Brain Injury Commission Report

November 14, 2011

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Section I: Executive Summary

Introduction

The Acquired Brain Injury (ABI) and Traumatic Brain Injury (TBI) Commission was established in outside section 160 of the FY2011 Budget. Since January 2011, the Brain Injury Commission has been meeting monthly to address serious gaps in services for individuals living with brain injury in Massachusetts.

The Commission consists of Governor-appointed experts and State Agency Representatives in the brain injury field. Many have studied it, worked with individuals with brain injury, have had brain injury themselves, or have family members with brain injury. In addition to the monthly meetings in Boston, meetings also took place at Berkshire County Arc in Pittsfield, at University of Massachusetts Medical Center in Worcester, and Spaulding Rehabilitation Center in Boston. Commission Members were invited to tour the facilities and learn about current services available to individuals living with brain injury in Massachusetts.

Overview of Major Findings and Gaps in Services

This report focuses on individuals with brain injury between the ages of eighteen and fifty-nine. Although this report does not include findings on children and elders, it recognizes that these are also important subject areas that still need to be researched further.

In their eleven month study, the Commission has found that ABI and TBI should no longer be dealt with as separate and distinct groups. Rather, both should fall under the heading of ABI, although in this report, ABI and TBI will both be dealt with separately. In addition, 100% of all monies collected by motor vehicle violations should be deposited in the Head Injury Treatment Services Fund rather than the 60% currently transferred.

The following services currently face gaps for all individuals with ABI:

- Case Management Services- families have identified the need for more case managers who are experienced with the post-acute phase of brain injury for persons with ABI
- Day Programs- there is a need for more day programs operating Monday-Friday to serve individuals with ABI. Day rehabilitation programs will also assist family members who are under the strain of caring for a loved one with ABI
- Social/Recreation Services- there is a need to expand social/recreation programs to both TBI and ABI patients
- Post-Acute Rehabilitation Services- rehabilitation services must extend beyond the maximum treatment period of 30 days, and cognitive remediation therapy must be

provided in the post-acute period of recovery in order to develop community and workforce-based skills

- MassHealth PCA Services- these services must be available to individuals with ABI who exhibit difficulty in performing Activities of Daily Living (ADL) and Independent Activities of Daily Living (IADL) tasks

- Technical Assistance and Consultation- there is an increased need to train professionals and service providers to specifically serve individuals with ABI

- Other Service Needs- these include transportation, respite care, residential programs, and behavioral health (substance abuse treatment and psychiatric services)

Overview of Administrative Recommendations

The Commission has five administrative recommendations in response to the observed gaps in services:

1. The epidemiological study needs to be continuously updated by the Massachusetts Department of Public Health (DPH) to determine the incidence, affected adult age groups, geographic location and etiology of ABI in Massachusetts

2. A comprehensive needs-assessment needs to be designed and implemented to identify and determine the specific service needs of adults living with ABI in Massachusetts

3. An Executive Office of Health and Human Services (EOHHS) interagency task force needs to be created to review findings, investigate current services, and identify analysis of needs assessments, programs developments, and barriers for youth transitioning into adult services

4. The focus of research needs to be on individuals with ABI between the ages of eighteen to fifty-nine in addition to TBI patients served by the Statewide Head Injury Program (SHIP). Commission Members also recommended the establishment of a designated program in the Brain Injury & Statewide Specialized Commission Services Department (BI & SSCS) of the Massachusetts Rehabilitation Commission (MRC)

5. The definition of Personal Care Assistance (PCA) under MassHealth's State Plan needs to be modified in order to allow more individuals to qualify for PCA services

Overview of Service Recommendations

The Commission has three service recommendations in response to the observed gaps in services:

1. Five regional day programs that are inclusive of transportation need to be developed for individuals with ABI on weekdays

2. Five regional ABI Multiservice Centers need to be developed to prioritize community-based services

3. Ten new Social/Recreation programs need to be developed statewide for ABI patients

Closing Remarks

The Commission Members and EOHHS which staffed the Commission should be thanked for their thoughtful, compassionate, and dedicated work. Understandably, this is a starting and not concluding point. There is clearly much work to be done in this area to assist the many people who suffer from ABI to become independent and to reach their full potentials as citizens of the Commonwealth.

Section II: Commission Overview

The Brain Injury Commission was established by the FY 2011 budget process (*see Appendix A*), in order to identify the gaps in service delivery for Massachusetts residents who exhibit a history of acquired brain injury (ABI). The appointed members of the Commission and their affiliations are detailed in Appendix B of this report.

The Commission began its work in February of 2011and met seven times through September 26, 2011. During the initial two meetings of the Brain Injury Commission, members developed and reached consensus regarding the intent and focus of the Commission, which is summarized in the following Mission Statement:

> *To advance the present scope of community-based long-term supports and services available to individuals with brain injury in Massachusetts by providing an analysis of current services, quality of service delivery, the related needs and gaps relative to access, capacity and resources, and to subsequently develop a series of prioritized recommendations for system change with a focus on positive outcomes for affected individuals.*

Over the course of the Commission meetings, community-based long-term supports and services were operationally defined to encompass a wide range of post-acute services and program models, including, but not limited to, rehabilitative and other day programs (e.g. recreation/social programs); residential supports and programs; case management; respite and other family support services. The target population of the Commission's deliberations was further clarified to include adults, ages 18 to 59 years of age. There was recognition by all Commission members that there are also significant needs for individuals with brain injury in both the pediatric and elder populations, but these age cohorts were outside the scope of its work.

Strategies for accomplishing the Commission's goals included an investigation of currently available services, both private and public, for persons with ABI in Massachusetts; identification of obstacles and challenges to accessing needed services; and review of current and potential funding sources. In addition, the Commission reached out to a diverse group of providers, individuals and family members impacted by brain injury and made sure that individuals representing all the regions of the Commonwealth were involved in discussions. All Commission meetings were open to the public and included opportunities for public input and more specifically, segments of two meetings were designated as community forums. The content of presentations made to the Commission and other information were also posted on the Executive Office of Health and Human Services website to ensure broad public access. A summary of the meeting topics is detailed in Appendix C and all of the meeting agendas and presentations can be found at www.mass.gov/hhs/braininjurycommission. A summary of the Commission's findings and related recommendations is detailed in Section IV of this report.

Section III: Definitions & Categories of Acquired Brain Injury

Acquired brain injury (ABI) refers to a wide range of disorders/diseases of the central nervous system (CNS), affecting the brain (cerebral hemispheres and cerebellum) and sub-cortical structures (diencephalon and brain stem). While ABI can occur at all ages, beginning in the perinatal/newborn period through adulthood, the majority of individuals who sustained an ABI are adults. In addition to age of onset, acquired brain injuries are further characterized by their location within the CNS as well as whether these disorders/diseases are static or progressive (e.g. Alzheimer's Disease). With respect to the latter, progressive disorders are usually associated with a decline in cognitive status (i.e., dementia) and gradual compromise of functional capacity.

Acquired brain injuries are also categorized by their etiology. All of this information was presented in detail to the Commission and can be found on the Commission website. Summarized below are descriptions of the major subcategories of ABI:

Infectious: Includes infections of the CNS (encephalitis, meningitis) resulting from bacteria, viral, parasitic and other infectious agents.

Metabolic: Refers to disorders which may be related to systemic disease (e.g., liver disease associated with hepatic encephalopathy) or other insults to the CNS, with the most common cause being anoxia (oxygen deprivation).

Neoplastic: This category includes primary (i.e. arising within the CNS) and secondary tumors. Secondary neoplasms, which are more prevalent, represent metastases from a primary cancer (e.g., lung, colon).

Neurotoxic: Refers to ABI resulting from environmental or occupational exposure to known toxins, such as heavy metals (e.g., lead) and gases (e.g. carbon monoxide), as well as drug and alcohol abuse.

Traumatic: An extrinsically-caused and most common type of ABI. The leading cause is falls, and other mechanisms for injury include motor-vehicle-related events, sports-related injury, military combat (e.g. blast-induced concussion), interpersonal and child abuse/violence (e.g. shaken baby syndrome). Currently, more than 51,000 Massachusetts residents sustain a TBI annually, and the majority of these injuries represent concussions or mild TBI (mTBI), evaluated in ER encounters (*see Appendix F, Reference 1).*

Neurovascular: Strokes represent the second leading cause of ABI, and are most commonly sustained by persons over the age of 60, although individuals under the age of 60, including children, may also experience a stroke (e.g. children with Sickle Cell Disease; young adults with a history of drug abuse). Currently more than 17,000 persons are hospitalized for treatment of stroke annually in Massachusetts (*see Appendix F, Reference 2*).

Brain Injury is recognized as a major public health crisis in the United States. According to the CDC: The incidence of traumatic brain injuries occurring each year is eight time that of breast cancer and 20 times that of HIV/AIDS; 5.3 Million Americans are living with a disability caused by brain injury; and lifetime costs for this total population associated with traumatic brain injury are conservatively estimated at $60 billion.

With the exception of traumatic brain injury and stroke, the incidence and prevalence of each of the subcategories of ABI in Massachusetts is currently unknown, and has not been ascertained since the mid-1980's, when a study was completed by the Massachusetts Rehabilitation Commission (MRC), in collaboration with the Department of Public Health (*see Appendix F, Reference 3*). Given the considerable needs of the adult population and the known epidemiological trends, the Brain Injury Commission decided to focus its work on ascertaining the service gaps and needs of persons with a history of ABI between the ages of 18 and 59. As indicated earlier in this report, the Commission acknowledged that the limits of this study were not to negate the needs of children and elders in the Commonwealth, but that these two cohorts were outside the scope of this time-limited work.

Section IV: Brief Review of Services and Summary of Gaps in Service Delivery: Challenges & Identified Needs

The Statewide Head Injury Program (SHIP) was established in 1985 at MRC as a result of grassroots advocacy efforts. It was the first national model of publicly-funded services for individuals with TBI. In addition to service provision, the Program has served as a centralized point of expertise across EOHHS agencies and this expertise is greatly enhanced by its longstanding collaboration with the Brain Injury Association of Massachusetts (BIAMA).

SHIP serves over 1,250 individuals with Traumatic Brain Injury (TBI) and many of their family members annually; it also maintains a waiting list for services of approximately the same size. In order to be eligible for any type of SHIP service, an individual must have an externally-caused TBI with related cognitive, physical and/or behavioral impairments, and be able to participate in community-based services. Services are funded through a combination of state appropriations (SHIP account, Turning 22 transition funds), the Head Injury Trust Fund (*see Appendix D*), Medicaid funding for specific programs and some Federal Grant funds.

The primary purpose of SHIP services is to assist individuals with TBI to develop skills and maintain or increase independence within their home, community or at work. The array of services provided through community providers includes information, referral, technical assistance & training, multicultural outreach, service coordination, limited day programs, assistive technology, respite care and limited transportation service delivery. There is also a program which provides outreach to returning Operations Enduring Freedom and Iraqi Freedom (OEF/OIF) Veterans with TBI. The blueprint for SHIP services was a 1988 Needs Assessment submitted to the Legislature and this was reinforced by a 2006 Consumer Focus Group Report and the MA Brain Injury Advisory Board's State Action Plan. These latter reports highlighted the top nine needs of this population as: vocational options, information on existing resources, recreational activities, case management or related support, diverse housing options, education for medical professionals & the general public, support groups, facilitated psychotherapy groups and rehabilitation services (occupational therapy (OT), physical therapy (PT) and Speech).

Identification of Current Challenges & Needs:

In order to ascertain the current gaps in service delivery for individuals with ABI, the Commission employed several strategies to identify the challenges and needs of this population. Commission meetings included: formal presentations by state agency members of the Commission; presentations by members of the Commission who represent and advocate on behalf of individuals living with brain injury and their families/caretakers; public forums and open meetings during which family members/significant others and individuals with ABI presented their concerns and needs; presentations by medical and rehabilitation facility/program representatives; and presentations by representatives of the major insurance carriers within the Commonwealth. The list of speakers and topics are included in Appendix D.

A number of the presentations identified the services and corresponding funding sources that presently exist for a limited number of individuals with ABI. This includes the services provided by the SHIP through the Massachusetts Rehabilitation Commission (MRC) that are funded through state appropriations, as well as three Medicaid Home and Community-based (HCBS) Waivers which are administered by MRC. These Medicaid-funded waivers include a TBI Waiver that serves 100 individuals and two ABI Waivers, which began enrolling participants in May 2010. The two ABI waivers will serve 300 people statewide over three years (100 individuals will be enrolled in structured residential programs and 200 will live in their own homes or apartments in the community). In addition, in July of 2012, two new HCBS waivers under the new Money Follows the Person (MFP) Demonstration Project will begin enrollment, and it is assumed that an unspecified number of the participants could be individuals with ABI transitioning from nursing facilities, chronic or rehabilitation hospitals, as long as they meet the eligibility criteria. It is important to note that these waivers do provide the enrolled participants with access to some of the services identified as gaps described below (e.g., day programs, transportation, respite care and PCA services for cuing and supervision), but the ABI waivers and the new opportunities under the MFP waivers will only be available to individuals who are transitioning from the types of facilities specified above. Even with the number of individuals to be served through these waivers, Commissioners determined that these waivers will not adequately meet the assumed needs of the much larger population affected by ABI, especially those individuals living in the community.

In its discussions, the Commission identified the need for a comprehensive menu of services that extended beyond the above-mentioned state-funded SHIP services and the HCBS waivers. The service needs delineated below were identified and prioritized.

Case Management Services

Acquired Brain Injury (ABI) is a catastrophic event experienced by the individual, which often results in lifelong cognitive, behavioral, physical, psychosocial and financial consequences. In order to effectively address these issues, information about, and access to, available community-based clinical specialists, resources, rehabilitation services, entitlements and eligibility criteria is critical to the facilitation of recovery and positive functional outcomes. Unfortunately, presentations to the Commission indicated that individuals with ABI and their family members/significant others are generally unfamiliar with these programs/services, which may be both private and publicly-funded, and/or the often complex process for accessing them. The need for case managers, who are experienced in addressing the post-acute needs of individuals with ABI, was identified as a priority by families, Commission members and other professionals. Currently, case management services may be available, depending upon private insurance benefits, during the acute treatment and/or rehabilitation period (i.e., acute hospitalization time period) for individuals with ABI. However, during the post-acute phase, case management services are generally lacking and the only publicly-funded case management services, available on a very limited basis, are those funded by the SHIP for eligible consumers who have sustained a traumatic brain injury only.

Day Programs

Currently, there is only one day program which has been specifically developed for individuals with brain injury in the Commonwealth. This program is funded through the state appropriation for SHIP, and only consumers whose brain injury has resulted from trauma (TBI) are eligible; this program currently serves 21 individuals. In addition, day habilitation programs currently funded by Medicaid may only serve individuals whose brain injury occurred prior to their 22nd birthday, and these programs primarily serve persons with developmental disabilities. The Commission heard numerous reports about the need for additional services of this type for individuals with ABI and specifically, additional day programs, operating Monday-Friday, was identified as a statewide need for individuals with ABI. It was recognized that day programs would also serve to assist family members/significant others who have frequently, and by necessity, experienced unemployment and associated financial stress in order to stay at home to care for and supervise a loved one who has sustained an ABI.

Social/Recreation Services

One of the most common and well documented psychological consequences of ABI is social isolation, which is often associated with chronic depression and the individual's perceived, and often significant, losses. Currently, there are 22 social/recreation programs within Massachusetts, but these are funded by SHIP and only available to individuals with TBI. Seven hundred (700) individuals are served annually through these programs. The need for additional social/recreation programs, which would be available to all individuals living with ABI, was identified. The primary goals of these programs would be to facilitate the development of social and other skills, to build relationships, and to enhance quality of life.

Post-Acute Rehabilitation Services

Professionals experienced in providing acute treatment and rehabilitation services to individuals with ABI substantiated that very significant numbers of individuals who have experienced an ABI have never been provided with rehabilitation. Even if an individual with ABI receives the benefit of acute rehabilitation services, these treatment services are, in most cases, provided for a maximum of 30 days and the focus is not on developing community-based skills, e.g. Independent Activities of Daily Living (IADL) skills.

Despite the prevalence of neuro-cognitive impairment among individuals with ABI, they have rarely had access to cognitive rehabilitation to assist in developing compensatory strategies, which are critical to skill acquisition, and to address the cognitive deficits that are typically identified and assessed by neuropsychological evaluation. Cognitive rehabilitation therapy, which is not currently covered by insurance, is most appropriately provided in the post-acute period of recovery (i.e., after discharge from acute care or rehabilitation *(Reference 6*). It is also important to note that higher functioning individuals with ABI often appear to be able to return to employment, but frequently meet with failure due to unaddressed cognitive impairments affecting their safety, productivity, relationships and independence. Access to cognitive rehabilitation, when the individual is capable of benefiting, can, for many, facilitate their capacity to contribute to society as productive and independent citizens.

MassHealth PCA Services

While PCA services are available to individuals with ABI who are determined to be eligible, access to this service is largely dependent upon the individual's physical care needs. As a result, this rules out many individuals with ABI who exhibit compromised capacity to perform ADL/IADL tasks because of their neuro-cognitive deficits (e.g. memory disorder). Commission presentations clearly identified that these individuals could benefit substantially from access to this service.

Technical Assistance & Consultation

The lack of experienced and qualified clinicians to meet the post-acute needs of individuals with ABI was identified as a statewide concern. Specifically, the lack of neuropsychologists and neuropsychiatrists was emphasized to the Commission. In addition, the need to provide technical assistance and training for clinical service providers (e.g., mental health professionals, VNA's, PCP's, home health aides and other direct care providers) was identified, particularly with respect to the cognitive/behavioral consequences of ABI which represent the most common residual long-term issues for this population and which frequently compromise an individual's ability to access and maintain available services. While SHIP has historically provided limited technical assistance and training for facilities and programs regarding TBI, the increased need to train professionals and service providers with respect to the recognition, assessment, and treatment of ABI was substantiated by presenters and Commission members. There is a significant need to enhance and expand the capacity of existing service providers and programs through training, continuing education programs, and case consultation so that they can effectively serve individuals with ABI.

Other Service Needs

While the categories of identified service needs delineated above have been prioritized and correspond to recommendations listed in Section V, additional service needs identified during Commission meetings are listed below.

Transportation: The lack of availability of transportation can add to the isolation experienced by those with ABI by limiting their ability to leave their homes and participate in community activities, such as shopping, religious services and social events. Access to public transportation varies greatly by geography as well as availability during evenings and weekends. For those unable to use public transportation and who require specialized transportation due to the deficits associated with their ABI, the problem of isolation is magnified. There is currently no funding source or mechanism to provide access to non-medical activities, including recreational opportunities, for these individuals requiring additional assistance.

Respite Care: There are currently limited respite services available to families/caretakers of individuals with ABI. This includes respite care models where the individual with ABI could be provided with short term respite care at a facility/program, or alternatively, where the provision of respite services occurs within the home in order to afford family members and other caretakers the opportunity to take a vacation/break for themselves.

Residential Programs: Currently, there are limited residential services (n=145) funded by SHIP for individuals with TBI. In addition, individuals in nursing homes, chronic or rehabilitation hospitals, will have an opportunity to transition into community residential programs under the ABI (n=100) and MFP (Money Follows the Person) residential waivers. Other than these initiatives, there are no other funding sources to develop or provide a continuum of residential services for individuals living with ABI in the community. This continuum would include such models as shared living and 24/7 residential programs. The lack of residential service options has historically contributed to admissions to skilled nursing/long-term care facilities and institutionalization.

Behavioral Health Services

Substance Abuse Treatment Services**:** While there is a significant and well documented incidence of substance abuse among individuals with ABI, and in particular TBI and young stroke survivors, these individuals are often unable to successfully participate in traditional substance abuse treatment programs.

Psychiatric Services**:** As noted above, there is limited availability/access to neuropsychiatrists within the Commonwealth to address the psychiatric/ behavioral and pharmacology needs of individuals with ABI. In addition, access to short-term psychiatric inpatient units for stabilization purposes and assessment/treatment of neurobehavioral disorders has been difficult to access. Multiple factors would appear to contribute to this issue. These include: concerns about disposition; the perceived incapacity of psychiatric programs to accommodate the physical care and cognitive needs of individuals with ABI within the psychiatric milieu; and the lack of inpatient clinicians skilled in treating the neurobehavioral/neuropsychiatric consequences of ABI. A 40-bed inpatient neurobehavioral unit was developed and is located in Stoughton, MA. However, the successful discharge of patients from this unit has been compromised by the lack of available step-down programs in the community; as a result, this unit has not historically been accessed for short-term stays.

Section V: Commission Recommendations

In response to the identified needs reviewed and prioritized above, and in accordance with the defined scope and focus of the Brain Injury Commission, recommendations are detailed below. These recommendations, which are not intended to be all inclusive, pertain to persons, ages 18-59, living with Acquired Brain Injury in the community. It is anticipated that once the goals/objectives related to these recommendations have been achieved, additional recommendations may be generated and considered. In order to financially support these recommendations, the following fiscal strategies were suggested.

- That 100% (currently 60%) of the revenues collected via the Head Injury Treatment Services Fund be transferred to the fund.
- That revenue sources utilized by other states to support the delivery of ABI services be further investigated & pursued *(see Appendix E).*
- That a new state appropriation be created.

Commission members recommended the following administrative and service development initiatives.

Administrative Recommendations

1. Epidemiological Study: The epidemiology of ABI in Massachusetts was last ascertained and analyzed in 1986-88. There is a need for current information regarding the demographics and other descriptive information about this population in order to undertake service planning. It is, therefore, recommended that the epidemiological study be updated by the Massachusetts Department of Public Health (DPH) to determine the incidence, affected age groups, geographic location and etiology of ABI in Massachusetts for all major categories of non-traumatic acquired brain injury, to include neoplastic, infectious, metabolic and toxic disorders of the central nervous system. It is further recommended that this epidemiological information continue to be updated on a regularly scheduled basis, to be determined by DPH. The report of the epidemiological study will be submitted to the Legislature by June 30, 2013 (FY'13).

   Anticipated Initial Cost: $50,000

2. Comprehensive Needs Assessment: In addition to gathering epidemiological data, there is a need to examine the prevalence of long-term service needs among adults living in the community with ABI. It is, therefore, also recommended that a comprehensive needs assessment be designed and implemented to identify and determine the specific service needs of persons with acquired brain injury in Massachusetts. This needs assessment

should minimally include the following menu of service options: post-acute rehabilitation/ skills training, case management, day programs, residential services, social/recreation needs, transportation, respite care, behavioral health needs and community supports. It is recommended that the needs assessment be designed and implemented by staff of the Massachusetts Rehabilitation Commission, in collaboration with the Brain Injury Association of Massachusetts (BIA-MA). In addition to the needs assessment, it will be critical to outreach to individuals with ABI and families/caretakers within specific geographic areas to better ascertain their needs (e.g. focus groups). A report regarding the findings of the needs assessment will be submitted to the Legislature by June 30, 2013 (FY'13).

Anticipated Costs: $150,000

3. EOHHS Task Force: It is recommended that an interagency task force of designated EOHHS agency representatives, to include, but not be limited to, the Massachusetts Rehabilitation Commission (MRC), Massachusetts Commission for the Blind (MCB), Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH), Department of Developmental Services (DDS), Department of Mental Health (DMH), Department of Public Health (DPH), Office of Elder Affairs (EOEA), and Office of Medicaid (OOM) be convened. This task force will:

    a. review the findings of the epidemiological study & the needs assessment

    b. investigate how persons with ABI are currently being served by existing health and human service agencies and identify strategies to improve and enhance the quality of those services.

    c. identify, based on an analysis of the needs assessment referenced above, regulations and policies that might be modified to improve, enhance and expand services for individuals with acquired brain injury statewide.

    d. identify potential joint program development and blended funding mechanisms to address service needs identified through the needs assessment for the ABI population.

    e. identify the barriers associated with accessing adult services experienced by youth with ABI who are transitioning from special education.

    It is expected that the task force will generate an initial report for the Legislature no later than June 30, 2014 (FY'14).

    Anticipated Cost: None

4. Based upon the results of both the epidemiological study and needs assessment, it is recommended that consideration be given to studying the feasibility and impact of expanding MRC's Brain Injury & Statewide Specialized Community Services Department (BI&SSCS)'s capacity to serve all individuals, between the ages of 18 and 59, with non-traumatic acquired brain injury, in addition to those with TBI currently served by the SHIP program. Commission members also recommended that an evaluation

be done on whether there is a need for a designated program, with dedicated staff, to be established within the BI&SSCS department of the Massachusetts Rehabilitation Commission to develop, oversee and monitor a menu of identified services for people with acquired brain injury in Massachusetts.

Anticipated Cost: To be determined

5. It is recommended that consideration be given to modifying the definition of Personal Care Assistance (PCA) under MassHealth's State Plan to allow individuals, who have cueing and supervision needs, to qualify for PCA services.

   Anticipated Costs: To be determined

Service Recommendations

1. It is recommended that five (5) regional day programs (e.g., club house models), inclusive of transportation, be developed to serve individuals with acquired brain injury. These programs would operate Monday through Friday and would provide services to an average of 25 individuals per program. It is recommended that these programs be developed, in response to an RFR, during FY'13 and fully operational by FY'14.

   Anticipated Costs: $500,000/day program, with a total cost of $2.5 M

2. It is recommended that five (5) regional ABI Multiservice Centers be developed. These centers would be designed to offer the following prioritized community-based services:

   a. Outreach to individuals with ABI
   b. Case Management (see definition in previous section)
   c. Skills Training, to include cognitive rehabilitation (see definition under Post-Acute Rehabilitation Services in previous section)
   d. Technical Assistance and Training/Continuing Education (see definition in previous section)
   e. Clinical Consultation by ABI specialists (see Technical Assistance and Consultation definition in previous section)

   The development of the Multiservice Center model would occur in response to an RFR during FY'13 and be fully operational by FY'14.

   Anticipated Costs: $1,000,000/Center, with a total cost of $5M

3. It is recommended that ten (10) new Social/Recreation programs be developed statewide for persons with ABI.

   Anticipated Costs: $300,000

Appendix A

The Brain Injury Commission was established in outside section 160 of the FY2011 budget and was approved by Governor Patrick on June 30, 2010. It was subsequently amended in two supplemental budgets. The first amendment clarified and expanded the Commission membership & the second amendment extended the timeline for submission of a report to the Legislature.

SECTION 160. There is hereby established a special commission to make an investigation and study relative to the rehabilitative residential and integrated community-based support services for persons with acquired brain injury and persons with traumatic brain injury in the commonwealth. The commission shall consist of the chairs of the joint committee on health care financing or their designees, who shall serve as co-chairs; 1 member of the house of representatives appointed by the minority leader; 1 member of the senate appointed by the minority leader; the secretary of health and human services or a designee; the assistant secretary for the office of disabilities and community services or a designee; the commissioner of public health or a designee from the office on health and disability; the commissioner of medical assistance or a designee; and 4 persons appointed by the governor. The target populations for the investigation shall be persons of all ages with neuro-cognitive and neuro-behavioral deficits stemming from traumatic or acquired brain injury.

The investigation and study shall include, but not be limited to the availability, nature and adequacy of the following services for the target population: acute and long-term medical and cognitive rehabilitation and outpatient services; therapy services; residential nursing care; structured day treatment and day activity programs; club programs; respite care services; community-based housing; home-based services; family support programs; case management; companion services; personal care attendant services; specialized medical equipment and supplies; environmental modifications; counseling and training; and prevocational services.

The commission shall file a report of its findings with the clerks of the house of representatives and the senate and the house and senate committees on ways and means not later than April 1, 2011. The report shall include recommendations for improving services for people with acquired or traumatic brain injury, the cost of maintaining or establishing those services and any legislation necessary to implement or allow for the development or expansion of services for the target population. – Approved June 30, 2010.

First Amendment: 01/03/2011; Chapter 409 in the Acts of 2010

SECTION 27. The first paragraph of section 160 of said chapter 131 is hereby amended by striking out the second sentence and inserting in place thereof the following sentence:- The commission shall consist of 2 members of the house of representatives, 1 of whom shall be appointed by the minority leader and 1 of whom shall be appointed by the speaker of the house, 2 members of the senate, 1 of whom shall be appointed by the minority leader and 1 of whom shall be appointed by the president of the senate, the secretary of health and human services or a designee; the assistant secretary of the office of disabilities and community services or a

designee; the commissioner of public health or a designee from the office on health and disability, the commissioner of the Massachusetts rehabilitation commission or a designee, the secretary of elder affairs, and the secretary of veterans services and 9 persons appointed by the governor. The co-chairs of the commission shall be designated by the president of the senate and the speaker of the house.

SECTION 28. The last paragraph of said section 160 of said chapter 131 is hereby amended by striking out the words "April 1, 2011" and inserting in place thereof the following words:- September 30, 2011.

Second Amendment: 10/27/11; Chapter 142 in the Acts of 2011

SECTION 89 The special commission established in section 160 of chapter 131 of the acts of 2010 is hereby revived and continued. The commission shall file its report with the clerks of the house of representatives and the senate and the house and senate committees on ways and means not later than December 30, 2011. The report shall include recommendations for improving services for people with acquired or traumatic brain injuries, the cost of maintaining or establishing those services and drafts of legislation necessary to implement those recommendations or to allow for the development or expansion of services for the target population.

Appendix B

Commission Members

Members of the General Court

Senator Harriette L. Chandler, Co-Chair
Representative Thomas Conroy, Co-Chair
Senator Robert Hedlund
Representative Kimberly Ferguson

Governor's Appointees

Suzanne Doswell, CBIST
Western Regional Manager
Brain Injury Association of Massachusetts

Michael Hirsh, M.D.
Professor of Pediatrics and Surgery, University of Massachusetts Medical School
Surgeon-In-Chief, University of Massachusetts Memorial Children's Medical Center

Arlene Korab
Executive Director
Brain Injury Association of Massachusetts (BIA-MA)

Francesca LaVecchia, Ph.D.
Chief Neuropsychologist, Brain Injury and Statewide Specialized Community Services
Massachusetts Rehabilitation Commission
Assistant Adjunct Professor, Psychiatry, Boston University School of Medicine

Adelaide Osborne
Vice President of Developmental and Specialized Services
Eliot Community Human Services, Inc.

Edna Pruce
Chairperson, Massachusetts Brain Injury Advisory Board

Jenny Quigley-Stickney, RN
Vice President of the Case Management Society of New England

Barbara Salisbury
Chief Executive Officer, Massachusetts Association for the Blind

Kenneth Singer
Executive Director, Berkshire County Arc & Chair of ADDP Brain Injury Committee

Ex-Officio State Agency Representatives

Peter Connolly, M.D.
Chief Medical Officer
Tewksbury Hospital

Rosalie Edes
Deputy Assistant Secretary, Office of Disability Policies and Programs
Executive Office of Health and Human Services

Debra Kamen
Assistant Commissioner, Community Living
Massachusetts Rehabilitation Commission

Cheryl Lussier Poppe
Deputy Secretary, Programs, Services and Personnel
Department of Veterans' Services

Lisa McDowell
Director, Institutional, Residential & Day Services
MassHealth Office of Long-Term Care, Office of Elder Affairs

Lem Roberson
Program Manager
Office of Behavioral Health, MassHealth

Appendix C

Commission Meeting Presentations & Speakers

February 7, 2011

Data on Brain Injury in Massachusetts: A Snapshot

- Jean Flatley McGuire, Ph.D., Assistant Secretary
  Disability Policies and Programs, Executive Office of Health and Human Services

Acquired Brain Injury: An Overview

- Francesca LaVecchia, Ph.D., Chief Neuropsychologist, Brain Injury and Statewide Specialized Community Services, Massachusetts Rehabilitation Commission

Personal Story

- Suzanne Doswell, CBIST, Western Regional Manager, Brain Injury Association of Massachusetts (BIA-MA)

Pediatric Trauma Data

- Michael Hirsh, M.D., UMASS Memorial Children's Medical Center

March 7, 2011

Overview of Services Provided by the Brain Injury and Statewide Specialized Community Services Department (MRC)

- Debra Kamen, Director, Brain Injury and Statewide Specialized Community Services (BISSCS), Massachusetts Rehabilitation Commission

Perspective from the Brain Injury Association of Massachusetts (BIA-MA)

- Arlene Korab, Executive Director, Brain Injury Association of Massachusetts (BIA-MA)

April 4, 2011

Introductions and Welcoming Remarks

- Kenneth Singer, Executive Director, Berkshire County ARC (BCARC)

Consumer Perspectives on Residential Support Services

- Michael Turner, Coordinator of Brain Injury Services, Berkshire County ARC (BCARC)

Consumer Perspective on ABI Waiver Individual Support Services

- Kevin Gallagher, Individual with a brain injury

Overview of Day Habilitation Program for Individuals with Brain Injury

- Michael Turner, Coordinator of Brain Injury Services, Berkshire County ARC (BCARC)

Consumer Perspectives on Support Groups & Social and Recreational Programs

- Suzanne Doswell, Manager of Western Regional Office, Brain Injury Association of Massachusetts (BIA-MA)
- Jeffrey Robinson, Individual with a brain injury, Berkshire Brain Injury Support Group and Brain Injury Association of Massachusetts Volunteer

- Peter Hubby, Father of an individual with a brain injury, Berkshire Brain Injury Support Group
- Steve Lang-Gunn, Father of an individual with a brain injury, Pioneer Valley Support Group
- Kim McCarthy, Spouse of an individual with a brain injury, Pioneer Valley Support Group

May 2, 2011

Introduction and Overview of Case Management and Community Support Services

- Robert Ferris, Regional Services Supervisor, Statewide Head Injury Program (MRC)

Overview of Regional Multi-Service Center and Services

- Mary Roach, Director, Neuro-Rehab Management
- Jenny Quigley-Stickney, Vice President of the Case Management Society of New England

Massachusetts Brain Injury Advisory Board - Overview

- Edna Pruce, Family Member, Chair, Massachusetts Brain Injury Advisory Board

June 6, 2011

Pediatric Brain Injury Rehabilitation – Adding Insult to Injury

- Michael P. Hirsh, M.D., FACS, FAAP, Surgeon-in-Chief, Physical Medicine and Rehabilitation, UMass Memorial Children's Medical Center

Rehabilitation of Pediatric Head Injury: The Continuum of Care

- Faren H. Williams, M.D., MS, Chief, Physical Medicine and Rehabilitation, UMass Memorial Children's Medical Center

Pediatric Brain Injury in the Trauma Center Setting in Central Mass: A Snapshot

- Christine Stine, M.D., Ph.D., Assistant Professor of Pediatrics and Child Neurology, UMass Memorial Medical Center

Medically Cleared-Now What?

- Patricia Vanase, LICSW, Pediatric Social worker, UMMC
- Jane Palmero, R.N.C., Pediatric Case Manager, UMMC

Overview of the ABI Home and Community-Based Services Waivers

- Amy Bernstein, Assistant Director, Community Based Waivers, MassHealth
- Debra Kamen, Assistant Commissioner (Community Living), Massachusetts Rehabilitation Commission

July 11, 2011

Presentations by Major Insurers within Massachusetts

- Jan Cook, M.D., Medical Director, Medical Innovation and Leadership at BlueCross/Blue Shield of MA
- Eric Linzer, Senior Vice President of Public Affairs and Operations, Massachusetts Association of Health Plans (MAHP)
- Neil Minkoff, M.D., Medical Director, MAHP
- Claire Levesque, M.D., Medical Director, Tufts Health Plan
- Julie Kaufman, M.D., Harvard Pilgrim Health Care
- Mohamed F. Ally, M.D., Senior Medical Director, Network Health
- Hollis S. Coblentz, D.O. Associate Medical Director, Fallon Community Health Plan
- Marc Emmerich, M.D., MassHealth, Associate Medical Director, OCA, Commonwealth Medicine

State and Waiver Supported Brain Injury Services

- Ken Singer, Executive Director, Berkshire County ARC
- Adelaide Osborne, Vice President of Developmental and Specialized Services, Eliot Community Human Services, Inc.

August 1, 2011

ABI Neurobehavioral and Neuro-cognitive Programs

- Lisa McDowell, Director, Institutional, Residential & Day Services, MassHealth, Office of Long-Term Care, Executive Office of Elder Affairs

Brain Injury Rehabilitation: Challenges and Opportunities

- Marilyn Spivack, Neurotrauma Outreach Coordinator, Spaulding Rehabilitation Hospital, Boston

Covered Behavioral Health Services and Rating Categories

- Lem Roberson, Program Manager, Office of Behavioral Health for MassHealth

Community-Based Services

- Jill Beardsley, MA, CAGS, LRC, Director, Community Support Associates, Inc.
- Ann Gillespie, COO, Community Rehab Care

September 26, 2011

Commission Review of Draft Commission Findings & Recommendations

Appendix D

Head Injury Treatment Services Trust Fund

The needs of people with TBI have grown significantly over the years as evidenced by a 75% increase in new applicants to SHIP over the past 5 years (growing from an average of 20/month in 2005 to 35/month in this fiscal year). During this same five year period, SHIP's state appropriations have experienced minimal increases due to salary reserve and annualization of T22 consumers. In order to respond to the growing waiting list for SHIP services, there has been an increased utilization of the Head Injury Trust Fund in order to meet these demands. Trust Fund expenditures increased over the past five years from $6.6 million in FY05 to $9.3 million in FY09. This increase was supported by annual fine revenue and a reliance on accessing the available trust fund balance.

As can be seen from the revenue & expenditure chart included below, Trust Fund revenue has decreased remarkably over the past few years due to a decrease in the number of citations issued and/or fines collected. In response to this decrease in revenue, MRC has had to reduce services provided. Even with these reductions to expenditures, there has still been erosion in the reserve funding for the Trust Fund. There was a carryover of $3.1Million in FY11 and in FY 12, there is an expectation that an estimated $878,000 will need to be used to cover the FY12 budgeted expenses. This is an indication that the balance forward of the Trust Fund will continue to decrease.

Services Covered by the Head Injury Trust Fund in FY 12

Total Funds Committed for FY 12: $6,753,459

Total Consumers Served: 1,400+ individuals
Services Funded:

- Interpreters
- Regional Head Injury Centers
- ABI Day Program
- Brain Injury Association of MA – information & referral, education & awareness, prevention and outreach
- Substance Abuse Treatment
- Transportation (non medical)
- Clinical Services including technical assistance, family assistance, waiver eligibility and clinical supervision of programs and staff
- Recreation
- Extended Homecare
- Community supports

Head Injury Trust Fund Revenue

	FY09 Actuals	FY10 Actuals	FY11 Actuals	FY'12 estimate
RMV Sub Total	***$ 4,768,711***	***$ 5,258,999***	***$ 4,804,652***	***$ 4,064,735***
Trial Court Sub Total	***$ 1,753,774***	***$ 1,756,788***	***$ 1,813,379***	***$ 1,800,000***
TRE (Interest)		$ 32,166	$ 9,162	$ 10,000
TRE (Interest)		$ -	$ 1,904	
*OSC (Supp)		$ -	$ 953,742	
Sub Total		***$ 32,166***	***$ 964,808***	***$ 10,000***
Total revenue	**$ 8,276,259**	**$ 7,047,953**	**$ 7,582,840**	**$ 5, 874,735**
Expenses	$ 9,313,604	$ 8,426,514	$ 6,440,454	$ 6,753,459
Surplus/Deficiency			1,142,385	(878,723)

*See legislation for this transfer in Ch 359 S 126 A 2010

Chapter 10: Section 59. Head Injury Treatment Services Trust Fund

Section 59. There is hereby established on the books of the commonwealth a separate fund known as the Head Injury Treatment Services Trust Fund. Said trust fund shall consist of monies paid to the commonwealth pursuant to sections 20 and 24 of chapter 90, sections 8 and 34 of chapter 90B and any interest or investment earnings on such monies, except for monies deposited in the Spinal Cord Injury Trust Fund under section 59A. The state treasurer, ex officio, shall be the custodian of said trust fund and shall receive, deposit and invest all monies transmitted to him under the provisions of this section and shall credit interest and earnings on the trust fund to said trust fund. Funds collected pursuant to said section 24 shall be expended without further appropriation for the purpose of developing and maintaining nonresidential rehabilitation services for head injured persons in such manner as the commissioner of rehabilitation may direct. Funds collected pursuant to said section 20 shall be expended without further appropriation for the purpose of developing and maintaining residential and nonresidential rehabilitation services for head injured persons in such manner as the commissioner of rehabilitation may direct. In order to ensure that said services established by the commissioner continue without interruption, the comptroller may certify for payment amounts in anticipation of revenues collected for the corresponding quarter during the previous fiscal year.

Appendix E

Revenue Sources Utilizes By Other States To Support ABI Services

(Based on contacts with States and NASHIA 2006 and 2010 funding and program reports)

States with Dedicated Funding (other than state appropriations)	States who lost Dedicated Funding in 2010	States with State Funding for TBI	States who lost State Funding for TBI in 2010
1. Alabama 2. Alaska 3. Arizona 4. California 5. Colorado 6. Florida 7. Georgia 8. Indiana 9. Kentucky 10. Louisiana 11. Massachusetts 12. Minnesota 13. Mississippi 14. Missouri 15. New Jersey 16. New Mexico 17. Oregon 18. Pennsylvania 19. South Carolina 20. Tennessee 21. Texas 22. Vermont 23. Virginia 24. Washington	1. Delaware	1. Alaska 2. Florida 3. Iowa 4. Kentucky 5. Maine 6. Maryland 7. Massachusetts 8. Missouri 9. Montana 10. Nevada 11. New Hampshire 12. New Mexico 13. New York 14. North Carolina 15. North Dakota 16. Ohio 17. Oregon 18. Pennsylvania 19. Rhode Island 20. South Carolina 21. Tennessee 22. Vermont 23. Virginia 24. Washington 25. Wyoming	1. California 2. Connecticut 3. Louisiana

Selected Examples of Dedicated Funding Streams:

1. **Alabama:** Mirrors MA funding streams. DUI's $1.5 million/year.
2. **Arizona:** Civil and criminal fees. $2 million/year.
3. **Colorado:** Mirrors MA funding streams. Speeding, DUI. $1.5 million/year.
4. **Florida:** DUI, BUI, moving violations, motorcycle tag, temporary license tag. $17 million/year.
5. **Georgia**: Mirrors MA funding streams. DUI. $2.3 million/year.
6. **Kentucky:** 5.5% of court costs and $12.50 on DUI convictions. Generated $3.3 million/year as of 2006, no current total revenue data provided.

7. **Louisiana:** Mirrors MA funding streams. DUI, speeding. $1.5 million/year.
8. **Minnesota:** Mirrors MA funding streams. DUI. $1 million/year.
9. **Mississippi:** DUI, moving violations. $3.5 million/year.
10. **Missouri:** Cost of court: $2 surcharge on all traffic and criminal violations. Generates around $750,000/year.
11. **New Jersey**: Fee deducted from auto registration: $3.8 million annually (2002)
12. **New Mexico:** Moving violations (excluding those captured by red light cameras): $1.5 million/year. No detail received on fee-levels.
13. **Pennsylvania:** All traffic violations: $3 million/year (1985 data)
14. **Tennessee:** Tennessee charges additional fines for specific motor vehicle infractions:
    a. Speeding $5
    b. Reckless Driving $30
    c. Driving with an invalid license $15
    d. DUI $15
    e. Accidents involving death or injury $15
    f. Drag Racing $25

    These revenue sources generated a total of $1,019,327 for FY10-11. This is down about $300,000 from its peak in 07/08, due to recession induced deductions in police force and increased use of speeding cameras (from which funds cannot be derived).
15. **Texas:** Felonies and misdemeanors: $10.5 million/year (1991)
16. **Virginia:** License reinstatement fee: Virginia charges an additional $30 on license reinstatements for individuals who had their license revoked for certain offenses (detail of offenses can be provided). $25 of the fee goes directly to their trust fund. At its best, the fees produced $1.2 - $1.4 million in additional revenue/year. Currently (FY'12), it is on course for $1 million in additional revenue.
17. **Washington:** A TBI account was created to be funded by $2.00 from every traffic infraction. The funds accumulated can only be spent after appropriation & are restricted to be used to support the activities outlined in the statewide TBI comprehensive plan which includes a public awareness campaign, information and referral services and covering the state staff, who provide support for the TBI Council.

Appendix F

REFERENCES

(Available upon request to the Massachusetts Rehabilitation Commission, Brain Injury and Statewide Specialized Community Services Program)

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5. MA Brain Injury Advisory Board's State Action Plan

6. Katz, D. I., Ashley, M. J., O'Shanick, G. J., Connors, S. H. (2006) Cognitive rehabilitation: the evidence, funding, and case advocacy in brain injury. A position paper of the Brain Injury Association of America. McLean, VA.