Massachusetts Rehabilitation Commission

Brain Injury Needs Assessment

November 2017

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EXECUTIVE SUMMARY

Massachusetts Rehabilitation Commission (MRC) contracted with Public Consulting Group, Inc. (PCG) in July 2016 to perform a needs assessment of the short and long-term service needs of individuals with brain injuries. This effort looked at the needs of both brain injury classifications: Traumatic Brain Injury (TBI) and Non-Traumatic Brain Injury (Non-TBI). Definitions for these classifications can be found in "Brain Injury Information and Prevalence" in Appendix A. The goal of the needs assessment is to provide MRC with meaningful and actionable recommendations aimed at improving the services and supports for all individuals with a brain injury in Massachusetts. MRC staff, other EHS agencies and the Executive Office of Elder Affairs, community providers, advocates, and individuals with a brain injury and their families all contributed to the data collection used for this assessment.

The primary findings of this report are:

- Survivors of brain injury and their families have difficulty in finding services and support due to the complexity of the service system and the scarcity of resources for individuals with brain injuries, particularly acquired brain injury.

- Individuals with brain injury caused by stroke, disease, and other non-traumatic causes who are in living in the community are not able to access state services other than a very few programs.

The overall system of care for individuals with a brain injury is complex. MRC is considered the lead agency for brain injury. However, several other state agencies also provide services to survivors. This multi-agency approach can be confusing to individuals, making it difficult for survivors to draw a clear roadmap of where to go for services. Even when individuals with brain injuries are served by other agencies, MRC's role in providing technical support and consultation should be clear to allow for easy facilitation of technical support.

MRC serves approximately 1,100 people annually through the Statewide Head Injury Program (SHIP) and close to another 700 individuals through home and community based waiver services. These services and supports are designed to specifically meet the needs of individuals with brain injuries. The 2014 Epidemiological Study and CDC reports indicate that between 68,000 and 100,000 people in Massachusetts sustain a brain injury each year based on emergency room and hospitalization records. However, the number of individuals living with disabilities as a result of brain injury in Massachusetts "could be substantially undercounted" (Lorenz & Katz, 2015) using this data collection strategy. Methods available to count the number of people with brain injuries in Massachusetts is complex and are based on annual emergency room and hospitalization records as well as data from people receiving services from the Commonwealth. This method does not completely account for the number of survivors each year. The numbers of survivors far outnumber new emergency room and hospitalization each year so the current service dollars available to survivors would not meet the needs of this population.

Strategies to track trends of people living with a brain injury in Massachusetts could be developed by recommending changes to community surveys, census and public health studies as well as the development of a new Massachusetts community survey. Establishing a new Brain Injury Commission to further study the current availability of survivor data along with recommendations to enhance this process is advisable.

Additionally, a large subset of individuals with a brain injury are not eligible for existing state funded supports. Individuals with non-traumatic brain injuries, caused by health episodes such as strokes, do not meet the eligibility requirements for SHIP. All survivors need access to supports and clear pathways to services aimed at addressing the lasting impact of their injuries.

INTRODUCTION AND PROJECT GOALS

In July of 2016, the Massachusetts Rehabilitation Commission (MRC) contracted with Public Consulting Group, Inc. (PCG) to perform a needs assessment of the short and long-term service needs of individuals with brain injuries. This effort stems from the 2011 Brain Injury Commission Report. The commission recommended a *"needs assessment be designed and implemented to identify and determine the specific service needs of persons with brain injury in Massachusetts."* The purpose of this report is to relay findings from the needs assessment as well as to provide MRC with recommendations aimed at improving the lives of individuals with brain injuries and their families.

The medical facilities in the Commonwealth of Massachusetts are world-renowned and utilize cutting edge treatments and interventions. These medical advances save thousands of lives once lost due to severity of injuries. However, many of these survivors are left with hidden injuries after the broken bones heal. Injuries to the brain are often not discovered during short, acute care stays. Medical personnel and individuals often assume the concussive symptoms will dissipate much like the physical injuries, with no lasting impact.

Unfortunately, individuals with brain injuries experience new symptoms months or even years after the initial injury. For many survivors, their brain injury requires lifelong attention. Individuals suffering from brain injuries often have significant challenges with their short-term memory. These memory issues impact a survivor's ability to perform tasks such as carrying out a multi-step morning routine, paying monthly bills, or performing the work functions they could perform before their injury. Many survivors often face co-morbid mental health conditions, joblessness, and in some cases, homelessness.

Negotiating the state service system sometimes results in a negative experience for brain injury survivors. Individuals may not know how to access supports and services for their brain injury or may become frustrated in attempting to access services that aren't focused on the needs of someone with a brain injury. Survivors find themselves exasperated with a complex system with limited service and rehabilitation options.

1 in 67, the estimated number of individuals with brain injury in Massachusetts

The number of people living with brain injury is often overlooked. According to the 2014 Epidemiological Study, there are approximately 100,000 people (or one in 67) in Massachusetts living with a brain injury. However, it is likely this statistic is under-reported since it only represents those seeking acute care services. There are likely thousands of others living with brain injuries that are unreported and who are without support to assist them. Emergency room visits in Massachusetts for traumatic brain injuries (TBI), those that are the result of blunt force or physical trauma to the head, averaged over 59,000 (59,326) annually between 2000-2010 (Hackman et al., 2014). More information and data regarding brain injuries along with its prevalence can be found in Appendix A.

Over the last 30 years, services for brain injury survivors in Massachusetts have evolved in several ways.

- In 1985, MRC created the Statewide Head Injury Program (SHIP) to serve survivors of traumatic brain injury. The program's service expenditures exceeded $27 million and served nearly one thousand people in Fiscal Year 2016.

- In 2008, two brain injury specific Home and Community Based Services (HCBS) programs (one for individuals requiring 24/7 support and one for individuals not requiring 24/7 support) were established as a result of a legal settlement agreement resolving a federal class action lawsuit (Hutchinson v. Patrick) brought on behalf of individuals with brain injuries. These two HCBS programs are the Acquired Brain Injury (ABI) Waivers. The ABI Waivers, coupled with the Money Follows the Person - now known as the Moving Forward Plan (MFP) Waivers (one 24/7 residential support waiver and one waiver with less than 24/7 support services available) and the Money Follows the Person Demonstration Grant, played a significant role in supporting deinstitutionalization for individuals with ABI. The Department of Developmental Services (DDS) operates the two residential waivers and MRC operates the two community services waivers. DDS' resources and expertise in residential contracting and administration, housing development, contract and financial management, quality management, and technology help qualified individuals find a residential setting in an expeditious manner. With support from and coordination through MassHealth, the two state agencies have worked together to share resources and knowledge for the benefit of all waiver participants. This arrangement allows brain injury survivors to benefit from DDS' residential infrastructure and quality oversight strength and MRC's subject matter expertise.

- In recent years, EOHHS agencies and MRC have worked together to build the capacity to better serve the brain injury community. MRC leads an effort with the Executive Office of Elder Affairs (EOEA) and the Brain Injury Association of Massachusetts to implement a federal grant from the Health Resources and Services Administration (HRSA) intended to maximize existing resources in both TBI and Elder Care Service delivery systems. The grant promotes outreach activities, training on early screening of TBI, and resource

sharing to improve services for individuals with a brain injury, particularly those aged 60 and older.

The Commonwealth must continue making progress in meeting the needs of the brain injury community, including those with non-traumatic brain injuries. MRC state funding is largely restricted to support the service needs of individuals with traumatic brain injuries and individuals receiving services through the ABI and MFP community waivers. The agency does not have funding to support the needs of individuals with non-traumatic brain injuries other than the individuals participating in the ABI or MFP waivers. Individuals whose non-traumatic brain injuries don't require extensive facility care have extremely limited availability of post-acute community services.

This report examines the needs of the brain injury community and identifies opportunities for MRC to improve the current system of care. Existing service models with proven success, such as SHIP and the ABI and MFP waivers, offer a blue print for expanding services and increasing accessibility to care. This includes implementing a state-funded program for individuals who have non-traumatic brain injuries as well as creating a short-term case management and eligibility unit to support individuals who are entering or reentering the brain injury system of services. This unit will work closely with the Brain Injury Association of Massachusetts to manage assessment, information and referral needs of individuals seeking services and support. These strategies, supported by consistent internal and external messaging, will reinforce MRC as the lead brain injury agency, simplify the system of care, and better serve the entire brain injury community. The methodology underlying this needs assessment is laid out in Appendix B.

FINDINGS

a. Best Practice Research

Due to the complexity of brain injury and the plethora of symptoms and co-morbid conditions that may arise, finding specific evidence-based models used to support individuals with brain injury is difficult. Instead, the research suggests expanding state service availability, types of services offered, and eligibility for home and community-based services are ways to meet the needs of this population.

The Statewide Head Injury Program is an example of a state brain injury program that provides quality services and supports for individuals who suffered a traumatic brain injury. Even though many other states have statewide brain injury trust funds, Massachusetts also adds to the trust fund with legislative appropriations allowing for a broader set of services for individuals with a brain injury (HRSA, 2012).

SHIP consists of a wide array of community-based services including, but not limited to: service coordination, community residential support services, recreation programs, education technical assistance, and substance abuse treatment. These tailored services are offered by a network of qualified providers with brain injury expertise who provide a support system similar to the Home and Community Bases Services (HCBS) brain injury waivers. These allow individuals, who would otherwise be treated in an institutional setting, the freedom and flexibility to determine their own path towards recovery through provision of necessary services and community supports.

SHIP has additional legislative appropriations that allows the program to operate at an increased capacity.

SHIP services are primarily available to individuals who have suffered an externally-caused brain injury resulting in cognitive, behavioral, or physical impairments (Kamen, 2006). There are two SHIP community based programs available to individuals with a non-traumatic brain injury. These include the MRC recreational programs and the Brain Injury Community Center in Worcester. In general, SHIP eligibility does not extend to individuals with a non-TBI, such as a person who experience medical occurrences such as a stroke, a brain tumor, or experience anoxia.

Massachusetts is one of the states also utilizing the federal match funds available through HCBS waivers to help support individuals with brain injuries. These programs have positive outcomes and provide cost savings to the state. They help keep individuals at home in the community and out of institutional care. This results in significant savings to the state and a better quality of life for the participants. Additionally, these programs are designed to keep the individual at the center of the planning and service development process. This ensures services are appropriately meeting the needs of the individual enrolled in the waiver. Even though there are few consistent models of support for individuals with a brain injury, there are proven benefits associated with using HCBS waivers as a service model.

b. Strengths in Current Service Delivery

MRC understands the needs of individuals with brain injuries and is dedicated to improving services and support. MRC is looking across all its programs to determine how the agency is meeting the needs of this population and how services can be improved. This effort is led by the Community Based Services Department (providing brain injury services within MRC). Department staff are well-trained in the clinical and related needs of individuals with brain injury and offer consumers individually developed services and supports.

The statewide advocacy organization, Brain Injury Association of Massachusetts is well established and willing to assist in improving statewide efforts to address the needs of individuals with a brain injury. The Brain Injury Association has played an instrumental role in advocating for funding support for individuals with brain injury at the state level, and its founder helped shape services on a national level, over three decades ago. The Brain Injury Association has an unwavering dedication to moving efforts for this population forward. They have

consistently increased the amount of revenue from law enforcement citations for moving violations for SHIP. Today, 100% of these surcharges are dedicated to SHIP. Additionally, they have secured additional state funds for this population and have advocated to get federal Medicaid programs in place to meet the needs of individuals with brain injuries.

Outside of advocacy efforts, The Brain Injury Association works on research efforts, holds support groups across the Commonwealth, conducts trainings for individuals, families and professionals to assist with the understanding of the long-term impact of the injury, and holds numerous community events to engage individuals in activities outside of their homes.

The stakeholder feedback process clearly demonstrated that The Brain Injury Association is an essential resource for survivors and families. They provide information and referral resources that are clear and understandable for the population. They are there to listen and support individuals at any stage of their injury. Many of the staff who work for The Brain Injury Association have experienced a brain injury of their own. Survivors connected to The Brain Injury Association spoke extensively about their positive experiences with the staff, support groups, and community engagement events.

There are several excellent models of service delivery to learn from and that can be replicated for the non-traumatic brain injury population. Services delivered by the MRC SHIP program are flexible, robust and individually tailored to meet the expressed needs of individuals. Furthermore, the services available through the Massachusetts HCBS ABI and MFP waivers have demonstrated success in supporting individuals with a significant range of service needs to remain in the community.

There is commitment within the current system of care to serve individuals with a brain injury as effectively as possible. The stakeholder engagement process revealed a strong desire by non-MRC service providers to improve services for those with a brain injury. For instance, one of the premier rehabilitation hospitals in New England, Spaulding Rehabilitation, goes above and beyond for patients to help coordinate post-discharge care, especially in situations where post-discharge options are limited (for example, a young adult whose needs might not be met at a traditional skilled nursing facility).

C. Areas for Improvement in Service Delivery

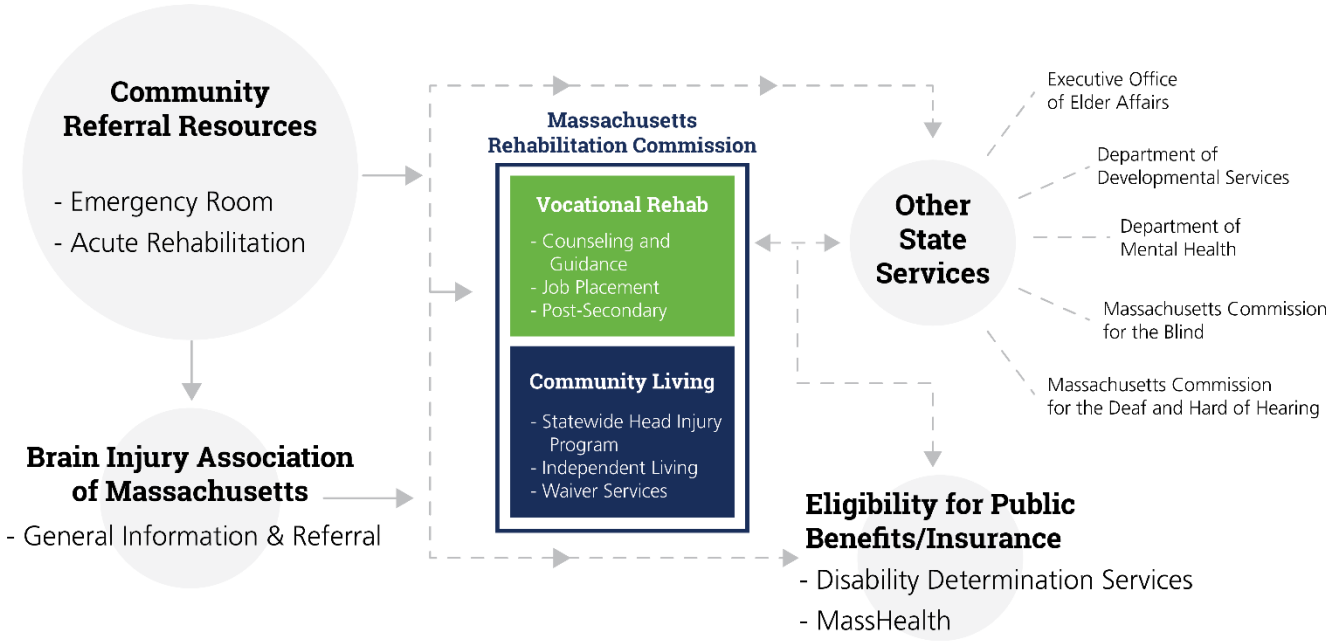
The current system of care is complex and sometimes confusing for individuals and their families to navigate. Currently, accessing services and support for individuals with a brain injury is at best complicated. Individuals enter community services differently depending on where the individual receives care for their injury. In many cases, a person goes to an emergency department in their local community to receive medical advice and treatment and is sent home with instructions for managing their concussion or broken bones. However, individuals and families may not be provided with adequate information about the potential longer term impact of the brain injury. Additionally, it is likely that whatever information is provided to an individual in an emergency setting will be mislaid due to the impact of a brain injury on the ability of an

individual to organize and retain information. More severely impacted individuals, those who might have experienced a stroke due to a drug overdose for instance, are admitted to the hospital. Once their initial symptoms are stable they are often sent home with a discharge plan that provides few instructions on what to expect from the brain trauma. In general, family members and individuals are not given a compass to guide them through this complex system of supports.

MRC is designated through the MassOptions system as the agency best able to provide information and referral for individuals with any brain injury. Pairing this designation with the fiscal resources necessary to provide ongoing services to individuals with both traumatic and non-traumatic brain injuries is logical and makes use of the training and expertise in MRC.

One of the key recommendations resulting from the 2014 “Brain Injury In Massachusetts” report was to provide 6 months of case management to all brain injury survivors. MRC proposes to provide this for individuals engaged in eligibility determination for MRC brain-injury services, as the best way to support individuals and their families in accessing services in MRC or other EHS or state programs.

Current Fragmented Brain Injury System of Care



The graphic above visually represents the complex web of services and supports available to the brain injury community along with numerous access points. As complex as this appears, imagine the difficulty of navigating this system with a brain injury that hinders memory and cognitive functioning.

Throughout the needs assessment process, survivors spoke about getting back to the life they once lived prior to their accident or onset of symptoms. Individuals voiced concerns related to housing, transportation, employment needs, accessing in-home support services, and insurance and other public benefits. It is abundantly clear that finding the path forward from an individual perspective is a daunting task. These services are scattered across the Commonwealth but there is no clear path to access this network of supports.

The current system of care lacks knowledge about brain injuries, particularly about the lasting impact and changing level of needs over a survivor's lifetime. Although several agencies provide services to individuals with brain injuries, one major concern of survivors is the lack of understanding about the complexities and ongoing needs related to their injury. Survivors of a brain injury are clear in their desires: they are looking to rebuild their lives and live as independently and autonomously as possible. In order to move towards that goal, survivors require skilled support over the course of their recovery.

Additionally, staff need a better understanding of how a brain injury may impact the abilities and talents of individuals with a brain injury who want to return to employment. Employment post-injury for survivors is a complicated issue. Individuals may or may not understand they might not be able to get back to the same job or career they had prior to their injury. Sometimes individuals present as less impaired or more impaired than is the case. Without knowledge of current tools and thinking regarding how to best support individuals with brain injuries, services used to rebuild skills and support adaptation to change might not be adequate to meet the individual's needs. During one focus group discussion, a woman told the story of her job as a high-level administrator before her injury. She was directed to a job that required her to lift heavy objects, something not recommended by her doctors due to the impact it could have on her brain injury. Consultation with the professionals within the Community Based Services team could have provided technical assistance and support for exploration of alternative career directions. This would facilitate skills building and promote better outcomes for brain injury survivors seeking meaningful employment opportunities.

The current system of care is not consistent across Massachusetts. Services are more robust in some areas and severely lacking in other regions. The focus group participants in communities across Massachusetts told stories and shared experiences of good service programs and providers. Others highlighted places where services did not meet their needs or have the capacity to support them. Providers shared their struggles with trying to maintain multiple locations for their programs due to current reimbursement and funding structures. Individuals liked their model, but the agency could not determine a way to keep it sustainable.

The current system of care does not allow survivors needing assistance maintaining their schedule and other daily living needs to access Personal Care Attendant (PCA) services through MassHealth. Under MassHealth regulations, PCA costs are not covered for individuals needing assistance with "cueing": a prompt to remember their activities of daily living. This includes remembering to shower, do laundry, take medication, or eat regularly. Individuals can actually do these activities unassisted, therefore, they do not qualify under the current structure. The PCA's role under the current regulations is focused on physically assisting an individual to

perform the activity. For many individuals, cueing means the difference between independent living and needing a more supervised support model.

The current system of care is lacking appropriate day rehabilitation, support, and employment readiness programs. There are an insufficient number of programs supporting individuals who need additional rehabilitation services, support in understanding the nature of their brain injury, and assistance in preparing to go back into the workforce. Individuals throughout the stakeholder engagement process spoke about wanting to go to a program on their own schedule and choose their activities and level of engagement. Most of the available programs are not flexible or designed to meet the needs of the brain injury population.

Brain injury survivors would benefit from a program model that offers all-inclusive community, clinical, and support services that support individuals in gaining skills and integrating into ordinary and customary community activities – work, school, and social opportunities. The recently opened Brain Injury Community Center in Worcester specifically tailors its community and support services to brain injury survivors, but unfortunately lacks the clinical services that would greatly improve the recovery process.

d. Results of Interviews, Surveys, and Focus Groups

Interviews with key stakeholders, along with provider and consumer surveys and focus groups, exposed many themes and challenges present in the brain injury community. Since the system of care is fragmented, many individuals do not know how to access the services and supports needed to get back to the life they once had before the brain injury. Instead, they're left to navigate the uncharted territory of their symptoms alone or, if they're fortunate, with a family member. But even this scenario compounds the lasting impact of the brain injury since family caretakers often must leave their jobs to take care of their loved ones. Others experience fatigue and burn out due to the intensity of support needed by their loved one.

Yet, within this fragmented system of care, there are several individuals and organizations committed to improving the lives of individuals with a brain injury. The dedicated case coordinators at MRC, for instance, work hard to ensure their clients receive the necessary supports and services. BIA-MA offers support groups and community events in addition to providing general information and referral services. Several provider agency programs, working primarily with SHIP and the ABI/MFP waivers, specialize in serving the brain injury community. They offer neuro-rehabilitative assessment, services and supports critical to helping individuals achieve independence. State Senator Harriette Chandler and State Representative Kimberly Ferguson, strong champions for services and supports for individuals with a brain injury, have worked towards requiring private insurance companies to cover cognitive rehabilitation. DDS, an agency with a primary focus on serving individuals with a developmental or intellectual disability, commits significant resources to effectively serve brain injury survivors in need of residential services.

Our findings from the surveys and focus groups reveal similar themes from the perspectives of individuals with a brain injury, their family members, and the providers that serve them. The primary findings are listed below.

Individuals with a brain injury require access to adequate supports and services that are both flexible and relevant to their needs. Many individuals expressed the need for more adequate rehabilitative programs to attend during the day. For instance, the Brain Injury Community Center (BICC) in Worcester was cited as a model that is structured enough to provide effective supports but also flexible enough for individuals whose brain injury causes low-energy and memory loss. BICC offers individually-tailored services that provide education, advocacy, and vocational supports for members to facilitate community integration and self-sufficiency. BICC also coordinates social recreational activities to engage individuals and help ensure emotional/physical wellbeing. Activities that promote social and physical wellness include: yoga, meditation, photography classes, art classes, and any other ideas with substantial interest from members. BICC, due to its person-centered operating principles, provides a wide variety of services that promote positive outcomes for individuals with brain injuries, including increased community participation and success[1].

Individuals also indicated they would benefit from not only therapies to regain function, but also assistance with ongoing memory issues and executive functioning skills. Individuals also expressed that while waiver services are generally good, they are not always flexible enough to empower those living in residential settings to get out in the community due to staffing ratios.

MRC can provide ongoing support and technical assistance to other human service agencies charged with serving individuals with brain injuries in residential habilitation programs. The two residential waivers that serve individuals with a brain injury – Money Follows the Person Residential Supports and Acquired Brain Injury – Residential Habilitation – help qualified individuals move from a nursing home or long-stay hospital to a qualified residence in the community and obtain community-based services. The University of Massachusetts Medical School, Division of Community Services, currently performs the eligibility determination of the residential and non-residential ABI and MFP waiver programs on behalf of MassHealth.

As the operating agency of the ABI and MFP residential waivers, the Department of Developmental Services (DDS) contributes significant resources to the current system of care. Able to leverage its expertise in contracting with over 2,300 licensed community residences, DDS has the infrastructure and housing development resources required to manage the complexities of residential living. Managing residential services is no simple task and requires resources in several areas, including an IT web-based case management system, contract management, quality management, housing, technology, incident reporting, and financial management. DDS also employs 30 service coordinators who have received brain injury specific trainings and are dedicated to serving only individuals with a brain injury. These service coordinators have a caseload appropriate to meeting the case management needs of individuals with a brain injury.

DDS continues to build capacity within its provider network to serve individuals with a brain injury, with 27 licensed providers across the Commonwealth delivering residential waiver services to the brain injury community. MRC and DDS have collaborated to provide training in brain injury

[1] https://www.bamsi.org/program/brain-injury-community-center/

to residential providers. To date five providers distributed throughout the commonwealth have made an investment to establish brain injury specialty practices but more are needed. Additionally, many providers would like MRC to provide additional trainings to help establish such practices.

DDS recognized that many residential providers struggled to meet the complex needs of individuals with brain injury, and has in conjunction with MRC and MassHealth restructured provider payment rates to better meet the needs of this population. DDS and MRC, with the support and leadership of MassHealth, have written operational policies for both residential (offering 24/7 support) and community living services (offering less than 24/7 support) for providers and are completing a handbook for consumers to clarify waiver brain injury programs and policies.

A single point of contact would help facilitate the coordination of state-funded services for individuals with a brain injury. Unless an individual qualifies for a federal waiver program, access to services and supports can be a difficult and confusing task. There are several pathways that individuals with a brain injury pursue to receive state-funded services. This adds confusion into an already complex system. Individuals are often confused when upon entering the community system from acute or rehabilitative care.

Individuals seeking support for brain injuries and their families would benefit from a brief initial needs assessment that clarifies service needs, followed by referral and a warm hand-off to the state agency or agencies that would best be able to support the needs of the individual. Furthermore, 76% of survey respondents indicated they were satisfied with their case management services, indicating that individuals with a brain injury would benefit from a point person for overall service coordination and enhanced information and referral services.

Co-morbidity of disease has a significant presence in the brain injury community. Co-morbid conditions, such as depression and/or substance abuse, along with a brain injury presents significant challenges for both individuals with a brain injury and the providers serving them. Nearly 60% of survey respondents (83 out of 135) reported more than 55 co-morbid conditions and these issues significantly impact their daily lives.

Doctors, hospitals, state agency staff, family, friends, and employers would benefit from access to training on brain injuries. MRC has performed several trainings in recent months to help staff from other state agencies understand the needs of the brain injury community. However, there is more to be done in this area to bridge the knowledge gap. For instance, emergency room staff should be aware that an individual with a brain injury might struggle with memory loss which would impact their ability to pursue adequate services and supports once discharged to the community.

Additional findings from the surveys include:

55 %	Revealed that they required changes in their plan of care because of a significant change in their health.
39 %	Indicated they would benefit from more authorized case management hours.
74 %	Receive services and supports directly in the community or their home.
45 %	Of providers indicated that plans of care are generally developed in a timely manner, yet these plans do not adequately address all the consumer's needs.

The challenge facing the Commonwealth is connecting a complex system of care and maximizing services and supports offered by the individuals and organizations dedicated to serving the brain injury community. The recommendations detailed in the following section focus on bridging the gaps that exist to better serve individuals with a brain injury.

RECOMMENDATIONS

The recommendations are aligned to achieve two goals:

1) To designate MRC as the lead agency supporting all individuals with a brain injury, including both TBI and non-TBI. Achieving this goal may require legislative action and will require improvements to the administrative and technology infrastructure of the agency.

2) To provide additional resources to enable MRC to provide support and services to individuals with non-TBI in need of state-funded services.

MRC began supporting individuals with traumatic brain injuries through SHIP more than three decades ago. In recent years, MRC also began supporting a limited number of Medicaid eligible participants, who spent more than 90 days in an approved facility, through the Medicaid home and community based waivers.

However, with some limited exceptions[2], MRC does not have the authority to serve individuals with a non-TBI. At this moment, while there are several state agencies providing services to non-TBI individuals, no single state agency has the designation as the lead agency for services to this population. MRC is designated through the Mass Options system as the initial referral agency for individuals with any brain injury. Without the designation and authorization by the legislature to provide services to more individuals with non-traumatic brain injuries, the agency is unable to provide support beyond information and referral to individuals with non-traumatic brain injuries. These individuals can go to the BIA-MA for information and referral, including referral to survivor support groups, but the resources available for these survivors are scarce and do not include the necessary individualized services to assist with their rehabilitation efforts and ongoing brain injury related needs.

For MRC to continue serving this ever-growing population[3] of survivors of brain injuries, the agency needs increased support from the Commonwealth. Nearly one in 67 people in Massachusetts has experienced a brain injury, with many more individuals with brain injury-related needs unidentified due to lack of reporting (Lorenz, 2015). A recent MRC report estimates around 59 incidents of brain injuries in Massachusetts *per day* (Hackman et al., 2014). These numbers highlight an overwhelming need for a robust system of care, particularly one that minimizes cost.

Nationwide, services directed toward TBI alone cost $76.5 billion dollars in 2010, with 15-20% of the individuals who have experienced a TBI requiring life-long supports (Lorenz, 2015). Strokes, a major cause of brain injuries, cost an estimated $34 billion dollars per year (Lorenz, 2015).

[2] MRC serves a limited number of non-TBI individuals through the ABI-N Waiver, MFP-CL Waiver, the Brain Injury Community Center in Worcester, and other social recreational programs.
[3] Advances in medicine and better ability to diagnose have contributed to an increase in brain injury prevalence.

With enhanced resources, MRC can continue to improve the lives of brain injury survivors and work with individuals to maintain or increase their level of independence at home, work and in their communities. Services will range from training and consultation for staff at other EOHHS agencies serving individuals with brain injury to direct services to individuals in the community not eligible for support through other resources.

This section organizes recommendations into the three categories:

A. Access to Services
B. System of Care
C. Other Recommendations

a. Access to Service

Previously, this report highlighted the difficulty survivors have navigating systems of support due to the nature of the way their brain processes information post-injury. Not only is the service system complex, but the most common symptoms of brain injury (memory impairment executive functioning, the skills that allow us to organize and initiate actions) mean that individuals with brain injuries are likely to find actually accessing the system more difficult. For an individual with a brain injury, a once simple task might take two to three times as long to accomplish and the individual might need cues and reminders throughout the process to finish it.

In the current service system, individuals with a brain injury often leave the emergency room or acute rehabilitation with a prescription for the physical pain but not a prescription outlining next steps for their brain injury. Some never get connected with the necessary supports as individuals get confused or lost moving from one system of care to another.

Those seeking services need to know where to go for assistance. Survivors and their families need to know that MRC is available to help with all their support needs. Currently, there are multiple points of contact for brain injury services, and depending which is used, a person may or may not find the services and supports they need. While emergency rooms tend to provide resources for short-term treatment, individuals may forget to reach out due to other newly developed memory issues. Proactive outreach to survivors of brain injuries post-discharge would help better support individuals with a brain injury.

Recommendation #1: Develop a state-funded program for individual with non-traumatic brain injuries.

There currently is not a state-funded program designed to serve individuals with a non-TBI diagnosis, such as survivors of a stroke or anoxia. A small subset of Medicaid-eligible individuals qualify for one of the waivers available to non-TBI participants. However, these waivers are only available to those who spend more than 90 days in an approved facility. A prominent rehabilitation facility in Boston for brain injury survivors, Spaulding Rehabilitation Hospital, states

their average length of stay is down to 24 days (a problem in and of itself, as this diminished stay doesn't support good post-acute rehabilitation planning).

SHIP is currently only available to an individual who has a "documented externally caused traumatic brain injury." In 2011, the Brain Injury Commission report recommended that *"consideration be given to studying the feasibility and impact of expanding MRC's…capacity to serve all individuals…with non-traumatic brain injury."*

MRC should:

- Create a state funded program for individuals with non-traumatic brain injuries. The eligibility process for this program can mirror that of SHIP. SHIP requires documentation verifying the injury for the clinical criteria. Income and financial need are not part of SHIP eligibility.

- Model the services and structure of this new state funded program after SHIP, with consideration for the model services offered through the HCBS ABI and MFP waivers. This approach is a solid path forward since many survivors and their family members expressed satisfaction with the support and services provided by MRC and SHIP.

Recommendation #2: Create Transitional Support Services at MRC

The ability for an individual to easily find services and supports to live a full and productive life after a brain injury is critical to successful and meaningful life outcomes. Given the complex presentation of individuals with a brain injury, developing Transitional Support Services for individuals with brain injuries will allow smooth entry into services, whether at MRC or at other state or private sector programs. A simplified and streamlined process addresses the memory loss issues and decline of executive functioning skills prevalent in this population that serve to prevent access to care.

This recommendation supports a fluid system of care that is responsive to the changing needs of brain injury survivors. It also offers a distinct "re-entry" point for individuals that experience a sudden need for services, since brain injury symptoms are often unpredictable and irregular.

MRC should create Transitional Support Services to provide short-term case management, designed to support individuals find the constellation of services that they need. As part of a team-based intake and assessment process within MRC, MRC staff would conduct an initial intake. Individuals would then be referred to Transitional Support Service staff for short-term case management. If needed, an eligibility determination for brain injury services will be conducted. If ongoing services are not indicated, the individual will be referred to Information and Referral services provided by the Brain Injury Association of Massachusetts. Staff in the Transitional Support Services unit, with specialized expertise in brain injuries, will be the main point of contact for an individual with a brain injury inquiring about services.

The anticipated cost of a Transitional Supports Services unit at MRC would be $300,000 a year. This annual cost would include three full-time eligibility specialists with an average annual salary of $68,000.

Recommendation #3: Build a Web-Based Case Management IT System.

MRC needs a more robust system for capturing individual information for assessing needs, accurate incident data, service planning, and case management/navigation notes. The Case Management IT System needs to be web-based, mobile, work across multiple platforms (desktops, laptops, smart phones, tablets, etc.) and work through a secured portal.

The system must have the ability to be utilized across MRC staff and providers to assist with the transition from Transitional Supports staff to other MRC services and supports. Sharing notes and needs assessment information will assist staff in getting acquainted with individuals, without the need for survivors to recall their needs and retell the story of their current circumstance. For individuals with short-term memory issues, this is essential

This type of robust web-based case management system creates improved efficiencies and outcomes for MRC, providers, and the individuals receiving services. Data collection improvements with the system will help to further improve services provided to individuals. This platform is utilized by the medical community to keep track of patient notes, test results, and provides a way for individuals to directly communicate with medical staff. For individuals with a brain injury, having access to a portal designed for them will give them a place to go for information like support groups, the phone number for BIA-MA, or to know what applications are in process or completed for needed services. All this information is provided in real-time, limiting the confusion of trying to determine where they are at in their service planning process.

The anticipated cost of a web-based Case Management IT System would be approximately $1.3 million for up-front implementation costs and approximately $300,000 per year for annual licensing, hosting, and maintenance costs.

Recommendation #4: Invest in more rehabilitation, support, and employment readiness programs capable of serving the needs of individuals with a brain injury.

This recommendation is similar to a recommendation included in the Brain Injury Commission report which calls for an investment in regional day/rehabilitation programs, social/recreational programs, and regional multi-service centers. Additionally, this recommendation supports the anticipated cost estimates provided in that report.

These programs should be tailored to meet the needs of individuals with a brain injury. This includes offering various services and supports to ensure individuals may choose what they need according to their own schedule.

One such program model to consider and build on is the Brain Injury Community Center in Worcester. This model is structured to offer effective supports but also flexible enough for

individuals whose brain injury causes low-energy and memory loss and therefore makes a full day program or every day program intolerable.

- BICC offers individually-tailored services that provide education, advocacy, and vocational supports for members to facilitate community integration and self-sufficiency. BICC also coordinates social recreational activities to engage individuals and help ensure emotional/physical wellbeing. Activities that promote social and physical wellness include: yoga, meditation, photography classes, art classes, and any other ideas with substantial interest from members. BICC, due to its person-centered operating principles, provides a wide variety of services designed to promote positive outcomes for individuals with brain injury[4].
- The one key element missing from the BICC program are clinical services. Individuals need easy access to occupational, physical, and speech therapies. Many also need help with their executive functioning skills which is provided through cognitive rehabilitation.

Rehabilitation / service / social and recreation programs should offer adequate flexibility since the spectrum of needs for individuals with a brain injury vary greatly. For instance, some might benefit from attending these programs daily while others might only have the energy to attend once or twice a week.

The annual anticipated costs of each program are listed below:

- $600,000 per rehabilitation program
- $1,000,000 per service center
- $30,000 per social/recreational program

b. Other Recommendations

Recommendation #5: Re-establish the Brain Injury Commission.

In 2011, the Brain Injury Commission provided a comprehensive report on the needs of the brain injury community. This report paved the way for several initiatives such as increasing training efforts to other state staff about the needs of the individuals with a brain injury. In fact, this current needs assessment was recommended by the 2011 Commission.

Language would need to be introduced into legislation calling for re-establishment of the Brain Injury Commission for sufficient time to support long-term planning and coordination efforts.

Members of the Commission should mirror those of the 2011 Brain Injury Commission, which included members of the House and Senate as well as Commissioners (or designees) from the agencies within EOHHS.

[4] https://www.bamsi.org/program/brain-injury-community-center/

Recommendation #6: Continue to increase training efforts and strengthen communication, both internally and externally, on brain injuries and service options.

While MRC has already performed several training efforts in the fall of 2016, more needs to be done to inform state staff and providers about the needs of the brain injury community. This is further emphasized in the survey results, with 61% of providers indicating they would benefit from continuing education and training opportunities.

Efforts should include the following steps and actions:

- Provide targeted subject matter training to MRC staff, including those with infrequent contact with individuals with a brain injury, such as vocational rehabilitation counselors.
- Offer bi-annual subject matter trainings to staff at other EOHHS agencies. MRC should continue to prioritize training staff at the Department of Disability Services and the Department of Mental Health since these agencies are most likely to serve individuals with a brain injury.
- Continue to provide brain injury subject matter expertise to DDS. Currently, DDS is working closely with MRC to develop brain injury provider and consumer handbooks to offer greater clarity to community providers and families. These collaborative efforts help ensure the needs of brain injury survivors are met.
- Provide opportunities for web-based and/or in-person training for providers of brain injury services and their staff, especially those also serving individuals with developmental disabilities.
- Trainings should convey consistent messaging regarding the available resources and services available to individuals with a brain injury.

Recommendation #7: Improve access to transportation and housing resources.

Access to transportation and housing resources is a critical component to an individual's journey to stabilization and independence. While there are elements to transportation and housing services that are out of the control of MRC (for example, MRC has no control over the rates charged by the Human Services Transportation office), moving forward with certain strategies will help individuals with a disability access critical transportation and housing resources.

These strategies include:

- Establish a federal-state transportation committee to develop further options for people with disabilities.
- Participate in Regional Planning Board meetings to ensure communities are directing resources to increase access to transportation and housing supports.

- Participate in planning and coordination of the *On-Demand Pilot Paratransit Program*[5], a one-year pilot that allows RIDE participants to book transportation with ride-share programs such as Uber and Lyft.

- Increase awareness and promote sign-ups for On-Demand Paratransit Program to ensure more RIDE customers are utilizing the pilot.

- Explore adding the brain injury population to the Housing Authorities preference list and other housing voucher programs.

Recommendation #8: Review existing MOUs and ISAs with Executive Office of Health and Human Services Agencies.

Memorandums of Understanding (MOUs) and Interagency Service Agreements (ISAs) are formal agreements intended to enhance data and information exchanges across state agencies. These agreements can promote collaboration and eliminate barriers to information sharing.

MRC should identify, review, and update existing MOUs or ISAs with other state agencies, particularly as they relate to the recommendations detailed above. These documents should emphasize coordination and serve as a conduit to data and information sharing required for effective service delivery.

[5] http://www.mbta.com/riding_the_t/accessible_services/default.asp?id=6442456760

APPENDIX A: BRAIN INJURY INFORMATION AND PREVALENCE

a. Brain Injury Information

The term “brain injury” is an umbrella term encompassing a wide range of conditions, injuries, and symptoms that affect the Central Nervous System (CNS), the brain, and its subcortical structures (MRC, 2011).

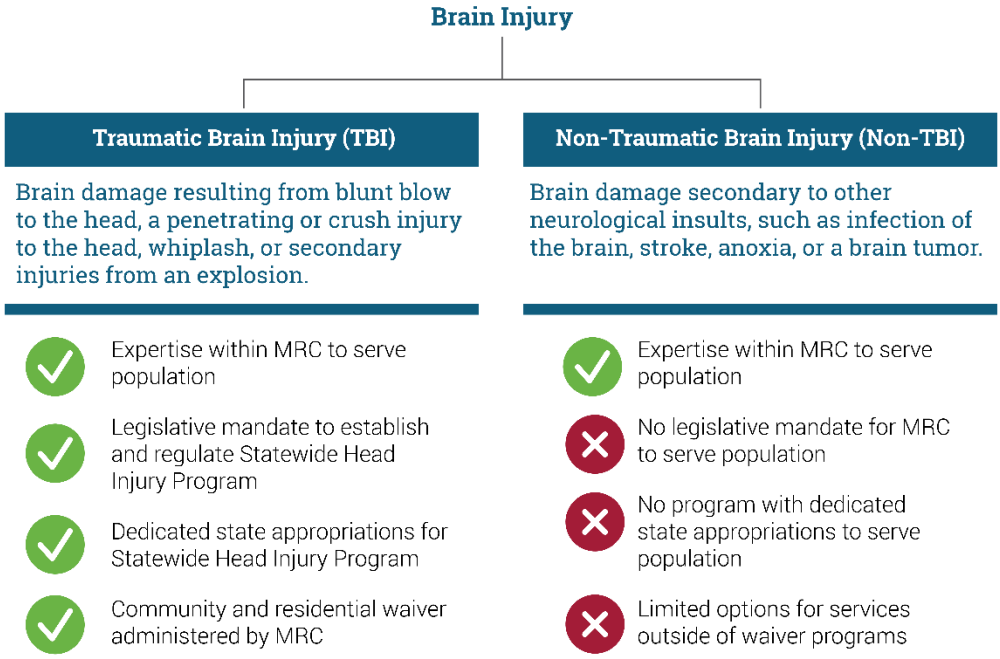
Brain injuries have two primary classifications: Traumatic Brain Injury (TBI) and Non-Traumatic Brain Injury (non-TBI or Acquired Brain Injury (ABI)). A TBI is an injury to the brain resulting from a blunt blow to the head, a penetrating or crush injury to the head, whiplash, or secondary injuries from an explosion. A non-TBI is a brain injury secondary to other neurological insults, such as infection of the brain, stroke, anoxia, or a brain tumor. These classifications are driven by medical diagnoses and do not imply that one injury is more or less traumatic for individuals and families than the other.

Current estimates by the Center for Disease Control and Prevention (CDC) indicate that more than 5.3 million Americans are currently living with a long-term need as a direct result of a brain injury (specifically, TBI)[6]. The symptoms and lasting effects of a brain injury present in different ways, including, but not limited to motor difficulties, cognitive impairments, language deficits, and social dysfunction.

The overall treatment and recovery of TBIs and non-TBIs should not be separately considered. Indeed, the 2011 Brain Injury Commission report noted that TBI and non-TBI individuals should *“no longer be dealt with as separate and distinct groups.”* All individuals with a brain injury can benefit from a variety of community and residential services. Those with a TBI can access resources through MRC, including SHIP, as well as the residential and community waivers. However, those with a non-TBI are not uniformly offered access to a system of care that would provide them and their family members critical services and support already established in the community.

[6] http://www.biama.org/facts

The graphic below shows the significant gap that exists and the challenge Massachusetts must address:



Furthermore, due to the complexities of a brain injury, other conditions often arise further complicating treatment and recovery. Mental health, substance abuse, and intellectual disabilities are examples of complications further challenging an individual's journey. Brain injuries are a significant public health concern that require a comprehensive system of care to manage the ever-changing needs of the affected population.

b. Brain Injury Prevalence

Brain injuries can happen to anyone at any age or stage of life. They are not limited to people involved in contact sports, such as football or hockey. They are also not limited to a specific population, such as the elderly or adolescents. Individuals with a brain injury need assistance across all spectrums of life. A solid network of support and services is a necessity for the journey to recovery. Senator Harriette Chandler, a strong advocate for survivors of brain injury, noted *"(supports) make a difference between whether they (survivors) exist or live."*

The impact of a brain injury on survivors can be lifelong but often invisible. According to the National Institute of Health (as cited in Rispoli et al., 2014), over 5 million individuals with Brain Injury in the United States require continuous support and assistance. The focus is typically on other complexities related to the injury, including physical or developmental disabilities. As an individual in

> ***"It comes down to revenues and resources (and these) are missing in action."*** – Senator Harriette Chandler

a focus group stated, *"they only made sure I had no broken bones (and said) I am doing great just because I had no physical ailments."*

The numbers impacted by brain injury and the related costs both indicate this public health issue needs and deserves immediate attention in Massachusetts. Many key stakeholders interviewed believed that access to services is worse now than twenty years ago. Key reasons are a growth in the number of brain injury survivors due to advances in medicine and near stagnant funds to meet survivors' various needs.

According to current estimates, Massachusetts has approximately 1 in 67 individuals living with a brain injury (Lorenz & Katz, 2015).

This translates to roughly ***100,000*** people currently in the Commonwealth with a brain injury. This public health concern is not just limited to athletes playing contact sports, to the elderly, or to individuals of any specific gender. The person could be your neighbor, your colleague, or your family member struggling to manage their brain injury and related symptoms.

Brain injuries create a large burden on the healthcare system.

Brain injuries are a public health concern that affects all demographics in the United States. In 2010, Traumatic Brain Injuries cost the healthcare system $76.5 billion dollars, with severe TBIs accounting for 90% of expenditures. Stroke, a subcategory of brain injury, cost approximately $34 billion dollars per year[7]. These large expenditures pose a heavy burden on states that are finding it more and more difficult to effectively support the needs of this population.

Access to post-acute inpatient or community-based rehabilitation has been shown to have positive cost-benefit impacts for individuals with brain injury, including lower long-term care costs. As Oddy & da Silva Ramos note (as cited in Lorenz & Katz, 2015), individuals with brain injury in the United Kingdom who had access to rehabilitation options within a year of their incident saw their direct care costs fall by 68%.

Additionally, Trexler and Reid note (as cited in Lorenz & Katz, 2015) that resource facilitation can provide substantial cost savings for states in terms of increased annual earning and avoided lost wages. Research conducted in Indiana has shown improved long-term functional outcomes for individuals who have been hospitalized for a TBI when given access to resources that support returning to work. Overall, the study identified a potential annual economic impact of $32 million in avoided lost wages and another $22 million in annual earnings for an estimated 4,000 people over age 15 in Indiana who have TBI-related disabilities.

Due to advancements in medical technology, more and more individuals are surviving brain injuries. One of the leading causes of brain injury, stroke, saw an 18.2% decrease in death. However, more survivors now require long-term support. According to the American Heart Association, stroke is the leading cause of long-term disability in the United States, with

[7] http://masshealthpolicyforum.brandeis.edu/forums/forum-pages/Severe%20Brain%20Injury%20.html

approximately 795,000 people suffering from strokes every year. States need to find novel ways to provide services that promote positive outcomes for more people[8].

The *2014 Acquired Brain Injury (ABI) Epidemiology Report* by Hackman et al. provided valuable data on exactly how prevalent brain injuries are in the Commonwealth. The following table details prevalence of various subcategories of brain injury in Massachusetts between 2008-2010. Data is taken from the *2014 Acquired Brain Injury (ABI) Epidemiology Report* (Hackman et al., 2014).

Brain Injury Subcategory	Average Annual Hospital-Treated Events Between 2008-2010
Central Nervous System Neoplasms (e.g. tumors)	461
Infectious Diseases	3,033
Metabolic Disorders	14,389
Neurotoxic Disorders	22,804
Traumatic Brain Injury (TBI)	67,048
Progressive Disorders of the Central Nervous System	N/A (Currently there is no centralized or mandated reporting system for this subcategory)

As the table above shows, the high incidences of certain brain injury subcategories range from 1.26 per day (CNS Neoplasms) to 183.7 incidents per day (TBI). As modern medical technology further increases the likelihood of survival of brain injury, there will also be an increase in the brain injury population that would require a system of support (Lorenz & Katz, 2015).

[8] http://www.heart.org/HEARTORG/General/Heart-and-Stroke-Association-Statistics_UCM_319064_SubHomePage.jsp

APPENDIX B: NEEDS ASSESSMENT METHODOLOGY

This needs assessment included four different methods of data collection in order to comprehensively capture the current state of brain injury services in Massachusetts. The four data collection methods utilized are as follows:

- Literature review,
- Stakeholder interviews,
- Provider and consumer focus groups, and
- Provider and consumer surveys.

This approach offered a comprehensive understanding of brain injury services in Massachusetts from the views of individuals, providers, state agency staff, and advocates.

a. Guiding Questions

PCG worked closely with MRC leadership and advocates to develop guiding questions that would serve as a framework for data collection. There were several key themes within the questions. These helped drive feedback efforts and captured valuable anecdotal information. The guiding questions were as follows:

1. What services do you receive and what services do you want?
2. What are your experiences with brain injury service delivery?
3. What parts of the service delivery system is working? What parts are not?
4. Are current services sufficient?
5. What are the major barriers preventing you from accessing the services you need?

These guiding questions synthesized the main goal of this effort: to provide MRC with recommendations aimed at improving the lives of individuals living with a brain injury. Furthermore, this framework helped facilitate focus group conversations and survey development.

b. Literature Review

From the outset, MRC identified key research areas related to services and supports. This gave the PCG team the necessary structure to capture the most relevant and useful information. The research areas identified by MRC were as follows:

Research Area	Details
MRC Documentation	A collection of reports and publications from previous MRC assessments and studies, ranging from focus group feedback reports to epidemiological studies.

Research Area	Details
Co-Morbid Complexities in Individuals with Brain Injury	A collection of scientific studies and journals that focuses on various co-morbid complexities individuals with brain injury may experience (existing either as pre-morbid conditions or because of their injury). The studies focused on the following co-morbid conditions and situations: • Substance abuse, • Developmental disabilities, • Mental health, • Homelessness, • Isolation, and • Involvement with the criminal justice system.
Transportation	Documentation that specifically highlights the transportation needs of individuals with brain injury.
Brain Injury Waivers of Peer States	A detailed look at ABI Home and Community-Based Services Waivers (HCBS). PCG identified five states that all have brain injury HCBS Waivers and examined their services offered, funding, expenditure, and capacity. The five states are: Connecticut, Wyoming, New Hampshire, Kentucky, and Utah.

MRC Documentation

Previous MRC documents and reports were critical to the literature review. MRC has produced several high-quality reports over the years that offer extensive insight into the challenges faced by the brain injury community. In particular, PCG leveraged four MRC documents:

Title	Year
The Status of People with Brain Injuries in Massachusetts: Epidemiological Aspects and Service Needs	1988
Consumer Focus Groups 2006: Statewide Head Injury Program	2006
Brain Injury Commission Report	2011
Brain Injury in Massachusetts	2014
Severe Brain Injury in Massachusetts: Assessing the Continuum of Care	2015

These documents gave an overall summary of the state of brain injury in Massachusetts. Some publications focused strictly on epidemiological statistics (*Brain Injury in Massachusetts*) and others focused on service delivery and its gaps (*Severe Brain Injury in Massachusetts: Assessing the Continuum of Care*). Furthermore, the 1988 and 2006 focus group reports provide a detailed look at services and support through the eyes of an individual with a brain injury.

Co-Morbid Conditions in Individuals with brain injury

As listed above, PCG focused on key co-morbid conditions with high prevalence in individuals with brain injury. The reviewed literature are as follows:

Title	Year
Cognitive Rehabilitation for Children with Brain Injury	2009
Treating Clients with Traumatic Brain Injury	2010
Traumatic Brain Injury Among Men in an Urban Homeless Shelter: Observational Study of Rates and Mechanisms of Injury	2014
Anxiety Disorders in Children and Adolescents in the Second Six Months After Traumatic Brain Injury	2015

The literature reviewed gave insight into substance abuse, developmental disabilities, mental health, and homelessness. In some cases, these conditions existed prior to the individual's brain injury, further complicating treatment and symptoms management. The complexities that arise from a brain injury often present obstacles for both individuals with brain injuries and service providers.

Transportation

A 2012 study, *Improving ADA Paratransit Demand Estimation: Regional Modeling,* highlighted key metrics in reducing paratransit demand by simply improving infrastructure and access to relevant activities for individuals with disabilities. **The study showed that a 10% increase in access to activities reduces the ADA paratransit registration rate by approximately 9%.** Increasing access to activities includes measures such as providing additional benches, repairing and clearing sidewalks of obstructions, and adding ramps (Bradley & Koffman, 2012). There were no definitive best practices from the literature reviewed; however, the Bradley & Koffman report does provide a foundation from which states can develop informed decisions based on empirical evidence.

c. Stakeholder Engagement

The stakeholders were a key element of this needs assessment as they provided first-hand accounts on the state of brain injury services in various perspectives. From the MRC leadership to individuals with a brain injury, the wide variety of individuals and entities provided a well-rounded view of the current state of brain injury services. Below is a list of the tools PCG utilized during stakeholder engagement:

Stakeholder Interviews: PCG conducted key stakeholder interviews with MRC staff and leadership, advocacy organizations, exemplar providers, and leaders in brain injury advocacy.

These interviews provided an in-depth view of MRC brain injury services and its strengths and weaknesses. The overwhelming support of stakeholders from these different areas provided constructive insights from their point of view. The prevalence of brain injury in Massachusetts (1 in 67) is high and thus garners support from many parts of the community (Lorenz & Katz, 2015). The passion for brain injury services continues to fuel advocacy efforts for individuals with brain injury.

PCG also interviewed executive leadership within the Department of Developmental Services. DDS currently operates two residential waivers that serve individuals with a brain injury (MA Acquired Brain Injury with Residential Habilitation and MA Money Follows the Person Residential Supports) and offer a valuable perspective to the needs of individuals and families living with a brain injury.

Surveys: PCG developed two web-based surveys on SurveyMonkey.com, one for providers and one for individuals with a brain injury. The survey was open from September 29th, 2016 to October 19th, 2016 and featured both web-based and paper options. Overall, **31 providers** responded to the survey online and over **139 individuals** responded to the survey in a mix of online and paper responses. PCG also provided personal technical assistance with a dedicated email inbox throughout the entire survey and focus group period.

31 providers and **139** consumers responded to the survey.

Focus Groups – PCG performed nine (9) total focus groups across all regions of Massachusetts for both providers and individuals in each respective region. The focus groups offered a chance for the brain injury community to voice their opinions and feedback on the current services and needs for individuals with a brain injury.

34 individuals from provider organizations and **46** consumers attended the

The map on the right shows the locations where focus groups were conducted within the Commonwealth: Boston, Pittsfield, Taunton, Burlington, and Westborough. The chosen cities and towns were based on the convenience of their location for each region and ease of access for providers and individuals in the area. Pittsfield, for example, could capture individuals from western Massachusetts while Taunton in the Southeast could capture individuals from Cape Cod.

APPENDIX C: RESEARCH REFERENCES AND CITATIONS

Bradley, Mark A., and David Koffman. Improving ADA Paratransit Demand Estimation: Regional Modeling. *Washington, D.C.: Transportation Research Board*, 2012. Print.

Center for Substance Abuse Treatment (2010). Treating Clients with Traumatic Brain Injury. Substance Abuse Treatment Advisory, 9(2).

CT ABI Waiver II (1085.R00.00). Retrieved October 20, 2016, from Medicaid.gov, https://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/waivers_faceted.html

CT Acquired Brain Injury (0302.R03.00). Retrieved October 20, 2016, from Medicaid.gov, https://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/waivers_faceted.html

EOHED. (2008, February 11). How to Obtain Housing Assistance. Retrieved October 20, 2016, from Mass.gov, http://www.mass.gov/hed/economic/eohed/dhcd/how-to-obtain-housing-assistance.html

EOHHS. (2010, April 27). Acquired Brain Injury Waivers. Retrieved October 20, 2016, from Medicaid.gov, http://www.mass.gov/eohhs/consumer/insurance/more-programs/acquired-brain-injury-waivers.html

Hackman H, LaVecchia F, Kamen D, et al. (2014) Acquired Brain Injury in Massachusetts. Boston, MA: *Massachusetts Department of Public Health and Massachusetts Rehabilitation Commission*; October, 2014.

Hendrickson, L., & Blume, R. (2008). Issue Brief: A Survey of Medicaid Brain Injury Programs. Rutgers Center for State Health Policy

HRSA. (2012, January). A Look at TBI Trust Fund Programs. HRSA Federal TBI Program.

Bradley, Mark A., and David Koffman. Improving ADA Paratransit Demand Estimation: Regional Modeling. *Washington, D.C.: Transportation Research Board*, 2012. Print.

Kamen, Deborah. MRC BISSCS. (2006). Consumer Focus Groups 2006. *Statewide Head Injury Program, MRC*.

KY Acquired Brain Injury (0333.R03.00). Retrieved October 20, 2016, from Medicaid.gov, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-State/Waiver-Descript-Factsheet/KY-Waiver-Factsheet.html#KY0477

KY Acquired Brain Injury, Long Term Care (0477.R01.00). Retrieved October 20, 2016, from Medicaid.gov, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-State/Waiver-Descript-Factsheet/KY-Waiver-Factsheet.html#KY0477

Lorenz, Laura, and Gabrielle Katz. (2015). Severe Brain Injury in Massachusetts: Assessing the Continuum of Care., *BIA-MA*.

MA Acquired Brain Injury Non-Residential Habilitation (40702.R01.00). Retrieved October 20, 2016, from Medicaid.gov, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-State/Waiver-Descript-Factsheet/MA-Waiver-Factsheet.html#MA40701

MA Acquired Brain Injury w/Residential Habilitation (40702.R01.00). Retrieved October 20, 2016, from Medicaid.gov, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-State/Waiver-Descript-Factsheet/MA-Waiver-Factsheet.html#MA40701

MA MFP Community Living (1027.R00.00). Retrieved October 20, 2016, from Medicaid.gov, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-State/Waiver-Descript-Factsheet/MA-Waiver-Factsheet.html#MA40701

MA MFP Residential Supports (1028.R00.00). Retrieved October 20, 2016, from Medicaid.gov, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-State/Waiver-Descript-Factsheet/MA-Waiver-Factsheet.html#MA40701

MA TBI (0359.R03.00). Retrieved October 20, 2016, from Medicaid.gov, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-State/Waiver-Descript-Factsheet/MA-Waiver-Factsheet.html#MA40701

Marek, K. D., Popejoy, L., Petroski, G., Mehr, D., Rantz, M., & Lin, W. (2005). Clinical Outcomes of Aging in Place. Nursing Research, 54(3). doi:10.1097/00006199-200505000-00008

Massachusetts Rehabilitation Commission, Statewide Head Injury Program. (1988). The Status of People with Brain Injuries in Massachusetts: Epidemiological Aspects and Service Needs

Max, J. E., Lopez, A., Wilde, E. A., Bigler, E. D., Schachar, R. J., Saunders, A., . . . Levin, H. S. (2015). Anxiety disorders in children and adolescents in the second six months after traumatic brain injury. Journal of Pediatric Rehabilitation Medicine PRM, 8(4), 345-355. doi:10.3233/prm-150352

MRC. (2011, November 14). Brain Injury Commission Report.

Multifamily Housing - Program Description. Retrieved October 20, 2016, from Medicaid.gov, http://portal.hud.gov/hudportal/HUD?src=/program_offices/housing/mfh/progdesc/disab811

NH BDS Acquired Brain Disorder Services (4177.R04.00). Retrieved October 20, 2016, from Medicaid.gov,https://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/waivers_faceted.html

Oddy, M., & Ramos, S. D. (2013). The clinical and cost-benefits of investing in neurobehavioural rehabilitation: A multi-centre study. Brain Injury, 27(13-14), 1500-1507. doi:10.3109/02699052.2013.830332

Reid, I., McGeary, K. A., & Hicks, M. J. (2011). Potential economic impact of resource facilitation for post traumatic brain injury workforce re-assimilation. Ball State University, Center for Business and Economic Research. Retrieved from: https://cms.bsu.edu/-/media/WWW/DepartmentalContent/GlobalHealth/PDF/011211EconomicImpactTBIFinal.pdf

Rispoli, M., Machalicek, W., & Lang, R. (2014). Assistive Technology for People with Acquired Brain Injury. Autism and Child Psychopathology Series Assistive Technologies for People with Diverse Abilities, 21-52. doi:10.1007/978-1-4899-8029-8_2

Slomine, B., & Locascio, G. (2009). Cognitive rehabilitation for children with acquired brain injury. Developmental Disabilities Research Reviews Dev Disabilities Res Revs, 15(2), 133-143. doi:10.1002/ddrr.56

Technical Assistance Program for Schools. Retrieved November 3, 2016, from Mass.gov, http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/head-injury/services/technical-assistance-program-for-schools.html

Topolovec-Vranic, J., Ennis, N., Howatt, M., Ouchterlony, D., Michalak, A., Masanic, C. Cusimano, M. D. (2014). Traumatic brain injury among men in an urban homeless shelter: Observational study of rates and mechanisms of injury. CMAJ Open, 2(2). doi:10.9778/cmajo.20130046

Trexler, L. E., Waldman, W., & Parrott, D. (2014). Resource Facilitation: Indiana Best Practices Manual for Return-to-Work or Return-to-School. Retrieved from: http://rhin.com/resource-facilitation-best-practices-manual-for-return-to-workschool/

UT Acquired Brain Injury (0292.R04.00). Retrieved October 20, 2016, from Medicaid.gov, https://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/waivers_faceted.html

WY Acquired Brain Injury (0370.R03.00). Retrieved October 20, 2016, from Medicaid.gov, https://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/waivers_faceted.html

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