ISSUE BRIEF

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A Policy Analysis of Access to Post-Acute Rehabilitation Services for People with Acquired Brain Injury in Massachusetts and Beyond

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EXECUTIVE SUMMARY

Acquired brain injuries (ABI) – from trauma, stroke, infectious diseases, and brain tumors – are a serious public health issue affecting individuals, families, and communities. Advances in emergency medicine and improved acute care have significantly increased the likelihood of surviving a severe brain injury. However, the American health care system comes up short on providing appropriate access to post-acute rehabilitation leading to higher health care costs and reduced quality of life.

The lack of access to post-acute rehabilitation after a severe brain injury limits opportunities for patients to return to work and have better function and quality of life, increases family caregiving and economic burdens, and strains public liabilities for long-term care. Post-acute rehabilitation is interdisciplinary – supporting physical, cognitive, and social skills – and intensive. Access can be limited by lack of insurance, lack of coverage or limits to coverage for rehabilitation, lack of services available close to home, and lack of understanding of the beneficial impact of rehabilitation access. Providing appropriate post-acute rehabilitation services benefits physical, cognitive, and emotional/behavioral function, return to work, independence, participation in the community. Access also reduces the total cost of their health care, particularly long-term care costs. Existing data, information, expert opinion, and patient experience support the effectiveness of rehabilitation services at improving function after severe brain injury.

We conducted an analysis of studies published in the last 20 years exploring outcomes and cost-effectiveness from access to rehabilitation after a serious acquired brain injury requiring hospitalization. Our analysis shows that on average the cost of rehabilitation is offset (recouped) in between 1 and 5 years (See Table 1). Patients with more severe injuries and higher dependency offset the cost of rehabilitation in a shorter time period. Average savings in a range of studies were estimated at $1.67 million per patient over their lifetime. These savings do not include a decrease in social costs gained from less reliance on other government programs, improved return to work rates, and benefits to families and society through easing of family caregiving and economic burdens.

We use the terms "post-acute rehabilitation" and "intensive, multidisciplinary rehabilitation" throughout this paper to refer to what is often called neurorehabilitation (see Table 2). Post-acute rehabilitation is 'transitional', to help the injured individual transition to community re-entry and encourage the brain to recover and compensate for the damage incurred. It aims to improve function and help patients return to work, live more independently, and reintegrate into the community. For people with more serious injuries and resulting disability, gains in ability to do more for oneself (independence) are highly desired (O'Neil-Pirozzi, Lorenz, Demore-Taber, & Samayoa, 2015a) and can reduce the level of care required in assisted living facilities and at home. Gains in independence from access to post-acute rehabilitation were maintained in a follow-up, multi-center study of brain injury rehabilitation patients with complex needs (Worthington, Matthews, Melia, & Oddy, 2006a) and in other studies of post-acute rehabilitation outcomes after severe brain injury (Griesbach, Kreber, Harrington, & Ashley, 2015; Oddy & da Silva Ramos, 2013; Turner-Stokes, 2007). While early and continuous access to rehabilitation has the best results, access to rehabilitation even many years after a severe brain injury can also lead to maintenance of function gains, improved function, and reduced disability.

In 2010, severe traumatic brain injury (TBI) consumed 90% of all TBI-related medical expenditures in the U.S. alone. In Massachusetts, people with more serious brain injuries from stroke and TBI resulting in disability are likely to be reliant on public funding for all or some of their health and long-term care within two years of their injury due to becoming impoverished after their medical care and loss of work. The most common necessary care includes assistance with activities of daily living (ADLs) or daily life functioning, supported community-based services, subsidized living expenses, healthcare and, with increasing age or limited opportunities for community placement, nursing home care.

The continuum of care for severe acquired brain injury includes prevention, hospital-based services, continued medical care and rehabilitation, and community-based programs. Traditionally the emphasis has been on acute medical care with less attention on post-acute rehabilitation and community-based care, where the majority of survivor time – and public costs – are spent. Investments in increased access to post-acute rehabilitation soon after injury will reduce the need for nursing home care and allow more people to live in the community with a better quality of life. Severe brain injury, in particular, represents a critical opportunity to realize cost savings from improved access to post-acute rehabilitation services.

Our policy recommendations are in five areas:

- <u>Increase access to post-acute rehabilitation.</u> Increase access to post-acute rehabilitation, especially for people who have sustained a severe brain injury, whether from TBI, stroke or other ABI, where the greatest cost-savings are observed. Ideally, ensure access within 12 months of injury, when capacity for improvement is greatest, and provide access in a continuous chain, without interruptions. Provide access to rehabilitation also at the chronic stage of injury. One approach to increase access to post-acute rehabilitation is to mandate rehabilitation coverage through state legislation, as has been done in Texas since 1995 (Texas Legislature, 2017). Another would be to provide these services universally through federally funded insurance programs: Medicaid and Medicare.
- <u>Maintain and strengthen prevention focus.</u> Maintain and enhance ongoing brain injury prevention activities. Examples are: seat belt and helmet usage; distracted, drunken, and drugged driving; pedestrian and home safety practices; and sports concussion. Further activities could be undertaken to support work by the Massachusetts Department of Public Health on fall prevention for seniors. Consider implementing new prevention measures similar to those in Victoria, Australia to reduce transport accidents through public education campaigns and investments in road infrastructure making high-risk roads and intersections safer for cyclists and pedestrians as well as vehicles (Transport Accident Commission (TAC), 2019).
- <u>Increase access to case management from injury to end-of-life.</u> Through state-sanctioned entities, provide independent case management (not tied to payers or providers) for as long as needed, for all patients at all income levels, as described by others (University of Missouri-Columbia, 2006). Case management, or a case manager assigned to support an injured individual to navigate the "ocean" of systems, providers, and payers and access appropriate services, can align patient and provider interests, increase timely access to services that support recovery (Health Affairs, 2012), and increase return-to-work, independence, and community participation, reduce lost annual wages, and increase annual earnings (Trexler et al., 2014; Reid et al., 2011). Provide case management to support access to medical care and social services and supports such as housing, day programming, and vocational rehabilitation (Malec, 2001; L.E. Trexler, Waldman, & Parrott, 2014). For persons with disabilities from severe brain injury, provide life-long case management, as has been done in Missouri and Victoria, Australia (Transport Accident Commission (TAC), 2019; University of Missouri-Columbia, 2006).

- Support return to work. Continue to support vocational rehabilitation activities and consider expansion based on experiences with the return-to-work program in Indiana. Entitled “Resource Facilitation,” the Indiana program has realized substantial cost savings to that state through reduced annual lost wages and increased annual earnings (Reid, McGeary, & Hicks, 2011; L.E. Trexler et al., 2014). Research supported by a collaboration of providers, state agencies, advocacy groups, and federal and local funders found that such interventions improve long-term function, increase earnings, and save money.
- Systematically collect outcome and cost data over the short- and long-term for people who sustain a serious brain injury. Such data are needed to support decision-making by policymakers. Establishing a brain injury or trauma registry is one approach to understanding outcomes over time. As of 2016, 24 U.S. states had established TBI and trauma registries (National Association of State Head Injury Administrators (NASHIA), 2016). Systematically collecting outcomes data at admission and discharge as well as over the long-term will allow the state to compare outcomes and savings across U.S. states with brain injury and trauma registries and will increase understanding of any rehabilitation savings that result from access. Incorporating cost-tracking elements as well as demographic and functional measures into any database established is highly recommended.

I. Introduction

After examining the scope of the problem, the paper provides a framework for understanding the continuum of care for severe brain injury and an analysis of research on the cost-effectiveness of post-acute care rehabilitation. An analysis of studies that examine potential savings from access to post-acute rehabilitation services concludes that increased access to intensive, multi-disciplinary rehabilitation services, including cognitive rehabilitation therapy, at any time after a serious brain injury, leads to significant health improvements and costs savings. As noted in a report by the (Center for Health Information and Analysis, 2016) "…researchers have concluded that CRT (cognitive rehabilitation therapy) in general is effective when managed by specialized and experienced multi-disciplinary teams, and evidence-based guidelines and recommendations exist regarding its provision."

What is post-acute rehabilitation after a brain injury?

Post-acute rehabilitation is interdisciplinary – supporting physical, cognitive, and social skills – and intensive, requiring patient participation for up to 5 to 6 hours per day, 5 to 6 days per week. Post-acute rehabilitation is considered 'transitional', to help the injured individual transition to community re-entry and encourage the brain to recover and compensate for the damage incurred. It is geared toward improving function and helping patients return to work, live more independently, and reintegrate into the community. While early intervention (starting 3 to 12 months post-injury) is recognized as likely to provide the greatest benefit (Gordon, Cantor, Ashman, & Brown, 2006), rehabilitation access in the chronic stage of injury yields functional benefits as well (Cicerone et al., 2008; Lewis & Horn, 2015; Oddy & da Silva Ramos, 2013). Although cognitive rehabilitation in particular is frequently denied after brain injury (Katz et al., 2006), social and vocational gains may be dependent on cognitive attainments first (Cicerone et al., 2008; Fortune et al., 2015). A greater understanding of the influence of cognitive status on healthcare utilization and outcomes is needed (Vangel et al., 2005).

The reduction in health care spending from access to rehabilitation comes from two main sources: (1) reduced long-term care expenditures (rehabilitation savings) due to improved function and reduced need for assistance with activities of daily living (ADLs) or daily life functioning in both the short and long-term, and 2) reduced length of stay in post-acute rehabilitation (cost-efficiency) (Lewis et al., 2017; Oberholzer & Muri, 2019) due to greater functional improvements (e.g., eat, dress, and manage behaviors), made sooner with early, continuous access. Our key policy recommendation is to increase access to post-acute rehabilitation within 3 to 12 months of a severe brain injury. In addition, we recommend the following: continue to invest in prevention; connect patients and families with case management services that begin with injury and continue across levels of care; support return to work through increased access to vocational services; and systematically collect demographic, treatment, outcomes and cost data for Massachusetts residents who sustain a brain injury.

Intensive interdisciplinary post-acute brain injury rehabilitation has been shown to result in statistically and clinically significant gains following brain injury, in a large cohort of adults in 23 facilities across the U.S. (Malec & Kean, 2016; Malec, Kean, & Monahan, 2017). Similar gains were found for outpatient or community-based rehabilitation.

Access to rehabilitation after a brain injury reduces family caregiving and economic burdens and public costs for ongoing care. When insurance will not pay for the potential for functional improvement after a moderate-to-severe acquired brain injury, the state picks up the cost of ongoing care.

In this paper, we use the terms 'cost efficiency' and 'rehabilitation savings' interchangeably as we review what is known about value for money in intensive, multi-disciplinary, post-acute rehabilitation services, particularly for people with more severe or serious acquired brain injuries from traumatic brain injury (TBI), stroke, brain tumor, and metabolic and infectious brain injuries. Our analysis of eight studies published in the last 20 years (see Table 1) shows that savings from access to rehabilitation in the studies for people with severe injuries ranged from $1.28 to $2.29 million with an average of $1.67 million in savings per patient over their lifetime. Cost-efficiency amounts (a.k.a. rehabilitation savings) begin to accrue once the direct cost of post-acute rehabilitation care has been "paid for" by savings from, for example, living in the community instead of in a nursing home. See appendix A for a glossary of economic analysis terms.

Economic evaluation plays an increasing role in prioritizing the implementation of preventive actions and treatment of TBI. Policy- and decision-makers often require information about the effectiveness of an intervention to assess whether an intervention is cost-effective (Lu et al., 2013).

In this paper as in Lorenz & Katz (2015), the term "severe brain injury" refers to "severe acquired brain injury," or any injury to the brain that occurs after birth, disrupts brain function, and has serious consequences (functional, cognitive, emotional/behavioral) for the injured individual. For our paper as for the Massachusetts Department of Health's epidemiology report of acquired brain injury in Massachusetts (Hackman et al., 2014), acquired brain injuries include traumatic brain injury, stroke, disruption of brain function due to infectious disease or metabolic disorders, and brain tumor. Our definition does not include neurodegenerative disorders such as Alzheimer's Disease, Multiple Sclerosis, and Parkinson's Disease, which do not usually result in an acute hospital admission. Clinically, severe TBI is defined as resulting in loss of consciousness for 6 to 24 hours or more (Corrigan, Selassie, & Orman, 2010). Yet even a "mild" TBI, which by definition involves loss of consciousness of 30 minutes or less, a Glasgow Coma Scale (GCS) of 13-15 within 30 minutes of the injury, and post-injury amnesia for 24 hours or less (American Congress of Rehabilitation Medicine (ACRM), 1993; Centers for Disease Control and Prevention (CDC), 2015), can result in long-term functional impairments (Corrigan et al., 2010) for an estimated 15 to

30% of people (Cajigal, 2007; Lewine et al., 2007). In the chronic phase of acquired brain injury from any cause, lifelong disabilities may affect the ability to work, perform activities of daily living (dressing, paying bills), participate in community life, and/or fulfill a family role.

> *Recent evidence suggests that, despite their substantially longer lengths of stay, the increased cost of rehabilitation is readily offset by long-term savings in the cost of care so that in-patient rehabilitation is in fact highly cost-efficient in the most dependent [i.e., seriously injured] group of patients* (Turner-Stokes, 2007).

II. Problem and Prevalence of Acquired Brain Injury

Acquired brain injury, from traumatic events, strokes, infectious diseases, and brain tumors, is a major public health problem. Advances in emergency medical care and neurosurgery mean that more people are surviving severe brain injuries (Jacobsson, Westerberg, & Lexell, 2010; L.E. Trexler et al., 2014). As a result, in the U.S. alone an estimated 10 million Americans are living with disabilities from TBI and stroke (Centers for Disease Control and Prevention, 2015; Centers for Disease Control and Prevention (CDC), 2015; Langlois, Rutland-Brown, & Wald, 2006). A major influence on the current rate of disability (37-40%) after hospitalization for brain injury is the lack of access to appropriate post-acute rehabilitation, despite evidence that intensive rehabilitation intervention (5-6 hours/day, 5-6 days per week) after hospitalization for brain injury can lead to earlier – and sustained – functional gains (Turner-Stokes, Pick, Nair, Disler, & Wade, 2015; Worthington et al., 2006a).

As reported in our 2015 issue brief (Lorenz, L., & Katz) acquired brain injury affects all categories of MA residents, from young to old, men and women, and people living in all regions of the state (Hackman et al., 2014). Estimates of the number of people living with disabilities from brain injury in MA are between 68,000 and 112,000, but could be substantially undercounted (Centers for Disease Control and Prevention (CDC), 2015; Dams-O'Connor et al., 2014; Langlois et al., 2006; United States Census Bureau, 2015). Severe TBI is more likely to result in hospitalization and in symptoms that persist, leading to partial or permanent disability (Centers for Disease Control and Prevention (CDC), 2015); an estimated 37% of people with severe TBI will need long-term cognitive and functional supports (Whiteneck et al., 2004).

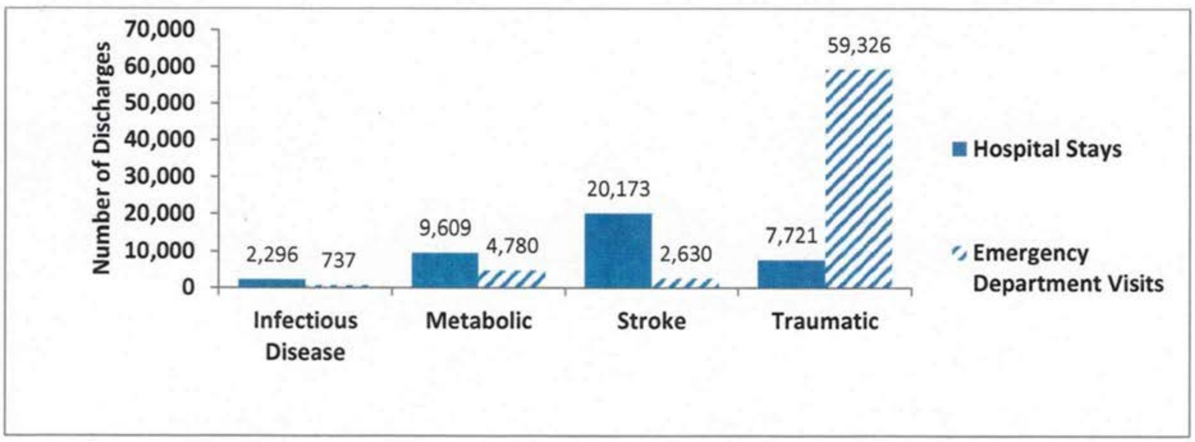
> *Acquired brain injury affects all categories of MA residents, from young to old, men and women, and people living in all regions of the state* (Hackman et al., 2014).

Between 2008 and 2010 in MA, there was an annual average of 59,326 emergency department visits for TBI, and 2,630 for stroke, 4,780 for metabolic disorders, and 737 for infectious diseases affecting the central nervous system (brain and spinal cord) (Hackman et al., 2014). As for hospital stays, the annual average was 7,721 stays for TBI, 20,173 for stroke, 9,609 for metabolic disorders, and 2,296 for infectious diseases affecting the central nervous system (Hackman et al., 2014). This number may under-represent injuries among children, adolescents, and veterans, who may not report a TBI (Centers for Disease

Control and Prevention (CDC), 2015). Also between 2008 and 2010, an annual average of 1,272 primary brain tumors were newly diagnosed in MA residents (Hackman et al., 2014). The leading causes of brain injuries in MA are traumatic brain injury (59,326) and stroke (20,173) (see Figure 1). On average 21 Massachusetts residents are discharged after a hospital stay for TBI every day and 55 residents every day after a hospital stay for stroke. (Centers for Disease Control and Prevention (CDC), 2015; Massachusetts Department of Public Health, 2013)

Many people in MA (and the U.S.) hospitalized for a brain injury, particularly a TBI, are not getting access to in-patient post-acute rehabilitation (Hackman et al., 2014; CDC, 2015a) or to case management or resource facilitation support to help them access needed services and, ideally, return to work (Health Affairs, 2012; L.E. Trexler et al., 2014). For many people in MA (and the U.S.) who are hospitalized for an ABI (TBI in particular), the patient survives the brain injury and is discharged directly to home (Hackman et al., 2014) without services or with in-home services (i.e., IV therapy services) (CDC, 2015a).

Figure 1. 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.

Brain injuries are a major contributor to disability in the U.S. – an estimated 1.1% to 2% of the US population experiences lingering effects of TBI (Thurman, Alverson, Dunn, Guerrero, & Sniezek, 1999; Zaloshnja, Miller, Langlois, & Selassie, 2008). Stroke has an impact on functional limitations second only to back pain and arthritis (Ma, Chan, & Carruthers, 2014), and 2.7% to 2.8% of the US population has disabilities from stroke (Go et al., 2013; Writing Group et al., 2017). Thus 40% of the estimated 12.1% of the U.S. population living with disabilities has been affected by TBI or stroke (Ma et al., 2014). Long-term disability is more common after moderate-to-severe brain injuries requiring hospitalization, or about 20% of all brain injuries diagnosed in hospital settings. An estimated 37% to 40% of people with severe injuries whose lives are saved due to acute medical care can be expected to have long-term disability (Whiteneck et al., 2004). A brain injury, particularly a severe one, shortens life expectancy, on average; a study of longitudinal records from the Traumatic Brain Injury Model Systems (TBIMS) found that a severe brain injury reduces life expectancy by an average of 9 years (Harrison-Felix et al., 2015). A second study of a TBIMS cohort and a California Department of Developmental Services cohort found that the average life expectancy for a man injured at age 40 (severe TBI) with mobility issues was 23 years, or 15 years shorter than that of an uninjured 40-year old U.S. male (Brooks, Shavelle, Strauss, Hammond, & Harrison-Felix, 2015). In other words, after a severe TBI, a man injured at age 40 years could be expected to live 23 to 32 more years, depending on the level of disability (Brooks et al., 2015). A severe brain injury no longer means an "end" to life for many, but it does mean life changes.

> *For many people in MA (and the U.S.) who are hospitalized for an ABI (TBI in particular), the patient survives the brain injury and is discharged directly to home (Hackman et al., 2014) without services or with in-home services (i.e., IV therapy services)* (CDC, 2014; Lorenz & Katz, 2015).

A major impediment to post-acute rehabilitation access after a severe brain injury is a lack of access to appropriate post-acute care rehabilitation services (World Health Organisation, 2017). Some of these services are not covered by insurance; access may be denied even when included in a policy; people cannot afford to pay for them on their own; and programs cannot afford to operate when services are not covered. Access can be limited by lack of insurance, lack of coverage or limits to coverage for rehabilitation, lack of services available close to home, and lack of understanding of the beneficial impact of rehabilitation access. Such access benefits physical, cognitive, and emotional/behavioral function, return to work, independence, and participation in the community, and reduces long-term costs. Having services covered is no guarantee of access, however, as seen in racial and ethnic disparities in access to rehabilitation services after brain injury (Meagher, Beadles, Doorey, & Charles, 2015).

Indirect Costs and Family Burden

Indirect costs incurred after a brain injury relate to lost or reduced ability to work. For each person who has a more severe brain injury, potentially two wage earners are lost: the injured individual and a caregiver, increasing the societal (taxpayer) toll (Centers for Disease Control and Prevention (CDC), 2015). Indirect costs related to loss of productivity and family burden due to brain injury can also be substantial and reducing them is a meaningful area for policy intervention. Lack of access to services for cognitive and behavioral rehabilitation in particular is known to have a negative impact on family caregivers (Jackson, McCrone, Mosweu, Siegert, & Turner-Stokes, 2014). Indirect costs and the economic impact on families and – as a result – the related impact on state funding is often ignored in economic evaluations of the impact of brain injuries (Alali et al., 2015). The problem of indirect costs and brain injury may increase over time as the shift accelerates from health to social care for the injured individual, increasing the family's burden (Jackson et al., 2014). Rehabilitation that improves or maintains function and reduces disability and dependence after a serious brain injury can help to reduce indirect costs and family burden (Turner-Stokes, 2007) and reduce the long-term burden on tax payers.

Brain injury is complex with cognitive, physical, and emotional/behavioral consequences, all of which need to be addressed to promote functional improvement and return to work. Access to cognitive rehabilitation in particular is disallowed by insurers or excluded from insurance policy coverage (Katz, Ashley, O'Shanick, & Connors, 2006), in part due to limited use of randomized controlled trials (RCTs) in rehabilitation, due to the ethical issues related to denying treatment that is known to be effective in order to create a control group, a requirement of RCT studies (See Appendix B, for further discussion of this issue.) However, there is sufficient evidence available to know that post-acute rehabilitation is both effective and cost-efficient.

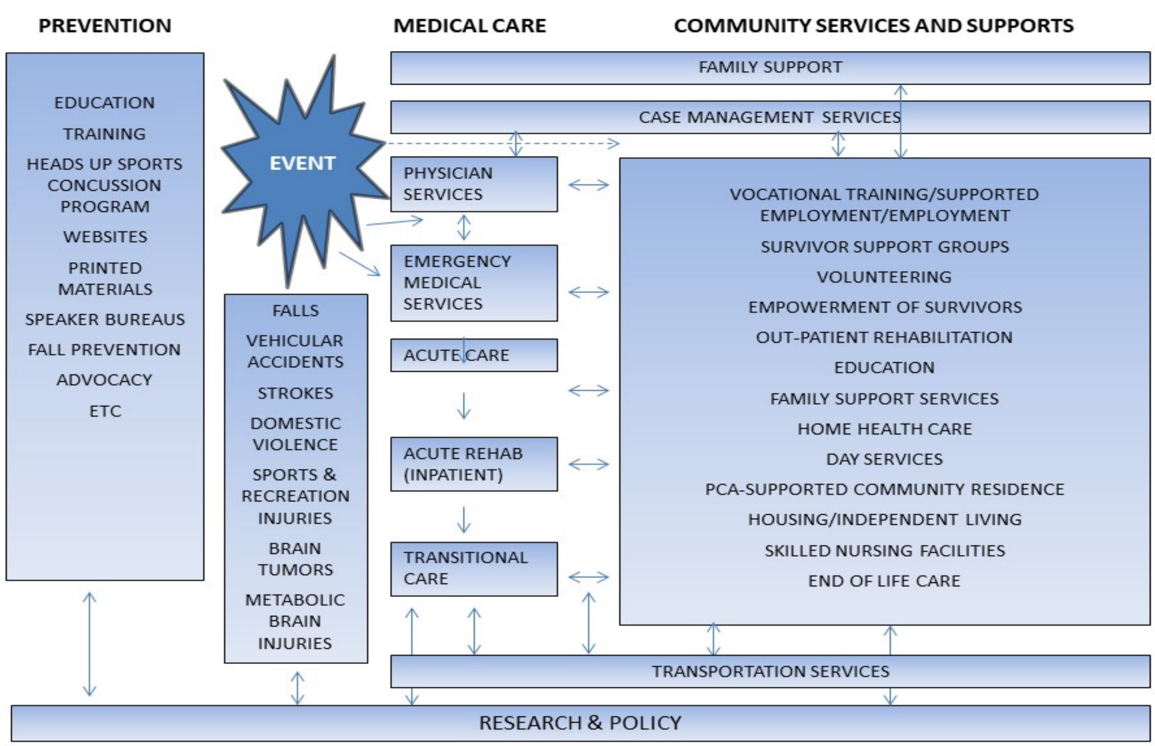
There is strong and growing evidence of interdisciplinary rehabilitation's effectiveness after severe brain injury that is not based on RCT studies (Turner-Stokes et al., 2015).

III. Framework: The Continuum of Care for Severe Acquired Brain

The continuum of care for severe acquired brain injury includes prevention, hospital-based services, post-hospital services, and community-based programs. Traditionally the emphasis has been on acute medical care with less attention on post-acute rehabilitation and community-based care, where the majority of survivor time – and public costs – are spent. Our depiction of the continuum of care for severe brain injury (see Figure 2) illustrates the fluid nature of the continuum as people with severe brain injuries, in particular, access to medical and social care throughout their lives.

Figure 2 also illustrates the role of families and their caregiving. Family support is often vital for facilitating access to needed services, supporting recovery, maintaining function, and improving quality of life for people with severe brain injury at all stages of the continuum. The economic impact on families and related impact on state funding is often ignored in economic evaluations of brain injury.

Figure 2: The Continuum of Care for severe acquired brain Injury in Massachusetts



Sources: Adapted from Lorenz & Katz (2015) and NASHIA (2005) with permission

The Medical Care phase after a brain injury is often covered in large part by an individual or families' health insurance. Delays or interruptions in access to post-acute rehabilitation services can mean lower gains in function (physical, cognitive, emotional/behavioral), quality of life, independence, and vocation (Andelic et al., 2014). Within six months of their injury, over 30% of residents in Massachusetts and other states who have survived a severe brain injury will have lost their private or employer-based health insurance (Lin, Canner, & Schneider, 2016). Those with more severe injuries are more likely to file for

> *Within six months of their injury, over 30% of residents in Massachusetts and other states who have survived a severe brain injury will have lost their private or employer-based health insurance (Lin et al., 2016).*

bankruptcy "with substantial levels of medical debt soon after the injury," including those insured by Medicaid at the time of their injury (Relyea-Chew et al., 2009). Those who have not qualified for Medicaid may be living at home with family support, which can include 24/7 care.

A Brief Look at Massachusetts

Following the 2008 settlement of a lawsuit (Hutchinson v. Patrick) brought by a woman who had been languishing in a nursing home in Massachusetts despite her potential to live less expensively and have better quality of life in the community with appropriate services and supports, Massachusetts established four new home and community based services (HCBS) waiver programs that move people with brain injury into quality community living (two HCBS waivers dedicated to people with ABI and two that serve disabled adults including people with ABI). At the time of the Hutchinson Settlement, an estimated 2,000 or more Massachusetts residents, including adolescents and young people[AB1] , were living in skilled nursing facilities in the state due to lack of independent community living opportunities for people who with severe brain injuries, and could benefit from placements in community residences with 24-hour staffing (group homes) and independent living environments (Brain Injury Association of Massachusetts (BIAMA), 2008). Since these waivers began operation they have moved over 1000 people from more restrictive (nursing homes and chronic/rehabilitation hospitals) to less restrictive (group homes and independent living environments) settings and provided access to rehabilitation and other services and supports intended to support community re-integration for people with disabilities from brain injury. To be eligible for services under the brain injury waivers an individual must apply while they are still living in a facility and have been living in a nursing home or a chronic disease/rehabilitation hospital for at least 90 days. Many are in the chronic phase of their injuries, represented in Figure 2 by Community Services and Supports.

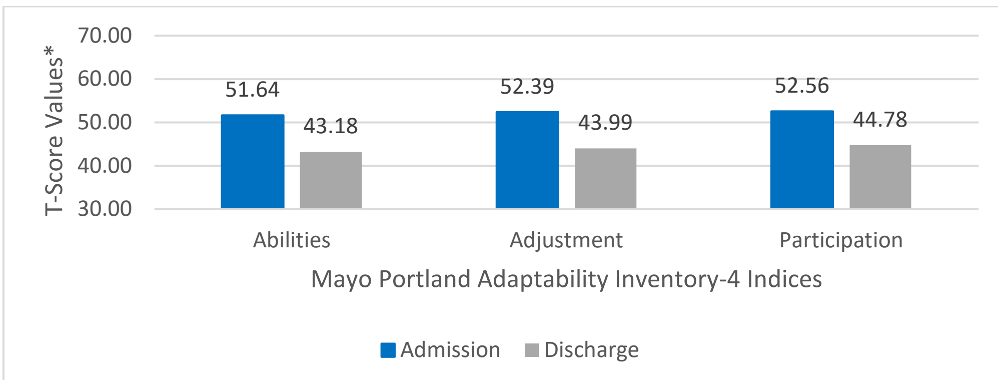
Data from a rehabilitation program that provides care to patients with TBI and stroke in Massachusetts show that also at the chronic level, improvements in abilities can be observed, although gains are greater and length of stay is lower for patients who begin treatment within 12 months of their injury (Figure 3).

> *Massachusetts patients admitted more than 1 year post-injury required a 46% longer stay (208 days v. 113 days) than those admitted within one year of injury.* (Provider program data for Massachusetts neurorehabilitation patients, 2019)

As seen in Figure 3, individuals admitted earlier were able to improve to a greater extent than those admitted later, as has been found with other studies (Lewis & Horn, 2015; Lewis et al., 2017; Oddy & da Silva Ramos, 2013; Turner-Stokes, 2007; Worthington et al., 2006a). Cost savings were observed in length of stay: Massachusetts patients admitted more than 1-year post-injury required a 46% longer stay (269 days v. 119 days) compared to those admitted within 1- year of injury. The cost-savings observed are similar to those from an analysis of the provider's national rehabilitation population: patients admitted between 1 and 4 years after their injury had a 44% increase in their length of stay (Lewis et al., 2017).

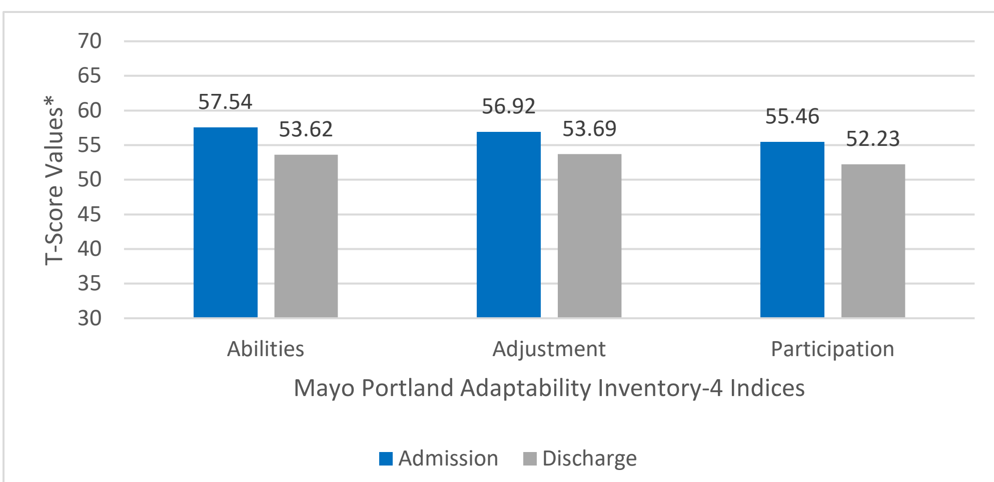
Figure 3. Outcomes in Massachusetts for neurorehabilitation patients (N=85) for patients with acquired brain injury diagnosis (traumatic brain injury and stroke) (2011-2019) using the Mayo-Portland Adaptability Inventory-4 Indices* (MPAI-4) (2019)

A. Outcomes for patients[1] having early access to inter-disciplinary rehabilitation (a.k.a neurorehabilitation) after acquired brain injury (traumatic brain injury and stroke) (n=72)



[1]Chronicity: 1-12 months from time of injury; Length of Stay: 119 days;
Average Age: 48 years; Average Change: 8 points

B. Outcomes for patients[2] having access to inter-disciplinary rehabilitation (a.k.a. neurorehabilitation) in the chronic phase of acquired brain injury (traumatic brain injury and stroke) (n=13)



[2]Chronicity: 12-48+ months; Length of Stay: 269 days; Average Age: 51 years; Average Change: 3 points *Note: Lower T-score values indicate reduction in disability; Mild impairment = 40; Moderate impairment = 50; Severe impairment = 60.* Source: NeuroRestorative

IV. Research on Post-Acute Rehabilitation

With rehabilitation, even individuals who have sustained severe brain injury can progress to less dependent placements in the community and maintain higher levels of independence with fewer hours of care support (Wood, McCrea, Wood, & Merriman, 1999). Access to rehabilitation after brain injury can also reap long-term economic benefits (Oddy & da Silva Ramos, 2013; Turner-Stokes, Williams, Bill, Bassett, & Sephton, 2016; Wood et al., 1999; Worthington et al., 2006a) and reduce the public burden of more severe brain injury. Among neurological conditions (dementia, bipolar disorder, multiple sclerosis, muscular dystrophy, ABI, and cerebral palsy), severe brain injury is estimated to incur greater economic costs than all other conditions (The Victoria Neurotrauma Initiative, 2009), and contribute substantially to long-term disability in the U.S. and globally (Writing Group et al., 2017). This section reviews evidence of cost-savings from access to rehabilitation, rehabilitation outcomes, cost-efficiency of rehabilitation access, serious brain injuries and public funding, and areas that can benefit from policy change.

> *A cost-efficient service is one that is 'effective without wasting time or effort or expense. … The cost of providing rehabilitation is largely determined by time (length of stay) and effort (intensity) on the part of the rehabilitation team* (Turner-Stokes, 2007, p. 1015**).**

A. Evidence of Cost-Savings from Access to Rehabilitation

We conducted an analysis of studies published in the last 20 years exploring outcomes and cost-effectiveness from access to rehabilitation after acquired brain injury that shows on average the cost of rehabilitation is offset (recouped) in between 14 months and 5 years (See Table 1). Patients with higher dependency on admission offset the cost of rehabilitation in a shorter time period; those with less dependency may take 2 to 5 years to offset rehabilitation costs and realize rehabilitation savings. Average lifetime savings identified in the six studies that examined cost savings from access to post-acute, intensive, multi-disciplinary rehabilitation services after a severe brain injury and were admitted within 1 year of injury ranged from $1.28M to $2.27M per patient, with an average of $1.67M in lifetime cost savings.

Study inclusion criteria were: a sample of patients with any type of acquired brain injury (e.g., TBI, stroke, brain tumor, encephalitis, meningitis, and anoxia) including a mixed population sample; participation in-patient, intensive, multi-disciplinary post-acute rehabilitation (also called specialist rehabilitation) at the post-acute level, including community-based intensive, multi-disciplinary rehabilitation; identified functional outcomes, in particular level of supervision or disability at admission and at discharge; and identified cost-savings. All but the earliest study (1999) measured outcomes using standardized measures such as the Supervision Rating Scale, the Disability Rating Scale, the Community Integration Questionnaire, and/or the Mayo-Portland Adaptability Inventory-4. All but one study identified the time to realize cost-savings vis-à-vis the investment in rehabilitation, or cost offset, which is the point at which rehabilitation costs are recouped by savings. Study exclusion criteria included: rehabilitation that was not intensive and multidisciplinary (e.g. vocational rehabilitation); cost-prediction based on a patient factor such as length of post-traumatic amnesia; and economic evaluations of the diagnosis and management of TBI or on health service utilization after TBI.

> *…treating TBI patients with early initiation of rehabilitation in a continuous chain of treatment is more cost-effective both in 1-year and 5-year perspectives compared with the strategy of a broken chain of treatment with a waiting period for TBI rehabilitation* (Andelic et al., 2014, p 1318).
>
> *Significant decreases in the cost projections, i.e., rehabilitation savings (RS), were found after rehabilitation for TBI. These RS were equivalent to those of patients with CVA [stroke]* (Griesbach et al., 2015, p. 704).

Table 1. Analysis of Rehabilitation Cost-Savings in Five Countries: Great Britain, Ireland, The Netherlands, Norway, and The United States (1999-2019) Studies are listed alphabetically by author.

Authors/ Journal/ Date	Location	Sample	LOS (Length of Stay)/ Rehab Type	Measure(s) Used	Outcomes	Costs Measured*	Cost savings* (admitted <1 year post-injury)**	Cost savings* (admitted >1 year post-injury)**	Cost Offset***	Notes
Andelic et al., *Journal of Neuro-trauma,* 2014 Andelic et al., *Journal of Neuro-trauma*, 2012	Norway	59 patients with sTBI who were followed for 5 years	54 days for continuous chain, 83 days for broken chain/ Medical and intensive in-patient rehab	DRS	Reduced dependency for group with continuous chain of rehab (starting in ICU) (Outcomes measured at 6 wk, 1 yr, and 5 yr follow-up)	Direct costs of post-acute rehab care (medical care provided)	At 5 years: $32,840 (NOK 200,000) [b] in rehab cost savings (only) for continuous chain access versus broken treatment	n/a (all patients admitted < 1 yr post-injury)	±1 year	Treatment trajectory of continuous chain rehab (started in ICU) had lower costs and better outcomes compared to a broken chain of rehab
Cooney & Carroll, *Clinical Medicine,* 2016	Ireland	62 patients w/ mixed ABI treated at National Rehab Hospital Brain Injury Program in 2011	79.9 days/ Specialist rehab to achieve > functional independence and participate in community	DRS	Significant reduction in dependency between admission and discharge	Direct costs of post-acute rehab care (medical care provided)	Per year: High-dependency group= $91,000/yr (€50,000)[c]; Mild-dependency group= $36,400/yr (€20,000)[c]	n/a (no patient admitted > 1 yr post-injury)	30 mo for the group as a whole; 15.6 mo for the high-dependency group	Looked at financial savings only; recommends analysis of QOL and vocational outcomes to better reflect value

Authors/ Journal/ Date	Location	Sample	LOS (Length of Stay)/ Rehab Type	Measure(s) Used	Outcomes	Costs Measured*	Cost savings* (admitted <1 year post-injury)**	Cost savings* (admitted >1 year post-injury)**	Cost Offset***	Notes
Griesbach et al., *Journal of Neurotrauma,* 2015	United States	38 patients (33 TBI, and 5 stroke)	Not specified; only patients with no rehab limits were included in study/ Compre-hensive post-acute rehab for 6 hrs per day	CIQ CNS DRS LSS MPAI-4 OSS	Significant improvement in outcome scales were observed after post-acute rehab; outcomes maintained at 1 yr follow-up	Comparison of projected lifecare costs based on admission and discharge reports	Lifetime care savings: (with admission at <3 mo and 3-12 mo): average TBI savings = $2.268M± $681M; average CVA savings = $1.232M ± $.416M	Lifetime care savings: Savings were negligible for patients admitted > 13 months post-injury	n/a (not studied)	Rehab Savings similar for TBI and CVA; projected life care costs were lower for TBI group
Oddy & Ramos, *Brain Injury,* 2013	Great Britain	196 sTBI and stroke with complex needs	Approx. 6 mo (average)/ Post-acute neuro-behavioral	MPAI-4 SRS	Significant shift to lower levels of supervision; maintained at 6 mo follow-up	Direct costs of post-acute rehab care (medical care provided)	Lifetime care savings: between $855,000 (£0.57M) and $1,695,000 (£1.13M)[a]	Lifetime care savings: between $285,000 and $1.29M (£0.19 to 0.86M)[a]	±1 year for early admittance group, and 4 to 5 years for late admittance	68% reduction in direct care costs

Authors/ Journal/ Date	Location	Sample	LOS (Length of Stay)/ Rehab Type	Measure(s) Used	Outcomes	Costs Measured*	Cost savings* (admitted <1 year post-injury)**	Cost savings* (admitted >1 year post-injury)**	Cost Offset***	Notes
Turner-Stokes, *Brain Injury,* 2007	Great Britain	410 mixed ABI in 5-year consecutive cohort; 3 levels of dependency	6 mo (average; ranged from 3.5 mo to 1 yr)/ Specialist inpatient multi-disciplinary rehab	NPDS NPCNA UK FIM+ FAM	Significant reduction in dependency between admission & discharge; gains maintained 6 mo later	Bed-day cost X LOS	Per year: High dependency group: $74,100/yr; Medium dependency group: $31,824/yr; Low dependency group: $10,140/yr[a]	n/a (all patients admitted within 8 months of injury)	14.2 mo for high dependency group, 22.3 mo. (med), and 27.7 (low) dependency group	Population of mixed ABI selected on the basis of severe dependency and long stay
Van Heugten et al., *J Rehabil Med,* 2011 Geurtsen et al., *APMR,* 2012	The Nether-lands	33 people (CE study) and 63(3-year outcomes study; majority sTBI in chronic phase (±5 yrs) and psycho-social problems	125 days (not counting weekends)/ Residential community integration program	CES-Depression Scale CIQ ERS WHO QOL Living situation and school and work status; Work hours	Consolidation of beneficial effects on independent living, societal participation, emotional well-being, and quality of life	Direct costs, indirect costs (work), and caregiver support (social costs)	n/a (all participants ±5 yrs post-injury)	Per year: Reduction of $21,840/yr (€12,000)[c] in informal care; $15,793/yr (€8,676)[c] total cost saving/year (due to > use of outpatient care after program)	8 yrs	Used Dutch guidelines for cost valuation; identified costs and savings or increases related to care consumption, caregiver support, and productivity

Authors/ Journal/ Date	Location	Sample	LOS (Length of Stay)/ Rehab Type	Measure(s) Used	Outcomes	Costs Measured*	Cost savings* (admitted <1 year post-injury)**	Cost savings* (admitted >1 year post-injury)**	Cost Offset***	Notes
Wood et al., *Brain Injury,* 1999	Great Britain	76 people w/severe ABI living in the community for at least 1 year after inpatient rehab of 6 mo or more; mixed ABI	14 mo (on average)/ Community-based neuro-behavioral rehab 1 yr or more after in-patient post-acute social and behavioral neuro-rehab	Care support; Costs of care; Employ-ment; Level of social recovery; Factors affecting outcomes	Differences in discharge placement; hours of supervision care; employment /educational status; neuro-behavioral problems	Savings in hours of care support needed in relation to LOS (length of rehab stay)	n/a (patients less than 1 yr post-injury were not studied separately)	Lifetime care savings: $1.65M (£1.098M) (admitted <2 yrs post-injury); $.881M (£.587M) (admitted 2-5 yrs); $.608M (£.405M) (admitted >5 yrs)	n/a (not studied)	Explored efficacy of community-based social and behav rehab to reduce social dependency w/severe neuro-behavioral. disability after ABI
Wor-thington et al., *Brain Injury,* 2009	Great Britain	133, mostly sTBI but includes mixed ABI	6 mo (on average)/ Specialist residential rehabilitation	ARS FAQ OERS SRC SRS	Difference in support costs after post-acute rehabilitation; follow-up at 18 mo	Direct costs of post-acute rehab care (medical care provided)	Lifetime care savings: $1.65M-1.2M (£1.1-0.8M) (when admitted <1 yr post-injury)	Lifetime care savings: $1.05-.75M (£0.7-0.5M) (admitted 1-2 yrs post-injury); $.75-.54M (£0.5-0.36M) (admitted >2 yrs)	2 years	Savings in costs of support in the medium and longer term

*per person; **per time period noted, including /5 yrs (1 study), /yr (3 studies) and /lifetime (4 studies); ***Time point when rehab costs are recouped by savings.

[a]Exchange rate of $1.5/£1 (2006-2013); [b]Exchange rate of $1/NOK 6.09 (2009); [c]Exchange rate of $1.82/€1 (2005 and 2011); (NOK-Norwegian krone; £= British pound; €= Euro; $= U.S. dollar).

Acronyms: ARS=Accommodation Rating Scale; BI=brain injury; CIQ=Community Integration Questionnaire; CES=Center for Epidemiological Studies; CNS=Center for Neuro Skills Scale; CVA=stroke; DRS=Disability Rating Scale; ERS=Employability Rating Scale; FAQ=Functional Activities Questionnaire; ICU=intensive care unit ; LOS=Length of Stay; LSS=Living Status Scale; M=million; mo=months; MPAI-4=Mayo-Portland Adaptability Inventory – 4th edition; OERS=Occupational Engagement Rating Scale; OSS=Occupational Status Scale; NDPS=Northwick Park Dependency Scale; NPCNA=Northwick Park Care Needs Assessment; QOL=quality of life; rehab=rehabilitation; SRC=Social Role Checklist; SRS=Supervision Rating Scale; sTBI= severe traumatic brain injury; TBI=traumatic brain injury; UK FIM+FAM=Functional Independence Measure, version 4 plus a derived Barthel Index; WHO QOL=World Health Organization Quality of Life Scale Abbreviated (5 scales); yr=year.

The eight studies summarized in Table 1 were published between 1999 and 2019. They examine outcomes and cost-efficiencies/cost savings related to rehabilitation access in five countries: Ireland (1), Great Britain (4), Norway (1), The Netherlands (1), and the United States (1). Across all studies, length of stay ranged from 54 days to 14 months. Rehabilitation savings were greatest for patients admitted within 1 year of their injuries, though savings for patients admitted two to five years or more post-injury were observed as well. Savings were primarily realized due to reduced supervision or support needed at discharge. For most studies, cost savings were extrapolated over the patient's lifetime using different discount strategies vis-à-vis expected lifetime and supervision needs. The Netherlands' study (van Heugten et al., 2011) is notable for its use of standardized Dutch guidelines to take a broader look at costs, including social or informal care costs as well as direct medical costs and examined outcomes from a longitudinal (3-year) perspective.

A 2013 paper by Humphreys et al. reviewed 10 peer-reviewed papers related to psychosocial costs associated with traumatic brain injury between 1993 and 2010 (Humphreys, Wood, Phillips, & Macey, 2013). Just two studies (Wood et al., 1999 and Worthington et al., 2006) looked at the cost-effectiveness of intensive, multi-disciplinary rehabilitation after a brain injury. They are included in our analysis as well, along with six other studies.

A Cochrane Review by Turner-Stokes et al (2015) noted maintenance of rehabilitation gains, thus supporting the cost-savings findings of the studies included in our analysis.

Cost-Savings Rating. A recently published paper by Oberholzer and Muri (2019) provides a summary of clinical practice recommendations related to neurorehabilitation access and a "cost-savings" grade (++, +, =/-) based on the recommendations of an international working group GRADE (Grading of Recommendations Assessment, Development, and Evaluation). U.S. agencies and organizations using GRADE include the Agency for Healthcare Research and Quality (AHRQ), American Academy of Family Physicians, American College of Physicians, Centers for Disease Control and Prevention (CDC), and Kaiser Permanente, among others. Founded in 2000 as an informal international collaboration, GRADE "has developed a common, sensible and transparent approach to grading quality (or certainty) of evidence and strength of recommendations" related to health care (www.gradeworkinggroup.org).

Table 2 provides recommendations for clinical practice related to neurorehabilitation after TBI based on a GRADE assessment of clinical practice recommendations and a cost-savings rating that analyzed both RCT and non-RCT-based research (Oberholzer & Muri, 2019).

Table 2. Recommendations for clinical practice using the GRADE (Grading of Recommendations Assessment, Development, and Evaluation) system for different neurorehabilitation approaches in traumatic brain injury (TBI)

Quality of Evidence	Rehabilitation	Patient Category	Outcome	Potential of Cost-Savings	Recommendation (GRADE System)
High	Intensive*	Severe TBI	Earlier gain in independence; Reduced LOS in hospital	+	Strongly recommended
Moderate/high	Specialist	Very severe/severe TBI	Improved independence; Reduced ongoing care	++	Recommended
	Specialist vocational programs	Moderate/ severe TBI	Gains in productivity	++	Strongly recommended
Moderate	Early	Severe TBI	Earlier gain in independence; Reduced LOS in hospital	+	Recommended
	Community based	Moderate/ severe TBI	Improved productivity	++	Recommended
Low/moderate	Behavioral management programs	TBI with severe behavioral problems	Improved social behavior; Reduced ongoing care support	+	Recommended
	Late and ongoing rehabilitation	Moderate/ severe TBI with enduring disability	Maintenance of independence/ productivity	=/-	Conditionally recommended

LOS=Length of stay; TBI=Traumatic Brain Injury. Source: (Oberholzer & Muri, 2019) (page 9 of 17).

* Intensive rehabilitation=4 or more hours/day of multi-disciplinary rehabilitation that includes cognitive rehabilitation.

A number of recommendations in Table 2 echo the findings and recommendations of the studies summarized in our analysis of cost-savings from access to rehabilitation after a severe brain injury (see Table 1). As shown in Table 2, intensive rehabilitation after severe TBI is strongly recommended for clinical practice due to the high quality of evidence and the related earlier gains in independence and reduced length of stay in the hospital, leading to potential cost-savings. In addition, specialist rehabilitation after very severe/severe TBI is recommended due to moderate/high evidence for improved independence and reduced ongoing care, with good potential for cost-savings. Early access to rehabilitation after severe TBI is recommended due to earlier gains in independence and reduced length of stay in the hospital, with potential for cost-savings (Oberholzer & Muri, 2019).

It is worth noting that the GRADE system recommends community-based rehabilitation after moderate-to-severe TBI due to improved productivity and high potential for cost-savings. This recommendation echoes the findings by Wood et al (1999) regarding neurobehavioral rehabilitation for people with behavioral issues after a brain injury. The GRADE system recommends access to behavioral management programs after TBI for people with emotional/behavioral issues to improve social behavior and reduce the need for ongoing care support, leading to potential cost-savings (Oberholzer & Muri, 2019) for this challenging population.

In sum, providing timely and continuous access to rehabilitation, particularly after severe TBI, results in greater functional gains and cost-efficiencies in short and the long-term. Rehabilitation savings have been shown to average $1.67 million per person over a lifetime (Andelic et al., 2014; Cooney & Carroll, 2016; Griesbach et al., 2015; Oddy & da Silva Ramos, 2013; Turner-Stokes, 2007; Worthington et al., 2006a). Providing access to rehabilitation after a brain injury is a policy imperative. Such access reduces family caregiving and economic burdens and public costs for ongoing care. When insurance does not pay for the potential for functional improvement after a moderate-to-severe acquired brain injury, the state picks up the cost of ongoing care.

B. Rehabilitation Outcomes

Evidence from a review of the brain injury rehabilitation literature finds that more intensive rehabilitation after moderate-to-severe brain injury is associated with earlier function gains, with no ceiling effect on therapeutic intensity (Turner-Stokes et al., 2015). Intensive interdisciplinary post-acute brain injury rehabilitation has been shown to result in statistically and clinically significant gains on the Mayo-Portland Adaptability Inventory (MPAI-4), a widely accepted measure of ability, function, and community participation following brain injury, in a large cohort of adults in 23 facilities across the U.S. (Malec & Kean, 2016; Malec et al., 2017). Similar gains were found for outpatient or community-based rehabilitation. Also in the U.S., a Veterans Affairs (VA) pilot program to enhance the rehabilitation, quality of life, and community integration of Veterans with severe TBI, access to specialist rehabilitation led to positive gains in the enrolled Veterans' physical and emotional health, abilities, adjustment, participation, and TBI symptoms; decreases in direct supervision needs; and high levels of satisfaction among Veterans and family members. Patients enrolled in the pilot within 12 months post-injury showed the greatest gains, though gains were observed for Veterans admitted between one and five years post-injury as well (McDonald, 2015).

Intensive rehabilitation for patients with more severe brain injuries has been shown to result in gains in functional ability, participation in society, performance of social roles, and independence (i.e., lower need for supervision each day) (Oddy & da Silva Ramos, 2013; Worthington et al., 2006a). Gains in independence were maintained in a follow-up, multi-center study of brain injury rehabilitation patients with complex needs (Worthington et al., 2006a). For people with more severe injuries and resulting disability, gains in ability to do more for oneself (independence) are highly desired (O'Neil-Pirozzi, Lorenz, Demore-Taber, & Samayoa, 2015b) and can reduce the level of care required in assisted living facilities and at home.

> *Rehabilitation effectiveness is most pronounced within the first year of TBI – and occupational status was notably improved when rehabilitation was initiated within the first 3 months after a TBI* (Griesbach et al., 2015, p. 710).
>
> *Some patients need longer to achieve maximal independence – but there is also evidence that the resulting savings in the cost of ongoing care can offset the initial investment in rehabilitation by several fold* (Turner-Stokes, 2011, p. 197)

There is growing recognition that the right rehabilitation provided at the right time for people with more severe injuries can mean that the "rest of life" journey will be a more positive one (Langlois et al., 2006; Marquez de la Plata, 2015; Turner-Stokes et al., 2015). Rehabilitation can lead to a "new normal" as patients regain skills, find new meaning in life, and take on productive roles (Lorenz & Katz, 2015). The right time ideally is as soon as a patient is able to participate in rehabilitation, though rehabilitation can be effective at a clinically significant level (Malec et al., 2017) with continued rehabilitation intervention also for people injured up to 22 months prior (Lewis & Horn, 2015) and beyond (Oddy & da Silva Ramos, 2013; Worthington et al., 2006a). Yet, in many U.S. states (and globally) access to post-acute rehabilitation – whether facility- or community-based – after a severe brain injury is uncommon (World Health Organisation, 2017) (Centers for Disease Control and Prevention, 2015; Hackman et al., 2014).

C. Cost-Efficiency of Rehabilitation Access

Lack of access to post-acute brain injury rehabilitation adversely impacts a patient's ability to recover from and compensate for their injury. This not only reduces the individual's quality of life, but impacts families, communities, and entails increased lifelong health and social services costs, particularly long-term care costs.

Acquired brain injuries – and in particular TBI and stroke – have a major economic impact on individuals, families, states, and the federal government. In 2010, the estimated total direct and indirect medical cost of TBI in the U.S. was $76.5 billion (Centers for Disease Control and Prevention (CDC), 2017). Globally, the socioeconomic cost of TBI has been estimated at $400 billion, or $1 out of every $200 of global GDB (Gross Domestic Purchases) annually (University of Cambridge, 2017). For stroke, the estimated direct medical cost in 2012-2013 in the U.S. was $17.9 billion, including hospital outpatient or office-based provider visits, hospital inpatient stays, ED (emergency department) visits, prescribed medicines, and home health care (Writing Group et al., 2017).

In 2010, severe TBI consumed 90% of all TBI-related medical expenditure in the U.S. alone. People in Massachusetts with more serious brain injuries from stroke and TBI resulting in disability are likely to be reliant on public funding for all or some of their health and long-term care within two years of their injury due to becoming impoverished after their medical care and loss of work. The most common necessary care includes assistance with activities of daily living (ADLs) or daily life functioning, supported community services, subsidized living expenses, healthcare and, with increasing age or limited opportunities for community placement, nursing home care. Although people with more severe brain injuries are less likely to return to work (Worthington et al., 2006a) rehabilitation that results in greater participation in productive activities and greater independence improves quality of life and reduces the level of necessary care (and costs) over a lifetime (Oddy & da Silva Ramos, 2013; Turner-Stokes et al., 2016), and reduces taxpayer burden (Oddy & da Silva Ramos, 2013). Investments in increased access to post-acute rehabilitation will reduce the need for nursing home care and allow more people to live in the community with better quality of life. TBI carries greater costs than back pain and arthritis due in part to the younger age at injury and severe disability that can result (Ma et al., 2014). Severe brain injury in particular represents a critical opportunity to realize cost savings from improved access to post-acute rehabilitation services.

D. A Focus on Policy Change

Four areas that can benefit from policy change to reduce the impact of severe brain injuries on state (and family) budgets are access to post-acute rehabilitation, prevention, case management, and vocational rehabilitation.

Access. Timely access to post-acute rehabilitation reduces care costs over a person's lifetime, improves return to work rates, eases family caregiving and economic burdens, and provides meaning and purpose to lives upended by severe brain injury. Timely access, especially for patients with more severe injuries, has been shown to reduce the hours of supervision needed per day (Oberholzer & Muri, 2019; Oddy & da Silva Ramos, 2013; Wood et al., 1999; Worthington, Matthews, Melia, & Oddy, 2006b). Research indicates that early rehabilitation investments (ideally starting at 3-12 months post-injury) lead to long-term gains in productivity for individuals, and, by relieving family caregiving, likely result in productivity gains for family members. Early and continuous access to rehabilitation has the best results; however, access to rehabilitation even many years after a severe injury can lead to the maintenance of function gains, improved function, and reduced disability (Hayden et al., 2013; Lewis & Horn, 2013; Lewis et al., 2017).

Prevention. Reduced incidence (prevention) of fatalities from car accidents is recognized as one of the 10 greatest public health achievements in the U.S. from 2001 and 2010 (Centers for Disease Control and Prevention (CDC), 2011). Common state-level prevention activities mandate seatbelt use, child safety seats, helmets, and lower blood-alcohol levels when driving (Centers for Disease Control and Prevention, 2018; Haegerich et al., 2014). Often state efforts are aimed at reducing vehicle injuries and deaths among teens.

Massachusetts has focused on the prevention of traumatic brain injury and provision of services and supports for injured people. Funded in part through a Head Injury Treatment Services Fund (HITS) surcharge on various driving offenses on state highways, BIAMA programs enlist brain injury survivors, family members, and professionals to educate civic groups, organizations and high schools about the facts and consequences of TBI. BIAMA has also teamed up with the CDC and clinical and research professionals to train coaches and athletic trainers to prevent harm to young people from concussions on the field, gridiron, or ice. Through a diversion program, BIAMA promotes brain injury awareness and prevention among adolescents whose behavior puts them at risk for injury – and thus prevent the potential for harm from brain injury for this at-risk group.

> *Reduced incidence of fatalities from car accidents is recognized as one of the 10 greatest public health achievements in the U.S. from 2001 and 2010* (CDC, 2011).

Case management. Increasing access to case management that can follow an individual from acute care to community-based care can facilitate access to needed care, including post-acute rehabilitation services and vocational programs. Case management, or a case manager assigned to support an injured individual to navigate the "ocean" of systems, providers, and payers and access appropriate services, can align patient and provider interests and increase timely access to services that support recovery (Health Affairs, 2012). Case management that is not tied to payers has the potential to help realize the rehabilitation cost-savings identified in this report.

Return to work. Cognitive impairments, as compared to severe disability levels overall, may complicate return to work (L. E. Trexler, Parrott, & Malec, 2016). Return to work gains may be increased from prior access to integrated rehabilitation services aimed at improving physical, cognitive, and emotional function (Fortune et al., 2015). Access to rehabilitation services after brain injury will increase the potential for return-to-work. In Indiana, resource facilitation has realized substantial cost savings to a state through reduced annual lost wages and increased annual earnings (Reid et al., 2011; L.E. Trexler et al., 2014). There is evidence that work-directed interventions in combination with education/coaching are effective regarding return to work after stroke and TBI, particularly for more severe injuries (Donker-Cools, Daams, Wind, & Frings-Dresen, 2016). In Great Britain, vocational rehab participants were claiming 13% fewer welfare benefits at one year and people who were working were significantly less anxious and depressed and had a significantly better health-related quality of life (Radford et al., 2013). In Great Britain, the cost associated with a 1% increase in returning to work was equivalent $6.06, and incremental cost-utility ratio (difference in quality of life) was $5,192 for a comprehensive vocational rehab plus 12 months of health and social care costs (Radford et al., 2013). For older and less-educated workers, longer vocational rehab may be necessary (Odgaard, Pedersen, Poulsen, Johnsen, & Nielsen, 2018).

> *Some patients need longer to achieve maximal independence – but there is also evidence that the resulting savings in the cost of ongoing care can offset the initial investment in rehabilitation by several fold* (Turner-Stokes et al., 2011, p. 197).

V. Policy Recommendations

Our policy analysis research identified that access to intensive, multi-disciplinary rehabilitation services within one year of a severe or more serious brain injury results in cost-savings in the short term through shorter length of stay, and in the long-term through reduced disability and reduced level of care and supervision needs. Timely access to services reduces care costs over a person's lifetime, improves return to work rates, eases family caregiving and economic burdens, and provides meaning and purpose to lives upended by severe brain injury. Our recommendations follow.

- Increase access to post-acute rehabilitation. Increase access to post-acute rehabilitation, especially for people who have sustained a severe brain injury, whether from TBI, stroke or other ABI, where the greatest cost-savings are observed. Ideally, ensure access within 12 months of injury, when capacity for improvement is greatest and the greatest short- and long-term cost savings are observed. Also provide access to rehabilitation at the chronic stage of injury due to its effectiveness at increasing independence and quality of life. One approach to increasing access is to mandate rehabilitation coverage through state legislation, as has been done in Texas since 1995 (Texas Legislature, 2017). Another would be to provide these services universally through federally funded insurance programs: Medicaid and Medicare.
- Maintain and strengthen prevention focus. Maintain ongoing brain injury prevention activities. One example is the programs sponsored by the Brain Injury Association of Massachusetts intended to prevent brain injuries by addressing the leading causes of brain injuries and contributing factors including: seat belt and helmet usage; distracted, drunken, and drugged driving; pedestrian and home safety practices; and sports concussion. The prevention programs of BIAMA are supported by a Head Injury Treatment Services Fund (HITS) surcharge on various driving offenses on state highways. A second state-level prevention activity is aiming to reduce falls among seniors. A commission established under the Massachusetts Department of Public Health that has been studying the effect of falls on older adults and the potential for reducing the number of falls, with the goal of formulating guidelines and a plan to reduce falls among Massachusetts elders. The Falls Commission was established through a legislative mandate. Consider also the example provided by Victoria, Australia under its Transport Accident Commission, which partners with other provincial entities to reduce transport accidents, for example through public education campaigns and investing in road infrastructure that makes roads safer for cyclists and pedestrians as well as vehicles on high-risk roads (Transport Accident Commission (TAC), 2019).
- Increase access to case management from injury to end-of-life. Case management, or a case manager assigned to support an injured individual to navigate the "ocean" of systems, providers, and payers and access appropriate services, can align patient and provider interests and increase timely access to services that support recovery (Health Affairs, 2012), and increase return-to-work, independence, and community participation, reduce annual lost wages, and increase annual earnings (Trexler et al., 2014; Reid et al., 2011). Through a state-sanctioned entity, provide independent case management (not tied to payers or providers) for as long as needed, for all patients at all income levels, as described by others (University of Missouri-Columbia, 2006), with the overarching goal of increasing access to rehabilitation services and reducing the long-term cost burden on the state. Provide case management to support access to medical care and to social services and supports such as housing, day programming, and vocational rehabilitation (Malec, 2001; L.E. Trexler et al., 2014). For persons with disabilities from severe brain injury, provide life-long case management, as has been done in Missouri and Victoria, Australia (Transport Accident Commission (TAC), 2019; University of Missouri-Columbia, 2006) to ensure timely access to rehabilitation and associated cost-savings.
- Support return to work. With a goal of enhancing rehabilitation savings, the state should continue to support vocational rehabilitation activities in the post-acute rehabilitation phase of brain injury and consider expanding the program based on experiences with return-to-work program in Indiana.

Entitled “Resource Facilitation,” the Indiana return-to-work program has realized substantial cost savings to that state through reduced annual lost wages and increased annual earnings (Reid et al., 2011; L.E. Trexler et al., 2014). Research supported by a collaboration of providers, state agencies, advocacy groups, and federal and local funders found that such interventions improve long-term function, increase earnings and save money. A review by Gordon et al. (2006) found that supportive employment, group cognitive skills training, and assistive technology can enhance vocational outcomes. Savings can be realized through lost wages avoided and additional annual earnings realized (Trexler et al., 2014; Reid et al., 2011). Minnesota and New Hampshire have adopted the Indiana approach to support return-to-work after brain injury.

- <u>Systematically collect outcome and cost data over the short- and long-term for people who sustain a serious brain injury.</u> Such data are needed to support decision-making by policymakers. Establishing a brain injury registry is one approach to understanding outcomes over time. As of 2016, 24 U.S. states had established TBI and trauma registries (National Association of State Head Injury Administrators (NASHIA), 2016). Systematically collecting outcomes data at admission and discharge as well as over the long-term will allow the state to compare outcomes and savings for Massachusetts residents with those in other U.S. states with brain injury and trauma registries and will increase understanding of any rehabilitation savings that result from access. Incorporating cost-tracking elements as well as demographic and functional measures into any database established is highly recommended. A registry could inform future prevention and access efforts and inform future updates to the state’s 2014 brain injury epidemiology report (Hackman et al., 2014). The Administration for Community Living (ACL) of the U.S. Department of Health and Human Services (HHS) grant requires partner states to maintain and enhance their TBI registry by better connecting individuals to person-centered services and collaborate with other state registries to broaden impact by working with existing infrastructure to expand referrals.

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Appendix A: Economic Analysis Terms vis a vis Rehabilitation after a Severe Brain Injury

Across the globe, multiple terms are used to describe the benefits or efficiencies of rehabilitation care vis a vis its outcomes.

Cost: "The cost of providing rehabilitation is largely determined by time (length of stay) and effort (Intensity) on the part of the rehabilitation team" (Turner-Stokes, 2007, p. 1015).

Cost benefit analysis (CBA): Measured in monetary units, "CBA represents a net value between the difference in willingness to pay and costs related to care" (Lu et al., 2013).

Cost-effective analysis (CEA): Measured in natural units (e.g., life-years gained, injuries prevented). CEA provides "an incremental cost-effectiveness ratio (ICER) or the ratio of incremental costs to incremental effect. CEA can also provide a Net Health Benefit (NHB), or the incremental effect minus the ratio of incremental costs to the threshold value, as set by a government entity" (Lu et al., 2013, p. 1926). A cost-effective service is 'economical in terms of the goods or services received for the money spent" (Turner-Stokes, 2007, p. 1015).

Cost efficiency (CE): "A cost-efficient service is one that is 'effective without wasting time or effort or expense', … or, in other words, provides value for money in rehabilitation services" (Turner-Stokes, 2007, p. 1015).

Cost-utility analysis (CUA): Measured in health-related quality of life. CUA is an incremental cost-effectiveness ratio or ICER, or the cost per change in quality of life or QALY. (Lu et al., 2014)

Rehabilitation savings (RS): The difference in projected life care costs for acquired brain injury (TBI and CVA) patients who completed a rehabilitation program as compared to patients who did not complete a rehabilitation program (Griesbach et al., 2015).

Appendix B: The RCT Dilemma vis a vis Access to Rehabilitation After a Severe Brain Injury

Randomized controlled trials (RCTs) study a particular intervention (i.e., new medication) in an isolated way. Evidence from RCT's is considered the "gold standard" for understanding a health intervention's outcomes. In rehabilitation, however, "not all questions can be addressed by RCTs or other experimental approaches" (Oberholzer & Muri, 2019). There is strong and growing evidence of interdisciplinary rehabilitation's effectiveness after severe brain injury that is not based on RCT studies (Turner-Stokes et al., 2015). Denial of services – necessary to any randomized controlled trial – has serious ethical considerations for a research subject who has had a brain injury and for their family (Turner-Stokes et al., 2015). Moreover, from a practical standpoint, is RCT evidence on rehabilitation truly translatable to the real world? Much rehabilitation research reflects "real life" contexts (i.e., with cohort samples having a range of acquired brain injuries, age, time since injury, and gender), which reduces their "gold standard" estimation. Yet rehabilitation research studies reflect actual patient populations. Non-RCT studies may in fact generate more robust outcomes from rehabilitation services, with greater generalizability to rehabilitation practice, systems, and policy than those generated by studies conducted in isolation from "real life" contexts (Worthington et al., 2006a).

> *"Trial-based (RCT) literature does not answer the question of which treatments work best for which patients over the long-term, and which models of rehabilitation services represent the best value for money in the context of life-long care" (Oberholzer and Muri, 2019, p. 8)*

Appendix C: Approach Used to Calculate Average Lifetime Savings
Key Sources

Criteria for inclusion to create average minimum and maximum cost savings:

- TBI
- Severe or high-dependency on admission
- Admitted <1 year post-injury
- Accessed post-acute intensive interdisciplinary rehab

Excluded:

- Andelic: >1 yr post-injury and looked at savings in a five year period (with 1 year as offset) (not lifetime, not/yr)
- Van Heugten: >1 yr post-injury
- Wood : >1 yr post-injury

For studies (2) that looked at cost savings/year (Cooney & Carroll and Turner-Stokes 2007), lifetime savings were calculated using Brooks et al (2015) findings re life-expectancy post-TBI:

- 81 years (life expectancy for general population per Brooks) – average age of cohort – 23 years for MAX and 9 years for MIN * per year savings

Minimum, maximum, and average savings (lifetime) for studies that estimated savings/year:

Cooney & Carroll (2016) (MAX: $91,000/year and MIN: $36,400/year (savings identified))

- Average age of cohort: 43.5 years
- Life expectancy: MAX: 28.5 years and MIN: 14.5 years
- Lifetime cost savings (28.5 years of life): **MAX: 2.593M** to 1.319M
- Lifetime cost savings (14.5 years of life): MIN: 1.320M to **.527M**
- MAX = $2.593M
- MIN = $.527M
- **Average: $1.56M**

Turner-Stokes (2007) ($74,100/year= average savings identified)

- Average age of cohort: 39.2 years
- Life expectancy: MAX: 30.2 years and MIN: 18.8 years
- Lifetime costs savings (30.2 years of life): MAX: $2.238M
- Lifetime cost savings (18.8 years): MIN: $1.393M
- **Average: $1.815M**

Minimum, maximum, and average savings (lifetime) for studies that calculated savings/lifetime:

Griesbach et al (2015) (TBI: $2.268M/lifetime, with SD of $.681M)

- MAX: $2.949M
- MIN: $1.587M

- **Average:** $**2.268M**

Oddy & Ramos (2013)

- MAX: $1.695M
- MIN: $.855M
- **Average:** $**1.275M**

Worthington et al (2009)

- MAX: $1.65M
- MIN: $1.2M
- **Average:** $**1.425M**

Summary findings of lifetime savings (5 studies):

- Average lifetime cost savings: $1.668M (1.67)
- Range of average savings: $1.275M to $2.268M

Key Resources

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