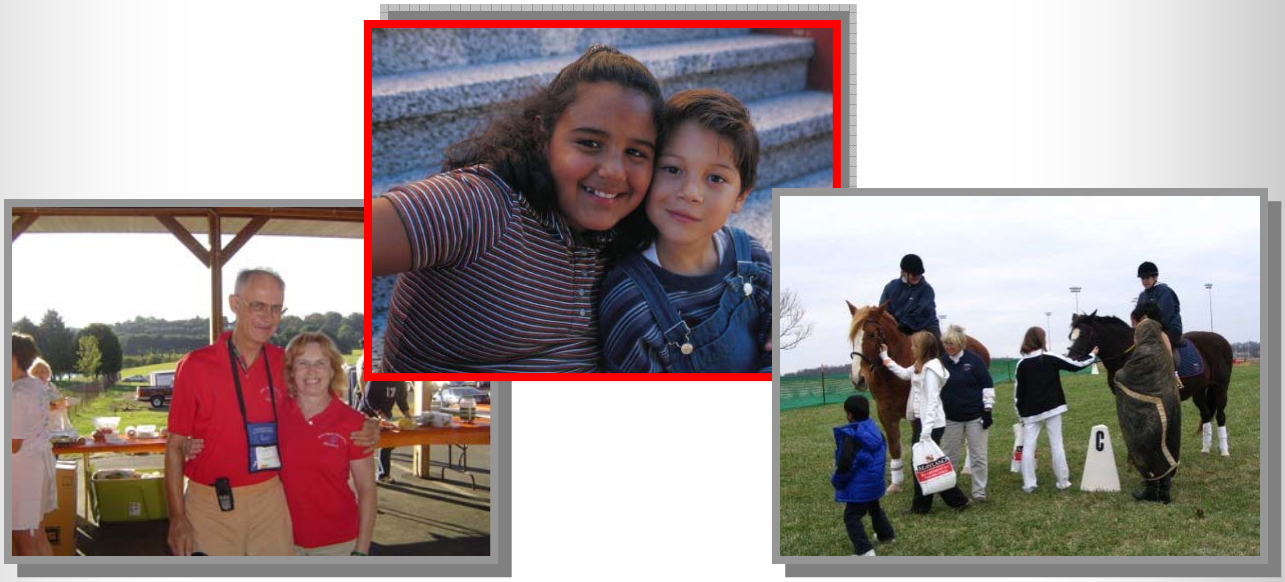

M A R Y L A N D

State Traumatic Brain Injury Advisory Board

ANNUAL REPORT

NOVEMBER 2006

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PREAMBLE

Traumatic Brain Injury (TBI) affects hundreds of thousands of Marylanders. While many brain injuries result in death, our focus of attention is on the living - on the survivors. Traumatic brain injury changes the way individuals function. It can affect cognitive, physical, and social abilities. In many cases, the community is not able to "see" our disabilities because they originate in the brain and not on the outside of our bodies. Brain injury is commonly referred to as the **"Silent Epidemic"** because the general community at-large has no comprehension of a brain injury and the disability is not as visible as someone who may use a wheelchair, walker or guide dog. We are often told, "*You look ok*", and it is implied then that we must "be ok". This is one of the most confusing and frustrating consequences of this catastrophic injury. While each hospitalization reported represented the individual incurring the brain injury, it does not include the people that immediately are also affected; family members, friends, employers, employees, caregivers, etc.

There are very few options for individuals with brain injury once they survive Shock Trauma and/or are released from the hospital. Some individuals are forced to live in long-term care nursing homes at a very young age because of the unavailability of community supports, care coordination, housing, attendant care, and funding. For those who are able to be discharged home, often family members must give up employment and use up all of the family financial and emotional resources to support the survivor. **Many individuals with brain injury could return to work, school or community and lead productive lives if knowledge and resources were available.** We do not want to be a burden on society. We want an opportunity to recover in our own communities, learn to live with our abilities and disabilities, and make a contribution back to our families and Maryland. Currently, the majority of individuals with brain injuries cannot.

The individuals with brain injury, family members and caregivers of the Maryland Traumatic Brain Injury Advisory Board are asking you to understand that we are here, and need and want to be recognized. We should have the same opportunities as any other Marylander. We need the Maryland State Legislature to understand what brain injury is, the number of Marylanders affected, how brain injuries occur, what treatment, resources and supports are needed to help us live healthy and productive lives.

As we attempt to go forward with our lives and try to utilize the current state agencies and services, we are often presented with obstacles that would challenge even those without brain injury. However, because of our cognitive deficits, these obstacles represent insurmountable hurdles. **Marylanders with brain injury do not have the same access to services and supports as other individuals in Maryland with disabilities. Maryland can and must do better.**

This Preamble is meant to convey the high price of brain injury for all Marylanders, not just survivors and their support network. The recommendations outlined in this report do not represent a "wish list", but, rather, a course of action that Board Members, and especially the individuals with brain injury, family members and caregivers, feel are mandatory and, at the very least, necessary, for Maryland to provide the highest quality of physical and neuropsychological care, educational and employment opportunities, financial assistance for

accommodations, psychosocial interaction, housing, as well as both short term and long term solutions for dealing with this increasing population.

We have attempted to attach a "human face" to our report---we are real people, not just numbers. Our very struggle for daily survival is often hampered by insufficient or non-existent assistance, uncoordinated resources, the confusion of understanding available benefits, a lack of long-term planning and goals, and a general lack of knowledge of brain injury by the general public and often even the medical community.

Board member and individual with brain injury, Sue Ferris, perhaps best sums up some of our collective feelings in her poignant poem:

I KNOW

Somehow I know
what it is like
to be someone lost outside their life
to have the topsy turn around
a different view
the same old town
felt differently this go around

Somehow I know what it feels to be
a whisper of the same old me
a shadow cast
inside
a soul
and feelings that just won't be told

Somehow I know what it is like
to walk the ledge in neuron life
the thoughts are there
the path is new
the single thread that changes me to you.
Sue Ferris ©2001

We realize this report will not "solve" all of the issues; nonetheless, it can serve as a beginning. We urge you to support the funding and recommendations in the following report in its entirety.

EXECUTIVE SUMMARY

In recognition of the needs for individuals with traumatic brain injury, the Maryland General Assembly created the State Traumatic Brain Injury Advisory Board to represent individuals with brain injury. The Board's mission, vision, legislative charge, and board member membership is noted in Appendix A and B respectively.

Traumatic brain injury strikes people of all ages and is the leading cause of death and disability in people under the age of 45. Each year in the United States, an estimated 1.5 million people incur traumatic brain injuries, principally as a result of automobile accidents, sports injuries, falls, and acts of violence. More than 5 million Americans have disabilities resulting from traumatic brain injury, more than the number of people with disabilities due to Alzheimer's disease, stroke, epilepsy, cerebral palsy, or spinal cord injury[1]. Maryland data is consistent with national trends (see Appendixes H through N).

Maryland Department of Health and Mental Hygiene, Center for Preventive Health Services has collected the majority of data regarding traumatic brain injury. They used the Maryland Health Services Cost Review Commission's hospital discharge data set and the Maryland Office of Vital Statistics' multiple-cause of death data set and death certificate data[2&3] which demonstrates:

- In 2005, **6,135 individuals** were admitted to a Maryland hospital with a traumatic brain injury diagnosis;
- Individuals 15-24 years and 35-44 years are at highest risk for brain injury;
- Males are about 1.5 times as likely as females to sustain an injury;
- Majority of injury cases are motor vehicle accidents (≈50%), falls (≈30%), and assaults (≈10%);
- Traumatic Brain Injury accounts for 12% of all injury related hospitalizations; and
- Annually 100 out of every 100,000 individuals admitted to a hospital have a brain injury.

It is difficult to predict the outcome of a brain injury as a patient's prognosis may not be known for many months or even years. Many factors contribute to the severity of brain injury including the location and severity of injury, pre-injury personality, age, and more.

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[1] Thurman, D, Alverson, C, Dunn, K, Guerrero, J, Sniezek, J. *Traumatic Brain Injury in the United States: A Public Health Perspective*. Journal of Head Trauma Rehabilitation, 14(6):602-15, 1999.

[2] Thurman, D, Sniezek J, Johnson D, Greenspan A, Smith S. *Guidelines for Surveillance of Central Nervous System Injury*. Atlanta: Author, 1994.

[3] Langlois, JA, Rutland-Brown, W, Thomas, KE. *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations, and Deaths*. National Center for Injury Prevention and Control, Centers for Disease Control and Prevention. October 2004.

Symptoms of brain injury may appear immediately after the injury occurs or may not appear for weeks following the injury. This is due to the physical damage to the brain and the cascading and cumulative biochemical changes within. The long-term effects and impact of brain injuries can be subtle and difficult to diagnose and substantiate. Serious brain injuries can be devastating, producing permanent cognitive and physical disability. B**rain injuries are a chronic, debilitating, and progressive in nature.**

Individuals who survive their injuries experience an array of physical, cognitive, and social changes. Physical impairments such as seizures, loss of functional use of one side of their body, fatigue, balance problems, hearing loss, and changes in vision or speech are common. Impairments in thinking and understanding ("cognitive") are very common and can be the most debilitating consequences of brain injury. They include memory loss, concentration difficulties, organizational problems, poor judgment, inability to initiate or complete tasks without reminders, and the inability to perform multiple tasks at the same time.

Individuals with brain injury often also experience behavioral impairments such as failure to recognize deficits, impulsivity, verbal outburst, physical aggression, and sexual dysfunction. These impairments are the result of the neurological damage the individual has sustained and are distinct from the anxiety and depression that may be the reaction of the individual to loss and life changes associated with the injury.

Beginning with the onset of injury and continuing through acute care, rehabilitation, and community integration, individuals with brain injury require immediate treatment and individualized services and supports that may be lifelong and changing over time. The resulting disability associated with a brain injury generally impacts an individual's ability to interact with their family and friends and return to home, school or work, and their community.

Community-based services and supports such as resource coordination, housing, day habilitation, employment, neuropsychological evaluations, school re-entry, caregiver respite, and other assistance and accommodations may be needed to avoid unnecessary placement in long-term care settings and to ensure independence, to ease stress on peer and family relationships, and to enhance performance in school and at work. These services and supports are difficult to access and may come from multiple private, and local, State and Federal programs.

Families and friends are generally the caretakers of individuals with brain injury who require long-term care. The February 1998 General Accounting Office Report, *Traumatic Brain Injury Programs Supporting Long-Term Services in Selected States (HEHS-98-55)*, concludes, "As families exhaust their resources, the public sector pays for a greater share of the services received."[4] That is, when ongoing needs surpass families' capacities for providing care, nursing home or community care costs can quickly exceed financial

[4] Glassbrenner, D. 2005. Motorcycle Helmet Use in 2005 — Overall Results. Report no. DOT HS-809-937. Washington, DC: National Highway Traffic Safety Administration.

resources. Families also pay a high emotional and social cost when they are deprived of a loved one who often seems to be replaced with a stranger.

This report highlights various challenges and needs presented to individuals with brain injury, their families, and the State of Maryland. Each recommendation is preceded by a description of the issue and followed by the rationale of the recommendations.

The following nine recommendations are included in this report:

1. **Expand Brain Injury Resource Coordination Services and Professional Training Statewide** *(Estimated Cost - $1Million)*
2. **Expand the Home and Community-Based Waiver for Individuals with Traumatic Brain Injury** *(Estimated Cost - $750,000 General Funds 1st Year)*
3. **Incorporate Services for Individuals with Brain Injury into Long-Term Care Efforts** *(No Cost)*
4. **Conduct a Maryland Insurance Agency Cost Market Analysis of Brain Injury Benefits and Payments** *(Estimated Cost – Nominal)*
5. **Establish the State of Maryland Dedicated Brain Injury Trust Fund** *(Estimated Cost – Nominal)*
6. **Expand The Governor's Employment Initiative for Persons with Acquired Brain Injuries** *(Estimated Cost - $1.7 Million)*
7. **Maintain Maryland's Current Motorcycle Helmet Law** *(No Cost)*
8. **Identify Students with Traumatic Brain Injury in Local School Systems with Appropriate Screening Materials** *(Estimated Cost – Nominal)*
9. **Create the Maryland Consortium for Traumatic Brain Injury** *(Private, Local, and State Combined Estimated Cost - $4 Million Annually)*

As members of the Maryland State Traumatic Brain Injury Advisory Board, we urge you to consider the thousands of lives that make up each issue, need, and recommendation as you read this report. The Governor, Maryland Legislature, and our communities need to:

- Recognize the breadth and scope of brain injury within Maryland;
- Identify specific areas requiring immediate as well as long term attention; and
- Implement the recommendations for improving the quality of life for our significant and growing population of individuals with brain injury, family members, support networks, and communities.

WHY SHOULD MARYLAND BE CONCERNED ABOUT TRAUMATIC BRAIN INJURY?

Disabilities related to traumatic brain injury are a serious public health problem. Their effect on the quality of life of individuals and families that are directly affected, as well as their economic effect on the health care system are expensive. Cost estimates related to treating people with traumatic brain injury in the United States range from $25 billion to $48 billion annually. The number of people who survive traumatic brain injury has increased significantly in recent years due to faster and more effective emergency care, quicker and safer transportation to specialized treatment facilities, and advances in acute medical management. States and the federal government play important roles in providing services to people with disabilities from brain injury.

In addition to providing services for people with brain injury to help them achieve as much independence as possible, state policymakers also can take actions to reduce the number of injuries that lead to debilitating conditions. **Car seats and seat belt use, bicycle helmets, awareness campaigns about shaken baby syndrome, violence reduction activities, and highway safety campaigns all help to reduce the number of brain injuries.** The state's role in providing services to people with traumatic brain injury is also affected by the U.S. Supreme Court decision, *Olmstead v. L.C. 527 U.S. 581* (1999). The Olmstead decision applies to any individual – including a person with a traumatic brain injury – who needs supports and social services in order to live in a community rather than an institutional setting.

COMMUNITY SERVICE

Complicated and Fragmented Service System

Individuals with brain injury are often not able to access the services and supports they need due to Maryland's complicated and fragmented service system. Individuals who sustain a brain injury may receive and/or be eligible for services within many different service delivery systems within Maryland. The entry points to needed services and supports may vary depending on factors such as the individual's needs and goals, natural supports, county of residence, age at injury, and co-occurring conditions. Each program has separate and duplicative application processes with specific application forms and requirements of supporting documentation both related to medical and financial eligibility. To apply for personal assistance services in Maryland, a person would need to complete up to eight different application processes.

Maryland, through 58 different agencies, currently spends in excess of $4.2 billion on services to people with disabilities. This figure represents almost 18 % of Maryland's total state budget. Since there are so many potential entry points to services and eligibility and access varies for each, it is challenging for individuals with brain injury to find and navigate the services and supports that they need in Maryland's service system. Individuals with brain injury may be eligible for services offered through many different private or public organizations but the difficulty accessing these services affects the individual's ability to receive appropriate services and supports. Depending on the individual's needs and other criteria, individuals with brain injury may be eligible for services from entities such as the Developmental Disabilities Administration, the State Department of Education, Division of Rehabilitation Services, the Public Mental Health System, and/or Medicaid. In addition to the Traumatic Brain Injury waiver, which went into effect in 2003, Maryland has three other home and community-based waivers that adults with brain injury may access for services: the Living at Home (Waiver for Individuals with Physical Disabilities), the Waiver for Older Adults, and the Developmental Disabilities waiver. The points of entry into each of these differ, as does the eligibility criteria, application procedures, and the scope of services. Individuals with brain injury and families need support to navigate the complexities of these service systems.

RECOMMENDATION # 1

Expand Brain Injury Resource Coordination Services and Professional Training Statewide

Rationale:

Information and referral data, compiled during Maryland's Traumatic Brain Injury Implementation Project (1999-2003), supports the assertion that individuals with brain injury and their families often lack a basic understanding and knowledge about the federal, state, and private resources that are available to them. In addition to the reasons outlined above,

there are several additional factors that contribute to this problem for people with brain injury. First, there is no standard process or information shared when an individual is discharged from an acute hospitalization. Individuals are often not given community support services and resource information. Second, after experiencing a traumatic event, it is difficult to retain and or understand information that may have been given at the time of discharge. Finally, individuals and families often report that they do not have the time, energy, or capability to apply for those services as they assume the primary caregiver role while also trying to maintain their family, home, and employment. Life-altering physical, cognitive and psychosocial changes coupled with huge financial burdens and significant stressors create an immediate and ongoing need for access to information, training, services, supports, and resources for both the person with brain injury and his/her personal support system.

The current resource coordination model, available in five Maryland counties and funded through federal grants and state general funds, involves both individual resource coordination combined with professional training to human service providers for the purpose of accessing and improving the services and resources available to individuals with brain injury. The projected cost of the statewide expansion is $1 million. This will support 15 additional resource coordinators and associated administrative costs.

Limited Home and Community-Based Services

Brain Injury is often a chronic, progressive, debilitating condition and many individuals who have sustained a brain injury require long-term services and supports to live in their own homes or in community-based homelike settings. Individuals often exhaust personal resources early in their recovery process and rely on Medicaid to reimburse for long-term care services. While individuals who sustain a brain injury at a developmental age (before age 22) may be eligible for long-term funding and community supports through the Developmental Disabilities Administration, individuals who sustain a brain injury as an adult (after age 21) have limited access or no access to specialized long-term services and supports. Some supports and programs (e.g. Living at Home Waiver, Older Adults Waiver) are available to adults with brain injury; however, they are often not adequate to support individuals with brain injury service needs because services are not specifically designed for individuals with a brain injury and case managers are therefore not trained in the area of brain injury support planning and monitoring.

The only specialized long-term program available to adults with brain injury is the Home and Community-Based Medicaid Waiver Program for Individuals with Traumatic Brain Injury, which is only funded to serve a maximum of 30 individuals (see the attached fact sheet in Appendix C). The Mental Hygiene Administration, in conjunction with the Office of Health Services, Division of Waiver Programs, administers this program. Given the current enrollment and referral status, the Mental Hygiene Administration expects the program will be full and have a waitlist by the middle of Fiscal Year 2007. The program's original purpose was to develop community-based resources for individuals with brain injury who were getting "stuck" in state psychiatric hospitals. Eligibility was recently expanded to include individuals with brain injury who are in state-owned and operated nursing facilities and Maryland licensed hospitals for chronic disease that are Commission on Accreditation of Rehabilitation Facilities (CARF) accredited for Brain Injury inpatient rehabilitation. The

expansion of the eligibility criteria has resulted in the availability of brain injury specific resources to individuals who have historically not had their needs met in nursing homes or state psychiatric hospitals or have received no supports at all. As a result, referrals to the program have increased significantly leading to full program utilization.

RECOMMENDATION # 2

Expand the Home and Community-Based Waiver for Individuals with Traumatic Brain Injury

Rationale:

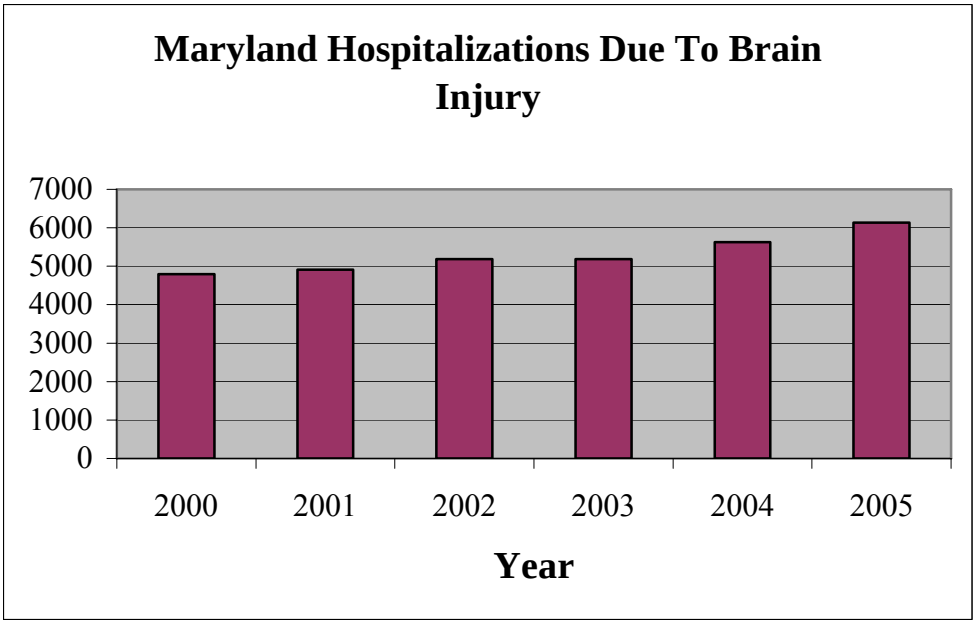
The individuals who are eligible for this Home and Community-Based Waiver for Individuals with Traumatic Brain Injury are very medically complicated and tend to have significant behavioral and/or social needs. In order to keep these individuals from long-term institutional care, the waiver can provide comprehensive services in the community. Demand for this type of comprehensive community service has increased since the waiver started for several reasons:

- Hospital and community case managers are more knowledgeable of waiver options;
- Eligibility requirements were expanded for the Fiscal Year 2007 to include patients from chronic care hospitals in an attempt to deter them from nursing home placement, especially for the younger patient; and
- Addition of individual support services to the program.

The Home and Community-Based Waiver for Individuals with Traumatic Brain Injury was developed specifically for individuals with brain injuries. Waiver services, case managers, and community providers were all developed for this specific service need. Expanding waiver capacity by 25 individuals per year for the next four years is an estimated increase of $1,500,000 total funds (750,000 General Funds) for the first year compared to paying for nursing facility cost of approximately $1.85 million per year for the same number of individuals or paying prolong specialty hospital service cost of $3,400 per day due to lack of appropriate and comprehensive discharge options.

Current and Future Planning Efforts

Traumatic brain injury is a growing disability that is historically not recognized within the long-term care planning and service delivery systems. Injuries and accidents happened daily adding to the hundreds of thousands of Marylanders affected by brain injury. Since 2000, there has been a steady increase in the number of hospitalizations due to traumatic brain injury as noted in the following chart:



With proper emergency response and advances in medical care, more and more people survive traumatic brain injury each year. Many of these individuals would not have survived ten years ago but now live with very complicated and expensive medical needs. With proper knowledge and resources, they can thrive within their own communities if State and local disability services and community providers recognize the needs of the brain injury community and adequately plan and fund appropriate, effective, and cost efficient services.

RECOMMENDATION # 3

Incorporate Services for Individuals with Brain Injury into Long-Term Care Efforts

Rationale:

The State of Maryland is evaluating current long-term care services and community support and planning for future service and support needs for people with disabilities and older adults. These efforts included the following areas: housing, attendant care, transportation, employment, etc. Given the growing numbers of reported brain injury, current and future services efforts must include the needs of individuals with brain injury so as to not exclude the long-term service needs of people with brain injuries.

The State Traumatic Brain Injury Board adopted this definition of "brain injury":

The term "**brain injury**" means an acquired injury to the brain that results in partial or total impairment in one or more areas of function. These areas of function include, but are not limited to, cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem solving; sensory, perceptual, motor abilities; psychosocial behavior; physical functioning; information processing; and speech.

A brain injury may be caused by any external or internal mechanism of injury, can vary in severity from mild to severe, and may result in short-term or long-term functional impairment. Acquired brain injuries include, but are not limited to, traumatic brain injuries and brain injuries associated with illnesses, anoxia, toxic exposures, or surgical interventions. The term does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma.

SERVICE FUNDING

Insurance Compliance

One of the most frequent concerns of individuals with brain injury, caregivers, family members, and advocates is the lack of insurance coverage available for medical and rehabilitation services. While both the private and public sectors finance acute care services to people with brain injury, federal and state governments pay for a large part of post-acute services received. Private insurance generally limits post-acute medical and rehabilitative services and does not pay for long-term care. Also individuals may quickly exhaust personal resources. When the private sector arbitrarily denies benefits to patients who have paid into their healthcare coverage, the patient loses the opportunity to continue their recovery, gain independent and functional skills. Consequently, the State of Maryland prematurely takes on the financial burden of providing the supports and services needed. With a Medicaid program that is already overburden and under funded, the State should require private insurance companies to uphold their financial and legal obligations to their customers.

RECOMMENDATION # 4

Conduct a Maryland Insurance Agency Cost Market Analysis of Brain Injury Benefits and Payments

Rationale:

While many believe that insurance companies routinely terminate benefits without regard to those for which a patient benefit is already legally entitled, the effect of this market analysis could provide credibility and verify the accuracy of this concern. All insurance companies operating in Maryland should be held accountable to provide the benefits for which their customers have paid in good faith. A cost market analysis by the Maryland Insurance Administration to determine the following is essential: (1) premium collected on behalf of individuals with brain injury to medical providers; (2) benefits; (3) payment to medical providers; and (4) benefits and payments denied to individuals with brain injury for requested medical services or equipment with reveal insurance compliance.

Insufficient Funds

Despite the growing increase in incidences and resulting cost to the State of Maryland, funding to support reintegration, services, training, and awareness is limited or nonexistent. Many individuals who sustain an injury exhaust all of their private and personal resources and are forced to discontinue their rehabilitation, even when it could potentially lead to greater independence, improved functioning, and employment. Many of these individuals are not eligible for Medicaid but need financial assistance for services and equipment. This is especially true for individuals who sustain their injury after the age of 22.

RECOMMENDATION # 5

Establish the State of Maryland Dedicated Brain Injury Trust Fund

Rationale:

Trust fund programs that benefit individuals who have sustained a brain injury are becoming more and more popular as states' appropriated general revenue sources are becoming more difficult to obtain and protect from budget cuts. Nationally, twenty-one states have funding either through designated general funds or specific funding, such as a trust, for brain injury services (see Appendix D). Currently, eighteen states have created dedicated trust funds in law to help pay for brain injury services. Estimated revenue varies widely for established programs from less than $1 million to $17 million. The average appears to be between $1 and $4 million annually. Sources of revenue also vary but are most often tied to traffic offenses – one of the leading causes of accidents and traumatic brain injuries.

Maryland's Trust Fund would be used to:

- provide individual support and services to individuals with brain injury and their family, as payer of last resort;
- develop and implement awareness and prevention programs; and
- develop and implement educational and training materials for individuals with brain injury, family/caregivers, professionals who serve them, and the general public.

The State of Maryland must establish a dedicated trust fund for individuals with brain injury funded through the fine levied to individuals who are convicted of a moving traffic violation from the courts.

EMPLOYMENT

Limited Employment Training

Many individuals can return to work after a brain injury if: they are given the proper rehabilitation in a timely manner; have access to funding and knowledgeable professionals with training in cognitive rehabilitation and brain injury; have the time to acknowledge their deficits; build compensatory strategies; and utilize longer term supportive employment services. Individuals with brain injury have not been successful in returning to work or maintaining employment because of their cognitive and behavioral deficits. These limitations require a more individualized approach and do not respond to the "one size fits all" model.

The State of Maryland is having limited success in preparing individuals with brain injury for and supporting them during their transition to employment. Brain injury is a difficult disability to serve in that no two injuries are alike and can be managed the same way. Historically, arranging for the array of auxiliary supports – substances abuse, mental health counselors, durable medical equipment, cognitive rehabilitation, etc. – was time consuming and ineffective due to lack of community capacity and few community providers available to provide this specialized vocational service. Vocational staff require an extensive understanding of the cognitive, behavioral, and emotional limitations of individuals with brain injury.

RECOMMENDATION # 6

Expand The Governor's Employment Initiative for Persons with Acquired Brain Injuries

Rationale:

The State recognized the need to redesign the limited brain injury rehabilitation or employment service delivery protocol to work more collaboratively with community providers and to enhance training to their staff. Through the State Disability Budget Initiative process, funding was allocated to create the Governor's Employment Initiative for Persons with Acquired Brain Injuries pilot program. Working in collaboration with community providers and the Brain Injury Association of Maryland, the program was fully implemented in September 2006 (see program's fact sheet in Appendix E). The pilot employment initiative has been extremely successful in its first five months. Accomplishments include:

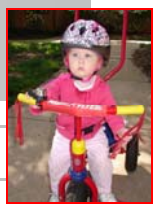
- Creation of a steering committee comprised of MDOD, DORS Administration and staff, community providers, Brain Injury Association of Maryland and researcher from the University of Maryland;
- Enrollment of over 34 participants from targeted regions;
- Successful employment of five individuals;

- Inclusion of a research component to evaluate the effectiveness of the brain injury program compared to the "standard" DORS work re-entry protocol; and
- Development of a consortium of brain injury professionals including DORS vocational counselors from around the State, Traumatic Brain Injury Federal Grant Director, community providers, and other brain injury professionals from around the state to: (1) discuss program challenges and successes, review case studies, and to build community capacity and (2) develop a forum for continuing education and training for new DORS counselors and community providers.

This initiative has been responsive to staff and participant needs, creative in its approach to service delivery, collaborative in every aspect, focused on positive outcomes, and cost effective. Expansion of this initiative will build community capacity, expand to underserved areas, increase staff development and give more individuals an opportunity to be wage earners.

Allocating $1.7 million dollars annually to the Division of Rehabilitation Services (DORS), who can contribute $300,000 in federal funds annually to provide these services. Increased funding would provide vocational services to at least 100 individuals with brain injury annually and provide funds for community capacity and professional development to the underserved areas like the Eastern Shore and Southern Maryland.

PREVENTION



Helmet Law

Unhelmeted riders have higher health care costs as a result of their crash injuries, and many lack health insurance. In November 2002, National Highway Traffic Safety Administration (NHTSA) reported that 25 studies of the costs of injuries from motorcycle crashes "consistently found that helmet use reduced the fatality rate, probability and severity of head injuries, cost of medical treatment, length of hospital stay, necessity for special medical treatments, and probability of long-term disability.

A number of studies examined the question of who pays for medical costs. Only slightly more than half of motorcycle crash victims have private health insurance coverage. For patients without private insurance, a majority of medical costs are paid by the government.[5] **Remember there is no cure for brain injury.**

RECOMMENDATION #7

Maintain Maryland's Current Motorcycle Helmet Law

Rationale:

Helmets decrease the severity of injury, the likelihood of death, and the overall cost of medical care. They are designed to cushion and protect riders' heads from the impact of a crash. Just like safety belts in cars, helmets cannot provide total protection against head injury or death, but they do reduce the incidence of both. NHTSA estimates that motorcycle helmets reduce the likelihood of a crash fatality by 37 %.[6] Norvell and Cummings found a 39 % reduction in the risk of death after adjusting for age, gender, and seat position. Helmets are highly effective in preventing brain injuries, which often require extensive treatment and may result in lifelong disability. In the event of a crash, unhelmeted motorcyclists are three times more likely than helmeted riders to suffer traumatic brain injuries.[7] Studies and findings from states that repealed their helmet law can be found in Appendix F. **The State of Maryland must maintain the current motorcycle helmet law.**

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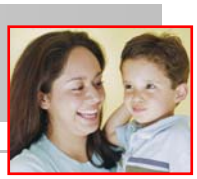
[5] Lawrence, B.A.; Max, W.; and Miller, T.R. 2002. Cost of Injuries Resulting from Motorcycle Crashes: A Literature Review. Report no. DOT HS-809-242. Washington, DC: National Highway Traffic Safety Administration.

[6] National Highway Traffic Safety Administration. 2005. Traffic Safety Facts: Motorcycle Helmet Use Laws. Washington, DC: US Department of Transportation.

[7] Norvell, D.C. and Cummings, P. 2002. Association of Helmet Use with Death in Motorcycle Crashes: A Matched-Pair Cohort Study. *American Journal of Epidemiology* 156:483-87.

RESEARCH



Lack of Accurate Data

Students with a brain injury are often not identified or incorrectly identified within our local school systems. The number of children reported to be hospitalized with a brain injury does not come close to the number of children that Maryland State Department of Education reports serving within the public school system. Children between the ages of 14 - 19 years of age have the highest incidence of traumatic brain injury, yet they are not accurately being identified nor appropriately served within the school system.

RECOMMENDATION # 8

Identify Students with Traumatic Brain Injury in Local School Systems with Appropriate Screening Materials

Rationale:

The local school systems and state operated programs must accurately report to Maryland State Department of Education (MSDE) the number of children with traumatic brain injuries in their data based reporting systems. Information in the data reporting system is used to compile annual reports which are used for planning for service needs such as support staff, special education teachers, funding, etc. Accurate identification of students with brain injury is critical to the success of the students and their right to free appropriate public education under the regulations of the Individuals with Disabilities Education Act (IDEA 2004). The development of training curriculum, tools, and materials for school personnel to assist in more accurate identification of children who sustain traumatic brain injuries is required. Local school systems needs more focus on identifying students with traumatic brain injury, including the use of available appropriate screening materials.

Need for Longitudinal Data

A number of research and clinical studies, as well as common experience show that brain injury is a chronic, sometimes progressive, neurological illness. This notion requires a shift in current "brain injury paradigms" and points to an urgent need for long-term data. *Longitudinal study structures* are needed to capture the evolving illnesses and disabilities associated with brain injury so that existing services can be refined to target specific needs, rather than continuing with the thought that "all things to all customers". The latter approach ends up becoming "less services for fewer and fewer people" given budget restraints and other types of limitations in resources.

The bulk of human suffering and societal cost of brain injury belongs in the realm of chronic, rather than acute, disability. The Maryland State Traumatic Brain Injury Advisory

Board has analyzed a large body of data from hospitals and emergency rooms that faithfully capture the realities of brain injury in the acute phase. However, as in other state and national registries, chronic data are missing. This gap in knowledge limits our understanding of what happens and why.

RECOMMENDATION # 9

Create the Maryland Consortium for Traumatic Brain Injury

Rationale:

Longitudinal, prospective structures are important for understanding and treating brain injury. The formation of two types of long-term data structures are critical to provide services, plan for the future, and meet the needs of this growing population. One would capture patients at entry point, i.e. immediately after the injury. The second would register patients at middle age. The first would measure how brain pathologies, clinical problems, and service needs evolve over time. The second would measure whether patients with moderate-to-severe brain injury will have a greater risk for neurodegenerative disease or other age-associated disorders of memory and cognition.

Longitudinal, prospective structures are important for understanding and treating brain injury. A very large number of brain injury patients emerge from motor vehicle accidents and suffer the type of injury known as diffuse axonal injury, a devastating blow to sensory, associative, and emotion-processing pathways that, based on recent research, is a progressive type of lesion. Brain injured patients emerge in the real world of social and occupational complexity where stress and sense of catastrophic inability to cope become often unbearable. This occurs even after they successfully complete acute and rehabilitative efforts in the sheltered environment of superb facilities that apply the best of modern medicine. Some patients show progressive withdrawal, others develop emotional illnesses and dementia, and yet more face chronic maladjustment. Given the 15-24 years-of-age peak incidence of brain injury in our Maryland population, these problems run for decades at a staggering personal and societal cost. Based on recent research, some of these individuals will eventually develop earlier or more severe forms of Alzheimer's dementia.

The *Maryland Consortium for Traumatic Brain Injury* would conduct a 10-year longitudinal study to:

- examine the impact that brain injury has on the individual, their family and society;
- the mechanisms of injury;
- the affect of acute care medicine on this population; and
- the medical, social, and community interventions needed to provide long-term care.

We propose to use an existing model for the longitudinal studies of cohorts of aging that captures in a prospective "real life" fashion, key events associated with age-associated health problems, including atherosclerosis and Alzheimer's disease. One such longitudinal cohort, the Baltimore Longitudinal study on Aging, continues to run strong and has made

enormous contributions in the field of Alzheimer's disease and aging in general. The existence of great academic medical centers in Baltimore such as University of Maryland Medical System, Johns Hopkins Medical System, and Shock-Trauma place our state in a unique position to pioneer such efforts and provide the example for other states and the federal government.

Based on previous experience with longitudinal studies, we propose a consortium-type arrangement. The Maryland Consortium for Traumatic Brain Injury (MDCTBI) should run for an initial period of 10 years and be funded with an initial annual budget of $4 million. Key professionals, funding, and other resources shall be sought from the various disciplines and state officials. Essential elements of a data capturing structure can be found in Appendix G. The Consortium's work will be promoted and disseminated among local, state, and federal entities, medical professionals, and researchers.

APPENDIX A

State Traumatic Brain Injury Advisory Board Legislative Charge

Mission:

To promote optimal quality of life for individuals with Traumatic Brain Injury and their families, the Maryland Traumatic Brain Injury Advisory Board shall investigate needs; identify gaps; facilitate collaboration among and between State agencies, public and private providers and the community; encourage and facilitate community participation in program implementation; and develop and disseminate to public officials an annual report that recommends oversight and funding, building provider capacity and training, and coordination of services.

Vision:

The State of Maryland is a leader in the development and implementation of consumer driven services and supports in the areas of brain injury prevention, advocacy, research, education, rehabilitation, and on-going community supports.

As per Article - Health – General Section 13-2101 through 13-21-05 established by House Bill 309 in the 2005 Session of Maryland General Assembly:

"The Advisory Committee shall:

(1) Investigate the needs of citizens with Traumatic Brain Injuries;

(2) Identify gaps in services to citizens with Traumatic Brain Injuries;

(3) Facilitate collaboration among state agencies that provide services to individuals with Traumatic Brain Injury;

(4) Facilitate collaboration among organizations and entities that provide services to individuals with Traumatic Brain Injuries;

(5) Encourage and facilitate community participation in program implementation;

(6) Issue an annual report to the Governor and, in accordance with 2-1246 of the State of Government Article, the General Assembly on or before November 30, 2005, and each November 30 thereafter summarizing the actions of the advisory board and containing recommendations for:

   i. Providing oversight in acquiring and utilizing state and federal funding dedicated to services for individuals with traumatic brain injury;

   ii. Building provider-capacity and provide training that address the needs of individuals with traumatic brain injury; and

   iii. Disseminate copies of the annual report to the President of the Senate, Speaker of the House, and the Secretary of each department represented on the advisory board."

APPENDIX B

State Traumatic Brain Injury Advisory Board Members

Diane Triplett - Chair
Brain Injury Association of Maryland
Baltimore, Maryland

Lissa Abrams
Department of Health and Mental Hygiene
Mental Hygiene Administration
Catonsville, Maryland

Greg Ayotte
Brain Injury Association of Maryland
Towson, Maryland

Janice Barrett
Statewide Independent Living Council
Silver Spring, Maryland

Mary Beachley
Maryland Institute for Emergency Medicaid Services Systems
Baltimore, Maryland

Diane Bolger
Department of Health and Mental Hygiene
Developmental Disabilities Administration
Baltimore, Maryland

Robert Chodos
Representing Individuals with Brain Injury
Annapolis, Maryland

Peter Cohen
Department of Health and Mental Hygiene
Alcohol and Drug Abuse Administration
Catonsville, Maryland

Scott Cole
Representing Individuals with Brain Injury
Odenton, Maryland

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

Vincent Culotta, PhD
Representing Professionals Working with Individuals with Brain Injury
Columbia, Maryland

Sandy Davis
Brain Injury Association of Maryland
Owings Mills, Maryland

Tracey DeShields
Department of Health and Mental Hygiene
Baltimore, Maryland

Sue Ferris
Representing Individuals with Brain Injury
Annapolis, Maryland

Nathaniel Fick
Brain Injury Association of Maryland
Fick & Petty
Towson, Maryland

Gayle Hafner
Maryland Disability Law Center
Baltimore, Maryland

Paul Hartman
Representing Individuals with Brain Injury
Frederick, Maryland

Martin Kerrigan
Representing Individuals with Brain Injury
Silver Spring, Maryland

Vassilis Koliatsos, MD
Representing Professionals Working with Individuals with Brain Injury
Baltimore, Maryland

Yvette McEarchern
Department of Health and Mental Hygiene
Maternal and Child Health Program
Baltimore, Maryland

Karen McQuillan
Representing Professionals Working with Individuals with Brain Injury
R Adams Cowley Shock Trauma Center
Baltimore, Maryland

Lee Murphy
Maryland State Department of Education
Baltimore, Maryland

Lt. William Powell
Representing Local Police Enforcement
Annapolis City Police
Annapolis, Maryland

Michael Roberts
Representing Individuals with Brain Injury
Germantown, Maryland

Michael Rudnick
Representing Families/Caregivers of Individuals with Brain Injury
Skyesville, Maryland

Sharon Sauls
Representing Professionals Working with Individuals with Brain Injury
SKY Neuro Rehab
Laurel, Maryland

Tracey Serpi
Department of Health and Mental Hygiene
Center for Preventive Health Services
Baltimore, Maryland

Mary Stapleton
Maryland State Department of Education
Baltimore, Maryland

Robert Vacin
Representing Families/Caregivers of Individuals with Brain Injury
LaPlata, Maryland

Cari Watrous
Maryland Department of Disabilities
Baltimore, Maryland

Michael Weinrick, PhD
National Institute of Health
Bethesda, Maryland

Jane Wessely
Department of Health and Mental Hygiene
Baltimore, Maryland

Sean Westley
Representing Families/Caregivers of Individuals with Brain Injury
Baltimore, Maryland

Richard Zeidman
Representing Families/Caregivers of Individuals with Brain Injury
Rockville, Maryland

Staff To The Board
Stefani O'Dea
Department of Health and Mental Hygiene
Mental Hygiene Administration
Catonsville, Maryland

Rhonda Workman
Maryland Department of Disabilities
Baltimore, Maryland

APPENDIX C

Traumatic Brain Injury Waiver Fact Sheet

Department of Health and Mental Hygiene

Waiver for Adults with Traumatic Brain Injury

Maryland's Home and Community Based Services Waiver for Adults with Traumatic Brain Injury provides residential habilitation, day habilitation, and supported employment services to Adults with Traumatic Brain Injuries.

Traumatic Brain Injury Waiver Services:

- Residential habilitation
- Day habilitation
- Supported employment
- Individual Support Services
- Case management

Waiver Participants are eligible for all Medicaid state plan services

WHO SHOULD APPLY

Maryland residents age 22 through 64 who have been diagnosed with traumatic brain injury and meet the following criteria.

ELIGIBILITY GUIDELINES

Medical Criteria

- Individuals with traumatic brain injury who require a specialty hospital or nursing facility level of care.

Technical Criteria

- Individuals must have experienced the (initial) traumatic brain injury after the age of 21
- Individuals must be inpatients in a State Mental Hygiene Administration facility, inpatients in a state owned and operated nursing facility, a Maryland licensed Special Hospital for Chronic Disease that is CARF accredited for Brain Injury Inpatient Rehabilitation, or individuals who have been placed by Medicaid in an out-of state facility.

Financial Requirements

- Monthly income of no more than $1809.
- Assets may not exceed $2000.

PERSONS INTERESTED SHOULD

Contact the Mental Hygiene Administration at
410-402-8476

Healthy People – Healthy Communities

APPENDIX D

Trust Fund Development At-A-Glance

"A Look at TBI Trust Fund Programs" 2006. Department of Health and Human Services Health Resource and Services Administration, Child and Health Bureau.

TRUST FUND DEVELOPMENT AT-A-GLANCE

Date Ratified	State	Revenue Sources	Estimated Revenue	Program Focus
1985	PA	All traffic violations	$3 million	Assessment, short-term community-based rehabilitation services, transition case management
1988	CA	.066 of state penalty fund	$1 million	7 regionally based projects addressing community support needs
1988	FL	DUI, BUI, moving viol, motorcycle tag, temp license tag	$17 million	Acute care, rehabilitation, community integration, nursing home transition, case management, Medicaid match, prevention, registry, special project grants
1991	MA	speeding, DUI	$6.8 million	Non-recurring, short-term community support services
1991	MN	DUI	$1 million	Registry, resource and service coordination
1991	TX	felonies and misdemeanor	$10.5 million	Inpatient, outpatient, and post-acute rehabilitation services
1992	AZ	civil & criminal	$2 million	Public information, prevention, education, community rehabilitation, transitional living, surveillance
1993	AL	DUI	$1.5 million	Registry, resource coordination
1993	LA	DUI, speeding	$1.5 million	Community-based services and supports
1993	TN	speeding, reck. op., DUI, rev. license.	$750-950,000	Registry, grants for 10 community-based projects
1996	MS	DUI moving viol.	$3.5 million	Registry, waiver match, services, transitional living, prevention, education, recreation
1997	NM	moving violations	$1.5 million	Service coordination, life skills training, crisis interim services
1997	VA	license reinst. fee	$1.2 million	Grants for community-based rehabilitation projects, applied research projects
1998	GA	DUI	$2.3 million	Community-based services and supports, support groups, AT
1998	KY	percent of court costs	$3.3 million	Community-based services and supports, surveillance registry
2002	CO	speeding DUI	$1.5 million	Care coordination, services, research, education
2002	HI	traffic offenses	$600,000	Service coordination, education, public awareness, registry
2002	MO	Cost of court	$800,000	Counseling, mentoring, education
2002	NJ	car registration	$3.8 million	Community-based services and supports, public awareness, education
2003	MT	car registration	$8,117	Advisory Council, grants for public awareness, prevention education
2004	CT	reckless driv., speeding DUI	$300,000	Undetermined – may focus on resource coordination

APPENDIX E

Governor's Employment Initiative

MARYLAND STATE DEPARTMENT OF EDUCATION
Achievement Matters Most

Nancy S. Grasmick
State Superintendent of Schools

Robert A. Burns
Assistant State Superintendent

Division of Rehabilitation Services
2301 Argonne Drive • Baltimore, MD 21218 • 410-554-9385 • Toll Free 888-554-0334 • 410-554-9411 TTY/TDD

The Governor's Employment Initiative for Persons With Acquired Brain Injuries Fact Sheet

Background

As part of the Administration's effort to expand employment opportunities for persons with significant disabilities, Governor Ehrlich included $850,000 of new state funds in his FY 2007 budget proposal specifically for the Governor's Employment Initiative for Persons with Acquired Brain Injuries. The Division of Rehabilitation Services committed an additional $150,000 in federal funding for services for persons with acquired brain injury. The goal of the initiative is to provide intensive vocational rehabilitation services to individuals with acquired brain injuries who require long-term, ongoing support services to assure success in employment.

The Division of Rehabilitation Services is the lead agency for the initiative. DORS is working with community rehabilitation programs and other community organizations to provide the necessary services, including job coaching, to eligible individuals to that they can obtain and be successful in employment. The project began on July 1, 2006.

Criteria for Participation

The project plans to provide to services to fifty (50) participants during the first year of the initiative. The following criteria have been established for individual participants:

- Meets federal eligibility criteria for the state vocational rehabilitation program; the primary cause of the disability must be a brain injury;
- Meets the DORS criteria for "most significant disability" ; and is
- Medically stable; not actively abusing substances (committed to recovery) or in crisis; and has housing and medical support in place.

Service Delivery Protocol

Five phases of service delivery have been identified, with delivery of services dependent on identified needs of the individual.

- Phase I: Assessment/Diagnostic Phase
- Phase II: Remediation- Compensatory Strategies
- Phase III: Work Readiness

- Phase IV: Job Development
- Phase V: Job Coaching and Supported Employment (This phase is unique in that DORS will provide the funding for long term job coaching support as part of post employment services).

Research and Project Evaluation Component

A research and evaluation element has been implemented in partnership with the University of Maryland to examine the efficacy of a specialized service delivery approach to effectively meet the needs of persons with brain injuries in achieving and maintaining employment. The confidentiality of participants is protected with data collection maintained on an aggregate basis only.

Information and Referral

The following eight DORS counselors have been identified for this initiative:
Beth Sayles, Hagerstown, bsayles@dors.state.md.us, 301-791-474760
Sam Hardesty, Annapolis, ahardesty@dors.state.md.us, 410-974-7608
Dennis Phillips, Southern Maryland, dphillips@dors.state.md.us, 240-725-5785
Sylvia Taylor, Baltimore City, staylor@dors.state.md.us, 410-333-6155
Henry Sanfilippo, Towson, hsanfilippo@dors.state.md.us, 410-321-4044
Terese Reamer, Ellicott City, treamer@dors.state.md.us, 410-480-7820
Karen Earl, Wheaton, kearl@dors.state.md.us, 301-949-3750
Douglas Hilker, Oxon Hill, dhilker@dors.state.md.us, 301-749-4660

Additional information can be found at the DORS website, www.dors.state.md.us; inquiries can be directed to JoAnne Materkowski, jmaterkowski@dors.state.md.us, 410-554-9387.

APPENDIX F

Helmet Law Data and Trends

In states that either reinstated or enacted universal motorcycle helmet laws, helmet use increased dramatically, and motorcyclist deaths and injuries decreased. In states that repealed or weakened their universal helmet laws, helmet use declined sharply, and motorcyclist deaths and injuries rose. National state's experience include:

- California's helmet use law covering all riders took effect on January 1, 1992. Helmet use jumped to 99 % from about 50 % before the law.[8] During the same period, the number of motorcyclist fatalities in California decreased 37 % to 327 in 1992 from 523 in 1991.[9]
- Nebraska reinstated a helmet law on January 1, 1989 after repealing an earlier law in 1977. The state then saw a 22 % reduction in motorcyclist serious head injuries.[10]
- From 1968 to 1977, Texas had a universal helmet use law estimated to have saved 650 lives, but the law was amended in 1977 to apply only to riders younger than 18. The weakened law coincided with a 35 % increase in motorcyclist fatalities. Texas reinstated its helmet law for all motorcyclists in September 1989. The month before the law took effect, the helmet use rate was 41 %. The rate jumped to 90 % during the first month of the law and had risen to 98 % by June 1990.[11] Serious injury crashes per registered motorcycle decreased 11 %.[12] But in September 1997, Texas again weakened its helmet law, requiring helmets only for riders younger than 21. Helmet use in Texas dropped to 66 % by May 1998, and operator fatalities increased 31 % in the first full year following the repeal.[13]
- In 2000, Florida's universal helmet law was weakened to exempt riders 21 and older who have at least $10,000 of medical insurance coverage. An Institute study found that the motorcyclist death rate in Florida increased by about 25 %, after the state weakened its

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[8] Kraus, J.F.; Peek, C.; and Williams, A.F. 1995. Compliance with the 1992 California Motorcycle Helmet Use Law. *American Journal of Public Health* 85:96-99.

[9] Kraus, J.F.; Peek, C.; McArthur, D.L.; and Williams, A.F. 1994. The Effect of the 1992 California Motorcycle Helmet Usage Law on Motorcycle Crash Fatalities and Injuries. *Journal of the American Medical Association* 272:1506-11.

[10] Muelleman, R.L.; Mlinek, E.J.; and Collicott, P.E. 1992. Motorcycle Crash Injuries and Costs: Effect of a Re-enacted Comprehensive Helmet Use Law. *American Journal of Emergency Medicine* 21:266-72.

[11] Lund, A.K.; Williams, A.F.; and Womack, K.N. 1991. Motorcycle Helmet Use in Texas. *Public Health Reports* 106:576-78.

[12] Mounce, N.; Brackett, Q.; Hinshaw, W.; Lund, A.K.; and Wells, J.K. 1992. The Reinstated Comprehensive Motorcycle Helmet Law in Texas. Arlington, VA: Insurance Institute for Highway Safety.

[13] Preusser, D.F.; Hedlund, J.H.; and Ulmer, R.G. 2000. Evaluation of Motorcycle Helmet Law Repeal in Arkansas and Texas. Washington, DC: National Highway Traffic Safety Administration.

helmet law. The death rate rose from 31 fatalities per 1,000 crash involvements before the law change (1998-99) to 39 fatalities after (2001-2002). An estimated 117 deaths could have been prevented during 2001-02 if the law had not been changed. [14] An evaluation of the Florida law change by NHTSA found a similar effect; motorcyclist deaths per 10,000 motorcycle registrations increased 21 % during the two years after the law was changed compared with the two years before. [15]

Among the specific findings of several of the studies:

- The National Highway Traffic Safety Administration (NHTSA) Crash Outcome Data Evaluation System study released in February 1996 showed average inpatient hospital charges for unhelmeted motorcyclists in crashes were 8 % higher than for helmeted riders ($15,578 compared with $14,377). [16]
- After California introduced a helmet use law in 1992, studies showed a decline in health care costs associated with head-injured motorcyclists. The rate of motorcyclists hospitalized for head injuries decreased by 48 % in 1993 compared with 1991, and total costs for patients with head injuries decreased by $20.5 million during this period. [17]
- A study of the effects of Nebraska's reinstated helmet use law on hospital costs found the total acute medical charges for injured motorcyclists declined 38 %. [10]

A NHTSA evaluation of the weakening of Florida's universal helmet law in 2000 to exclude riders 21 and older who have at least $10,000 of medical insurance coverage found a huge increase in hospital admissions of cyclists with injuries to the head, brain, and skull. Such injuries went up 82 % during the 30 months immediately following the law change. The average inflation-adjusted cost of treating these injuries went up from about $34,500 before the helmet law was weakened to nearly $40,000 after. Less than one-quarter of the injured motorcyclists would be covered by the $10,000 medical insurance requirement for riders who chose not to use helmets. [15]

Studies conducted in Nebraska, Washington, California, and Massachusetts indicate how injured motorcyclists burden taxpayers. Forty-one percent of motorcyclists injured in Nebraska

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[14] Kyrychenko, S.Y. and McCartt, A.T. 2006. Florida Weakened Motorcycle Helmet Law: Effects on Death Rates in Motorcycle Crashes. *Traffic Injury Prevention* 7:55-60.

[15] Ulmer, R.G. and Northrup, V.S. 2005. Evaluation of the Repeal of the All-Rider Motorcycle Helmet Law in Florida. Report no. DOT HS-809-849. Washington, DC: National Highway Traffic Safety Administration.

[16] National Highway Traffic Safety Administration. 1996. Report to Congress: Benefits of Safety Belts and Motorcycle Helmets. Report no. DOT HS-808-347. Washington, DC: US Department of Transportation.

[17] Max, W.; Stark, B.; and Root, S. 1998. Putting a Lid on Injury Costs: The Economic Impact of the California Motorcycle Helmet Law. *Journal of Trauma* 45:550-56.

from January 1988 to January 1990 lacked health insurance or received Medicaid or Medicare. [18] In Seattle, 63 % of trauma care for injured motorcyclists in 1985 was paid by public funds.[19] In Sacramento, public funds paid 82 % of the costs to treat orthopedic injuries sustained by motorcyclists during 1980-83.[20] Forty-six percent of motorcyclists treated at Massachusetts General Hospital during 1982-83 were uninsured.[21]

[18] Muelleman, R.L.; Mlinek, E.J.; and Collicott, P.E. 1992. Motorcycle Crash Injuries and Costs: Effect of a Re-enacted Comprehensive Helmet Use Law. *American Journal of Emergency Medicine* 21:266-72.

[19] Rivara, F.P.; Dicker, B.G.; Bergman, A.B.; Dacey, R.; and Herman, C. 1988. The Public Cost of Motorcycle Trauma. *Journal of the American Medical Association* 260:221-23.

[20] Bray, T.; Szabo, R.; Timmerman, L.; Yen, L.; and Madison, M. 1985. Cost of Orthopedic Injuries Sustained in Motorcycle Accidents. *Journal of the American Medical Association* 254:2452-53.

[21] Bach, B.R. and Wyman, E.T. 1986. Financial Charges of Hospitalized Motorcyclists at the Massachusetts General Hospital. *Journal of Trauma* 26:343-47.

APPENDIX G

Longitudinal Data Capturing Structure Essential Elements

a) ***An entry point at onset of injury,*** i.e. The Shock Trauma Center and other level one trauma centers within the state.

b) ***An entry point at a predetermined middle-age landmark,*** e.g. 50 years of age; such patients would be recruited from the community based on local advertisement.

c) ***A brain bank*** to allow further studies of brain pathology. Such a Bank should include i) severe brain injury with early terminal outcomes (to be established with the Medical Examiner's office, possibly at the Medical Examiner's office) and ii) brains of older individuals with histories of brain injury of various severities who die from any cause. The second type of material should be collected on the basis of patient registries as in the case of brains of patients with histories of dementia, i.e. the Brain Resource Center at Johns Hopkins and elsewhere.

d) ***A radiology core*** for in vivo imaging of patients with the diffuse axonal injury type of brain injury. This will use both traditional (i.e. MRI) and axonal imaging (i.e. DTI) modalities and examine patients at different time points post-injury.

e) ***A clinical core*** that would collect and analyze longitudinal health data including general medical neurological and psychiatric. This could be either using established brain injury clinics or rehabilitation programs in the State of Maryland and add to their individual resources or use a centralized operation to which patients should be regularly transferred (i.e. every six months). There are advantages and disadvantages in the two options.

f) ***An administrative core*** coordinating regular meetings of consortium participants for the purpose of exchanging ideas, comparing notes and forming interim hypotheses guiding in certain directions in service or research. This core should have a scientific board that would have a certain amount of additional funding to pilot grants specific to a certain region of inquiry that is clinically and service-oriented, based on perceived need. This allowance should not be used as a traditional research funding venue, but as a mode of "purchasing" information by specialists in a given area of relevance to the mission of consortium.

g) ***A public education/community liaison core*** that is essential to disseminate information pertaining to brain injury in the state of Maryland, help with recruitment and ensure access to special groups that may be underrepresented in clinic or rehabilitation populations. Proper representation of patients in data registries is not simply a matter of fairness but also crucial to improve the validity of the analyzed samples. Such core functions could, for example, be undertaken by the Brain Injury Association of Maryland can undertake such core functions.

The initial meeting of the consortium participants and representatives of the State and the public is proposed to take place in February of 2008 in order to finalize participating sites, responsible faculty and staff and decide on the proper allocation of resources. Counties with the highest incidence of brain injury should proportionately be taken into consideration, i.e. Montgomery, Prince George's, Baltimore and Baltimore City.

APPENDIX H

National Data

"According to the Centers for Disease Control and Prevention (CDC), *at least* 5.3 million individuals in the United States have a permanent disability as a result of traumatic brain injury. [22] Advances in emergency medicine, faster response time from the scene of injury to the emergency department, and highly trained and skilled responders have all contributed to increased survival rates for individuals who are severely injured. As an increasing number of individuals with traumatic brain injuries survive severe injuries, families and other advocates look to the state and federal government for assistance with the medical, rehabilitation, long-term care, and other needs associated with brain injury.

According to the CDC, **each year an estimated 1.4 million individuals in the United States sustain a traumatic brain injury**. Of those injured, 1.1 million have injuries serious enough to require treatment in hospital emergency departments. Annually, more than 235,000 people are hospitalized and 50,000 people die as a result of their injuries. An estimated 80-90,000 Americans with traumatic brain injuries experience permanent impairs their physical, cognitive, and psychosocial functioning which in turn impacts their ability to return to home, school, and work.

Approximately 475,000 children ages birth to 14 receive a traumatic brain injury with emergency department visits counting for more than 90 % of the traumatic brain injuries in this age group. The risk for incurring a traumatic brain injury is highest among adolescents, young adults, and persons over the age of 75, with the risk among males twice the risk among females. African Americans have the highest death and hospitalization rates from traumatic brain injuries.[23] The reasons for these disparities are not well known. Transportation incidents, primarily **motor vehicle crashes, are the leading cause of traumatic brain injury-related hospitalizations**, whereas **falls are the leading cause of all traumatic brain injuries**. The injury rates for falls are highest among children ages birth to four years and adults age 75 or older. The injury rates for both motor vehicle and assault-related traumatic brain injuries are highest among adolescents ages 15 to 19. [23]

Drug and alcohol abuse also has been associated with traumatic brain injuries as both a contributing factor to the injury and as a complicating factor in rehabilitation.[24] Individuals

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[22] Norvell, D.C. and Cummings, P. 2002. Association of Helmet Use with Death in Motorcycle Crashes: A Matched-Pair Cohort Study. *American Journal of Epidemiology* 156:483-87.

[23] Goldstein, J.P. 1986. The Effect of Motorcycle Helmet Use on the Probability of Fatality and the Severity of Head and Neck Injuries: A Latent Variable Framework. *Evaluation Review* 10:355-75.

[24] Glassbrenner, D. 2005. Motorcycle Helmet Use in 2005 — Overall Results. Report no. DOT HS-809-937. Washington, DC: National Highway Traffic Safety Administration.

who sustain one concussion or mild brain injury are more apt to experience additional concussions, and the cumulative effect of repeated concussions, as is frequently seen in sports-related traumatic brain injuries, increases the likelihood of long-term neurological damage and learning disability. [25]

Whether the injury is the result of a car crash, a slip and fall, assault, or sports activity, the economic consequences of traumatic brain injuries can be enormous. **In the United States, the average lifetime cost of care for a person with a severe injury ranges from $600,000 to $1,875,000**.[26] This does not include lost earnings of the injured person or family caregivers. The total cost of traumatic brain injuries to the nation is estimated at $56.3 billion annually. [27]

[25] McKnight, A.J. and McKnight, A.S. 1994. The Effects of Motorcycle Helmets Upon Seeing and Hearing. Report no. DOT HS-808-399. Washington, DC: National Highway Traffic Safety Administration.

[26] National Highway Traffic Safety Administration. 2005. Without Motorcycle Helmets, We All Pay the Price. Washington, DC: US Department of Transportation.

[27] Ulmer, R.G. and Northrup, V.S. 2005. Evaluation of the Repeal of the All-Rider Motorcycle Helmet Law in Florida. Report no. DOT HS-809-849. Washington, DC: National Highway Traffic Safety Administration.

APPENDIX I

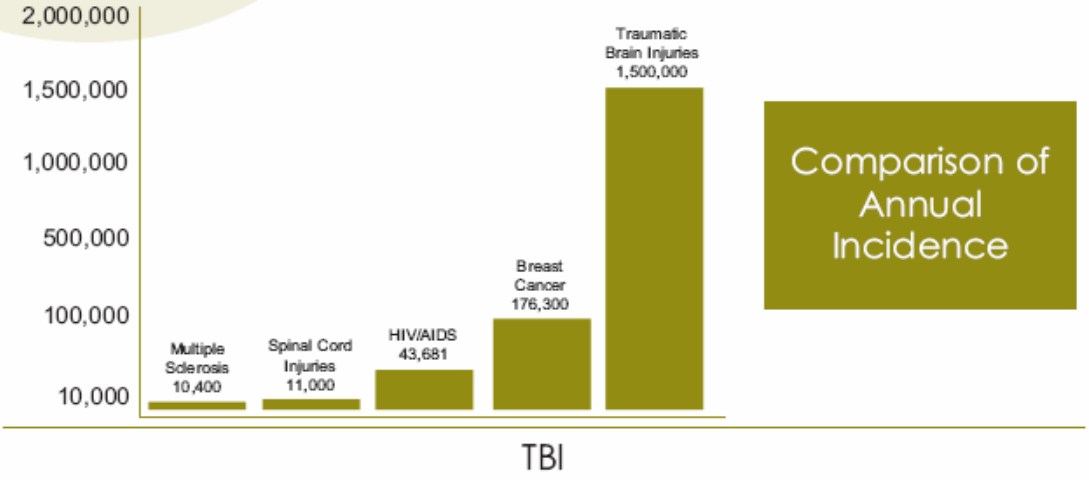
Brain Injury Association of America – TBI Incidence

Brain Injury Association of America

8201 Greensboro Dr., Suite 611
McLean, VA 22102
Family Helpline: 1-800-444-6443
familyhelpline@biausa.org
www.biausa.org

TBI Incidence

A Comparison of Traumatic Brain Injury and Leading Injuries or Diseases



On an annual basis in the United States:

- 1.5 million people will sustain a TBI annually.[1]
- 50,000 people will die annually as a result of TBI.[1]
- 80,000 people annually experience the onset of long-term disabilities following TBI.[1]
- There are currently 5.3 million Americans living with a disability as a result of a TBI.[1]

Breast Cancer

On an annual basis in the United States:

- In 1999 there were 175,000 new instances of breast cancer in women and 1,300 new instances in men.[4]
- In 1999, 43,300 women and 400 men died from breast cancer.[4]

Creating a better future through brain injury prevention, research, education and advocacy

This fact sheet is supported in part by project U 93 MC 00010-05-01 Partnership for Information and Communication (PIC) Cooperative Agreement with the Department of Health and Human Services (DHHS) Health Resources and Services Administration, Maternal and Child Health Bureau, Federal TBI Program.

2004

Spinal Cord Injury

On an annual basis in the United States:

- Nearly 11,000 people sustain a traumatic spinal cord injury.[5]
- More than 190,000 people in the U.S. live with paralysis caused by spinal cord injury.[5]
- 85 percent of all spinal cord injury patients who survive 24 hours after their injury are still living ten years after the incident.[5]

HIV/AIDS

On an annual basis in the United States:

- The following number of people died from an AIDS-related illness:[2]

1999 - 16,273	1998 - 17,930	1997 - 21,923	1996 - 37,787
1995 - 50,610	1994 - 49,869	1993 - 45,381	

- The following number of people were diagnosed with HIV/AIDS:[3]

1996 - 60,618	1997 - 49,704	1998 - 43,681

Multiple Sclerosis

On an annual basis in the United States:

- It is estimated that 10,400 people are diagnosed with MS on a yearly basis, broken down to 200 new instances per week.[6]

Sources:

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4. American Cancer Society. "Cancer Facts and Figures 1999, Selected Cancers," WWW: American Cancer Society, (January 16, 2001) http:www.cancer.org/statistics/cff99/selectedcancers.html
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APPENDIX J

Facts About Traumatic Brain Injury

Facts about Traumatic Brain Injury

What is a traumatic brain injury?

A traumatic brain injury (TBI) is defined as a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain. Not all blows or jolts to the head result in a TBI. The severity of such an injury may range from "mild," i.e., a brief change in mental status or consciousness to "severe," i.e., an extended period of unconsciousness or amnesia after the injury. A TBI can result in short or long-term problems with independent function.

How many people have TBI?

Of the 1.4 million who sustain a TBI each year in the United States:

- 50,000 die;
- 235,000 are hospitalized; and
- 1.1 million are treated and released from an emergency department.[1]

The number of people with TBI who are not seen in an emergency department or who receive no care is unknown.

What causes TBI?

The leading causes of TBI are:

- Falls (28%);
- Motor vehicle-traffic crashes (20%);
- Struck by/against (19%); and
- Assaults (11%).[1]

Blasts are a leading cause of TBI for active duty military personnel in war zones.[2]

Who is at highest risk for TBI?

- Males are about 1.5 times as likely as females to sustain a TBI.[1]
- The two age groups at highest risk for TBI are 0 to 4 year olds and 15 to 19 year olds.[1]
- Certain military duties (e.g., paratrooper) increase the risk of sustaining a TBI.[3]
- African Americans have the highest death rate from TBI.[1]

What are the costs of TBI?

Direct medical costs and indirect costs such as lost productivity of TBI totaled an estimated $56.3 billion in the United States in 1995.[4]

What are the long-term consequences of TBI?

The Centers for Disease Control and Prevention estimates that at least 5.3 million Americans currently have a long-term or lifelong need for help to perform activities of daily living as a result of a TBI.[5]

According to one study, about 40% of those hospitalized with a TBI had at least one unmet need for services one year after their injury. The most frequent unmet needs were:

- Improving memory and problem solving;
- Managing stress and emotional upsets;
- Controlling one's temper; and
- Improving one's job skills.[6]

TBI can cause a wide range of functional changes affecting thinking, sensation, language, and/or emotions. It can also cause epilepsy and increase the risk for conditions such as Alzheimer's disease, Parkinson's disease, and other brain disorders that become more prevalent with age.[7]

Collaborating Organizations

Brain Injury Association of America
www.biausa.org
800-444-6443

Centers for Disease Control and Prevention
www.cdc.gov
800-311-3435

Defense and Veterans Brain Injury Center
www.dvbic.org
800-870-9244

Health Resources and Services Administration
www.hrsa.gov
301-443-3376

National Association of State Head Injury Administrators
www.nashia.org
301-656-3500

National Brain Injury Research Treatment and Training Foundation
www.nbirtt.org
434-220-4824

National Center for Medical Rehabilitation Research, NICHD, NIH
www.nichd.nih.gov/about/ncmrr
800-370-2943

National Institute on Disability and Rehabilitation Research
www.ed.gov/about/offices/list/osers/nidrr
202-245-7640

National Institute of Neurological Disorders and Stroke, NIH
www.ninds.nih.gov
800-352-9424

North American Brain Injury Society
www.nabis.org
703-960-6500

Social Security Administration
www.ssa.gov
800-772-1213

Updated 8/05

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3. Ivins BJ, Schwab K, Warden D, Harvey S, Hoilien M, Powell J, et al. Traumatic brain injury in U.S. army paratroopers: prevalence and character. Journal of Trauma Injury, Infection and Critical Care 2003;55(4): 617-21.
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APPENDIX K

Maryland Data and Trends

Data

The Maryland Department of Health and Mental Hygiene, Center for Preventive Health Services has housed most of the Maryland data for traumatic brain injury. An overview of Maryland traumatic brain injury related data for Emergency Room Visits, Hospitalizations, and Deaths can be found in Appendix L, M, and N.

Trends

Information collected by the Brain Injury Association of Maryland, Maryland's sole advocacy organization for individuals with Brain Injury reveals the following trends and needs among Marylanders who sustain a traumatic brain injury:

1. **Changes in private insurance coverage:**
   - Private insurance companies are authorizing shorter hospital and acute rehabilitation hospital length of stays resulting in patients being discharge with acute and complicated medical needs. This has coined the phrase "Sicker & Sooner" in the medical community.
   - No or limited authorization for community re-entry services including medical, day habilitation, and or rehabilitative services. This in turn continues to shrink the number of rehabilitation and community re-entry providers who can afford to offer specialized services, especially in rural areas of the State.
   - Insurance providers are referring to lower cost, non-specialized facilities – cheaper and sometimes easier to refer to a nursing home facility/institution verses a Commission on Accreditation of Rehabilitation Facilities (CARF) accredited for Brain Injury inpatient rehabilitation and licensed medical and/or community providers. Too many individuals, especially young individuals, are being forced to reside in long-term care institutions because of lack of education, funding, and community resources.
   - **Tremendous increasing costs to public sector – since private insurance is terminating coverage sooner, the public sector is paying sooner.**

2. **Lack of awareness about brain injury even within medical and disability community**
   - Little funding or resources allocated for educational activities that promote prevention of brain injury – No cure for brain injury.
   - Medical community in early stages of understanding brain injury and the resulting disability conditions associated with it.
   - Prognosis for traumatic brain injury is unknown – no good acute data to indicate which patients will need long term supports.

- Need for good surveillance data that will identify prevalence and incidence within Maryland, longitudinal data that will chronic issues and best practices for short and long-term care.

3. **Expensive medical, social, and chronic disability to treat**
   - One of the most expensive injuries to treat starting at the site of impact (accident, fall, assault, etc), inpatient and outpatient medical services, community supports, chronic needs, and medical complications that we are only beginning to understand.
   - **Enormous burden on family :**
     - **Financial burden -** usually loss of income from two family members: the individual that was injured and unable to return to employment and a family member that needs to stay home and care for the survivor.
     - **Emotional burden** – struggle to learn to live with and support the new family dynamics (role reversals, loss of ability to parent), loss of life style, living with a person who is not the same – changes in personality, behaviors, and skills
     - **Aging caregivers** – as persons with brain injury continue to survivor catastrophic injuries and chronic progressive related conditions, caregivers are aging and unable to physically, emotionally, and financially continue to manage the care.

4. **Gaps in Resources**
   - **Lack of family education starting at trauma centers and emergency rooms** – no time or resources spent on family education starting from the on-set of injury. Resources are spent on financial justification or hospital admission and treatment.
   - **Fragmented delivery system for disability community** – with no education family is met with a system that is uncoordinated, confusing, and time consuming
   - **Lack in short and long-term residential options** for highest risk population (15-35 year old), especially when home is not an option
   - **Growing Emergency Room admissions for treatment** – many families and community providers are forced to take individual to emergency room for treatment of medical or behavioral issues because:
     - Few community providers to treat psychiatric and or medical conditions
     - No funding to treat conditions within the community

5. **New Population of Individuals with Brain Injury**
   - Enormous numbers of soldiers returning from current war in Iraq
   - Growing number of individuals within and or newly released from correctional facilities
   - Growing number of seniors are being diagnosis with traumatic brain injury and present new and different challenges

6. **Ethical issues – why are we saving some of these lives at our trauma centers if there is no support or resources for them and their families at the other end of the continuum?**

APPENDIX L

Traumatic Brain Injury Emergency Department Visits - Center for Preventive Health Services - DHMH

NUMBER OF INJURY-RELATED ED VISITS FOR TBI BY YEAR, AGE, GENDER, AND CAUSE OF INJURY, MARYLAND 2002-04

		YEARS		
	TOTAL 2002-04	2002	2003	2004
TOTAL	63,589	**19,967**	**21,252**	**22,370**
AGE				
0-4 YRS	9,895	3,192	3,196	3,507
5-14 YRS	**11,558**	3,719	3,819	4,020
15-24 YRS	13,207	4,160	4,401	4,646
25-34 YRS	**7,122**	2,346	2,378	2,398
35-44 YRS	6,997	2,258	2,356	2,383
45-54 YRS	**5,068**	1,514	1,787	1,767
55-64 YRS	2,895	798	1,017	1,080
65-74 YRS	**2,121**	605	704	812
75-84 YRS	2,793	826	936	1,031
85+ YRS	1,933	549	658	726
GENDER				
MALE	35,865	11,388	11,985	12,492
FEMALE	**27,718**	8,578	9,263	9,877
UNKNOWN	6	#	#	#
RACE				
WHITE	40,333	12,747	13,491	14,095
AFRICAN AMERICAN	**18,639**	5,880	6,211	6,548
ASIAN/PACIFIC ISLANDERS	1,033	312	344	377
AMERICAN INDIAN/ESKIMO/ ALEUT	**122**	38	44	40
OTHER	3,279	935	1,088	1,256
UNKNOWN	**183**	55	74	54
CAUSE				
CUT/PIERCE	324	106	108	110
DROWNING	**18**	7	#	8
FALL	25,279	7,565	8,489	9,225
FIRE/BURN	**21**	6	10	#
FIREARM	68	23	19	26
MACHINERY	**63**	20	22	21
MOTOR VEHICLE TRAFFIC	**11,577**	3,658	3,896	4,023
NATURAL ENVIRONMENT	131	42	39	50
OTHER/UNSPECIFIED	3,719	1,096	1,295	1,328
OVEREXERTION	78	31	21	26
PEDAL CYCLIST, OTHER	1,332	441	399	492
PEDESTRIAN, OTHER	74	12	27	35
POISONING	34	8	8	18
STRUCK BY/AGAINST	18,009	5,787	5,944	6,278
SUFFOCATION	10	6	#	#
TRANSPORT, OTHER	1,006	334	301	371
MISSING/NO E-CODE	1,846	825	670	351

APPENDIX M

Traumatic Brain Injury Hospitalizations - Center for Preventive Health Services - DHMH

NUMBER OF INJURY-RELATED HOSPITALIZATIONS FOR TBI BY YEAR, AGE, GENDER, AND CAUSE OF INJURY, MARYLAND 2002-04

		YEARS		
	TOTAL	2002	2003	2004
TOTAL	15,857	5,126	5,151	5,580
AGE				
0-4 YRS	444	154	157	133
5-14 YRS	645	223	194	228
15-24 YRS	3,552	1,173	1,115	1,264
25-34 YRS	2,135	726	680	729
35-44 YRS	2,342	791	781	770
45-54 YRS	1,900	607	600	693
55-64 YRS	1,136	319	387	430
65-74 YRS	1,092	344	359	389
75-84 YRS	1,628	483	557	588
85+ YRS	**983**	**306**	**321**	**356**
GENDER				
MALE	10,417	3,351	3,391	3,675
FEMALE	5,416	1,764	1,753	1,899
UNKNOWN	24	11	7	6
RACE				
WHITE	9,655	3,079	3,090	3,486
AFRICAN AMERICAN	4,673	1,559	1,536	1,578
ASIAN/PACIFIC ISLANDERS	248	72	86	90
AMERICAN INDIAN/ESKIMO/ ALEUT	19	#	#	10
OTHER	1,136	362	388	386
UNKNOWN	126	49	47	30
CAUSE				
CUT/PIERCE	97	33	30	34
DROWNING	#	#	#	#
FALL	5,071	1,542	1,716	1,813
FIRE/BURN	10	#	0	6
FIREARM	263	88	76	99
MACHINERY	36	13	9	14
MOTOR VEHICLE TRAFFIC	6,711	2,271	2,120	2,320
NATURAL ENVIRONMENT	40	12	16	12
OTHER/UNSPECIFIED	793	269	268	256
OVEREXERTION	#	#	#	0
PEDAL CYCLIST, OTHER	**222**	**71**	**68**	**83**
PEDESTRIAN, OTHER	24	#	10	9
POISONING	39	16	13	10
STRUCK BY/AGAINST	**1,463**	**481**	**475**	**507**
SUFFOCATION	6	#	#	#
TRANSPORT, OTHER	352	110	117	125
MISSING/NO E-CODE	722	206	227	289

APPENDIX N

Traumatic Brain Injury Deaths - Center for Preventive Health Services - DHMH

NUMBER OF INJURY-RELATED DEATHS FOR TBI BY YEAR, AGE, GENDER, AND CAUSE OF INJURY, MARYLAND 2002-04

		YEARS		
	TOTAL	2002	2003	2004
TOTAL	1,969	610	692	667
AGE				
0-4 YRS	**24**	**9**	**11**	**4**
5-14 YRS	44	10	16	18
15-24 YRS	**327**	**117**	**107**	**103**
25-34 YRS	242	80	85	77
35-44 YRS	**249**	**74**	**81**	**94**
45-54 YRS	243	76	79	88
55-64 YRS	**167**	**45**	**60**	**62**
65-74 YRS	196	66	72	58
75-84 YRS	258	76	92	90
85+ YRS	216	57	87	72
GENDER				
MALE	1,501	473	510	518
FEMALE	**468**	**137**	**182**	**149**
UNKNOWN				
RACE				
WHITE	1,297	393	454	450
AFRICAN AMERICAN	**626**	**203**	**223**	**200**
OTHER	42	13	12	17
UNKNOWN	**4**	**1**	**3**	**0**
CAUSE				
CUT/PIERCE	9	3	4	2
DROWNING	**3**	**1**	**1**	**1**
FALL	538	147	206	185
FIREARM	**840**	**282**	**284**	**274**
MACHINERY	6	2	2	2
MV TRAFFIC	**309**	**93**	**108**	**108**
PEDAL CYCLE	2	0	2	0
PEDESTRIAN	**6**	**0**	**3**	**3**
LAND TRANSPORT	20	6	7	7
TRANSPORT, OTHER	3	1	0	2
NATURAL/ENVIRONMENT	1	0	0	1
POISONING	17	4	9	4
STRUCK BY/AGAINST	37	20	5	12
SUFFOCATION	8	1	2	5
OTHER/ UNSPECIFIED	170	50	59	61