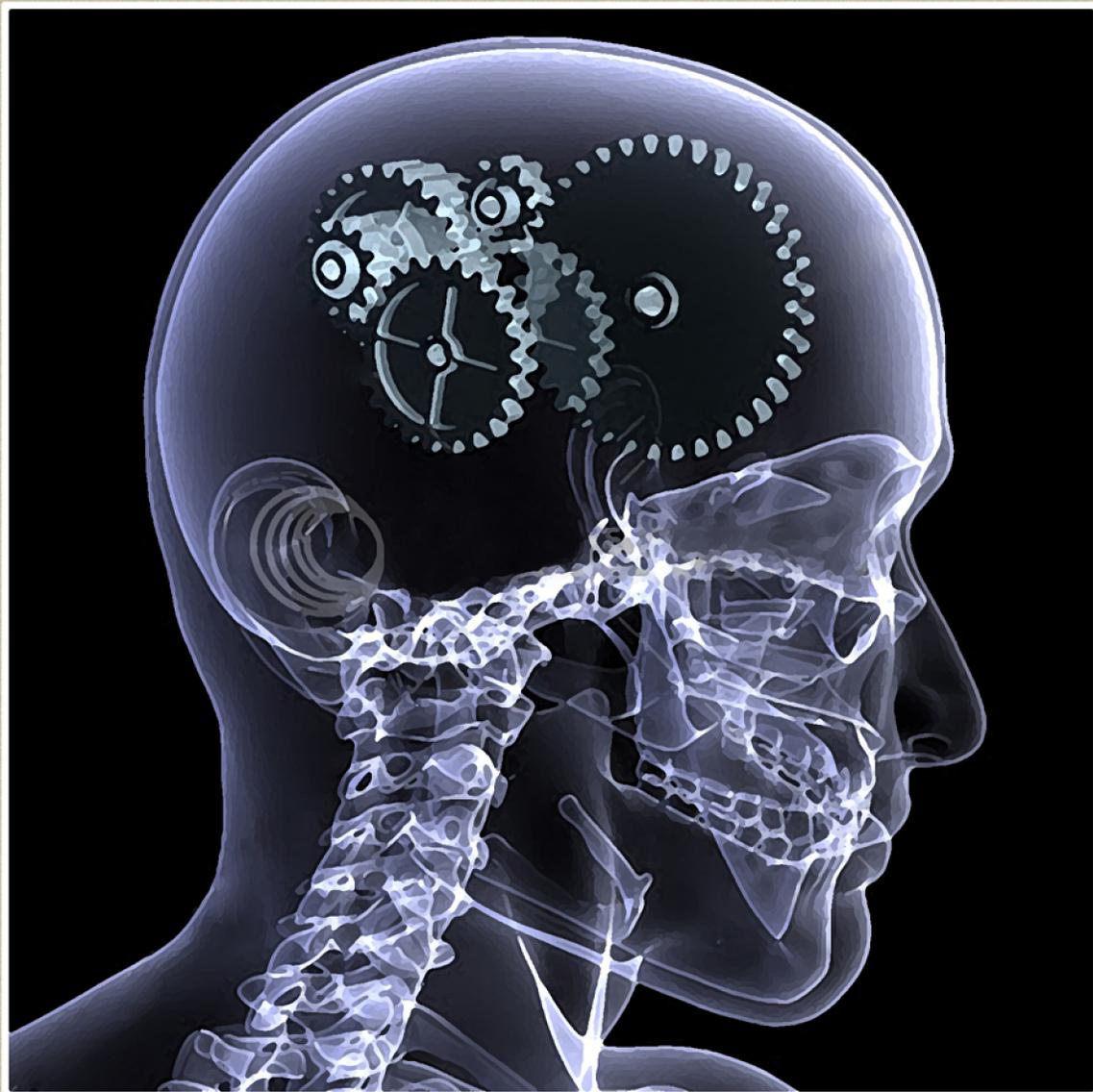


MARYLAND

Traumatic Brain Injury Advisory Board



2017
Annual Report

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EXECUTIVE SUMMARY

Traumatic brain injury is “an injury that disrupts the normal function of the brain caused by a bump, blow, or jolt to the head or a penetrating head injury [or] explosive blasts.” Centers for Disease Control and Prevention (CDC). Moderate and severe traumatic brain injury can lead to a lifetime of physical, cognitive, emotional, and behavioral changes. Despite initial hospitalization and inpatient rehabilitation services, about 50% of people with moderate or severe traumatic brain injury will experience further decline in their daily lives or die within five years of their injury.

To examine traumatic brain injury, the State Traumatic Brain Injury Advisory Board was established in 2005 by Senate Bill 395 (Chapter 306). The Traumatic Brain Injury Advisory Board consists of 36 voting members 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.

Maryland Health-General Article § 13–2105(1) requires the Traumatic Brain Injury Advisory Board to submit an annual report summarizing the actions of the Traumatic Brain Injury Advisory Board 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.

Health-General Article § 13–2105(2) requires the Traumatic Brain Injury Advisory Board to include information concerning the number of individuals served and the services, which is discussed in the Maryland Department of Health report on the state Brain Injury Trust Fund under Health-General Article § 13–21A–02(i).

State of the State in Brain Injury

-) In Maryland, the overall incidence of traumatic brain injury related emergency department visits increased between 2012 and 2015 while traumatic brain injury related deaths and hospitalizations decreased.
-) Seniors, ages 65 and older, had the highest rates of traumatic brain injury related deaths and traumatic brain injury related hospitalizations. The highest rate of traumatic brain injury related emergency department visits were for Marylanders aged 5–24.
-) Unintentional falls are the leading cause of injury for traumatic brain injury related deaths, emergency department visits, and hospitalizations.

-) There is a significantly higher rate of traumatic brain injury related deaths and hospitalization for males than females; however, the rate of traumatic brain injury related emergency department visits is equally distributed among both males and females.
-) Certain rural counties and Baltimore City are experiencing higher rates of traumatic brain injury related deaths, emergency department visits, and hospitalizations than other jurisdictions. The densely populated counties of Prince George's and Montgomery have the lowest rates of traumatic brain injury related deaths, emergency department visits, and hospitalizations.

Services, Supports, and Gaps in Maryland

-) 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 nursing facility and home and community based services), 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 lack of coordination of these 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.

Recommendations for Maryland

-) Appropriately screen for and identify children and youth with brain injuries.
-) Implement brain injury screening protocols for participants in Maryland's public health systems, including behavioral health services, veteran's initiatives, and home and community based services.
-) Expand and improve services offered through the Brain Injury Waiver.
-) Fund the State of Maryland Dedicated Brain Injury Trust Fund to support care coordination and evidenced based practices.
-) In order to comply with Health-General Article § 20-108, establish and administer a central registry of individuals living with a disability as a result of a brain injuries and ensure that those individuals and their families are provided information about appropriate resources and assistance.

INTRODUCTION TO THE MARYLAND TRAUMATIC BRAIN INJURY ADVISORY BOARD

The Maryland Traumatic Brain Injury Advisory Board (TBIAB) was authorized in October 2005 under Chapter 306. See also Chapter 236, Acts of 2008. The TBIAB consists of 36 voting members, who represent consumers and survivors, families and caregivers, advocates, government officials, educators, health care professionals, and elected officials. For a complete list of members, see *infra*, pp. 23–25.

The statutory charge of the TBIAB is to:

-) investigate the needs of citizens with traumatic brain injuries (TBI);
-) identify gaps in services to citizens with TBIs;
-) facilitate collaboration among state agencies that provide services to individuals with TBIs;
-) facilitate collaboration among organizations and entities that provide services to individuals with TBIs; and
-) encourage and facilitate community participation in program implementation.

The TBIAB is required by Health-General Article (HG) § 13–2105(6), in accordance with § 2–1246 of the State Government Article, to issue an annual report to the Governor and the General Assembly that contains recommendations for:

-) providing oversight in acquiring and utilizing state and federal funding dedicated to services for individuals with TBIs;
-) building provider capacity and provider training to address the needs of individuals with TBIs; and
-) improving the coordination of services for individuals with TBIs.

MARYLAND BRAIN INJURY TRUST FUND

Pursuant to HG § 13–21A–02(i), the Maryland Department of Health (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.

This report reflects the work done by the TBIAB during CY 2017* and includes a list of recommendations for ways Maryland can enhance systems of care for Marylanders affected by brain injury as well as increase awareness about brain injury and brain injury prevention. Additionally, this report reflects the Brain Injury Trust Fund’s status.

* The Maryland TBIAB requests TBI incidence data from the Center for Injury Epidemiology at the Maryland Department of Health to be included in this annual report. The Center for Injury Epidemiology utilizes hospital discharge data, emergency department data, and mortality data, and submits compiled data to the CDC annually. Although the work of the TBIAB in this report is reflective of CY 2017, the latest full data set from the Center for Injury Epidemiology is at least two years old. Therefore, this report will discuss data from 2015.

STATE OF THE STATE IN BRAIN INJURY

Maryland TBI Incidence Data

The Center for Injury Epidemiology at the Department tracks TBI related deaths, hospitalizations, and emergency department (ED) visits. Between 2012 and 2015, TBI related ED visits continued to increase while TBI related deaths and hospitalizations decreased. See 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 (all Internet materials as last visited Nov. 1, 2017).

Summary of Maryland TBI Incidence Data Trends, 2012–2015:

Overall Incidence: TBI related ED visits increased over time while TBI related deaths and hospitalizations decreased.

Age Related Trends: Seniors ages 65 and older had the highest rates of TBI related deaths and TBI related hospitalizations. The highest rate of TBI related ED visits were for Marylanders aged 5–24.

Race Related Trends: White Marylanders have a much higher rate of TBI related deaths, ED visits, and hospitalizations than black Marylanders and all other races.

Mechanism of Injury Trends: Unintentional falls are leading cause of injury for TBI related deaths, ED visits, and hospitalizations.

Gender Trends: There is a significantly higher rate of TBI related deaths and hospitalization for males than females; however, the rate of TBI related ED visits is equally distributed among both males and females.

County Trends: Certain rural counties and Baltimore City are experiencing higher rates of TBI related deaths, ED visits, and hospitalizations than other jurisdictions. The densely populated counties of Prince George's and Montgomery have the lowest rates of TBI related deaths, ED visits, and hospitalizations.

In summary, seniors are falling and this is resulting in death, increased utilization of EDs, and hospitalizations. Teens and young adults are high utilizers of EDs due to TBIs, presumably concussions. Rural counties are disproportionately impacted by TBI related deaths, ED visits, and hospitalizations. Severe TBI that results in death or hospitalization are more common in males than females, but TBIs treated in EDs are equally distributed among males and females. White Marylanders have the highest rate of TBI related deaths, ED visits, and hospitalizations.

TBI Related Deaths

In Maryland, the number of TBI related deaths between 2012 and 2015 ranged from 649 per year to 706. The rates were highest in 2012 (706 deaths), steadily decreased in 2013 (664 deaths) and 2014 (649 deaths), then rose again slightly in 2015 (686 deaths).

In 2015:

- J The age range with the highest number of TBI related deaths is 85 and older followed by 75–84-year olds.
- J TBI related deaths in Maryland are almost three times higher in males (513 deaths) than females (173 deaths).
- J TBI related deaths are more than two times more common in white Marylanders (469 deaths) than black Marylanders (205 deaths) with other races (12 deaths) having a much lower rate of death due to TBI.
- J The most common cause of TBI related deaths is by firearm (279 deaths) followed by unintentional falls (278 deaths). TBI related suicides decreased steadily between 2012 (216 deaths) and 2015 (187 deaths).

TBI Related ED Visits

The number of TBI related ED visits increased steadily between 2012 (38,128 visits) and 2015 (39,721 visits).

In 2015:

- J The highest rate of TBI related ED visits were among Marylanders aged 15–24 (7,021 visits) and ages 5–14 (5,833 visits).
- J TBI related ED visits among Marylanders are equally distributed among males (19,983 visits) and females (19,731 visits).
- J TBI related ED visits are much more common for white Marylanders (21,956 visits) than black Marylanders (11,861 visits), and the number of visits lag behind for all other racial groups combined (5,904).
- J The most common cause of injury for TBI related ED visits was unintentional falls (19,141 visits), followed by being struck by or against (7,935 visits), and motor vehicle accidents (6,652 visits).
- J The top five counties with the highest rate of TBI related ED visits were Allegany, Garrett, Calvert, Washington, and St. Mary's.

TBI Related Hospitalizations

TBI related hospitalizations have decreased steadily between 2012 (5,231 hospitalizations) and 2014 (4,279 hospitalizations), with a slight increase in 2015 (4,422 hospitalizations).

In 2015:

- J The highest rate of TBI related hospitalizations were Marylanders aged 85 and older (754 hospitalizations) and those aged 75–84 (751 hospitalizations).
- J The rate of TBI related hospitalizations was one and half times higher for males (2,673 hospitalizations) than females (1,747 hospitalizations).
- J The rate of TBI related hospitalizations was two times higher for white Marylanders (2,666 hospitalizations) than black Marylanders (1,208 hospitalizations) with other racial groups at a rate of 548 hospitalizations in 2015.
- J Unintentional falls (2,527 hospitalizations) are by far the most common mechanism of injury of TBI related hospitalizations, followed by motor vehicle accidents (1,038) as the second leading cause.

What is Missing from the Data?

Data Gaps

The number of people who seek treatment for a TBI in an urgent care center or a physician's office or who seek no treatment at all is not included in these data. The reliance on urgent care centers for emergency and primary care needs has grown dramatically over the past several years. This missing data is likely to be significant and therefore the available incidence data in Maryland is only a fraction of the overall incidence. It should be noted that this incidence data gap is not unique to Maryland and the CDC is seeking federal funding to improve data collection measures.

It is quite possible that age, race, and gender trends could be very different if data were available for injuries treated in urgent care centers or other similar settings. Because some patients have limited financial resources and may not have access to health insurance, they are opting to use urgent care centers or are foregoing treatment all together.

Other Types of Acquired Brain Injuries

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 a growing number of opioid related overdoses and other unintentional poisoning. The interplay between opiate use and brain injury as well as the history of brain injury and risk

of accidental poisoning, such as an opiate overdose, is also significant but not widely discussed.

A person with a brain injury is 11 times more likely to die from an accidental poisoning from drugs or alcohol than a person without a history of brain injury.

See CDC, TBIs and Injuries, <https://www.cdc.gov/features/traumatic-brain-injury/index.html>.

The incidence of anoxic and hypoxic brain injuries is increasing due to the opioid epidemic in Maryland. Opiate use depresses the nervous system and affects breathing. In an overdose, the brain is deprived of oxygen resulting in brain damage or death.

Overdose = Brain Injury

Ensuring that individuals with brain injury are targeted for overdose prevention efforts is important. Likewise, ensuring that individuals who survive an overdose have access to needed services and supports to accommodate their needs related to their brain injury is also important.

Secondary Impact of Brain Injury

Of growing concern is the secondary impact of brain injury on homelessness, incarceration, unemployment, and domestic violence. Increasing evidence suggests a correlational and sometimes causal relationship between brain injury and these issues.

-) Since 2015, Healthcare for the Homeless Maryland screened 170 clients for a history of TBI and found 67.6% screened positive for a brain injury that caused a loss of consciousness.
-) The estimated prevalence of TBI in the overall offender population is 60.25% according to the Journal of Head Trauma Rehabilitation (2014).
-) Domestic violence is a common cause of brain injury in women, who constitute the vast majority of victims of severe physical violence by an intimate partner. The head and face are common targets of intimate partner assaults, and victims often suffer head, neck, and facial injuries. Jackson, H., et al., Traumatic Brain Injury: A Hidden Consequence for Battered Women, Professional Psychology: Research and Practice, 33, 1, 39–45 (2002).
-) According to the CDC and the National Institute on Disability, Independent Living, and Rehabilitation Research, 55% of people with moderate to severe TBI, who are still alive

five years after injury, do not have a job but were employed at the time of their injury.

Prevention of Secondary Impact

Although efforts exist in the State to prevent TBI such as falls prevention programs and safer vehicle functionality, little emphasis has been given to preventing the secondary impact of brain injury. Early intervention and referral to appropriate treatment and supports is needed to improve outcomes, reduce rates of incarceration, homelessness, substance abuse, and unemployment.

- J Available data demonstrates alarming differences between the large numbers of school age students who receive a diagnosis of brain injury in the hospitals as compared to the very small number of students in schools who have the same diagnosis. This means that hundreds of students with brain injuries are most likely not receiving the educational services they need nor will they likely receive the clinical supports needed to reduce the risk of future substance abuse, incarceration, and unemployment.
- J Similarly adults who sustain a brain injury may exhibit symptoms that are misdiagnosed or even if diagnosed, may not receive the linkages to the services and supports they need to promote recovery and reduce the risk of behavioral health conditions, incarceration, and homelessness.

UNDERSTANDING BRAIN INJURY

The CDC defines TBI as “an injury that disrupts the normal function of the brain ... caused by a bump, blow, or jolt to the head or a penetrating head injury [or] explosive blasts.” Acquired brain injury, is defined as an injury to the brain which is not hereditary, congenital, degenerative, or induced by birth trauma. Brain Injury may be classified as mild, moderate, or severe depending on the patient’s neurologic signs and symptoms. Everyone experiences brain injury differently. Symptoms may include: difficulties with memory, attention, learning, or coordination; headaches; fatigue; sleep disturbances; mood disorders; post-traumatic epilepsy; and increased risk of dementia. Caregivers of people with brain injury may also experience negative health effects, including stress-related disorders and depression.

Brain Injury is Common

More people survive a brain injury than ever before, largely due to improved emergency medical care. It is estimated that, in the United States, between 3.2 and 5.3 million people are living with a TBI-related disability. In 2013, the CDC estimated that nationally 2.8 million Americans were treated in EDs, hospitalized, or died as a result of a TBI. In Maryland alone, there are more than 600 TBI related deaths per year, over 5,000 TBI related hospitalizations per year, and almost 40,000 TBI related ED visits per year. Center for Injury Epidemiology, online at https://phpa.health.maryland.gov/ohpetup/Documents/TBI_AdvisoryBoard_data_Sept2017_Final.pdf.

Service members are also at a heightened risk of TBI. The Department of Defense and the Defense and Veteran's Brain Injury Center estimate that 22% of all combat casualties from the conflicts in Iraq and Afghanistan are brain injuries, compared to 12% of Vietnam related combat casualties. Sixty to eighty percent of soldiers who have other blast injuries may also have TBIs. While, about 80% of all TBI's in the civilian population are mild traumatic brain injuries (mTBI); in the military population, the primary causes of TBI in veterans specifically of Iraq and Afghanistan, are blasts, blast plus motor vehicle accidents, motor vehicle accidents alone, and gunshot wounds. Exposure to blasts is unlike other causes of mTBI and may produce different symptoms and natural history. For example, veterans seem to experience the post concussive symptoms described above for longer than the civilian population; some studies show most will still have residual symptoms 18–24 months after the injury. In addition, many veterans have multiple medical problems. The comorbidity of post-traumatic stress disorder, history of mTBI, chronic pain, and substance abuse is common and may complicate recovery from any single diagnosis. Summerall, E. Lanier, Traumatic Brain Injury and PTSD: Focus on Veterans, PTSD: National Center for PTSD, U.S. Department of Veterans Affairs, <https://www.ptsd.va.gov/professional/co-occurring/traumatic-brain-injury-ptsd.asp>.

Moderate to Severe Brain Injuries Have Long-Term Consequences

According to the CDC and National Institute on Disability, Independent Living, and Rehabilitation Research, moderate and severe TBI can lead to a lifetime of physical, cognitive, emotional, and behavioral changes. These changes may affect a person's ability to function in their everyday life.

Despite initial hospitalization and inpatient rehabilitation services, about 50% of people with moderate to severe TBI will experience further decline in their daily lives or die within five years of their injury. Of those who are still alive five years after injury:

- J *57% are moderately or severely disabled.*
- J *55% do not have a job (but were employed at the time of their injury).*
- J *50% return to a hospital at least once.*
- J *33% rely on others for help with everyday activities.*
- J *29% use illicit drugs or misuse alcohol.*
- J *12% reside in nursing homes or other institutions.*

Brain Injury Can Be Costly

According to the CDC, the national annual cost associated with TBI is estimated to be \$76.5 billion. The average lifetime health care costs for a person with a TBI are \$85,000, but can exceed \$3 million, depending on the severity of the injury and other factors. According to the Hilltop Institute at the University of Maryland Baltimore County (UMBC), the number of Medicaid beneficiaries in Maryland with TBI increased by 37% between 2007 and 2011. On average, 7,000 Medicaid beneficiaries had a history of brain injury; approximately 61% of these beneficiaries are under the age of 50. Between FY 2010 to FY 2012, approximately 3,000 Maryland Medicaid beneficiaries with a history of brain injury had a nursing facility stay. Compared to their non-brain-injured counterparts, these beneficiaries were younger and their annual average costs to Medicaid were higher. Individuals with brain injury enter nursing facilities at a significantly younger age than individuals who have not sustained a brain injury, meaning that they are likely to need a greater amount of nursing care over their lifetime.

SERVICES, SUPPORTS, AND GAPS IN MARYLAND

Maryland has an array of high quality but uncoordinated services in place for individuals who have sustained a brain injury and their families. However, there are significant gaps that must be eliminated.

Acute Health Care

1. 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.

Gap: Many individuals who sustain TBI, such as a concussion, do not seek treatment in these settings. They often seek treatment in a physician's office or an urgent care center, or seek no treatment at all. As a result, 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. See Crosscutting and Emerging Issues for Future Investigation by the TBIAB, *infra*, at 20.

2. Brain Injury Rehabilitation

Maryland offers rehabilitation services, accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF), for inpatient and outpatient rehabilitation facilities and programs.

Gap: The length of stays in inpatient facilities has decreased significantly over the years and it is now increasingly more common for individuals with a brain injury to receive rehabilitation in a nursing facility or to have little or no access to rehabilitation services. There are no specialized brain injury units within

Maryland nursing facilities and therefore access to rehabilitation services that are designed for individuals with brain injury are more limited than ever before. See *ibid.*

3. 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.

Gap: Although 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 and 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.

Patient navigator roles have been created at most Maryland hospitals as a result of new Medicare reimbursement structures; however, patient navigators are typically only involved for 30 days post discharge from a hospital setting. Case coordination is needed for months or years post brain injury. See Recommended Actions for Maryland, Part IV, *infra*, at 18–19.

4. TBI Registry

Maryland 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 shall establish a central registry to compile information about disabled individuals with reportable conditions. 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.

Gap: As far as the TBIAB is aware, hospitals are not reporting the occurrences of disabled individuals in their institutions with “head injuries” within 7 days, nor implementing the statutorily required central registry to compile information about disabled individuals with reportable conditions, 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 dealing with brain injury. It limits individuals and family members from 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. The failure to implement this statute also negatively impacts “disabled individuals” with the other listed “reportable conditions,” namely spinal cord injury, stroke, and amputation.

Community Living Services

1. Home and Community Based Services

Services that are provided in a person's home or in the community as an alternative to care in an institutional setting such as a nursing facility. Maryland operates six home and community based waiver programs, including one designed for individuals with brain injury, and three state plan programs that offer personal care and other supports.

Gap: Private or commercial insurance does not cover home and community based supports that assist individuals with remaining at home and 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 UMBC, of the approximate 7,000 Maryland Medicaid beneficiaries who had sustained a TBI, only 11% were enrolled in home and community based services. See Recommended Actions of Maryland, Part II, *infra*, at 15–16.

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

Gap: Eligibility for the Brain Injury Waiver currently is based on “facility-based access,” meaning it is limited to individuals 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. See Recommended Actions of Maryland, Part III, *infra*, at 17–18.

3. 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.

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

*The Behavioral Health Administration (BHA) implemented a brain injury screening protocol into the authorization process for certain behavioral health services in 2017.

*Maryland HealthCare for the Homeless implemented a brain injury screening for clients receiving mental health services as well as training for providers to assist with accommodating treatment.

Gap: There is a lack of behavioral health services that meet the needs of people who have cognitive, physical, and behavioral impairments resulting from a brain injury. Brain injury and lack of appropriate care can result in higher rates of incarceration, suicide, and unnecessary utilization of ED and hospitals. Marylanders with brain injury who are experiencing a behavioral health crisis have limited access to interventions that are designed for this population. Although brain injury can result in behavioral health conditions, brain injury is not a qualifying clinical diagnosis for behavioral health services in Maryland. Co-occurring mental health diagnosis may qualify some individuals with brain injury for behavioral health services; however, most behavioral health services are designed for individuals with serious mental illness and they are unequipped and often unwilling to treat individuals with brain injury, who often require cognitive behavioral approaches and also have sensitivities to medications that are typically used to treat mental illness. See Recommended Actions of Maryland, Part II, *infra*, at 15–16.

Education Supports

1. Special Education Services

The Individuals with Disabilities Education Act (IDEA), 104 Stat. 1142, requires schools to protect the rights of children with disabilities and ensure these students have access to a free and appropriate education. IDEA covers children with specific disabilities, including brain injury.

Gap: There is a significant discrepancy between the number of school-age children being treated in Maryland hospitals who are diagnosed with TBI and the number of Maryland students receiving special education services with a diagnosis of TBI. In 2014 alone there were 620 TBI related hospitalizations and 17,932 ED visits for youth ages <1 to 24. Yet, there are only 234 Maryland students receiving special education services under the IDEA classification code of TBI. This underidentification or misidentification may occur because TBI symptoms overlap with symptoms of other disabilities including emotional disability and learning disability as defined by the IDEA. Incorrectly diagnosing students with emotional disturbance or specific learning disability while failing to recognize TBI is likely to lead to inappropriate individualized education programs because goals and objectives do not address the student’s unique needs. See Recommended Actions of Maryland, Part I, *infra*, at 14–14.

RECOMMENDATIONS FOR MARYLAND

The TBIAB recommends the following four steps be taken in Maryland to address the needs and gaps in services for Marylanders with brain injuries:

I. Appropriately screen for and identify children and youth with brain injuries.

The Maryland State Department of Education should improve screening for students with brain injuries by:

-) requiring local education agencies to add screening questions, to existing annual school health forms and special education screenings, designed to capture incidents of head injury or loss of consciousness suffered at any time by the student. A protocol for responding to positive responses to that question should be developed as part of the screening process for special education services;
-) requiring schools to mandate a signature from a qualified medical professional on the concussion screening questionnaire that is required for all high school athletes in Maryland. Head injuries are currently self-reported on that questionnaire; and
-) increasing dissemination of concussion prevention and awareness materials and brain injury training to school psychologists, pupil personnel workers, counselors, teachers, administrators, specialists, health room staff, athletic departments, coaches, trainers, students, and parents.

Changes since the Last Report

There has been no change since the last report.

Analysis

In 2014 alone there were 620 TBI related hospitalizations and 17,932 ED visits for youth ages <1 to 24 (unpublished data retrieved by the Maryland Violence and Injury Prevention Program from the Health Services Cost Review Commission data sets, October 2016). 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 or in urgent care facilities. Yet, in spite of the large number of severe brain injuries among school-aged children in Maryland, there are currently only 234 Maryland students receiving special education services under the IDEA classification code of TBI.

Underidentification of brain injury may occur because TBI symptoms can be misinterpreted as other disabilities, such as emotional disability and learning disability. The inappropriate diagnosis of TBI leads to incorrectly identifying students as having an emotional or learning disability, while failing to recognize the underlying TBI, leads to inappropriate individualized education plans with goals and objectives that do not address the student's actual needs.

Other states, such as Pennsylvania and Colorado, have already begun implementing programs that specifically address the needs of students with brain injuries and their families. TBI can have a significant impact on classroom performance and behavior in children and youth. It is critical that TBI be fully understood by all involved in developing programs for students with disabilities so that appropriate assessments, especially neuropsychological assessments, are obtained. Without proper identification and assessment, students with a diagnosis of TBI cannot be identified or served appropriately and their ability to be successful in school and transition to adulthood is compromised, and the likelihood of consuming limited state resources in the future increases.

II. Implement brain injury screening protocols for participants in Maryland’s public health and corrections systems, including behavioral health services, veterans’ initiatives, jails and prisons, and home and community based services and offer appropriate accommodations to treatment.

The Department’s agencies and correctional facilities should improve services offered to Marylanders with brain injury by:

-) requiring providers of state funded programs designed to support individuals experiencing homelessness, substance abuse, and veterans to screen consumers for a history of TBI and accommodate treatment as needed; and
-) screening inmates of Maryland jails and prisons for history of brain injury and accommodate approaches and release planning as needed.

Changes since the Last Report

BHA implemented a brief brain injury screening into the online authorization process for certain behavioral health services, *i.e.*, 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. The implementation of the TBI screening questions is part of a larger federal initiative called the Balancing Incentives Program, intended to improve access to home and community services. The initial implementation of the TBI quick screen was implemented in 2017. 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 tentatively scheduled for the next fiscal year. Data is not yet available.

<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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Healthcare for the Homeless initiated TBI screening in 2015 with individuals receiving services and found that of 170 clients screened, 67.6% screened positive for a brain injury with a loss of consciousness.

Of those that screened positive for a history of brain injury:

-) 30.6% had an injury before the age of 15.
-) 39.4% had an injury with loss of conscious greater than 30 minutes.
-) 35.9% had multiple head injuries.
-) 8.8% had a recent injury.
-) Most significantly, 48.2% had other experiences or medical conditions that would likely impact the effects of the injury, such as alcohol use or a seizure disorder.
-) A positive screening for a history of brain injury was also highly correlated with chronic health conditions (87%) or a mental health diagnosis (92%).
-) Additionally, 58% of those with a Worst injury of 3 or higher have a history of or ongoing alcohol abuse, and 51% have a history of or experience ongoing substance abuse.

Analysis

Many people who seek services through Maryland's public behavioral health system, home and community based services, and veterans' initiatives have an undiagnosed brain injury. It is crucial that these programs implement a brain injury screening protocol in order to identify individuals with a history of brain injury and provide accommodations as needed to ensure that the services provided adequately meet their needs.

Brain injury is often not a visible disability, and yet a history of a brain injury can result in significant deficits that can impact clinical outcomes, social functioning, employment, and mental health. Many individuals who have sustained a 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. By encouraging agencies that provide human service programs to spread brain injury awareness, they may help educate consumers of their health needs. 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 who are experiencing homelessness, victims of domestic violence, and recipients of all home and community services.

III. Expand and improve services offered through the Brain Injury Waiver.

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

-) changing the eligibility for the Brain Injury Waiver to a neurobehavioral needs-based set of criteria rather than facility-based access; and
-) assessing the Brain Injury Waiver's supported employment and individual support services definitions and rate structures to determine whether there are structural or financial barriers to improving employment or independent living outcomes for waiver participants.

Changes since the Last Report

The Department's Brain injury waiver renewal application was approved by Centers for Medicare and Medicaid Services in 2016. The renewal includes a change to the supported employment service limitations. This change will increase the availability of supported employment services to Brain Injury Waiver participants. Additionally, the Department provided technical assistance and training to Brain Injury Waiver providers during the summer and fall of 2017 to enhance provider capacity to support participants in obtaining and maintaining competitive employment. A vocational rehabilitation specialist with hands-on experience with assisting individuals with brain injury obtain and maintain employment was contracted to provide onsite training to providers as well as the opportunity to participate in ongoing monthly technical assistance calls to help with implementation of new supported employment practices.

Analysis

There are currently over 7,000 Medicaid beneficiaries living with a brain injury in Maryland. Fewer than 800 of those beneficiaries are enrolled in Medicaid Home and Community Based Services, and approximately 100 people are served through the Maryland Brain Injury Waiver. Approximately 3,000 Medicaid beneficiaries with brain injury receive services in a Maryland nursing facility each year. At least 150 people have inquired about brain injury waiver services since 2005 according to available reports generated through the web-based waiver administrative system called Long Term Services and Supports (LTSS) Maryland.

Despite the prevalence of brain injury among Medicaid beneficiaries, there is a low cap on enrollment 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, and work readiness and recovery from mental illness and/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. Expanding access to this valuable program can reduce rates of homelessness, institutionalization, incarceration, and overall cost to the State for individuals in need of these specialized services.

Employment and housing drive recovery. It is important for the brain injury waiver program to demonstrate positive outcomes related to employment and independent housing. The Department should implement the changes approved in the waiver application and also complete a rate study to ensure that the supported employment and individual support service rates are not a barrier to providing an effective employment service or supports in independent housing.

IV. Fund the State of Maryland Dedicated Brain Injury Trust Fund to support care coordination and evidence-based practices.

The State should support a system of coordinated case management for people with brain injury by:

-) dedicating \$499,999 in the state budget to the State of Maryland Dedicated Brain Injury Trust Fund to serve as a funding source for a statewide care coordination pilot program for Marylanders who sustain a brain injury; and
-) exploring potential sustainable sources of revenue for the Brain Injury Trust Fund.

Changes since the Last Report

There has been no change since the last report.

Analysis

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. The Trust has not received any new funds since the passage of Senate Bill 632, Chapter 511 of the Acts of 2013. Therefore, the Department was unable to provide services to any individuals with a brain injury through this fund since its inception. In planning to accept future funds through a dedicated funding source or private donation, the Department did establish an account (PSA Code M258S) for this purpose and has the capacity to allocate funding for services if monies are received. Additionally, the Department has established a Trust Fund Advisory Committee and obtained two independent reports: The first reports on brain injury trust funds across the country and the second describes insurance coverage and case management utilization in Maryland and evidence-based practices.

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, see *Data Gaps, supra*, at 6:

-) 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. In order to comply with HG § 20–108, 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.

The State should improve screening for individuals with disabilities as a result of brain injury by:

-) establishing and administering 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.

Changes since the Last Report

In July 2016, the National Association of State Head Injury Administrators created a report compiling information about TBI Registries in the United States. Through review of this report, the TBIAB discovered that Chapter 416 of the Acts of 1984, HG § 20–108, mandates that the State, through the Department, establish a central registry and compile data to monitor four “reportable conditions”: spinal cord injury, stroke, amputation, and head injury. The TBIAB was unable to obtain information regarding the database collection of “head injuries” as a reportable condition nor the established policies and procedures in place to notify individuals and family members about appropriate information and assistance.

Analysis

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, particularly those dealing with 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 they are required to do and should have already been doing for over three decades.

CROSSCUTTING AND EMERGING ISSUES FOR FUTURE INVESTIGATION BY THE TBIAB

-) Individuals with brain injury are 11 times more likely to die from an accidental poisoning than individuals without a brain injury. It is important to target overdose prevention efforts to individuals with brain injury. Likewise, ensuring that individuals who survive an overdose have access to needed services and supports to accommodate their needs related to their brain injury is also important.
-) Under identification of brain injury as a condition contributing to homelessness.
-) Monitoring initiatives related to affordable housing and accessible transportation to ensure the needs of Marylanders with brain injury are addressed.
-) Issues related to transitioning from youth to adult healthcare and social services for children who have sustained a brain injury.
-) Gaps in incidence data reporting systems in Maryland as more individuals seek care in urgent care centers and physician offices rather than hospital settings.

- J) Lack of or needs for specialized services in long-term care settings, where more than 2,000 Marylanders with brain injury reside. Maryland needs a brain injury ombudsman program that monitors program quality, protects participants' rights, and resolves conflicts that arise among program participants, families, and providers of waiver services. This ombudsman model is well established and exists for residents of nursing facilities and assisted living facilities in Maryland. For Marylanders with brain injury who are enrolled in other home and community based services or who are not currently receiving home and community services, an ombudsman is needed to help advocate for effective services, policies, and programs to meet their needs.

MARYLAND ACCOMPLISHMENTS

Since the establishment of the TBIAB, some 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.

Advocacy

The Brain Injury Association of Maryland is the only advocacy organization geared specifically to individuals with brain injury. Other advocacy organizations; such as 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.

Brain Injury Trust Fund

The Maryland Brain Injury Trust Fund was created during the 2013 Legislative Session. In order for the fund to be able to cover needed services for Marylanders with brain injury, a sustainable revenue source will need to be created.

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, *i.e.*, Louisiana, Texas, Arkansas, and Florida, have repealed only to reinstate all-rider helmet laws due to the significant increase in motorcycle deaths.

In CY 2017:

- J The Brain Injury Association of Maryland, which holds several seats on the TBIAB, hosted a two-day brain injury conference in March, which was attended by over 450 individuals and families affected by brain injury, advocates, government representatives, and health care and human service professionals. The Maryland State Department of Education partners with the Brain Injury Association of Maryland to offer scholarships to educators, therapists, and health professionals who work for the public school system to attend this conference.
- J BHA employs a full-time trainer to enhance the ability of human service professionals and home and community based services providers to identify and support individuals with brain injury within their programs.
- J The TBIAB has created several subcommittees to promote the work of the board, consisting of advisory board members and nonmembers, including: Survivors and Families Empowered (SAFE), the Brain Injury Waiver and Long Term Services Advisory subcommittee, and the Education subcommittee. Additional ad hoc committees are formed as needed.
- J The Brain Injury Association in conjunction with TBIAB hosted a brain injury awareness conference in Annapolis to educate legislators about brain injury in honor of Brain Injury Awareness month (March).
- J One of the consistent TBIAB recommendations has involved the creation and funding of a dedicated Brain Injury Trust Fund. In 2013, pursuant to Senate Bill 632, the Maryland General Assembly created the Maryland Traumatic Brain Injury Trust Fund. In June 2016, the executive director of the Brain Injury Association of Maryland met with the Governor's deputy chief of staff and the deputy secretary of the Maryland Department of Disabilities. The trust fund was discussed including the need for consistent funding and desire that trust funds be used to provide case management for individuals with brain injuries that did not currently have such a service.
- J Members of the TBIAB also participate on the Maryland Public Secondary Schools Athletic Association's (MPSSAA) Traumatic Brain Injury/Sports-Related Concussions Task Force, which meets annually. This year the task force was included as part of MPSSAA's Medical Advisory Committee on October 25, 2016, to discuss updates to both the parent and student acknowledgement, Medical Clearance forms, and review progress.
- J Based on recommendations from the TBIAB, the Department has drafted meaningful changes to the Home and Community Based Waiver program for individuals with brain injury aimed toward improving employment outcomes for participants. BHA continues to contract with Brain Injury Association of Maryland to provide program information and application assistance to individuals in need of brain injury waiver services.

- J Maryland Healthcare for Homeless implemented a TBI screening protocol into their mental health services and have trained clinicians to better support clients with history of TBI.

MARYLAND BRAIN INJURY RESOURCES

Governor 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/Pages/eip.aspx>

MARYLAND TBIAB MEMBERSHIP

Thirty-six members constitute the Maryland TBIAB. 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 Government 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 one standing committee, SAFE. 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, promote prevention, education, and effective interventions that impact outcomes in order to support recovery and quality of life for every Marylander affected by brain injury.

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Maryland Legislative Appointments (ex-officio)

Senator Nancy J. King
Democrat, District 39,
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**Delegate Jeffrey D.
Waldstreicher**
Democrat, District 18,
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