Maryland Traumatic Brain Injury Advisory Board

March 14, 2022

The Hon. Larry Hogan Governor State of Maryland 100 State Circle Annapolis, MD 21401–1991

The Hon. Bill Ferguson President of the Senate Maryland General Assembly H-107 State House Annapolis, MD 21401–1991

Mohammed Choudhury State Superintendent Maryland State Department of Education 200 West Baltimore Street Baltimore, MD 21201–2595

Carol Beatty Secretary Maryland Department of Disabilities 217 Redwood Street, Suite 1300 Baltimore, MD 21202 The Hon. Adrienne Jones Speaker of the House Maryland General Assembly H-101 State House Annapolis, MD 21401–1991

Dennis Schrader Secretary Maryland Department of Health 201 W Preston Street Baltimore MD 21201

Re: Health-General § 13–2105—State Traumatic Brain Injury Advisory Board Annual Report - 2021

Dear Governor Hogan, President Ferguson, Speaker Jones, Superintendent Choudhury, and Secretaries Schrader and Beatty:

Pursuant to Maryland Health-General §13–2105, the Maryland Traumatic Brain Injury Advisory Board respectfully submits its annual report.

The views in this report reflect those of an independent group of experts with a broad range of personal and professional experience both in Maryland and nationally. The information and recommendations in this report are intended to educate policy makers and influence state policy and does not necessarily reflect the current views of the state agencies involved.

If you have any questions regarding this report, please contact Stefani O'Dea, Director of the Office of Older Adults and Long Term Services and Supports, Maryland Behavioral Health Administration, at (410) 402-8300 or Stefani.odea@maryland.gov.

Sincerely,

Martin Kerrigan

Martin Kerrigan Chair, Maryland Traumatic Brain Injury Advisory Board

Enclosure

cc: Heather Shek, Director, Director, MDH Office of Governmental Affairs Aliya Jones, M.D., MBA, Deputy Secretary Behavioral Health Sarah Albert, MSAR# 10380

MARYLAND

Traumatic Brain Injury Advisory Board





2021

Annual Report

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The Maryland Traumatic Brain Injury Advisory Board is partnering with the Brain Injury Association of Maryland (BIAMD) to highlight the Marylanders with brain injuries this board was created to represent. As part of BIAMD's Unmasking Brain Injury 2.0 project, Marylanders with brain injuries and their caregivers were asked to create masks to help us put a face on this "invisible epidemic". BIAMD then asked them to tell their story and describe their mask.

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







PREFACE

Every brain is different. Every brain injury is different. Every brain injury recovery is different. Therefore, it is vital to listen to a wide variety of voices when determining what recommendations should be forwarded to Maryland's Governor and other policy makers. The views in this report reflect a broad range of experiences including those of individuals with brain injuries, family members of those with brain injuries, professional healthcare providers, educators, lawyers, law enforcement, state government representatives, and non-profit advocacy groups.

The Maryland Traumatic Brain Injury Advisory Board (TBIAB) consists of 36 voting members each of whom volunteer their time, energy, and expertise. The Board (TBIAB) was initially introduced in 2005 by Senate Bill 395, Chapter 306 of the Laws of Maryland. Board members review available data and publications as well as promising practices from other states. The board values the input of individuals who are living with a brain injury (or TBI) related disability and family members who are caring for individuals with brain injury. The information and recommendations in this report are intended to educate policy makers and influence state policy and do not necessarily reflect the current views of the state agencies involved.

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

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

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

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

EXECUTIVE SUMMARY

Brain Injury is the leading cause of injury-related death and disability in the United States. Brain Injury may occur from a traumatic injury or a non-traumatic injury or disease and each year affects at least 20,000 Marylanders of all ages.¹

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

The following recommendations of the TBIAB are intended to address service gaps and reduce the public health burden of brain injury through appropriate resource linkage, training, effective screening practices, and availability of specialized services:

- I. Appropriately identify children and youth with brain injuries.
- II. Implement brain injury screening protocols and offer treatment accommodations to individuals receiving behavioral health services and to those incarcerated in jails and prisons.
- III. Expand and improve services offered through the Maryland Brain Injury Waiver.
- IV. Increase funding to allow implementation of the Maryland Brain Injury Trust Fund program.
- V. In order to comply with HG § 20–108, establish a central registry of individuals living with a disability as a result of a brain injury and ensure that these individuals and their families are provided information about appropriate resources and assistance.

The Maryland TBI Advisory Board supports changes proposed to the statute that change the references and definition of traumatic brain injury to a broader brain injury definition, prioritize individuals with lived experience with brain injury for appointment to the Board and correct the names of state agencies that have changed since the statute first took effect.

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¹ Maryland Department of Health Center for Environmental, Occupational, and Injury Epidemiology, Traumatic Brain Injury (TBI)-related Emergency Department (ED) visits and Hospitalizations: Maryland 2016–2018 (Oct. 13, 2020).

UNDERSTANDING BRAIN INJURY

CAUSES OF BRAIN INJURY

The human brain can be injured in many ways. Most people are aware of brain injuries caused by contact sports and by blast injuries that occur during military conflict. These causes of brain injury have been the subject of national news coverage over the past twenty years. Many people, when they think about brain injury, may think first about our professional football players and members and veterans of our military and while these injuries are significant they represent a small number of the total brain injuries sustained every year.

Brain injury can also be caused by a penetrating gunshot wound to the head, something residents of our urban areas, particularly those of color, experience in great numbers.² Brain injuries can be caused by motor vehicle crashes and bicycle crashes. Pedestrians hit by motor vehicles can incur a brain injury. Falls can also cause brain injury, a significant problem among our growing older adult population.

Some of the underrecognized causes of brain injury include those resulting from intimate partner violence, childhood physical abuse, drug overdoses, and most recently, complications from the coronavirus disease 2019 (COVID-19) outbreak.

WHAT IS AN ACQUIRED BRAIN INJURY?

An acquired brain injury (ABI) is defined as damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease.³

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

WHAT IS A TRAUMATIC BRAIN INJURY?

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² The Center For Injury Prevention And Policy, R Adams Cowley Shock Trauma Center, University Of Maryland, Prevention Matters: Violence Prevention, available at <a href="https://www.umms.org/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence/prevention-policy/violence/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence/ummc/-/media/files/ummc/-/media/f

https://www.umms.org/ummc/-/media/files/ummc/health-services/shock-trauma/center-injury-prevention-policy/violence-prevention/center-for-injury-prevention-and-policy-violence-prevention-fact-sheet.pdf?upd=20180517192532 &la=en&hash=0972CD6C6947AE0D744E0EB90F9D3102662EC0D1 (all Internet materials as last visited October 23, 2020).

³ Kamalakannan, Gudlavalleti, Gudlavalleti, Goenka, and Kuper, Challenges in understanding the epidemiology of acquired brain injury in India. Ann Indian Acad Neurol. 2015 Jan-Mar; 18(1): 66–70, online at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4350218/.

A Traumatic Brain Injury (TBI) is caused by external forces to the brain including motor vehicle crashes, motorcycle and scooter crashes, falls, assaults, sports injuries, blast exposure, gunshot wounds to the head, objects falling on the head, and sharp objects penetrating the skull.

SEVERITY OF INJURY

"Severity of injury" refers to the degree or extent of brain tissue damage. Brain injury may be classified as mild, moderate, or severe, depending on the individual's neurologic signs and symptoms.⁴ The degree of damage is estimated by measuring the duration of loss of consciousness and coma, length of amnesia (memory loss), and brain scans.⁵

Table. Degree of Damage to the Brain

Severity of Injury	Percentage Affected	Signs and Symptoms
Mild TBI	80% of all brain injuries- characterized by no loss of consciousness or a loss of consciousness (LOC) of less than 30 minutes and/or a period of confusion referred to as post traumatic amnesia (PTA) of less than 60 minutes	 Vomiting & dizziness Lethargy Memory loss for the period immediately, before and after the injury and difficulty attending to and learning new information during this time period (PTA)
Moderate TBI	10–13% of all brain injuries-characterized by LOC of 30 minutes to 24 hours, and PTA of 1–24 hours	 Signs of brain injury including bleeding, contusions Period of time (PTA) where memory and learning are impacted is longer than after a mild TBI Signs of injury to the brain injury evident on a CAT scan or other neuroimaging assessments
Severe TBI	7–10% of all brain injuries-characterized by LOC and PTA greater than 24 hours	 Unconsciousness (coma) for over 24 hours, can last days, weeks, months, or years No sleep/wake cycle during

⁴ Model System Knowledge Translation Center, online at https://msktc.org/.

⁵ Brain Injury Association of America, online at https://www.biausa.org/brain-injury/about-brain-injury/basics/injury-severity.

	period of coma • Signs of injury to the brain evident on a CAT scan or other neuroimaging assessments
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SYMPTOMS & RECOVERY

Each individual's presentation of symptoms and recovery varies widely despite the severity of brain injury. Therefore, it is essential to note that the functional deficits in the areas of cognition, physical abilities, and behavioral health vary from person to person depending on a variety of factors including: age at the time of injury, appropriate and timely access to medical care, and access to support and services. Brain injury symptoms can consist of impaired mobility, coordination, dexterity, memory, learning, attention, sleep, and sense of sight, hearing, vision, taste, and/or smell. Additional reported symptoms are headaches, fatigue, mood disorders, and post-traumatic epilepsy. Approximately twenty percent of individuals with a history of TBI develop a post-TBI seizure disorder, which worsens behavioral outcomes.⁶





Steve S. Bicycle Accident

The majority of individuals who present with a "mild" traumatic brain injury or concussion recover within two weeks. However, some individuals with mild brain injury experience a complicated course of recovery. A complicated recovery is especially true when individuals have incurred multiple mild brain injuries. The populations where multiple mild brain injuries are common include those who have served in the armed forces, athletes, victims of intimate partner violence, and children who are exposed to abuse. Although it is rare for individuals to have long term negative consequences of a single mild TBI, multiple mild traumatic brain

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⁶ Semple, Zamani, Rayner, Shultz, Jones, Affective, neurocognitive and psychosocial disorders associated with traumatic brain injury and post-traumatic epilepsy (2019), online at

https://research.monash.edu/en/publications/affective-neurocognitive-and-psychosocial-disorders-associated-wi.

⁷ Clendenen, Partner-inflicted brain injury: recognizing invisible injuries and finding hope for healing (March 19, 2020), online at https://www.futureswithoutviolence.org/Partner-Inflicted+Brain+Injury.

injuries can result in increased levels of disability with each mild injury incurred, especially if they occur within close proximity to each other.⁸

History of brain injury is associated with challenges in obtaining and maintaining employment, interpersonal challenges, the onset of mental illness, increased risk of incarceration, dementia, mental illness and substance use disorders, and early death. Research from the TBI Model Systems estimates individuals living with moderate to severe brain injury have a reduced life span of nine years compared to their uninjured peers.⁹

The adverse effects of an acquired brain injury are not just limited to the individual. Caregivers of people with brain injury report stress, grief, and loss¹⁰ and may also experience adverse health effects, including stress-related disorders and depression.¹¹

PREVENTING TRAUMATIC BRAIN INJURY

The TBIAB exists to ensure effective treatment and rehabilitative services for those affected by TBI. However, it is equally as important from a public health perspective, to identify and decrease risk factors to prevent TBI and its associated disability. Prevention strategies to reduce the likelihood of sustaining a brain injury include but are not limited to: wearing a seatbelt when driving or riding in a motor vehicle, securing children ages zero to eight in a child safety seat, wearing a helmet or appropriate headgear when playing contact sports, biking, motorcycling, snowmobiling or riding a scooter. Additionally, older adults should talk with their physician about evaluating their risk for falling, assess their home for fall-related hazards, have regular eye exams and have their pharmacist review their medications for fall risk. For young children, it is important to: ensure play areas are safe, install window guards to keep young children from falling out of windows, use safety gates at the top and bottom of stairs, and choose playgrounds with soft material underneath. For more information on preventing TBI please visit the Centers for Disease Control and Prevention (CDC) website. 12

While not commonly associated with reducing brain injury, other prevention efforts are equally important such as substance abuse and overdose prevention efforts, domestic violence resources, infection prevention, and suicide prevention efforts. Individualizing practices within the behavioral health profession to screen for a lifetime history of brain injury as well as targeted

⁸ Vynorius, Paquin, Seichepine, Lifetime Multiple Mild Traumatic Brain Injuries Are Associated with Cognitive and Mood Symptoms in Young Healthy College Students (October 31, 2016), online at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5086577/.

⁹ Harrison-Felix et al., Life Expectancy after Inpatient Rehabilitation for Traumatic Brain Injury in the United States (November 4, 2014), online at https://pubmed.ncbi.nlm.nih.gov/25057965/.

¹⁰ Kratz et al., Traumatic brain injury caregivers: A qualitative analysis of spouse and parent perspectives on quality of life (June 8, 2015), online at https://pubmed.ncbi.nlm.nih.gov/26052805/.

¹¹ Brickell, French, Lippa, and Lange, Burden among caregivers of service members and veterans following traumatic brain injury, vol. 32:12 (August 27, 2018), online at

 $[\]underline{https://www.tandfonline.com/doi/abs/10.1080/02699052.2018.1503328?journalCode=ibij20.}$

¹² CDC Traumatic Brain Injury & Concussion, Prevention (last reviewed Mar. 4, 2019), online at https://www.cdc.gov/traumaticbraininjury/prevention.html.

prevention and outreach to individuals with brain injury would reduce the rate of substance use among individuals with brain injury, and reduce the chance of overdose related brain injuries.







BRAIN INJURY INCIDENCE DATA

NATIONAL INCIDENCE DATA

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

According to the Center for Disease Control and Prevention:

- In 2014, about 2.87 million emergency department (ED) visits, hospitalizations, or deaths were related to TBI, including over 837,000 of these health events among children.
- TBI contributed to the deaths of 56,800 people, including 2,529 deaths among children. These consisted of TBI alone or TBI in combination with other injuries.
- In 2014, an estimated 812,000 children (age 17 or younger) were treated in a U.S. hospital ED for concussion or TBI alone, or in combination with other injuries.
- Between 2006 and 2014, while age-adjusted rates of TBI related ED visits increased by 54%, hospitalization rates decreased by 8% and death rates decreased by 6%.
- The total cost of ED visits, hospitalizations, and deaths related to TBI, either alone or in combination with other injuries, exceeds \$82 billion annually—this includes medical and work loss costs.¹³

MARYLAND INCIDENCE DATA¹⁴

¹³ CDC Traumatic Brain Injury & Concussion, Get the Facts, online at https://www.cdc.gov/traumaticbraininjury/get the facts.html.

¹⁴ Maryland Department of Health Center for Environmental, Occupational, and Injury Epidemiology, Traumatic Brain Injury (TBI)-related Emergency Department (ED) visits and Hospitalizations: Maryland 2016–2018 (Oct. 13, 2020).

According to the Maryland Department of Health Center for Environmental, Occupational, and Injury Epidemiology, in Maryland in 2018, there were:

• 4,221 TBI related hospitalizations and 15,205 TBI related ED visits with some rural counties and Baltimore City particularly impacted.

Figure 1. Mean annual rate of TBI related ED visit by county of residence, Maryland 2016-2018

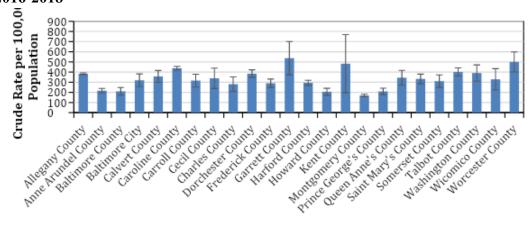
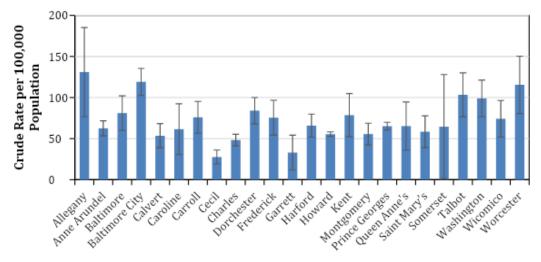


Figure 2. Mean annual rate of TBI related hospitalizations by county of residence, Maryland 2016–2018



UNCAPTURED AND UNDERREPORTED DATA

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

A TBI module based on the Ohio State University TBI ID Method for eliciting lifetime history of TBI was included in one of three versions of the 2021 Behavior Risk Factor Surveillance System for the 2021 survey. (BRFSS) is the nation's premier system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. ¹⁵ The survey results will allow MDH to estimate prevalence of TBI in Maryland including those who were not treated in emergency rooms or hospitals. Results are expected in the summer of 2022 and will be shared in a future TBI Advisory Board Report.

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, opioid-related overdoses and other unintentional poisonings, intimate partner violence, and brain damage caused by COVID-19 and other viruses.





Kimberley L. Domestic Abuse Incident

BRAIN INJURY SCREENING

Throughout this report, screening for a history of brain injury is recommended for students, individuals receiving behavioral health services, incarcerated individuals, for those receiving home and community-based services, veterans, and individuals experiencing homelessness as well as individuals who have experienced intimate partner violence. Screening for a history of brain injury is important because many injuries to the brain are unreported or untreated. Even

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¹⁵ Eagye, Whiteneck, Harrison-Felix, Report on Methods to Estimate Traumatic Brain Injury Prevalence and Home and Community Based Services Use by State, Traumatic Brain Injury Model Systems, National Data and Statistical Center, Craig Hospital (September 30, 2019), online at

 $[\]frac{https://static1.squarespace.com/static/5eb2bae2bb8af12ca7ab9f12/t/5f6e46b9853fc630b55bdbb8/1601062591214/ACL+Report+on+TBI+Prevalence+and+HCBS+by+State+FINAL.pdf.}$

when an injury is treated, the long-term consequences and the secondary impact of the injury on the social determinants of health may be unknown.

Simple, validated screening tools such as the Ohio State University TBI Identification Screen can be completed within minutes and do not have to be administered by a clinician with an advanced degree. Screening can identify a possible lifetime exposure to brain injury that can inform the need for specific brain injury clinical assessment and interventions as well help guide both service providers and the individual and their supporters as to what kinds of structure, support and accommodations will help them to better engage and benefit from treatment and rehabilitation services.

Several brain injury screening tools exist.¹⁶ The Maryland Behavioral Health Administration, Maryland's lead agency on Brain Injury, has implemented a modified version of the Ohio State University TBI Identification method into certain services.¹⁷

LATEST BRAIN INJURY RESEARCH

Long Covid and the Brain¹⁸

Covid-19 can impact several body systems including the nervous system, resulting in loss of smell and taste and in some cases causing stroke. Eighteen months into the Covid 19 pandemic, researchers are studying the long term effects of the Covid 19 virus. Studies to date, while limited, indicate the most common persistent symptoms for individuals who have been infected with Covid-19 are fatigue, dyspnea (difficulty breathing), and brain fog. These symptoms can have a negative effect on both cognition and mental health. Current theories regarding the causes of extended symptomology include Post Viral Syndrome¹⁹ and Post Intensive Care Syndrome²⁰. As additional studies are completed and research is published, it is important to consider the future service needs of individuals with long Covid. The service needs of this population may mirror those of individuals who have sustained an acquired brain injury from other causes such as anoxia caused by overdose or other infections.

Intimate Partner Violence—A July 2020 Government Accountability Office (GAO) report indicated that one in three adults has experienced intimate partner violence and may have

¹⁶ NASHIA Resource List, online at https://www.nashia.org/resources-list?category=Screening%20Tools.

¹⁷ Screening for TBI Using the OSU TBI-ID Method, The Ohio State University Wexner Medical Center, online at https://wexnermedical.osu.edu/neurological-institute/departments-and-centers/research-centers/ohio-valley-center-for-brain-injury-prevention-and-rehabilitation/for-professionals/screening-for-tbi.

¹⁸ COVID-19: Persistent Symptoms, PICS, Post-Viral Syndrome or Something Else? Julie Miller, BSN, RN, CCRN-K, October 21, 2020

¹⁹ Post-viral syndrome is triggered by a reaction to a virus in the form of sustained inflammation. Post-viral syndrome is a wide range of complex conditions involving physical, cognitive, emotional and neurological difficulties that vary in severity over time.

²⁰ Post-intensive care syndrome is made up of health problems that remain after critical illness. They are present when the patient is in the ICU and may persist after the patient returns home. These problems can involve the patient's body, thoughts, feelings, or mind and may affect the family.

experienced a brain injury as a result of physical blows to the head or strangulation.²¹ The GAO recommends a federal plan for better data reporting around brain injury resulting from intimate partner violence. During the Covid-19 Pandemic, intimate partner violence increased as a result of increased substance use, stress, unemployment, and increased amounts of time victims spend with abusers with limited contact with friends and other support networks.

Overdose, Substance Use Disorders, and Brain Injury—The interplay between substance misuse and brain injury is significant. TBI is common among people who have a substance-related disorder. Over 20% of non-institutionalized adults in the United States have had at least one TBI with a loss of consciousness, and this estimate more than doubles among people with a substance-related disorder. Individuals with co-occurring substance-related disorders and mental health problems are even more likely to have a history of TBI. The increased vulnerability for misuse and addiction to other substances (e.g., alcohol) among people with TBI suggests the same may be true with opioids.²² Factors, such as post injury chronic pain, pre- and post- injury substance use, and TBI-related neurobehavioral changes contribute to the disproportionately high risk of individuals with TBI developing an Opioid Use Disorder.²³

Individuals who have sustained a brain injury are at increased risk accidental poisoning, such as an opiate overdose. Anoxic and hypoxic brain injuries are on the rise due to the high use of opioids. Opiate use depresses the nervous system and affects breathing. In a drug overdose, the brain is at risk of being deprived of oxygen resulting in brain damage or death.²⁴

An **overdose** is an injury to the body (poisoning) that happens when a drug is taken in excessive amounts. An overdose can be fatal or nonfatal. Opioid overdose induces respiratory depression that can lead to an anoxic/hypoxic brain injury.²⁵

Mild TBI and risk of mental health issues—A study reveals that approximately one in five individuals may experience mental health symptoms up to six months after mild traumatic brain injury, suggesting the importance of follow-up care for these individuals. Scientists also identified factors that may increase the risk of developing post-traumatic stress disorder (PTSD) and/or major depressive disorder following mild TBI. These include lower levels of education, self-identifying as African American and having a history of mental illness. In addition, if the head injury was caused by an assault or other violent attack, that increased the risk of developing PTSD. Risk of mental health symptoms was not associated with other injury-related occurrences

²¹Government Accountability Office, Report GAO-20-534 (June 12, 2020), online at https://www.gao.gov/products/GAO-20-534

²² Brandeis University, Heller School for Social Policy and Management, Publications and Products, online at https://heller.brandeis.edu/ibh/research/inroads/publications-products.html.

²³ Adams, Corrigan, and Dams-O'Connor, Opioid Use among Individuals with Traumatic Brain Injury: A Perfect Storm?, Journal of Neurotrauma, vol. 37, no. 1 (December 11, 2019), online at https://www.liebertpub.com/doi/abs/10.1089/neu.2019.6451.

²⁴ Adams, Rachel Sayko, Corrigan, John D., Dams-O'Connor, Kristen. (2019). "Opioid Use among Individuals with Traumatic Brain Injury: A Perfect Storm?" Journal of Neurotrauma, 36, 1-6. PMID:31333067.

²⁵ Brain Injury and Opioid Overdose: Fast Facts, online at https://static1.squarespace.com/static/5eb2bae2bb8af12ca7ab9f12/t/5f0dee1187f836204a58de36/1594748434440/opioid-braininjury-connection+%281%29.pdf.

such as duration of loss of consciousness or posttraumatic amnesia. The study was supported by the National Institute of Neurological Disorders and Stroke, part of the National Institutes of Health. The findings were published in JAMA Psychiatry.²⁶

Suicide and Brain Injury—Recently, the correlation between a history of brain injury and risk of completed suicide has been in the news and a focus of research. A large-scale registry-based cohort study in Denmark found that those with TBI compared with the general population without TBI had an increased risk of suicide, with risk being higher for those with severe TBI.²⁷

TBI and Adverse Childhood Experiences—Adverse Childhood Experiences (ACEs) are significant risk factors for physical and mental illnesses in adulthood. Based on literature reviews, correlation between adverse childhood experiences and TBI occurrence was identified. The review highlights the importance of screening and treatment of ACEs. Exposure to ACEs is associated with increased risk of TBI. Specific types of adverse childhood experiences associated with risk of TBI include childhood physical abuse, psychological abuse, household member incarceration, and household member drug abuse. Clinicians and researchers should screen for a history of adverse childhood experiences in all people with TBI as pre-injury health conditions can affect recovery.²⁸

TBI and Homelessness- The lifetime prevalence of TBI is high among homeless and marginally housed individuals, and a history of TBI is associated with poorer health and general functioning. According to a 2020 meta-analysis of 22 studies addressing TBI and homelessness, the lifetime prevalence of any severity of TBI in homeless and marginally housed individuals was 53.1% and the lifetime prevalence of moderate or severe TBI was 22.5%.

SERVICES, SUPPORTS, AND GAPS IN MARYLAND²⁹

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

Services and supports that are currently available to Marylanders who sustain a brain injury include: trauma and emergency services, inpatient and outpatient rehabilitation, long-term services and supports (both institutional services such as home- and community-based and nursing facility services), special education services and educational accommodations for students, behavioral health services, case management, and active support from advocacy organizations.

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²⁶ Murray B. Stein et al. Risk of Posttraumatic Stress Disorder and Major Depression in Civilian Patients After Mild Traumatic Brain Injury A TRACK-TBI Study. *JAMA Psychiatry*, 2019 DOI: <u>10.1001/jamapsychiatry.2018.4288</u>.

²⁷ https://jamanetwork.com/journals/jama/fullarticle/2697009.

²⁸ Zechen Ma, Mark T. Bayley, Laure Perrier, Priya Dhir, Lana Dépatie, Paul Comper, Lesley Ruttan, Christine Lay & Sarah E. P. Munce (2019) The association between adverse childhood experiences and adult traumatic brain injury/concussion: a scoping review, Disability and Rehabilitation, 41:11, 1360-1366, DOI: 10.1080/09638288.2018.1424957.

²⁹ See Appendix A, *infra* pp. 25–28, for more details about Maryland services and service gaps.

The gaps in Maryland largely revolve around the absence of available services within many geographic areas in the State and a lack of coordination and specialization of these services and supports. Further complicating these issues are limited access to case management and homeand community-based supports, limited TBI incidence and prevalence data, 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. See Appendix A for additional details related to services and service

gaps.







Caregiver

Skiing Accident

MARYLAND ACCOMPLISHMENTS³⁰

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

RECOMMENDATIONS FOR MARYLAND

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

I. Appropriately identify children and youth with brain injuries.

The State of Maryland should improve identification of students with brain injuries by requiring local education agencies to add questions, designed to capture incidence of brain injury or loss of consciousness suffered at any time by the student, to the special education identification process.

Why is this important?

Recently, the under identification of students with lasting TBI sequelae is gaining more attention nationally and several states are considering how to best address this problem. According to the

³⁰ See Appendix B, *infra* pp. 29–30, for more information about Maryland Brain Injury accomplishments.

Department in 2017 alone there were 4,794 ED visits and 210 hospitalizations for Marylanders ages 0–18 years old with a diagnosis of TBI.³¹ This total does not capture the full extent of brain injury among this population, as it does not include those seen by private practitioners, in urgent care facilities, or those who did not seek medical care following a brain injury. It also most likely does not capture most incidences of "mild" and "moderate" brain injury, even though the effects from these types of brain injuries can have long term impacts on an individual's cognition and functioning. Despite the number of severe brain injuries reported among school-aged children, there are currently only 223 Maryland students identified as requiring special education services as the result of a traumatic brain injury.³² This is 0.2% of the total population of students currently receiving special education services in Maryland schools.

Under-identification of brain injury may occur because TBI symptoms can be misinterpreted as other disabilities, such as emotional disturbance and specific learning disability which may lead to inappropriate individualized education plans with goals and objectives that do not fully address the student's actual needs. Improved identification of TBI through the creation and use of additional questions will help increase the likelihood that: (1) students who were not previously identified as having a brain injury will receive further assessments to determine their need for additional services, supports, and accommodations; (2) screening evidence will guide and inform the selection of appropriate assessments for students identified as having a TBI; and (3) services, supports, and accommodations will be individually determined based on an appreciation of the students' history of TBI and an interpretation of their assessment results.

According to a 2017 study published by the National Institutes of Health the effects of TBI on cognition, emotional functioning and behavior are well known, but educational professionals sometimes fail to connect learning and other problems to a TBI. This delayed recognition of TBI may "lead to unnecessary chronic and disruptive problems in activities and participation" including learning and school.³³

Brain injury often has a significant impact on the development and functioning of an individual. This is especially true in the developing brains of children and adolescents. Difficulties with problem solving, impulsivity, memory, new learning, and self-regulation are some of the common sequelae of brain injury and represent just some of the serious and potentially lifelong consequences of TBI. The CDC 2018 Report to Congress³⁴ includes information and tools for healthcare providers, educators, parents, and students to assist with acute medical management of brain injury in children as well as recommendations for long-term monitoring and transition to

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³¹ Maryland Department of Health Maryland Department of Health Center for Environmental, Occupational, and Injury Epidemiology, Traumatic Brain Injury (TBI)-related Emergency Department (ED) visits and Hospitalizations.

³² Maryland State Department of Education's 2019 Special Education Census.

³³ Van Heigten, Renauld, and Resch, The role of early intervention in improving the level of activities and participation in youths after mild traumatic brain injury: a scoping review, Concussion, 2017 Nov; 2(3): CNC38. Published online 2017 Aug. 10. DOI: 10.2217/cnc-2016-0030.

³⁴ CDC National Center for Injury Prevention and Control, Division of Unintentional Injury Prevention, Report to Congress: The Management of Traumatic Brain Injury in Children (2018), online at https://www.cdc.gov/traumaticbraininjury/pdf/reportstocongress/managementoftbiinchildren/TBI-ReporttoCongress-508.pdf.

school. The report demonstrates increasing evidence of the relationship between long-term disability and behavioral health conditions that impact functional achievements in adulthood, highlighting the importance of timely, appropriate intervention with children.





Teth Motor Vehicle Accident

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

In 2019, legislation designed to study identifying practices was introduced in the Maryland House of Delegates, where it passed unanimously. The proposed legislation did not make it out of committee in the Senate.³⁵

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

The Department of Health should:

 Convert the TBI screening questions that are currently built into the authorization process for two mental health services to mandatory responses (they are currently optional questions); and

³⁵ See General Assembly of Maryland, HB0708, online at

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

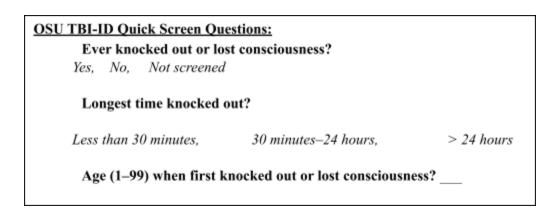
 Extend these questions to additional public behavioral health service authorization workflows.

Why is this important?

Individuals who sustain a brain injury have an increased risk of developing a mental illness, a substance use disorder, becoming incarcerated, and/or experiencing homelessness. Most individuals who sustain a brain injury in Maryland will not receive services from a specialized brain injury program or provider. Most will either receive no services or receive services from systems or programs that are designed for other diagnoses or disabilities. The unique constellation of deficits that can result from a brain injury are often misinterpreted as malingering or non-compliance when in fact the individual receiving services may be struggling with cognitive, physical, or behavioral challenges that interfere with the individual's ability to engage with and benefit from services. Research suggests that awareness of a possible brain injury in someone's history and implementation of simple strategies and supports can greatly enhance treatment outcomes.

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

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



For mobile treatment services, in FY17, 2,863 people received a mobile treatment service. Forty-seven percent of those individuals were administered the brief screen. Of those, five percent screened positive for a history of brain injury. In FY18, 3,764 people received mobile

treatment services. Forty-two percent of those individuals were administered the brief screen and three percent screened positive for a history of brain injury.

For psychiatric rehabilitation services, in FY17, 10,830 people received the service. Fifty-seven percent of those individuals were administered the brief screen and five percent of those screened positive for a history of brain injury. In FY18, 17,272 received the service. Sixty-one percent were administered the brief screen and four percent screened positive for a history of brain injury. These data indicate that between 3-5% of those screened reported a history of brain injury but that at least half of service utilizers did not receive the screening, likely because screening is currently an optional process.

III. Expand access and improve services offered through the Maryland Brain Injury Waiver³⁶

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

- Piloting a change in the eligibility for the Brain Injury Waiver to allow access from private nursing facilities;
- Increasing the Individual Support Service (ISS) rate to ensure the administrative costs of providing this service are reimbursed and to promote supported housing through utilization of this waiver service; and
- Studying hybrid virtual/ in person day habilitation service model.

Why is this important?

Most individuals with brain injury will not receive services from the Brain Injury waiver. Approximately 3,000 Medicaid beneficiaries with brain injury receive services in a Maryland nursing facility each year.³⁷ Currently individuals in private nursing facilities are not eligible for the brain injury waiver because of the facility based technical eligibility criteria currently required for the program. Western Maryland Hospital Center (WMHC), one of the facilities currently included in the facility-based eligibility criteria, has closed their brain injury unit as the demand for COVID-19 related post-acute services increased. This has limited access to Maryland's Brain Injury Waiver Program. The brain injury waiver program has a limited number of available waiver slots each year, but does not fill its maximum allowed slots each year because technical eligibility criteria are so limited. Piloting access to this program for Maryland

³⁶ Maryland's Home and Community Based Services Waiver for Individuals with Brain Injury is a Medicaid program that provides community-based services to individuals with brain injury as an alternative to care in an institutional setting such as a nursing facility or chronic hospital.

³⁷ The Hilltop Institute, 2013.

nursing facility residents will ensure that program capacity is utilized and that individuals who require these specialized services have access.

Historically, brain injury waiver service utilization has been highest for residential services and day habilitation, costly services with limited provider capacity. Affordable housing initiatives—such as Bridge Subsidy, HUD 811, and Weinberg and Mainstream Housing—have become increasingly available since the implementation of Maryland's Money Follows the Person Demonstration Project. Five years ago, the waitlist for these programs was year's long but now waiver participants are able to access these programs within months. This has resulted in a positive change in service utilization for the brain injury waiver. Currently, approximately 16% of the waiver population has transitioned to independent housing with waiver support services, and more waiver participants are currently on the waitlist for the subsidized housing programs. Overall costs to the State for participants who have transitioned to independent housing is on average less than half of that for participants living in a provider owned or controlled residential setting. Brain injury providers however have expressed concern about the inadequacy of the rates and the volume of uncompensated services they are providing to participants to ensure their health and welfare. Evidence suggests that housing and employment drive recovery and have positive impacts on self-report of quality of life. A large number of waiver participants indicate during the annual participant experience survey an interest in living independently. This convergence of participant needs and preferences with affordable housing opportunities has created a priority for the Department to address in terms of rate and service adequacy.

Medicaid's Office of Community Long Term Services and Supports, with input from stakeholders, updated the service definition for individual support service in June 2020, but the rate disparity has not yet been addressed.



Martin K. Hit by a Car



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

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

• allocating appropriate state general funds to the Trust Fund;

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

Why is this important?

Pursuant to HG § 13–21A–02(i), the Department is required to submit a report on the State Brain Injury Trust Fund, including the number of individuals served and the services provided in the preceding fiscal year using the fund. The Department has been unable to provide services to any individuals with a brain injury through this fund since its inception because of inadequate funding.

The Department has established a Trust Fund Advisory Committee to advise and assist with developing a list of covered services, service descriptions, provider requirements, and conditions for participant participation. This committee projects that annual revenue must reach \$500,000 in order for service provision to begin. This would provide approximately 50 Marylanders with brain injury 10 hours of case management/support services per week. Since the passage of Senate Bill 632, Chapter 511 of the Acts of 2013, the Department has accrued \$64,745.28 through the voluntary vehicle registration donation program at time of this report. Average monthly donations increased in April 2021 from less than \$2000 per month to \$8,000 per month when the donation option changed from a flat \$1 donation to any whole dollar amount. This is a positive trend; however still not enough to meet the annual revenue target; hence the need for a state general fund allocation.

Currently, 24 states have created brain injury trust fund programs and Maryland's is by far the most poorly funded.

If adequately funded, this fund would provide services to individuals with a medically documented brain injury with incomes $\leq 300\%$ of the federal poverty level who are in need of case management and other support services and not eligible for services under Maryland's Brain Injury Waiver.

Case management or care coordination is the highest priority service to be covered through this fund as it significantly improves timely access to available services and supports, which potentially reduces costs over time. The benefits of case management (also often referred to as resource facilitation) are underscored in the findings of a randomized controlled trial conducted by Trexler, Parrott and Malec, published in the Archives of Physical Medical Rehabilitation in 2016.³⁸ This study found beneficial employment outcomes for 44 individuals receiving outpatient services post brain injury. Following an intervention of 15 months of resource facilitation services, 69% of those who received resource facilitation services were able to return to work as compared to 50% of the control participants.

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³⁸ Trexler, Parrott, Malec, Replication of a Prospective Randomized Controlled Trail of Resource Facilitation to Improve Return to Work and School After Brain Injury (October 9, 2015), online at https://pubmed.ncbi.nlm.nih.gov/26452718/.

The TBIAB is very appreciative of the efforts of legislators and state leaders at the Maryland Department of Transportation (MDOT) and the Maryland Department of Health (MDH) for the creation of a revenue source for Maryland's Brain Injury Trust fund. The MDOT created a voluntary donation option for vehicle registration transactions completed via kiosk or online. Donations are transferred to Maryland's Brain Injury Trust fund, managed by BHA. Revenues are not yet sufficient to support the types of services identified in the law. The Brain Injury Trust Fund Advisory committee, under the leadership of the BHA, has begun drafting program requirements and procedures in anticipation of reaching the target funding level.







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

Why is this important?

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

As far as the TBIAB is aware, hospitals are not reporting the occurrences of individuals with disabilities in their institutions with "head injuries." In addition, as far as the TBIAB is aware, the Department has not implemented the statutorily required central registry to compile information about individuals with disabilities with reportable conditions. Furthermore, as far as the TBIAB is aware, the Department is not notifying the individual or the individual's parent or guardian of any assistance or services that may be available from the State and of the eligibility requirements for such assistance or services within 15 days.

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

MARYLAND BRAIN INJURY RESOURCES

Maryland Department of Health' Behavioral Health Administration (BHA) is Maryland's Lead State Agency for Brain Injury responsible for coordinating and expanding services for individuals with brain injury. BHA operates Maryland's Brain Injury Waiver, staffs Maryland's TBI Advisory Board, and is the recipient of federal TBI Grant funding administered by the Administration for Community Living and authorized through the TBI Act. https://bha.health.maryland.gov/Pages/Traumatic-Brain-Injury.aspx

Brain Injury Association of Maryland is a private non-profit organization and a chartered state affiliate of the Brain Injury Association of America. BIAMD provides direct support and advocacy for individuals living with brain injury, their friends and family, professionals, and the general public. BIAMD serves as Maryland's primary brain injury resource for *Maryland Access Point* (No Wrong Door System) and the case management vendor for Maryland's *Brain Injury Waiver program*. www.biamd.org

Disability Rights Maryland (DRM) is Maryland's designated Protection & Advocacy agency. DRM is federally mandated to advance the civil rights of people with disabilities. DRM provides free legal services to Marylanders of any age with all types of disabilities (developmental,

intellectual, psychiatric, physical, sensory, learning, and traumatic brain injury). DRM envisions a world where people with disabilities are fully included in all aspects of community life. DRM helps people with disabilities pursue opportunities to participate fully in all aspects of community life, and champion their rights to self-determination, dignity, equality, opportunity, and freedom from discrimination and harm. https://disabilityrightsmd.org/

Maryland TBI Advisory Board (TBIAB) was initially introduced in 2005 by Senate Bill 395, Chapter 306 of the Laws of Maryland and is required to submit an annual report to the Governor, the General Assembly and the Secretaries of Health and Disabilities and the Superintendent of the State Department of Education. The website for TBIAB reports, meeting minutes, and board manual is as follows: https://bha.health.maryland.gov/Pages/mdtbiadvisoryboard.aspx

MARYLAND TBIAB MEMBERSHIP

Membership of the Maryland TBIAB is set forth in HG §§ 13–2101 through 13–2105. Membership consists of individuals who have sustained a brain injury, family members and caregivers, advocacy organizations, professionals working in the field of brain injury treatment and rehabilitation, Maryland state agencies, and two members of the Maryland state legislature. Half of the membership is appointed 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 Survivors and Families Empowered (SAFE), a standing committee. The SAFE committee was created as a place for the members of the Maryland TBIAB who are living with a brain injury or who are family members of individuals with brain injuries to obtain support and a sense of unity in board matters. One of the main goals of the committee is to ensure that individuals with brain injury and family members are active participants in board meetings and activities.

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

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

Board Membership

Gil Abramson, Esq

Jeronica Baldwin

Sandra Bastinelli

Baltimore, MD

Office of Long Term Services and Supports, Baltimore City Representing Individuals with Brain Injury Carroll County

Jody Boone

Division of Rehabilitation Services Baltimore City Joan Carney, Ed.D.

Brain Injury Association of Maryland Baltimore City Larry Cadenhead

Representing Families and Caregivers of Individuals with Brain Injury Howard County

Joyce Dantzler

Center for Injury and Sexual Assault Prevention, Maryland Department of Health Baltimore City Norma Eisenberg

Representing Families and Caregivers of Individuals with Brain Injury Howard County Laurie Elinoff

Representing Individuals with Brain Injury, Statewide Independent Living Council Anne Arundel County

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Brain Injury Association of Maryland Baltimore City Martin Kerrigan, Chair

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Claudette Mathews, RN

Office of Genetics and People with Special Health Care Needs

Kara Melcavage

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Behavioral Health Administration, Maryland Department of Health Baltimore County

Bryan Pugh

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Mellissa Ruff, LCSW

Representing Families and Caregivers of Individuals with Brain Injury Baltimore City

Gabriel Rubinstein

Disability Rights Maryland, Baltimore City

Lisa Schoenbrodt

Loyola University of Maryland Speech Language Hearing Science Baltimore City

Lt. Stephen Thomas

Law Enforcement
Anne Arundel County

Adrienne Walker-Pittman

Representing Individuals with Brain Injury Baltimore City

Heather Wheeler, PT, DPT

University of Maryland Rehabilitation and Orthopedic Institute Baltimore County

Maryland Legislative Appointments (ex-officio)

Senator Nancy J. King

Democrat, District 39, Montgomery County

House of Delegates,

Vacant

Staff to the TBIAB

Kirsten Robb-McGrathMaryland Department of Disabilities Baltimore City

Nikisha Marion Behavioral Health

Administration, Maryland Department of Health Baltimore County

Arin Jayes & Chris Shaffer

Brain Injury Association of Maryland

APPENDIX A

DESCRIPTION OF MARYLAND SERVICE SYSTEMS

SERVICE AREA AVAILABLE SERVICES SERVICE GAPS

Trauma Care³⁹

Emergency care for TBI is provided by Maryland's Institute for Emergency Medical Services System (MIEMSS), a coordinated statewide network that includes volunteer and career emergency medical system providers, medical and nursing personnel, communications, transportation systems, trauma and specialty care centers, and EDs.

Many individuals who sustain TBI, such as a concussion, do not seek treatment in these settings. They often see treatment in a physician's office or an urgent care center or seek no treatment at all. As a result, a TBI can be undiagnosed or misdiagnosed and the impact of the injury and resulting deficits underestimated, leading to lack of adequate follow up and supports. See recommendation #4 Trust Fund.

Brain Injury Rehabilitation

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

The length of stays in inpatient facilities has decreased significantly over the years, and it is now increasingly more common for individuals with brain injury to receive rehabilitation in a nursing facility (no nursing facilities have specialized brain injury programs) or to have little or no access to rehabilitation services.

See recommendation #4 Trust Fund and #3 Brain Injury Waiver.

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

Maryland only offers case management to those enrolled in home- and community-based services, including targeted case management for individuals with mental illness. Most Marylanders with brain injury are not enrolled in

³⁹ MIEMSS, 2018–2019 Annual Report, online at https://www.miemss.org/home/Portals/0/Docs/AnnualReports/Annual-Report-2019.pdf?ver=2020-10-07-145042-71

case-management services, which are provided under a number of programs, vary in name and scope and are offered by a variety of providers. Case management has been demonstrated to help reduce readmissions to hospitals and improve rehabilitation outcomes.

those Medicaid programs. The lack of case management limits timely access to appropriate services and supports and thereby negatively affects clinical outcomes. See recommendation #4 Trust Fund.

TBI Registry

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

This statute was not implemented, and hospitals are not currently reporting "head injuries" to the Department. This gap in reporting, compiling, and notification is negatively affecting the lives of every Maryland family dealing with brain injury. As a result, individuals and family members receive limited to no information and resources when the opportunity for recovery afforded by access to appropriate care is most critical. The long-term negative impact affects public health at the systemic level as well as the lives of individuals with brain injury and their families. See recommendation #5 TBI Registry.

Home- and Community-Base d Services

Services are provided in an individual's home or in the community as an alternative to care in an institutional setting, such as a nursing facility. Maryland operates eight Medicaid-funded home- and community-based waiver

Private or commercial insurance does not cover home- and community-based supports that assist individuals with remaining at home and also prevents admission to nursing facilities for long-term care. Medicaid does cover these programs, including one designed for individuals with brain injury, and five additional programs that offer personal care and other supports. home- and community-based services. *See recommendation #3 Brain Injury Waiver*.

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 injuries, who meet the financial, medical, and technical eligibility for the program.

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 recommendation #3 Brain Injury Waiver.

Behavioral Health Services

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

Behavioral health providers do not routinely screen the individuals they serve for a history of a brain injury. This often leads to misdiagnosis, under-identification, and insufficient supports and services for both children and adults. See recommendation #2 Screening.

Special Education Services

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

There is a discrepancy between the number of school-age children being treated in Maryland hospitals for a TBI and the number of Maryland students receiving special education services with a diagnosis of TBI. This under-identification or

misidentification may occur because TBI symptoms overlap with symptoms of other disabilities as defined by the IDEA. Incorrectly diagnosing students and failing to recognize TBI is likely to lead to inappropriate individualized education programs because the goals and objectives do not address the student's unique needs. See recommendation #1 Students.

APPENDIX B

MARYLAND ACCOMPLISHMENTS

Leadership of Individuals with Brain Injury and Families/ Caregivers

Individuals with TBI and other disabilities, particularly those from culturally and linguistically diverse populations, have the right to be engaged in and lead the decision-making processes related to their services and supports. Maryland is a nationally recognized leader in how to integrate individuals with lived experience of brain injury and their families onto the TBI Advisory Board and promote leadership opportunities for these important stakeholders. The federal Administration on Community Living requires grantees such as Maryland to strive to include the following representation on the State TBI Advisory Board: at least 50% membership of people with TBI and family member(s) of individuals with TBI, the Centers for Independent Living and/or the State Independent Living Council, an Aging and Disability Resource Center, the Protection & Advocacy agency in the state, and the long-term care ombudsman. Maryland's TBI Advisory Board is proud to report that seventy-six percent (76%) of its membership have either personally experienced a brain injury or are caregivers or family members of a person with a brain injury and has active members representing the Centers for Independent Living, the Protection and Advocacy organization, and the Aging and Disability Resource Center. Maryland's TBI Advisory Board strives for full participation of all members and has created a nationally recognized standing committee called Survivors and Families Empowered (SAFE), which meets prior to every full advisory board meeting and reports out to the full advisory board at every meeting.

Unmasking Brain Injury

Since 2019, the TBIAB has been including masks in the annual report to help educate policy makers about what it is like to live with brain injury. The mission of Unmasking Brain Injury, a nonprofit organization based out of North Carolina, is to promote awareness of the prevalence of brain injury; to give survivors a voice and the means to educate others of what it's like to live with a brain injury; to show others that persons living with a disability due to their brain injury are like anyone else, deserving of dignity, respect, compassion and the opportunity to prove their

value as citizens in their respective communities. In the spring of 2018, members of the TBIAB in association with the Brain Injury Association of Maryland participated in the national Unmasking Brain Injury initiative by providing masks and craft supplies to individuals with brain injuries to tell their stories and express their feelings about brain injury through art. Since then, the Brain Injury Association of Maryland has assisted 68 Marylanders with brain injury to create a mask that tells their story. These masks are incredibly powerful. The stories behind them demonstrate hardship, pain, strength, determination, resilience and joy. The TBIAB strongly encourages the readers of this report to visit this site and learn about Brain Injury from the perspective of Marylanders with firsthand experience of this life altering injury.⁴⁰

Advocacy

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

Brain Injury Trust Fund

The Maryland Brain Injury Trust Fund was created during the 2013 Legislative Session without a revenue stream but, in December 2018, a voluntary donation program was created at the Maryland Department of Transportation. Now Marylanders renewing their vehicle registration online or at a kiosk can donate to Maryland's Brain Injury Trust Fund. Since the passage of Senate Bill 632, Chapter 511 of the Acts of 2013, the Department has accrued \$64,745.28 through the voluntary vehicle registration donation program at time of this report. Average monthly donations increased in April 2021 from less than \$2000 per month to \$8,000 per month when the donation option changed from a flat \$1 donation to any whole dollar amount. This is notable accomplishment; however, it is also important to note that the revenues generated through this program are too low to support the initiation of services.

Federal Grant Funding

In 2019, the Behavioral Health Administration was awarded a three-year federal Traumatic Brain Injury Partner Grant from the Administration for Community Living. The grant focused on training behavioral health professionals about brain injury and how to screen and support individuals with a history of brain injury who are receiving services through the public behavioral health system. The grant also supported BHA's collaboration with local Overdose

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⁴⁰ Brain Injury Association of Maryland, Unmasking Brain Injury, online at https://www.biamd.org/unmasking-brain-injury-20.html.

Fatality Review Teams, local police department's Crisis Intervention Training and the Department of Aging. A No Cost Extension to the current grant will run through the spring of 2022, at which point, BHA will continue to expand these efforts and collaborations across the state upon award of a new 5-year Federal Partner Grant from the Administration for Community Living.

Legislative

Concussion Law- On May 19, 2011, the concussion bill was signed into law, mandating the implementation of concussion awareness programs throughout the State, and requiring student athletes who demonstrate signs of a concussion to be removed from practice or play. Helmet Law- Board members have successfully advocated against the repeal of Maryland's motorcycle helmet law. Multiple states (e.g., Louisiana, Texas, Arkansas) have repealed only to reinstate all-rider helmet laws due to the significant increase in motorcycle deaths.