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
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

<table>
<thead>
<tr>
<th>Symptom Domain</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive Function</td>
<td>Impairments in attention, memory, executive function important to everyday activities and social role participation</td>
</tr>
<tr>
<td>Behavioral Function</td>
<td>Increased aggression and childlike behavior that contributes to difficulties returning to work or school, personal relationships, and social functioning</td>
</tr>
<tr>
<td>Physical Function</td>
<td>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</td>
</tr>
<tr>
<td>Social Role Participation</td>
<td>Can include work, volunteering, recreation and leisure pursuits, and social and family role function</td>
</tr>
</tbody>
</table>

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)

• Reinstate the Brain Injury Commission
• Expand 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

- Gabby Katz, MPP Candidate, Issue Brief co-author
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- The Board of the Massachusetts Health Policy Forum
- Nicole Godaire and the Brain Injury Association of Massachusetts
- Peter Noonan and Supportive Living Inc.