The Continuum of Care for Severe Brain Injury and the “Case” of Massachusetts

NASHIA Professional Ethics Series

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Intro/Background

• Acquired brain injury is a major public health problem in Massachusetts as in many states
• In the MA policy context,\textsuperscript{1,2} ABI includes:
  – Traumatic brain injury
  – Stroke
  – ABI-related infectious diseases (e.g., encephalitis)
  – Metabolic disorders affecting the CNS (brain and spinal cord)
  – Brain tumor

\textsuperscript{1}BI Commission Report (2011); \textsuperscript{2}Hackman, H., LaVecchia, F., & Kamen, D. et al. (2014)
Massachusetts Health Policy Forum

A Massachusetts Health Policy Forum on the Continuum of Care for Severe Brain Injury was held near the State House In December 2015\textsuperscript{15}

Methods used to develop the forum’s issue brief and slides:

• 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

\textsuperscript{15}Lorenz & Katz, 2015 – available online at: \url{http://masshealthpolicyforum.brandeis.edu/forums/forum-pages/Severe%20Brain%20Injury%20.html}
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\(^7,8\)
• Services that help people to find a “new normal” lead to improved quality of life, function, and productivity – and reduce societal (public) costs

7-Marquez de la Plata, 2015; 8-Langlois et al, 2006;
Intro/Background

• Many patients (especially with severe TBI) are not receiving services after initial treatment:
  – Inpatient post-acute rehabilitation\(^2,3\)
  – Case management\(^1,4,5\)
  – Brain-injury specific community programming\(^1,3\)

Governance and data for decision-making are also major gaps\(^6\)

For our purposes today, 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,\textsuperscript{3,9} or

- Resulted in disabilities affecting ability to work, care for one’s self, participate in community life, and/or fulfill a family role

\textsuperscript{3-CDC, 2014; 9-Corrigan et al, 2010}
Scope of the Problem

• ABI affects all categories of MA residents:
  – Young and old
  – Men and women
  – People in all regions of the state

• 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)\(^2\)\(^,\)\(^3\),\(^8\),\(^10\)

• An estimated 37% of people clinically diagnosed with severe TBI will need life-long supports\(^11\)

• An estimated 15-20% of all TBIs result in life-long disabilities\(^12\),\(^13\)

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

• An average of 21 Massachusetts residents were discharged per day after a hospital stay for TBI between 2008 and 2010.²

• An average 55 were discharged after a hospital stay for stroke.

• People are being missed – youth, veterans, others who do not report injuries/are not treated in EDs⁸,¹⁴

² Hackman et al, 2014; ⁸ Langlois et al, 2006; ¹⁴ Faul et al, 2010
## 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

3-CDC, 2014; 15-Mozaffarian et al, 2015
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)
The Continuum of Care for S-ABI

PREVENTION
- Education
- Training
- Heads Up Sports Program
- Concussion
- Websites
- Printed Materials
- Speaker Bureaus
- Fall Prevention
- Advocacy
- Etc

MEDICAL CARE
- Physician Services
- Emergency Medical Services
- Acute Care
- Acute Rehab (Inpatient)
- Transitional Care

COMMUNITY SERVICES AND SUPPORTS
- Case Management Services
- Skilled Nursing Facilities
- Out-Patient Rehabilitation
- Education
- Family Support Services
- Housing/Independent Living
- PCA-Supported Community Residence
- Day Services
- Vocational Training/Supported Employment/Employment
- Survivor Support Groups
- Volunteering
- Empowerment of Survivors
- End of Life Care

TRANSPORTATION SERVICES

RESEARCH & POLICY
The Continuum of Care for S-ABI

• Now we will review a summary of gaps and disparities identified by the stakeholders interviewed and supported in the literature
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 (Done)
- 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 (in process)
- Reduce further harm from TBI among young people involved in correctional system and veterans
Informed Decision-making: Ethics of Evidence

• A major challenge to informed decision-making for the severe brain injury population is having data and evidence of:
  ✓ Observed functional outcomes
  ✓ Observed health outcomes
  ✓ Self-report quality of life outcomes
  ✓ Cost-effectiveness of services and supports
Is this hierarchy sufficient for generating evidence related to severe brain injury??

Source: Millbank Memorial Fund, Center for Evidence-Based Policy, Feb 10, 2016
Need more evidence of rehabilitation outcomes/effectiveness

Problems include:

- Small sample sizes
- Lack of standardization of variables and definitions
- Lack of representative samples
- Rehab outcomes as measured by clinical tests do not have real world value from funder (or patient!) perspectives!!
The Problem

- Shift to Payer Driven Model
- Poor Public Policy
- Lack of Industry Data

Reduced Access to Care

Practice-Based Evidence – a data solution?\textsuperscript{16}

The Solution

Develop Data Plan
- Identify Project Goals
- Identify Tools
- Identify Collection Processes
- Ensure Data Security

Collect & Manage Data
- Collect Data
- Identify Research Questions
- Analyze Data
- Publish Results
- Develop Benchmarks

Advocate for Access to Services
- Develop Care Standards
- Change Public Policy
- Impact legislation
- Shift away from Payer Driven model

Increase Access to Care

16-Murphy, 2015 ACRM
A conundrum...

• *If access to care is denied, how can evidence be generated??*

Solutions could include:

• Fund pilot studies or database projects that use standardized outcomes measures and will track data and outcomes over time

• Collaborate with academic and clinical researchers to apply for federal and/or foundation funding to conduct studies and/or establish database projects

• Collaborate with program providers to develop practice-based approaches using standardized measures and common databases

**Working together we can get more done...**

17- Lewis & Horn, 2015.
Can people who were hospitalized for brain injury show improvements along the continuum of care after discharge?

A practice-based evidence study of neurorehabilitation along the continuum of care using MPAI-4 as an outcome measure examined the effectiveness of four levels of post-hospital care (active neurorehabilitation, neurobehavioral intensive, day treatment, and supported living) and the functional variables most important to their success.

17- Lewis & Horn, 2015.
Post-Hospital Continuum of Care

- **Post-hospital Community Neurorehabilitation Care** (NR) since 1970; neurorehabilitation programs following the hospital course within an applied setting for skills use and generalization.

- **Neurobehavioral Intense** (NBI) – significant behavioral intensity programs; focus is on behavioral stability targeting irritability, impaired awareness, social contact, problem solving, goal directed initiation.

- **Day Treatment** (DT) – extension from residential neurorehabilitation; live at home or in the community and focus on skills use.

- **Supported Living** (SL) – designed for those who require a longer level of care that is more gradual; focus is on quality and instrumental activities of daily living.

17- Lewis & Horn, 2015.
## Post-Hospital BI Continuum of Care

### Patient Demographic Characteristics

<table>
<thead>
<tr>
<th>Program Type</th>
<th>Sample Size</th>
<th>Mean Age</th>
<th>Gender M/F</th>
<th>Ave. LOS days</th>
<th>Onset</th>
<th>% TBI</th>
</tr>
</thead>
<tbody>
<tr>
<td>NR</td>
<td>808</td>
<td>43.5</td>
<td>76%/34%</td>
<td>129</td>
<td>21.6m</td>
<td>71%</td>
</tr>
<tr>
<td>NBI</td>
<td>122</td>
<td>38</td>
<td>83%/17%</td>
<td>294</td>
<td>80.3m</td>
<td>82%</td>
</tr>
<tr>
<td>DT</td>
<td>146</td>
<td>42</td>
<td>71%/29%</td>
<td>153</td>
<td>35.4m</td>
<td>65%</td>
</tr>
<tr>
<td>SL</td>
<td>86</td>
<td>45.7</td>
<td>80%/20%</td>
<td>348</td>
<td>83.7m</td>
<td>79%</td>
</tr>
</tbody>
</table>

17- Lewis & Horn, 2015.
Outcomes: MPAI-4 (Instrumental ADLs and Community Skills)

Program Effectiveness: Reduction in Disability MPAI-4 Participation Scale

People at all levels improved to varying degrees. At chronic stage, maintaining function is key.  

17- Lewis & Horn, 2015.
An evidence challenge: What measures?

- Inconsistent use of a wide range of brain injury outcome measures has challenged development of evidence for this population.
- The federal government (NIH and CDC) has invested in changing how rehabilitation outcomes are measured and standardizing measurement approaches across brain disorders.\(^{16}\)

18- Carlozzi et al. 2011
Two Sources of Vetted Measures

• NINDS CDE (National Institute for Neurological Disorders and Stroke, Common Data Elements):
  – For TBI: https://commondataelements.ninds.nih.gov/tbi.aspx#tab=Data_Standards
  – For Stroke: https://commondataelements.ninds.nih.gov/Stroke.aspx#tab=Data_Standards
  – Also available for other neurological conditions

• COMBI (Center for Outcome Measures in Brain Injury): http://www.tbims.org/combi/
<table>
<thead>
<tr>
<th>Measure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>MPAI-4</td>
<td>Mayo-Portland Adaptability Index -4</td>
</tr>
<tr>
<td>ABS/BIAF</td>
<td>Agitated Behavior Scale/Behavior Identification Assessment Score</td>
</tr>
<tr>
<td>CRS</td>
<td>JFK Coma Recovery Scale</td>
</tr>
<tr>
<td>DRS</td>
<td>Disability Rating Scale</td>
</tr>
<tr>
<td>SRS</td>
<td>Supervision Rating Scale</td>
</tr>
<tr>
<td>SWLS</td>
<td>Satisfaction With Life Scale</td>
</tr>
<tr>
<td>WHO-QOL Brief</td>
<td>World Health Organization – Quality of Life (QOL)</td>
</tr>
<tr>
<td>EuroQOL</td>
<td>Self-report QOL for Economic/Cost-effectiveness Analysis</td>
</tr>
</tbody>
</table>
Goal: Speed up translation of evidence to policy and practice

• Use of standardized measures has the potential to generate evidence of rehabilitation efficacy across studies with small sample sizes and reduce the current 17-year delay from bench to bedside for evidence generated by randomized controlled trials.\(^\text{19}\)

19-Duncan, 2011
Are standardized measures sufficient?

• Is exclusive use of standardized measures sufficient and ethical for this population?

• Data on consumer perspectives are also needed –
How understand consumer perspectives?

• Use qualitative research – to **hear** voices, opinions, perspectives

• Use arts-based research – to **see** opinions, perspectives, feelings

• Use participatory research – to **empower** consumers to be part of the solution
Qualitative findings can put observed outcomes and contributing factors in perspective

• **First** we will look at a study that explored perspectives of people with disabilities from moderate to severe brain injury on their transition to community-based living\(^1\)\(^8\)

• **Second** we will review a participatory study of lived experience with brain injury using a participatory arts-based method\(^1\)\(^9\)

• **Third** we will review development of a video of survivor testimony for the Massachusetts Health Policy Forum on the continuum of care for severe brain injury

20- O’Neil-Pirozzi, Lorenz, Samayoa, Demore-Taber, 2015; 21- Lorenz & Kolb, 2009
Consumer perspectives on post ABI residential transition

• Brain injury survivors experience many transitions post-injury
• It is important that they experience these in the most supportive and integrative way possible
• 21 adults with chronic ABI (mean age: 51 years; avg time since injury: 28 years) residing in community-based supported group homes were interviewed; interviews were recorded, transcribed, and coded. Approximately ½ had been living with family and ½ in nursing homes prior to their most recent transition.
• Participants discussed positive and negative insights and experiences regarding residential transitions

O’Neil-Pirozzi, Lorenz, Samayoa, Demore-Taber, 2015
### Survivor-suggested transition practices and strategies

<table>
<thead>
<tr>
<th>Transition theme</th>
<th>Suggestion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling invested in the transition process</td>
<td>Be told about the possibility of moving as a first step; Discuss the pros n cons of moving; tour the new place; have a say in the decision</td>
</tr>
<tr>
<td>Transitioning to more or less structure</td>
<td>Staff should sit down and explain the rules and why things are the way they are</td>
</tr>
<tr>
<td>Finding a balance between support and independence</td>
<td>Staff name tags would make it easier to know who to ask for help. Have times for staff to get to know residents and vice versa.</td>
</tr>
<tr>
<td>Defining a new purpose in life</td>
<td>Counsellors should meet with residents to talk and to give help. All residents should be in exercise class to use different muscles and build them up. Help people work.</td>
</tr>
<tr>
<td>Engaging in hobbies and interests</td>
<td>Do more in the community (e.g. choral singing, museums). Reduce empty time, provide more to do.</td>
</tr>
<tr>
<td>Experiencing faith, fulfillment, and acceptance</td>
<td>It takes a while to adjust, and everyone needs to be patient. Don’t give up.</td>
</tr>
</tbody>
</table>

O’Neil-Pirozzi, Lorenz, Samayoa, Demore-Taber, 2015
Translation to practice

- Study findings (survivor suggestions and interests) have contributed to development of wellness programming to support physical, cognitive, and social fitness for people with disabilities from moderate to severe brain injury living in the community.
  - Programming is now offered 40 weeks per year (in four 10-week sessions).
  - Physical, health, and satisfaction with life outcomes are being tracked.
  - Qualitative interview studies to understand survivor, staff, and family member perspectives on wellness programming and their suggestions for improvement have continued.
  - Recreational funding from the Massachusetts Rehabilitation Commission, assistance from student interns, subsidized contributions from participants, and philanthropic donations all contribute to the sustained capacity to provide and expand wellness programming to date.

O’Neil-Pirozzi, Lorenz, Samayoa, Demore-Taber, 2015
Now let’s look at a participatory arts-based study

- Eight members of a brain injury support group in Framingham volunteered to participate in a 10-week photovoice project.
- They were aged 40 to 60 years old and had been injured between 4 and 35 years prior.
- 6 had TBI, 1 had a brain tumor, and 1 had a stroke; none were working at the start of the study; all had long-term disabilities from their brain injuries.
- The study was a voluntary activity of a Brain Injury Association of Massachusetts’ support group, with recreational funding from the Massachusetts Rehabilitation Commission.
Participants represented their lives, point of view, and experience using photographs and text in a participatory group process called photovoice.\textsuperscript{21,22}

Three facilitators: an academic researcher and two people with brain injury

\textsuperscript{21– Lorenz & Kolb, 2009; 22– Wang & Burris, 1997}
The final exhibit had 9 themes, with 4 or more photos each.

Participants developed themes in collaboration with facilitators.

Photos and captions described the long-term nature of brain injury healing.

Acceptance was an important if elusive goal.

Participants and facilitators did extensive outreach.

Now let's look at some photos...

23- Lorenz & Webster, 2007; 24- Lorenz, 2010
Ethical Issues and Photovoice

• Using photography at the community level means addressing potential ethical issues in the planning stage and during implementation:
  • Work through/with existing groups, such as support groups, to facilitate recruitment and sustain momentum for outreach, translation of findings, and participant leadership opportunities long-term
  • Provide brief ethics training on being a community researcher and taking photographs – e.g. asking permission to take someone’s photo and use it in a public setting. Provide tools to support and record permission.
  • If working with individuals from minority groups, consider establishing an ethics committee of community representatives (e.g., elders) to ensure community comfort with study approaches, findings, and outreach activities/products²⁵

²⁵- Castleden H, Garvin T, Nation H., 2008
Ethical Issues and Photovoice continued

• Provide multiple opportunities to take photos, discuss experiences, and write captions. Understanding grows over time.
• Provide opportunities for one-on-one support to take photos and write captions. Encourage collaboration with Occupational Therapy graduate students and other student interns to support participation.
• Consider conducting photo interviews with participants after the project is completed, to hear any additional insights they may have.
• Involve participants in the analysis of your data (photos and captions) and outreach and do a member check\textsuperscript{26}

Photovoice projects around the world – and including through the Veterans Health Administration – have provided opportunities for people with disabilities to have their voices heard...

26- Lorenz & Paiewonsky, 2015
Physical Health

• What is the photographer’s perspective on these steps?
Physical Health

Thank God there’s a handrail
This is the front steps of where I’m living. There are three stone steps. It makes it difficult to walk up them. Thank God there’s a handrail.

People commented that for someone with physical challenges after brain injury, these steps can seem like a mountain.
Cognitive Health

What does the photographer want to convey?
Cognitive Health

Individuals with chronic ABI have limited access to rehabilitation – yet may be motivated to make the effort to maintain or improve function – on their own and with others.

Reconnect old pathways
Using crossword and word searchers to reconnect pathways in the brain.
Social Health

What does the photographer want to convey?
As we each traverse our own paths toward the image of the person we’d like to be, why not share our experiences with others? We can attempt to help raise public awareness of TBI as an ever-recurring human condition. We can try to help direct newer victims or their families toward available resources. In the process of sharing we may find reciprocal support for our own personal journeys.

Advocacy can be a meaningful activity after severe brain injury. How use this motivation to help support informed decision-making?
Video testimony...

Massachusetts Health Policy Forums usually include a 10-minute presentation by someone from the community. For the severe ABI forum, a video of survivor testimony was prepared instead:

- 12 people recommended by stakeholders interviewed for the issue brief were contacted about participating
- 8 people accepted the invitation and were sent the interview guide, so they could prepare what they wanted to say
- 5 people were filmed - on the same day, in the same location. 3 were unable to participate due to health or other issues.
- Testimony from each person filmed was included in the final video. All attended the Forum as well.

See the video at: [http://masshealthpolicyforum.brandeis.edu/forums/forum-pages/Severe%20Brain%20Injury%20.html](http://masshealthpolicyforum.brandeis.edu/forums/forum-pages/Severe%20Brain%20Injury%20.html)
In conclusion...

• Access to rehabilitation services at all stages of the continuum of care for severe brain injury is limited
• People with chronic moderate to severe brain injury living in the community can maintain and improve function
• The Evidence Hierarchy challenges development of evidence for informed decision-making for the severe brain injury population
• Practice-based evidence using standardized measures can support informed decision-making for this population. Include self-report as well as observed measures
• Including the perspectives of individuals with severe brain injuries collected using structured qualitative and participatory approaches is ethical decision-making practice
In conclusion...

- Massachusetts has been a national leader in the prevention and treatment of brain injury
- For example, Massachusetts is home to the foundation that became the Brain Injury Association of America
- The recent brain injury epidemiology carried out by the Massachusetts Department of Public Health and the Massachusetts Rehabilitation Commission is the first in the nation (as far as we know!) to examine not just TBI but the broader umbrella of ABI and their associated hospital stays and emergency department (ED) visits
- Gaps and disparities in services and information related to the continuum of care for severe brain injury remain
Thank you...

To you, for all you do to support function and quality of life for individuals with severe brain injury in your states and

To NASHIA for its ongoing, important work and

To the people and organizations that have contributed to the information presented here:

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