to begin service provision. This would provide approximately 50 Marylanders with brain injury 10 hours of case management/ support services per week. Currently, 24 states have created brain injury trust fund programs and Maryland's is by far the most poorly funded.

If adequately funded, this fund would provide services to individuals with a medically documented brain injury with incomes 300% of the federal poverty level who are in need of case management in order to navigate Maryland's service delivery system. BHA has been tasked with identifying the services to be covered under the fund and the costs of providing those services, as well as developing the policies and procedures for administration of the fund.

Case management or care coordination is the highest priority service to be covered through this fund for the following reasons:

-) it significantly improves timely access to available services and supports, which potentially reduces costs over time;
-) it is considered a best practice among state brain injury programs as well as the workman’s compensation industry and the Department of Defense;
-) only a small percentage of Marylanders with brain injury are able to access Medicaid-funded case-management services, and private insurance does not cover case-management; and
-) the existence of an established brain injury case-management or care-coordination program will help identify the other gaps and priorities that may need to be covered through the fund.

V. Establish and administer a central registry of individuals living with a disability as a result of a brain injury and ensure that these individuals and their families are provided information about appropriate resources and assistance in order to comply with HG § 20–108.

The Department of Health must establish and administer a central registry to compile information about individuals with brain injuries (“head injuries”) and ensure that those individuals and their families are provided information about appropriate resources and assistance.

Progress made since the Last Report

BHA was awarded a three-year federal grant in June 2018. Among other grant activities, BHA will use these grant funds to establish an implementation strategy for the Maryland TBI Registry.

Why is this important?

Under HG § 20–108, each hospital is required to report to the Department within seven days of the occurrence of a “reportable condition.” Within 15 days of receiving a report of an individual with a reportable condition, the Department shall notify the individual or the individual’s parent or guardian of any assistance or services that may be available from the state and of the eligibility requirements for such assistance or services. Upon request from the individual, the Department shall refer the individual to appropriate divisions of the Department and other agencies, public or private, which provide rehabilitation services for persons with reportable conditions.

As far as the TBIAB is aware, hospitals are not reporting the occurrences of individuals with disabilities in their institutions with “head injuries” within seven days. In addition, as far as the TBIAB is aware, the Department has not implemented the statutorily required central registry to

compile information about individuals with disabilities with reportable conditions. Furthermore, as far as the TBIAB is aware, the Department is not notifying the individual or the individual's parent or guardian of any assistance or services that may be available from the state and of the eligibility requirements for such assistance or services within 15 days.

This gap in reporting, compiling, and notification is negatively affecting the lives of every Maryland family, especially those living with the medical and behavioral health consequences of brain injury. It impairs data collection and analysis for purposes of legislative and policy initiatives. It limits the number of individuals and family members receiving timely information and resources at the most vulnerable time of this family crisis. It restricts the ability of state agencies and advocacy groups to present accurate pictures of the severity and breadth of impact of brain injury in Maryland. It leaves many families without the critical information and contacts, and more importantly, the hope they need to address the myriad of issues created when a loved one has a brain injury. The failure to implement this statute also negatively impacts individuals with the other listed "reportable conditions," including spinal cord injury, stroke, and amputation. With this recommendation, the TBIAB is merely asking for the Department to do what, by law, should have been doing over the past 30 years.

MARYLAND BRAIN INJURY RESOURCES

Governor TBI Advisory Board

Website for TBIAB reports, meeting minutes, and manual

<https://bha.health.maryland.gov/Pages/mdtbiadvisoryboard.aspx>

Advocacy, Information, and Assistance

Brain Injury Association of Maryland

www.biamd.org

Maryland Lead Agency of Brain Injury

Maryland BHA

<https://bha.health.maryland.gov/Pages/Traumatic-Brain-Injury.aspx>

Maryland Injury Data

The Department's Violence and Injury Program

https://phpa.health.maryland.gov/ohpetup/Documents/TBI_AdvisoryBoard_data_Sept2017_Final.pdf

Legal

Disability Rights Maryland

<https://disabilityrightsmd.org/>



Kimberley L.
Domestic Abuse
Incident



MARYLAND TBIAB MEMBERSHIP

Thirty-six members constitute the Maryland TBIAB, as set forth in HG §§ 13–2101 through 13–2105. Membership consists of individuals who have sustained a brain injury, family members and caregivers, advocacy organizations, professionals working in the field of brain injury treatment and rehabilitation, Maryland state agencies, and two members of the Maryland state legislature. Half of the membership is appointment by the Governor, and half is appointed by the directors of the agencies that are required by statute to serve on the board.

TBIAB has established SAFE, a standing committee. The SAFE committee was created as a place for the members of the Maryland TBIAB who are living with a brain injury or who are family members of individuals with brain injuries to obtain support and a sense of unity in board matters. One of the main goals of the committee is to ensure that individuals with brain injury and family members are active participants in board meetings and activities.

The *Vision* of the TBIAB is to prevent brain injury and maximize the quality of life for every Marylander affected by brain injury.

The *Mission* of the TBAIB is to identify needs, gaps in services, and potential funding resources by building relationships and collaborating with elected officials and heads of state agencies that will influence policy and promote prevention, education, and effective interventions in order to support recovery and quality of life for every Marylander affected by brain injury.

Board Membership

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APPENDIX A

DESCRIPTION OF MARYLAND SERVICE SYSTEMS

SERVICE AREA	AVAILABLE SERVICES	SERVICE GAPS
Trauma Care	Emergency care for TBI is provided by Maryland's Emergency Medical Services (EMS) System, a coordinated statewide network that includes volunteer and career EMS providers, medical and nursing personnel, communications, transportation systems, trauma and specialty care centers, and EDs.	Many individuals who sustain TBI, such as a concussion, do not seek treatment in these settings. They often see treatment in a physician's office or an urgent care center or seek no treatment at all. As a result, a TBI can be undiagnosed or misdiagnosed and the impact of the injury and resulting deficits underestimated, leading to lack of adequate follow up and supports.
Brain Injury Rehabilitation	Maryland offers inpatient and outpatient rehabilitation services, accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF), for inpatient and outpatient rehabilitation facilities and programs.	The length of stays in inpatient facilities has decreased significantly over the years, and it is now increasingly more common for individuals with brain injury to receive rehabilitation in a nursing facility (no nursing facilities have specialized brain injury programs) or to have little or no access to rehabilitation services.
Case Management	Case management is defined by the Centers for Medicare and Medicaid Services as a service that helps eligible people gain access to needed medical, social, educational, and other services. Maryland's Medicaid case-management services, which are provided under a number of programs, vary in name and scope and are offered by a variety of providers. Case management has been demonstrated to help reduce readmissions to hospitals and improve rehabilitation outcomes.	Maryland only offers case management to those enrolled in home- and community-based services, including targeted case management for individuals with mental illness. Most Marylanders with brain injury are not enrolled in those Medicaid programs. The lack of case management limits timely access to appropriate services and supports and thereby negatively affects clinical outcomes.

TBI Registry

Maryland law, set forth in HG § 20–108, makes “head injury” a “reportable condition.” Each hospital is required to report to the Department within seven days of the occurrence of a reportable condition. The Department is required to establish a central registry to compile information about disabled individuals with reportable conditions and within 15 days of receiving a report of an individual with a reportable condition, notify the individual or the individual’s parent or guardian of any assistance or services that may be available from the state and of the eligibility requirements for such assistance or services. Upon request from the individual, the Department shall refer the individual to appropriate divisions of the Department and other agencies, public or private, which provide rehabilitation services for persons with reportable conditions.

This statute was not implemented, and hospitals are not currently reporting “head injuries” to the Department. This gap in reporting, compiling, and notification is negatively affecting the lives of every Maryland family dealing with brain injury. As a result, individuals and family members receive limited to no information and resources when the opportunity for recovery afforded by access to appropriate care is most critical. The long term negative impact affects public health at the systemic level as well as the lives of individuals with brain injury and their families

Home- and Community-Based Services

Services are provided in an individual’s home or in the community as an alternative to care in an institutional setting, such as a nursing facility. Maryland operates eight Medicaid-funded home- and community-based waiver programs, including one designed for individuals with brain injury, and five additional programs that offer personal care and other supports.

Private or commercial insurance does not cover home- and community-based supports that assist individuals with remaining at home and also prevents admission to nursing facilities for long-term care. Medicaid does cover these home- and community-based services. However, in a 2012 study conducted by the Hilltop Institute at University of Maryland Baltimore County, of the approximate 7,000 Maryland Medicaid beneficiaries who had sustained a TBI, only 11% were enrolled in home- and community-based services.

Brain Injury Waiver

There is one home- and community-based program in Maryland designed specifically for individuals with brain injury. It is a small specialty program

Eligibility for the Brain Injury Waiver currently is based on “facility-based access,” meaning it is limited to individuals

designed to support individuals with moderate to severe deficits resulting from their injuries, who meet the financial, medical, and technical eligibility for the program.

transitioning out of four state-operated chronic hospital or nursing facility settings and five state psychiatric hospital settings. This limits access to the program for individuals who are in need of this level of support but do not reside in one of those institutional settings.

Behavioral Health Services

Maryland has integrated mental health services and substance-related disorder services. These conditions frequently occur in conjunction with, or as a result of, a brain injury. The cognitive, emotional, and behavioral symptoms that result from brain injury can impact the effectiveness of traditional behavioral health services.

Behavioral health providers do not routinely screen the individuals they serve for a history of a brain injury. This often leads to misdiagnosis, under-identification, and insufficient supports and services for both children and adults.

Special Education Services

The Individuals with Disabilities Education Act (IDEA) requires schools to protect the rights of children with disabilities and ensure these students have access to free and appropriate education. IDEA covers children with specific disabilities, including TBI.

There is a significant discrepancy between the number of school-age children being treated in Maryland hospitals for a TBI and the number of Maryland students receiving special education services with a diagnosis of TBI. This under-identification or misidentification may occur because TBI symptoms overlap with symptoms of other disabilities, including emotional disturbance and learning disability as defined by the IDEA. Incorrectly diagnosing students and failing to recognize TBI is likely to lead to inappropriate individualized education programs because the goals and objectives do not address the student's unique needs.

APPENDIX B

MARYLAND ACCOMPLISHMENTS

Advocacy

The Brain Injury Association of Maryland is the only advocacy organization geared specifically to individuals with brain injury. Two additional advocacy organizations, the Centers for Independent Living and Disability Rights Maryland, the state's protection and advocacy organization, provide assistance to individuals with disabilities, including brain injury. All three of these organizations are represented on the TBIAB. The Brain Injury Association in conjunction with TBIAB hosted a brain injury awareness day event in March 2019 in Annapolis to educate legislators about brain injury in honor of Brain Injury Awareness Month (March). A press conference was held announcing the creation of the new Brain Injury Trust Fund donation program. Additionally, over 60 masks and stories were placed on display in the House Office Building to bring awareness to the struggles and successes of Marylanders with brain injury.

Brain Injury Trust Fund

The Maryland Brain Injury Trust Fund was created during the 2013 Legislative Session without a revenue stream but in December 2018, a voluntary donation program was created at the Maryland Department of Transportation. Now Marylanders renewing their vehicle registration online or at a kiosk can donate to Maryland's Brain Injury Trust Fund. This is notable accomplishment; however, it is also important to note that the revenues generated through this program are too low to support the initiation of services.

Concussion Law

On May 19, 2011, the concussion bill was signed into law, mandating the implementation of concussion awareness programs throughout the state and requiring student athletes who demonstrate signs of a concussion to be removed from practice or play.

Helmet Law

Board members have successfully advocated against the repeal of Maryland's motorcycle helmet law. Multiple states (*e.g.*, Louisiana, Texas, Arkansas, and Florida) have repealed only to reinstate all-rider helmet laws due to the significant increase in motorcycle deaths.

Federal Grant Funding

BHA was awarded a three-year federal TBI grant creating the STAR model: (1) **Screen** individuals receiving behavioral health services for a history brain injury; (2) **Train** behavioral health/ human service to provide cognitively accessible services and interventions utilizing person centered practices; (3) **Activate/Support** stakeholders; and (4) **Reduce** the risk of overdose for Marylanders who have sustained a brain injury.