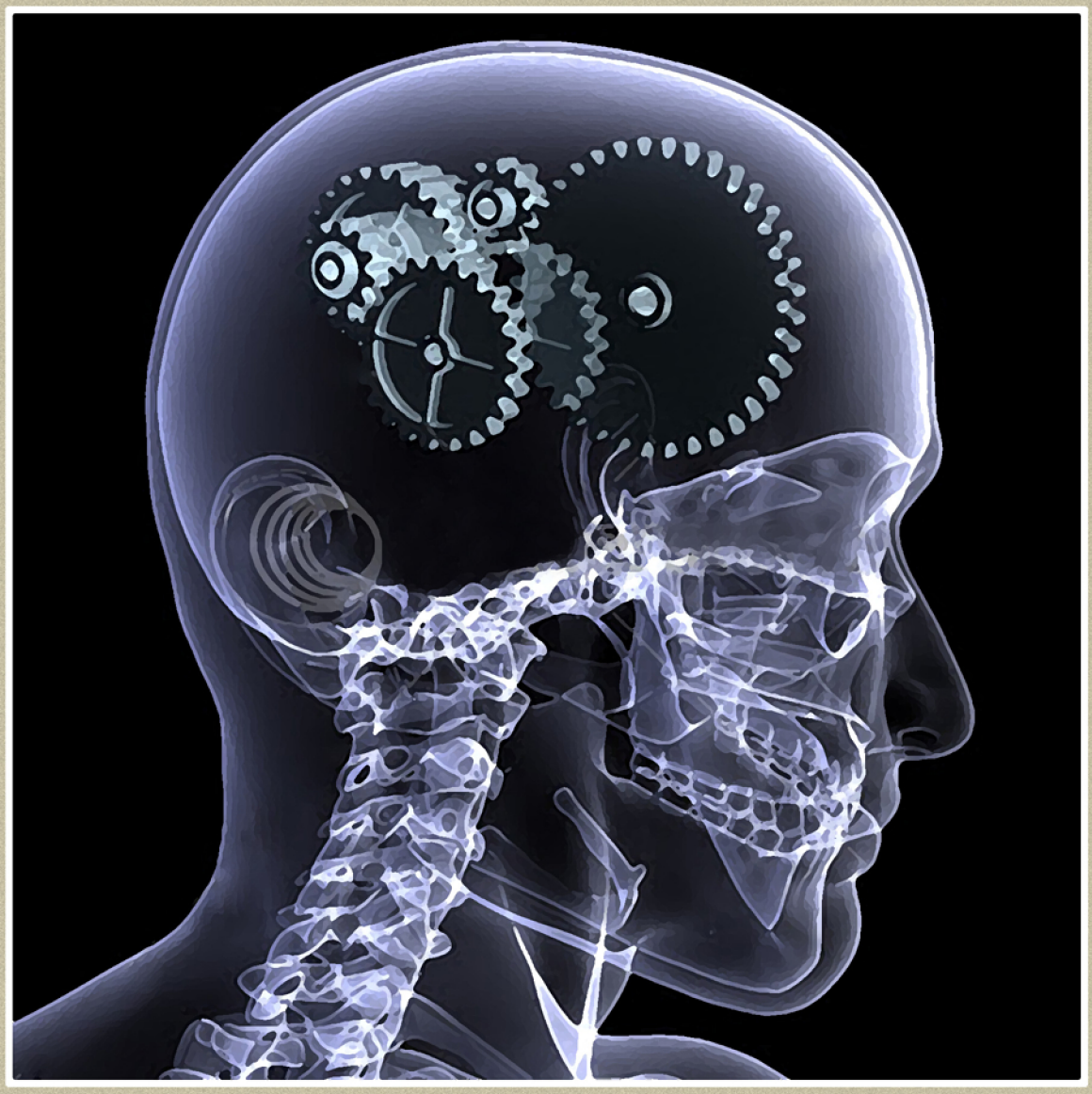
# MARYLAND

## Traumatic Brain Injury Advisory Board



# 2016

## Annual Report

# Report Summary



- Traumatic brain injury (TBI) 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." (CDC)
- A TBI may be classified as mild, moderate, or severe depending on the patient's neurologic signs and symptoms. Symptoms may include: difficulties with memory, attention, learning, or coordination; headaches; fatigue; sleep disturbances; mood disorders; post-traumatic epilepsy; and increased risk of dementia.
- Moderate and severe traumatic brain injury TBI 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 TBI will experience further decline in their daily lives or die within 5 years of their injury.
- Among those with moderate or severe TBI still alive 5 years after injury, 57% are moderately or severely disabled, 55% do not have a job (but were employed at the time of their injury), 29% use illicit drugs or misuse alcohol, and 12% reside in nursing homes or other institutions.
- The leading causes of non-fatal TBI in the United States are falls (35%), motor vehicle-related injuries (17%), and strikes or blows to the head from or against an object (17%), such as in sports injuries. Nationally, the leading causes of TBI-related deaths are motor vehicle crashes, suicides, and falls. In Maryland, the leading causes of TBI-related deaths are unintentional falls and firearms.



- 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 a 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.
- Progress and changes since the last annual TBIAB report include implementation of brain injury screening protocol into the authorization process for certain behavioral health services and changes to the supported employment service offered through the Brain Injury Waiver program.



- All Maryland schools should 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.

# Introduction to the Maryland Traumatic Brain Injury Advisory Board (TBIAB)

The Maryland State Traumatic Brain Injury Advisory Board (TBIAB) was authorized in October 2005 as Chapter 306, Acts of 2005. The TBIAB consists of 36 voting members, who represent consumers, families and caregivers, advocates, government officials, health care professionals and elected officials. For a complete list of members, please see Appendix A.

- The *Vision* of the TBI Advisory Board is to prevent brain injury and maximize the quality of life for every Marylander affected by brain injury.
- The *Mission* of the board is to identify needs, gaps in services, and potential funding resources by building relationships and collaborating with elected officials and heads of state agencies so as to influence policy, and promote prevention, education, and effective interventions that improve outcomes in order to support recovery and quality of life for every Marylander affected by brain injury.

The statutory charge of the TBIAB is to:

- Investigate the needs of citizens with traumatic brain injuries;
- Identify gaps in services to citizens with traumatic brain injuries;
- Facilitate collaboration among State agencies that provide services to individuals with traumatic brain injuries;
- Facilitate collaboration among organizations and entities that provide services to individuals with traumatic brain injuries; and
- Encourage and facilitate community participation in program implementation.

The TBIAB is required by § 13-2105(6) of the Health General Article, Md. Ann. Code, 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 traumatic brain injuries;
- Building provider capacity and provider training to address the needs of individuals with traumatic brain injuries; and
- Improving the coordination of services for individuals with traumatic brain injuries;
- Including information concerning the number of individuals served (through the Trust fund) and the services provided in the preceding fiscal year to individuals with traumatic brain injury.

*Maryland Brain Injury Trust Fund Report:* Pursuant to HG § 13-2105(6)(ii), Md. Ann. Code, the Department of Health and Mental Hygiene ("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 following report reflects the work done by the TBIAB during CY2016 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 status.

# UNDERSTANDING BRAIN INJURY: A National and State Perspective

The Centers for Disease Control and Prevention (CDC) define traumatic brain injury (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 (ABI), 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 million and 5.3 million people are living with a TBI-related disability. In 2010, the CDC estimated that TBIs accounted for 2,213,826 injuries requiring treatment and release from emergency rooms; 283,630 injuries requiring hospitalization; and 52,844 injuries resulting in death. During 2014, 649 Marylanders died a as result of a TBI; 4,279 Marylanders were hospitalized as a result of a TBI and 39,177 emergency department visits in Maryland were attributed to TBI-related injuries (unpublished data retrieved by the Maryland Violence and Injury Prevention Program from the Health Services Cost Review Commission (HSCRC) data sets, October 2016). Children, seniors and military service members are at heightened risk for brain injury. In the United States, children aged 0–4 years, adolescents aged 15–19 years, and adults aged 75 years and older are among the most likely to experience a TBI requiring emergency room care hospitalization. Maryland Core Injury and Violence data for 2014 indicates that there were 620 TBI related hospitalizations and 17,932 emergency department visits for youth ages <1 to 24. Adults aged 75 years and older have the highest rates of TBI-related hospitalizations and deaths. Service members are also at a heightened risk of TBI. From 2000 through 2011, 235,046 service members (or 4.2% of the 5,603,720 who served in the Army, Air Force, Navy, and Marine Corps) were diagnosed with a TBI.

**Moderate to severe brain injuries have long term consequences.** According to the CDC and National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), moderate and severe traumatic brain injury (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 5 years of their injury. *O*f those who are still alive 5 years after injury:

- *57% are moderately or severely disabled.*
- *55% do not have a job (but were employed at the time of their injury).*

***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 5 years of their injury. (CDC, NIDILRR)***

- *50% return to a hospital at least once.*
- *33% rely on others for help with everyday activities.*
- *29% use illicit drugs or misuse alcohol.*
- *12% reside in nursing homes or other institutions.*

Some of the health consequences of TBI can be prevented or reduced. Attending to these lifelong issues also known as chronic disease management, is crucial for improving the lives of persons with TBI. People with moderate to severe TBI typically face a variety of chronic health problems. These issues add costs and burden to people with TBI, their families, and society.

**Without proper identification and supports, brain injury affects the whole community.** Across all demographics, individuals with TBI have higher incidences of unemployment and court-involvement than their peers without brain injury. Approximately 45% of U.S. veterans of the Iraq and Afghanistan wars who suffered TBI are unemployed.[1] Approximately 30% of juvenile offenders have sustained a previous TBI.[2] The estimated prevalence of TBI in the overall offender population is 60.25**%**. Several studies have also found that larger percentages of people experiencing homelessness have a history of brain injury as compared to the general population. The resulting difficulties include increased risk of sustaining multiple subsequent brain injuries and greater difficulty re-integrating into functional roles in the community. [3]

**Brain injury can result from everyday activities, as well as exposure to high-risk activities or violence.** The leading causes of non-fatal TBI in the United States are falls (35%), motor vehicle-related injuries (17%), and strikes or blows to the head from or against an object (17%), such as in sports injuries. Nationally, the leading causes of TBI-related deaths are motor vehicle crashes, suicides, and falls. In Maryland, the leading causes of TBI-related death are unintentional falls and firearms.

**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, 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 FY2010 to FY2012, 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.

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1Journal of Head Trauma Rehabilitation: Post Author Corrections: October 13, 2014 Associations Between Traumatic Brain Injury,14

2Farrer, TJ., Frost, RB., & Hedges, DW (2013) Journal of Child Psychology

3Topolovec-Vranic et al., (2014) Canadian Medical Association Journal

| *Acute Health Care* | |
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| **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 emergency departments. | **Gap:** Many individuals who sustain a mild brain injury, such as a concussion, do not seek treatment in emergency settings. They are more likely to seek treatment in a physician's office or an urgent care center, or to seek no treatment at all. As a result, TBI can be misdiagnosed and/or the impact of the injury and resulting deficits underestimated, leading to lack of adequate follow up and supports. Additionally, state and national incidence data is based on hospital data, so it is widely accepted that the true incidence of TBI is much higher than what is reported by the CDC and state surveillance systems, since there is currently no system for tracking TBIs treated in non-hospital settings, such as urgent care centers and physician offices. ***See cross cutting and emerging issues page 13.*** |
| **Brain Injury Rehabilitation.** Maryland offers rehabilitation services that are provided by the Commission on Accreditation of Rehabilitation Facilities (CARF)-accredited 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 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 is more limited than ever before. ***See cross cutting and emerging issues page 13.*** |
| **Case Management.** Case management is defined by the Centers for Medicare and Medicaid Services (CMS) 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 re-admissions 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.<br><br>New *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 pages 10-11.*** |
| *Community Living Services* | |
| **Home and Community Based Services.** These are 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 and three state plan | **Gap:** Private or commercial insurance does not cover home and community based supports that assist individuals with remaining at home and prevent admission to nursing facilities for long term care. Medicaid does cover these home and community based services. However, of the approximate 7,000 Maryland Medicaid beneficiaries who have sustained a TBI, only 11% are enrolled in home and community based services according to analysis of Medicaid claims data by the Hilltop Institute at University of |

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| programs that offer personal care and other supports. | Maryland, Baltimore Campus in 2012. ***See recommended actions pages 9-10.*** |
| **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/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 and otherwise eligible but are not receiving treatment in one of those institutional settings. ***See recommended actions pages 9-10.*** |
| **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, under-identification, and insufficient supports and services for both children and adults.<br>*Note: the Behavioral Health Administration (BHA) is implementing a brain injury screening protocol into the authorization process for certain behavioral health services in 2017.<br>**Gap:** There is a lack of appropriate behavioral health supports for people with brain injury. Lack of appropriate care can result in higher rates of incarceration, suicide, and unnecessary utilization of emergency department 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 diagnoses 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 pages 8-9.*** |
| ***Education Supports*** | |
| **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 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 Emergency Department visits for youth ages <1 to 24. Yet, there are only 233 Maryland students receiving special education services under the Individuals with Disabilities Education Act (IDEA) classification code of TBI. This under- or mis-identification 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 |

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| | lead to inappropriate Individualized Education Programs (IEPs) because goals and objectives do not address the student's unique needs. ***See recommended actions pages 7-8.*** |

# RECOMMENDATIONS FOR MARYLAND

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

I. *All Maryland Schools should appropriately screen for and identify children and youth with brain injuries.*
II. *Implement brain injury screening protocols for participants in Maryland's public health systems, including behavioral health services, Veterans' initiatives, and home and community based services and offer appropriate accommodations to treatment.*
III. *Expand and improve services offered through the Brain Injury Waiver.*
IV. *Fund the State of Maryland Dedicated Brain Injury Trust Fund to support care coordination and evidence-based practices.*

## *I. All Maryland Schools should appropriately screen for and identify children and youth with brain injuries.*

**RECOMMENDED ACTIONS:**

Require that the Maryland State Department of Education (MSDE) improve screening for students with brain injuries by:

- Requiring local education agencies to add screening questions to existing annual school health forms 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 require 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.
- Increasing dissemination of concussion prevention and awareness materials and brain injury training to school psychologists, counselors, teachers, administrators, specialists, health room staff, athletic departments, coaches, trainers, students and parents.

**PROGRESS/CHANGES SINCE LAST REPORT:**

No progress or change since last report.

**ANALYSIS:**

In 2014 alone, there were 620 TBI-related hospitalizations and 17,932 Emergency Department 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 (HSCRC) data sets, October 2016). This total does not capture the full extent of brain injury among this age population because 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 233 Maryland students receiving special education services under the Individuals with Disabilities Education Act (IDEA) classification code of TBI.

Under-identification 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 (IEPs) 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, 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 of participants in Maryland's public health services, including behavioral health services, veteran's initiatives, and home and community based services and offer appropriate accommodations to treatment.*

**RECOMMENDED ACTIONS:**

Maryland's health and human service agencies should improve services offered to Marylanders with brain injury by:

- Screening individuals who receive services through all of Maryland's public health systems for a history of brain injury and providing accommodations for the cognitive and behavioral issues that commonly occur following a brain injury.

**PROGRESS/CHANGES SINCE LAST REPORT:**

The Behavioral Health Administration (BHA) will be implementing a brief brain injury screening into the online authorization process for certain behavioral health services (psychiatric rehab and mobile treatment) in early 2017. The screening questions are based on the Ohio State University (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 based services. The initial implementation of the "TBI quick screen" will initially be voluntary for providers as training on brain injury screening and accommodations to behavioral health treatment is offered statewide. BHA intends to mandate the TBI quick screen in the next phase of implementation tentatively scheduled for the next fiscal year.

**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 a history of brain injury and provide accommodations as needed to ensure that the services provided adequately meet their needs.

**OSU TBI-ID Quick Screen Questions**

- ✓ **Ever knocked out or lost consciousness?**
  *Yes No Not screened*
- ✓ **Longest time knocked out?**
  *Less than 30 minutes, 30 minutes- 24 hours, > 24 hours*
- ✓ **Age (1-99) when first knocked out or lost consciousness? ___**

Brain injury is often not a visible disability, and yet a history of a brain injury may 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 to services provided to individuals who are experiencing homelessness, victims of domestic violence, and recipients of all home and community based services.

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

**RECOMMENDED ACTIONS:**

Encourage the Department to improve the quality and quantity of resources for people with complex medical needs resulting from traumatic brain injury by:

- Creating 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.
- Assessing the Brain Injury Waiver's supported employment services and rate structure to determine whether there are structural or financial barriers to improving employment outcomes for waiver participants.

- Changing the eligibility for the Brain Injury Waiver to a neurobehavioral needs-based set of criteria rather than facility-based access.

**PROGRESS/ CHANGES SINCE LAST REPORT:**

DHMH has submitted a Brain injury waiver renewal application to CMS. The renewal would include a change to the supported employment service limitations. This change will increase the availability of supported employment services to brain injury waiver participants.

**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 fewer than 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.

Low enrollment in the Brain Injury Waiver is due to narrow technical eligibility and limited available slots in the program as well as limited provider capacity. 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/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.

A Brain Injury Ombudsman program is needed in Maryland. For those who do participate in the Brain Injury Waiver, an ombudsman is needed to assist participants, families and providers to resolve conflicts, complaints and concerns about quality. 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.

Employment is recognized as a successful outcome for the population served through the Brain Injury Waiver. DHMH plans to increase the availability of supported employment services to brain injury waiver participants. The TBIAB believes it is also important for the Department to conduct a rate study to determine if providers are being reimbursed appropriately, another factor that affects the quality and availability of these services.

## *IV. Fund the State of Maryland Dedicated Brain Injury Trust Fund to support the provision of care coordination and evidenced based practices.*

**RECOMMENDED ACTIONS:**

The State of Maryland 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.
- Exploring potential sustainable sources of revenue for the Brain Injury Trust Fund.

**PROGRESS/CHANGES SINCE LAST REPORT:**

No progress or change since last report.

**ANALYSIS:**

Pursuant to Health-General Art., 13-21A-02(i), Md. Ann. Code, the Department of Health and Mental Hygiene ("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 at or below 300 percent of the federal poverty level (FPL) who have exhausted all other health, rehabilitation, and disability benefits. The Maryland Behavioral Health Administration (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 Maryland Gap in Services page 5):

- 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 worker'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.

# Maryland Accomplishments

Since the establishment of the Maryland TBI Advisory Board, 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 Board 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.

### *Legislation and Advocacy*

**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 have repealed only to reinstate all-rider helmet laws due to the significant increase in motor cycle deaths (Louisiana, Texas, Arkansas, and Florida).

In CY2016:

- The Brain Injury Association of Maryland (BIAMD), 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, health care and human service professionals. The Maryland State Department of Education partners with the BIAMD to offer scholarships to educators, therapists, and health professionals who work for the public school system to attend this conference.
- The Department's Behavioral Health Administration 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. In CY16, twenty-seven trainings will be conducted reaching over five hundred people.
- The TBIAB has created several subcommittees to promote the work of the board, consisting of Advisory Board members and non-members, including: SAFE (Survivors and Families Empowered), the Brain Injury Waiver and Long Term Services Advisory subcommittee, and the Education subcommittee. Additional ad hoc committees are formed as needed.
- 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).
- One of the consistent TBIAB recommendations has involved the creation and funding of a dedicated Brain Injury Trust Fund. In 2013, pursuant to SB632, 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 who did not currently have such a service.
- Members of the TBIAB also participate on the Maryland Public Secondary Schools Athletic Association (Traumatic Brain Injury/Sports Related Task Force which meets annually. This year the Task Force was included as part of MPSSA's Medical Advisory Committee on October 25, 2016 to

discuss updates to both the parent/student acknowledgement and Medical Clearance Forms and review progress.

- Based on recommendations from the TBIAB, the Department of Health and Mental Hygiene has drafted meaningful changes to the Home and Community Based Waiver program for Individuals with Brain Injury aimed toward improving employment outcomes for participants. The Behavioral Health Administration (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. Nine new people have been enrolled in CY2016. BIAMD assisted BHA with piloting and implementing the Mayo Portland Adaptability Inventory, a requirement of Maryland Balancing Incentives Program initiative.
- In CY2016, the TBIAB finalized a five (5) year strategic plan, developed a TBI Advisory Board Manual for members, and created a website to store all meeting information as well as TBI resources: http://bha.dhmh.maryland.gov/Pages/mdtbiadvisoryboard.aspx.

# Crossing Cutting and emerging Issues for future Investigation by the TBIAB

- 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.
- Lack of or needs for specialized services in long term care settings, where more than 2000 Marylanders with brain injury reside.

# Maryland TBI Advisory Board Membership

Thirty-six members constitute the Maryland Traumatic Brain Injury Advisory Board. (Health-General Article, §§ 13-2101 through 13-2105, Md. Ann. Code) 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 General Assembly. 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.

The Board has established one standing committee, SAFE (Survivors and Families Empowered). The SAFE committee was created as a place for the members of the Maryland Traumatic Brain Injury Advisory Board 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.

# *Appendix A*
# *Board Membership*

**Grace Anyadike**
Department of Health and Mental Hygiene/ Behavioral Health Administration
Catonsville, Maryland

**Angela Baldwin-Austin**
Representing Individuals with Brain Injury
District Heights, Maryland

**Bob Berlow**
Disability Rights Maryland
Baltimore, Maryland

**Jody Boone**
Division of Rehabilitation Services
Baltimore, Maryland

**Joan Carney, Ed.D.**
Brain Injury Association of Maryland
Baltimore, Maryland

**Jan Caughlan**
Healthcare for the Homeless
Baltimore, Maryland

**Alison Cernich, Ph.D., ABPP-Cn** (ex-officio)
National Institutes of Health
Montgomery County

**Mary Lou Coppinger**
Representing Families/Caregivers of Individuals with Brain Injury
Baltimore, Maryland

**Joyce Dantzler**
Department of Health and Mental Hygiene/ Center for Injury and Sexual Assault Prevention
Baltimore, Maryland

**Corey Davis**
Representing Individuals with Brain Injury
Berlin, Maryland

**Christine Deeley Wood**
Representing Families & Caregivers
Montgomery County

**Norma Eisenberg**
Representing Families/ Caregivers of Individuals with Brain Injury

**Laurie Elinoff**
Statewide Independent Living Council/ Representing Individuals with Brain Injury
Millersville, Maryland

**Denise Farmer**
Department of Health and Mental Hygiene/ Office of Health Services
Baltimore, Maryland

**Janet Furman**
Department of Health and Mental Hygiene/ Developmental Disabilities Administration
Baltimore, Maryland

**Pamela Harman**
Veteran's Administration
Washington, D.C.

**Paul Hartman**
Center for Independent Living/ Representing Individuals with Brain Injury
Frederick, Maryland

**Marny Helfrich, M.Ed.**
Maryland State Department of Education/ Division of Special Education/ Early Intervention Services
Baltimore, Maryland

**Linda Hutchinson-Troyer**
Brain Injury Association of Maryland
Baltimore, Maryland

**Martin Kerrigan, Chair**
Brain Injury Association of Maryland
Baltimore, Maryland

**Terry Kirtz**
Representing Families/ Caregivers of Individuals with Brain Injury
Washington Grove, Maryland

**Margo D. Lauterbach, MD**
The Neuropsychiatry Program at Sheppard Pratt
Baltimore, Maryland

**Carole A. Mays, RN, MS, CEN**
Maryland Institute for Emergency Medical Services Systems
Baltimore, Maryland

**Jamie McElwee**
Western Maryland Hospital Center/ Brain Injury Program
Hagerstown, Maryland

**Arnold Mosco, Ph.D.**
Representing Families/ Caregivers of Individuals with Brain Injury
Arnold, Maryland

**Stefani O'Dea**
Behavioral Health Administration
Catonsville, Maryland

**Keisha R. Peterson**
Office of Genetics and People with Special Health Care Needs/ DHMH
Baltimore, Maryland

**Bryan Pugh**
Brain Injury Association of Maryland
Baltimore, Maryland

**Lisa Schoenbrodt**
Loyola University of MD Speech Language Hearing Science
Baltimore, Maryland

**Adrienne Walker-Pittman**
Representing Individuals with Brain Injury
Baltimore, Maryland

**Cari Watrous**
Maryland Department of Disabilities
Baltimore, Maryland

**Buddy Weaver**
Representing Families/ Caregivers of Individuals with Brain Injury
Charles County, Maryland

*Maryland Legislative Appointments (ex-officio)*

**Senator Nancy J. King**
Democrat, District 39, Montgomery County

**Delegate Jeffrey D. Waldstreicher**
Democrat, District 18, Montgomery County

*Staff to the Board*

**Linnette Rivera (previously held by Anne Blackfield)**
Maryland Department of Disabilities
Baltimore, Maryland

**Nikisha Marion**
Behavioral Health Administration
Catonsville, Maryland