ACQUIRED BRAIN INJURY COMMISSION REPORT

May 15, 2021

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Section I: Executive Summary

Introduction

The Acquired Brain Injury (ABI) Commission was established in FY 2011 to identify the gaps in service delivery for Massachusetts residents who exhibit a history of acquired brain injury (ABI). (Appendix B). To that end, the ABI Commission developed 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.

In 2019, the ABI Commission was reconvened and chaired by Senate President Emerita Harriette L. Chandler and Representative Kimberly N. Ferguson; a full list of Commission members can be found in Appendix B. A summary of the FY 2019 ABI Commission's focus and activities are summarized in Appendices D and E of this report. As the FY 2019 ABI Commission report was being developed, the COVID-19 pandemic struck, and on March 10, 2020, Governor Baker declared a State of Emergency which was then followed by a Stay-at-Home Advisory effective on March 24th. The FY 2019 ABI Commission meetings and the completion of this report were temporarily paused as a result of the pandemic. It is important to note that much of this report was drafted prior to the onset of the COVID-19 pandemic and may not be reflective of current utilization and spending figures. In addition, a new category of individuals with ABI has been identified: those experiencing the neurological complications of COVID-19 who may require services in the future.

Status of Persons with ABI: Key Findings of the ABI Commission

Each year thousands of Massachusetts residents sustain acquired brain injuries (ABI), which include a range of neurological disorders/diseases affecting the brain, with onset after birth. The causes of ABI include stroke, infection, brain tumors, metabolic and toxic disorders (e.g., anoxia-diminished oxygen related to drug overdose) and trauma, the leading cause of acquired brain injury. Descriptions of the major categories and epidemiology of ABI are detailed in Section III of this report.

While an ABI can occur at any age, beginning in the newborn period, most individuals who experience an ABI are adults. The consequences of ABI may be catastrophic, often permanent, and complex affecting one's cognitive, motor (e.g., paralysis), sensory (e.g., blindness), communication, and functional status. Acquired brain injuries are also associated with neuropsychiatric/behavioral and substance use disorders. Individuals with ABI require a range of community-based services and supports, which may be needed throughout their lives, and which are detailed in Section V of this report.

In FY 2019, the ABI Commission identified unmet needs and challenges for those individuals who have sustained an ABI and reside in the Commonwealth. Key findings of the Commission are detailed below:

1. The majority of recommendations made by the FY 2011 ABI Commission to address the identified needs of those who have experienced ABI in Massachusetts have not been implemented.

2. The Statewide Head Injury Program (SHIP) was established in 1985 within the Massachusetts Rehabilitation Commission (MRC) to address the community-based service and support needs of persons with traumatic brain injury (TBI), only. However, individuals who have sustained an ABI resulting from stroke, infection, brain tumors, metabolic/toxic and other causes are not eligible for SHIP services, and there is no other designated state agency to which these individuals can apply to receive the same menu of services available to those with a traumatic brain injury.

3. The Statewide Head Injury Program (SHIP) needs additional resources to meet the needs of individuals who have sustained a TBI, which affects more than 74,000 people in Massachusetts annually. Currently, the Statewide Head Injury Program (SHIP) serves 654 individuals who have sustained a TBI.

4. There is a critical need to invest in the development and expansion of programs and services to persons living with all types of acquired brain injuries, including traumatic brain injury. Recommended programs and services, detailed below, include brain injury day supports, regional multi-service centers, and cognitive rehabilitation.

5. The FY 2011 Commission recommended that the epidemiology of ABI in Massachusetts be ascertained regularly to provide up-to-date information for the purposes of planning state-funded services and supports to persons with ABI. The information currently available regarding the epidemiology of ABI in Massachusetts is more than 10 years old.

6. There is an ongoing need for training and education regarding ABI by brain injury specialists for clinicians and other professionals; staff working in residential, day and other community-based programs; and others (e.g., mental health program settings).

7. As documented in public forums scheduled by the Commission, there is a need for specialized case management and service navigation for persons with ABI and their families who are generally unfamiliar with the supports, services, clinical and other resources that are available to persons with ABI.

Commission Recommendations

Based upon the key findings summarized above, and in an effort to enhance access and expand services and supports for persons with ABI, the Commission developed and prioritized the following recommendations, which are detailed in Section V of this report:

Recommendation #1: Establish an Acquired Brain Injury Advisory Board & Council

In February of 2021, bills were filed by Senate President Emerita Senator Harriette L. Chandler (D-Worcester), Representative Kimberly N. Ferguson (R– Holden), and Representative Gerard J. Cassidy (D-Brockton) to establish an Acquired Brain Injury Advisory Board and Council. (Appendix G.)

If enacted, the acquired brain injury advisory board shall collaborate with appropriate state secretariats and their agencies, members of the legislature, individuals with acquired brain injuries and their family members, providers, clinicians, advocacy groups and other key stakeholders to review, advise, and report on services and supports, and public policy there under for individuals with acquired brain injuries and their families.

Said advisory board directives shall include, but are not limited to, reviewing data concerning the epidemiology of acquired brain injury and the needs of individuals with acquired brain injury and their families; reviewing efforts to increase access to rehabilitative, residential and integrated community-based support services for persons with acquired brain injury; monitoring the implementation of the acquired brain injury commission recommendations regarding the improvement of such services; reviewing and advising on the annual brain injury state plan; and reviewing ongoing state public policy initiatives and state funding.

In addition, the bill calls for the establishment of an Acquired Brain Injury Advisory Council as a permanent structure within MRC to oversee the service and policy needs of those with ABI. As required by the Administration for Community Living and the US Department of Health & Human Services, 50% of the members should be comprised of survivors and family members. This council was established in May of 2021.

The Massachusetts Brain Injury Council aims to review, reflect, and advise on the needs of brain injury survivors and caregivers across the Commonwealth. The work of the council is guided by the council's mission and vision, which was developed by its members with lived experiences: The mission of the council is to provide a voice for survivors of brain injury, family members and community partners to ensure policies and initiatives reflect the needs of the diverse brain injury population in the Commonwealth

Through the Brain Injury Council, four themed subcommittees were created as the focus of the strategic plan: Behavioral Health, Diversity, Equity and Inclusion, Education, and Service Needs. Each subcommittee is comprised of individuals with lived experiences, state agency representatives and community-based providers. The subcommittees discussed a variety of themes to develop the priorities and goals that will be included in Brain Injury Strategic Plan.

Recommendation #2: Invest in the Development of Programs for Individuals with ABI

A. Provide new investments in the Statewide Head Injury Program (SHIP) to enable more individuals with traumatic brain injury (TBI) who are currently eligible or may become eligible to receive SHIP-funded state services according to their need. Additional details, cost assumption and projections are detailed in Section V.

1. Currently, the SHIP program has an annual budget of $21,651,939 and serves 654 individuals with traumatic brain injury. Of the 654 consumers served by SHIP, approximately 10% receive residential supports, while 80% require only community supports (e.g., day center services, supported employment, homecare, and recreation).
2. Additional investments in SHIP would allow the program to serve more individuals with TBI. In order to serve newly eligible individuals based on projected demand levels described below, the SHIP program would need over $6 million in new funding annually.
3. The four-year expansion of additional SHIP services needs to be incremental and purposefully implemented. The development of infrastructure will be key in initial years, hiring and training a new team to deliver supports to newly engaged SHIP consumers.
4. In addition to serving more individuals with TBI, MRC can support individuals with Acquired Brain Injury through MRC's funded Day Service Centers, integrating individuals with TBI and other types of ABI within the Center's membership.

B. To further explore the need to serve individuals with Acquired Brain Injuries (ABI) with the full array of services, MRC will conduct a person-centered analysis of individual service needs for those with all types of ABI, combined with a comprehensive cost analysis to determine the needed funding resources to further expand services for individuals with ABI.

C. Establish a new budget appropriation line item with additional funding to serve individuals with all types of ABI including but not limited to creating regional Brain Injury Community Centers, MRC Multiservice Centers, and other day services and supports.

D. Once additional funding resources are determined, MRC would be committed to revise the regulations of the Statewide Head Injury Program and expand the definition for those who are eligible to include all persons with acquired brain injury in addition to those who have experienced traumatic brain injury.

Recommendation #3: Expansion of Head Injury Treatment Services (HITS) Trust Fund

Legislation should be filed to increase funding for HITS Trust Fund by:

A. Authorizing 100% of revenues collected for Operating Under the Influence of Alcohol (OUI) and Driving Under the Influence of Drug (DUI) offenses to be deposited in the HITS Trust Fund.

B. Increasing and staggering fines for multiple offenses of Speeding, Driving to Endanger, Operating Under the Influence of Alcohol (OUI) and Driving Under the Influence of Drug (DUI) or other possible funding sources to be designated for the HITS Trust Fund.

C. Designating a percentage of fines collected for violations related to roadway safety (i.e., amendment of Hands-Free Law; Primary Seat Belt Bill) to the HITS Trust Fund.

Recommendation #4: Update of Epidemiological Data on Acquired Brain Injury Every Five Years

As was recommended in the FY 2011 Commission Report, the epidemiology of ABI in Massachusetts should be updated every five years by the Massachusetts Department of Public Health (DPH), preferably utilizing the methodology established in 2014 and the revised ICD-10-CM codes.

Recommendation #5: Establish and Fund a Traumatic Brain Injury Registry

It is recommended that the state establish a Traumatic Brain Injury (TBI) Registry either through modification of the existing state trauma registry or the development of a standalone registry.

It is further recommended that the Massachusetts Department of Public Health (DPH), in collaboration with the Massachusetts Rehabilitation Commission (MRC) and the Brain Injury Association of Massachusetts (BIA-MA), develop a plan for identification of and outreach to individuals with TBI as well as determining the data points to be collected.

Recommendation #6: Enhance Access to Cognitive Rehabilitation

One of the most common long-term consequences of acquired brain injury is residual cognitive impairment. There is a lack of access for brain injury survivors for cognitive rehabilitation which currently is not typically included as a mandated benefit. Per the recommendation of the FY'11 Commission, the following companion bills (S629-H1078) were filed by Representative Kimberly N. Ferguson and Senator Harriette L. Chandler for commercial health insurance plans to cover cognitive rehabilitation for individuals with ABI. The Center for Health Information and Analysis (CHIA) reviewed the bill for a cost analysis and found that the typical members' monthly health insurance premium would be between $.01 (0.003%) and $0.19 (0.040%), or an average cost of $0.08 per month (35). Based upon a separate cost analysis, it is recommended that cognitive rehabilitation be considered as a covered service by MassHealth.

Recommendation #7: Opportunities to Increase Access to Cueing and Supervision Supports

It is recommended that the Massachusetts Rehabilitation Commission (MRC) and MassHealth establish a joint working group to identify the size and characteristics of the population of persons with brain injury in the Commonwealth who may need cueing and supervision to complete activities of daily living but not hands on assistance, and are unable to access programs that provide this support (e.g., AFC, MassHealth integrated care plans, HCBS waiver programs, and the state Home Care program). It is further recommended that this analysis be completed within 12 months, and that the Executive Office of Health and Human Services (EOHHS) provide a clear inventory of the services that provide cueing and supervision and based on the analysis of the working group determine whether there are unmet needs that require further evaluation of current services.

Recommendation #8: Revise Concussion Law

It is recommended that the state ensure that all students including those who are not engaged in extracurricular sports who sustain a concussion are provided return to learn accommodations. It is

further recommended that strategies be developed to ensure improved compliance with the existing concussion law.

Recommendation #9:
Enhance Education and Training regarding ABI provided by Brain Injury Specialists

It is recommended that additional training and education opportunities should include, but not be limited to, the following

A. MRC with the guidance of the Advisory Council will recommend required staff training for providers and agency staff to better address the different types of acquired brain injuries and their physical, behavioral, and cognitive consequences.

B. Educational seminars for families, significant others, and persons with ABI regarding resources, services, and the consequences of ABI.

C. Training for hospital-based staff regarding available state-funded and other resources for persons with ABI.

D. Topic-specific training/educational programs, as well as person-specific technical assistance, for Executive Office of Health and Human Services (EOHHS) agency staff, providers, vocational rehabilitation counselors, schools and other community-based agencies and community providers.

Closing Remarks

The ABI Commission members are thanked for their thoughtful, compassionate, and dedicated work. This report does not mark the completion of the goals of the ABI Commission. An Acquired Brain Injury Advisory Board is crucial to oversee the implementation of the recommendations generated by the ABI Commission and to provide guidance and direction to the state in determining how to best improve services and supports for people living with ABI in the Commonwealth. There is clearly much work to be done to assist those with ABI to recover, become more independent and to improve the quality of their lives.

Section II: Acquired Brain Injury Commission Overview

Background

The Acquired Brain Injury (ABI) Commission was first established in FY'11 (hereinafter the FY '11 ABI Commission), after recognizing that the Commonwealth needed to address serious gaps in services for individuals living with ABI in Massachusetts. (Appendix B)

After meeting for over a year, the FY '11 ABI Commission identified a number of service gaps for individuals with ABI, including Case Management Services, Day Programs, Social/Recreation Services, Post-Acute Rehabilitation Services, MassHealth PCA Services, Technical Assistance and Consultation, and Other Service Needs, including transportation, respite care, residential programs, and behavioral health (substance use disorder treatment and psychiatric services). The activities and recommendations generated by the FY '11 ABI Commission are summarized in a report released in December of 2011 (9).

The FY '11 ABI Commission recommended that 100% of all monies collected by motor vehicle violations be deposited in the Head Injury Treatment Services (HITS) Trust Fund (9). In addition, the FY '11 ABI Commission recommended that revenue sources utilized by other states to support the delivery of ABI services be further investigated and pursued and that a new state appropriation be created (9).

The FY '11 ABI Commission made five administrative recommendations in response to the observed gaps in services, including:

1. Design and complete a comprehensive epidemiological study of acquired brain injury in Massachusetts. The FY'11 ABI Commission also recommended that epidemiological information continue to be updated on a regularly scheduled basis 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 ABI, to include traumatic, neoplastic, infectious, metabolic, and toxic disorders of the central nervous system.

2. Design and complete a comprehensive needs assessment designed and implemented to identify and determine the specific service needs of adults living with ABI in Massachusetts.

3. Convene an interagency task force of designated Executive Office of Health and Human Services (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), Executive Office of Elder Affairs (EOEA), and Office of Medicaid (MassHealth) be convened.

This task force was expected to:

a. Review findings of the epidemiological study and 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 ABI statewide.

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

e. Identify the barriers associated with accessing adult services experienced by youth with ABI who are transitioning from special education to adult service agencies.

f. Generate a report to the legislature by FY '14.

4. Based upon the results of both the epidemiological study and needs assessment, consideration should be given to studying the feasibility and impact of expanding MRC's Statewide Head Injury Program's capacity to serve all individuals, between the ages of 18 and 59, with ABI, in addition to those with TBI currently served by SHIP. It was also recommended that an evaluation be done on whether there is a need for a designated program, with dedicated staff, to be established with MRC to develop, oversee, and monitor a menu of identified services for people with ABI in Massachusetts.

5. That the definition of Personal Care Attendant (PCA) under MassHealth's State Plan be modified to allow individuals who have cueing, and supervision needs to qualify for PCA services (9).

The FY '11 ABI Commission also generated three service recommendations in response to the observed gaps in services, including:

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

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

3. Ten new Social/Recreation programs to be developed statewide for persons with ABI (9).

For the next eight years, Senate President Emerita Harriette L. Chandler (D-Worcester), Representative Kimberly N. Ferguson (R-Holden), the Brain Injury Association of Massachusetts

(BIA-MA), ABI individuals, families, and providers utilized the FY '11 ABI commission report to advocate for services in the state.

Several goals were achieved with bipartisan support, including:

1. 100% of money collected from speeding tickets and driving to endanger violations and 75% for Operating under the Influence and Alcohol and Drugs are deposited in the HITS Trust Fund (15).

2. For the first time since 1988, an epidemiological study of ABI in Massachusetts was completed by DPH and MRC in October 2014 for the years 2008-2010. (11)

3. One pilot community center, located in Worcester, was established.

4. MRC conducted a Brain Injury Needs Assessment on the short and long-term service needs of individuals with brain injury. MRC contracted with Public Consulting Group, Inc. (PCG) in July 2016 to perform the Needs Assessment. The goal was to provide MRC with meaningful and actionable recommendations aimed at improving services and supports for all individuals with an acquired brain injury in the state. Contributors to the data collection for this assessment included MRC staff, other Executive Office of Health and Human Services (EOHHS) agencies, community providers, advocates, adults with ABI, and their families (12). The Needs Assessment was released by EOHHS just prior to convening the FY '19 ABI Commission.

Numerous other recommendations from the first report and numerous gaps in service remain for individuals with ABI, including:

1. Only 75% for Operating under the Influence and Alcohol and Drugs are deposited in the HITS Trust Fund (15).

2. The EOHHS interagency task force was not established.

3. The epidemiology of ABI by DPH has not been updated since 2014.

4. A study to determine the feasibility and impact of expanding MRC's capacity to serve all individuals, between the ages of 18 and 59, with non-traumatic ABI has not been completed.

5. The definition of Personal Care Attendant (PCA) under MassHealth's State Plan was not modified.

6. Four of the five recommended additional community centers have not been developed.

7. None of the five regional ABI Multiservice Centers have been developed.

8. Increased access to post-acute rehabilitation, especially for people who have sustained a severe brain injury, whether from TBI, stroke or other ABI is needed in the state. (25) In response, a bill requiring commercial health insurance plans to cover cognitive rehabilitation for persons with an ABI was filed in the last three legislative sessions. In October 2016, the Center for Health Information and Analysis (CHIA) released a cost benefit analysis (35).

Acquired Brain Injury Commission 2019-2020

Under the leadership of Senate President Emerita Harriette Chandler, Senator Dean Tran, Representative Kimberly Ferguson, and Representative Gerard Cassidy, the Acquired Brain Injury Commission was re-established in the FY '19 budget, outside Section 76, after confirming that the Commonwealth had not addressed numerous recommendations made by the 2011 Commission, and that numerous gaps in services remained for individuals with ABI. (Appendix B). The re-established ABI Commission (hereinafter the FY '19 ABI Commission), convened in April 2019 and reviewed the FY '11 ABI Commission Report and the Needs Assessment.

The FY '19 ABI Commission consisted of Governor-appointed experts and state agency representatives. Other appointees have studied ABI, worked with individuals with ABI, have experienced ABI themselves, or have family members with an ABI.

Appointed members of the FY '19 ABI Commission and their affiliations are detailed in Appendix C of this report. During the first meeting, members learned about the FY '11 ABI Commission's recommendations and accomplishments and discussed the focus of the Commission for the next year.

Strategies for accomplishing the FY '19 ABI 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 FY '19 ABI Commission reached out to a diverse group of providers, as well as individuals and family members impacted by ABI to ensure individuals representing all regions of the Commonwealth were involved in listening sessions.

In addition to the monthly meetings in Boston, regional listening sessions also took place in Pittsfield, Worcester, Boston, Gloucester, and Brockton. FY '19 ABI Commission members were invited to tour a residential home and the Brain Injury Community Center (pilot regional center) in Worcester to learn about current services available to individuals living with ABI in Massachusetts.

All FY '19 ABI Commission meetings were open to the public and followed state ethics law. Presentations made to the FY '19 ABI Commission and other information were also posted on **https://www.mass.gov/orgs/brain-injury-commission** to ensure broad public access. Meeting materials can be found in Appendix D and at **https://www.mass.gov/lists/brain-injury-commission-meeting-materials-and-minutes#other-meeting-materials-.** Feedback from the five Regional Meetings are in Appendix E and meeting minutes are at **https://www.mass.gov/lists/brain-injury-commission-meeting-materials-and-minutes#2019-**

meeting-minutes-. A Summary of the FY '19 ABI Commission's findings and related recommendations are detailed in Section VI of this report.

Section III: Acquired Brain Injury Definitions and Epidemiology

Acquired brain injury (ABI) includes a wide range of disorders/diseases affecting the brain, with onset after birth. While ABI can occur at all ages, beginning in the perinatal/newborn period through adulthood, the majority of individuals who sustain an ABI are adults. In addition to age of onset, the long-term consequences of ABI are associated with their severity and the sites of injury within the brain, and some acquired disorders/diseases are progressive (e.g., Chronic Traumatic Encephalopathy, a neurodegenerative disorder associated with repetitive head trauma). 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, and detailed below are descriptions of the major categories of ABI (1):

Infectious Disorders: Includes primary infections of the central nervous system (CNS), including encephalitis/ meningitis resulting from bacteria, viral, parasitic, and other infectious agents. The nervous system may also be secondarily affected by other types of infections (e.g., HIV infection; Lyme Disease).

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) which may occur in a variety of contexts.

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 outside the nervous system (e.g., lung, colon). While some primary brain tumors are malignant and associated with compromised life expectancy, most individuals are diagnosed with benign brain tumors, with a median age of 60 years at time of diagnosis, although brain tumors represent the most common solid tumor in children. In Massachusetts, the five-year total for primary tumors of the CNS reported to the Central Brain Tumor Registry of the United States (CBTRUS) was 6,712 (2012-2016), with an average of 1,342 new primary CNS tumors diagnosed annually. For the 5-year total, more than 61% were benign (2).

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.

Neurovascular: Strokes represent the second leading cause of ABI, with more than 795,000 individuals experiencing a stroke annually in the US. Most commonly strokes occur in persons over the age of 65, although 34% of individuals hospitalized for stroke in the US are under the age of 65 (3). In Massachusetts (2015-2017), the stroke hospitalization rate for Medicare beneficiaries was 10 per 1,000 (national rate: 11.6/1,000). Overall, approximately 140,000 individual die as a result of stroke in the US annually; the national stroke death rate for all ages (2016-2018) was 37.4 per 100,000. In Massachusetts, the death rate was 27.2/100,000 (4). Children and younger adults may also experience a stroke (e.g., children with Sickle Cell Disease; young adults with a history of drug abuse), and recently younger adults (ages 33-49 years of age) diagnosed with coronavirus infection

have presented with large vessel strokes (5).

Most individuals (87%) sustain a stroke because of a sudden blockage in an artery supplying the brain (i.e., ischemic stroke), while others experience bleeding into the brain (hemorrhagic stroke), which is associated with higher mortality. Risk factors for stroke include diabetes, heart disease, hypertension, and personal modifiable behaviors (e.g., illicit drug use). Risk for stroke is approximately twice as high for blacks in comparison to whites, and blacks have the highest stroke-related death rate.

Traumatic: Is extrinsically caused and the most common type of ABI affecting 2.87 million individuals in the United States annually (6). In 2015, 5,062 individuals in Massachusetts were hospitalized for treatment of traumatic brain injuries (TBI), while an additional 68,260 were evaluated at emergency departments (EDs); 820 deaths were associated with TBI. Massachusetts residents 65 years and older had the highest number and rate for TBI-related deaths and hospitalizations (54%), while children under age one and adults ages 85 and older had the highest rates for TBI-related ED visits (7).

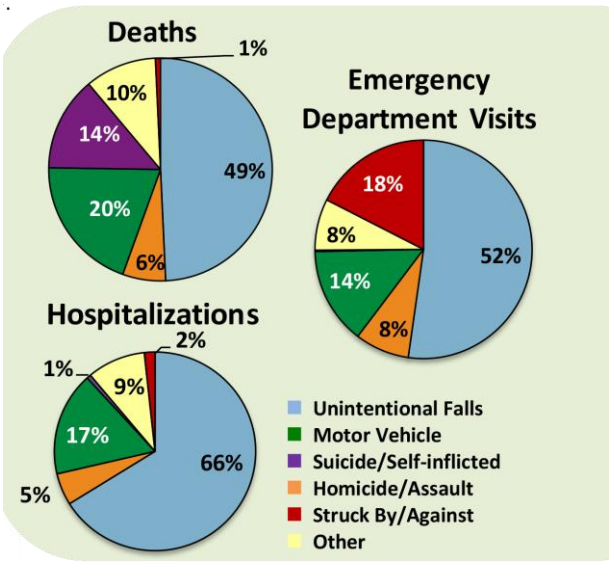


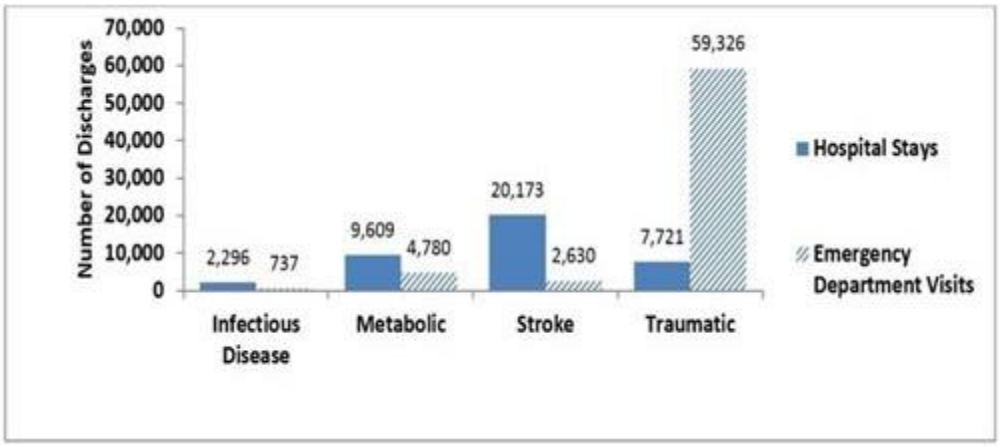
Figure 1: Percentage of Annual TBI-Related Deaths, Hospitalizations and Emergency Department Visits, by External Cause, MA Residents, 2015

The leading cause of TBI is falls and fall related TBI deaths have increased significantly (17%) in the US from 2008-2017 (8). In Massachusetts, unintentional falls account for most TBI-related hospitalizations and ED visits, as well as 49% of deaths. Other mechanisms for injury include motor-vehicle-related events; sports-related injury; child abuse (e.g., shaken baby syndrome); interpersonal violence and other intentional causes (e.g., suicide and homicide attempts); and military combat (e.g., blast injuries associated with exposure to improvised explosive devices-IEDs). With respect to the latter, it is important to note that epidemiological data for blast TBI is not included in the national or Massachusetts discharge data summarized above.

Acquired Brain Injury in Massachusetts

As was recommended and prioritized in the FY '11 ABI Commission report (9), a comprehensive study of the epidemiology of acquired brain injury in Massachusetts was completed in a collaborative effort by the Massachusetts Rehabilitation Commission and the Massachusetts Department of Public Health, including a team of epidemiology content specialists (e.g., stroke, TBI, etc.). Prior to the 2014 Epidemiology Report, an epidemiology study on ABI in Massachusetts had not been ascertained in more than two decades (10), and the goals of this study were to estimate the magnitude of the ABI population; affected age groups; region of residence; and other pertinent descriptive information (e.g., discharge depositions; insurance coverage; lengths of stay) for select subgroups of ABI, for which discharge data for three consecutive years (2008-2010) from ED visits, observational stays and inpatient hospitalizations was available. The Massachusetts Cancer Registry provided data regarding primary brain tumors.

Figure 2: Average Annual Number of Hospital Stays and Emergency Department Visits Associated with Select Categories of ABI, MA Residents, 2008-2010



Source: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis. Note: Categories are not mutually exclusive.

The reader is referred to the epidemiological report issued by MRC and DPH in October of 2014 for detailed information regarding the methodology employed, data findings and limitations of findings (11). A summary of key information included in the report is listed below:

1. The leading causes of ABI in Massachusetts, consistent with national trends, were stroke and traumatic brain injury (TBI), with the majority of individuals who sustain a TBI evaluated in ED visits.

2. Average lengths of stay (LOS) for individuals hospitalized for ABI ranged from 5.3 to 8.5 days.

3. Most individuals hospitalized for an ABI were not transferred to either a rehabilitation hospital or unit within a hospital.

4. Most individuals (50-70%) hospitalized for ABI were discharged home with no, or time-limited, services (e.g., VNA).

5. Most hospital stays for TBI, stroke, and metabolic disorders were among persons 60 years of age or older. For newly diagnosed brain tumors, both malignant and benign, approximately 50% occurred in persons aged 60 or older.

6. Most individuals (75-96%) hospitalized for treatment of an ABI survive.

7. For a significant percentage of individuals hospitalized for ABI (i.e., 48-81%), and 42% of persons diagnosed with a primary brain tumor, insurance was a public payor source (i.e., MassHealth, Medicare, etc.).

8. Within each of the selected categories of ABI included in this study, disorder-specific limitations are reviewed in the final report. In addition, it is important to note that many categories of ABI were not ascertained due to the absence of discharge data (e.g., for individuals with substance use-related brain injury; persons with various forms of HIV-related neurocognitive disorders). In addition, it is important to note that individuals who may have sustained an ABI but received treatment in free-standing urgent care/emergency clinics, Veteran's Health Administration (VHA), or other federal facilities are not included in the data collected.

While the FY '11 ABI Commission recommended for periodic and comprehensive updates of epidemiological data, except for select populations, this has not occurred since 2014 utilizing data collected for the years 2008-2010. The importance of updated data is exemplified by more recent epidemiological information regarding traumatic brain injury in Massachusetts. The average annual ED visits for TBI in 2008-2010 was 59,326, while more recently (2015) and as noted above, there were 68,260 ED visits for TBI in Massachusetts, consistent with national trends observed by the CDC, which have also documented an increase in ED visits for assessment and treatment of TBI.

Section IV: Services for Acquired Brain Injury: Current Status

Statewide Head Injury Program (SHIP)

The Statewide Head Injury Program (SHIP) was established in 1985 within the Massachusetts Rehabilitation Commission (MRC) as a result of grassroots advocacy efforts led by the Brain Injury Association of Massachusetts (BIA-MA). It was the first national model for publicly funded services for individuals with traumatic brain injury (TBI) and is the lead brain injury agency in the Commonwealth. Over the last 35 years, brain injury services in Massachusetts have evolved in several ways.

SHIP has served as a centralized point of expertise across Executive Office of Health and Human Services (EOHHS) agencies and this expertise is greatly enhanced by its longstanding collaboration with BIA-MA (9).

The blueprint for SHIP and brain injury services in Massachusetts was a 1988 Needs Assessment submitted to the Legislature which was reinforced by a 2006 Consumer Focus Group Report and State Plan document developed by a Massachusetts Acquired Brain Injury Advisory Board (9).

SHIP was established by 107 CMR 12.04 in 1985. To be eligible for SHIP services, 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 (budget line item 4120-6000), the Head Injury Treatment Services (HITS) Trust Fund (budget line item 4120-6002), Medicaid funding for specific programs, and government line items (9).

In 1993, the HITS Trust Fund was established (14). The HITS Trust Fund collects mandatory civil fines for speeding violations, Driving to Endanger, Operating Under the Influence of Drugs and Alcohol (OUI/DWI), and Operating Under the Influence Boating (14). Originally, a percentage of the violation fines collected went to the HITS Trust Fund and the remainder to the state general funds. In 2014, and as recommended by the FY '11 Commission, 100% of the fines for speeding ($50) and Driving to Endanger ($250) were allocated to the HITS Trust Fund; however, the percentage for OUI/DWI was not increased (15).

Trust funds present a disadvantage as a source of revenue designed to support programs and services. Ideally the trust fund should be a means to address emergency service needs annually rather than a source of revenue to support programs and services. When fines decrease, funding decreases, while at the same time, there may be an increased need for services (29). The HITS Trust Fund has decreased dramatically due to low traffic citations in Massachusetts. In 2016, there was a 35% drop in traffic violations compared to 2009 for the state while in Boston there was a 54% drop in traffic violations between 2010 and 2015 (30). Further, because of the COVID-19 pandemic, in the first three weeks of April 2020, police departments across the state wrote 95% fewer tickets for moving violations, such as speeding, compared with the same period in 2019 (31). It is anticipated that reduced speeding ticket citations will continue to significantly decrease monies for the HITS Trust Fund.

The primary purpose of SHIP is to assist individuals with TBI to develop skills and maintain or increase independence within their home, community, or work. According to SHIP, the average age of a person receiving SHIP services is 53 years old, 30% female, 63% male and 8% unknown (13). According to a presentation to the FY '19 ABI Commission, only 910 people are "actively" receiving SHIP-funded services: 102 in Boston, 68 in Central, 166 in Metro South, 97 in Metro West, 150 in Southeast, 173 in West and 152 in Northeast (13).

SHIP consists of a wide array of community-based services including, but not limited to skills training, adult companion, limited residential and shared living and regional service centers (head injury centers). According to the presentation of SHIP's services to the FY '19 ABI Commission, the most utilized services include: 59% Case Management/Coordination; 10% Day Services; and 10% 24-hour Residential and Supported Living Programs (13).

Needs Assessment

Numerous comments came during the Listening Sessions on improvements for interacting with SHIP, including: the need to know the services that are available, the cumbersome application process, similar documents submitted for each MRC program, length of time after submitting the application to learn about eligibility, and eligibility determined but still waiting for services due to lack of funding.

As noted in Section II of this report, the FY '11 ABI Commission recommended that MRC conduct a Needs Assessment. Based upon the findings of the Needs Assessment, it was recommended that MRC build a web-based case management IT system (12). A robust system would allow MRC to capture individual information for assessing needs, including collection of accurate incident data, service planning, and case management and navigation notes (12). The system could be utilized across MRC staff, consumers, and providers to assist with transition to other MRC services and supports. A web-based case management system would create improved efficiencies and outcomes for MRC, providers, and individuals receiving services (12). A web-based case management IT system will enable MRC to develop modern infrastructure and enable staff to spend less time on administrative processes.

In the Fall of 2020, MRC developed "MRC Connect" to create one entry point for the majority of programs within the Community Living and Vocational Rehabilitation Divisions of the agency. Programs that are included within the system include: Statewide Head Injury Program (SHIP), Vocational Rehabilitation, Home Care Assistance Program (HCAP) and Supported Living (SL). Benefits of the online application include additional avenues for consumers to be referred (in addition to Chapter 688 referrals), improved customer service by increasing access, timely eligibility determination, increased referrals that would align with MRC's ongoing consumer technology initiative and an integrated resource team that would support services across programs within MRC (12).

MassHealth State Plan

Individuals with MassHealth have access to medically necessary long-term services and supports (LTSS) under the MassHealth (Medicaid) State Plan benefit. Federal law requires that services covered under a state's Medicaid State Plan must be available to all eligible individuals regardless of diagnosis.

In practical terms, the comparability requirement means that State Plan services cannot be targeted to a subpopulation of MassHealth members. The MassHealth State Plan benefit includes several services that may be accessed individuals with brain injury, though not exclusively. These services include personal care assistance through the state's Personal Care Attendant (PCA) program, adult day health, and adult foster care, as well as physical, occupational, and speech and language therapy, for instance.

Home and Community Based Services (HCBS) Waivers

An exception to the comparability requirement for Medicaid programs exists in 1915(c) of the Social Security Act, which establishes authority for Home and Community Based Services (HCBS) waivers. With approval from the federal Centers for Medicare and Medicaid Services (CMS), states can design HCBS waiver programs to serve specific populations of Medicaid-eligible individuals. HCBS Waiver programs provide access to additional services for individuals enrolled in them, in addition to the services covered in their MassHealth State Plan benefit. Massachusetts has ten HCBS waiver programs, of which six are particularly relevant for adults with brain injury:

- Traumatic Brain Injury (TBI) Waiver, in operation since 2001;
- Acquired Brain Injury – Residential Habilitation (ABI-RH) Waiver, in operation since 2010;
- Acquired Brain Injury – Non-residential Habilitation (ABI-N) Waiver in operation since 2010;
- Moving Forward Plan – Residential Supports (MFP-RS) Waiver, in operation since 2013;
- Moving Forward Plan – Community Living (MFP-CL) Waiver, in operation since 2013; and
- Frail Elder Waiver (FEW), in operation since the 1980s.

Eligibility for HCBS waivers is two-pronged, requiring both financial and clinical eligibility. Under federal law, individuals must require a facility level of care to qualify for HCBS waivers. Each waiver program's eligibility requirements are further tailored to a specific target population. The needs of a given waiver program's target population drive the design of the menu of specific services available in that waiver program.

In addition to having access to waiver services, HCBS waiver participants receive expert waiver case management by staff of the state agencies (or associated entities) that operate these waivers. MassHealth administers all ten HCBS waivers, while responsibility for day-to-day operation of waiver programs lies with the state agencies with subject matter expertise and specialized provider network infrastructure. MRC is the operating agency for the TBI, ABI-N, and MFP-CL waivers; the Department of Developmental Services (DDS) is the operating agency for the ABI-RH and MFP-RS waivers; and the Executive Office of Elder Affairs (EOEA) is the operating agency for the Frail Elder Waiver.

Home Care Program

Operated by the Executive Office of Elder Affairs (EOEA), the Massachusetts Home Care Program provides care management and in-home support services to help older adults including those with disabilities to successfully age in place within Massachusetts. Eligibility for the Home Care Program is based on age, residence, and ability to carry out daily tasks. The Home Care Program offers a variety of in-home assistance to help eligible older adults to continue to live independently and safely at home. The minimum age for eligibility is 60. As noted in Section III above, epidemiological data shows that

most hospital stays for TBI, stroke, and metabolic disorders in Massachusetts were among persons 60 years of age or older, and for newly diagnosed brain tumors, both malignant and benign, approximately 50% occurred in persons aged 60 or older. While not targeted for individuals with brain injury, therefore, the Home Care Program is a key resource for in home services for the brain injury population.

In addition, MRC's Homemaking Services are available to individuals under the age of 60 with a disability who require direct help with meal preparation, grocery shopping, laundry and light housekeeping. Homemaking Services are provided through either an agency or an individual caregiver under a self-directed model.

Other Initiatives

MRC has a long history of partnering with other state agencies and the federal government to create and strengthen a system of services and supports that maximize the independence, well-being, and health of people with TBI across the lifespan. EOHHS agencies with MRC's leadership have worked together to build capacity by maximizing existing resources in the Veterans, Elders and Substance Use Disorder delivery systems.

Supported by time limited federal grants, resources have been maximized to promote outreach activities, training on early screening of TBI, and resource sharing to improve services for individuals with brain injury. These initiatives were funded through the Traumatic Brain Injury (TBI) State Partnership Program through the Traumatic Brain Injury Reauthorization Act of 1996 (P.L. 104-166), which is administered by the Administration for Community Living (ACL). As part of the TBI Act, participating states are required to provide the 2:1 state match, support a state TBI Advisory Board, create an annual TBI State Plan, and create and/or expand a TBI Registry.

The Commonwealth has a robust Injury Surveillance Program (ISP) based at DPH. Since 2001, the ISP has conducted routine surveillance of TBIs in Massachusetts utilizing high quality statewide data from vital records, inpatient hospital (all hospitals, not just trauma centers) discharges, outpatient observation stays, and emergency department discharge databases. These data sources are used to examine counts of individuals treated for TBI and trends, demographic disparities, causes, outcomes, and hospital charges associated with these events (19).

The TBI State Partnership Program administered by MRC has increased awareness and screening resulting in improved identification of individuals who sustain a TBI to the state's TBI Service System; improved access to appropriate information, resources, services and supports for those who sustain TBI and their families; and enhanced the state's "No Wrong Door" model by incorporating a TBI component that provides simplified, streamlined and consumer-directed access to appropriate services for a high risk population.

Section V: Current Challenges and Needs

Identification of Current Challenges and Needs

To ascertain the current gaps in service delivery for individuals with acquired brain injury (ABI), the FY '19 ABI Commission employed several strategies. The FY '19 ABI 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 ABI and their families; public forums and regional listening sessions during which individuals with ABI, family members/significant others, professionals and providers presented their concerns and needs; presentations by medical and rehabilitation facility/program representatives; and presentations by representatives of the insurance industry. The list of speakers and topics are included in Appendix D. The dates and themes from the Listening Sessions are included in Appendix D & E.

The Commission finds that there is a need to enhance the Commonwealth's capacity to address the needs of individuals of all ages with ABI, in addition to those with TBI. Currently, MRC funding is largely restricted to supporting the service needs of individuals with TBI. Services in the ABI, MFP, TBI, and Frail Elder waiver programs—and the waiver case management provided by staff of the state agencies (or their agents) that operate these waivers—are available only to enrolled waiver participants. As noted above, eligibility for these programs is limited to those who meet both clinical and financial requirements, and program capacity is finite. For individuals who are not eligible for one of the HCBS waiver programs but who qualify for MassHealth, a range of in-home and community-based long-term services and supports (LTSS) are available through the State Plan. These services range from self-directed personal care attendant (PCA) services and home health aide, to medical equipment and supplies, to adult foster care and adult day health. In addition, the Executive Office of Elder Affairs's Home Care Program, offering a variety of in home assistance based on income levels, and designed to help eligible older adults live independently and safely at home, provides care management and in-home support services. Eligibility for the Home Care Program is based on age—the minimum age is 60—as well as residence, the ability to carry out daily tasks and income which is utilized to determine an individual's potential contribution for the cost of services.

Despite this relatively broad array of services available through these programs, gaps remain in terms of access to needed services for certain Massachuetts residents with brain injury. As noted, the SHIP program only serves individuals with TBI; HCBS waivers, under federal authority, can only serve eligible individuals who require a facility level of care; personal care services in the MassHealth State Plan PCA program are not covered if the individual needs cuing and supervision but not hands-on assistance; and the Home Care Program is available to adults over 60 years of age but not to other younger inidividuals.

Further, the overall system of care for individuals with an ABI is complex and individuals may not know how to access supports and services for their brain injury or may become frustrated in attempting to access services that are not focused on the need of someone with a brain injury (12).

Exisisting service models with proven success, such as SHIP and the ABI and MFP waivers, offer a blue print for expanding services and increasing access to needed services.

Pathway to Recovery

The pathway to recovery for ABI includes prevention, acute and post-acute hospital-based services, other community-based clinical services, and non-medical community-based programs. Historically, the emphasis has been on acute medical care with less attention on post-acute rehabilitation and community-based services, where the majority of public costs are spent. Persons with ABI may need access to treatment, rehabilitation, and long-term supports at any time during their life span. Family support is often vital for facilitating access to needed services supporting recovery, maintaining function, and improving quality of life for people with ABI at all stages of recovery.

The Acute Treatment of ABI pathway is summarized in Figure 3 and includes emergency department (ED) visits, observational stays, and inpatient hospitalizations. During an inpatient stay, the individual may receive treatment in intensive care or specialty units (e.g., neuro-oncology). For those individuals who require inpatient hospital stays, data is available from the Center for Health Information and Analysis (CHIA) regarding disposition and post-acute transfers (e.g., skilled nursing, rehabilitation hospital/unit). However, the majority (50% - 70%) of individuals hospitalized for treatment of an ABI are discharged home, after a brief acute length of stay (LOS), either with time-limited services (e.g., VNA) or no services stipulated at time of discharge. Disposition data for individuals who receive ED treatment; those who are evaluated and treated at other facilities (e.g., free standing clinic, private practice, in-theater military facility); and those undiagnosed (e.g., homeless; uninsured) are not available (11).

Figure 3: Acute Treatment of Acquired Brain Injury

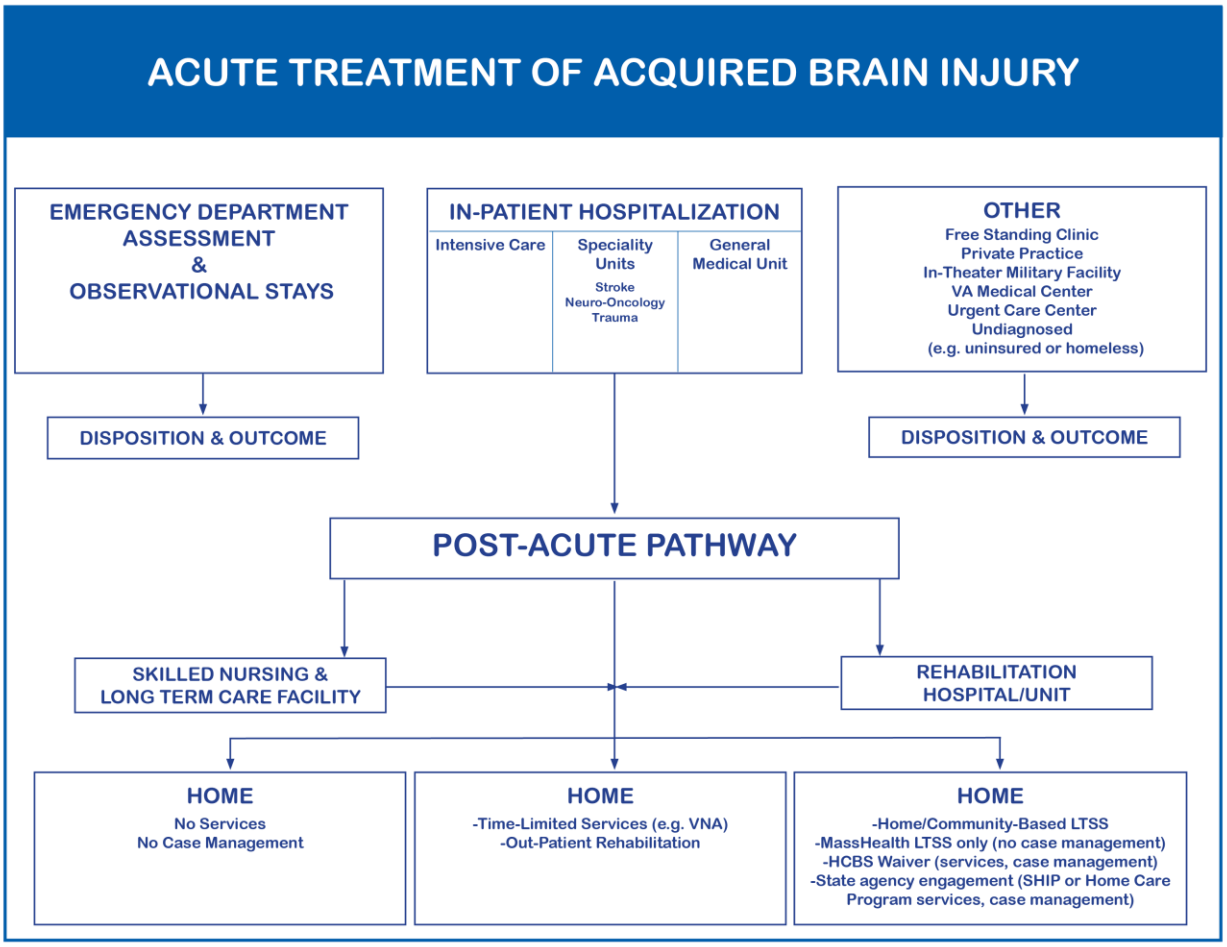


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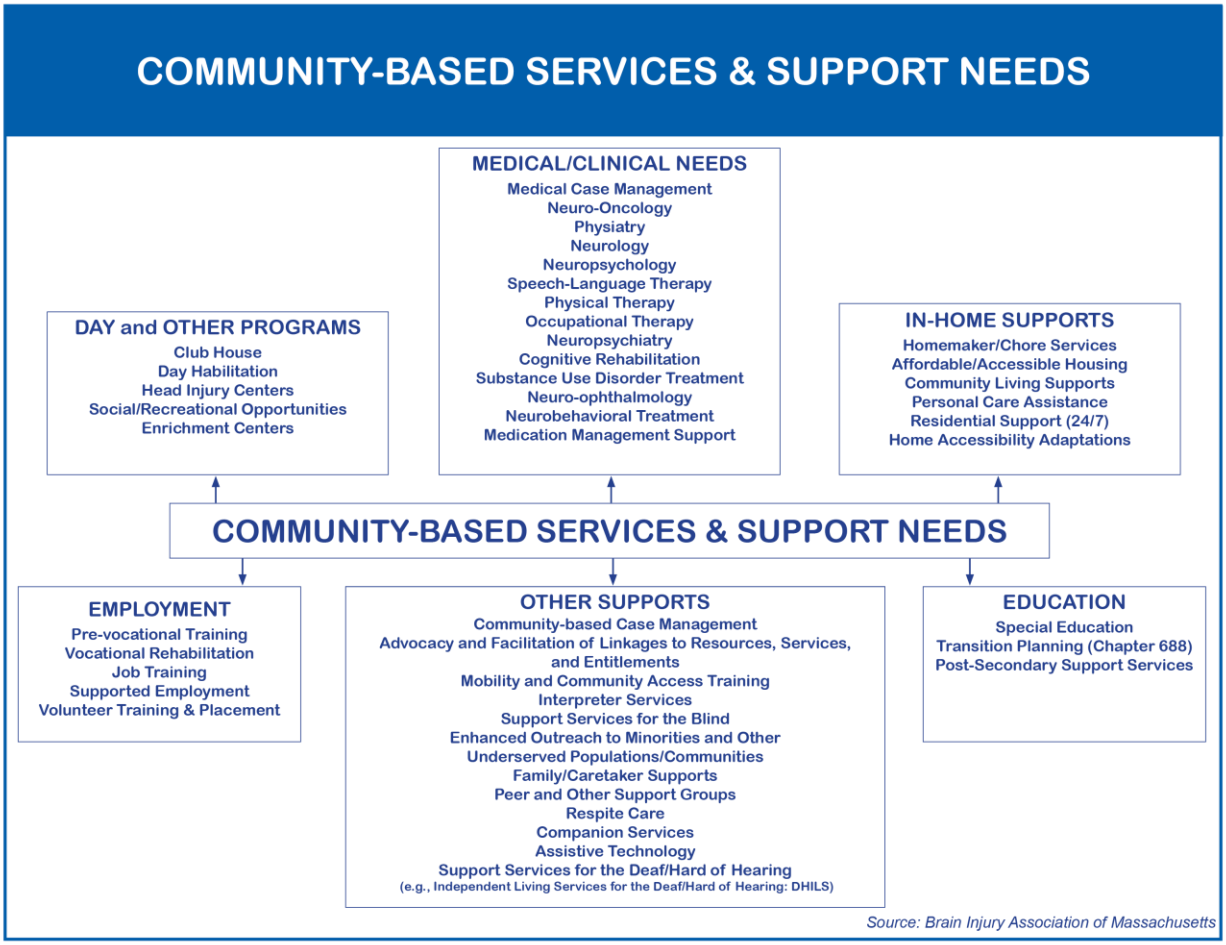
Figure 4: Community-Based Services and Support Needs



Individuals who sustain ABI often require a range of community-based services, which are summarized in Figure 4.

However, the FY '19 ABI Commission members learned of the numerous obstacles and challenges to accessing needed services, including the lack of awareness of resources available from the Massachusetts Rehabilitation Commission (MRC) and the Brain Injury Association of Massachusetts (BIA-MA), as well as other resources and services available through other state agencies, including MassHealth and EOEA. Stakeholder feedback given to researchers for the Needs Assessment report and at the Listening Sessions clearly demonstrate that MRC and BIA-MA are an essential resource for survivors and families. BIA-MA provides information and referral resources that are clear and understandable for the population. Individuals with ABI and family members who testified spoke extensively about their positive experiences with BIA-MA staff, support groups and educational offerings but wished that they had become aware of available resources sooner in their journey and that there were more resources in hospitals to guide them to community services and supports (12).

Often after an emergency department visit for an ABI, the individual and family are sent home without adequate information about the potential longer-term impact. It is also common that

information that is provided to an individual in an emergency setting will be mislaid due to the impact of an ABI on the ability of an individual to organize and retain information. Family members and individuals need this information to guide them through this complex system of supports (12).

State-Funded Services

Negotiating the state service system often results in a negative experience for persons with ABI. Individuals may not know how to access supports and services for their ABI or may become frustrated in attempting to access services that are not focused on the needs of someone with an ABI. Persons with ABI find themselves exasperated with a complex system with limited services and rehabilitation options (12).

Individuals must meet financial and/or clinical eligibility requirements to qualify for publicly funded services through state agencies. Even if individuals meet eligibility requirements, some state funded programs that can provide needed services for individuals with acquired brain injury have limited capacity due to funding or other constraints, and often such programs serve a broader population that includes, but is not limited to, individuals with ABI.

Finally, and importantly, the services and supports—particularly non-medical/clinical services—identified in Figure 4, that are critical for individuals with ABI, are in almost all cases altogether unavailable under private insurance.

Currently there is not a designated state agency which serves all people with ABI. As outlined in Figure 5, multiple state programs, run by multiple state agencies, may serve people with ABI, although most of these programs are not specialized for people with brain injuries and serve a broader population.

Figure 5. State-Funded Programs and Benefits

State-Funded Programs & Benefits					
	Program/Benefit	**Lead Agencies**	**Serves Individuals with Traumatic Brain Injuries**	**Serves Individuals with Non-Traumatic Brain Injuries**	**Serves Other Populations**
Specialized for Persons with Brain Injury	Statewide Head Injury Program (SHIP)	MRC	✓		
	Traumatic Brain Injury Waiver (TBI)	MRC MassHealth	✓		
	ABI Non-residential Habilitation Waiver (ABI-N)	MRC MassHealth	✓	✓	
	ABI Residential Habilitation Waiver (ABI-RH)	DDS, MRC MassHealth	✓	✓	
	MFP Community Living Waiver (MFP-CL)	MRC MassHealth	✓	✓	✓
	MFP Residential Supports Waiver (MFP-RS)	DDS, MRC MassHealth	✓	✓	✓
	Frail Elder Waiver (FEW)	EOEA MassHealth	✓	✓	✓
	State Home Care Program	EOEA	✓	✓	✓
	MassHealth LTSS	MassHealth	✓	✓	✓

Detailed in the subsections below are additional challenges and needs identified by the FY'19 ABI Commission.

Day Support

Both the FY '11 and FY '19 ABI Commissions documented the need for a continuum of day program supports and programs, which operate Monday-Friday, throughout the Commonwealth. While some availability of day programs exist, access is limited to those determined eligible for the MassHealth Home and Community-Based waivers; Medicaid eligibility; and eligibility for SHIP. Another very significant obstacle identified is the lack of accessible public transportation outside of

major urban locations.

The additional programs, which are specifically designed for, and provide opportunities for all individuals with ABI are needed. The overall goals and range of supports offered by day programs would potentially include, but not be limited to, the following:

- Opportunities for Socialization
- Peer Support
- Community Access/Activities
- Recreation and Sports Activities
- Wellness Programs
- Pre-vocational Training
- IADL Skills Enhancement
- Computer Training
- Facilitated Groups (e.g., Understanding ABI, Stress Management)

In addition, in some day program models, therapeutic services and other services provided by licensed clinicians and ABI specialists may be provided:

- Case Management
- Rehabilitation Therapies (e.g., PT, OT, and SLP)
- Assistive Technology Assessment and Services
- Cognitive Rehabilitation
- Medication Management Assistance

Several day program models are described below:

Brain Injury Community Centers assist members to increase natural supports, interpersonal relationships, and the utilization of resources; to become more self-sufficient through self-advocacy, education, and employment; to empower informed choices; enhance general health and wellness; and to augment independent living skills, and participate fully in, and enjoy, all aspects of their community. The FY'11 Commission recommended that the state fund five Brain Injury Community Centers across the Commonwealth. Since then, the state has funded one pilot center located in Worcester. During the Listening Sessions, overwhelming positive comments were received regarding the pilot community center and the need for this type of program in all areas of the state with emphasis on intensive case management.

The pilot community center was funded from an increase in the FY'16 state budget with specific outside language for SHIP that allowed services for individuals with ABI. The pilot community center is designed to serve adults (age 22+) who have been impacted by an ABI and is a model for additional centers. Eligibility includes documentation of an ABI as well as a referral from MRC (18) (32).

Historically the Statewide Head Injury Program developed Head Injury Centers focused on assessment of functional skills, ongoing skills training, education, support coordination and

outreach. In FY'21 these centers were discontinued, and MRC issued a new RFR for the development of four additional brain injury community centers to serve individuals with traumatic brain injury.

Brain Injury Day Support Programs are a fulfilling experience for participants in their journey through rehabilitation and reintegration into the community. These programs help people with ABI to become more functional and engaged with others. In some programs, physical, occupational, and speech therapy are provided as needed, and are overseen by licensed professionals. Day Support programs offers a wide array of supports and activities that enhance the individual's quality of life, sense of self-worth and dignity. They also provide volunteer opportunities, pre-employment skill building, career development, social and recreational services, adaptive sports, art and music therapy, community involvement, and educational assistance. Only adults with acquired brain injuries who have been determined eligible for MFP or the ABI waivers are eligible for Day Support programs. (33)

Day Habilitation services are a Medicaid benefit for individuals with developmental/intellectual disabilities and/or neurogenerative disorders. Individuals with ABI who have been determined eligible for the MFP or ABI waivers are also able to gain access to the day habilitation programs as an option for day support services. Persons served each have an individually designed service plan that outlines their support needs and personal skill-based goals. The plan is structured to encourage independence, enhance social activity, and improve the quality of individuals' lives. Services under the program could include employment, skills training, occupational training, skill development, community participation, medical supports, medication administration, physical therapy, occupational therapy and speech and language therapy. (34). Day habilitation programs have historically not been regarded as the preferred setting by individuals with ABI. Persons with ABI believe that their functional status, support needs, and goals are significantly different than those of individuals with developmental disorders, intellectual disabilities, and neurodegenerative disorders. The service and supports provided by the day habilitation programs, as they are currently designed, also do not provide appropriate supports to those who have been in the workforce, sustained a brain injury, and hope to return to the work force. Where this model is not always tailored to the needs and preferences of persons with ABI, the Commission finds that investments in other types of day programs for persons with ABI is needed.

Regionally Based Multi-Service Centers were identified as needed by participants in the FY'11 ABI Commission, including professionals, persons with ABI and family members. The regional multi-service centers would provide individuals access to clinicians and other specialists experienced and trained in working with individuals with ABI outside of the Boston region, where teaching and rehabilitation hospitals are primarily located. In response to this identified need, the FY'11 ABI Commission recommended the development of five regional multi-service centers. Needed services include outreach to individuals with ABI, case management, cognitive rehabilitation, skills training, technical assistance, training/continuing education, and clinical consultation by ABI specialists (9). To date, none of these recommended centers have been developed.

Case Management

ABI is a catastrophic event experienced by the individual and the family, which often results in lifelong cognitive, behavioral, physical, psychosocial, and financial consequences. 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. Individuals with ABI and their family members and significant others are often unfamiliar with programs and services, which may be both private and publicly funded, and/or the often-complex process for accessing them (9).

The need for case managers, who are experienced in addressing the post-acute needs of individuals with ABI, was identified as a priority by attendees at the Listening Sessions. Currently, case management may be available, depending upon private insurance benefits, during the acute treatment and/or rehabilitation period for individuals with ABI. However, during the post-acute phase, while case management is provided for SHIP-eligible individuals, HCBS waiver participants, and state Home Care Program participants, it is generally not available to individuals who are not enrolled in those programs. The vast majority of caregivers are not trained or equipped for lifetime case management or service coordination.

The Needs Assessment recommended that MRC should create Transitional Support Services to provide navigation and short-term case management, designed to support individuals to find the constellation of services that are needed. Transitional Support Services would allow MRC to conduct an initial intake to help determine, if needed, an eligibility determination for brain injury services and short-term case management (12). Transitional Support Services would help individuals to receive immediate services while waiting for eligibility under SHIP (12).

HCBS waivers

Under federal law, two basic eligibility requirements of all Home and Community Based Services (HCBS) waiver programs are: (1) financial eligibility for Medicaid (MassHealth), and (2) clinical need for facility level of care. Each of the Commonwealth's HCBS programs has additional eligibility requirements that reflect the program's unique purpose of supporting a specific population. For instance, the Frail Elder Waiver has a minimum age requirement of 60 years of age, and the two ABI Waiver programs require documentation of an acquired brain injury sustained after the applicant's 22nd birthday. The ABI and MFP waivers are unique among the state's HCBS waiver programs that they require applicants be living in a nursing facility, or a chronic disease, rehabilitation, or psychiatric hospital for at least 90 consecutive days at the time of application. This requirement reflects these programs' design to support individuals living in long-stay facility settings to move back to community-based settings (e.g., their own homes, with family, or in small group homes in the community).

Not everyone with an ABI requires a clinical level of care, but many need some type of support to be a part of their community. During Listening Sessions, many professionals commented that they often receive calls from people with an ABI or their family to request services, but those individuals do not fit the eligibility requirements for the various HCBS waiver programs.

Personal Care Services

MassHealth's State Plan Personal Care Attendant (PCA) service is a covered benefit under the State Plan, meaning that it is covered--when medically necessary--for MassHealth members as part of the standard benefit. Under MassHealth regulations, however, an individual must require physical (hands-on) assistance with two or more of seven activities of daily living (ADLs) to qualify for PCA services: mobility, bathing/grooming, dressing/undressing, passive range-of-motion exercises, taking medications, eating, and toileting. Individuals whose only need is assistance with "cueing" (a prompt to remember to perform their activities of daily living, (ADL) or other tasks, or other cognitive supports), or supervision to perform such tasks, but who do not require physical assistance, do not qualify for PCA services under the current rules. For many individuals, cueing means the difference between independent living and needing a more supervised model (12).

In the ABI-N, MFP-CL, and FEW HCBS Waiver programs, as well as in the state Home Care Program, personal care services are available to participants who require cueing and supervision. (Personal care, including cueing and supervision, is provided as part of 24/7 residential services in the ABI-RH and MFP-RS waivers.) The capacity of these programs has expanded significantly since the FY'11 Commission's recommendation to expand the MassHealth State Plan PCA service definition to include cueing and supervision. In the ABI-N, MFP-CL, and FEW waivers, for instance, capacity increased by 7,533 slots from 2011 to 2021. The Commission notes, however, that there remains an accessibility gap for the subset of individuals with ABI who are not eligible for those programs, for instance, individuals with private insurance that does not cover as broad a scope of services as covered under MassHealth, as well as MassHealth-eligible individuals who are under age 60 and do not meet HCBS waiver eligibility requirements.

Post-Acute Rehabilitation

Post-acute rehabilitation is interdisciplinary, supporting physical, cognitive, and social skills, and intensive, requiring patient participation for up to 5 to 6 hours per day, 5 to 6 days per week. Post-acute rehabilitation is considered 'transitional,' to help the injured individual transition to community re-entry and encourage the brain to recover and compensate for the damage incurred. It is geared toward improving function and helping patients return to work, live more independently, and reintegrate into the community. While early intervention (starting 3 to 12 months post-injury) is recognized as likely to provide the greatest benefit (21), rehabilitation access in the chronic stage of injury yields functional benefits as well (22) (23) (24).

Cognitive rehabilitation therapy, which is currently not covered by commercial health insurance or MassHealth, is most appropriately provided in the post-acute period. Although cognitive rehabilitation is frequently denied, and a largely uncovered rehabilitative service, after brain injury, social and vocational gains may be dependent on cognitive attainments first (25).

Senate President Emerita Harriette Chandler and Representative Kimberly Ferguson filed a cognitive rehabilitation bill in the last three legislative sessions. (An Act Improving Lives by Ensuring Access to Brain Injury Treatment) The bill requires commercial health insurance plans to cover cognitive rehabilitation for a person with an ABI. The Center for Health Information and Analysis (CHIA) reviewed the bill for a cost analysis and found that the typical member's monthly

health insurance premiums would be between $0.01 (0.003%) and $0.19 (0.040%), or an average of cost $.08 per month (35).

In November 2019, the Massachusetts Health Policy Forum at the Heller School for Social Policy and Management at Brandeis University released a policy analysis on Access to Post-Acute Rehabilitation Services for People with Acquired Brain Injury in Massachusetts and Beyond. The report's key policy recommendation is to increase access to post-acute care/rehabilitation within 3 to 12 months of a severe brain injury. The report analyzed eight studies published in the last 20 years which show that savings from access to rehabilitation for people with severe injuries ranged from $1.28 million to $2.29 million (25).

An emerging population with neurological complications associated with COVID-19 has been identified. On December 23, 2020, the Massachusetts legislature passed, and the Governor signed an omnibus health care bill that requires commercial health insurance plans, the Group Insurance Commission (GIC), and MassHealth to cover cognitive rehabilitation specifically for COVID-19 patients.

Concussion Law

A concussion is a type of TBI, caused by a bump, blow, or jolt to the head or by a hit to the body that causes the head and brain to move rapidly back and forth. Passed in July 2010, the Massachusetts sports concussion law applies to public high school and middle schools and schools affiliated with the Massachusetts Interscholastic Athletic Association (MIAA). It is designed to ensure student athletes that suffer suspected concussions receive the proper treatment and do not return to action too quickly (26). The law requires education for coaches, parents, volunteers and young athletes regarding the signs and symptoms of concussion, guidelines for managing a concussion, and information on the risks and consequences of not acting (27). Schools must also maintain and report statistics on the total number of students that sustain a concussion when engaged in any extracurricular athletic activity (27).

In 2015, as part of broader efforts to evaluate the Massachusetts concussion law, the Massachusetts Department of Public Health (DPH) engaged researchers at the Boston Medical Center's Injury Prevention Center to conduct a series of focus groups with school nurses and athletic trainers in order to identify challenges of the regulations at the local level. The study found that mandated year-end school reporting on concussion incidence to DPH, a requirement of the Massachusetts regulations, indicates that more than a third of student concussions reported were not related to extracurricular sports. The study concluded some school nurses had applied components of the regulations to all students with concussion, regardless of how, where or when the injury occurred (37).

In June 2018, DPH published "Returning to School After Concussion, Guidelines for Massachusetts Schools". This booklet provides guidance and tools for school staff, particularly teachers, guidance counselors and school nurses, as they support students in the "return to learn" process of returning to school after a concussion (36).

Provider's Work Force

At the Listening Sessions, several providers of state-funded services discussed how to improve services and resources available to persons with an ABI. Major issues raised were workforce and staffing shortages. It was noted that the skilled workforce is shrinking while the service population grows. Staff that are hired also need access to more specialized training.

Providers stated that the shortage of staff is compounded by inadequate rates. Rates do not fully address the cost of employee benefits, specialized training, and unfunded state mandates. Providers also felt they were competing with other industries that will pay more not only for entry level positions but also nursing and clinical positions.

Technical Assistance & Education

Historically, the Statewide Head Injury Program (SHIP) and the Brain Injury Association of Massachusetts (BIA-MA) have developed educational programs and trainings for community-based provider organizations regarding traumatic and other types of acquired brain injuries, their consequences and management. In addition and supported by ACL (formerly HRSA) grants awarded to MRC, educational/training curricula have been developed for service providers and other organizations regarding identified, and in some cases underserved, populations including Asians, Latinx/Hispanic and Black individuals with TBI; veterans with blast TBI sustained in military combat during the global war on terrorism; traumatic brain injury among elders; and individuals who present with the co-morbidities of substance use disorder and TBI. In response to the need to educate the expanded number of organizations providing services/supports to ABI/MFP waiver participants, the BIA-MA developed a comprehensive ABI curriculum and continuing education series in 2016. These BIA-MA educational programs and seminars are offered annually and presented by senior level clinicians and brain injury specialists.

The FY'11 & FY'19 Commission identified the ongoing need to provide technical assistance and training for service providers (e.g., mental health professional, VNA's, PCP's, home health aides and other direct care providers) particularly with respect to the cognitive/behavioral consequences of ABI which represent the most common residual long-term issue for this population, and which frequently compromise an individual's ability to access and maintain available services (9).

There is a significant need to enhance the competency of service providers and programs through technical assistance and case consultation so that they may effectively serve individuals with ABI (9). Supported by ACL systems change and TBI State Partnership grants, MRC in collaboration with the Brain Injury Association of Massachusetts, Department of Public of Health, Executive Office of Elders Affairs, and Department of Veterans Services, have strengthened services for families and individuals living with brain injury through training and technical assistance. The Needs Assessment recommended continued training efforts should provide targeted subject matter training for those in EOHHS agencies (12). Further, the Needs Assessment recommended targeted training, and conveying consistent messaging regarding available resources and services.

During the five Regional Listening Sessions, a number of themes emerged on the need for additional education, training, and community outreach. In addition, attendees stressed the need for specific

informational/educational materials to be drafted which target emergency rooms, doctor's offices, and other medical facilities.

Transportation

The lack of available and accessible public transportation can intensify the isolation experienced by many with an ABI. Numerous attendees at the Listening Sessions spoke to the hardship of being unable to leave their homes and participating in community activities, such as shopping, religious services, and social events. The lack of transportation also makes it difficult to access doctor's appointments or out-patient therapies. 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 is compounded. Non-medical transportation is a covered service in HCBS waivers, but there is currently no funding source or mechanism to provide access for a broader population to non-medical activities, including recreational opportunities (9). As a result of the COVID-19 pandemic and the increased use in telemedicine, virtual support group meetings and programming have helped to meet the needs of individuals without transportation.

Residential

Availability of residential services (residential settings that provide 24/7 staffing and support, whether in a group home setting, in the home of the individual, or in the home of the caregiver) is limited due to state funding. SHIP provides a limited number of residential homes for eligible individuals with a TBI. A presentation on SHIP's services to the FY '19 Commission documented that only 10% of SHIP eligible consumers receive residential and supported living services. Individuals in nursing homes, chronic or rehabilitation hospitals, have an opportunity to transition into community residential programs under the ABI-RH and MFP-RS residential waivers, which are operated by the Department of Developmental Services. As of December 2020, enrollment was approximately 560 for ABI-RH and 265 for MFP-RS. Adult Foster Care, covered under the MassHealth State Plan, is a residential service supporting the personal care needs of individuals who cannot safely live alone due to medical, physical, cognitive, or psychiatric needs. Unlike the residential services provided through SHIP and the TBI, ABI-RH, and MFP-RS waivers, AFC does not include habilitation (skills building) support that is often needed by individuals with ABI. 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 (9). This continuum would include such models as shared living and 24/7 residential programs (9).

Substance Use Disorder and Mental Health

One of the most common comorbid disorders exhibited by individuals who sustain ABI is substance use disorder (SUD) which, undiagnosed and unaddressed, serves to compromise recovery and functional capacity (11).

In 2018, MRC in partnership with the DPH, BIA-MA, and others were awarded an ACL grant to implement "Bridges Between." The goals of this project included: the building of collaborative connections between TBI and SUD treatment/service providers; strengthening of services for

families and individuals living with TBI and SUD; and training for staff providing services to individuals with TBI and SUD (19).

MRC conducted a survey of both MRC staff and brain injury providers in 2018 and the survey indicated that 64% of respondents felt they were equipped to support brain injured clients with a brain injury, mental health, and substance use disorder in the community (19).

Section VI: Commission Recommendations

Thousands of individuals sustain acquired brain injuries annually in the Commonwealth, and the majority are unable to access state-funded and other needed community-based services and supports. In addition, there is no designated state agency responsible for providing said services and supports for all persons who have experienced an ABI. In an effort to enhance access and expand services and supports for persons with ABI, the Commission developed and prioritized the following recommendations:

Recommendation #1: Establish an Acquired Brain Injury Advisory Board & Council

In February of 2021, a bill was filed by Senate President Emerita Harriette L. Chandler, Representative Kimberly N. Ferguson and Representative Gerard J. Cassidy to establish an Acquired Brain Injury Advisory Board. (See Appendix G)

If enacted, an acquired brain injury advisory board shall be established to collaborate with appropriate state secretariats and their agencies, members of the legislature, individuals with acquired brain injuries and their family members, providers, clinicians, advocacy groups and other key stakeholders to review, advise, and report on services and supports, and public policy for individuals with acquired brain injuries and their families.

Said advisory board directives shall include, but are not limited to, reviewing data concerning the epidemiology of acquired brain injury and the needs of individuals with acquired brain injury and their families; reviewing efforts to increase access to rehabilitative, residential and integrated community-based support services for persons with acquired brain injury; monitoring the implementation of the acquired brain injury commission recommendations regarding the improvement of such services; reviewing and advising on the annual brain injury state plan; and reviewing ongoing state public policy initiatives and state funding.

In addition, the bill calls for the establishment of an Acquired Brain Injury Advisory Council as a permanent structure within MRC to oversee the service and policy needs of those with ABI. As required by the Administration for Community Living and the US Department of Health & Human Services, 50% of the members should be comprised of survivors and family members. This council was established in May 2021.

The Massachusetts Brain Injury Council aims to review, reflect, and advise on the needs of brain injury survivors and caregivers across the Commonwealth. The work of the council is guided by the council's mission and vision, which was developed by its members with lived experiences: The mission of the council is to provide a voice for survivors of brain injury, family members and community partners to ensure policies and initiatives reflect the needs of the diverse brain injury population in the Commonwealth

Through the Brain Injury Council, four themed subcommittees were created as the focus of the strategic plan: Behavioral Health, Diversity, Equity and Inclusion, Education, and Service Needs. Each subcommittee is comprised of individuals with lived experiences, state agency representatives and community-based providers. The subcommittees discussed a variety of themes to develop the priorities and goals that will be included in Brain Injury Strategic Plan.

Recommendation #2: Invest in the Development of Programs for Individuals with ABI

A. New investments in the Statewide Head Injury Program (SHIP) to enable more individuals with traumatic brain injury (TBI) who are currently eligible or may become eligible to receive SHIP-funded state services according to their need.

The current SHIP program has an annual budget of $21,651,939 and serves 654 individuals with traumatic brain injury. Of the 654 consumers served by SHIP, approximately 10% receive residential supports, while 90% require only community supports (e.g., day center services, supported employment, homecare, and recreation).

The annual per consumer costs range from $10,000 - $15,000 for consumers requiring only community services and $100,000 – $260,000 for consumers receiving residential services. The large cost range for residential services is reflective of the varying levels of complexity and needs of the individuals served. More detailed analysis estimates that the annual per consumer costs for intensive residential service is approximately $200,000 per year, compared to approximately $60,000 per person in the Shared/Supported Living model.

Additional investments in SHIP would allow the program to serve more individuals with TBI. In order to serve newly eligible individuals based on projected demand levels described below, the SHIP program would need over $6 million in new funding annually. The demand and service assumptions used to inform the fiscal impact noted above are approximate projections only and based on limited eligibility information through MRC Connect data from a three-month period (December 2020-February 2021). This data forecasts a demand rate of 126 new consumers annually with the current service split of 20/80; approximately 20% (n=36) needing residential supports and 80% (n=90) needing only community services (e.g., day center services, supported employment, recreation).

The cost estimates across a four-year period (FY22-FY25), outlined in the table below, also assume an increase in the number of consumers with residential needs served in the lower-cost. Shared/Supported Living Service models which would ultimately allow more individuals to access these services. The projected annual costs also include a modest increase in funding (~$1 million) for additional MRC personnel and staff training that would be needed to serve this expanded population.

The four-year expansion of additional SHIP services needs to be incremental and purposefully implemented. The development of infrastructure will be key in initial years, hiring and training a new team to deliver supports to newly engaged SHIP consumers.

The table below illustrates in more detail projected growth and total costs for expanding the SHIP program over a four-year period.

	Consumers Supported Projection			Program Cost Projections		
	Consumers	Using Residential Services - **20%**	Using Day and Community Services (excl. Residential) - **80%**	Consumer Cost	Program Support Cost	Total Cost Per Year
Current State:						
FY21 - Consumers Receiving Services	**654**	**135**	**519**			
Future State - Projection:						
FY22 126 individuals	**126**	**36**	**90**	6,133,171.00	187,250.00	6,320,421.00
Memo: Cumulative Consumer Supported	*780*	*171*	*609*			
FY23- 126 new individuals	**126**	**36**	**90**	6,133,171.00	187,250.00	6,320,421.00
Memo: Cumulative Consumer Supported	*906*	*207*	*699*			
FY24 – 126 new individuals	**126**	**36**	**90**	6,133,171.00	187,250.00	6,320,421.00
Memo: Cumulative Consumer Supported	*1,032*	*243*	*789*			
FY25- 126 new individuals	**126**	**36**	**90**	6,133,171.00	187,250.00	6,320,421.00
Memo: Cumulative Consumer Supported	*1,158*	*279*	*879*			
Total New Consumers Served	**504**	**142**	**360**			

Pending legislative authority MRC can support individuals with Acquired Brain Injury through MRC's funded Brain Injury Community Centers, integrating individuals with different types of acquired brain injuries in addition to those with TBI.

B. To further explore the need to serve individuals with Acquired Brain Injuries (ABI) with the full array of services, MRC will conduct a person-centered analysis of individual service needs for those with ABI, combined with a comprehensive cost analysis to determine the needed funding resources to further expand services for individuals ABI.

C. Establish a new budget appropriation line item with additional funding to serve individuals with all types of ABI, including but not limited to, creating regional Brain Injury Community Centers, MRC Multiservice Centers, and other day services and supports.

D. Once additional funding resources are determined, MRC would be committed to revise the regulations of the State Head Injury Program and expand the definition for those who are eligible to include all persons with acquired brain injury in addition to those who have experienced traumatic brain injury.

E. Regional Multi Service Centers

The FY '11 ABI Commission documented the need for access to clinical specialists, case management services, rehabilitation therapists, and other professionals experienced in working with individuals who have experienced an ABI. These professionals are available in the Boston region primarily, but not available in most regions of the Commonwealth, except for limited clinical consultation and technical assistance services which have been

historically provided by SHIP. The FY'11 Commission therefore, recommended that five (5) regionally based ABI Multiservice Centers be developed, and that these centers provide needed expertise to individuals with ABI and their families.

The menu of services to be provided would potentially include the following:

1. Specialized Case Management for persons with ABI
2. Assessment and Clinical Consultation by ABI specialists, including clinical neuropsychology, speech and language pathology, behavioral psychology, and neuropharmacology
3. Time-limited group, post-acute rehabilitation (e.g., cognitive rehabilitation sessions for concussion and other neurocognitive disorders)
4. Psychotherapy, facilitated Support Groups, and Family Counseling
5. Assistive Technology Assessments (e.g., cognitive orthotics; computer-assisted programs)
6. Technical Assistance and Training for community-based providers
7. Case Consultation

Anticipated Costs: *It is anticipated that the ABI Multiservice Centers would be supported with blended funding. Specifically, this would include a state-funding and reimbursement through MassHealth, Medicare and commercial insurers for clinical services provided by licensed clinicians. It is recommended that an RFR be developed and issued to fund one pilot Multiservice Center to serve as a model for the Commonwealth. A community-based organization with a licensed clinic would be the preferred provider, with respect to developing this model.*

$ 1,000,000 estimated per center *Total Funding: $5M estimated*

F. Brain Injury Day Supports

Since 2011, the ABI Brain Injury Commission has documented the need for day supports and day services designed to meet the needs of individuals with ABI. These services should be accessible geographically and provide short-term supports for people with mild brain injuries, as well as long-term support, for those with moderate-severe consequences of injury.

It is recommended that additional models for day supports be developed, including models that would enhance services for individuals with ABI.

G. Brain Injury Community Centers

The Massachusetts Rehabilitation Commission issued an RFR in 2021 to develop four additional Brain Injury Community Centers. It is recommended that four (4) additional programs, inclusive of transportation, be developed and/or enhanced to serve individuals with acquired brain injury.

Recommendation #3: Expansion of Head Injury Treatment Services Trust Fund

A. File legislation authorizing 100% of revenues collected for Operating Under the Influence of Alcohol (OUI) and Driving Under the Influence of Drug (DUI) offenses to be deposited in the Head Injury Treatment Services (HITS) Trust Fund.

B. File legislation to increase and stagger fines for multiple offenses of Speeding, Driving to Endanger, Operating Under the Influence of Alcohol (OUI) and Driving Under the Influence of Drug (DUI) or other possible funding sources for the Head Injury Treatment Services (HITS) Trust Fund.

C. File and monitor roadway safety legislation that include a percentage of fines collected to be deposited in the Head Injury Treatment Services (HITS) Trust Fund. (i.e., amendment of Hands-Free Law; Primary Seat Belt Bill).

Recommendation #4: Update of Epidemiological Data on Acquired Brain Injury Every Five Years

As recommended by the FY '11 Commission, an epidemiological study of acquired brain injury in Massachusetts was completed in 2014 by the Massachusetts Department of Public Health (DPH) in collaboration with the Massachusetts Rehabilitation Commission (MRC). Hospital-based discharge data for three consecutive years (2008-2010) of emergency department, observational and inpatient stays were analyzed with respect to affected age groups, gender, geographic region, payer source, and disposition for all major categories of ABI.

A team of DPH epidemiologists and clinicians developed the methodology utilized for this study, as well as inclusion/exclusion criteria for the diagnoses from the International Classification of Diseases (ICD-9-CM) and ICD for Oncology (ICD-0), which included all diagnoses utilized for eligibility for the ABI waivers.

As was recommended by the FY '11 Commission, and in order to inform the development of services and programs for persons with ABI, it is recommended that the epidemiology of ABI in Massachusetts be updated every five years by DPH, preferably utilizing the methodology established in 2014 and the revised ICD-10-CM codes.

Recommendation #5: Establish and Fund a Traumatic Brain Injury Registry

It is recommended that the state establish a Traumatic Brain Injury (TBI) Registry either through modification of the existing state trauma registry or the development of a standalone registry. There are registries in the state for stroke and cancer (brain tumor); however, for the leading cause of TBI, there is no registry. Data from the registry will be used to identify individuals in a timely manner who can benefit from services and the provision of information on these services. Currently many individuals are not aware of the services available or may find out about them many years after their injury. The registry can also be used to monitor counts of individuals treated for TBI, and the severity with these TBI's, trends, demographic disparities, causes, long term outcomes, and hospital charges associated with these events.

It is recommended that the Massachusetts Department of Public Health (DPH), in collaboration with the Massachusetts Rehabilitation Commission (MRC) and the Brain Injury Association of Massachusetts (BIA-MA), develop a plan for identification and outreach of individuals with TBI as well as determining the data points to be collected. Outreach activities should ensure that racial/ethnic minorities and other underserved populations be included in planning and implementation efforts for the registry.

Recommendation #6: Enhance Access to Cognitive Rehabilitation

One of the most common long-term consequences of acquired brain injury is residual cognitive impairment. There is a lack of access for brain injury survivors for cognitive rehabilitation which currently is not typically included as a mandated benefit. Per the recommendation of the FY'11 Commission the following companion bills (S629-H1078) were filed by Representative Kimberly N. Ferguson and Senate President Emerita Harriette L. Chandler requiring commercial health insurance plans to cover cognitive rehabilitation for individuals with ABI. The Center for Health Information and Analysis (CHIA) reviewed the bill for a cost analysis and found that the typical member's monthly health insurance premium would be between $.01 (0.003%) and $0.19 (0.040%), or an average cost of $0.08 per month ($0.08) (35). Based upon a separate cost analysis, it is recommended that cognitive rehabilitation be considered as a covered service by MassHealth.

Recommendation #7: Opportunities to Increase Access to Cueing and Supervision Supports

It is recommended that the Massachusetts Rehabilitation Commission (MRC) and MassHealth establish a joint working group to identify the size and characteristics of the population of persons with brain injury in the Commonwealth who may need cueing and supervision to complete activities of daily living but not hands on assistance, and are unable to access programs that provide this support (e.g., AFC, MassHealth integrated care plans, HCBS waiver programs, and the state Home Care program). It is further recommended that this analysis be completed within 12 months, and that the Executive Office of Health and Human Services (EOHHS) provide a clear inventory of the services that provide cueing and supervision and based on the analysis of the working group determine whether there are unmet needs that require further evaluation of current services.

Recommendation #8: Revise Concussion Law

The majority of individuals who sustain a traumatic brain injury (TBI) are diagnosed with a mild TBI or concussion. The Massachusetts Youth Sports Concussion Law went into effect in July of 2010 in an effort to promote the prevention, identification, consistent evaluation, and management (e.g., criteria for return to play) of a TBI sustained during an extracurricular (e.g., marching band) or athletic activity. This law and corresponding regulations only apply to students in grades 6 through high school who participate in extracurricular sports and affiliation with MIAA.

A. It is recommended that the state ensure that all students including those who are not engaged in extracurricular sports who sustain a concussion are provided return to learn accommodations.

B. It is recommended that strategies be developed to ensure improved compliance with the existing concussion law. The Massachusetts Department of Public Health (DPH) has documented less than optimal response outcomes related to sports-related concussion,

with 49.5% of youth who reported symptoms (e.g., loss of consciousness, headache, vision problems) of concussion continuing to play sports on the day of injury (37).

Recommendation #9: Enhance Education and Training regarding ABI provided by Brain Injury Specialists

Training and education, provided by brain injury specialists, to clinicians and other professionals; staff of residential, day and other community-based programs; and others (e.g., mental health center staff) responsible for providing services to individuals with acquired brain injury remains an ongoing need. Suggested training and education opportunities should include, but not be limited to, the following:

A. MRC with the guidance of the Advisory Council will recommend required staff training for providers and agency staff to better address the different types of acquired brain injuries and their physical, behavioral and cognitive consequences.

B. Educational seminars for families, significant others, and persons with ABI: Given the documented short lengths of stay in hospital-based programs, as well as the fact that most individuals who have experienced an ABI have not had the benefit of comprehensive rehabilitation and/or access to brain injury specialists, the FY'19 Commission identified the need for information regarding resources, services, and the consequences of ABI for families, significant others, and persons with ABI. Informational sessions should be held regionally and provided by brain injury specialists, including case managers.

C. Training for hospital-based staff regarding available resources for persons with ABI: These trainings should include information regarding the ABI and MFP waivers; BIA-MA; SHIP and other state-funded programs and services.

D. Topic-specific training/educational programs, as well as person-specific technical assistance, for Executive Office of Health and Human Services (EOHHS) agency staff, providers, vocational rehabilitation counselors, schools and other community-based agencies and service providers.

Anticipated Costs: *It is recommended that $600,000 be designated and overseen by MRC and cost shared with DDS to implement these training initiatives to be offered by qualified education and training providers.*

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Appendix A

42 U.S.C. 300d-52 - State grants for projects regarding traumatic brain injury

(a) In general

The Secretary, acting through the Administrator of the Health Resources and Services Administration, may make grants to States and American Indian consortia for the purpose of carrying out projects to improve access to rehabilitation and other services regarding traumatic brain injury.

(b) State advisory board

(1) In general

The Secretary may make a grant under subsection (a) of this section only if the State or American Indian consortium involved agrees to establish an advisory board within the appropriate health department of the State or American Indian consortium or within another department as designated by the chief executive officer of the State or American Indian consortium.

(2) Functions

An advisory board established under paragraph (1) shall advise and make recommendations to the State or American Indian consortium on ways to improve services coordination regarding traumatic brain injury. Such advisory boards shall encourage citizen participation through the establishment of public hearings and other types of community outreach programs. In developing recommendations under this paragraph, such boards shall consult with Federal, State, and local governmental agencies and with citizens groups and other private entities.

(3) Composition

An advisory board established under paragraph (1) shall be composed of—

(A) representatives of—

(i) the corresponding State or American Indian consortium agencies involved;

(ii) public and nonprofit private health related organizations;

(iii) other disability advisory or planning groups within the State or American Indian consortium;

(iv) members of an organization or foundation representing individuals with traumatic brain injury in that State or American Indian consortium; and

(v) injury control programs at the State or local level if such programs exist; and

(B) a substantial number of individuals with traumatic brain injury, or the family members of such individuals.

Appendix B

FY ’11 Acquired Brain Injury Commission

The FY ’11 brain (ABI) Commission was originally established in outside section 160 of the FY2011 budget and was approved by Governor Deval Patrick on June 30, 2010. The first amendment clarified and expanded the Commission membership, and 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.

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.

FY '19 Acquired Brain Injury Commission

The FY '19 Acquired Brain Injury (ABI) Commission was authorized by FY '19 budget, outside section 76 and was signed by Governor Charlie Baker on July 26, 2018. The first amendment extended the timeline for submission of a report to the Legislature.

SECTION 76 There shall be a special commission governed by section 2A of chapter 4 of the General Laws to: (i) review data concerning the epidemiology of brain injury and the needs of individuals with acquired brain injury and persons with traumatic brain injury and their families; (ii) analyze the current status of rehabilitative residential and integrated community-based support services for persons with acquired brain injury and persons with traumatic brain injury; and (iii) make recommendations regarding the improvement of such services.

The commission shall consist of the following members or their designees: 2 members of the house of representatives, 1 of whom shall be appointed by the minority leader; 2 members of the senate, 1 of whom shall be appointed by the minority leader; the secretary of health and human services; the assistant secretary of the office of disabilities and community services; the commissioner of public health; the commissioner of the Massachusetts rehabilitation commission; the secretary of elder affairs; the secretary of veterans services; the executive director of the Brain Injury Association of Massachusetts, Inc.; and 8 persons to be 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.

The commission shall review the recommendations of the special commission established in section 160 of chapter 131 of the acts of 2010 and provide any updates to the recommendations. The commission shall also review the availability, nature and adequacy of the following services for the target population: (i) acute and long-term medical and cognitive rehabilitation and outpatient services; (ii) therapy services; (iii) residential nursing care; (iv) structured day treatment and day activity programs; (v) club programs; (vi) respite care services; (vii) community-based housing; (viii) home-based services; (ix) family support programs; (x) case management; (xi) companion services; (xii) personal care attendant services; (xiii) specialized medical equipment and supplies; (xiv) environmental modifications; (xv) counseling and training; and (xvi) prevocational services.

The commission shall file a report of its findings and recommendations, together with drafts of legislation necessary to carry those recommendations into effect, by filing the same with the clerks of the senate and the house of representatives and the chairs of the senate and house committees

on ways and means not later than June 30, 2019. The report shall include, but not be limited to, findings regarding the cost of maintaining or establishing recommended services and the drafts of legislation shall include proposals to implement or allow for the development or expansion of services for the target population.

First Amendment: Section 76 of chapter 154 of the Acts of 2018

Representative Gerard Cassidy Section and Senator Harriette each filed amendments to 76 of chapter 154 of the acts of 2018 to strike out the words “June 30, 2019” and inserting in place thereof the following words: "April 1, 2020"

Second Amendment: Section 76 of chapter 154 of the Acts of 2018

Representative Kimberly Ferguson filed amendments to Section 76 of chapter 154 of the acts of 2018, as most recently amended by section 36 of chapter 142 of the acts of 2019, is hereby amended by striking out the words “April 1, 2020” and inserting in place thereof the following words: “December 31, 2020”.

Appendix C

Commission Members

Member of the General Court

Senate President Emerita Harriette L. Chandler, Co-Chair
Representative Kimberly N. Ferguson, Co-Chair
Senator Dean Tran*
Representative Gerard Cassidy

Governor's Appointees

Beth Adams, M.Ed, LRC
Neurotrauma Rehabilitation Specialist/Program Manager
Massachusetts General Hospital

Imiogele P. Aisiku MD MBA
Emergency Medicine**,** Pulmonary and Critical Care
Brigham and Women's Hospital

Nicole Godaire, CBIS
Chief Executive Officer
Brain Injury Association of Massachusetts (BIA-MA)

Ted Johnson
Former NFL player
Brain Injury Survivor

Dr. Swathi Kiran, PhD, CCC-SLP
Associate Dean for Research
Professor in Neurorehabilitation
Boston University

Adelaide Osborne
Former Commissioner
Massachusetts Rehabilitation Commission

Helene Robillard
Support Group Leader
Brain Injury Survivor

Marilyn Price Spivack
Family member
Founder of Brain Injury Association of America
Brain Injury Association of Massachusetts
Spaulding Rehabilitation Hospital

David Urion, MD, FANN
Associate, Department of Neurology
Boston Children's Hospital

Ex-Officio State Agency Representatives

Dorothée Alsentzer
Deputy Director
Home and Community Based Services Waivers
MassHealth

Carole Malone
Assistant Secretary
Executive Office of Elder Affairs

Lauren Peters
Undersecretary
Executive Office of Health and Human Services

Yves Singletary
Deputy Director
Bureau of Community Health & Prevention
Department of Public Health

Francisco Ureña**
Secretary
Department of Veteran Services
Former Marine

Toni Wolf
Commissioner
Massachusetts Rehabilitation Commission

*Senator Dean Tran was not re-elected in November 2020.

**Secretary Francisco Ureña resigned in June 2020.

Appendix D

FY '19 ABI Commission Meeting Presentations and Speakers

April 1, 2019

State Ethics Commission
David Giannotti, Division Chief, Public Education and Communications

Open Meeting Law
Lauren Cleary, Associate General Counsel, Executive Office of Health and Human Services

Robert Jones, Deputy Chief of Staff, Executive Office of Health and Human Services

Brain Injury Commission—Brain Injury Epidemiology Report (November 24, 2011) and Needs Assessment (November 2017)

Nicole Godaire, Chief Executive Officer, Brain Injury Association of Massachusetts

Board Members Discussion of Next Steps and Focus of Future Meetings

May 6, 2019

Overview of Services Offered by State Agencies

Home and Community Based Services Waivers--MassHealth
Dorothée Alsentzer, Deputy Director, Home and Community Based Services Waivers, MassHealth

Massachusetts Rehabilitation Commission--Statewide Head Injury Program
Toni Wolf, Commissioner

Frail Elder Waiver—Executive Office of Elder Affairs
Carole Malone, Assistant Secretary Elder Affairs

Department of Public Health
Yves Singletary, Bureau of Community Health & Prevention

Veteran Affairs
Francisco Ureña, Secretary, Department of Veteran Services

June 3, 2019

Emergency Medicine and Acute Care
Dr. Imoigele Aisiku, MD, MBA Brigham and Women's Hospital

Continuum of Brain Injury Rehabilitation and Care
Beth Adams, Neurotrauma Rehabilitation Specialist/Program Manager

Rehabilitation Hospitals and Inpatient Rehab Facilities
Dr. Chris Carter, Ph.D., Spaulding Rehabilitation Hospital

Community Based Services, Day Programming, Residential Supports
Michelle Martin and Tony Simonelli, Brockton Area Multi-Services, Inc. (BAMSI)

July 9, 2019

Community Based Services, Therapy, Case Management
Eileen Chernoff and Ann Gillespie, Community Rehab Care

September 10, 2019

Mild Traumatic Brain Injury and Blast Exposure in Context: Deployment Trauma in Post 9/11 Veterans
Regina McGlinchey, PhD, and Walter Musto, CMSgt (RET) RING

Regional Meetings Review and Discussion

October 1, 2019

Sports Concussions, Their Sequelae, Where Do We Go From Here
Beth Adams, Neurotrauma Rehabilitation Specialist/Program Manager

November 12, 2019

State Insurance Providers
Whitney Moyer, Chief, MassHealth OLTSS
David Adam Russe, LMSW, Heath Systems Manager Tricare
Matthew Veno, First Deputy Commissioner, Division of Insurance

December 9, 2019

HomeBase
Alexis Iaccarino, MD

Massachusetts Rehabilitation Commission
Commissioner Toni Wolf
Lindsay Hough and Amanda Harris, Deloitte Consulting, LLC

February 6, 2020

Commission Review of Presentations & Recommendations

February 24, 2020

Commission Review of Presentations & Recommendations

Appendix E

Listening Sessions

VA Brockton Healthcare System	July 15, 2019
The Gloucester House	July 22, 2019
Berkshire Community College	August 12, 2019
Worcester City Hall	August 26, 2019
Massachusetts State House	September 10, 2019

Appendix F

Listening Session Feedback

SHIP/MRC

- 2 people mentioned help needed at SHIP to fill out the application. Revise application.
- SHIP services needed faster, not waiting over a year.
- Time to change criteria for SHIP services to cover all ABI.
- SHIP database needed.
- Improve communication between SHIP and consumers.
- SHIP needs better funding.
- Days Services—problem arises when people do not attend for various reasons. Fixed everyday costs do not go away. More flexible model needed.
- People coming to day programs, sometimes need more than 1-1. Not just money, hire a resource coordinator.
- Help with navigating the system.
- State agencies better share information.
- 4 people praised New Start Center but wanted more funding to add new centers in state.
- Telehealth example if unable to fund more New Start programs?
- Club House with 24-hour setting?
- Educate individuals on navigating the system.
- Need robust service delivery system.
- Better employment services from MRC.
- 3 people testified about the gaps in services and wishing for better access to services.
- Any federal money to help states provide better services for people with BI.
- Improve assistive technology.
- Better training for state staff for people with disabilities.
- System of Care---confusion---people do not know how to get from point A to point B.
- Pleased with programs offered at BIA.
- Funds needed for SHIP to help more with mental health issues.

Concussions

- 2 people mentioned Baseline concussion testing.
- Educate teachers on BI and concussions.

Waiver Programs

- Better training for state staff for people with disabilities.
- ABI waiver needs to be changed.

Medical Community

- Individuals in the medical field not educated enough about state services.
- Have medical schools educate students more on BI and ABI.
- In service training for Mass Medical Society.
- Every case worker at discharge should recommend SHIP or MassHealth and give support at this point for filling out the forms. Inform them about BIA.
- Additional education for doctors in the western part of the state on TBI/concussions.
- Provide information materials for patients/families at the ER, doctor's offices etc.
- Education for professionals on ABI/TBI.
- ERs need to distribute information on BI and BIA-MA.
- Berkshire County has a severe shortage of doctors/providers for BI.
- ERs need to distribute information better.
- Doctors needed in Berkshires. Incentives for medical students to move out to western part of state.
- Help doctors better understand the invisible injury.
- Hand-out should be given out—include info on provider resources, what services are available. Train doctors and their staff to talk about services.
- Educate doctors with continuing education forum.
- Misdiagnosis of BI in MA compared with NY.
- Communication needs to be improved between medical community and survivors/families.
- Better information needs to be shared with BI survivor and family members.
- Educate doctors and families better. Make sure people know about BIA support groups.

Elderly

- Focus recommendations for elderly with BI.
- Interagency activities between Elder Affairs---TBI with the aging community. Think outside the box.
- Increase services for people aging with BI.
- Funding needed with the coalition with BI and aging.

Youth/Schools

- More focus on sports related TBIs and TBIs for children.
- Focus recommendations for young kids with BI.
- Better education for schools on BI.
- Employers and schools need more info on BI.

Veterans

- Veterans and coordinated education on BI.

- Veterans with BI need to work better with Veterans Administration for western residents.

Transportation

- 8 speakers mentioned need for better transportation
- Uber/Lyft to help with transportation

Regional Issues

- Medical specialists in brain injury/concussion needed for the southeastern part of MA. Spaulding location in Sandwich needs more doctors.
- Housing problems in various parts of the state.
- Berkshire Medical needs to change protocol for dealing with people with BI.
- Lack of service providers in the western part of the state.
- Baystate support group in Springfield is vital.
- Western hospital did not tell family about BIA.

Opioids and Mental Health

- Skilled professionals needed with background also in mental health, drugs/alcohol, and BI.
- Mental health and BI agencies work together. Better understand these communities.
- Better support for cooccurring conditions. DDS and substance abuse.
- Coordination between DDS, MassHealth, MRC and UMass---coordination of staff also the BI world and SUD.
- Jails should ask if one has had a BI/substance abuse.

Cognitive Rehabilitation

- 2 people spoke about cognitive rehabilitation covered by insurance and more facilities/providers offering the service.

Providers

- Better the infrastructure for providers.
- Staff in residential facilities need more training on BI.
- 4 testified about the staffing crisis in nursing homes, facilities…. Wages need to be increased. Need to increase funding rates.
- Amounts need to be adjusted for new residential development.
- 2 testified about the need for more money when new person added to home.
- Not all facilities are used for MA residents in western part of state.

- Change the 90-day requirement in a nursing home so more people can be eligible for services.

- Peer support in residential homes.
- Rate provisions---problems for nurses and behavioral specialists.
- Occupancy rates.
- Reexamine the ABI waiver for the 90-day requirement in a nursing home.

Miscellaneous

- MassHealth vs. Medicare for survivor.
- Guardianship for adult survivor because refuses to go into residential home.
- 2 comments on 1st responders and need for better education.
- Should fire, police and ER people speak before Commission.
- Help with legal issues surrounding domestic violence/divorce/restraining orders.
- Law school students to help with legal issues in western part of the state.
- Legal assistance for person or family.
- Introduce/promote alternative medicine to aide one in recovery and living after BI.
- Convince insurance to cover alternative medicine.
- Should there be a federal agency to lead states with a different lead agency in the state.
- State card to show one has a BI.
- More support groups in the state.
- Pay care givers
- 4 spoke about the need for more education.
- Help fund BIA-MA more.
- BIA's support groups are awesome, could always use more of them.
- Felt she was part of the tribe once she found BIA.
- Increase public education on BI not just focus on concussions.
- Increase education for caregivers.
- Issue surrounding pensions and collecting early because of a BI. (person could not collect social security because never paid into it)
- Fishing fees
- Disability insurance and coverage for BI.
- Aging parents caring for child with BI. Child is self-sufficient but cannot live on own. Residential options
- Make TBI not the invisible injury.
- Teach people to better advocate for themselves.

Appendix G

State Programs Supporting People with Acquired Brain Injury

This appendix provides information on the Statewide Head Injury Program (SHIP), the State Home Care program, MassHealth-covered long-term services and supports (LTSS), and six Home and Community Based Services (HCBS) waiver programs in the Commonwealth that serve individuals with brain injury.

Statewide Head Injury Program

The Statewide Head Injury Program (SHIP) is one of the programs of the Massachusetts Rehabilitation Program (MRC) Community Based Services.

SHIP provides a range of community-based services for people who have sustained a TBI including skills training, adult companion, residential services, shared living, and a regional service center.

To be eligible for SHIP services you must

- be a resident of Massachusetts
- have a confirmed traumatic brain injury
- have difficulty managing your everyday life since the injury
- document the difficulties are caused by the brain injury
- be willing and able to participate in and benefit from services

SHIP's budget is determined annually by the state legislature. The program is not available immediately to all those eligible. Some individuals remain eligible without services for a period of time.

Traumatic Brain Injury (TBI) waiver

The Traumatic Brain Injury (TBI) waiver began in 2001 and is operated by Massachusetts Rehabilitation Commission. This waiver serves up to 100 participants each year. The TBI waiver provides community-based services to Medicaid eligible person with traumatic brain injury.

The TBI waiver helps people who have a traumatic brain injury and who want to live in the community. To be eligible, people must require a facility level of care (nursing facility or hospital). Waiver services are set up to provide extra help. Waiver members can also use state services and the informal support of families and caregivers.

Eligibility requirements are:

- Must be 18 or over and have experienced a TBI
- Meet the clinical requirements (require a nursing facility or hospital level of care for brain injury)
- Need TBI waiver services
- Be able to be safely served within the terms of the TBI waiver
- Meet the financial requirements to qualify for MassHealth Standard in the community (special financial rules exist for waiver applicants and participants)

Acquired Brain Injury waivers

Massachusetts Rehabilitation Commission, Department of Developmental Services, and MassHealth, in conjunction with UMass Medical School, offer two acquired brain injury (ABI) home and community-based services waivers to help MassHealth-eligible person with ABI move from a nursing facility or chronic disease or rehabilitation hospital back to their community. The ABI waivers help by making the move from the facility to the community easier and by providing community-based services.

The two ABI waivers are

- **ABI–Residential Habilitation (ABI-RH)** – for people who need supervision and staffing 24 hours a day, seven days a week in a provider-operated residence
- **ABI–Non-residential Habilitation (ABI-N)** – for people who can move to their own home or apartment or to the home of someone else and receive services in the community.

To qualify for one of the ABI waivers, an individual must

- Be living in a nursing facility or in a chronic or rehabilitation hospital for at least 90 days
- Meet clinical eligibility requirements (require a nursing facility or hospital level of care)
- Have experienced an acquired brain injury at age 22 or older. An acquired brain injury can result from a stroke, brain trauma, infection of the brain (such as encephalitis), brain tumor, or anoxia (lack of oxygen)
- Need ABI waiver services
- Be able to be safely served in the community within the terms of the ABI waivers
- Meet the financial requirements to qualify for MassHealth Standard in the community (special financial rules exist for waiver applicants and participants)

Also, for the ABI-RH waiver, the person must need residential support services with staff supervision 24 hours a day, 7 days a week

Moving Forward Plan waivers

The Moving Forward Plan (MFP) waivers are home- and community-based services waivers designed to help MassHealth-eligible persons move from a nursing facility, or chronic disease, rehabilitation, or psychiatric hospital back to their community. The MFP waivers help by making the move from the facility to the community easier and by providing community-based services.

The two MFP waivers are:

- **MFP Residential Supports (MFP-RS) waiver** – for people who need supervision and staffing 24 hours a day, seven days a week in a provider-operated residence.
- **MFP Community Living (MFP-CL) waiver** – for people who can move to their own home or apartment or to the home of someone else and receive services in the community.

To qualify for one of the MFP waivers, an individual must

- Be living in a nursing facility or in a chronic disease, rehabilitation, or psychiatric hospital for at least 90 days
- Either be 18 years of age or older and have a disability or 65 years of age or older
- Meet clinical requirements (require a nursing facility or hospital level of care)
- Need MFP waiver services
- Be able to be safely served in the community within the terms of the MFP waivers
- Meet the financial requirements to qualify for MassHealth Standard in the community (special financial rules exist for waiver applicants and participants)

Also, for the MFP-RS waiver, the person must need residential support services with staff supervision 24 hours a day, 7 days a week.

Frail Elder Waiver

The Executive Office of Elder Affairs (EOEA) operates the Frail Elder Waiver for MassHealth-eligible elders who need in-home supports to successfully age in place, often helping elders to avoid institutionalization as their needs increase. FEW supports individuals with a variety of needs that can be met with supports ranging from basic to intensive levels. To qualify for the Frail Elder Waiver, an individual must

- Either be age 60-64 years of age and have a disability, or be 65 years of age or older
- Meet clinical requirements (require a nursing facility level of care)
- Need FEW services
- Be able to be safely served within the terms of the FEW
- Meet the financial requirements to qualify for MassHealth Standard in the community (special financial rules exist for waiver applicants and participants)

Home Care Program

The Executive Office of Elder Affairs (EOEA) operates the state Home Care Program provides care management and in-home support services to help older adults, people with disabilities, and people with Alzheimer's Disease or related dementia successfully age in place within Massachusetts. Eligibility for the Home Care Program is based on age, residence, and ability to carry out daily tasks. Care management and in-home services support adults 60 years and older or residents aged under 60 with early on-set Alzheimer's disease or related dementia.

MassHealth Long Term Services and Supports (LTSS)

Where medically necessary, MassHealth members have access to a range of in-home and community-based long-term services and supports as part of their covered benefit. Many of these services are relevant for persons with ABI—for example PCA services, adult day health, adult foster care, and a wide range of medical equipment.

Appendix H

SENATE DOCKET, NO. 2471 FILED ON: 2/19/2021

SENATE . . . . . No. 83

The Commonwealth of Massachusetts

PRESENTED BY:

Harriette L. Chandler

To the Honorable Senate and House of Representatives of the Commonwealth of Massachusetts in General Court assembled:

The undersigned legislators and/or citizens respectfully petition for the adoption of the accompanying bill:

An Act to establish an acquired brain injury advisory board.

PETITION OF:

NAME:	DISTRICT/ADDRESS:	
Harriette L. Chandler	*First Worcester*	
Susan Williams Gifford	*2nd Plymouth*	*3/3/2021*
Patrick M. O'Connor	*Plymouth and Norfolk*	*3/3/2021*
Joanne M. Comerford	*Hampshire, Franklin and Worcester*	*3/5/2021*
Walter F. Timilty	*Norfolk, Bristol and Plymouth*	*3/17/2021*
Adam Gomez	*Hampden*	*9/9/2021*

SENATE DOCKET, NO. 2471 FILED ON: 2/19/2021

SENATE . . . . . No. 83

By Ms. Chandler, a petition (accompanied by bill, Senate, No. 83) of Harriette L. Chandler, Susan Williams Gifford, Patrick M. O'Connor, Joanne M. Comerford and others for legislation to establish an acquired brain injury advisory board. Children, Families and Persons with Disabilities.

The Commonwealth of Massachusetts

In the One Hundred and Ninety-Second General Court
(2021-2022)

An Act to establish an acquired brain injury advisory board.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

SECTION 1. An acquired brain injury advisory board shall be established to collaborate with appropriate state secretariats and their agencies, members of the legislature, individuals with acquired brain injuries and their family members, providers, clinicians, advocacy groups and other key stakeholders to review, advise, and report on services and supports, and public policy there under for individuals with acquired brain injuries and their families.

SECTION 2: Said advisory board shall consist of 2 members of the Senate, 1 of whom shall be appointed by the President, 1 of whom shall be appointed by the Minority leader; 2 members of the House of Representatives, 1 of whom shall be appointed by the Speaker, 1 of whom shall be appointed by the Minority leader; the Secretary of Health and Human Services or their designee; the Secretary of the Executive Office of Public Safety or their designee; the Secretary of Elder Affairs or their designee; the Secretary of Veterans Services or their designee; the Commissioner of the Department of Public Health or their designee; 2 members from the Massachusetts Rehabilitation Commission, 1 who shall be the Commissioner or their designee, 1 who shall be appointed by the Commissioner; the Commissioner of the Department of Developmental

Services or their designee; the Commissioner of the Department of Mental Health or their designee; the MassHealth Director or their designee; the Chief Executive Officer at the Brain Injury Association of Massachusetts, Inc. or their designee; and 8 members who shall be appointed by the Governor, 2 of whom shall be family members, caretakers or significant others of a person with acquired brain injury, 2 of whom shall be individuals with acquired brain injury, including but not limited to individuals who have experienced traumatic brain injury, stroke, brain tumors or other disorders, 1 of whom shall be a community based provider of services to individuals with acquired brain injury 1 of whom shall be a community based provider of services to individuals with acquired brain injury serving minorities and other underserved populations, 1 of whom shall be from a disability advisory group or a protection and advocacy representative, 1 of whom shall be a clinician.

SECTION 3. Said advisory board directives shall include, but are not limited to, reviewing data concerning the epidemiology of acquired brain injury and the needs of individuals with acquired brain injury and their families; reviewing efforts to increase access to rehabilitative, residential and integrated community based support services for persons with acquired brain injury; monitoring the implementation of the acquired brain injury commission recommendations regarding the improvement of such services; reviewing and advising on the annual brain injury state plan; and reviewing ongoing state public policy initiatives and state funding.

SECTION 4: A brain injury council shall be established and supported by the Massachusetts Rehabilitation Commission. Said council shall consist of members meeting criteria as required by the Administration for Community Living & the U.S. Department of Health and Humans Services (42 U.S.C. 300d-52) and shall include individuals and families with acquired brain injury. Said council shall report to said advisory board.

SECTION 5: Said advisory board shall file a bi-annual report with the Governor, the Secretary of the Executive Office of Health and Human Services, the Senate President, the Speaker of the

House of Representatives, and the clerks of the Senate and House of Representatives. Said report shall include but not be limited to a summary of ongoing needs of individuals with acquired brain injury, the status of progress made in increasing access to rehabilitative, residential and integrated community-based support services for individuals with acquired brain injury; and the status of progress made in implementing the acquired brain injury commission recommendations regarding the improvement of such services.

SECTION 6. Said advisory board shall meet quarterly, at minimum, and may establish subcommittees as necessary to carry out its objectives.

HOUSE DOCKET, NO. 4027 FILED ON: 2/19/2021

HOUSE . . . . . No. 214

The Commonwealth of Massachusetts

PRESENTED BY:

Kimberly N. Ferguson and Gerard J. Cassidy

To the Honorable Senate and House of Representatives of the Commonwealth of Massachusetts in General Court assembled:

The undersigned legislators and/or citizens respectfully petition for the adoption of the accompanying bill:

An Act to establish an acquired brain injury advisory board.

PETITION OF:

NAME:	DISTRICT/ADDRESS:	DATE ADDED:
Kimberly N. Ferguson	*1st Worcester*	*2/19/2021*
Gerard J. Cassidy	*9th Plymouth*	*2/19/2021*
David Henry Argosky LeBoeuf	*17th Worcester*	*2/22/2021*
Patrick Joseph Kearney	*4th Plymouth*	*2/22/2021*
Paul A. Schmid, III	*8th Bristol*	*2/23/2021*
Donald R. Berthiaume, Jr.	*5th Worcester*	*2/24/2021*
Timothy R. Whelan	*1st Barnstable*	*2/24/2021*
Shawn Dooley	*9th Norfolk*	*2/24/2021*
Angelo L. D'Emilia	*8th Plymouth*	*2/24/2021*
Colleen M. Garry	*36th Middlesex*	*2/25/2021*
Steven S. Howitt	*4th Bristol*	*2/25/2021*
Christopher Hendricks	*11th Bristol*	*2/25/2021*
Michael S. Day	*31st Middlesex*	*2/25/2021*
Steven G. Xiarhos	*5th Barnstable*	*2/25/2021*
Mathew J. Muratore	*1st Plymouth*	*2/26/2021*
Jonathan D. Zlotnik	*2nd Worcester*	*2/26/2021*
Meghan Kilcoyne	*12th Worcester*	*2/26/2021*
Jack Patrick Lewis	*7th Middlesex*	*2/26/2021*
Norman J. Orrall	*12th Bristol*	*2/26/2021*
Susan Williams Gifford	*2nd Plymouth*	*3/3/2021*
Hannah Kane	*11th Worcester*	*3/2/2021*
Patrick M. O'Connor	*Plymouth and Norfolk*	*3/3/2021*
Lindsay N. Sabadosa	*1st Hampshire*	*3/2/2021*

Walter F. Timilty	*Norfolk, Bristol and Plymouth*	*3/17/2021*
Sean Garballey	*23rd Middlesex*	*3/30/2021*

HOUSE DOCKET, NO. 4027 FILED ON: 2/19/2021

HOUSE . . . . . No. 214

By Representatives Ferguson of Holden and Cassidy of Brockton, a petition (accompanied by bill, House, No. 214) of Kimberly N. Ferguson, Gerard J. Cassidy and others for legislation to establish an acquired brain injury advisory board (including members of the General Court) to review, advise and report on services, supports and public policy for individuals with acquired brain injuries and their families. Children, Families and Persons with Disabilities.

The Commonwealth of Massachusetts

In the One Hundred and Ninety-Second General Court
(2021-2022)

An Act to establish an acquired brain injury advisory board.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

SECTION 1. An acquired brain injury advisory board shall be established to collaborate with appropriate state secretariats and their agencies, members of the legislature, individuals with acquired brain injuries and their family members, providers, clinicians, advocacy groups and other key stakeholders to review, advise, and report on services and supports, and public policy there under for individuals with acquired brain injuries and their families.

SECTION 2: Said advisory board shall consist of 2 members of the Senate, 1 of whom shall be appointed by the President, 1 of whom shall be appointed by the Minority Leader; 2 members of the House of Representatives, 1 of whom shall be appointed by the Speaker, 1 of whom shall be appointed by the Minority Leader; the Secretary of Health and Human Services or their designee; the Secretary of the Executive Office of Public Safety or their designee; the Secretary of Elder Affairs or their designee; the Secretary of Veterans Services or their designee; the Commissioner

of the Department of Public Health or their designee; 2 members from the Massachusetts Rehabilitation Commission, 1 who shall be the Commissioner or their designee, 1 who shall be appointed by the Commissioner; the Commissioner of the Department of Developmental Services or their designee; the Commissioner of the Department of Mental Health or their designee; the MassHealth Director or their designee; the Chief Executive Officer at the Brain Injury Association of Massachusetts, Inc. or their designee; and 8 members who shall be appointed by the Governor, 2 of whom shall be family members, caretakers or significant others of a person with acquired brain injury, 2 of whom shall be individuals with acquired brain injury, including but not limited to individuals who have experienced traumatic brain injury, stroke, brain tumors or other disorders, 1 of whom shall be a community based provider of services to individuals with acquired brain injury 1 of whom shall be a community based provider of services to individuals with acquired brain injury serving minorities and other underserved populations, 1 of whom shall be from a disability advisory group or a protection and advocacy representative, 1 of whom shall be a clinician.

SECTION 3. Said advisory board directives shall include, but are not limited to, reviewing data concerning the epidemiology of acquired brain injury and the needs of individuals with acquired brain injury and their families; reviewing efforts to increase access to rehabilitative, residential and integrated community based support services for persons with acquired brain injury; monitoring the implementation of the acquired brain injury commission recommendations regarding the improvement of such services; reviewing and advising on the annual brain injury state plan; and reviewing ongoing state public policy initiatives and state funding.

SECTION 4: A brain injury council shall be established and supported by the Massachusetts Rehabilitation Commission. Said council shall consist of members meeting criteria as required by the Administration for Community Living & the U.S. Department of Health and Humans Services (42 U.S.C. 300d-52) and shall include individuals and families with acquired brain injury. Said council shall report to said advisory board.

SECTION 5: Said advisory board shall file a biennial report with the Governor, the Secretary of the Executive Office of Health and Human Services, the Senate President, the Speaker of the House of Representatives, and the clerks of the Senate and House of Representatives. Said report shall include but not be limited to a summary of ongoing needs of individuals with acquired brain injury, the status of progress made in increasing access to rehabilitative, residential and integrated community-based support services for individuals with acquired brain injury; and the status of progress made in implementing the acquired brain injury commission recommendations regarding the improvement of such services.

SECTION 6. Said advisory board shall meet quarterly, at minimum, and may establish subcommittees as necessary to carry out its objectives.