

BRAIN INJURY STRATEGIC PLAN 2023-2027



Massachusetts Rehabilitation Commission

Introduction

This strategic plan serves as a foundation to guide the state to improve services, supports and system for those living with brain injuries. The Brain Injury Council discussed themes to guide their work as a council and the development of this plan.

*The Brain Injury Council created four subcommittees, **Behavioral Health**, **Diversity, Equity and Inclusion**, **Education**, **Service Needs**. Each subcommittee consisted of individuals with lived experiences, state agency, and community-based providers and advocates. The subcommittees identified priorities for each of these areas and drafted the goals that are included in this plan.*

Glossary of Terms:

Behavioral Health: Refers to both mental health and substance use.

BIA-MA: Brain Injury Association of Massachusetts

Brain Injury: Any injury to the brain, which occurs after birth.

Community or Brain Injury Community: Our brain injury community includes individuals with lived experience, family members, caregivers, state agencies, health care and other community-based providers. This plan prioritizes understanding and improving service systems in underserved populations and locations.

Healthcare: A field that is dedicated to the maintenance or restoration of physical and behavioral health.

Human Services: Programs or facilities for meeting health, welfare, and other needs of a society or group.

Individual with lived experience: A person who identifies as having a brain injury.

MRC: Massachusetts Rehabilitation Commission

SHIP: Statewide Head Injury Program



Brain Injury Strategic Plan

DISCUSSION TOPIC #1



Behavioral Health

- Awareness
- Screening
- Resources
- Cross-System Collaboration

DISCUSSION TOPIC #2



Diversity, Equity, and Inclusion

- Barriers to services
- Marginalized communities
- Cultural Impacts
- Awareness

DISCUSSION TOPIC #3



Education

- Stigma
- Awareness
- Education
- Resource Navigation

DISCUSSION TOPIC #4



Service Needs

- Barriers to Services
- Transportation
- Resource Navigation
- Brain Injury Registry

The Strategic Plan is a blend of the elements discussed in subcommittees. The plan ensures that the main points are included in the goals and objectives presented on the following pages.



Diversity, Equity, Inclusion and Accessibility were major themes during the development of this strategic plan. The workplans developed to achieve these goals and objectives will focus on supporting underserved populations, communities and those with co-occurring conditions including behavioral health diagnoses.

Focus: Education

Goal 1: Educate the public about risk factors, prevention, long-term effects of brain injuries, and available services & supports.

- Identify engaged community members (Champions) to assist with public messaging.
- Develop a public service campaign about brain injuries, services and supports.

Goal 2: Develop brain injury training materials for professionals and providers. Training material will be inclusive of different experiences in the brain injury community.

- Collaborate with brain injury specialists and other community members to improve person-centered training materials.

Goal 3: Educate individuals, families, and caregivers about brain injury resources.

- Partner with the healthcare community to distribute information about brain injury resources.
- Raise awareness and increase utilization & contact with the state brain injury resources, services, and supports.

Focus: Resource Facilitation

Goal 1: Expand awareness of brain injury resources and services.

- Educate the human services workforce about brain injury, screening, and accommodations.
- Raise awareness within the health care community of brain injury risk factors and resources. Resources include state funded specialized services, BIA-MA and other community-based programs.

Goal 2: Enhance a system of community supports for individuals living with brain injuries.

- Develop an active network to share information about brain injury services and supports. (Examples include community-based professionals, school-based settings, leaders, advocates.)
- Enhance the peer support system to include brain injury mentors.
- Inform relevant state and advocacy partners about the need for accessible transportation in underserved communities.

Focus: Data Collection

Goal 1: Identify gaps in services, for those affected by brain injury.

- Explore best practices to connect people to brain injury services and supports.
- Collect feedback on available service system to ensure services meet the needs of those with brain injury and/or cognitive impairments.

Goal 2: Develop an effective brain injury screening framework to use in several health and human service settings.

- Identify and embed brain injury screening in varied agencies and organizations.
- Identify a brain injury screening tool that includes clear follow-up actions and resources.
- Develop and implement an education, distribution, and monitoring plan for screening.

What state resources exist?

The Statewide Head Injury Program (SHIP) was established in 1985 within the Massachusetts Rehabilitation Commission (MRC) as a result of grassroots advocacy efforts. It was the first national model for publicly funded services for individuals with traumatic brain injury (TBI) and is the lead brain injury agency in the Commonwealth.

SHIP was established by 107 CMR 12.04 in 1985. To be eligible for SHIP services, an individual must have an externally caused TBI with related cognitive, physical and/or behavioral impairments and be able to participate in community-based services. Services are funded through a combination of state appropriations, SHIP account (budget line item 4120-6000), the Head Injury Treatment Services (HITS) Trust Fund (budget line item 4120-6002), Medicaid funding for specific programs, and government line items.

The primary purpose of the Statewide Head Injury Program (SHIP) is to assist individuals with TBI to develop skills and maintain or increase independence within their home, community, or work.

According to SHIP, the average age of a person receiving SHIP services is 53 years old, 30% female, 63% male, and 8% unknown. SHIP consists of a wide array of community-based services including, but not limited to skills training, adult companion, limited residential and shared living, and Brain Injury Community Centers serving individuals with all types of ABI.



Summary of Massachusetts Data (2016-2018)

**8,831
HOSPITAL
STAYS**

There was an average of **8,831** hospital stays and nearly **63,000** emergency department visits associated with a traumatic brain injury annually among MA residents for the time period studied.

67%

The leading most common mechanism of injury was unintentional fall accounting for **67%** of TBI-related inpatient stays and approximately **51%** of emergency department visits.

**70
YEARS**

TBI-related hospital stays were highest among adults **70 years** of age and older.

**0-2
YEARS**

Children **0-2 years** of age had the highest rate for TBI-related emergency department visits.

**MOST
GO
HOME**

Although most persons with TBI treated in the inpatient setting were discharged home, a sizable proportion of older adults were discharged to skilled nursing facilities.

11.6%

Only **11.6%** of all individuals were discharged from an inpatient stay to a rehabilitation hospital or unit.

**DEATHS
6.4%**

The majority of those with a traumatic brain injury discharge diagnosis who were hospitalized survive, while **6.4%** died 2016-2018. The highest death rates overall were for those 70 years of age and older, and the death rate for males was more than twice that of females (2015-2017).

72%

Medicare and Medicaid were the primary payers for the majority (**72%** combined) of inpatient hospitalizations.

ABOUT THE BRAIN

Massachusetts Brain Injury Council

The purpose of this information is to share who helped develop the Brain Injury Strategic Plan. We want to ensure people recognize that this is a plan that focuses on concerns and topics identified by those with lived experience of brain injuries and community partners.

About the Council

The mission of the Massachusetts Rehabilitation Commission (MRC) is to work together to break down barriers and make a better state possible for those with disabilities — one that is truly equitable, accessible, and inclusive. MRC engages individuals with lived experiences of disabilities and ensures their voices are front and center in the design, development, and delivery of MRC services and supports. MRC includes individuals with lived experiences of disabilities in a variety of councils, advisory boards, and focus groups pertaining to the delivery of services throughout the Commonwealth.

In August 2021, the Massachusetts Brain Injury Council was established, consisting of individuals with lived experience of brain injury, family members, and a wide variety of community partners including state agencies, community-based providers, and advocates.

INJURY COUNCIL

The purpose of the Brain Injury Council is:



To ensure

individual(s) with lived experience and family voice guides the way the state thinks about, develops, and delivers supports and services.



To provide

a space for individual(s) with lived experience, family, and community partners to forge relationships and collaboratively guide this work.



To provide

ongoing feedback and thought leadership regarding the brain injury strategic plan, which is a blueprint for how services should be prioritized, developed, designed, and implemented.



The work

of the council is guided by the council's mission and vision, which was developed by our members with lived experiences.

COUNCIL MEM

COUNCIL MEMBERS*

Beth Adams

Massachusetts
General Hospital

Rachel Adams

Brandeis University

Betsy Bizarro

Individual with
Lived Experience

Pam Borys

Individual with
Lived Experience

Gary Brennan

Individual with
Lived Experience

Maureen Butler

Massachusetts
Rehabilitation
Commission

Dr. Chris Carter

Spaulding
Rehabilitation
Network

Dawn Clark

Dept. Public Health

Jill Conlon

Brockton Area
Multi-Service Inc.

Jim Cremer

Dept. Public Health-
Bureau Of Substance
Addiction Services

Michelle Demore-Taber

Advocates

Anthony Faccenda

Individual with Lived
Experience

George Farrington

Individual With Lived
Experience

Pedro Fontes

Individual with Lived
Experience

Marylouise Gamache

Exec. Office of Health and
Human Services

Nicole Godaire

Brain Injury Association
of Massachusetts

Shaun Grady

Individual with Lived
Experience

Dr. Holly Hackman

Dept. of Public Health

Bill Holland

Individual with Lived
Experience

Julie Hwayoung-Shepard

Dept. of Mental Health

Dr. Swathi Kiran

Boston University

Carole Malone

Asst. Secretary Exec.
Office of Elder Affairs

Nancy Murphy

Disability Law Center

Alex Niederhauser

Individual with Lived
Experience

Carol O'Loughlin

Dept. of Mental Health

Dr. Therese O'Neil Pirozzi

Northeastern University &
Spaulding Rehabilitation
Network

Annette Peele

Exec. Office of Elder Affairs

Ann Pike-Paris

Family Member with
Lived Experience

Edna Pruce

Family Member with
Lived Experience

BERS & STAFF

Ali Rheaume

Individual with Lived Experience

Rock Richard-Oscar

Individual with Lived Experience

Helene Robillard

Individual with Lived Experience

Rosa Rodriguez

Massachusetts Rehabilitation Commission

Lisa Saba

Dept. Developmental Services

June Sauvageau

Northeast Independent Living Program

Amanda Smart

Individual with Lived Experience

Marilyn Spivack

Family Member with Lived Experience

Helen Stewart

Individual with Lived Experience

Don Summerfield

Individual with Lived Experience

Rebekah Thomas

Dept. Public Health, Injury Prevention

Madeline-Resnick

Individual with Lived Experience

Terri Vandercook

Individual with Lived Experience

James Zachazewski

Boston Public Schools

Julia Zubiago

MassHealth

*** This list is comprised of current and past council members that supported the creation of this strategic plan.**

COUNCIL SUPPORT STAFF

Amanda Baczko

Massachusetts Rehabilitation Commission

Kelly Buttiglieri

Brain Injury Association of Massachusetts

Cynthia Cardeli

Brain Injury Association of Massachusetts

Audria Chea

Massachusetts Rehabilitation Commission

Manel Desvallons

Massachusetts Rehabilitation Commission

Amanda Tower

Massachusetts Rehabilitation Commission



If you are interested in becoming involved with the Brain Injury Council and their efforts to improve education and services through Massachusetts, please contact the Massachusetts Rehabilitation Commission Office of Individual and Family Engagement. **Email: mrc.disabilityengagement@mass.gov**

What is Brain Injury?

An Acquired Brain Injury (ABI) is any injury to the brain, which occurs after birth and can be caused by:

1

*Trauma to the brain, which is externally caused**

2

Metabolic disorders which may be related to cardiovascular disease, nutritional deficiencies

3

Endocrine disorders or diminished oxygen (anoxia)

4

Brain tumors

5

Toxins, poisons, alcohol, and drug use

6

Diseases and conditions affecting the blood supply to the brain (stroke)

7

Infectious diseases (encephalitis, meningitis)

** Traumatic brain injury (TBI) is the leading cause of ABI, and a major cause of death and disability.*

What are the consequences of ABI?

Consequences of ABI can range from mild to severe, and the effects can be temporary or permanent. Individuals who sustain an ABI often experience a variety of symptoms over time. Some of the common disorders and impairments associated with ABI include:

1

Motor Impairment: Balance, muscle weakness, gait problems, discoordination and paralysis

2

Physical Health: Seizures, chronic pain, sleep, and headache disorders

3

Sensory: Loss of touch, hearing, sense of smell and/or taste, as well as blindness or other visual impairments

4

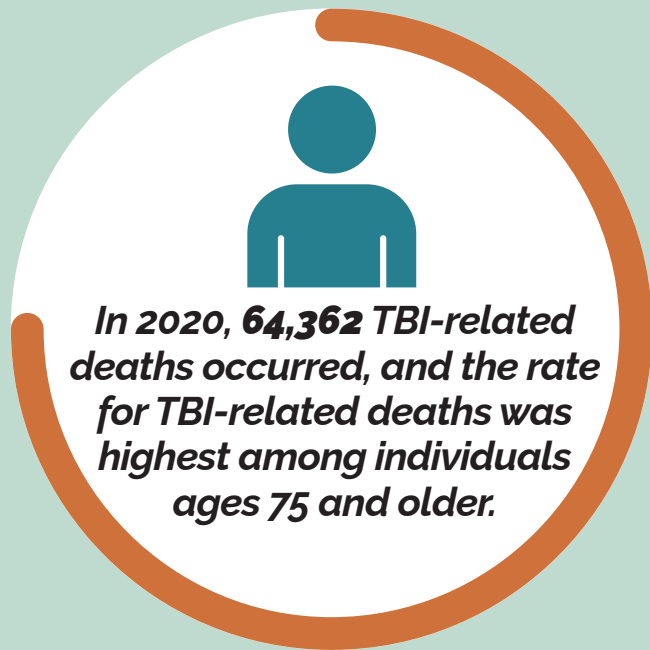
Cognitive: Impairment of attentional capacity and performance on tests of logic, reasoning, memory, language, organization, learning, orientation, and perception

5

Behavioral Health: Depression, social withdrawal, personality changes, impulsivity, difficulty regulating one's emotional responses and substance use

What are the leading causes of TBI incidents in the US?

TBI-related deaths in 2020



Deaths by suicide

35.5% Suicide accounted for 35.5% of TBI-related deaths, and firearm-related suicide is the most common cause of TBI-related deaths in the United States.

Fall related deaths

30% Unintentional falls account for 30% of deaths, and TBI-related death rates attributable to both suicide and falls were highest among individuals aged 75 and older.

Male to female ratio 3:1



The age-adjusted rate of TBI-related deaths among males was more than three times that of females.

Motor vehicle related deaths



Deaths related to unintentional motor vehicle crashes

Deaths related to unintentional motor vehicle crashes were highest 15-24 and 25-34 years of age.

Who has the highest rates of TBI-related death?

American Indians or Alaskan Native (AI/AN) and Non-Hispanic males have the highest rates of TBI-related death based on a CDC report.

AI
AN



Massachusetts Rehabilitation Commission

600 Washington Street, Boston, MA 02111
Phone (617) 204-3600 | mass.gov/mrc