



ISSUE BRIEF

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Severe Brain Injury in Massachusetts: Assessing the Continuum of Care

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Executive Summary

Acquired brain injury (ABI) is a major public health problem in Massachusetts (Hackman et al, 2014) and includes traumatic brain injury (TBI), stroke, ABI-related infectious diseases, metabolic disorders affecting the central nervous system (brain and spinal cord), and brain tumor. Advances in emergency medical care and neurosurgery mean that more people are surviving severe traumatic brain injury (Trexler et al, 2014). Yet many patients with severe TBI in particular, are not receiving inpatient services after initial treatment (Hackman et al, 2014; CDC, 2014) or later that are known to be effective (Malec & Kean, 2015; Lewis & Horn, 2015; BI Commission, 2011; Kolakowsky-Hayner et al, 2000; Interviews). These services include post-acute rehabilitation, case management, and brain injury-specific community programming (CDC, 2014; BI Commission, 2011; Interviews). Governance and data for decision-making are also major gaps in the continuum of care for severe brain injury in MA (Interviews; NASHIA, 2005).

The last two decades saw a surge in interest in the brain, with advances in neuroscience, diagnosis and measurement of brain injury, rehabilitation services, and brain theory (Boyle, 2001). Severe brain injury however is the new “hidden epidemic” in our society. For many, an injury to the brain is not a short-term event that can be “cured” but the beginning of a life-long disability (CDC, 2014; Langlois et al, 2006). Fortunately, even after a severe brain injury, when the right rehabilitation is provided at the right time, the “rest of life” journey can be a positive one for many (Marquez de la Plata, 2015; Langlois et al, 2006). Severe brain injury can lead to a “new normal” as patients regain skills, find new meaning and in life, and take on new family, volunteer, and work roles.

Throughout this brief, the term “severe brain injury” refers to “severe acquired brain injury,” or any injury to the brain that occurs after birth. This definition does not include neurodegenerative disorders such as Alzheimer’s Disease, Multiple Sclerosis, and Parkinson’s Disease which do not usually result in an acute hospital admission. Clinically, severe TBI is defined as resulting in loss of consciousness for 6 to 24 hours or more (Corrigan et al, 2010; CDC, 2014). Yet even a “mild” TBI can result in long-term functional impairments (Corrigan et al, 2010) for an estimated 15 to 30% of people (Lewine et al, 2007; Cajigal, 2007). In the chronic phase of acquired brain injury from any cause, lifelong disabilities may affect the ability to work, perform activities of daily living (dressing, paying bills), participate in community life, and/or fulfill a family role.

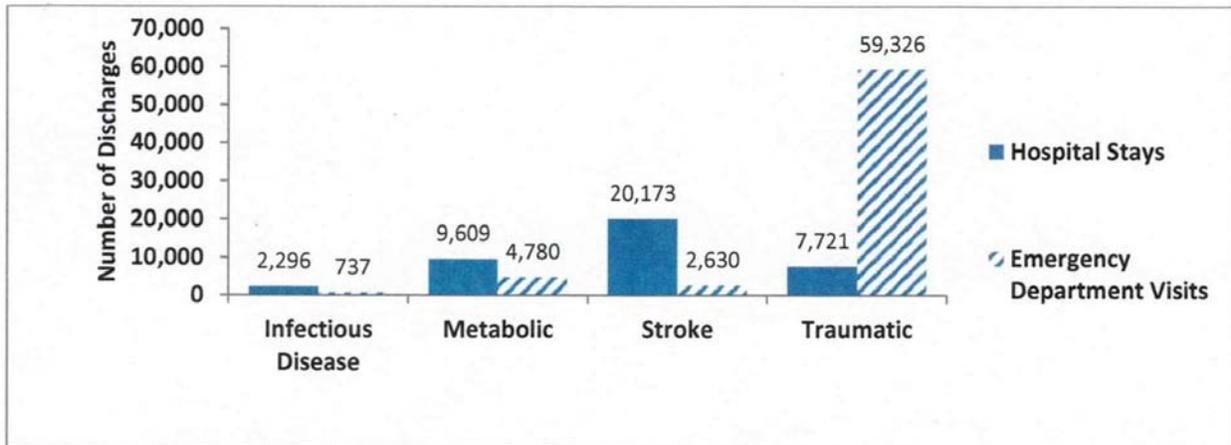
Scope of the Problem

Acquired brain injury affects all categories of MA residents, from young to old, men and women, and people living in all regions of the state (Hackman et al, 2014). Estimates of the number of people living with disabilities from brain injury in MA are between 68,000 and 112,000, but could be substantially undercounted (CDC, 2014; Langlois et al, 2006; U.S. Census Bureau, 2015). Severe TBI is more likely to result in hospitalization and in symptoms that persist, leading to partial or permanent disability (CDC, 2014); an estimated 37% of people with severe TBI will need long-term cognitive and functional supports (Whiteneck et al, 2004).

Between 2008 and 2010 in MA there was an annual average of 59,326 emergency department visits for TBI, and 2,630 for stroke, 4,780 for metabolic disorders, and 737 for infectious diseases affecting the central nervous system (brain and spinal cord) (Hackman et al, 2014). As for hospital stays, the annual average was 7,721 stays for TBI, 20,173 for stroke, 9,609 for metabolic disorders, and 2,296 for infectious diseases affecting the central nervous system (Hackman et al, 2014). This number may under-represent injuries among children, adolescents, and veterans, who may not report a TBI (CDC, 2014). Also between 2008 and 2010 an annual average of 1,272 primary brain tumors were newly diagnosed in MA residents (Hackman et al, 2014). The leading causes of brain injuries in MA are traumatic brain injury (59,326) and stroke (20,173) (see Figure 1). On average 21 Massachusetts residents are discharged after a hospital stay for TBI every day, and 55 residents every day after a hospital stay for stroke. Falls are the leading cause of nonfatal injury for people 65 years and older in MA and the U.S. (CDC, 2015; MDPH, 2013).

Many people in MA (and the U.S.) hospitalized for a brain injury, particularly a TBI, are not getting access to in-patient post-acute rehabilitation (Hackman et al, 2014; CDC, 2014) or to case management or resource facilitation support to help them access needed services and, ideally, return to work (Health Affairs, 2012; Trexler et al, 2014; Interviews). For many people in MA (and the U.S.) who are hospitalized for an ABI (TBI in particular), the patient survives the brain injury and is discharged directly to home (Hackman et al, 2014) without services or with in-home services (i.e., IV therapy services) (CDC, 2014; Interviews).

Figure 1. Average annual number of hospital stays and emergency department visits associated with select categories of ABI, MA residents, 2008-2010



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

Goals and Research Methods

This issue brief evaluates the continuum of care for severe acquired brain injuries in the Commonwealth from access to emergency and acute care, to post-acute rehabilitation and community services and supports. We describe gaps and disparities in access across the continuum. We examine brain injury costs, expenditures, and funding requirements. We describe some best policy and practice examples in the Commonwealth and across the country, and make recommendations to improve access across the continuum of care.

To meet these objectives, we:

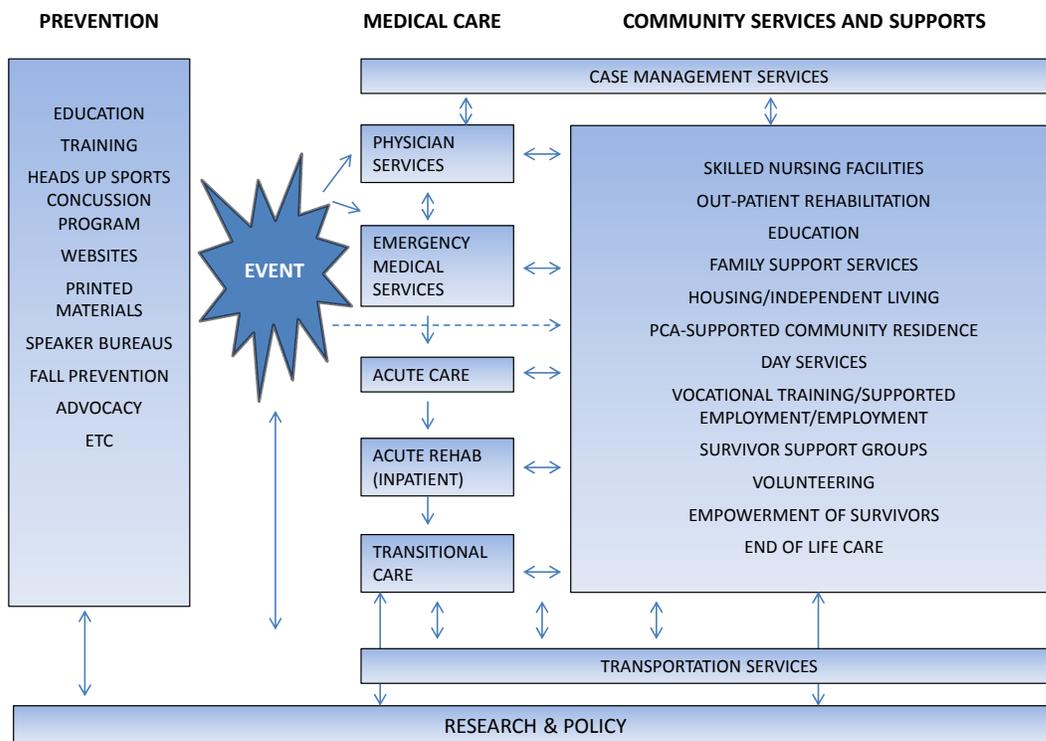
- Identify the scope of the problem and impacted populations;
- Describe the scarcity of access to rehabilitation services after severe brain injury;
- Identify gaps in policies and programs along the continuum of care;
- Identify successful models from Massachusetts and other states;
- Make recommendations for study and action to address identified gaps.

The gaps and recommendations outlined in this brief emerged as we conducted, coded, and analyzed interviews with 38 brain injury stakeholders in the state and elsewhere (see Appendices 1 and 2). We also conducted a targeted literature review aimed at understanding the gaps and solutions described by stakeholders. We also interviewed five Massachusetts residents with disabilities from severe brain injuries and prepared a video documenting their testimony (see Appendices 1 and 3).

The Continuum of Care for Severe Acquired Brain Injury

The continuum of care for severe acquired brain injury includes prevention, hospital-based services, post-hospital services, and community programs. Traditionally the emphasis has been on acute medical care with less attention on post-acute rehabilitation and community-based care, where the majority of survivor time – and public costs – are spent. Our depiction (see Figure 2) shows an expanded community stage and illustrates the fluid nature of the continuum as people in the community continually access medical care throughout their lives. Figure 2 does not attempt to illustrate the role of families and their caregiving in this continuum. Family support is often vital for facilitating access to needed services supporting recovery, maintaining function, and improving quality of life for people with severe brain injury at all stages of the continuum.

Figure 2: The Continuum of Care for Severe Acquired Brain Injury in Massachusetts



Source: Adapted from NASHIA, 2005 with permission

Gaps and Disparities in Care and Services after Severe Brain Injury

1. Governance: Public services for people with severe brain injury are uncoordinated and scattered between different organizations (Interviews). While coordination within agencies or funding streams may be good (Interview), greater coordination and oversight across MA agencies and departments serving the severe brain injury population would improve efficiency and outcomes including quality of life. MA state agencies serving people with severe brain injury include MassHealth, a major payer of long-term services and supports after severe brain injury (Smith, 2014). The Massachusetts Rehabilitation Commission (MRC) manages and operates the TBI Waiver, the non-residential ABI Waiver (ABI-N), and Money Follows the Person Community Living (MFP-CL) Waivers, and also provides funding for recreational/social services and pays for day programs and independent and 24/7 living for a limited number of people with TBI. The Department of Developmental Services (DDS) manages and operates the ABI residential habilitation (ABI-RH) Waiver and MFP residential supports (MFP-RS) Waiver. The TBI, ABI, and MFP Waiver programs currently serve approximately 500 people. MassHealth also supports people with severe brain injury in skilled nursing facilities, and many people with brain injury are eligible for Medicaid health insurance coverage.

Other MA agencies and departments serving the severe brain injury population include the Department of Correction, which serves people with brain injury in prisons. The Department of Education establishes guidelines for schools serving students with disabilities after a brain injury (DOE, 2015), and the Statewide Head Injury Program provides technical assistance and training on brain injury for MA teachers (SHIP, 2015). The Office of Elder Affairs serves MA elders with brain injury. The Massachusetts Department of Public Health (MDPH) has collaborated with MRC leadership to undertake the recent epidemiology study. MRC and the Executive Office of Health and Human Services (EOHHS) collaborate with the Brain Injury Association of Massachusetts (BIA-MA) to deliver prevention programs, including fall prevention for MA older adults (see Appendix 9). The Massachusetts Bay Transportation Authority (MBTA) provides transportation services for people with severe brain injury through The Ride.

2. Post-Acute Rehabilitation: While good emergency care saves lives after a severe brain injury, access to rehabilitation to support recovery is suboptimal (Kolakowsky-Hayner et al, 2000; Interviews), and patients in coma who are candidates for rehabilitation “encounter eligibility requirements that severely limit access to care” (Giacino et al, 2014:109; Interviews). Services for traumatic and non-traumatic brain injury are often considered together, while stroke services and programs are often considered in a separate category (Interview), in part due to the larger research evidence-base for stroke treatment protocols. Twenty years ago someone with a severe brain injury might stay in a post-acute rehabilitation hospital for far longer than is currently allowed (Interviews). Today their length of stay has been significantly reduced (Interviews). Research has shown that access to rehabilitation services in the first few weeks and months following severe brain injury leads to better outcomes (CDC, 2014; Marquez de la Plata, 2015), even for patients in coma (Giacino et al, 2014). Access to rehabilitation in the chronic phase of severe brain injury is also limited despite evidence that access at this phase also improves outcomes though improvements are less (Lewis & Horn, 2015; Malec & Kean, 2015), and despite the “essential benefits package” of the Affordable Care Act (ACA), which includes

“rehabilitative and habilitative services and devices” to “restore function, maintain functioning as well as prevent deterioration in functioning” (AAPM&R, 2015).

“Within days after injury, the brain begins the process of repairing itself ... Timeliness of admission to post-acute brain injury rehabilitation service influences the effectiveness of rehabilitation and results in fewer days of treatment and greater functional gains.” (CDC, 2014)

3. Transitions: Case Management: Independent case management (also known as Resource Facilitation) that is not tied to providers or payers is lacking (Interviews). A brain injury changes life suddenly, maybe forever. Patients and caregivers are overwhelmed and do not know what services are available (Interviews). Case management can align patient and provider interests and increase timely access to services that support recovery (Health Affairs, 2012), and resource facilitation has been shown to significantly increase return-to-work, independence, and community participation after severe brain injury, reduce annual lost wages, and increase annual earnings (Trexler et al, 2014; Reid et al, 2011) (See Appendix 10).

4. Transportation: Transportation is also needed to support appropriate care and transitions between types of care. Often people with severe brain injuries need someone to accompany them during travel. Many need specialized transportation, such as a handicap accessible van (Interviews). There are transportation systems in place across the state, and The Ride is a good example, but it operates only where the MBTA operates. The gap between the availability of transportation and the need is great.

5. Data for Decision-Making: Payers and providers at all stages of care need data and information to understand outcomes from services and supports (Horn et al, 2015; Interviews) and to support transitions (Abel et al, 2014; HealthIT.gov, 2013; MeHI, 2013). One problem is a mismatch in stakeholder interests (Interviews). Policymakers want to know how many people are getting helped, because that is what public funding pays for (Interviews). Families care about meaningful engagement with the community (Interviews). Payers care about functional outcomes (Interviews). MA needs to identify key brain injury-related data of interest and ways to collect and share them, and a better understanding of the needs of people who have been living in the community for years (BI Commission, 2011; Truelle et al, 2010; Interviews). The use of practice-based evidence grounded in programmatic data (as opposed to evidence from randomized controlled trial studies) should be emphasized (Corrigan, 2015).

6. Community: Housing and Day Programming: People on disability in MA are priced out of market-rate apartments (TAC, 2015). The gap between supply and demand is great (Interviews) despite a menu of housing options available for people with brain injury in the state (EOHHS, 2012). Home and Community-Based Services (HCBS) Waivers are moving people from nursing homes to the community to save costs (or to be cost neutral) and to give people choice and control over where to live (USDHHS, 2000; MRC, 2004; Interviews). The Statewide Head Injury Program (SHIP) provides community residential support services for eligible people with traumatic brain injuries.

subsidized community housing (Section 8) for elders and persons with disabilities provides access to housing for some. The MassHealth Transitional Living Program supports a small number of people in residential programs (Smith, 2014). Shelters serve homeless people with brain injury.

There is also a lack of day programming that meets the needs and preferences of people with severe brain injury. Day programming is paid for by SHIP, MassHealth, and the Waiver programs, but most people do not have access to specialized brain injury-specific day programming (Interviews) that support physical, cognitive, and social function, despite evidence that such programming can support recovery (Malec, 2001) and return to work (Trexler et al, 2014).

7. Prevention: Preventing further harm from brain injury for MA youth in the juvenile justice system could provide significant individual and societal benefits. The concept of harm reduction, borrowed from the substance abuse field (Larson & Lorenz, 2014) can inform these efforts. TBIs among adolescents often go unreported despite potential significant long-term effects (Hughes et al, 2015; Interviews). Studies have found that between 50% and 71% of incarcerated young people have had a TBI (Hughes et al, 2015; Perron & Howard, 2008). Typical behavioral issues afterwards include aggression, talking back, and poor decision-making (Hughes et al, 2015; Interviews) which contribute to recidivism (Virginia Collaborative, 2013). Parents, teachers, and correctional officers may not connect these behaviors with a TBI that could have occurred in childhood, for example from shaken baby syndrome (Interviews).

Recommendations

We recommend addressing gaps in governance, post-acute rehabilitation, transitions, data for decision-making, community services and supports, and prevention.

1. Governance: Coordinate existing government programs and supports.

- Reinststate the Brain Injury Commission, to study, recommend, and support policy action in this area (NASHIA, 2014).
- Establish an inter-agency task force to review opportunities to collaborate, for example, on grant applications for demonstration projects. Possible agencies include: Executive Office of Health and Human Services (EOHHS), MA Department of Public Health (MDPH), Massachusetts Rehabilitation Commission (MRC), Office of Elder Affairs (OEA), Department of Mental Health (DMH), Department of Developmental Services (DDS), MassHealth, Department of Correction (DOC), MA Department of Housing and Community Development (DHCD), and municipal departments of public health (BI Commission, 2011; NASHIA, 2014).
- Establish a stakeholder task force of advocates, providers, survivors, and family members charged with advising the Brain Injury Commission and policymakers on problems, needs, and strategies from stakeholder perspectives (NASHIA, 2014). The Brain Injury Association of MA (BIA-MA) could be charged with leading this task force.
- Expand the mandate of MRC to serve people with all types of acquired brain injuries, not just traumatic brain injury. Establish MRC as the central administrative body guiding state brain injury efforts (NASHIA, 2014).

2. *Post-acute rehabilitation: Increase access to post-acute rehabilitation after severe brain injury.*

- Identify best practices for optimal lengths of stay for patients with severe brain injury from any cause, and including patients in coma (Cope et al, 2005; Katz, 2012; Giacino et al, 2014).
- Expand options to provide and pay for rehabilitation opportunities in the community for long-term survivors (Malec, 2001), and explore the “medical necessity” (e.g. including maintenance or prevention of deterioration of functioning) of rehabilitative and habilitative services for people with disabilities under the Affordable Care Act (ACA) (AAPM&R, 2011).
- Mandate insurance coverage in MA for cognitive rehabilitation (Katz et al, 2006; BI Commission, 2011; TBIAC, 2014; Interviews).

3. *Transitions: Increase access to case management.*

- Through MRC, provide independent case management or resource facilitation, not tied to payers, for at least 6 months upon hospitalization for brain injury and potentially for as long as needed, for all patients at all income levels (University of Missouri-Columbia, 2006; Trexler et al, 2014).
- Through MRC, provide case management to support access to medical care and to social services and supports such as housing, day programming, and vocational rehabilitation (Trexler et al, 2014; Malec, 2001). For persons with disabilities from severe brain injury, provide life-long case management (Interviews).

4. *Transportation: Increase access to transportation.*

- Charge the Brain Injury Commission with studying transportation needs and solutions for the severe brain injury population.

5. *Data for Decision-Making: Identify data needs of key stakeholders and establish an interactive data system that meets state and provider needs.*

- Through EOHHS and BIA-MA, provide training to improve medical coding practice for brain injuries with the shift to ICD-10 (Liebson et al, 2011; Interviews)
- Through EOHHS encourage use of standardized outcome measures across providers (NINDS, 2015) by offering incentives, as done to support the MA Health Information Hlway (MeHI, 2013).
- Charge EOHHS with improving Health Information Exchange (HIE) data-sharing from the system to providers (Interviews).
- Through EOHHS, establish a MA brain injury registry or other longitudinal database that builds on the Mass Hlway or builds on practice-based evidence from MA providers (Malec & Kean, 2015).to enable monitoring of brain injury spending and outcomes and inform policy and practice (Gliksch et al, 2014; Interviews). Include social and behavioral domains (e.g. community integration or participation) as well as medical ones (IOM, 2014; Truelle et al, 2010). Explore opportunities to subscribe to established web-based brain injury outcomes databases such as OutcomeInfo, developed with support from the National Institute of Neurological Disorders and Stroke (NINDS) (Murphy et al, 2015).

6. *Community: Strengthen housing options and community programming.*

- Through MRC (SHIP), DDS, DHCD, non-profit organizations, and town governments, expand access to a menu of affordable housing options for people with severe brain injury capable of living with supports in the community (EOHHS, 2012).
- Through MRC, support access to skill-building programming through brain injury-specific day programming and support groups (Malec, 2001; Trexler et al, 2014).
- Through MRC, implement the regional multi-service center whose funding has not been approved. Approve funding for four more centers as proposed (BI Commission, 2011).
- Through MRC, expand funding for recreational and social activities.

7. *Prevention: Reduce further harm from brain injury among young people and veterans.*

- Charge DOC, DHCD, and MDPH with investigating the scope of brain injury among young people in MA involved in the criminal justice system and with developing strategies to screen for TBI, help those working in the system to better accommodate TBI-related disabilities, and better support transition out of the system, and as a result reduce the harm from brain injury in this population (Virginia Collaborative, 2013).
- Count Massachusetts veterans with TBI, and develop strategies to prevent further harm, for example homelessness. MDPH could lead, in collaboration with Veterans Affairs.
- Investigate the potential for Community Health Workers to assist in closing gaps related to brain injury in underserved MA communities (Ballester, 2005; Bovbjerg et al, 2013; Health Affairs, 2012; ICER, 2013). MDPH could be charged with working with municipal departments of health on this effort (Health Affairs, 2012).

Conclusion

Massachusetts has been a national leader in the prevention and treatment of brain injury. The state is home to the foundation that became the Brain Injury Association of America. The recent brain injury epidemiology carried out by MDPH and MRC is the first in the nation to examine not just traumatic brain injury but the broader umbrella of acquired brain injuries and their numbers of hospital stays and emergency department (ED) visits associated with different categories of acquired brain injury. Yet gaps and disparities in services and information remain. The Commonwealth has a strong base to build on to improve the continuum of care for severe brain injury and in doing so will remain a national leader.

Introduction

This issue brief evaluates the continuum of care for severe acquired brain injuries in the Commonwealth from access to emergency and acute rehabilitation care, to post-acute rehabilitation and community services and supports. We describe gaps and disparities in access across the continuum. We examine brain injury costs, expenditures, and funding requirements. We describe some best policy and practice examples in the Commonwealth and across the country. We make recommendations to improve access and services across the continuum of care. To meet these objectives, in the following sections we:

- Identify the scope of the problem and populations impacted;
- Describe the scarcity of access to rehabilitation services after severe brain injury;
- Identify gaps in policies and programs along the continuum of care;
- Identify successful models from Massachusetts and other states;
- Make recommendations for study and action to address identified gaps.

See a list of supporting materials in Appendix 4.

Current data are underestimates. Roughly between 67,696 and 112,121 people live with disability from brain injury in MA (CDC, 2014; Langlois et al, 2006; U.S. Census Bureau, 2015). On average 21 MA residents are discharged from hospital every day after a traumatic brain injury stay and 55 on average per day after a stroke. An estimated 37% of those hospitalized for TBI may experience long-term impairments requiring continued supports (Whiteneck et al, 2004). Clinical indices of initial severity of injury may not indicate the severity of impact on someone’s life and function (Trexler et al, 2014). A “mild” TBI is clinically diagnosed in part by a loss of consciousness (if any) for 30 minutes or less, and a “severe” TBI by loss of consciousness for 6 to 24 hours or more (Corrigan et al, 2010; CDC, 2014). Yet even a “mild” TBI can result in long-term functional impairments (Corrigan et al, 2010) for an estimated 15 to 30% of people (Lewine et al, 2007; Cajigal, 2007).

Current epidemiological data continue to underestimate the problem of brain injury (Langlois et al, 2006), inhibiting informed decision-making by government, payers, and providers for patients and populations (Interviews). Consistent diagnosis coding practices for TBI are lacking (Liebson et al, 2010; Interviews). One problem is that people who do not seek care for TBI or who seek it outside a hospital or emergency department are not counted (Langlois et al, 2006; Faul et al, 2010). Information for those counted does not reflect injury severity or any duration of impairment (CDC, 2014; Hackman et al, 2014; Langlois et al, 2006). Another problem is that MA does not yet have a data system in place that can track brain injury patient outcomes over time and inform policy (Interviews).

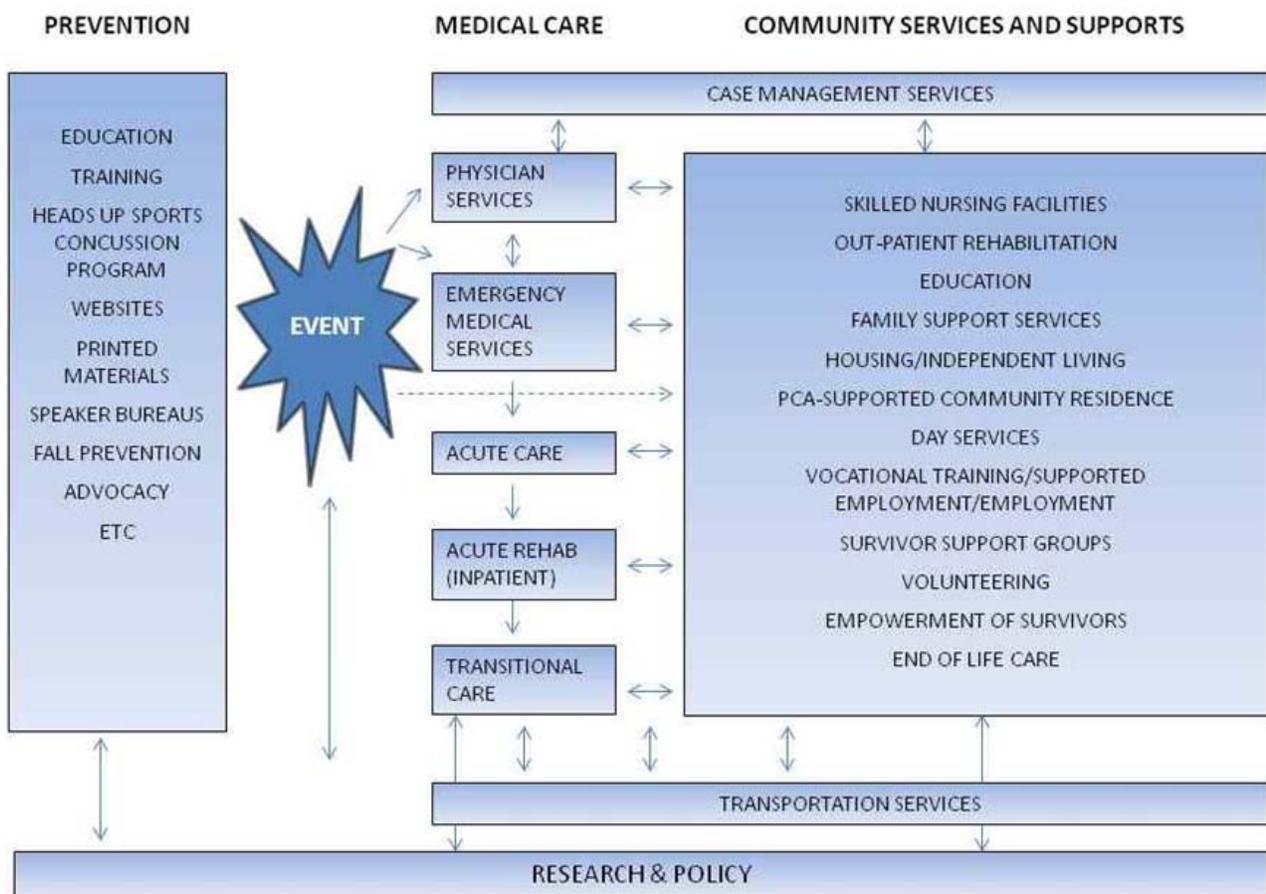
The Walking Wounded Are Discounted: *“One of the problems is that persons with brain injury look like everyone else, so they don’t stand out in a crowd. This makes them more easily discounted or ignored.” (Harriette L. Chandler, Majority Leader, Massachusetts Senate)*

Recommendations for governance, post-acute rehabilitation, case management, transportation, housing, and brain-injury-specific day programming. We recommend reinstating the Brain Injury Commission and expanding MRC’s mandate to include all brain injuries not just traumatic ones, increasing access to post-acute rehabilitation after severe brain injury, increasing access to case management, studying transportation needs and solutions, establishing an interactive, longitudinal data system, strengthening community housing options, improving access to brain injury-specific day programming, and reducing further harm from brain injury among young people and veterans.

The Continuum of Care for Severe Acquired Brain Injury

We frame our approach to investigating gaps in services for severe brain injury through the lens of the Continuum of Care (NASHIA, 2005) including prevention, hospital-based services, post-hospital services, and community programs. Treatment of acquired brain injury has traditionally emphasized medical care and minimized community services, where the majority of survivor time – and costs – are spent (NASHIA, 2005). Our depiction shows an expanded community stage (See figure 2). People with brain injury access the continuum at many different stages, from prevention to emergency care, post-acute rehabilitation, or community services. Our depiction illustrates the fluid nature of the continuum as people in the community continually access medical care throughout their lives. Figure 2 does not however attempt to illustrate the role of families and their caregiving in this continuum. Family support is often vital for facilitating access to needed services supporting recovery, maintaining function, and improving quality of life for people with severe brain injury at all stages of the continuum.

Figure 2: The Continuum of Care for Severe Brain Injury in Massachusetts



Source: Adapted from NASHIA, 2005

Problems exist across the continuum. State responsibility for brain injuries are scattered and a more coordinated system of governance across the many state agencies and departments serving people with severe brain injury could maximize the effects of current spending (Interviews). Access is lacking to post-acute rehabilitation services (Kolakowsky-Hayner et al, 2000; Interviews), case management (BI Commission, 2011; Interviews), transportation (BI Commission, 2011; Interviews), housing (EOHHS, 2012; Interviews),

and brain injury-specific day programming (BI Commission 2011; Interviews). Greater access to post-acute rehabilitation will improve health and outcomes and reduce long-term health costs, particularly taxpayer costs (Oddy & da Silva Ramos, 2013; AAPM&R, 2011). Independent case management and resource facilitation would have similar positive effects (Health Affairs, 2012; Trexler et al, 2014; BI Commission, 2011; Interviews). Enhanced transportation services for people with disabilities from brain injury are essential to access care and community programming, and improve quality of life (BI Commission, 2011; Interviews). There is also a housing crisis for people with severe brain injuries as market based housing becomes increasingly out of reach (TAC, 2015). Most people in MA do not have access to specialized day programming programs that support cognitive, social, and physical function (Interviews). Further, while the state has invested in a range of effective prevention efforts (Hackman et al, 2014), rethinking prevention to include prevention of further harm from brain injury could reduce societal costs in MA, particularly for youth involved in the juvenile justice system (Vaughn, 2014; Hughes et al, 2015; Virginia Collaborative, 2013; Interviews).

Research Methods

The gaps and recommendations outlined above emerged as we conducted, coded, and analyzed interviews with 38 brain injury stakeholders in the state and elsewhere (see Appendix 1 and 2). Our list includes people who were involved in development of the 2011 Commission Report as well as people who are newer to brain injury in the state and those working at a national level wrestling with similar challenges. We also conducted a targeted literature review aimed at understanding the gaps and solutions described by stakeholders. They include the 2004 Massachusetts Rehabilitation Commission report on Supportive Living, the 2011 Brain Injury Commission Report, and the 2014 Massachusetts Acquired Brain Injury Epidemiology Report.

Below we describe the scope of the problem, major gaps in access to services and supports, model solutions, and recommendations.

Scope of the Problem

Acquired brain injury is a substantial public health program in MA (Hackman et al, 2014). It includes a range of disorders and diseases impacting the brain including traumatic brain injury (TBI), stroke, ABI-related infectious diseases, metabolic disorders affecting the central nervous system (brain and spinal cord), and brain tumor (Hackman et al, 2014; Boyle, 2001). Brain-related disorders and diseases account for more long-term health costs and hospitalizations than almost all other diseases combined (Boyle, 2001).

We use the term brain injury to describe any acquired brain injury that occurs after birth, and focus on “the big five” acquired brain injuries: traumatic brain injury, stroke, metabolic, infectious, and brain tumor as described in the MA Acquired Brain Injury Epidemiology Report (Hackman et al, 2014). (This definition does not include neurodegenerative disorders such as Alzheimer’s Disease, Multiple Sclerosis, and Parkinson’s Disease which do not usually result in an acute hospital admission.) Infectious diseases leading to brain injury include meningitis and encephalitis. Metabolic disorders, including heart disease and diabetes, can be associated with conditions (e.g. cardiac arrest, coma) causing brain injury. One of the leading categories of brain injury in MA and the U.S. is traumatic brain injury (TBI), caused by an external blow or force to the brain (Hackman et al, 2014; CDC, 2014). The major causes of TBI in MA are falls, strikes by/against an object or person, motor vehicle crashes, and assaults (Hackman et al, 2014). Stroke, which interrupts the flow of blood and oxygen to the brain (MedlinePlus, 2015) is another leading category of brain injury in the MA and the U.S.

The consequences of brain injury, whatever the cause, are complex and can impact many aspects of life and function (CDC, 2014). Severe brain injury is diagnosed in part as resulting in loss of consciousness for 6 to 24 hours or more (Corrigan et al, 2010; CDC, 2014). Patients who experience severe TBI may show relatively good physical outcomes but poorer cognitive and emotional ones (Wilde et al, 2010). A recent Colorado study found that 37% of people hospitalized for TBI needed assistance with activities of daily living one year after discharge (Whiteneck et al, 2014). Patients with stroke may have problems speaking and communicating, swallowing, thinking and memory, and muscle, joint, and nerve problems (MedlinePlus, 2015). Often a brain injury affects more than one part of the brain, and the consequences can affect more than one domain of function (CDC, 2014; DVBIC, 2015) (see Table 1).

Table 1. Acquired Brain Injury Outcomes: Symptom Domains and Descriptions

Symptom Domain	Description
Cognitive function	Impairments in attention, memory, executive function important to everyday activities and social role participation.
Behavioral function	Increased aggression and childlike behavior that contributes to difficulties returning to work or school, personal relationships, and social functioning.
Physical function	Nerve damage, impairment in motor functioning (e.g. walking), strength and coordination, and loss of sense of touch, smell, and taste, which may increase difficulties performing day-to-day activities safely and independently.
Social role participation	Can include work, volunteering, recreation and leisure pursuits, and social and family role function.

Source: Adapted from CDC, 2014.

Gauging the Severity of the Problem

The precise number of people living with disabilities from brain injury in MA is unknown at this time, but an estimate is between 67,696 and 112,121 based on national estimates of long-term disability after brain injury and the size of the MA population (CDC, 2014; Langlois et al, 2006; U.S. Census Bureau, 2015). Severe TBI is more likely to result in hospitalization, and in symptoms that persist, leading to partial or permanent disability (CDC, 2014). Nationally, the number of people with disabilities from traumatic brain injury (TBI) is estimated to be 3.2 to 5.4 million people, or about 2% of the population based on data from two states (CDC, 2014; Langlois et al, 2006). In 2014 MA comprised about 2.1% of the U.S. population (U.S. Census Bureau, 2015). The number of people in MA living with disabilities from any acquired brain injury (stroke, brain tumor, TBI, other) is likely much greater.

One way to gauge the severity of the problem of acquired brain injury in MA is to examine annual numbers of hospital stays and emergency department (ED) visits associated with different categories of acquired brain injury. Between 2008 and 2010 in MA there was an annual average of 59,326 emergency department visits for TBI, and 2,630 for stroke, 4,780 for metabolic disorders, and 737 for infectious diseases affecting the central nervous system (brain and spinal cord). As for hospital stays, the annual average was 7,721 stays for TBI, 20,173 for stroke, 9,609 for metabolic disorders, and 2,296 for infectious diseases affecting the brain and spinal cord (Hackman et al, 2014) (see Figure 1).

During the same time period, 1,272 primary brain tumors were newly diagnosed in MA residents on average, annually (Hackman et al, 2014). The categories of ABI resulting in the highest average annual hospital stays and emergency department visits between 2008 and 2010 in MA were TBI (59,326) and stroke (20,173) (Hackman et al, 2014) (see Figures 3 and 4). Nationally, TBI accounts for approximately 2.5 million ED visits, hospitalizations and deaths each year (CDC, 2014) (See Figure 4). Nationally in 2012, 795,000 people had a stroke, about 130,000 Americans died of stroke, and an estimated 6.6 million people over the age of 20 were living with stroke (Mozaffarian et al, 2015).

A respondent's perspective on MA residents affected by brain injury: *"We have so many people with brain injury – it's not just people falling off roofs, but the young athlete who gets a sports concussion, or the veteran who comes back from serving the military."* (Interview)

People with TBIs are being missed. These numbers do not account for people who were not treated in an emergency department, did not have a hospital stay, or were treated at a military or Veterans Affairs hospital (Faul et al, 2010). Respondents noted that in MA as well, many TBIs go undiagnosed, from the playground and the baseball field to the battlefield (Interviews).

In MA brain injury from any cause affects all categories of residents, from young to old, and all races and ethnicities, all genders, and residents in all regions of the state. No community escapes this injury. We have evidence of the growing issue of acquired brain injury among older adults in MA (Hackman et al, 2014; Kronenberg, 2013). Concerns about prevention, awareness, treatment, and brain injury supports and services including housing for persons with acquired brain injury over age 60 will continue to grow as the state's population ages. Ongoing efforts to prevent and mitigate brain injury, such as the Executive Offices of Health and Human Services' HRSA-funded project "Improving MA Systems of Care for Elders Sustaining a TBI," among older MA residents should continue and inform future planning (See Appendix 6).

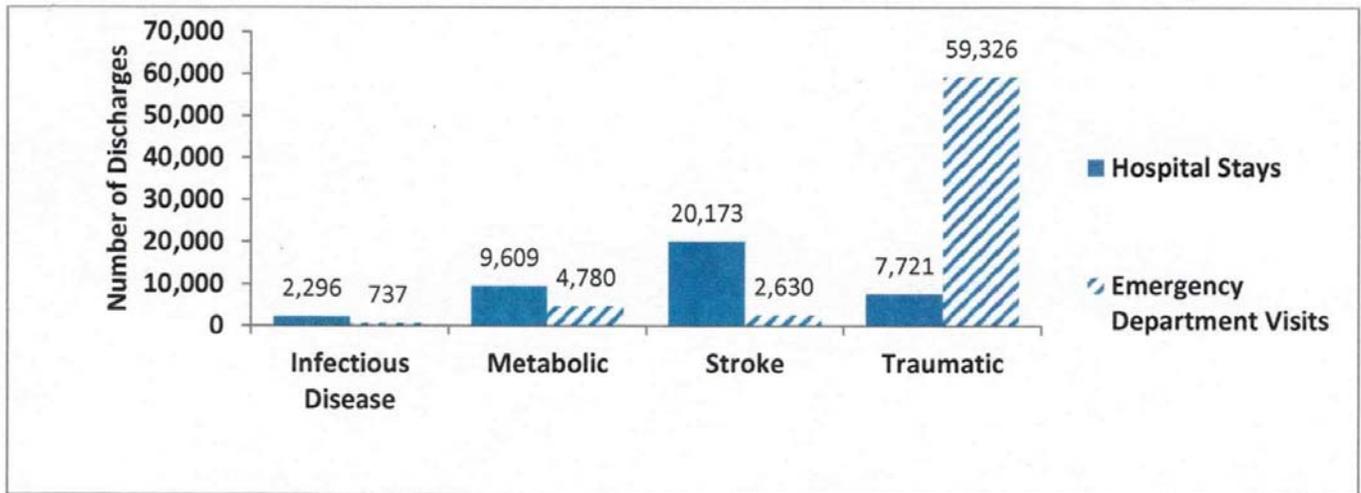
One undercounted group of particular interest is youth with TBI in the juvenile justice system. We are also undercounting the extent of brain injury among veterans. While most TBIs among veterans of the wars in Afghanistan and Iraq have had so-called mild TBI, an estimated 15 to 20% have disabilities due to their injury (Hoge et al, 2008). The interplay of brain injury and post-traumatic stress compound the impacts (Carlson et al, 2010). Working with the Veterans Administration to count Massachusetts veterans with TBI, and develop strategies to support them better is a social justice issue.

Where do brain injury patients go after hospitalization? Timely access to rehabilitation services is known to improve outcome (Marquez de la Plata, 2015). Yet many brain injury hospitalizations in MA between 2008 and 2010, particularly for TBI but also other ABIs resulted in the patient surviving and being discharged to home and to a lesser extent skilled nursing facilities or rehabilitation hospitals (Hackman et al, 2014; Interviews). The MA experience echoes national data tracked for TBI (CDC, 2014). We need to better understand who is being sent home and who is receiving services in MA, the underlying reasons for lack of access to rehabilitation and habilitative services after severe brain injury, and strategies for improving access (for descriptions of strategies being used by other states, see Appendix 10).

A respondent's perspective on the Commonwealth's ABI Epidemiology Report: "Now with the epi report, we know how many people we have, where they are. Can you imagine trying to solve a problem for people if you don't even know who they are or how many? So that was a major step forward." (Harriette L. Chandler, Majority Leader, Massachusetts Senate)

Massachusetts leads the way – again. Massachusetts is the first state to gather epidemiological data for acquired brain injury, not just TBI (see Figure 3). Nationally epidemiological data on different categories of ABI are not tracked by any single entity. Thus we can compare MA and U.S. data only for traumatic brain injuries (TBI) where Massachusetts has a significantly higher rate than the nation. MA has an average annual rate of TBI emergency department visits of 910.4 per 100,000 persons (Hackman et al, 2014). The CDC (2014) estimated an annual rate in 2010 the U.S. of 823.7 per 100,000 persons. One reason for the apparently higher MA rate could be the Commonwealth's health reform efforts before the Affordable Care Act; if more people had access to insurance during the 2008-2010 time period perhaps they were more likely to seek medical care after any ABI and be counted in epidemiological studies. Another may be greater awareness in MA of the potential long-term risks of, for example, sports concussions (CDC, 2014) due to BIA-MA, EOHHS, and other TBI awareness and prevention efforts, similarly encouraging more consistent care-seeking behavior among Massachusetts residents who get injured.

Figure 1. Average annual number of hospital stays and emergency department visits associated with select categories of ABI, MA residents, 2008-2010



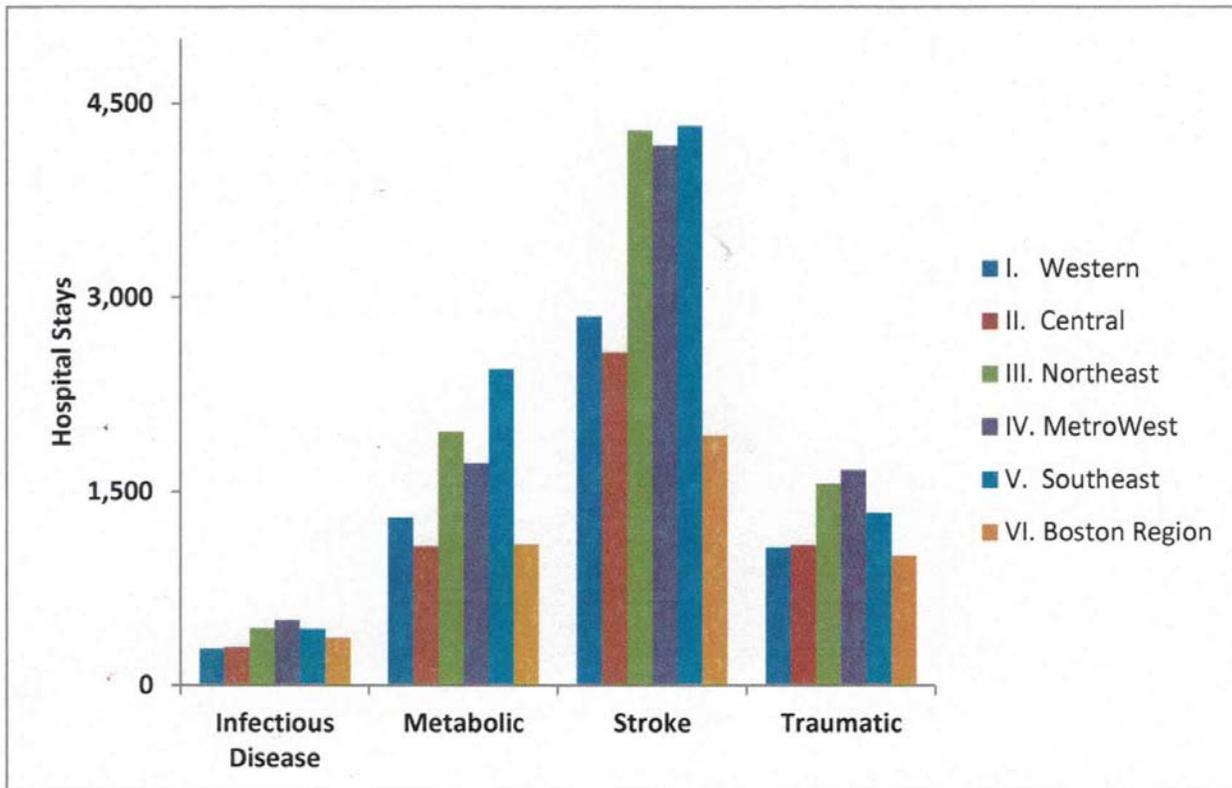
Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis. Note: Categories are not mutually exclusive.

The rate of emergency department visits associated with TBI in MA has been increasing, while rates of TBI-hospitalization have remained relatively stable (Hackman et al, 2014), similar to the U.S. between 2007 and 2010 (CDC, 2014) (see Figure 4). The CDC (2014) has suggested that increased awareness of TBI may have resulted in more persons seeking care, while a continued reduction in motor vehicle crashes nationwide reduced the incidence of TBI-related deaths.

Gender, Age, and Race/ethnicity and Region. Rates of emergency department (ED) visits and hospital stays associated with most categories of ABI differ only slightly by gender (Hackman et al, 2014). TBI shows a higher proportion of ED visits and hospital stays among males: 53.8% of ED visits and 56.6% of hospital stays. As for age and geographic distributions, acquired brain injury affects all age subgroups and individuals from all geographic regions in the state. However, the majority of hospital stays for metabolic disorders affecting the central nervous system (brain and spinal cord), stroke, and TBI were among persons 60 years of age or older (Hackman et al, 2014). These older adults represented 50% of hospital stays for TBI; 84% for stroke; and 58% for metabolic disorders affecting the central nervous system (brain and spinal cord) (Hackman et al, 2014). In addition, approximately 50% of both malignant and benign brain tumors (excluding the spinal cord) are newly diagnosed in adults 60 years or older (Hackman et al, 2014). As for race/ethnicity, Blacks and Hispanics had higher crude rates of ED visits and hospital stays for infectious disease-related acquired brain injury compared with White and Asian non-Hispanic MA residents. White, non-Hispanics had a higher average annual crude rate of stroke-related ED visits and stroke and TBI hospital stays in comparison to all other groups, while Black, non-Hispanics had a higher crude rate of TBI-related ED visits when compared with other racial/ethnic groups.

Each region of the state is affected by all categories of acquired brain injury (see Figure 3). Further information is needed to understand why certain regions are more impacted by, for example, stroke or traumatic injuries. Regional variations by average age of population may be a factor, as well as care-seeking behavior.

Figure 3. Average annual number of hospital stays associated with select categories of ABI by Executive Office of Health and Human Services Region of Residence, 2008-2010, MA residents



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

Severe Brain Injury Costs. Cost data are available for TBI and stroke. A severe TBI not only impacts the life of individuals and their families; it also has a large societal toll (CDC, 2014). In 2010 in the U.S., the cost and lost productivity of TBI was estimated to be \$76.5 billion and severe TBI consumed 90% of all TBI medical expenditure in the U.S. (CDC, 2014). Severe TBIs are more likely to incur costs from supported housing, nursing home or rehabilitation care, and lost earnings (CDC, 2014). Stroke costs the U.S. an estimated \$34 billion each year (Mozaffarian et al, 2015), a total that includes the cost of health care services, medications to treat stroke, and missed days of work (CDC, 2015).

Falls among older adults. Among community-dwelling older adults, fall-related injury is expensive (Hackman et al, 2014; CDC, 2015). Acute care hospital charges associated with fall-related injuries in 2010 in MA totaled over \$630 million (MDPH, 2013). Lifetime medical and work-loss cost is estimated to be over \$1.7 billion (Kronenberg, 2013). MA fall prevention, awareness, and training efforts will produce substantial cost savings (MDPH, 2010).

Residential post-acute rehabilitation: Cost-benefits. The majority of people in MA who are hospitalized for TBI in particular are discharged directly home after a hospital stay (Hackman et al, 2014) and do not have sufficient access to post-acute inpatient or community-based rehabilitation (Kolakowsky-Hayner et al, 2000; Interviews). Yet such access has been observed to have positive cost-benefit impacts including lower long-term care costs, reduced need for supervision, and increased ability to work (Oddy & da Silva Ramos, 2013). Early admission to rehabilitation leads to better functional outcomes (Marquez de la Plata, 2015), but cost-benefits of access later on in the course of recovery are also significant (Oddy & da Silva Ramos, 2013; Horn & Lewis, 2015; Malec & Kean, 2015). For people admitted to rehabilitation in the United Kingdom within a year of their brain injury, direct care costs were reduced by 68%, and by 37% for those admitted after one year (Oddy & da Silva Ramos, 2013). In addition to improvements in quality of life, there are considerable long-term savings associated with increased access to rehabilitation.

Case management or resource facilitation: Cost-benefits. For many patients with severe acquired brain injury and their family members, a lack of understanding about insurance guidelines, payment systems, public health insurance, vocational training, and Waiver programs is common (Trexler et al, 2014; Interviews). Case management assistance to help patients navigate the “ocean” of systems, providers, and payers and access appropriate services is lacking (Trexler et al, 2014; Interviews). Resource Facilitation, an approach developed in Indiana and adopted in Minnesota and New Hampshire for supporting return to work after brain injury, has been found to contribute significantly to return to work (64% for those with access to resource facilitation at follow-up versus 36% without resource facilitation) and significantly better function in randomized controlled trial studies of people hospitalized for traumatic brain injury (Trexler et al, 2014). These findings were replicated with larger follow-on randomized controlled trial studies involving people in both the acute and chronic phase of TBI (Trexler et al, 2014). A study of the potential annual economic impact of the resource facilitation provided identified \$32,017,775 in lost wages avoided, and another \$22.5 million in additional annual earnings estimated for approximately 4,200 people aged 15+ in Indiana who are estimated to experience disabilities after TBI in any given year (Trexler et al, 2014; Reid et al, 2011) (see Appendix 10).

Transportation: Recently the MA Department of Transportation reported that The Ride provides 2.1 million trips each year for people with disabilities at a cost of \$97 million. Changes being discussed to off-set costs include raising fares to the maximum allowed by the Americans with Disabilities Act, limiting The Ride service to only the area it must cover under the Americans with Disabilities Act, and reducing some of The Ride’s overhead costs by partnering with taxis or other transportation companies (Young, 2015). Affordable solutions to the transportation needs of people with severe brain injury both inside and outside the catchment area of The Ride are needed.

Prevention: A cost savings effort. Ongoing prevention efforts to reduce falls, strokes, sports-related TBI, and motor vehicle crashes (Hackman et al, 2014) could realize substantial savings in the state. In 2010 circulatory conditions (e.g. stroke) made up 20% of all hospital stay costs nationwide (Pfundtner et al, 2013). In 2010 brain injury was one of the top 5 most expensive hospital stay conditions in the US, almost double the average cost for the 20 conditions studied (\$18,000 versus \$9,700) (Pfundtner et al, 2013).

MA Budget for FY2016. Future efforts should investigate the gap between funding and needs (Interviews). In the Governor's proposed budget FY 16, for the Statewide Head Injury Program (SHIP) under MRC was \$14,659,292, a decrease of \$700,000 from FY '15 (MMPI, 2015). The final approved budget by the Massachusetts legislature was \$15,817,983, an increase of \$1,158,691. The increase is to fund a multi-service center in Worcester and to make up for the 9C cuts in February of 2015.

For FY 2016, the state legislature approved a final amount of \$7,755,843 for the Head Injury Treatment Services Trust Fund for FY 2016. Nationwide 23 states pay for TBI programs through TBI Trust Fund Programs from traffic fines or surcharges for vehicle registration, and motor vehicle licenses (NASHIA, 2014).

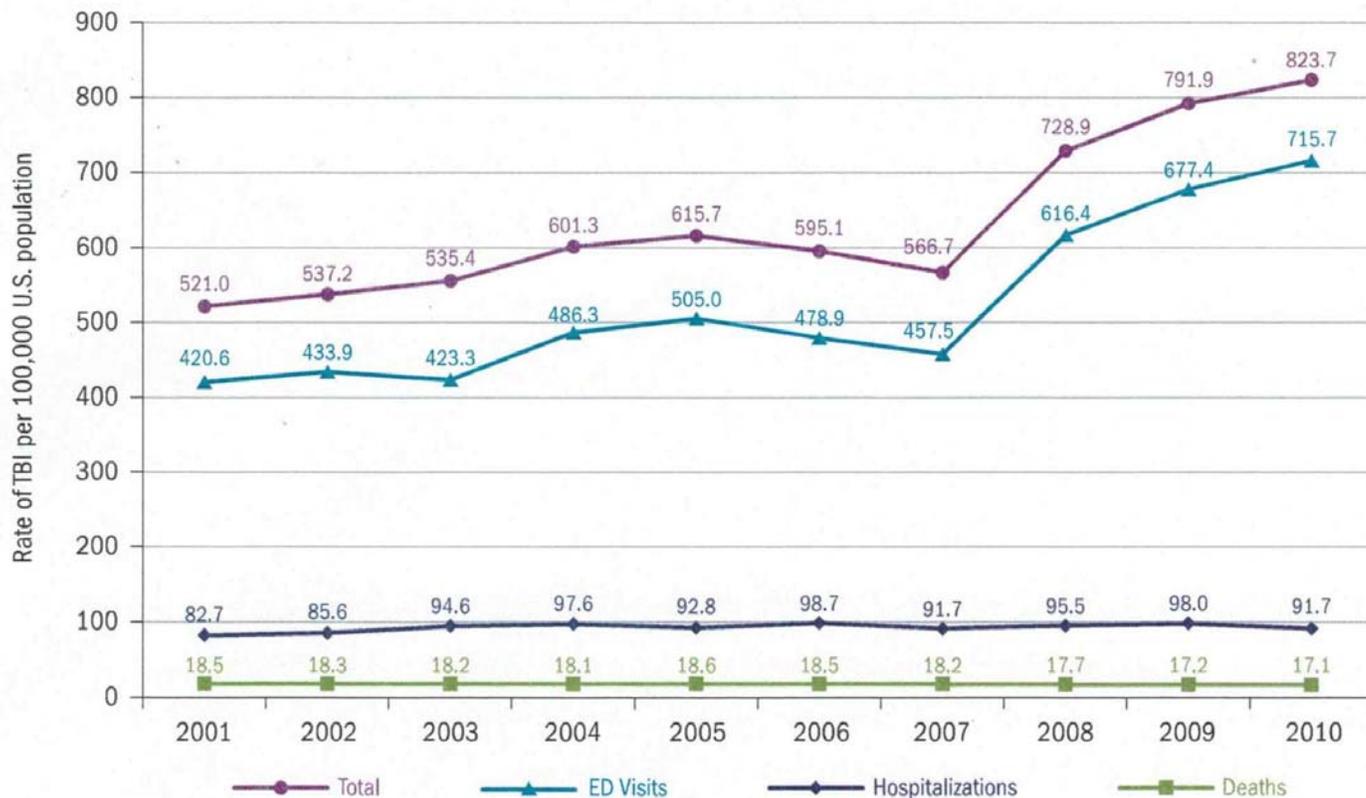
In the Governor's proposed FY2016 budget, the Hutchinson Settlement program account (ABI Waiver) is \$46,412,000, equivalent to less than 1% of the total MassHealth Program Accounts proposed for FY2016, and an increase of 44% over FY2015 estimated spending of \$34,318,00 (MPI, 2015). This relatively small proportion of the MassHealth program budget makes a great difference in the lives of the people who benefit from the ABI Waivers (residential and non-residential). In addition, it is important to recognize that MassHealth is a major payer of long-term services and supports after severe brain injury (Smith, 2014). MassHealth supports people with severe brain injury in skilled nursing facilities, and many people with brain injury are eligible for Medicaid health insurance coverage (See Appendix 6).

Over the years, MassHealth has operated five brain injury home and community-based services (HCBS) Waivers that have moved approximately 500 people with brain injury into the community. The Traumatic Brain Injury (TBI) Waiver has been in operation since 2004. In addition, the HCBS Frail Elder Waiver has been serving frail elders with ABI such as strokes, metabolic disorders, and brain tumors. Two additional HCBS Waivers, specifically to address people with ABI who are in nursing homes, were put in place following the Hutchinson settlement (CPR, 2015). (For a list of services provided under the TBI, ABI, and MFP Waivers see Appendix 7.)

The HCBS needs of the estimated 67,696 to 112,121 people in MA with disabilities from brain injury who are not living in nursing homes have not been assessed, as was called for in the BI Commission Report (2011). Nationwide, states are currently administering 27 brain injury HCBS Waiver programs (Vaughn, 2015). (For a description of costs required to fully implement the recommendations of the 2011 Brain Injury Commission Report, with updates based on a BIA-MA analysis of the SHIP eligibility list, see Appendix 8.)

A few states, including North Dakota and Alaska, receive state appropriated funding (general revenue) for specific brain TBI services such as service coordination and brain injury training for educators and mental health providers, for screening programs in correctional facilities, and for programs to serve veterans and returning service members (NASHIA, 2014).

Figure 4. Annual age-adjusted rates of TBI-related emergency department (ED) visits, hospitalizations, and deaths—United States, 2001-2010



Source: CDC 2014, p 20

Gaps and Disparities in Care and Services after Severe Brain Injury

Our research identified seven key areas of gaps and disparities in care and services after severe brain injury. The first is overarching: the lack of governance in MA to oversee policy and programming related to acquired brain injury across the many MA agencies and departments serving this population. There is also significant need for greater access to post-acute rehabilitation, case management, transportation, data for decision-making, housing, and access to community supports and services.

A respondent’s perspective on the continuum of care for brain injury in Massachusetts:

“Although Massachusetts has accomplished a great deal in 30 years of focused efforts for people with brain injuries and their families, we have yet to design and implement a fully comprehensive and integrated system of care.” (Marilyn Price Spivack, Neurotrauma Outreach Coordinator, Spaulding Rehabilitation Hospital)

MA needs an integrated system of care that includes “ongoing treatment, community integration, and cognitive-behavioral supports” of people with brain injury (CDC, 2014, p. 45). Nationally calls for a system of care for brain injury are long-standing (Cope et al, 2005). We examine gaps and disparities in MA with the lens of a continuum (or system) of care in mind.

1. Governance. Better coordination and oversight of these functions would lead to improved outcomes and a more efficient allocation of scarce resources. While coordination within agencies or funding streams (e.g., MassHealth) is good (Interview), public services overall for people with severe brain injury are scattered between different agencies, departments, and organizations and are not always well coordinated (Interviews). MassHealth is a major payer of long-term services and supports (Smith, 2014) including five Waiver programs that are moving people with brain injury into quality community living: the TBI Waiver, the ABI residential habilitation Waiver (ABI-RH), the ABI non-residential Waiver (ABI-N), the Money Follows the Person Community Living Waiver (MFP-CL) and the MFP residential supports Waiver (MFP-RS). MassHealth also supports people with severe brain injury in skilled nursing facilities, and many people with brain injury are eligible for Medicaid health insurance coverage. The Massachusetts Rehabilitation Commission (MRC) manages and operates the TBI Waiver (residential and non-residential components), the ABI non-residential Waiver (ABI-N), and the Money Follows the Person Community Living Waiver (MFP-CL) Waiver, and provides funding for recreational/social services and pays for day programs for people with traumatic brain injuries primarily. The Department of Developmental Services (DDS) manages and operates the ABI residential habilitation (ABI-RH) and MFP residential supports (MFP-RS) Waivers.

However, the HCBS Waivers serve a small proportion of people with severe brain injury in MA. A sampling of other agencies and departments serving this population includes: the Department of Correction, which serves people in jails and prisons. The Department of Education establishes guidelines for schools serving students with disabilities after a brain injury (DOE, 2015), and the Statewide Head Injury Program provides technical assistance and training on brain injury for MA teachers (SHIP, 2015), among other programs. The Office of Elder Affairs serves MA older adults with brain injury, and the Massachusetts Department of Public Health (MDPH) has collaborated with MRC leadership to undertake the recent epidemiology study. The MRC and the Executive Office of Health and Human Services (EOHHS) collaborate with the Brain Injury Association of Massachusetts to deliver prevention programs, including fall prevention for MA elders (see Appendix 9). The Massachusetts Bay Transportation Authority (MBTA) provides transportation services for people with severe brain injury through The Ride.

2. Post-Acute Rehabilitation: Access to rehabilitation care at the post-acute stage of recovery is a problem in MA and elsewhere (CDC, 2014) despite increasing evidence of its effectiveness (Malec & Kean, 2015; Lewis & Horn, 2015; BI Commission, 2011; Interviews). Services for traumatic and non-traumatic brain injury are often considered together, while stroke services and programs are often considered in a separate category (Interview), in part due to the larger research evidence-base for stroke treatment protocols. The lack of access to post-acute rehabilitation inhibits long-term outcomes: physical, cognitive, and social (CDC, 2014, Marquez de la Plata, 2015) and increases long-term costs, including taxpayer costs (Oddy & da Silva Ramos, 2013; AAPM&R, 2011). Twenty years ago someone with a severe brain injury, whatever the cause, might stay in a post-acute rehabilitation hospital for longer than is currently allowed (Interviews). Today a hospital stay after severe brain injury might be limited to three weeks or less (Trexler et al, 2014; Interviews).

Research shows that access to rehabilitation services in the first few weeks and months following severe brain injury leads to better outcomes (CDC, 2014; Marquez de la Plata, 2015; Lewis & Horn, 2015; Oddy & da Silva Ramos, 2013). Timeliness of admission to post-acute brain injury rehabilitation service results in fewer days of treatment needed overall and greater functional gains (CDC, 2014).

Access to rehabilitation in the chronic phase of injury is also being denied (Interviews) despite growing evidence that it improve outcomes, though to a lesser extent (Lewis & Horn, 2015; Oddy & da Silva Ramos, 2013; Malec & Kean, 2015; Malec, 2001), and despite the “essential benefits package” of the Affordable Care Act (ACA), which includes “rehabilitative and habilitative services and devices” to “restore function, maintain functioning as well as prevent deterioration in functioning” (AAPM&R, 2011). Disorders of consciousness (coma) patients are at a particular disadvantage under current rules because their capacity to “actively participate” in rehabilitation is limited, yet it is now known that brains of coma patients can be quite active, and once out of coma they can make remarkable recoveries (Giacino et al, 2014; Katz, 2012; Berube et al, 2006).

Figure 5: Perspectives on post-acute care from respondents

- Short lengths of stay and lack of access to inpatient rehabilitation after acute care increases the number of Emergency Department visits because people are not getting proper follow-up care.
- Discharge placement is so difficult. So facilities don't take them because they can't move them out afterwards. Patients have nowhere to go.
- A lot of people with low income but good family support have been driving over an hour to come to our post-acute care outpatient services. But so many people don't have those family supports. Where do they end up? On the street, basically.
- Most insurance plans use a set of criteria that are evidence-based and measurable, and it's much easier to measure physical gains than cognitive gains.
- Assumptions are made that if a patient can walk, bathe, and cook, then they do not need rehabilitation. Discharging someone with confusion and other cognitive issues can create a whole other host of risk factors. Maybe they can walk and talk. But they can't actually function in the world and manage their money and medications.
- Sometimes investing money in rehabilitation up front can save in the long run because people are less likely to end up the Emergency Department down the road. But companies that buy insurance don't see it that way. They are worried about their costs today from actual policies, and not 5 years down the road because they don't know if that person will still be enrolled in that plan.
- Resources for rehabilitation are more restrictive now than they ever have been, even though we know more about what is needed than we ever have before. The irony is that the Commonwealth ends up picking up the costs for these individuals for the long-term.

3. Transitions: Case Management: The continuum of care today is largely unmanaged and uncoordinated (Interviews). Patients are falling through the cracks at critical transition points between acute, rehab and long-term care (Interviews). After a severe brain injury patients and caregivers are overwhelmed and do not know what services are available (Interviews).

Figure 6: Perspectives on case management from respondents

- It is not just a lack of case management, but no case management. This is almost an impossible situation, and people are not equipped to figure this out on their own. *(Harriette L. Chandler, Majority Leader, Massachusetts Senate)*
- Case management is only available while the patient is under coverage. Once they leave they are no longer covered.
- Medical case managers play a liaison and communication role among medical providers. Families cannot facilitate or successfully advocate for access to rehab and other services because of the steep learning curve after a family member has a brain injury. It can be an emotionally challenging time for them.
- Case management that is person-centered means working in the system using a problem-solving process, and using resources wisely for both the patient and the system.
- Case managers work with patients, families, and payers to determine concerns and needs from all parties and make a plan that creates a win/win situation.
- Without a case manager, the cost of services may be reduced, but the long-term cost to society gets lost.
- Sometimes the family thinks that this level of service is as good as it gets, and they don't even challenge it.

4. Transportation: Transportation is also needed to support appropriate care and transitions between types of care and programming (Interviews). Most people interviewed cited transportation as a major gap in MA. Often people with severe brain injuries need someone to accompany them during travel. Many need specialized transportation, such as a handicap accessible van (Interviews). There are transportation systems in place across the state, and The Ride is a good example, though it operates only where the MBTA operates. The Ride provides 2.1 million trips each year for people with disabilities at a cost of \$97 million. Even so, the gap between the availability of transportation and the need for all people with disabilities in MA, including those with severe brain injury is great. Cost savings measures being discussed for The Ride include increasing the per-ride charge to the highest allowed under the Americans with Disabilities Act, and reducing the geographic area covered (Young, 2015).

Figure 7: Perspectives on transportation from respondents

- Transportation needs to be included in our solutions for brain injury moving forward. *(Harriette L. Chandler, Majority Leader, Massachusetts Senate)*
- To improve transportation, our need is so great that we cannot depend on volunteers. We need very consistent, dependable service and the money for it. *(Harriette L. Chandler, Majority Leader, Massachusetts Senate)*
- Transportation involves both the actual transportation and the human services.
- More access to transportation could enable survivors to have a higher quality of life.
- We can't rely on The Ride to drop and pick people up on time so we have to contract out for transportation, and it's expensive.
- Transportation is a major obstacle to utilizing some of the services out there.
- The Ride requires money. Disability payments are prioritized for food and medicine, there may not be enough left for the Ride.

5. Data for Decision-Making: Payers and providers at all stages of the continuum of care need data and information to understand outcomes (Horn et al, 2015; Interviews) and support transitions (Abel et al, 2014; HealthIT.gov, 2013; MeHI, 2013). One problem is a mismatch in stakeholder interests (Interviews). Policy-makers want to know how many people are getting helped, because that is what public funding pays for (Interviews). Families care about meaningful engagement with the community (Interviews). Payers care about functional outcomes, particularly physical ones (Interviews). MA needs to identify key brain injury-related data of interest and ways to collect them and share them, and a better understanding of the needs of people who have been living in the community for years (BI Commission, 2011; Interviews). The use of practice-based evidence grounded in programmatic data should be emphasized (Corrigan, 2015), not just evidence from randomized controlled trial studies. Opportunities to subscribe to established, web-based brain injury outcomes databases such as OutcomeInfo, developed with support from the National Institute of Neurological Disorders and Stroke (NINDS) should be explored.

A related issue is initial coding of the injury (Leibson et al, 2011; Interviews). People whose brain injuries are miscoded may not be treated appropriately or made eligible for appropriate services. The new ICD-10 now being published further complicates this issue with newly added codes (Interviews). Another related issue is deciding how to measure outcomes (Wilde et al, 2010; NINDS, 2015). Lack of use of common measures hinders understanding of outcomes, costs, and cost-benefits (Interviews; Wilde et al, 2010).

Figure 8: Perspectives on data from respondents

- Here in Massachusetts we don't have a good surveillance and monitoring system. Patients are lost very early in their recovery.
- As providers we need to show value in what we do. We need policy makers and payers to see where their money is going and who are they serving.
- I think that a Brain Injury Registry would be the most important first step we could do. If we got a registry up and running we could track outcomes and determine the value of interventions for that problem.
- We need a better electronic health information system that shows whether people get better, stay the same, or decrease their function.
- We need to know the needs of the people identified by the epi report. Then we need to look at the systems we already have, and figure out how to integrate brain injury into them instead of reinventing the wheel or establishing a whole new system.
- Seamless health information sharing is critical, critical, critical. Providers often feel that they are being asked for data and reports, but that they don't get a lot back in return. They feel frustrated.
- A brain injury registry that leveraged industry-wide accepted standards and created a data set for data mining and benchmarking and could help guide care would be great.

6. Community Supports: Housing and Day Programming. People on disability in MA are priced out of market-rate apartments (TAC, 2015). The gap between supply and demand is great (Interviews) despite a menu of housing options available for people with brain injury in the state (EOHHS, 2012). HCBS Waivers are moving people from nursing homes to the community (see Appendix 9).

The Statewide Head Injury Program (SHIP) provides community residential support services for eligible people with traumatic injuries. Subsidized community housing (Section 8) for elders and persons with disabilities provides access to housing for some. The MassHealth Transitional Living Program supports a small number of people in residential programs (Smith, 2014). Shelters serve homeless people with brain injury.

Figure 9: Perspectives on housing from respondents

- The same structure and system for disability and elder housing needs to be put in place for persons with brain injury, along with alternative housing, too. (*Harriette L. Chandler, Majority Leader, Massachusetts Senate*)
- The Waivers are only for those in nursing homes, so clearly where there is lacking is residential services for those who are at home in the community. Increasing SHIP residential service funding would help.
- It is more cost effective to provide services for a larger group than a smaller group in a residence. There are economies of scale. You need two staff on overnight for transfers or emergencies no matter how many people are in the home – whether four or eight.
- If you are able to live independently and your financial resources are low, then subsidized community housing can work for you. But there is usually a waiting list, and you have to spend down your funds first.
- Some of the programs providing housing are no better than nursing home if the resident is sitting at home all day. Payers are even paying more money to do that.
- The HUD 811 program is one way to build affordable housing for people with disabilities. HUD is a primary funder and then you can apply to DHCD as a secondary funder. Raising sufficient funds for housing can mean applying to 9 different funders.
- Expanding funding for the Transitional Living Program would be one way to provide housing for more people and give people with brain injury and their families more choices.

Day Programming. There is a lack of day programming that meets the needs and preferences of people with severe brain injury (Interviews). Day programming is paid for by SHIP, MassHealth, and the Waiver programs, but most people do not have access to brain injury-specific day programming (Interviews), despite evidence that it can support recovery (Malec, 2001; Trexler et al, 2014).

People with brain injury may have high expectations for their daily lives and may want to participate only in activities of interest to them, and not every day (Interviews). People who have experience with both the Developmentally Disabled (DD) population and the brain injury population noted that adults with DD are more used to a proscribed daily environment than the typical brain injury survivor injured as an adult (Interviews). After brain injury fatigue is a common challenge, further challenging daily participation in community programming (Interviews).

Figure 10: Perspectives on community programming from respondents

- The number one issue I think in terms of the brain injury population is their day supports. They want meaningful things to do. Currently there is no mechanism to provide this range of options in a way that is financially viable. We are losing a fortune on individuals who don't want to go to day program, because then we have to staff them at home, and that's a huge cost, higher than the day program.
- The underlying assumption is that all four residents in a Waiver home will go to a day program five days a week, saving staff spending. But many people with brain injury can't sustain that schedule without adverse consequences. In a perfect world you could reduce staff hours during the week and add them onto the weekend, but that's not how brain injury works.
- The adult DD population historically has been more prescribed, but the brain injury population is not as prescribed. These folks were married, have children, many had a career, and now their life is different, but they have high expectations of what they want their lives to look like, so we have to help them figure out how we can get to their goals.

7. Prevention: Preventing further harm from brain injury for MA youth in the juvenile justice system could provide significant individual and societal benefits. The concept of harm reduction, borrowed from the substance abuse field (Larson & Lorenz, 2014) can inform these efforts. TBIs among adolescents often go unreported despite potential significant long-term effects (Hughes et al, 2015; Interviews). Studies have found that between 50% and 71% of incarcerated young people have had a TBI (Hughes et al, 2015; Peron & Howard, 2008). Typical behavioral issues afterwards include aggression, talking back, and poor decision-making (Hughes et al, 2015; Interviews) which contribute to recidivism (Virginia Collaborative, 2013). Parents, teachers, and correctional officers may not connect these behaviors with a TBI that could have occurred in childhood, for example from shaken baby syndrome (Interviews).

Recommendations and Models

In this section we provide recommendations to address the gaps in governance, post-acute rehabilitation, transitions, data for decision-making, community services and supports, and prevention described above and highlight some best practice models from Massachusetts and other states.

1. Governance. Coordinate existing government programs and supports.

- Reinstatement of the Brain Injury Commission, to study, recommend, and support policy action in this area (NASHIA, 2014).
- Establish an inter-agency task force to review opportunities to collaborate, for example, on grant applications for demonstration projects. Possible agencies include: Executive Office of Health and Human Services (EOHHS), MA Department of Public Health (MDPH), Massachusetts Rehabilitation Commission (MRC), Office of Elder Affairs (OEA), Department of Mental Health (DMH), Department of Developmental Services (DDS), MassHealth, Department of Correction (DOC), MA Department of Housing and Community Development (DHCD), and municipal departments of public health (BI Commission, 2011; NASHIA, 2014).

- Establish a stakeholder task force of advocates, providers, survivors, and family members charged with advising the Brain Injury Commission and policymakers on problems, needs, and strategies from stakeholder perspectives (NASHIA, 2014). The Brain Injury Association of MA (BIA-MA) could be charged with leading this task force.
- Expand the mandate of MRC to serve people with all types of brain injuries, not just traumatic brain injury. Establish MRC as the central administrative body guiding state brain injury efforts (NASHIA, 2014).

States have addressed governance needs by enacting legislation or Executive Orders to develop service infrastructure necessary to develop and to expand service delivery to fill in the gaps, including:

- An **advisory body** (*council/board/task force*) charged with responsibility for planning and recommending policies to address gaps in services, including coordinated systems of care.
- A **State agency** responsible for an array of community services and supports.
- **Funding** mechanisms to pay for services and supports (i.e. State, Trust Fund, Medicaid).

(Source: NASHIA, 2014)

A few states, including Iowa, Massachusetts, and Missouri, created their brain injury programs from state general revenue appropriations and contract with community providers for a variety of services including case management. Using state funds means flexibility in defining services, program eligibility, and provider qualifications (Lauer, 2011) Almost half of states have passed legislation to assess fees, fines, or surcharges to traffic-related offenses and dedicate the funding to TBI programs and services. Pennsylvania was the first state to do this (Lauer, 2011).

2. **Post-acute rehabilitation: Increase access to post-acute rehabilitation after severe brain injury.**

- Identify best practices for optimal lengths of stay for patients with severe brain injury from any cause, and including patients in coma (Giacino et al, 2014; Katz, 2012; Cope et al, 2005).
- Expand options to provide and pay for rehabilitation opportunities in the community for long-term survivors (Malec, 2001)), and explore the “medical necessity” (e.g. including maintenance or prevention of deterioration of functioning) of rehabilitative and habilitative services for people with disabilities under the Affordable Care Act (ACA) (AAPM&R, 2011).
- Mandate insurance coverage in MA for cognitive rehabilitation (TBIAC, 2014; BI Commission, 2011; Katz et al, 2006).

Increasing access to post-acute rehabilitation for persons with severe brain injury does not have to increase claims costs. In 2001 Texas mandated coverage of cognitive rehabilitation therapy after brain injury under all insurance plans excluding Medicare, Workers Compensation, and indemnity type plans (TBIAC, 2014). Between 2003 and 2005, brain injury-mandated benefit claims in Texas increased significantly while brain injury claims costs decreased by half (TBIAC, 2014). Actual claims cost and estimated premium costs per policy declined (TBIAC, 2014).

3. Transitions: Increase access to case management.

- Through MRC, provide independent case management or resource facilitation, not tied to payers, for at least 6 months upon hospitalization for brain injury, and potentially for as long as needed, for all patients at all income levels (University of Missouri-Columbia, 2006; Trexler et al, 2014).
- Through MRC, provide case management to support access to medical care and to social services and supports such as housing, day programming, and vocational rehabilitation (Trexler et al, 2014; Malec, 2001). For persons with disabilities from severe brain injury, provide life-long case management (Interviews).

A recommended model of care transition support includes encouraging patients and family members to take an active role in their care and use of a transition coach (Coleman et al, 2006). In Missouri the Department of Health and Senior Services established a TBI Early Referral Program that offers the services of a brain injury coordinator for at least 6 months to everyone with a brain injury regardless of income (University of Missouri-Columbia, 2006). The coordinator arranges for community-based services prior to discharge. Early referral clients had higher rates of doctor visits and personal care services, but significantly lower rates of emergency department visits compared to people not in the program (University of Missouri-Columbia, 2006). (See Appendix 10)

In Indiana, resource facilitation has realized substantial cost savings to a state through reduced annual lost wages and increased annual earnings (Trexler et al, 2014; Reid et al, 2011). Research supported by a collaboration of providers, advocacy groups, state agencies, and federal and local funders has informed development of an evidence-based model of resource facilitation that supports return to work and improved long-term functional outcomes for people who have been hospitalized for traumatic brain injury (Trexler et al, 2014). A study of the potential annual economic impact of the resource facilitation provided identified \$32,017,775 in lost wages avoided, and another \$22.5 million in additional annual earnings estimated for the approximately 4,200 people aged 15+ in Indiana estimated to experience disabilities after TBI in any given year (Trexler et al, 2014; Reid et al, 2011). (See Appendix 10)

4. Transportation: Increase access to transportation.

- Charge the Brain Injury Commission with studying transportation needs and solutions for the severe brain injury population (Interviews).

A volunteer solution to the transportation crisis for people with brain injuries is not ideal, but it could help to fill this universal gap in the state. Nauset Neighbors is a volunteer service that is increasing access to transportation for elders in 6 Cape Cod communities (Nauset Neighbors, 2015). Social visits and handyman services are included also. Volunteers work in a “virtual space” as they field requests and connect volunteers with clients. The program is part of a nationwide nonprofit collaboration called “Village to Village” that provides software and training for the program (Nauset Neighbors, 2015). (See Appendix 9)

5. Data for Decision-Making: Identify data needs of key stakeholders and establish an interactive system that meets state and provider needs.

- Through EOHHS and BIA-MA, provide training to improve medical coding practice for brain injuries with the shift to ICD-10 (Liebson et al, 2011).
- Through EOHHS encourage use of standardized outcome measures across providers (NINDS, 2015) by offering incentives, as done to support the MA Health Information Hlway (MeHI, 2013).
- Charge EOHHS with improving Health Information Exchange (HIE) data sharing from the system to providers (Interviews).
- Through EOHHS, establish a MA brain injury registry or other longitudinal data system that builds on the Mass Hlway or builds on practice-based evidence from MA providers (Malec & Kean, 2015) to enable monitoring of brain injury spending and outcomes, to inform policy and practice (Gliklich et al, 2014). Include social and behavioral domains (e.g. community integration or participation) as well as medical ones (IOM, 2014; Truelle et al, 2010). Explore opportunities to subscribe to established, web-based brain injury outcomes databases such as OutcomeInfo, developed with support from the National Institute of Neurological Disorders and Stroke (NINDS) (Murphy et al, 2015).

In MA, the Mass Hlway is a publically supported Health Information Exchange (HIE) that enables the secure electronic transfer of health and other patient information among diverse providers (MeHI, 2013). (See Appendix 9)

A national brain injury outcomes database, OutcomeInfo, established with funding from the National Institute of Neurological Disorders and Stroke (NINDS), has developed a Web-based database system for accumulating, reporting and analyzing assessment and outcome measures for acquired brain injury (ABI). A primary objective was to provide aggregate data to states to assist with evaluation of needs and services, with an underlying goal of increasing access to needed services. Organizations voluntarily submit de-identified patient information, including demographic and brain injury specific outcomes data, to OutcomeInfo. Organizations can access their information at any time and can compare their own data with national averages which reflect de-identified data for similar populations. The web-based collaborative database is cost-effective and the pooled data set is large enough to have an impact for advocacy and policy. The types of programs participating in the database include Intensive Residential Rehabilitation (IRR), Supportive Living Residential (SLR), Intensive Rehabilitation Outpatient/Community-based (IRC), and Supported Living Community-based (SLC). Subscribers can run individual client reports and program/collective reports (Murphy et al, 2015) (See Appendix 10).

The Department of Defense and Veterans Affairs has established a Psychological Health and Traumatic Brain Injury Registry to provide standardized and centralized data to inform understanding of outcomes, guide clinical practice, improve service access as people move from one base to another or between care settings or transition from military to veteran status, and generate policy recommendations to improve quality of patient care (DVBIC, 2014) (See Appendix 10).

The Agency for Healthcare Research and Quality has developed guidelines for disease registry projects that could inform MA efforts (Gliklich et al, 2014) (See Appendix 10).

The use of practice-based evidence research (PBER), grounded in programmatic data (as opposed to relying on data from randomized controlled trial studies) should be emphasized (Corrigan, 2015).

6. **Community: Strengthen housing options and community programming.**

- Through MRC, DDS, DHCD, SHIP, non-profit organizations, and town governments, expand access to a menu of affordable housing options for people with severe brain injury capable of living with supports in the community (EOHHS, 2012).
- Through MRC, support access to skill-building programming through brain injury-specific day programming and support groups (Malec, 2001; Trexler et al, 2014).
- Through MRC, implement the regional multi-service center whose funding has been approved. Approve funding for four more centers as proposed (BI Commission, 2011).
- Through MRC, expand funding for recreational and social activities.

The Balancing Incentives Program of the MA Executive Office of Health and Human Services (EOHHS) is working to improve access to home and community-based services for MA residents with disabilities and behavioral health needs (EOHHS, 2014). Program elements include a No Wrong Door system for better access to long-term services and supports, standardized assessments, and better provision of case management (EOHHS, 2014). EOHHS has a community housing and services memorandum of understanding with 18 entities to study ways to understand housing needs for elders, people with disabilities, and people who are homeless; reduce fragmentation of housing services; avoid institutionalization of care, and implement a demonstration project for the chronically homeless (EOHHS, 2012). Findings will inform efforts to increase housing options for people with severe brain injury in MA. (See Appendix 9)

Sample models of community programming include: (1) the Krempels Center in New Hampshire provides programming 3 days per week for people with acquired brain injuries. Participants help determine programming, which is supported by university interns (Krempels, 2015). (2) Head Injury Community Services in Quincy, which has served SHIP clients with traumatic brain injuries for 23 years, offers day programming run by case managers 3 days and 1 evening per week and is based on client interests (NR, 2015). (3) The Advocates Brain Injury Day Program in Lexington is run by rehabilitation therapists and supports cognitive and social skill-building. Offered 5 days per week, it is one example of the small, brain injury-specific day programs being developed for Waiver clients throughout the state (Advocates, 2015). (4) BIA-MA support groups, often run by facilitators with brain injury, provide inexpensive social and recreational support and connect people to services (BIA-MA, 2015). (See Appendices 9 and 10)

Community programming specific to brain injury provides opportunities to build new skills, socialize, and work toward goals, which could include employment, volunteering, or fulfilling a family role. People we spoke to noted that rehabilitation-like activities offered in the community can be effective at helping people get back on their feet and participating in life. Neuroscience findings about brain plasticity tell us that opportunities to build skills can be helpful even years after the injury.

7. **Prevention: Reduce further harm from brain injury among young people and veterans.**

- Charge DOC, DHCD, and MDPH with investigating the scope of brain injury among young people in MA involved in the criminal justice system and with developing strategies to screen for TBI, help those working in the system to better accommodate TBI-related disabilities, and better support transition out of the system, and as a result reduce the harm from brain injury in this population (Virginia Collaborative, 2013).

A particular population of interest is youth with TBI in the juvenile justice system, a problem that is gaining in national and international attention (Hughes et al, 2015; NASHIA, 2014; Virginia Collaborative, 2013). Several states (notably Minnesota, Nebraska, Texas, Utah, and Virginia) are attempting to quantify and address this problem (Virginia Collaborative, 2013). The impact of injuries that occur in middle school become a lot more apparent later on (Interview). (See Appendix 10)

Conclusion

Massachusetts has long been a national leader in the prevention and treatment of brain injury. Our state was the first home of the foundation that became the Brain Injury Association of America. The recent brain injury epidemiology study carried out by the Massachusetts Department of Public Health in collaboration with the Massachusetts Rehabilitation Commission is the first in the nation to examine not just TBI but the broader umbrella of acquired brain injuries and their rate of Emergency Department visits and hospital stays in our state. Yet gaps and disparities in needed information and services remain. Brain injuries occur every day in the Commonwealth and could happen to any of us or our family members.

While Massachusetts provides some of the best acute care in the world, there are significant gaps in treatment and social supports that when addressed could improve quality of life and care, outcomes, and, potentially, societal costs. Government services could be better organized and coordinated, rehab care could help many who currently fall through the cracks and potentially reduce long-term care costs. Case management could help patients and families negotiate the confusing array of medical and social services available and improve vocational outcomes. Improving social services such as transportation, housing, day programming, and recreation and social activities could contribute to better quality of life as well as vocation and function. Expanding prevention services to incorporate efforts to reduce the harm that results from brain injuries for young people in underserved communities, youth involved in the juvenile justice system, and veterans could have a positive impact on vulnerable populations and individuals and realize cost-savings to the Commonwealth.

We hope that this policy issue brief assessing the continuum of care for severe brain injury will inform ongoing efforts in the Commonwealth and encourage continued action by all stakeholders to improve services across the continuum of care, from prevention to acute care, post-acute rehabilitation, transitions, community services, and research. It is clear that here in Massachusetts we have a strong base to build on to improve the continuum of care for severe brain injury. It is also clear that there is much work to be done.

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Appendix 1

People Interviewed for the Issue Brief and the Survivor Testimony Video

Note: Affiliation listed for some individuals has changed since the time they were interviewed for this issue

Amy Bernstein, MassHealth

Bruce Bird, VinFen

Chris Carter, Spaulding Rehabilitation Hospital

Harriette L. Chandler, Majority Leader, Massachusetts Senate

Eileen Chernoff, Community Rehab Care

Peter Chochrek, ABI survivor*

Michelle Demore-Taber, Advocates

Anton Dodek, Blue Cross Blue Shield

Susan Gaffney, Advocates

Joe Giacino, Spaulding Rehabilitation Hospital

Ann Gillespie, Community Rehab Care

Nicole Godaire, BIA-MA

Michele Goody, MassHealth

Shaun Grady, ABI Survivor*

Scott Green, Netsmart

Ben Jackson, Head Injury Community Services

Karen M Janulewicz , ABI survivor*

Kathee Jordan, Seven Hills

Douglas Katz, Braintree Rehabilitation Hospital and Boston University

Barb Kresge, Krempels Center, New Hampshire

Francesca LaVecchia, Boston University, School of Medicine

Ross Merritt, NetSmart

Therese O'Neil-Pirozzi, Northeastern University and Harvard-Spaulding TBI Model System

Nicky Osborne, Massachusetts Rehabilitation Commission

Peter Noonan, Supportive Living Inc

Theresa Rankin, Virginia Housing & Support Services Consortium, Brain Injury Services, Inc.

Jack Reed, Head Injury Community Services

Mary Roach, NeuroRehab Management Inc.

Donald Rondeau, ABI survivor*

Lisa Saba, NeuroRestorative

Nancy Schmidt, Spaulding Rehabilitation Hospital

Ken Singer, Berkshire County ARC

Amanda Smart, Survivor

Kenneth J. Smith, LTSS, MassHealth

Marilyn Spivack, Spaulding Rehabilitation Hospital

Pat Stark, Wingate Worcester

Eileen Stefan, ABI survivor*

Rob Taber, Genesis

Michael Turner, Berkshire County ARC

Tom Wagner, Advocates

Susan Vaughn, NASHIA

Michel Weaver, Learning Services

Barbara Webster, BIA-MA

* ABI survivors who provided video testimony.

Appendix 2

Issue Brief Interview Guide

Questions:

Where does your organization or agency fit in the brain injury continuum of care involved in supporting or providing brain injury services or supports?

Where do you get the funding for your work?

What is the range of severity in the clients you serve?

What types of professionals do you have on your staff?

How do you measure your success and how do you track it?

What policies and organizations support your work?

Are there any barriers or limitations you face in your work?

How do you see your work changing over time?

What is the Commonwealth doing right about acquired brain injury?

What are some best practices and successes from your perspective?
(In the Commonwealth? Elsewhere?)

What has contributed to the success of the efforts/programs you have mentioned?

What could be done to further strengthen these efforts/programs?

Where are there gaps and limitations in supports and services?

What is contributing to these gaps and limitations?

How would you recommend closing these gaps and limitations?

How do these gaps and limitations impact individuals? Families? Communities?

Who needs to be involved in closing these gaps moving forward?

What if anything gives you hope for the future of brain injury treatment and services?

What if anything would you like to know more about?

What if anything do you think policymakers need to know?

Have I missed asking any questions or raising any issues you think are important?

Appendix 3

Video Testimony Interview Guide

Questions:

- (1) Tell me a little bit about yourself and your life before your injury and after your injury.
- (2) What if any services have helped you recover from your brain injury? Tell me about one service in particular that has helped you.
 - Examples of services are:
 - Inpatient rehabilitation, case management, outpatient or community-based rehabilitation, housing, supported independent living, support with activities of daily living, transportation, support groups, and community programming.
- (3) What if any services did you not have access to, or maybe not enough access? Tell me about one service in particular that could have helped you or could help you now.
 - Examples of services are:
 - Inpatient rehabilitation, case management, outpatient or community-based rehabilitation, housing, supported independent living, support with activities of daily living, transportation, support groups, and community programming.
 - What happened that prevented your access?
 - What might be different in your life or recovery if you had access to this service?
- (4) What do you want to tell policymakers about the gaps in brain injury services in our state?
- (5) What are your hopes for the future, and what could help you get there?

Appendix 4 Acronyms

AAA:	Area Agencies on Aging	HRSA:	Health Research and Services Administration
ABI:	Acquired brain injury	ISP:	Individual Service Plans
ALFA:	Assisted Living Facilities Association	MDPH:	MA Department of Public Health
ASAPs:	Aging Service Access Points	MeHI	Massachusetts eHealth Institute
BI:	Brain Injury	MFP:	Money Follows the Person
BIA-MA:	Brain Injury Association of Massachusetts	MRC:	Massachusetts Rehabilitation Commission
BI&SSCS:	Brain Injury and Statewide Specialized Community Services	NASHIA:	National Association of State Head Injury Administrators
CDC:	Centers for Disease Control and Prevention	OEA:	MA Office of Elder Affairs
CHW:	Community Health Worker	OT:	Occupational therapy
COA	Councils on Aging	PARF:	Post Acute Brain Injury Providers
DDS:	MA Department of Developmental Services	PBER:	Practice-Based Evidence Research
DHCD:	MA Department of Housing and Community Development	PT:	Physical therapy
DMH:	MA Department of Mental Health	RF:	Resource Facilitation
DOC:	MA Department of Corrections	SHIP:	Statewide Head Injury Program
ED:	Emergency Department	SLI:	Supportive Living, Inc.
EOHHS:	Executive Office of Health and Human Services	SPL:	Speech and language pathology
HCBS:	Home and Community-Based Services	SSDI:	Social Security Disability Insurance
HICS:	Head Injury Community Services	SSI:	Social Security Insurance
HIE:	Health Information Exchange	TBI:	Traumatic brain injury
		TBIAC:	Texas Traumatic Brain Injury Advisory Council
		VNAs:	Visiting Nurse Associations

Appendix 5

Essential Reading

Essential reading that has informed this issue brief is listed and described below.

Brain Injury Commission Report, November 14, 2011

In fiscal year 2011, a Brain Injury Commission was established by legislative action. Governor Deval L. Patrick appointed the members of this Commission, who included persons with acquired brain injury, state agency representatives, family members of persons with ABI, and providers of community-based brain injury services within the Commonwealth of Massachusetts. The Commission, which held monthly public meetings, identified gaps in service delivery, and other needs as well as challenges experienced by Massachusetts residents who had an ABI. These service needs and associated recommendations are detailed in the Commission's final report, which can be accessed at www.mass.gov/hhs/braininjurycommission.

Acquired Brain Injury in Massachusetts, October 2014

A recommendation prioritized by the Brain Injury Commission's 2011 report was to complete an epidemiological study of ABI in Massachusetts to inform development of long-term community-based support services for adults and children with acquired brain injury. The report, published in October 2014 by the Massachusetts Rehabilitation Commission in collaboration with the Massachusetts Department of Public Health, includes an estimate of the magnitude of the population; affected age groups; regions of residence; and other pertinent descriptive information for five major subcategories of ABI, including traumatic brain injury (TBI), stroke, ABI-related infectious diseases, metabolic disorders affecting the central nervous system (brain and spinal cord), and brain tumor. The report also provides a chapter describing ABI prevention activities in the Commonwealth. The epi report may be accessed at <http://www.mass.gov/eohhs/docs/mrc/acquired-brain-injury-ma.pdf>.

Supported Living: A Cost Effective Model of Independent Living for People with Disabilities, Massachusetts Rehabilitation Commission, June 2004

This report describes the supported living model in Massachusetts, and its participants, services provided, costs, benefits, and success stories. The full report can be found at: <http://www.supportedliving.org.au/site/wp-content/uploads/Supported-Living-A-cost-effective-model-of-independent-living-for-people-with-disabilities.pdf>

Report to Congress: Traumatic Brain Injury in the United States: Epidemiology and Rehabilitation, 2014.

Prepared by the Centers for Disease Control and Prevention's National Center for Injury Prevention and Control, Division of Unintended Injury Prevention, this report to Congress describes the national incidence of traumatic brain injury, including trends over time; describes data on the prevalence of TBI-related disability; reviews the adequacy of TBI outcome measures; describes factors that influence differential TBI outcomes; and assesses the current status and effectiveness of TBI rehabilitation services. The report can be accessed at: http://www.cdc.gov/traumaticbraininjury/pdf/TBI_Report_to_Congress_Epi_and_Rehab-a.pdf.

The Challenge! Volume 9, Issue 2

Published four times per year by the Brain Injury Association of America, *The Challenge*, addresses policy-related acquired brain injury topics and includes public policy news, research breakthroughs, medical advances, legal and financial issues, and survivor stories. The Spring 2015 issue (Volume 9, Issue 2), focused on the role of rehabilitation, informed development of this issue brief and explored what works in rehabilitation and what is needed to improve it. Access issues of the publication at <http://www.biausa.org/brain-injury-publications.htm>.

Resource Facilitation: Indiana Best Practices Manual for Return-to-Work or Return-to-School by Trexler, L. E., Waldman, W., & Parrott, D. (2014)

Developed to guide providers in the delivery of Resource Facilitation (RF) services, this manual provides a rationale and historical overview of Indiana's RF efforts, addresses recovery issues that influence long-term vocational and other outcomes after a hospitalization for brain injury, describes system barriers that create gaps in the continuum of care, defines the RF team's roles and organizational structure, presents the RF service model and the research and training that support it, and makes recommendations for the future. The model is grounded in evidence from randomized controlled trial studies and was funded by grants from the Health Resources and Services Administration (HRSA) and the Indiana Spinal Cord and Brain Injury Research Board and funding from the Rehabilitation Hospital of Indiana Foundation. The guide is intended to inform state efforts to improve vocational outcomes after a hospitalization for brain injury. To obtain a copy, visit <http://rhin.com/resource-facilitation-best-practices-manual-for-return-to-workschool/>.

Appendix 6

State Programs Supporting People with Severe Brain Injury

This appendix provides information on the Massachusetts Rehabilitation Commission (MRC) and its agency the Statewide Head Injury Program (SHIP) and on the five brain injury Home and Community-Based Services (HCBS) Waiver programs in the Commonwealth. For information on specific services provided under the TBI, ABI, and MFP Waivers, see Appendix 7.

6.1. MRC- Massachusetts Rehabilitation Commission

The Massachusetts Rehabilitation Commission (MRC) is one of the agencies within the Executive Office of Health and Human Services (EOHHS) Secretariat. The goal of MRC is assist individuals with disabilities (including Traumatic Brain Injury) to live and work independently. MRC offers a range of services including: Vocational Rehabilitation, Community Living, and Disability Determination Services for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI):

- Vocational Rehabilitation helps people with disabilities find and maintain employment.
- Community Living offers brain injury and specialized community services, protective services, supported living services, independent living center services, independent living programs for people turning 22, assistive technology program, home care assistance, consumer involvement, acquired brain injury Waivers, and money follows the person and home and community based Waivers.
- The disability determination service is funded by the Social Security Administration and determines initial and ongoing Social Security Disability Insurance (SSDI) and Social Security Insurance (SSI) eligibility for those with disabilities.

Many of the services listed above, while paid for by MRC, are contracted out to private non-profit and for-profit organizations that specialize in brain injury treatment and recovery. MRC also helps survivors and their families connect with services they may be eligible in the state. Because of this resource intensive work, MRC is limited in the number of persons that it can serve or the services it can provide at any one time. The Brain Injury Association of Massachusetts (BIA-MA) estimates that more than 4,000 people are eligible for services but unable to receive them at the current time. MRC is a key stakeholder in coordinating state appropriated benefits for eligible individuals with brain injuries.

6.1.a. Brain Injury and Statewide Specialized Community Services (BI&SSCS), a.k.a. SHIP- Statewide Head Injury Program

The Statewide Head Injury Program (SHIP) or Brain Injury and Statewide Specialized Community Services (BI&SSCS), is a part of the Community Living division of MRC. The SHIP budget is determined annually by the state legislature, and their client-base is persons with TBI. SHIP provides a range of community-based services for people who have sustained a TBI including: case management, social/recreational programs, skills training via regionally-based head injury centers, respite, residential services/programs, and family support services (<http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/head-injury/>). Eligibility requirements include being a MA resident, having sustained a TBI, having associated impairments in physical and/or cognitive and/or behavioral functioning, and being able to participate in the

community-based services. Like MRC, SHIP is confined to its budget and is not an entitlement program available immediately to all of those eligible. Some individuals have remained eligible without services for up to six or more years.

A Caution. Through the ABI and MFP Waivers, MassHealth, MRC, and DDS are moving people with severe brain injury into the community, and creating opportunities for them to participate fully in community life alongside everyone else. Economic theory tells us that there are two sides to this coin – supply and demand. MA is creating the supply of people with brain injury living in the community through the HCBS residential and non-residential Waiver programs. However, we need to consider the demand side as well, and ways to encourage community demand to include people with severe brain injury in community life. People without disabilities may feel challenged approaching and speaking with someone in a wheelchair or with cognitive and behavioral challenges; they may have concerns about incorporating someone with severe brain injury into ongoing community programs and activities. Outreach is needed to create awareness of the benefits of community inclusion for all and to encourage community-based efforts to increase participation in community life for people with severe brain injury.

Figure 11: SHIP’s population and funding challenges, respondent perspectives

SHIP does not serve stroke or brain tumors. They cannot serve anyone with another form of ABI (besides TBI). That’s the regulation. *(Francesca LaVecchia, Boston University School of Medicine)*

Whether TBI or ABI, the effects are similar because it is all the same organ. They have similar areas of disfunction. Having an agency just for TBI is like creating an agency for the heart but then limiting services to those just with a coronary. *(Francesca LaVecchia, Boston University School of Medicine)*

To expand SHIP, funding has to be there. *(Harriette L. Chandler, Majority Leader, Massachusetts Senate)*

There are more than 4,000 people eligible for SHIP services but not yet receiving them. The faster they get services, the less likely they are to depend on state services and more likely to go back into the community and start working. *(Nicole Godaire, Executive Director, Brain Injury Association of Massachusetts)*

6.2 Home and Community-Based (HCBS) Waivers for People with Brain Injury

6.2.a. Traumatic Brain Injury (TBI) Waiver

The Traumatic Brain Injury Waiver is operated by MRC. This Waiver provides community-based services to Medicaid-eligible persons with traumatic brain injury (TBI). Eligibility requirements are:

- Must be 18 or over and have experienced a Traumatic Brain Injury (TBI)
- Meet the clinical requirements and needs of the Waiver services available
- Must be financially qualified for MassHealth

The TBI Waiver provides case management to all those eligible and approved. Case managers help set individual community based goals and draft a person-centered service plan to meet them. The TBI Waiver began operating in 2001 and serves up to 100 participants each year. The TBI Waiver serves people living in group homes, shared living, and in their own homes or apartments.

6.2.b. Acquired Brain Injury Waivers

MRC, DDS, and MassHealth, in conjunction with UMass Medical School, offer two acquired brain injury (ABI) home- and community-based services Waivers to help Medicaid-eligible persons with ABI move to the community and obtain community-based services. The ABI Waivers are comprised of both residential-habilitation Waiver (ABI-RH) and the non residential habilitation (ABI-N). DDS now manages the ABI residential habilitation Waiver, and MRC manages the non-residential ABI Waiver.

As with other Medicaid services the state receives approximately 50% federal reimbursement for services delivered through these Waivers. Their goal is to move people with ABI from a nursing home back into the community. Eligibility requirements are:

- Must be living in nursing home, or chronic or rehabilitation hospital, for at least 90 days
- Must have experienced an ABI at age 22 or older
- Meet the clinical requirements and needs of the Waiver services available
- Must be financially qualified for MassHealth

For purposes of eligibility for these two Waivers, ABI is defined as all forms of brain injuries that occur after attaining the age of 22, including brain injuries caused by external force (TBI), but does not include Alzheimer's Disease or other similar neurodegenerative diseases whose primary manifestation is dementia. The ABI Waivers provide case management to all those eligible and approved. They also help set individual community-based goals and draft a person-centered service plan to meet them.

Since 2010, under the ABI-N and ABI-RH Waivers, 320 people have transitioned into the community and another 150 who are clinically eligible are working towards transition. These Waivers are grounded in cost-savings, consumer choice, and quality of life goals. The community living or residential habilitation must be cost-neutral compared to the cost of a similar population living in nursing homes and non-acute hospitals. Although the ABI Waiver has helped many to transition to a better quality of life, its reach is limited.

6.2.c. Money Follows the Person (MFP)

MassHealth offers two Home and Community-Based Services (HCBS) Waivers called Money Follows the Person (MFP) that help people living in institutionalized settings move into community based settings. This program has broader eligibility criteria than the HCBS TBI or ABI Waivers and includes:

- Must be living in nursing home, or chronic or rehabilitation hospital, for at least 90 days
- Be 18 years old or older and have a disability, or be age 65 or older;
- Meet the clinical requirements for and be in need of MFP Waiver services;
- Can be safely served in the community within the terms of the MFP Waivers;
- Meet the financial requirements to qualify for MassHealth
- Meet the requirements for participation in the MFP Demonstration
- Can transition to a MFP qualified residence in the community. A qualified residence includes:
 - A home owned or leased by the applicant or family member
 - An apartment with an individual lease or a community-based residential setting in which no more than four unrelated individuals reside or
 - An assisted-living residence accommodating no more than five residents that has an apartment with separate living, sleeping, bathing and cooking areas, lockable entrance and exit doors, and meets other criteria.

MFP, like the ABI Waiver, is subdivided into two Waivers: Money Follows the Person- Residential Supports (MFP-RS) and Money Follows the Person- Community Living (MFP-CL). For both Waivers, beneficiaries who need behavioral support (mental health or substance abuse services) will receive it through the Massachusetts Behavioral Health Partnership. A portion of the 250 MFP Waiver clients enrolled to date are people with brain injuries, as well as a portion of the 300 who are eligible and working towards transition. It is estimated that at least 100 are persons with ABI. As with the earlier TBI and ABI Waivers, DDS is managing the residential Waiver, while MRC manages the non-residential Waiver.

Figure 12: Perspectives on the Commonwealth’s HCBS brain injury Waivers from respondents

- From my perspective, the people on the Waivers are blessed because in many ways. The emphasis going forward needs to be on the people in the community who are not on the Waiver and who have been waiting to get services for decades.
- Everyone in Waiver day programs has cognitive impairments. Most common are short-term memory loss, and problems with problem solving, reasoning, initiating, and divided attention. Quite a few have psychological or emotional difficulties like frustration and anger when they are not understanding fully or if they can’t perform a task the way they used to.
- Rates need to be more realistic across the board.
- It is time consuming to transition someone out of a Skilled Nursing Facility (SNF) to other services. Even once they are in the community it can still take another year or more to get them enrolled in day services.
- It’s wonderful when we can move people out of SNFs into community based housing, but the housing just fills one need. Then there is the challenge of community activities and giving them the option of getting involved in the community. You get reimbursed for food, shelter, and safety -- the basic needs and to take care of IADLs and ADLs. You are not funded to take people bowling.
- Someone can give you tickets to the Red Sox for your Waiver residents. But you can’t get there. In a Waiver home, if you have 2 people who want to go the Red Sox but you can only afford to have 2 staff in the home at any one time and you need 2 staff to accompany half of the residents to the game, then you can’t go.
- Not enough experienced people in Massachusetts are looking for jobs working with the brain injury population, or they don’t have the experience required to provide higher levels of care. We can’t attract people from out-of-state, either, because it’s more expensive to live here but the rate of payment is the same everywhere.

Appendix 7

Specific Services Available Under Home and Community Based Waivers in Massachusetts: TBI, ABI, and MFP

Traumatic Brain Injury (TBI)-Specific Waiver

Services offered under the TBI Waiver include:

- Shared living – 24-hour supports
- Residential habilitation
- Day services
- Supported employment
- Transportation
- Specialized medical equipment
- Transitional assistance
- Homemaker
- Personal care
- Adult companion
- Individual support and community habilitation
- Respite
- Chore
- Home accessibility adaptations

ABI-Specific Waiver

Services offered under the ABI residential habilitation Waiver (ABI-RH) include:

- Assisted living services
- Shared living – 24-hour supports
- Residential habilitation
- Day service
- Supported employment
- Transportation
- Occupational, physical, or speech therapy
- Specialized medical equipment
- Transitional assistance

Services offered under the ABI *non* residential-habilitation Waiver (ABI-N) include:

- Day services
- Supported employment
- Transportation
- Occupational, physical, or speech therapy
- Specialized medical equipment
- Transitional assistance
- Homemaker
- Personal care
- Adult companion
- Individual support and community habilitation
- Respite
- Chore
- Home accessibility adaptations

MFP-Specific Waiver

Services offered under the MFP-RS (residential habilitation) Waiver include:

- Residential Habilitation (group home)
- Shared Living – 24-Hour Supports
- Assisted Living Services
- Day Services
- Home Accessibility Adaptations
- Individual Support and Community Habilitation
- Occupational Therapy
- Peer Support
- Physical Therapy
- Prevocational Services
- Residential Family Training
- Skilled Nursing
- Specialized Medical Equipment
- Speech Therapy
- Supported Employment
- Transportation

Services under the MFP-CL (non-residential) Waiver include:

- Adult Companion
- Chore Service
- Community Family Training
- Day Services
- Home Accessibility Adaptations
- Home Health Aide
- Homemaker
- Independent Living Supports
- Individual Support and Community Habilitation
- Occupational Therapy
- Peer Support
- Personal Care
- Physical Therapy
- Prevocational Services
- Respite
- Shared Home Supports
- Skilled Nursing
- Specialized Medical Equipment
- Speech Therapy
- Supported Employment
- Supportive Home Care Aide
- Transportation
- Vehicle Modification

Appendix (8)

Costs to Implement Recommendations in the Brain Injury Commission Report (2011), with Updates from BIA-MA (2015)

The BI Commission report made administrative and service recommendations for the state. Administrative recommendations included updating the prior ABI epidemiological study, conducting a comprehensive needs assessment to determine service needs of adults with ABI in the state, establishing an interagency task force in EOHHS to identify needs of youth with ABI transitioning into adult service, and modification of the definition of Personal Care Assistance under MassHealth's state plan.

With the leadership of Senator Harriette Chandler, Representative Kimberly Ferguson and Representative Thomas Conroy the Head Injury Treatment Services Trust Fund (HITS) was increased from 60% to 100% during 2012 and 2013. The Acquired Brain Injury in Massachusetts epidemiological study was published by the Massachusetts Department of Public Health and the Massachusetts Rehabilitation Commission in October of 2014. A bill was filed in the MA legislature in January of 2015 to require commercial health insurance agencies to cover cognitive rehabilitation for brain injured survivors.

The Brain Injury Commission service recommendations include establishing a comprehensive needs assessment inter-agency task force in EOHHS and expanding coverage of SHIP services to people with ABI. (See Table 1, below.)

Table (1): BI Commission Report Administrative Recommendations

Service Recommendation	Purpose	Estimated Costs (\$)
Comprehensive Needs Assessment	Determine service needs of adults with ABI in the state	\$150,000
Interagency Task Force in EOHHS	Identify needs of youth with ABI transitioning into adult service	*To be determined
Expand coverage of SHIP services to people with ABI	Serve all MA residents between the ages of 18-59 with an ABI in addition to those with TBI	*To be determined
Personal Care Assistance defined	Allow individuals, who have cueing and supervision needs to qualify for PCA services	*To be determined
		Total \$150,000

**The Brain Injury Commission did not provide costs*

The Brain Injury Commission service recommendations include establishing five ABI day programs (using a clubhouse model), five regional ABI multiservice centers, and 10 new ABI social/recreation programs statewide. The Commission estimated that it will cost approximately \$7.8 million to provide Regional ABI Multi-Service Centers, Day Programs, and Social Recreation. (See Table 2, below.)

Table (2): BI Commission Report Recommendations of Needed Services

Line Item	Purpose	Services	Needs*	Persons Served*	Estimated Costs (\$)
Regional ABI Multi-Service Centers	Provide outreach to individuals with acquired brain injury	Case management, skills training, cognitive rehab, and TA	5 centers	*N/A	\$5,000,000
Day Programs	Support community living and community integration through skill building/re-learning	Build skills: behavior mgt., cognitive self mgt. independent living, and community integration	5 programs	*N/A	\$2,500,000
Social/Recreation Programs	Reduce social isolation and build cog. and social skills for ABI persons in the community	Interactive activities to improve cognitive and social functioning	10 programs \$15,000 per program	*N/A	\$300,000
Residential Services	Enable persons with medical, physical, and behavioral challenges from ABI to live in the community	24/7 residential services for persons with more intensive medical, cognitive, and/or behavioral needs	*N/A	*N/A	*N/A
PCA Services	PCA services should be available to individuals with ABI who exhibit difficulty in performing Activities of Daily Living (ADL) and Independent Activities of Daily Living (IADL) tasks	Increase PCA supports for those with ABI	*N/A	*N/A	*N/A
				TOTAL	\$7,800,000

*The Brain Injury Commission did not state the number of individuals needing services or state estimated costs

BIA-MA has estimated that approximately \$16,425,000 in state funding is needed to eliminate the list of 4,318 eligible persons with traumatic brain injury who are not yet receiving SHIP supports, which include residential services, community based services and case management, technical assistance and shared living. (See Table 3, below.)

Table (3): Estimated Annual Persons Served and Costs to Implement, as Updated by BIA-MA 2015*

Line Item	Purpose	Services	Needs	Persons Served	Estimated Costs (\$)
Residential Services	Enable persons with medical, physical, and behavioral challenges from ABI to live in the community	24/7 residential services for persons with more intensive medical, cognitive, and/or behavioral needs	17.5 homes	70	\$10,500,000
Community-based Services and Case management	Support independent living for persons with ABI, living in the community by coordinating access and developing strategies for daily life	Improve access to services and resources; improve transitions along the ABI continuum of care	Expansion of current MRC Program	750	\$4,500,000
Technical Assistance	Formalize and Expand the Technical Assistance Model	Provide statewide access to clinical expertise & education for local education and state agencies that serve individuals with ABI	N/A	N/A	\$150,000
Shared Living	Enable persons with medical, physical, and behavioral challenges from ABI to live in the community	24/7 residential services for persons with less intensive medical, cognitive, and/or behavioral needs	2 homes	15	\$1,275,000
				Total	\$16,425,000

The number of eligible consumers does not include all individuals with ABI. In order to fully implement the BI Commission report (Table 1-2) and including BIA-MA updates based on current costs and SHIP’s list of eligible consumers, there is a need to increase state funding by \$24,375,000. This number does not include the \$15,817,983 from the FY 16 state budget for the MRC’s line item (4120-6000).

Table 1: BI Commission Administrative Recommendations	\$150,000
Table 2: BI Commission Service Recommendations	\$7,800,000
Table 3: BIA-MA Recommendations and cost estimates	\$16,425,000
Total Table (1-3)	\$24,375,000

Appendix 9

MA Programs/Models – A Sampling of Best Practice Examples

Below we describe some best practices examples recommended by the people we interviewed. The range of programs described here is neither comprehensive nor complete. Summaries of some are included in the recommendations section of this brief. We hope that these examples will inspire continued support for successful ongoing solutions and new support for future efforts to close the gaps and disparities described earlier.

9.1. Falls Prevention - EOHHS

MRC and the Statewide Head Injury Program are testing a service delivery model, entitled “Improving MA Systems of Care for Elders Sustaining TBI” that identifies gaps in services unique to the elder population, maximizes existing resources in both the TBI and elder care service delivery systems, and creates a blueprint to enhance and improve systems of care to better serve elders who sustain a TBI and their families. A major goal of the project is to preserve and enhance the independence of Massachusetts’ elders. The grant project is:

- Focusing on outreach and awareness activities;
- Developing linkages across community-based providers systems and state agency staff;
- Making information and resources available that target this high risk group;
- Cross-training professionals to improve access to appropriate resources and services for elders with TBI and their families;
- Developing support groups for families of elders with TBI;
- And enhancing the state’s “No Wrong Door” model that provides simplified, streamlined, and consumer-directed access and coordination of services.

Collaborating entities include: Aging Service Access Points (ASAPs), Area Agencies on Aging (AAA), Visiting Nurse Associations (VNAs), Geriatric Care Managers, Assisted Living Facilities (Mass-ALFA), Councils on Aging (COAs), Senior Centers, and BIA-MA. The program is adapting information published by the CDC and other states, as identified through the National Association of State Head Injury Administrators (NASHIA).

The program builds on the prevention work of the MA Falls Prevention Coalition since 2007. Members include MA Department of Public Health, the MA Senior Care Association, the Home Care Alliance of MA, and BIA-MA. The grant is piloting this project in the Commonwealth’s Northeast and Metrowest regions, which have the highest numbers of seniors sustaining TBI after age 59. Lessons learned will be applied statewide in future. This pilot project is funded by a grant from the Health Resources and Services Administration (HRSA). For more information on falls prevention efforts in MA:

- <http://www.mass.gov/eohhs/docs/dph/injury-surveillance/falls-prevention-phase-1-report.pdf>
- <http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/intellectual-disability/provider-support/health-promotion/falls-prevention-campaign.html>

9.2. Transitions and Case Management

9.2.a. Commonwealth Care Alliance (CCA)

The Commonwealth Care Alliance (CCA) began in the 1970’s in MA as an integrated provider network of community health centers in low-income communities across the state.

CCA is a non-profit organization that has pioneered care delivery innovations to improve the lives and independence of the frail, sick, and disabled. CCA is unique in that they specialize in “primary care and care coordination multi-disciplinary clinical teams” that provide coverage in both acute and long-term care settings. Their integrated approach has reduced hospital re-admission rates and facilitated faster access to a broader network of providers and services. Their evidence based self-management programs have improved the health and autonomy of both members and family caregivers.

CCA is a value-based insurance program funded by public funds and provides a unique and cost-effective structure for private insurers to consider when managing the care of persons with severe brain injury. In 2008 monthly medical costs for disabled patients were \$3,601 compared to \$5,210 for Medicaid fee-for-service patients, showing a true cost-effectiveness of the program (Meyer, 2011).

For more information on the Commonwealth Care Alliance:

- <http://www.commonwealthcarealliance.org/>
- <http://www.mass.gov/eohhs/docs/masshealth/onecare/enrollment-reports/enrollment-report-july2015.pdf> (July 2015 OneCare enrollment report)
- <http://www.commonwealthcarealliance.org/wp-content/uploads/2013/04/Annual-Report-2013.pdf> (2013 Commonwealth Care Alliance report)
- Meyer, H. (2011). A new care paradigm slashes hospital use and nursing home stays for the elderly and the physically and mentally disabled. *Health Affairs*, 30(3), pp. 412-415. <http://content.healthaffairs.org/content/30/3/412.full>

9.2.b. One Care (MassHealth + Medicare)

One Care was created in October of 2013 to help MA residents with disabilities that are eligible for both Medicaid (MassHealth) and Medicare also known as “dual eligibles.” Those enrolled in One Care obtain coordinated care through a single entity and one case manager, rather than through MassHealth and Medicare separately. Both federal and state funding supports One Care. To be eligible for One Care, consumers must be:

- age 21 to 64 at the time of enrollment;
- eligible for MassHealth Standard or CommonHealth;
- enrolled in Medicare Parts A & B and eligible for Medicare Part D;
- without other public or private comprehensive insurance;
- not enrolled in a Home and Community-based Services (HCBS) Waiver; and
- not residing in an Intermediate Care Facility (ICF/MR).

When a person is determined eligible, One Care assigns a case manager who works with the beneficiary to develop a person-centered plan that meets both individual health and community goals. The beneficiary is also assigned a One Care team of experts through their choice of a One Care plan. One Care plans cover a standardized set of medical and community based services. One important community based service covered is non-emergency medical transportation to doctors’ appointments or rehabilitation centers, as well as non-medical transportation to promote access to and independence in the community. One Care streamlines the complicated coverage system of MassHealth and Medicare under one group that oftentimes allows beneficiaries faster access to appropriate services.

A February 2015 Kaiser report suggested “savings from the demonstration are expected to result primarily from reductions in emergency department and inpatient use on both the behavioral health and medical side.” At the same time they noted stakeholder concerns on rates not being sufficient enough to provide up-front care in crisis stabilization services to prevent emergency room visits and inpatient stays may weaken the overall predicted savings. Elders with brain injury are eligible for services under this program.

Figure 13: A perspective on OneCare for dual eligibles with brain injury from a respondent

“OneCare is community based services and preventative care, and provides supports and services to individuals in their community settings. So oftentimes a nurse practitioner comes into the home to meet with the individual as well as their therapist. Frequently people who have had brain injury might not be able to follow through as well as they would like with outpatient services, so going into the home really helps going around some of those challenges. Under the program, care is provided by a team of people. Many clients have trauma histories as well as brain injury, and the program has therapists trained in trauma specific issues and strategies.”(Interview)

For more information on OneCare:

- <http://www.mass.gov/eohhs/consumer/insurance/one-care/>
- <http://www.mass.gov/eohhs/docs/masshealth/onecare/services-covered-by-one-care.pdf>
(services covered by one care)
- <http://www.mass.gov/eohhs/docs/masshealth/onecare/enrollment-reports/enrollment-report-july2015.pdf> (July 2015 OneCare enrollment report)
- <http://www.bostonglobe.com/opinion/2015/08/10/one-care-deserves-time-work/15jLgpY4a7cah6szkwrBfN/story.html?event=event12>
- <http://kff.org/report-section/early-insights-from-one-care-massachusetts-issue-brief-8725/>

9.3. Transportation

Nauset Neighbors

Nauset Neighbors is an all-volunteer non-profit organization that serves the elderly community in 6 Cape Cod communities. One call provides access to the following services: transportation; occasional light household or yard tasks; technical assistance with email, cell phones, remote control, and other needs; and social, educational and cultural opportunities. Members pay an annual fee of \$75 for an individual or \$95 for a family, though fees are waived or reduced for hardship. There is no central office, and all volunteers work off of a virtual space. As of August 23, 2015 the organization was serving 306 members, had 333 volunteers, and had a waiting list of 20 people. They had 396 service requests booked for September-November; 67% for transportation.

To access transportation and other services, a member calls a central number, which gets rerouted to a calling manager through Google voice. The call manager places the request on an online sign-up list where volunteers regularly check and agree to take up certain tasks. The call manager calls the volunteer to thank them, and then calls the member to confirm the ride or service. Volunteers are trained on how to accommodate elders, and could similarly be trained on how to accommodate brain injury survivors through BIA-MA training programs already in existence.

Nauset Neighbors is part of a collation called the Village to Village network which aims to create an open network of information sharing and experiences with other communities offering these types of services. Challenges with sustainability of any volunteer program remain.

For more information on Nauset Neighbors:

- http://nausetneighbors.org/content.aspx?page_id=0&club_id=502670
(Nauset neighbors homepage)
- http://www.vtvnetwork.org/content.aspx?page_id=22&club_id=691012&module_id=65139
(Village 2 Village network)
- https://s3.amazonaws.com/ClubExpressClubFiles/502670/documents/Report_2015_08_22_130924531.pdf?AWSAccessKeyId=AKIAIB6I23VLX7E4J7Q&Expires=1440429440&response-content-disposition=inline%3B%20filename%3DReport_2015_08_22.pdf&Signature=MJI7aBXXFdr9PAr5Da7UQzKcTn8%3D (weekly report, aug 23)

9.4. Data and Information Sharing:

Massachusetts eHealth Institute (MeHI)

The Massachusetts eHealth Institute (MeHI) is a designated state agency for:

- Coordinating healthcare innovation, technology and competitiveness
- Accelerating the adoption of health information technologies
- Promoting health IT to improve the safety, quality and efficiency of health care in Massachusetts
- Advancing the dissemination of electronic health records systems in all health care provider settings
- Connecting providers through statewide HIE

By January 2017, all providers (not just physicians) in the Commonwealth are expected to implement fully interoperable electronic health records systems that connect through statewide health information exchange.

MeHI is a way for providers serving persons with severe ABI in Massachusetts to ensure more seamless care transitions, for example from acute care to inpatient rehabilitation, or from residential care to an Emergency Department or rehabilitation facility, and home again.

For more information on the Massachusetts eHealth Institute:

- <http://mehi.masstech.org/education/presentations>

9.5. Community – Day programming and Support Groups

9.5.a. Head Injury Community Services (HICS) a.k.a. Quincy Day Program

Head Injury Community Services (HICS) is a day program that also provides case management at the community level for SHIP-eligible consumers. HICS functions under the non-profit organization Neuro-Rehab Management Inc, is located in Quincy, MA and has served SHIP clients for 23 years. They help participants reach goals described in Individual Service Plans (ISP) and annually review these plans with a case manager and the consumer. Skill-development goals include: independent living skills, community living skills, social skills, and prevocational skills. Activities include: recreation and leisure, health and wellness, and case management services (NR, 2015). Case management provided through HICS has helped participants to obtain and maintain jobs, prevent or remedy homelessness, prevent substance abuse, and otherwise mitigate potential large-scale (and costly) problems (Interview). HICS has four full-time case managers, two directors, and one part

time secretary that serve a population of 20 to 50 people depending on the week (Interview). Interviewees noted that access to HICS services early on after injury contributes to client progress. Facilitating increased case management for person with brain injury could result in cost savings to society, while also improving survivors' quality of life (Interviews).

Figure 14: A perspective on community programming from a respondent

“Brain injury day programs can help people get back on their feet, gain some confidence, redefine themselves, and then get back to work. They can serve as transitional programs. Some will treat the programs as “my community” and come for life. It all depends on people’s goals and what they are hoping to achieve.”(Interview)

For more information on Head Injury Community Services:

- <http://www.neurorehabmgt.com/services.html>

9.5.b. BIA-MA Support Groups

The Brain Injury Association of Massachusetts (BIA-MA) sponsors support groups across the state “that provide survivors and their loved ones a forum for sharing information about brain injury as well as a compassionate and understanding peer group and an opportunity to socialize and make new friends with others through recreational activities and outings (<http://www.BIA-MA.org/groups>).” Currently there are 45 support groups sponsored by BIA-MA that meet throughout East/Central, Southeast/Cape, and Western MA. Research has shown that support groups are a way to significantly improve the well-being and psychosocial outcomes of participants through higher levels of community integration and lowering depression scores (Fleming et al, 2009).

Many support groups with funding from MRC/SHIP facilitate access to recreational activities and educational workshops on such topics as nutrition, art therapy, and poetry. With minimal staff and sliding scale activity fees, support group are a low cost way to provide opportunities to build skills for independent functioning and socially interact with peers. As noted by one facilitator, “Massachusetts brain injury support groups provide social and community supports that help to meet the non-medical needs of survivors.” The biggest hurdle of support groups is transportation to group meetings (Interview).

Figure 15: Perspectives on support groups from respondents

- These aren't sit around and whine groups. These groups do a lot more than share issues. There is a lot of focus on how to help people get out into communities.
- One woman started out in a wheelchair in a group home started coming to a support group and through their resources and support, got out of wheelchair, learned how to walk, got into own apartment and started working part time.
- Some people are able to take what they need from it and then move to other parts of their lives. Participation is somewhat fluid - some go back to school part time or get involved in other cause and could be good thing. Usually if they stop coming it means they're busy doing other things.

For more information on brain injury support groups in MA:

- <http://www.BIA-MA.org/groups>
- <http://www.BIA-MA.org/pdfs/support%20group%20lists/Support%20Group%20List%2000MASTER%207.29.15.pdf>

Appendix 10

Programs in Other States – A Sampling of Best Practice Examples

Below we describe a range of programs in other states that that people interviewed for this policy brief suggested could inform efforts to improve the continuum of care for severe brain injury in our state. Examples are provided under the following headings: Access to post-acute rehabilitation, case management, data for decision-making, community programming, and harm reduction.

10.1. Access to Post-Acute Rehabilitation

10.1.a. Texas Cognitive Rehabilitation Bill – Mandating Access to Cognitive Rehabilitation

In 2001, Texas mandated coverage of cognitive rehabilitation under all health insurance plans excluding Medicare, Workers Compensation, and indemnity type plans. Types of mandated coverage included: cognitive rehabilitation therapy, cognitive communication therapy, neuro-cognitive therapy and rehabilitation, neurobehavioral, neuro-physiological, neuropsychological, and psycho-physiological testing or treatment, neurofeedback therapy, remediation, post-acute transition services, or community reintegration services necessary as a result of and related to an acquired brain injury. Additionally the bill required insurance companies to have trained personnel in brain injury to be a part of the approval process.

Finally, the bill stipulated a mandatory analysis of these therapies to be completed by the Sunset Advisory Committee by 2007. The 2007 report showed “from 2003 to 2005 the number of ABI mandated benefit claims increased significantly while ABI claims costs decreased by half. These trends largely reflect carriers’ improved ability to identify and more accurately report on claim costs from ABI mandated benefits. Actual claims cost per policy and estimated premium cost per policy have also declined” (Advisory Report, 2007). This policy shows a reduction in overall costs for insurers and increased quality of care when providing additional services to ABI survivors.

For more information on the Texas Cognitive Rehabilitation Bill:

- <http://www.hhsc.state.tx.us/reports/2014/TBIAC-report-2014.pdf>

10.2. Case Management

10.2.a. Missouri TBI Early Referral Program: Bridging the Gap from Hospitalization to Community

- The TBI Early Referral Program of the Missouri Bureau of Special Health Care Needs, under the Department of Health and Senior Services, is a person-centered, community-based procedure for providing case management for people who are hospitalized for a TBI. Under the program, clients are offered the services of a TBI service coordinator while an inpatient or outpatient in an acute rehabilitation facility.

10.1.b. RiverRidge Center, Kennebunk, ME – Access to Rehabilitation in a Skilled Nursing Setting

Located in southern Maine, RiverRidge Center is one of the few long-term skilled nursing facilities near MA with a specific program for brain injury survivors. RiverRidge offers tailored brain injury services including Physical, Speech, Occupational and Recreational Therapy, 24-hour Skilled Nursing Care, Case Management, Social Services and Community Integration across the care continuum in brain injury specific inpatient, out-patient, and residential care programs (<http://www.genesishcc.com/RiverRidge>). According to the CMS Nursing Home Compare Website, RiverRidge Center received a 5 out of 5 overall rating with a much higher staffing average than the state and national average (<https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-02-12-2.html>). It is particularly difficult to find beds for brain injury patients who have behavioral problems, which is common in this population (Interviews). MA facilities commonly send brain injury patients out of state to access RiverRidge Center services of. MassHealth has published a Request for Response (RFR) for skilled nursing homes to apply for a funding add-on to provide additional services for persons with brain injury, but few have applied to the RFR.

Figure 16: A respondent perspective on providing rehabilitation in long-term care facilities

“By the time brain injury survivors make it through the system of needing long-term care in a skilled facility, many times they have spent down their funding and become reliant on public assistance or Mass Health. Since brain injury survivors require an extra level of assistance with additional staffing and rehabilitation services for true rehabilitation, oftentimes at a greater cost, nursing homes cannot just survive on Medicaid to provide this. Thus we are left outsourcing our long-term care facility services to those who are not eligible to go directly into the community.” (Interview)

For more information on RiverRidge Center:

- <http://www.genesishcc.com/RiverRidge>
- <http://www.genesishcc.com/our-services/rehabilitation-therapy/neurorehabilitation>
- <http://www.genesishcc.com/RiverRidge/services-amenities>
- <https://www.medicare.gov/nursinghomecompare/profile.html#profTab=0&ID=205065&state=ME&lat=0&lng=0&name=RIVER%2520RIDGE%2520CENTER&Distn=0.0>
- <http://www.maseniorcare.org/FacilitySearch.aspx>

The service coordinator collaborates with the client, family and hospital discharge planner to identify and coordinate community-based services prior to discharge, so they are available when the client is discharged. Services include assistance in locating and accessing medical care, housing, counseling, transportation, rehabilitation, vocational training, and cognitive-behavioral therapy.

The program’s goal is to increase access to needed services, improve inter-agency collaboration, and minimize fragmentation or duplication of services. In 2003, piloting of the program began at five hospital sites. A program evaluation that included a control group found that clients in the Early Referral group had significantly greater functional limitations when referred to the program, but better functioning over time in terms of social integration, emotional well-being, and vocation, without requiring additional time from a service coordinator. Within two years of referral, the Early Referral group had higher rates of and costs for doctor visits and personal care services, although they were significantly less likely to receive emergency room care.

For more information on Missouri's TBI Early Referral Program:

- University of Missouri-Columbia. (2006). *2005 Missouri TBI early referral program evaluation: Bridging the gap from hospitalization to community*. http://health.mo.gov/living/families/shcn/pdf/TBIEarlyReferral_FinalReport.pdf

10.2.b. Indiana Resource Facilitation

In Indiana, case management, also known as Resource Facilitation, has realized substantial cost savings to a state through reduced annual lost wages and increased annual earnings (Trexler et al, 2014; Reid et al, 2011). Research supported by a collaboration of providers, state agencies, advocacy groups, and federal and local funders has informed development of an evidence-based model of Resource Facilitation that supports return to work and improved long-term functional outcomes for people who have been hospitalized for traumatic brain injury (Trexler et al, 2014). A study of the potential annual economic impact of the Resource Facilitation provided identified \$32,017,775 in lost wages avoided, and another \$22.5 million in additional annual earnings estimated for approximately 4,200 people aged 15+ in Indiana who are estimated to experience disabilities after TBI in any given year (Trexler et al, 2014; Reid et al, 2011).

For more information on Indiana's Resource Facilitation program:

- <http://rhin.com/resource-facilitation-best-practices-manual-for-return-to-workschool/>
- <http://www.nashia.org/pdf/sos2013/presentations/trexler-resource-facilitation.pdf>
- <http://biaindiana.org/resources/resource-facilitation/>
- <http://nashia.org/pdf/biaaresfacilconsensus.pdf>

In addition, Minnesota and New Hampshire have Resource Facilitation Programs. For more information see:

- <https://www.braininjurymn.org/aboutUs/program.php>
- <http://www.bianh.org/bisnrf.html>

10.3. Data for Decision-making

10.3.a. Longitudinal Data on Post-Acute and Community-Based Outcomes - OutcomeInfo, Inventive Software Solutions

This national post-inpatient brain injury outcomes database was developed as part of a Small Business Technology Transfer (STTR) grant under the National Institute of Neurological Disorders and Stroke (NINDS). The project objective was to develop a Web-based national database system for accumulating, reporting and analyzing assessment and outcome measures for acquired brain injury (ABI). The project has expanded and enhanced a prototype brain injury outcome database using a brain injury-specific outcome measure called the Mayo-Portland Adaptability Inventory-4 (MPAI-4) among other measures. Inventive Software initially developed the database with a small user group of six post acute brain injury providers (PARF) in Pennsylvania, in order to provide aggregate data to states to assist with evaluation of needs and services, with an underlying goal of increasing access to needed services. OutcomeInfo is a secure, web-based system. Organizations voluntarily submit de-identified patient or consumer information, including demographic and brain injury specific outcomes data, to OutcomeInfo. Organizations subscribing to OutcomeInfo can

access their information at any time and can compare their demographic data and outcomes data with national averages that reflect de-identified data for similar populations. The collaborative database is cost-effective and the pooled data set is large enough to provide evidence and thus have an impact for advocacy and policy. Types of programs participating in the database include Intensive Residential Rehabilitation (IRR), Supportive Living Residential (SLR), Intensive Rehabilitation Outpatient/Community-based (IRC), and Supported Living Community-based (SLC).

MPAI-4 is a national industry standard, used by a growing number of providers in MA and throughout the U.S. Other measures being used include the Disability Rating Scale, Supervision Rating Scale, and Satisfaction with Life Scale. Subscribers can run individual client reports and program/collective reports (Murphy et al, 2015).

For more information: <http://www.inventivesoftware.net/Products/OutcomeInfo.aspx>

10.3.b. Department of Defense and Veteran Affairs: Psychological Health & Traumatic Brain Injury Registry

The goal of the planned registry is to provide standardized and centralized data to help inform long-term studies of service members and veterans with service-related injuries. Improved access to this integrated data will help providers better understand psychological health and TBI conditions. This information will also help improve clinical practice guidelines and policy recommendations to enhance the quality of patient care.

- Data collected and catalogued may include:
- Demographic information
- Clinical data regarding injury (e.g. type, cause)
- Diagnosis
- Medical and surgical interventions
- Other treatments including education and rehabilitation
- Outcomes related to injuries

The registry will be a central health system or database to catalogue and access psychological health and TBI data for military and veteran populations.

For more information on the Defense and Veteran Affairs PH & TBI Registry and other disease-specific registries:

- http://www.dcoe.mil/About_DCoE/DoD_VA_PH_TBI_Registry.aspx
- Gliklich et al. (2014). Registries for Evaluating Patient Outcomes: A User's Guide. Third Edition. Two Volumes. AJRQ Publication No. 13(14)-EHC111. Rockville, MD: Agency for Healthcare Research and Quality. <http://www.effectivehealthcare.ahrq.gov/registries-guide-3.cfm>
- Institute of Medicine (IOM). 2014. Capturing social and behavioral domains in electronic health records: Phase 1. Washington, DCL The National Academies Press. http://www.dcoe.mil/Libraries/Documents/Phase_1_IOM_Capturing_Social_Behavioral_2014_18709.pdf

10.4. Community Programming

Krepels Center, NH

The Krepels Center is a non-profit community day program in Portsmouth, NH designed to support people living in the community with disabilities from ABI. Their services are intended to help people reach their own goals of independence in the community through informal support groups and activities, for example cooking skills and writing groups. At any given time the center has about 100 members, 45 interns, and 2 paid staff. Krepels is open three days a week from 9am-2pm, and offers 12 to 15 groups a day run by staff, university student interns, and volunteers. Funding for Krepels comes from a combination of philanthropic sources and fundraising, plus member fees. Every semester Krepels' members review potential group sessions and vote to approve or revise the groups offered.

For more information on Krepels Center:

- Krepels Center- <http://www.krepelscenter.org/>
- Foundation for Sea Coast Health- <http://www.ffsh.org/>

10.5. Harm Reduction for Youth with Brain Injury Who Are Involved in the Criminal Justice System

A summit report provides information on HRSA-funded efforts in five states (Minnesota, Nebraska, Virginia, Texas, and Utah) to address the problem of youth with traumatic brain injury involved in the criminal justice system.

For more information on efforts by these states to quantify and address this problem:

- <https://vadr.org/cbs/downloads/VirginiaCollaborativePolicySummitProceedingsReport.docx>