



# Reviewing the Research

Massachusetts Health Policy Forum #45

“Severe Brain Injury in Massachusetts:  
Assessing the Continuum of Care”

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## Intro/Background

- Acquired brain injury is a major public health problem in Massachusetts
- In the MA policy context, ABI includes:
  - Traumatic brain injury
  - Stroke
  - ABI-related infectious diseases (e.g., encephalitis)
  - Metabolic disorders affecting the CNS (brain and spinal cord)
  - Brain tumor



## Intro/Background

- Many patients (especially with severe TBI) are not receiving services after initial treatment:
  - Inpatient post-acute rehabilitation
  - Case management
  - Brain-injury specific community programming

Governance and data for decision-making are also major gaps



## Intro/Background

- The last 20 years have seen major advancements in our understanding of the brain
- Severe brain injury is the new “hidden epidemic” in our society and state
- When the right rehabilitation is provided at the right time, the “rest of life” journey can be positive
- Services that help people to find a “new normal” lead to improved quality of life, function, and productivity – and reduce societal (public) costs



## Intro/Background

- Severe acquired brain injury is any injury to the brain that occurs after birth, has sudden onset and has
  - Involved loss of consciousness for 6 to 24 hours or more, or
  - Resulted in disabilities affecting ability to work, care for one's self, participate in community life, and/or fulfill a family role

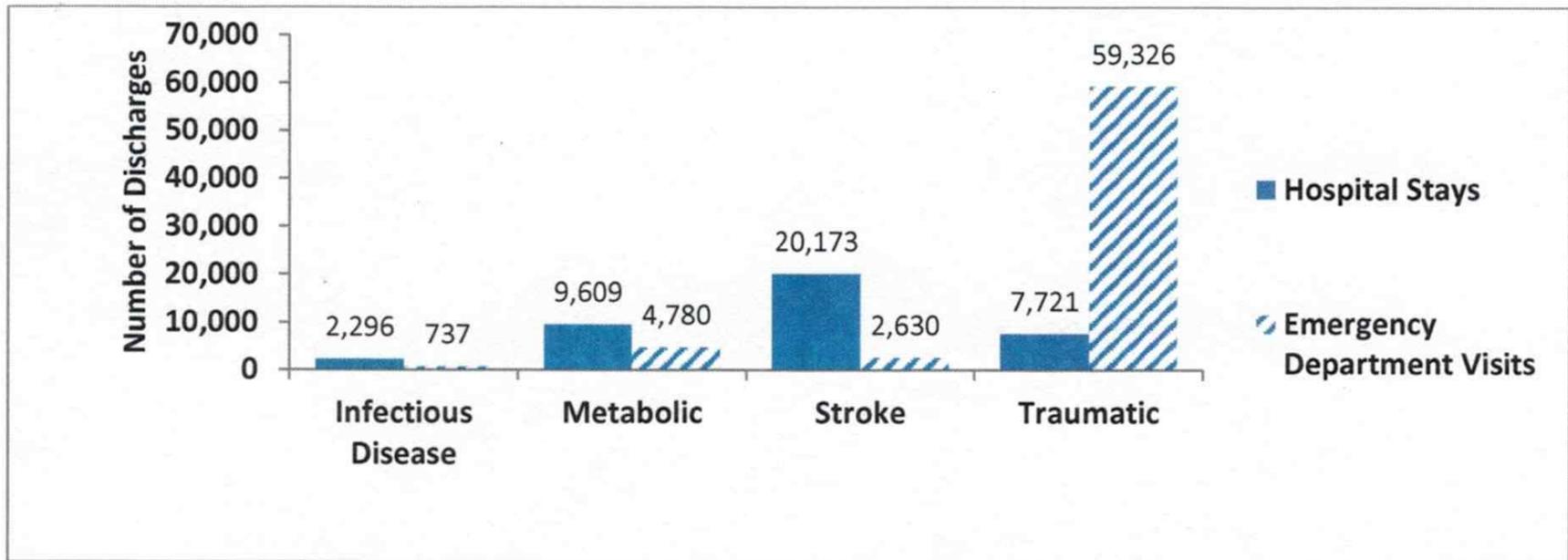


# Scope of the Problem

- ABI affects all categories of MA residents:
  - Young and old
  - Men and women
  - People in all regions of the state (2014 MA ABI epi report)
- An estimated 68,000 to 112,000 adults are living with disabilities from TBI in MA (MA population/U.S. population est. to have long-term disability from TBI)
- An estimated 37% of people clinically diagnosed with severe TBI will need life-long supports
- An estimated 15-20% of all TBIs result in life-long disabilities

# Scope of the Problem

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



**Sources:** MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

**Note:** Categories are not mutually exclusive

# Scope of the Problem

- From 2008 to 2010 on average each year in MA:
  - 1,272 primary brain tumors were newly diagnosed
  - 21 residents were discharged after a hospital stay for TBI
  - 55 residents were discharged after a hospital stay for stroke
- People are being missed – youth, veterans, others who do not report injuries/are not treated in EDs
- Falls are the leading cause of nonfatal brain injury for people 65 years and older in MA and the U.S.
- Blows to the head (e.g. from sports concussions), motor vehicle crashes, and assaults are also major causes of TBI in MA



# Scope of the Problem

## Acquired Brain Injury Outcomes: Symptom Domains and Descriptions

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

Source: Adapted from CDC, 2014



# Scope of the Problem

## Costs in the U.S.:

- Cost of TBI = \$76.5 billion/year in 2010
- Severe TBIs consume 90% of all TBI medical expenditure
- Severe TBIs incur more costs from supported housing, nursing home & rehab care, and lost earnings
- Stroke costs an estimated \$34 billion/year

# Scope of the Problem

## Costs in MA:

- MassHealth is an important payer of health and other services for people with severe ABI
- Fall-related injuries = \$630 million in 2010
- Fall-related lifetime medical and work-loss costs = \$1.7 billion
- Transportation by The Ride for people with any disability = \$97 million for 2.1 million trips/year
- HITS = \$7,755,843 (Proposed FY2016)
- Hutchinson Settlement (ABI Waiver) = \$46,412,000 (Proposed FY2016)



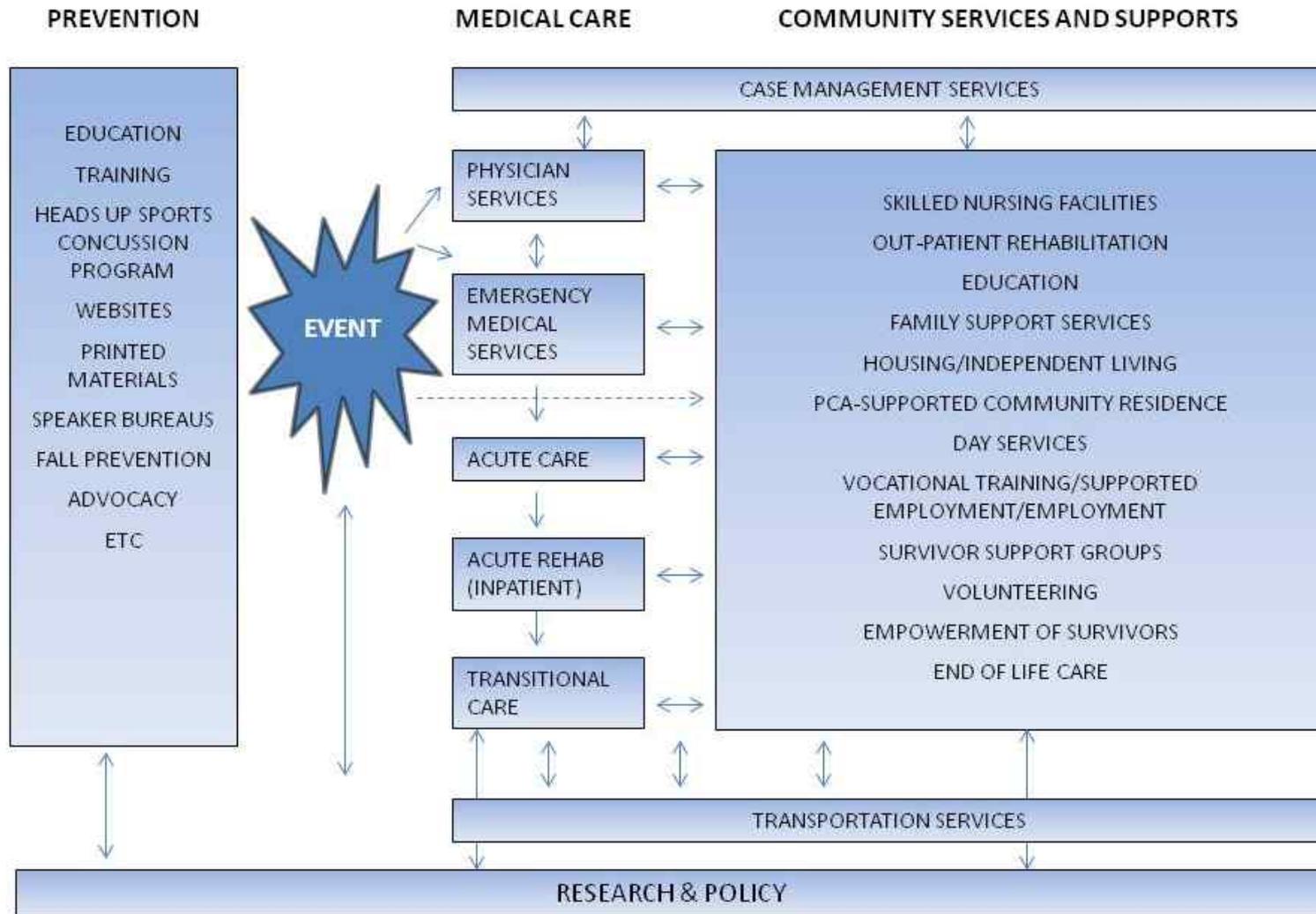
# Goals and Research Methods

**Goal:** Evaluate the continuum of care for severe ABI in the Commonwealth

## **Methods**

- Interviews with 38 ABI stakeholders in MA and elsewhere
- A targeted literature review aimed at understanding gaps and solutions described
- Review and comment by more than a dozen people

# The Continuum of Care for S-ABI





# Gaps and Disparities

- **Governance:**

- Public services for people with severe ABI are uncoordinated and scattered between different agencies and organizations (e.g. MassHealth, MRC, MDPH, DHCD, DMH, EOHHS, DOE, MBTA, municipalities, and others)

(Coordination within a given agency or funding stream is not in question)



# Gaps and Disparities

- **Post-Acute Rehabilitation:**
  - Access to rehabilitation is suboptimal
  - Patients in coma who are candidates for rehabilitation encounter eligibility requirements that severely limit access to care
  - Length of stay for any ABI hospitalization has been significantly reduced over the past 20+ years
  - Access to rehabilitation in the chronic phase is limited despite evidence of potential for improvement



# Gaps and Disparities

- **Transitions - Case Management:**
  - Patients and caregivers are overwhelmed and do not know what services are available
  - Independent case management not tied to providers or payers is lacking
  - Case management can align patient and provider interests and facilitate timely access to services
  - CM/Resource Facilitation can significantly increase return to work



# Gaps and Disparities

- **Transportation:**

- Lack hinders care transitions and participation in community life
- Challenges:
  - May require a care-giver to accompany the person with severe ABI
  - May require specialized transportation
- Options are limited - The Ride only operates where the MBTA operates and the cost can be prohibitive



# Gaps and Disparities

- **Data for Decision-Making:**
  - Needed to identify outcomes from services and supports, or ROI
  - No system in place for collecting and sharing data on inputs and outcomes
  - Lack of knowledge of the needs of people who have been living in the community for years hinders action
  - Randomized Controlled Trial studies for this population are ethically problematic (Practice-based Evidence Research grounded in programmatic data should be emphasized)



# Gaps and Disparities

- **Community Housing and Day Programming:**
  - People on disability in MA are priced out of market-rate apartments
  - The gap between supply of housing and need for housing is great
  - HCBS Waivers are moving people from nursing homes to the community but reach is limited
  - SHIP's impact is limited by TBI requirement
  - Expanded housing options are needed: Transitional Living Program, Section 8 housing, Shelters
  - C-B brain injury-specific day programming is needed



## Gaps and Disparities

- **Prevention of Severe Consequences (and Societal Costs):**
  - Between 50 and 71% of incarcerated young people have had a TBI
  - Typical behavioral issues after TBI - aggression, talking back, and poor decision-making – exacerbate the problem and contribute to recidivism
  - Parents, teachers, and correctional officers may not connect these behaviors with a TBI in childhood
  - Prevention of further harm from TBI among young people involved in the correction system is needed



# Recommendations (Summary)

- Reinstatement of the Brain Injury Commission
- Expansion of the mandate of MRC to include all ABIs
- Increase access to post-acute rehabilitation after severe ABI
- Increase access to case management/resource facilitation
- Study transportation needs and solutions
- Establish an interactive, longitudinal data system to track inputs and outcomes or join an existing national database
- Strengthen community housing options
- Improve access to BI-specific day programming
- Reduce further harm from TBI among young people involved in correctional system and veterans



# Thank You

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