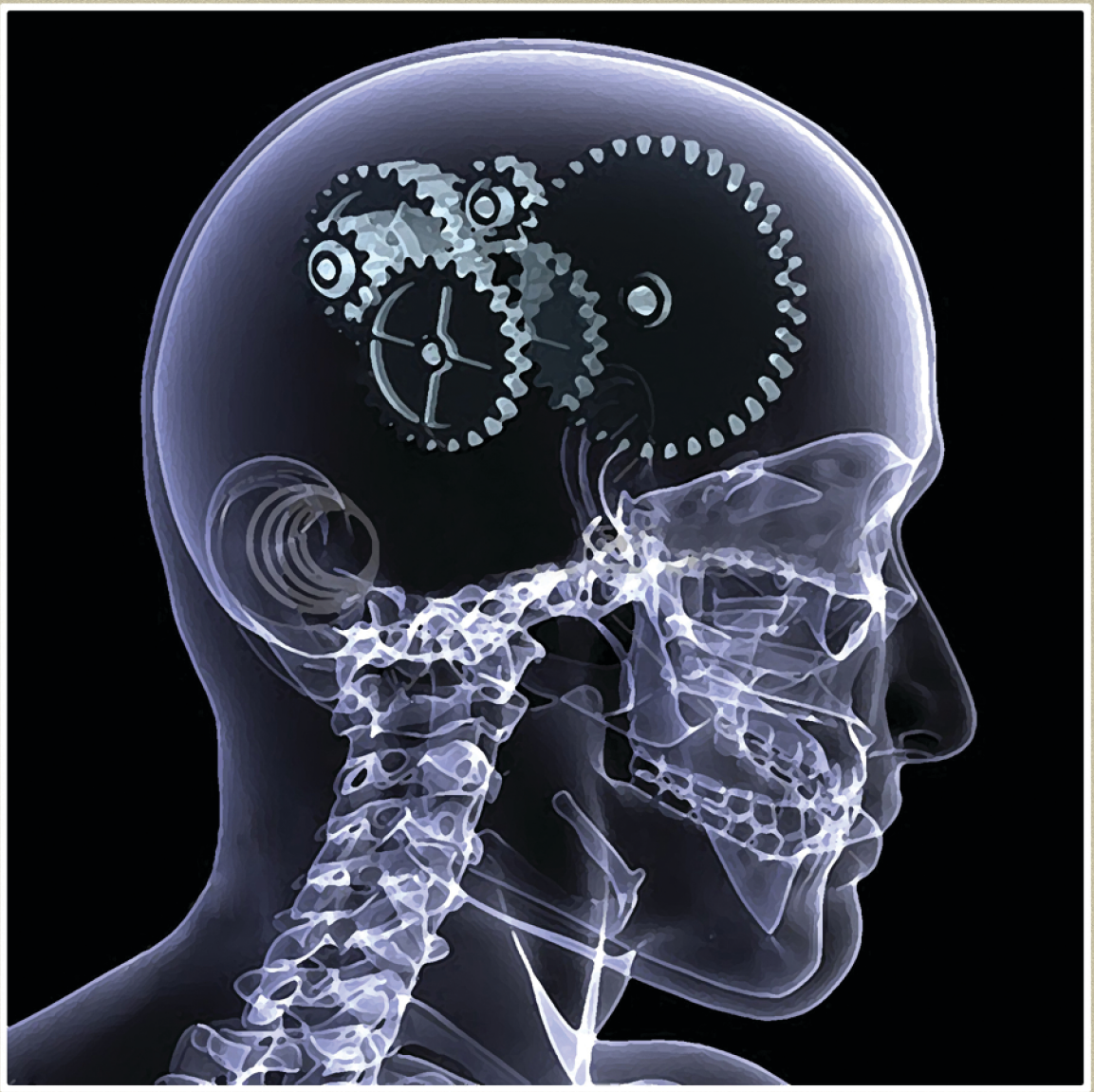
MARYLAND
Traumatic Brain Injury Advisory Board



2013
Annual Report

November 26, 2013

c/o Mental Hygiene Administration
Spring Grove Hospital/ Dix Building
55 Wade Avenue
Catonsville, MD 21228

The Honorable Martin O'Malley, Governor
State House - 100 State Circle
Annapolis, Maryland 21401 - 1925

Thomas V. Mike Miller, Jr., President of Senate
State House, H-107
Annapolis, Maryland 21401 - 1991

Michael Erin Busch, Speaker of House of Delegates
State House, H-101
Annapolis, Maryland 21401 – 1991

Dear Governor O'Malley, Senator Miller, and Delegate Busch:

To quote a 2013 report to Congress, Brain Injury "is one of the highest priorities in public health and medicine because of its magnitude, cost, and consequences (e.g., death and disability), and because it is often preventable."

The State of Maryland must address this public health issue by improving prevention efforts and access to appropriate treatment and services. The Maryland Traumatic Brain Injury Advisory Board is required to issue an annual report to the governor and the General Assembly by § 13-2105(6) of the Health General Article in accordance with § 2-1246 of the State Government Article.

The enclosed report contains six recommendations which the Advisory Board believes represent the needs of individuals with brain injuries, their families, and communities in the state of Maryland. It is critical that the State of Maryland implement these essential recommendations, which will lead to better outcomes for individuals with brain injuries, their families and their communities and will ultimately save the state of Maryland money.

If you have any questions or require additional information, please contact me through Stefani O'Dea, Chief of Long Term Care, Maryland Mental Hygiene Administration at (410) 402- 8476, or by email to stefani.odea@maryland.gov

Sincerely,

Martin Kerrigan, Chair

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Glossary of Terms

TBI……Traumatic Brain Injury
DHMH……Department of Health and Mental Hygiene
MSDE……Maryland State Department of Education
CDC……..Centers for Disease Control
IDEA…….Individuals with Disabilities Education Act
TBI Waiver…….Medicaid Waiver for Adults with Traumatic Brain injury
ED……Emergency Department

Executive Summary

TBI is the leading cause of death and disability in the United States (Coronado et al 2009). In Maryland TBI is already at epidemic levels and according to some reports is increasing. Behind the statistics, are our friends and neighbors, colleagues and family members, their lives interrupted if not shattered with concurrent financial costs to individuals and the state. Therein lies our challenge. Maryland needs to build upon measures already in place, such as ensuring that the newly created but unfunded TBI Trust Fund has a sustainable revenue source, to ensure that high quality care is accessible and available for all Marylanders who sustain a brain injury.

> *TBI is "one of the highest priorities in public health and medicine because of its magnitude, cost, and consequences (e.g., death and disability), and because it is often preventable."*
> Report to Congress, 2013

If there is a silver lining to this dark cloud it is that, according to a recent report to Congress by the several federal agencies (Report to Congress), TBI is often preventable.[1] Therein lies our opportunity. The conclusion of the Report to Congress suggests that if we act, decisively and wisely, we treat TBI as "one of the highest priorities in public health and medicine," Maryland can reverse the trends, reduce the future incidence of TBI, and consequent human and financial costs to individuals and the state, and quickly identify and properly treat TBIs that are not prevented.

Concussion and other brain injuries can happen anywhere, to anyone, at any time. From high profile cases like those of Baltimore Orioles Second Baseman Brian Roberts to tragic cases like those of Derek Sheely, the Frostburg State College football player who died days after collapsing during practice in August 2011. From those of our returning warriors and brave police and firefighters, to our relatives, friends, and neighbors injured in school, on the field or off, playing sports, or driving to or at work and our senior citizens and very young children, who are injured daily from accidental falls. Each of these individuals continues to struggle with the devastating effects on their ability to work, to learn, to care for themselves and their loved ones.

While Maryland has taken important steps toward addressing this problem, there is still much more work to be done. Do we have the will? Do we have the courage to ensure that all Marylanders have access to the quality care they need for as long as they need it? The State of Maryland needs to address the needs of all citizens affected by brain injury. In this report, the Traumatic Brain Injury Advisory Board presents the facts as we know them and makes realistic and fiscally responsible suggestions for action that Maryland can take to educate our citizens, identify all TBI as close to the incident date as possible and provide needed services for survivors.

[1] "Traumatic Brain Injury in the United States: Understanding the Public Health Problem among Current and Former Military Personnel" (CDC, NIH, DoD, DVA June 2013) (CDC Report).

THE STAGGERING INCIDENCE OF TBI NATIONALLY AND IN OUR OWN BACKYARD

Centers for Disease Control (CDC) Data

- 5.3 million people live in the United States with a disability resulting from a TBI. (CDC 2010)
- Approximately 511,000 TBIs occur among children ages 0 to 14 years; 90% of the brain injuries in this age group result in ED visits. (CDC, 2010)
- The annual economic cost of TBI in the United States, including direct medical and rehabilitation costs, as well as indirect societal economic costs is $60 billion (Finkelstein, Corso & Miller, 2006). Costs are highest for severe TBI per claimant compared to moderate and mild TBI (Prana, Ruseckaite & Collie, 2012).

Maryland TBI Incidence Data 2007- 2011 (provided by DHMH, updated November 2013)
TBI related Hospitalizations

- After a three year trend of declining hospitalizations due to TBI, hospitalizations increased by 21% between 2010 and 2011.
- Individuals over age 44 experienced the largest increase in TBI related hospitalizations with rates increasing with age. For example, the 45-54 year old age group experienced a 23% increase in hospitalizations and the 75 and older age groups experienced a 46% increase.
- The most common cause of TBI related hospitalizations was fall followed by motor vehicle accidents.

TBI related Emergency Department (ED) Visits

- TBI related ED visits continue to steadily increase each year with a 7% increase between 2010 and 2011.
- The age groups with the highest rates of ED visits due to TBI are 5-14 and 65-74 year olds.
- The most common causes of TBI related ED visits are falls followed closely by struck by/against. Sports related concussions often call into the category of struck by/against or in the category of falls.
- This data reinforces public concern about sports related concussions for youth and TBI caused by falls for seniors.

TBI and its Attendant Costs are Rising in Maryland

According to a 2012 Medicaid claims data analysis conducted by the Hilltop Institute at University of Maryland Baltimore Campus (UMBC):

- The number of Medicaid beneficiaries with TBI **increased** by 37% between 2007 and 2011, with an average of 7,287 Medicaid beneficiaries per year.
- 89% were not enrolled in any Home and Community Based Services (HCBS).
- 61% of the beneficiaries with TBI were under age 50.

Students with TBI may be under identified in Maryland Public Schools

- Over 6,500 children, and youth between the ages of birth and 21were hospitalized for a traumatic brain injury (TBI) between 2005-2009.
- Additional unknown numbers of children sustained TBI but were not admitted to the hospital.
- Yet, only 225 children, less than .24% of the total population of students aged 3 – 21 receiving Special Education services in Maryland are currently identified as TBI under the IDEA.

There is high Prevalence of Brain Injury in Maryland Nursing Facilities

According to the July 2013 study titled, *Medicaid Expenditures for Persons with Traumatic Brain Injury while residing in Maryland Nursing facilities: A follow-up Study*, the Hilltop Institute at UMBC found:

- Approximately 3,000 Maryland Medicaid beneficiaries with a history of brain injury had nursing facility (NF) stay during the Fiscal Year (FY) 2010 to FY 2012 study period.
- The prevalence rate of Medicaid beneficiaries with TBI or Anoxia in Maryland nursing facilities was 13 percent in FY12.
- FY12 Medicaid costs for persons with a TBI and/or Anoxia diagnosis while residing in a NF were $16,000 higher per person than those of their non-TBI diagnosed counterparts
- For nursing facility patients with TBI who had longer stays (>11 months), the average per person total annual costs were $91,443. Higher annual costs were associated with higher non-NF costs (e.g., inpatient hospital, emergency department services, medicine). For individuals with lower annual costs, most costs are nursing facility costs.
- In FY 2012, the ratio of persons under age 65 to those 65 and older for persons with a TBI diagnosis was nearly even at 5:5; the same ratio for nursing facility users with no TBI diagnosis was 2:8. This implies that there are larger numbers of young nursing facility residents with TBI than there are young nursing facility residents without brain injury.
- On average 16 percent of individuals who transitioned from FY 2010 to FY 2012 through Maryland's Money Follows the Person Demonstration Program had a history of TBI and/or Anoxia.

This study in its entirety can be found on the Hilltop Institute's website http://www.hilltopinstitute.org/publications/MedicaidExpendituresForPersonsWithTBI-FollowupAnalysis-July2013.pdf

Service Members Sustain High Rates of TBI

- From 2000 through the first quarter of 2012, at least 244,217 service members sustained a traumatic brain injury (TBI) according to the Defense Department.
- The Department of Veterans Affairs (VA) estimates that approximately 20% of the 2.3 million service members who have been deployed since September 2001 have sustained a TBI.
- In Maryland, 31,927 Active Duty Military personnel and 12,221 reservists have been deployed since September 11, 2001. Applying the 20% incidence rate means that Maryland is currently home to 8,830 Veterans and/or service members living with the effects of a TBI

Research Findings and Recommendations

- A growing body of literature is adding to our understanding of TBI, its identification, effects, and treatment. For example, while it relatively well known that concussion has obvious effects on learning, a new report cites "increasing evidence that using a concussed brain to learn may worsen concussion symptoms and perhaps even prolong recovery." This report goes on to say that "increasing cognitive activities are hypothesized to add additional stress to an energy deprived brain, which may worsen symptoms."[2] The implications of these findings for our students and the way schools perceive and meet their needs cannot be overstated.
- The Report to Congress identifies TBI as, "one of the highest priorities in public health and medicine because of its magnitude, cost, and consequences (e.g., death and disability), and because it is often preventable." The report then makes recommendations regarding research, classification of TBI, and data collection for active service members, Veterans and civilians.
- A report published in September 2013 by six leading national organizations that represents individuals with brain injury and their families confirms the need for better research and data collection and identifies the gaps and barriers to treatment and services for individuals with brain injury and their families.[3] The report cites the need for a national brain injury plan that not only includes federal funds allocation for TBI programs but also the modification of existing programs. The Report specifically recommends the coordination of efforts and resources such as those described in the Individuals with Disabilities Education Act (IDEA), the Older Americans Act, and Substance Abuse and Mental Health Services Administration's (SAMHSA) co occurring disorders initiatives to better serve Americans with brain injury.

National Issues Impacting Brain Injury Policy

- Components of the Affordable Care Act (ACA), including long term care reform initiatives and health insurance exchanges, have been implemented. While these initiatives aim to improve access to healthcare and to expand community based long term services and supports to individuals who are aging or disabled, the outcome of these additional initiatives have yet to be fully realized.
- The National Football League (NFL) agreed to a $765 million settlement to conclude a class-action law suit brought by more than 4,500 former players who filed concussion-related lawsuits. For two years, scores of players filed suit against the NFL, claiming the league misled them on the sport's dangers. The settlement funds medical exams and research as well as provides compensation for former players who are suffering from the debilitating effects of repeated concussions. The Frontline expose regarding the NFL's reluctance to acknowledge the long term effects of concussions can be viewed at http://www.pbs.org/wgbh/pages/frontline/sports/league-of-denial/debating-the-science-of-concussions/

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[2] Halstead *et al.*, "Returning to Learning Following a Concussion" (Pediatrics October 27, 2013)

[3]The organizations are theAmerican Congress of Rehabilitation Medicine, Brain Injury Association of America, Friends of the TBI Model Systems, National Association of State Head Injury Administrators, North American Brain Injury Society, and United States Brain Injury Alliance.

- The National High School Sports-Related Injury Surveillance Study (RIO Study) for school year 2011-2012 found that concussions made up 22% of all reported injuries for all high school sports. (Comstock, et. al., 2012). In addition, one out of four reported high school football injuries and one out of three reported boys high school lacrosse injuries were concussions. (National High School Sports-Related Injury Surveillance Study – High School Rio Study 2011-2012)

Maryland Initiatives impacting Brain injury Policy

- Senate Bill 632 passed unanimously in the 2013 legislative session and was signed into law by Governor Martin O'Malley on May 16, 2013, resulting in the creation of the Maryland Brain Injury Trust Fund. The bill passed without an identified revenue source and the established fund is not yet able to pay for needed services and supports as intended. A report is due to the Maryland Legislature by January 1, 2014.
- In 2011 Governor O'Malley signed into law legislation to protect public school athletes and others from concussion. The following year the Maryland State Board of Education (MSBE) enacted emergency regulations and ordered the Maryland State Department of Education (MSDE) to study the problem. MSDE convened a task force to study the problem and reported to MSBE on January 22, 2013 and on May 21, 2013 MSDE enacted regulations to implement the 2011 law. COMAR § 13A.08.06. In August 2013, MSDE issued a press release highlighting new recommendations prompted by the law and regulations. "These new provisions mandate training for each coach and physical education teacher in concussion risk and management and require local school systems to implement policies for notifying student athletes, parents and others about concussion risks, removal and return to play criteria, and the risks of not reporting injury. The regulations also mandate immediate removal of students athletes suspected of having a concussion from practice or play, written clearance after receiving appropriate medical assessment before return to play, and to use specified return to play protocols. The regulations also require Youth Sports Programs using school facilities to provide concussion information to parents."
- Maryland Health Benefit Exchange opened October 1, 2013. According to an October 25, 2013 press release, over 3,100 households have enrolled in Maryland Health Connection and over 82,000 Maryland are signed up to be automatically enrolled in Medicaid effective Jan 1, 2014. Mandatory health benefits have been established for the plans offered through the exchange. Additionally, in an effort to improve and expand the availability of community based long term services and supports in Maryland, the Department of Health and Mental Hygiene (DHMH) is implementing several of the long term care reform initiatives offered through the affordable care act including Money Follows the Person, the Balancing Incentives Program and Community First Choice.

Despite these important events occurring in our nation and specifically in our State, Traumatic Brain Injury (TBI) remains a public health crisis as evidenced by national and state brain injury data trends. The incidence and prevalence of TBI remains staggering and the costs associated with treatment, long term supports and indirect costs continue to rise. Advancement in medical technology and practice has resulted in greater numbers of people surviving catastrophic injuries and living with resulting deficits, disabilities, and co-morbid medical and behavioral health conditions. Falls are on the rise, especially in the growing senior population. Prevention and timely access to effective treatment and supports is the strategy that Maryland must employ to decrease the incidence of TBI, improve outcomes for Marylanders who sustain a TBI, and reduce the long-term costs for the State.

Issues related to preventing, identifying and treating traumatic brain injury have gained national recognition in large part due to growing public awareness about these injuries, which stems from widespread media coverage regarding the issue of concussions and sports and returning service members who have experienced TBI's as a result of Incendiary Explosive Devices (IEDs) and other non-penetrating and penetrating brain injuries.

Whereas TBI has for many years been an epidemic among civilian population, it has now reached epidemic proportion among our returning service members. In fact, traumatic brain injury is the "signature wound" of the conflicts in Iraq and Afghanistan. The long term support needs of service members who were deployed during these conflicts and sustained TBI's are not yet known as the link between TBI and neurodegenerative disorders is currently being studied. The research into the long term effects of multiple concussions and a condition called Chronic Traumatic Encephalopathy, or CTE, will have application to Veterans and civilians including athletes and other individuals who have experienced multiple concussions such as military personnel, individuals with epilepsy, and victims of domestic violence (Saulle and Greenwald 2012).

According to Maryland TBI incidence data provided by DHMH, falls are the most common cause of TBI related emergency room visits and hospitalizations, According to the CDC, more than one third of adults 65 and older fall each year in the United States. Falls are among the most serious and common problems that threaten the independence and quality of life for older adults. Falls are a strong predictor of placement in a skilled-nursing facility among older adults living in the community (Journal of Medicine October 1997).

According to a web based needs and resource assessment in 2012 by the Maryland Mental Hygiene Administration as the Brain Injury Association of Maryland, sixty (60)% of individuals with brain injury and thirty-nine (39)% of family members surveyed are dissatisfied with services available to people with brain injury in the state. Concerns voiced include; ***lack of awareness and understanding among the public and professionals, difficulty managing complex medical care without assistance, not enough providers, not enough access due to geographic location and/or funding for cognitive therapy, lack of case management, behavioral health services, and lack of neurobehavioral facilities especially for young people.***

Traumatic brain Injury also has a significant impact on our criminal justice system. A meta analysis found in the Journal of Head Trauma Rehabilitation in 2012 looked at 20 epidemiological studies of TBI among the offender population and found that 60% of incarcerated individuals had a history of TBI. This disproportionately large prevalence rate would indicate a need for more appropriate resource allocation, screening, and management of offenders in order to improve behavior management while incarcerated as well as to improve release planning and reduce recidivism.

The Maryland TBI Advisory Board recognizes the research around the rates of traumatic injury among the following populations; incarcerated individuals, victims of domestic violence, veterans of the Iraq and Afghanistan wars, amateur and professional athletes, and individuals struggling with behavioral health disorders such as serious mental illness and substance abuse. For many living with brain injury, the specific cognitive, physical, and behavioral sequela following injury are complicated by one or more behavioral health disorders and that negatively impact their ability to thrive at home, in the community, classroom and workplace. Strategies to address the interaction of brain injury and co-occurring disorders among all individuals living with brain injury include cross training among behavioral health and rehabilitation professionals across settings and the implementation of a brief TBI screening such as the HELPS to aid in the identification of those whose brain injury related challenges pose a barrier to full community participation, improvement in treatment and recovery outcomes, and in the case of incarcerated individuals, to improve release planning and reduce recidivism.

According to the literature:

Offender Population

- Approximately **30%** of juvenile offenders have sustained a previous TBI. (Farrer, TJ., Frost, RB., & Hedges, DW. Journal of Child Psychology 2013)
- Estimated prevalence of TBI in overall offender population, **60.25%**. (Shiroma, E.J., Ferguson, PL., Pickelsimer, EE. In Journal of Head Trauma Rehabilitation 2012)

Domestic Violence

- Greater than **90%** of all injuries secondary to domestic violence occur to the head, neck or face region (Monahan & O'Leary 1999) **Adapted from The Alabama Department of Rehabilitation Services DV Training**
- One study found that of 167 individuals treated for domestic violence related health issues, 30% experienced a loss of consciousness on at least one occasion and 67% reported residual problems that were potentially TBI related (Corrigan et.al. 2003)
- Another study demonstrated that 57 of 99 battered women interviewed had brain injured related symptomatology (Valera and Berenbaum 2003)

Behavioral Health

- Depression is the most common Axis I psychiatric disorder after TBI followed by alcohol abuse, panic disorder, specific phobia and psychotic disorders (Gordon et. al 2004)
- Between 37-51% of individuals hospitalized for TBI were intoxicated at the time of injury & have a history of alcohol misuse (Parry & Jones 2006)

Based on available epidemiological data, Medicaid claims data, and current trends in health care and public policy, the Maryland Traumatic Brain Injury Advisory Board strongly recommends the following action steps in Maryland to address the needs and gaps ion services for Marylanders with Brain Injury. The order of the recommendations does not reflect the importance of the issue. The Board feels that all recommendations are equally important.

- Appropriately identify, assess, and provide services for children and youth with brain injuries.
- Create a statewide system of case management for individuals with brain injury.
- Expand the capacity of the Maryland licensed Chronic Hospitals, Nursing Facilities, and Home and Community-Based Services to address the neurobehavioral needs of Marylanders with brain injury.
- Fully fund the State of Maryland Dedicated Brain Injury Trust Fund.
- Modify the technical eligibility requirements for the Home and Community-Based Waiver for Adults with Traumatic Brain Injury.
- Strengthen the supports and resources available through the Maryland Commitment to Veterans (MCV) Program to support Veterans who have a sustained a TBI.

Appropriately identify, assess, and provide services for children and youth with brain injuries.

FACTS: In Maryland, over 6,500 children, and youth between the ages of birth and 21were hospitalized for a traumatic brain injury (TBI) between 2005-2009. This total does not include additional numbers of children that were seen by a medical professional but were not admitted to the hospital. Despite this significant number of brain injuries in Maryland's school aged population, the Maryland State Department of Education (MSDE) reports only 225 children, less than .24% of the total population of students aged 3 – 21 receiving Special Education services in Maryland under the Individuals with Disabilities Education Act (IDEA), were receiving those services under a TBI classification code in 2013. Last year, the Center on Brain Injury Research & Training, a division of the Rehabilitation Research and Training Center (RRTC) on Interventions for Children and Youth with Traumatic Brain Injury, funded by the National Institute on Disability and Rehabilitation Research (NIDRR) conducted a national survey of state departments of education. Their findings indicated that a majority of the states report inaccuracy in identifying students with TBI for special education services. Among the contributing factors to the inaccuracy identified were: a lack of awareness about TBI as a disability (e.g., educators didn't understand the long-term consequences of TBI), lack of communication between hospital and school, mis-identification of students with TBI under different eligibility categories, under-reporting of injuries by parents, and a narrow definition of TBI that excludes other forms of acquired brain injury (stroke, tumor, surgery, etc.).

RECOMMENDED ACTION:
Require the Maryland State Department of Education (MSDE) to increase public and professional awareness of brain injury in children and youth and the possible adverse effects on learning and behavior through the following:

- Include a question regarding any form of "head trauma" or loss of consciousness suffered at any time by a student during all screening processes and on required yearly school health forms and to develop a processor protocol for school health personnel to inform school Individualized Education Plan (IEP) teams of students with a positive response to that question.
- Require schools to follow up with students and families following a concussion or suspected concussion regarding the student's physical condition and school performance. This follow up should occur at regular scheduled intervals following the onset of the injury.
- Provide training and information to families, students, and school personnel, throughout the state, related to brain injury utilizing resources such as the Specialized Health Needs Interagency Collaboration project already supported by MSDE.
- Work with the Traumatic Brain Injury/ Sports Related Concussions Task Force (already established) to do the following:
    - Increase dissemination of concussion awareness trainings to school athletic departments, coaches, and trainers throughout the State educational system.
    - Incorporate/emphasize "Return to Learn" as well as "Return to Play" in trainings.
    - Develop and implement a "Return to Learn" protocol which can be used throughout the State.
- Incorporate required education regarding brain injury for teachers through staff development opportunities and/or during pre-service week.

- Incorporate brain injury awareness and education into parent/teacher/student association meetings.
- Institute mandatory sign off from medical professional on screening questionnaire that is required for all high school athletes in Maryland. The screening is currently based on self reporting.
- Create or designate a "Brain Injury Specialist" position within MSDE to serve as liaison between MSDE, local school systems, and the medical community. This would be a pilot position that is focused in a few select counties. Duties of this position would include providing technical assistance, support, and training to the MSDE as well as to local education agencies.

JUSTIFICATION:

TBI can have a significant impact on classroom performance and behavior in children and youth. Recognizing this, Congress added TBI as a category for special education eligibility in 1991, and the term, as defined by the U.S. Department of Education, is codified at 34 C.F.R. § 300.8(12). Despite the existence of this category there is a significant discrepancy between TBI incidence data and data from MSDE regarding the number of school aged individuals that incur a TBI every year and the number of students currently identified as requiring educational support in schools due to a TBI. Without proper identification and assessment, students with a diagnosis of TBI cannot be identified or served appropriately. The discrepancy between Maryland's hospital discharge data and the number of students currently identified by IDEA as TBI implies that there are students with TBI that are either misidentified or not identified at all under IDEA. Often times, TBI survivors can exhibit symptoms that lead to mis-identification into IDEA codes of emotional disturbance, speech and language disorder or even intellectual disability. Therefore, it is critical that TBI be fully understood by all involved in developing programs for students with disabilities. This is crucial so that all appropriate assessments, especially neuropsychological assessments, are obtained and that appropriate resources can be distributed to this population. As the ability of students with TBI to be successful in school and successfully transition to adulthood is compromised, the likelihood of consuming valuable State resources in the future increases.

Create a statewide system of case management for individuals with brain injury.

FACTS: Every year, over 5,000 Marylanders experience a TBI that is serious enough to require hospitalization. There are more than 40,000 Emergency Department visits each year resulting from a TBI. The percentage of Medicaid recipients living in Maryland with a TBI has increased by 37% since 2007.

RECOMMENDED ACTION:
Require the Department of Health and Mental Hygiene (DHMH) to create a statewide system of case management for individuals with brain injury.

JUSTIFICATION:

Despite the high incidence of TBI in our state, the growing trends of TBI among our aging population, and the increased burden on the Medicaid system as a result, there is no case management system in Maryland for individuals with brain injury. Even though multiple case management programs exist in Maryland, a diagnosis of brain injury does not qualify for any of these programs thereby limiting access to this needed and cost effective service. The average cost of targeted case management per person is $2,000 per annually.

The effects of brain injury can be severe and long lasting. Individuals with brain injury, especially those with moderate to severe injuries, are at risk of a wide array of social and health related problems such as substance abuse, social isolation, criminal activity, suicide, homelessness, and co-morbid medical and behavioral health conditions. Rates of unemployment following brain injury range from 60-90%. Available literature suggests that case management has a positive and significant impact on employment and community integration for individuals with brain injury (Journal of Head Trauma Rehabilitation, 2010). Case management is also an integral of Maryland's affordable housing initiatives such has the HUD811 program.

> *"I am alone and cannot manage complex medical care. I need help. I need assistance and I need a brain."*
>
> *Marylander with TBI, Needs and Resources Assessmentcomment*

DHMH modified its brain injury resource coordination program model in 2012. Resource Coordination services are now provided by the Brain Injury Association of Maryland (BIAM). DHMH is maximizing resources by leveraging the infrastructure of Maryland Access Point (MAP-Maryland's "no wrong door" to long term care services and supports) program. While the Board supports this coordinated and statewide effort, it is not a replacement for an individual case management service. The Board feels it will be important for DHMH to capture data about Marylanders with brain injury that access MAP and the BIAM.

Expand the capacity of the Maryland licensed Chronic Hospitals, Nursing Facilities, and Home and Community-Based Services to address the neurobehavioral needs of Marylanders with brain injury.

FACTS: Maryland does not have a continuum of care to meet the complex neurobehavioral needs of individuals with brain injuries. The literature suggests that up to ten percent (10%) of individuals who sustain a brain injury require long term, intensive supports because of neurobehavioral issues (BIAA/McMorrow). The lack of appropriate long term intensive services increases costs for Maryland Medicaid and Maryland Department of Corrections because the unmet needs result in inappropriate state paid services, unnecessary hospitalizations, and incarceration.

RECOMMENDED ACTION:
Require the Department of Health and Mental Hygiene to:

- Create a brain injury neurobehavioral level of care and specialty designation in Maryland licensed chronic hospital(s) and/or nursing facility(s).
- Implement the recommendations of the Money Follows the Person Behavioral Health Committee related to improving the capacity of Home and Community-Based Services (HCBS) to supports Medicaid beneficiaries with brain injury and other behavioral health issues.

JUSTIFICATION:

While awareness of the cognitive and physical changes that occur after a brain injury and the subsequent rehabilitative needs are becoming increasingly familiar to the public and to healthcare providers, the behavioral changes and challenges remain an under-recognized and under-treated issue. Yet behavioral deficits are a major impediment to the brain injury recovery process and impact an individual's ability to engage in rehabilitation, return home to family, return to work, maintain personal safety, and transition out of long term care institutional settings. Common behavioral challenges include verbal and physical aggression, agitation, limited self-awareness, altered sexual functioning, impulsivity and social disinhibition (NASHIA, 2006). The literature suggests that agitation and aggression develops in 20-49% of children who sustain a TBI and 25-33% of adults who sustain a TBI, usually within one year of sustaining the injury (Kim et. al. 2007 & Baguley, Cooper, Flemingham 2006).

Some individuals with brain injury who experience significant neurobehavioral and neuropsychiatric challenges require specialized and integrated treatment programs designed for those with brain injury. These programs are essential to ensuring the safety of this population as well as the communities they live in. Those who reach this level of need have almost always depleted any personal resources they or their family may have and are often reliant upon publicly funded programs, or are incarcerated as a result of their behavioral challenges. States have experienced class action lawsuits on behalf of individuals with brain injury who are institutionalized in nursing facilities or state psychiatric hospitals because of the lack of available resources in the community. The CDC reports that as much as 87% of the prison population in the U.S. has sustained at least one TBI. Individuals get "stuck" in emergency departments and community hospitals because appropriate and safe discharge options are not available. When appropriate services are not available within a state, many states (including Maryland) resort to paying for specialized services out of state ranging in price from $800-$1,200.00 per day for the few who manage to access those services.

Fully fund the State of Maryland Dedicated Brain Injury Trust fund.

FACTS: On May 16, 2013, Governor Martin O'Malley signed S.B. 632 (Chapter 511), creating the State Brain Injury Trust Fund into law. The fund is to be administered by the Department of Health and Mental Hygiene and is to be used to support services for Maryland's residents with brain injuries.

RECOMMENDED ACTION:
Recognizing that the trust fund covered services are broadly defined in regards to the scope and array of potential available services it can fund, the board seeks to collaborate with the Governor, the General Assembly and the Maryland Department of Health and Mental Hygiene (DHMH) to identify a sustainable revenue source for the Trust Fund and to develop policies and procedures guiding administration of the fund, eligibility, and covered services.

JUSTIFICATION:
In 2013, the Maryland Traumatic Brain Injury Trust Fund was created. The Board is extremely appreciative to the many individuals who helped pass this legislation. While the creation of the Trust Fund was a huge accomplishment, a revenue source is needed in order for the fund to be able to be able to pay for needed services and supports for Marylanders with brain injury as it was intended.

Over the years, 22 states, including Maryland, have enacted similar legislation to generate revenue earmarked for TBI programs and services. Most states have targeted fines associated with traffic offenses to be set aside for TBI programs, since traffic crashes have been a primary cause of TBI, particularly with regard to severe TBI. Some states have also found other ways to generate funding, such as boating while intoxicated and additional fees assessed to driver's license. These funds are then placed in a separate state account and are generally allowed to accumulate interest over fiscal years in order to have sufficient level to pay for programs and services. In other words, the funds are not returned to the state treasurer at the end of the fiscal year so that they have to start over when the new fiscal year starts. The amount generated varies widely, as well as the purpose of the fund, and how it is administered. Estimated revenue varies widely for established programs, from less than $1 million to $22 million. The average is between $1 million and $4 million annually.

State funding generated from trust fund programs allow states to provide services to non-Medicaid eligible individuals and/or provide services that are not covered by Medicaid to Medicaid beneficiaries.

Modify the technical eligibility requirements for the Home and Community-Based Waiver for Adults with Traumatic Brain Injury

FACTS: There are over 7,000 Maryland Medicaid beneficiaries with a history of TBI each year. Fewer than 800 of those beneficiaries are enrolled in Medicaid Home and Community Based Services. Approximately 3,000 Medicaid beneficiaries with brain injury receive services in a Maryland nursing facility each year. The TBI waiver access is limited to individuals transitioning out of certain hospital settings.

RECOMMENDED ACTIONS:
Require the Department of Health and Mental Hygiene to:

- Accept and process applications for Maryland's TBI Home and Community-Based Waiver for Individuals with Traumatic Brain Injury from qualified individuals regardless of whether their Medicaid paid institutional setting is owned and operated privately or by the state.
- Increase the number of facilities that meet the technical eligibility requirements for the waiver.

JUSTIFICATION:

Since 2007, The Department of Health and Mental Hygiene (DHMH) has expanded access to the TBI waiver via Maryland's Money Follows the Person Project. Through its flexible use of Medicaid funds, DHMH has eliminated barriers to provide a limited number of individuals with brain injuries the long term services and supports they need to be able to live in the community setting of their choice. DHMH has promoted forward thinking policies, like adopting a more inclusive definition of brain injury and creating innovative pilot programs to expand the opportunities for brain injured individuals to live outside of an institutional setting. DHMH identified an additional "entry point" facility for Maryland Veterans with TBI in August 2013, Charlotte Hall Veterans Home in southern Maryland. In order to optimize the State of Maryland's rebalancing efforts, reduce the proportion of Long Term Services and Supports (LTSS) spending on nursing facilities, and reflect the public policy of Person Centered Planning and Money Follows the Person, Maryland should modify the technical eligibility requirements for the Home and Community-Based Waiver for Individuals with Traumatic Brain Injury to include applicants in private facilities.

Despite Maryland's "ongoing commitment to serving individuals in the most integrated setting," there are many individuals with brain injury, who are not able to access Maryland's TBI waiver services simply because their Medicaid-paid stay is in a privately owned nursing facility rather than a state owned facility. In addition, only five facilities currently meet the technical eligibility criteria allowing an individual to apply for Maryland's TBI waiver. A 2013 study by the Hilltop Institute at the University of Maryland, Baltimore Campus (UMBC) concluded that over 3,000 Marylanders with TBI currently reside, and receive long term care services, in private nursing facilities. FY12 Medicaid costs for persons with a TBI and/or Anoxia diagnosis while residing in a NF were $16,000 higher per person than those of their non-TBI diagnosed counterparts.

While many of the 3,000 people in the study may choose to stay in a facility, and many who want to transition may be well served with another Home and Community Based waiver, many residents with brain injury will not be able to transition from an institutional setting to a community setting without the TBI Waiver. By accepting and processing applications for Maryland's TBI Waiver regardless of a state or privately owned institutional setting, Maryland will not only be able

Strengthen the supports and resources available through the Maryland Commitment to Veterans (MCV) Program to support Veterans who have sustained a TBI.

to better implement its "rebalancing" objectives under the Money Follows the Person Project but also improve the overall care of brain injured individuals in our state .

FACTS: The United States Department of Veterans Affairs projects that by the end of 2013, there will be 443,076 Veterans living in Maryland, with the vast majority of them living in Baltimore, Anne Arundel, Montgomery and Prince Georges counties and Baltimore City. The literature suggests that TBI may affect 20% of the 2.3 million service members nationwide who have deployed since 2000. Despite this statistic, and the large number of Marylanders possibly affected, there is currently no formal screening process to determine the number of Veterans living in Maryland who have sustained or have likely sustained a brain injury.

In 2008, Governor Martin O'Malley signed Chapter 555 into law, establishing a Maryland's Commitment to Veterans (MCV) initiative to establish a three-year behavioral health initiative for veterans living in Maryland. In 2011, the MCV was codified with no sunset. The MCV provides a link to services for veterans and their families including behavioral health, transportation to health services, and assistance in obtaining other services. In addition, MCV has contracted with the University of Maryland, School of Public Health to provide training to providers regarding health and behavioral health issues particular to Veterans and their families. That Memorandum of Understanding (MOU) is set to end at the conclusion of FY14.

Furthermore, on Aug. 31, 2013 President Barack Obama signed an executive order to improve access to mental health services for veterans, service members, and military families. As part of that executive order, President Obama directed numerous federal agencies to develop a National Research Action Plan. Among its many initiatives, the order established two joint research consortia, The Consortium to Alleviate PTSD (CAP), and the Chronic Effects of Neurotrauma Consortium (CENC) that will develop strategies to improve early diagnosis and treatment effectiveness for TBI and Post Traumatic Stress Disorder (PTSD).

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RECOMMENDED ACTIONS:

The Maryland Commitment to Veterans Program must implement the following in order to better meet the needs of Maryland Veterans with brain injury:

• Screen all Veterans who access the program for a history of brain injury and report the aggregate data to the Maryland State Traumatic Brain Injury Advisory Board.

• Continue provider training efforts to ensure that impact of TBI as well as the co-morbid conditions of TBI and PTSD are understood.

• Identify and establish brain injury providers and services for Veterans.

• Promote best practices developed by programs such as the Defense and Veterans Brain Injury Center, The Consortium to Alleviate PTSD, and The Chronic Effects of Neurotrauma Consortium (CENC).

JUSTIFICATION:

TBI has been named the 'signature deficit' of the Iraq and Afghanistan wars, and has been linked to numerous other physical and mental health issues in veterans of other wars. Many Maryland

Veterans struggle with multiple impairments resulting from TBI; impairments resulting from even mild TBI can affect vocational, academic, physical, cognitive, and emotional aspects of the lives of our returning service members and their families. Those with more significant impairments may need long-term rehabilitation and long-term care. Studies have demonstrated that for patients with brain injuries, the most effective means of full rehabilitation involve an active case manager and an interdisciplinary team, and yet these services are inconsistent and varying throughout the state. Compounding the problem for many former service members is the fact that many of Maryland's affected veterans were members of the National Guard who did not enroll with the Department of Veterans Affairs upon their return and their benefits have expired. With no direct screening for brain injury, the numbers of those affected are difficult, if not impossible to come by.

Through its MOU with the University of Maryland, The MCV has previously been able to train providers serving veterans, to increase the providers' competence in addressing the needs and concerns of veterans reintegrating to civilian life, and learning new clinical strategies for use with veterans and their families. That MOU has not been renewed despite its success.

The Board is not aware of any efforts that the MCV Program has made to collect data related to TBI, develop TBI-specific resources for veterans, or include TBI related resources and information on its website or in project reports yet it is not being addressed by the State of Maryland. In order to fully serve this population of wounded warriors, it is imperative that their needs and those of their families be the focus of a new initiative

The Maryland Traumatic Brain Injury (TBI) Advisory Board was established in 2005 and charged with advising the State Legislature and the Governor on the impact of brain injury on the State. The Board is responsible for writing an annual report with recommendations regarding needed services and supports for individuals living with brain injury as well as prevention efforts. The Board consists of individuals with brain injury and family members, experts in the field of brain injury, professionals who work with individuals with brain injuries, representatives from State Agencies, advocacy organizations, and caregivers of individuals with brain injuries. A list of Advisory Board members is attached as Appendix A.

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 feel support and to foster 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.

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 important policy changes and decisions, including:

- Senate Bill 632 passed unanimously in the 2013 legislative session and was signed into law by Gov. Martin O'Malley on May 16, 2013, resulting in the creation of the Maryland Brain Injury Trust Fund. The bill passed without an identified revenue source and the established fund is not yet able to pay for needed services and supports as intended. A report is due to the legislature by January 1, 2014.
- In response to a recommendation contained in the 2011 report, DHMH agreed to modify the definition of brain injury of brain injury that is used in the Home and Community Based Services Waiver for Adults with TBI to a broader acquired brain injury definition.
- On May 19, 2011, Governor Martin O'Malley signed a concussion bill 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. An August 2013 press release highlighted new recommendations from the Maryland State Department of Education (MSDE), prompted by regulations adopted by the Maryland State Board of Education in the Spring of 2013, limiting the number of contact practices in collision sports. MSDE also recommends improved instruction by coaches in contact sports and defines interscholastic sports by types: collision, contact, limited contact, and non-contact.
- For years, MSDE has provided scholarship opportunities for educators and other school personnel to attend the annual Brain Injury Association of Maryland conference.
- 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, Florida).

Grace Anyadike
Department of Health and Mental Hygiene
Alcohol and Drug Abuse Administration
Catonsville, Maryland
(410) 402-8634
grace.anyadike@maryland.gov

Angela Baldwin-Austin
Representing Individuals with Brain Injury
District Heights, Maryland
(301) 875-7434
Abd1969@verizon.net

Bob Berlow
Maryland Disability Law Center
Baltimore, Maryland
(410) 727-6352
bobb@mdlclaw.org

Jody Boone
Division of Rehabilitation Service
Baltimore, Maryland
(410) 554-9451
jboone@dors.state.md.us

Rianna Brown, J.D.
Department of Health and Mental Hygiene
Baltimore, Maryland
rianna.brown@maryland.gov

Jan Caughlan
Healthcare for the Homeless
Baltimore, Maryland
(410) 788-7611
jcaughlan@hchmd.org

Mary Lou Coppinger
Representing Families/Caregivers of Individuals with Brain Injury
Baltimore, Maryland
(410) 285-3036
mlcbcop1@gmail.com

Joyce Dantzler
Center for Injury and Sexual Assault Prevention
Department of Health and Mental Hygiene
Baltimore, Maryland
(410) 767-1372
Joyce.dantzler@maryland.gov

Corey Davis
Representing Individuals with Brain Injury
Berlin, Maryland
Corey.davis@yahoo.com

Sandy Davis
Brain Injury Association of Maryland
Owings Mills, Maryland
(410) 225-8091
Sandra.davis@erickson.com

Christine Deeley Wood
Representing Families & Caregivers
Montgomery County, Maryland
(240) 413-3369
cmdeeleywood@gmail.com

Laurie Elinoff
Statewide Independent Living Council
Representing Individuals with Brain Injury
Millersville, Maryland
(410) 729-8461
ljelinoff@gmail.com

Janet Furman
Department of Health and Mental Hygiene
Developmental Disabilities Administration
Baltimore, Maryland
(410) 767-5929
jfurman@dhmh.state.md.us

Pamela Harman
Veteran's Administration
Washington D.C.
(301) 464-5244
Pamela.harman@va.gov

Paul Hartman
Center for Independent Living
Representing Individuals with Brain Injury
Frederick, Maryland
(301) 846-7811
paulhartman@thefreedomcenter-md.org

KathleenD. Heck, Ph.D.
Maryland State Department of Education
Division of Special Education/ Early Intervention Services
Baltimore, Maryland
(410) 767-0739
kheck@msde.state.md.us

Linda Hutchinson- Troyer
Brain Injury Association of Maryland
Baltimore, Maryland
(410) 601-1199
LHTroyer@Lifebridgehealth.org

Martin Kerrigan
Representing Individuals with Brain Injury
Columbia, Maryland
(443) 756-3419
mwkerri1@hotmail.com

Terry Kirtz
Representing Families/Caregivers of Individuals with Brain Injury
Washington Grove, Maryland
(301) 990-7935
ttkirtz@hotmail.com

Vassilis Koliatsos, MD
The Neuropsychiatry Program at Sheppard Pratt
Baltimore, Maryland
(410) 938-4826
koliat@jhmi.edu

Jennifer Massetti
R Adams Cowley Shock Trauma Center
Baltimore, Maryland
(410) 328-5754
jmassetti@umm.edu

Carole A. Mays, RN, MS, CEN
Maryland Institute for Emergency Medical Services Systems
Baltimore, Maryland
(410) 706-0853
cmays@miemss.org

Stefani O'Dea
Department of Health and Mental Hygiene
Mental Hygiene Administration
Catonsville, Maryland
(410) 402-8476
stefani.odea@maryland.gov

Bryan Pugh
Brain Injury Association of Maryland
Baltimore, Maryland
(410) 448-2924
pugh@biamd.org

Diane Triplett
Brain Injury Association of Maryland
Baltimore, Maryland
(410) 448-2924
Diane.triplett@neurorestorative.com

Adrienne Walker-Pittman
Representing Individuals with Brain Injury
Baltimore, Maryland
(410) 281-1348
iptdst@comcast.net

Cari Watrous
Maryland Department of Disabilities
Baltimore, Maryland
(410) 767-3616
cwatrous@mdod.state.md.us

Michael Weinreich, MD
National Institute of Health
Bethesda, Maryland
(301) 402 4201
Mw287k@nih.gov

Sean Westley
Representing Families/Caregivers of Individuals with Brain Injury
Baltimore, Maryland
(410) 467-3036
Sean-westley@uscorp.com

Denise White
Department of Health and Mental Hygiene
Baltimore, Maryland
(410) 767-5220
denise.white@maryland.gov

Patricia Williamson
Children's Medical Services Program
Department of Health and Mental Hygiene
Baltimore, Maryland
(410) 767-5164
Patricia.williamson@maryland.gov

Richard Zeidman
Representing Families/Caregivers of Individuals with Brain Injury
Rockville, Maryland
(301) 279-7979
rickezeidman@verizon.net

Maryland Legislative Appointments

Senator Nancy J. King
Democrat, District 39, Montgomery County
(410) 841-3686
nancy.king@senate.state.md.us

Delegate Jeffrey D. Waldstreicher
Democrat, District 18, Montgomery County
(410) 841-3130
jeff.waldstreicher@house.state.md.us

Staff to the Board

Nikisha Marion
Mental Hygiene Administration
Catonsville, Maryland
(410) 402-8476
Nikisha.marion@maryland.gov

Victor Henderson
Maryland Department of Disabilities
Baltimore, Maryland
(410) 767-3635
vhenderson@mdod.state.md.us

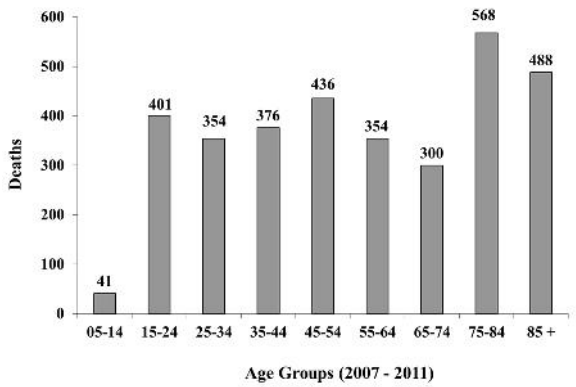
Appendix B
Maryland TBI Incidence Data

TBI-related Fatalities, Maryland Residents, 5-year experience, 2007-2011

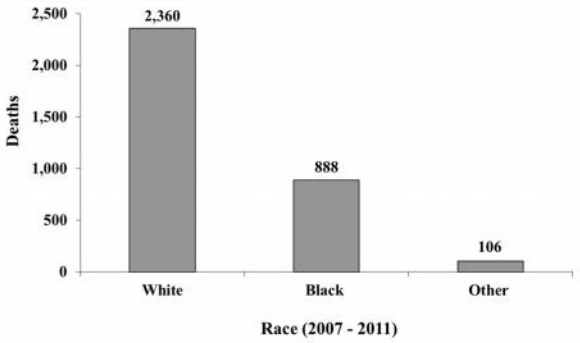
Years

	2007	2008	2009	2010	2011	07-11
Number of Deaths	730	701	715	601	610	3357
	2007	2008	2009	2010	2011	07-11
Age of Decedents*						
05-14	11	10	12	xx	8	>41
15-24	104	78	97	69	53	401
25-34	78	86	67	66	57	354
35-44	99	72	86	60	59	376
45-54	84	104	98	83	67	436
55-64	79	59	80	57	79	354
65-74	59	61	61	58	61	300
75-84	117	120	107	105	119	568
85 +	90	106	98	95	99	488

xx= cell counts suppressed to preserve confidentiality

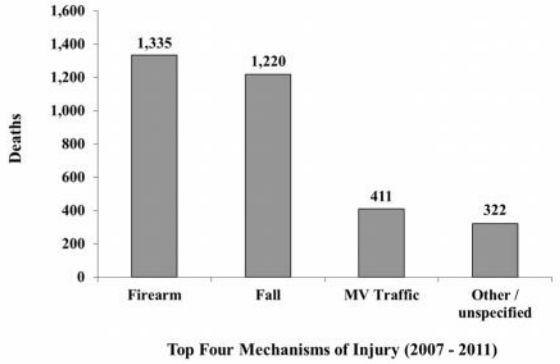


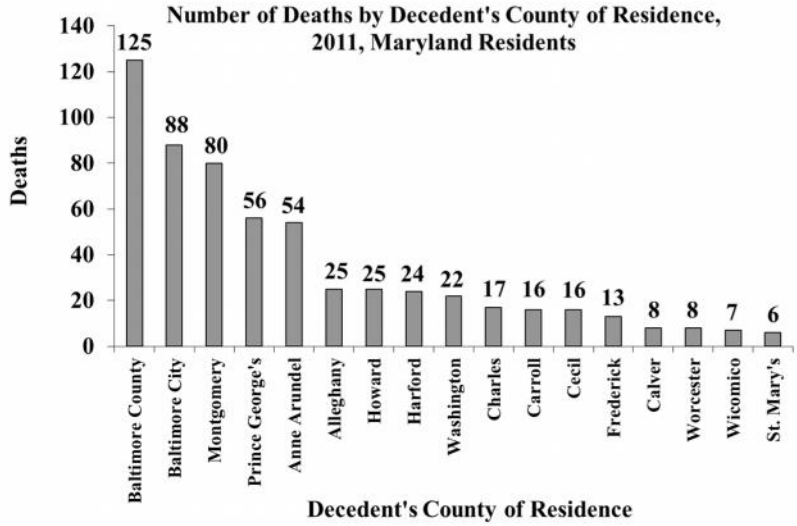
	2007	2008	2009	2010	2011	07-11
Gender of Decedents						
Female	194	202	186	148	181	911
Male	536	499	529	453	429	2446



	2007	2008	2009	2010	2011	07-11
Race of Decedents*						
White	508	493	482	430	447	2360
Black/African	205	188	199	154	142	888
Other Race	17	20	31	17	21	106

	2007	2008	2009	2010	2011	07-11
Top Four Mechanisms of Injury						
Firearm	280	282	287	233	250	1335
Fall	244	246	239	231	253	1220
MV Traffic	108	94	103	60	46	411
Other/unspecified	87	68	62	60	45	322





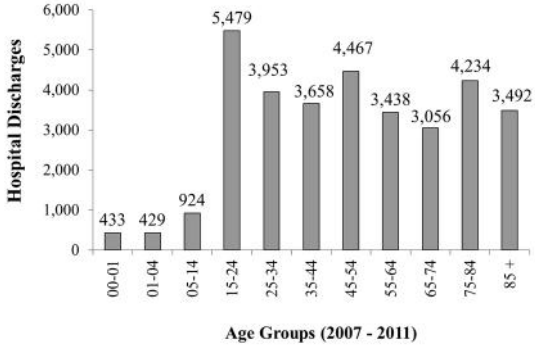
Note- The following counties had cell counts <6 and are therefore not included in the graph to preserve confidentiality: Caroline, Dorchester, Garrett, Kent, Queen Anne's, Somerset, Talbot.

TBI-related Inpatient Hospital Discharges (non-fatal), Maryland Residents / Maryland Hospitals, 5-year experience, 2007 – 2011

Years

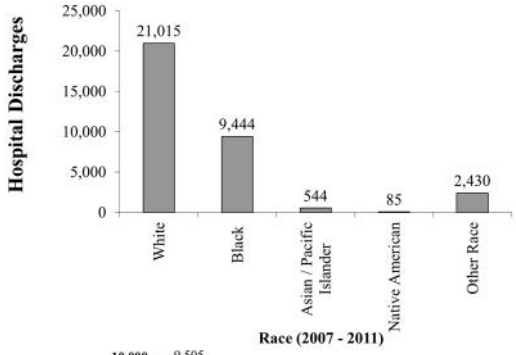
	2007	2008	2009	2010	2011	07 - 11
Number of Hospital Discharges[1,2]	7,039	7,056	6,946	5,668	6,862	33,571

	2007	2008	2009	2010	2011	07 - 11
Age of Injured[1,2]						
00-00	99	95	107	67	65	433
01-04	97	93	96	68	75	429
05-14	251	191	194	148	140	924
15-24	1,322	1,238	1,045	920	954	5,479
25-34	868	878	770	700	737	3,953
35-44	877	805	750	596	630	3,658
45-54	882	944	957	755	929	4,467
55-64	640	674	710	642	772	3,438
65-74	571	605	658	508	714	3,056
75-84	827	871	898	666	972	4,234
85 +	605	662	761	596	868	3,492

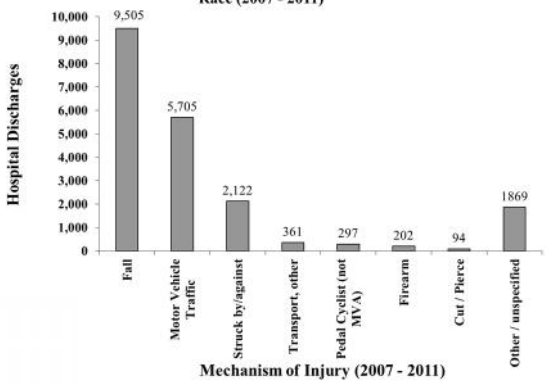


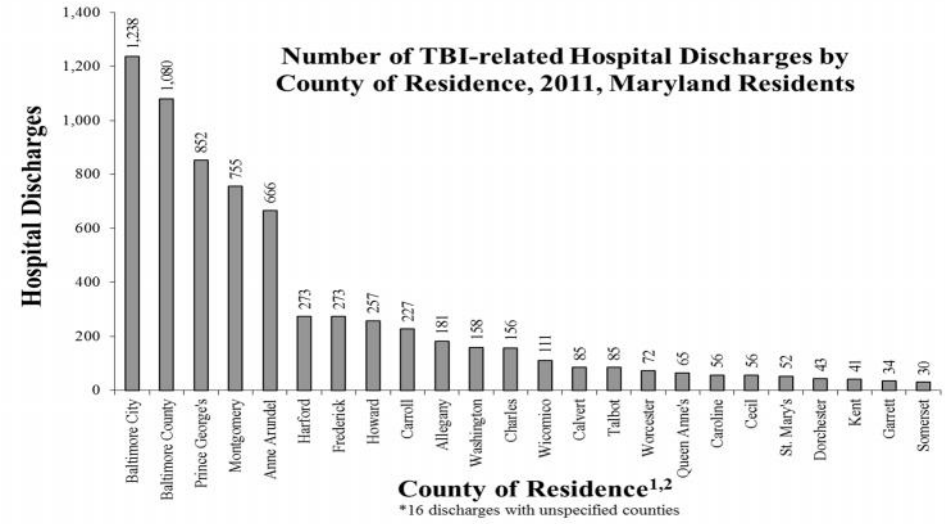
	2007	2008	2009	2010	2011	07 - 11
Gender of Injured[1,2]						
Male	4,411	4,397	4,258	3,620	4,201	20,887
Female	2,625	2,655	2,688	2,047	2,658	12,673

	2007	2008	2009	2010	2011	07 - 11
Race of Injured[1,2]						
White	4,417	4,433	4,308	3,491	4,366	21,015
Black/African	1,981	1,938	1,975	1,627	1,923	9,444
Asian/Pacific Islander	109	113	121	94	107	544
Native American	13	10	21	16	25	85
Other Race	498	551	513	437	431	2,430



	2007	2008	2009	2010	2011	07 - 11
Mechanism of Injury[1,3]						
Fall	1,776	1,824	1,964	1,925	2,016	9,505
Motor Vehicle Traffic	1,427	1,256	1,100	1,022	900	5,705
Struck by/against	440	472	453	374	383	2,122
Transport, Other	92	70	68	69	62	361
Pedal Cyclist (not MV)	66	61	61	63	46	297
Firearm	35	21	34	46	66	202
Cut/pierce	31	19	9	23	12	94
Other/unspecified	404	482	427	216	340	1,869





[1]All cases are discharges of persons who survived to discharge. Any hospital stay during which the victim died is not included.

[2]Based on cases where TBI diagnosis was identified anywhere among the several diagnoses associated with the patient's hospitalization.

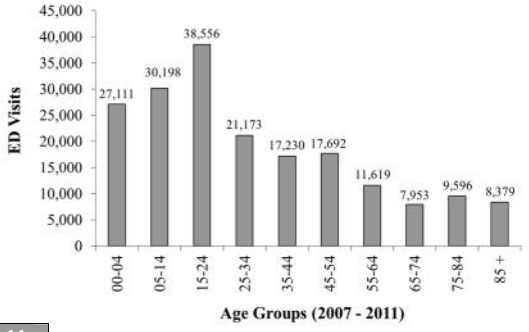
[3]Table is limited to case where a TBI diagnosis was the Principal Diagnosis - clearly the main reason for the hospital stay. A valid External Cause code found in the primary 'E-Code' position of the discharge record indicates the mechanism. If no valid E-Code was found, then the record was classified to the 'Other/ Unspecified' category.

TBI-related Emergency Department Visits (non-fatal), Maryland Residents / Maryland Hospitals, 5-year experience, 2007 - 2011

Years

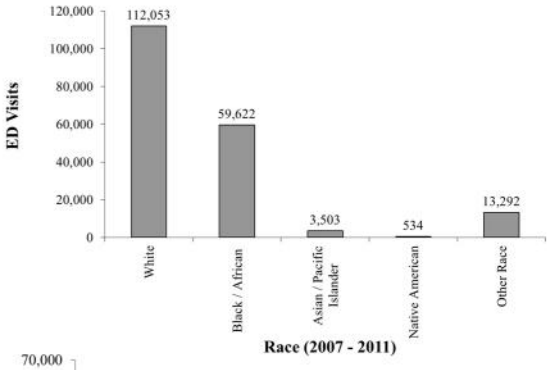
	2007	2008	2009	2010	2011	07- 11
Number of Emergency Dept. Visits[1]	30,867	31,980	40,725	41,472	44,472	189,516

	2007	2008	2009	2010		07 - 11
Age of Injured[1]						
00-04	4,667	4,718	6,128	5,714	5,884	27,111
05-14	4,907	4,921	6,641	6,465	7,264	30,198
15-24	6,461	6,601	8,216	8,404	8,874	38,556
25-34	3,361	3,596	4,451	4,690	5,075	21,173
35-44	3,042	3,086	3,668	3,658	3,776	17,230
45-54	2,726	2,909	3,779	3,988	4,290	17,692
55-64	1,684	1,833	2,521	2,676	2,905	11,619
65-74	1,216	1,238	1,683	1,790	2,026	7,953
75-84	1,547	1,671	1,983	2,108	2,287	9,596
85 +	1,246	1,410	1,654	1,979	2,090	8,379

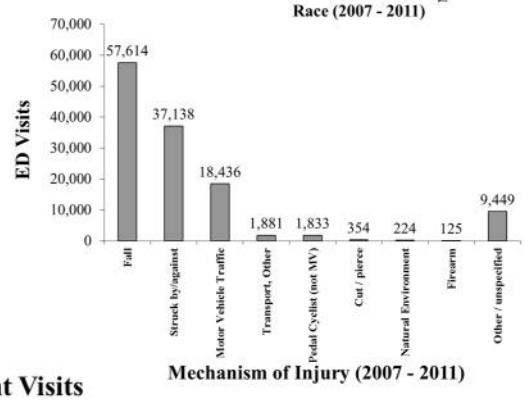


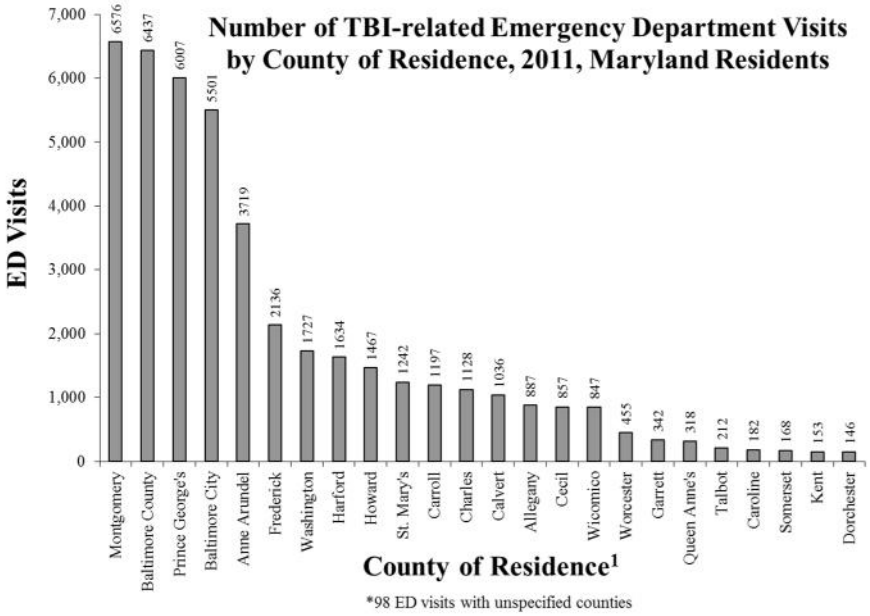
	2007	2008	2009	2010	2011	07 – 11
Gender of Injured[1]						
Male	17,238	17,487	21,627	21,959	23,351	101,662
Female	13,618	14,489	19,088	19,512	21,119	87,862

	2007	2008	2009	2010	2011	07- 11
Race of Injured[1]						
White	18,574	18,854	24,250	24,111	26,264	112,053
Black/African	9,494	10,089	12,600	13,399	14,040	59,622
Asian/Pacific Islander	547	589	775	781	811	3,503
Native American	87	86	87	83	191	534
Other Race	2,052	2,299	2,895	2,992	3,054	13,292



	2007	2008	2009	2010	2011	07 - 11
Mechanism of Injury[2]						
Fall	8,940	9,253	12,910	12,987	13,524	57,614
Struck by/against	5,957	5,992	8,356	7,958	8,875	37,138
Motor Vehicle Traffic	3,084	3,142	4,010	3,924	4,276	18,436
Transport, Other	351	329	400	407	394	1,881
Pedal Cyclist (not MV)	296	333	447	349	408	1,833
Cut/pierce	50	79	60	91	74	354
Natural Environment	34	38	51	51	50	224
Firearm	38	20	29	19	19	125
Other/unspecified	2,028	1,984	2,513	1,595	1,329	9,449





[1] Based on cases where a TBI diagnosis was identified anywhere among the several diagnoses associated with the patient's visit AND a specific Emergency Department service charge was recorded in the outpatient ambulatory care record.

[2] Table is limited to cases where a TBI diagnosis was the Principal Emergency Diagnosis – clearly the main reason for the visit. A valid External Cause code found in the primary 'E-Code' position of the discharge record indicates the mechanism. If no valid E-Code was found, then the record was classified to the 'Other/ Unspecified' category.

Jeff Rehfeld: a Story of Success after Traumatic Brain Injury

In 2010, Jeff Rehfeld was in an auto accident that left him with a severe traumatic brain injury and cognitive deficits. Before his accident, Jeff struggled with addictions as well as bipolar disorder. The brain injury brought new challenges to his life, but may have also saved it.

Jeff began inpatient rehabilitation at a Maryland Specialty Hospital. He applied for the Waiver for Adults with Traumatic Brain Injury which allows participants to get the same level of service in the community as they do in a chronic hospital or nursing facility and was accepted. "I tried to keep a positive attitude", Jeff recalls as he waited to find a service provider who was willing to give him a chance even though he had a tracheostomy tube that made his service needs more complicated.

Jeff transitioned to (the Waiver Program) and began to rebuild his life. He found a church and located several local AA groups where he attends three times per week. He says, "I would feel good if I can help one person stay sober one more day," so he started volunteering at Sheppard Pratt sharing his experience with AA and encouraging others to get involved.

Jeff turned his attention to another goal that will increase his independence: employment. He worked with (Waiver Provider) staff and the Division of Rehabilitation Service (DORS) to focus on his strengths as he considered the type of work in which he would be most successful. He was dedicated to his search, following up on every application that he submitted. One local grocery store manager was impressed by his initiative and hired him as a stock clerk. "I try to have a good attitude whenever I am at work", he says.

Jeff is successfully managing his bipolar disorder with support through (outpatient) neuropsychiatry, therapy and learning to self medicate. Jeff has increased his use of the bus system and travels independently to and from work, as well as therapy. Jeff has been so successful in increasing his independence and building a support network that he is making plans to move into independent housing in the next few months.