



REPORT TO CONGRESS

# Traumatic Brain Injury In the United States: Epidemiology and Rehabilitation

Submitted by the Centers for Disease Control and Prevention  
National Center for Injury Prevention and Control  
Division of Unintentional Injury Prevention



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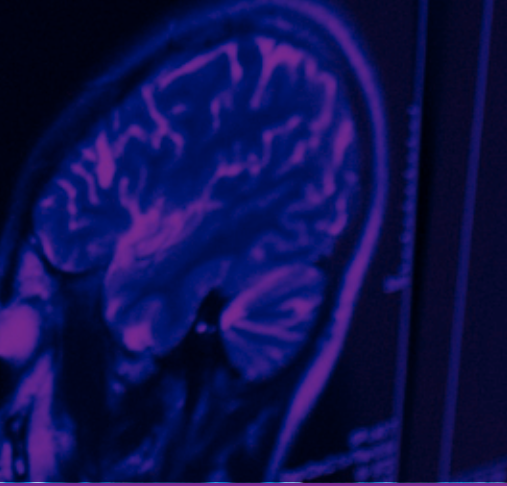
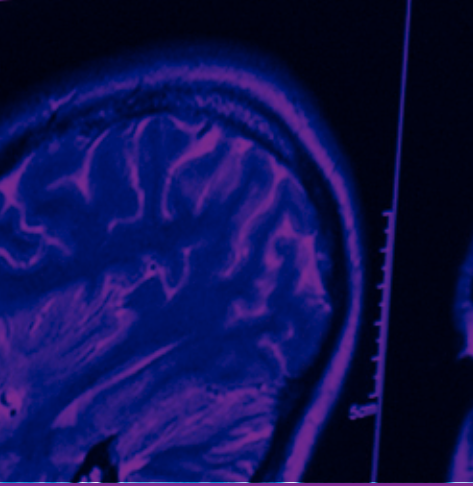
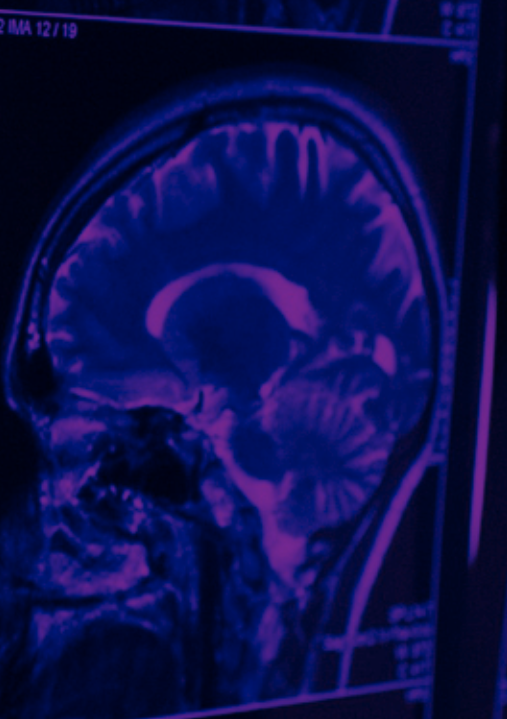
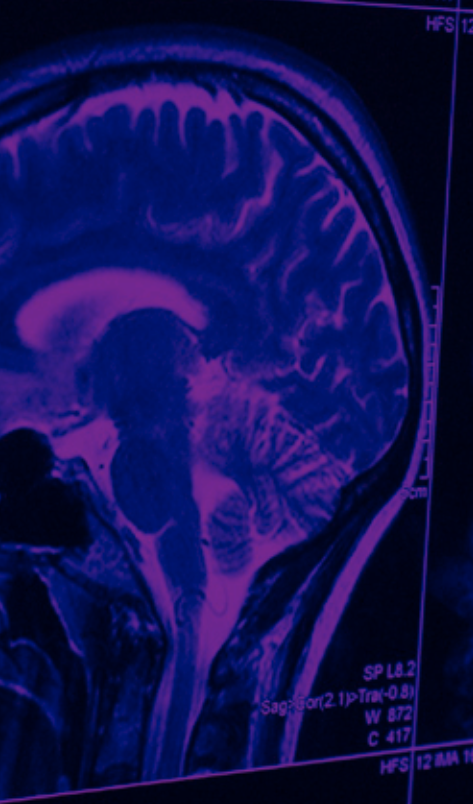
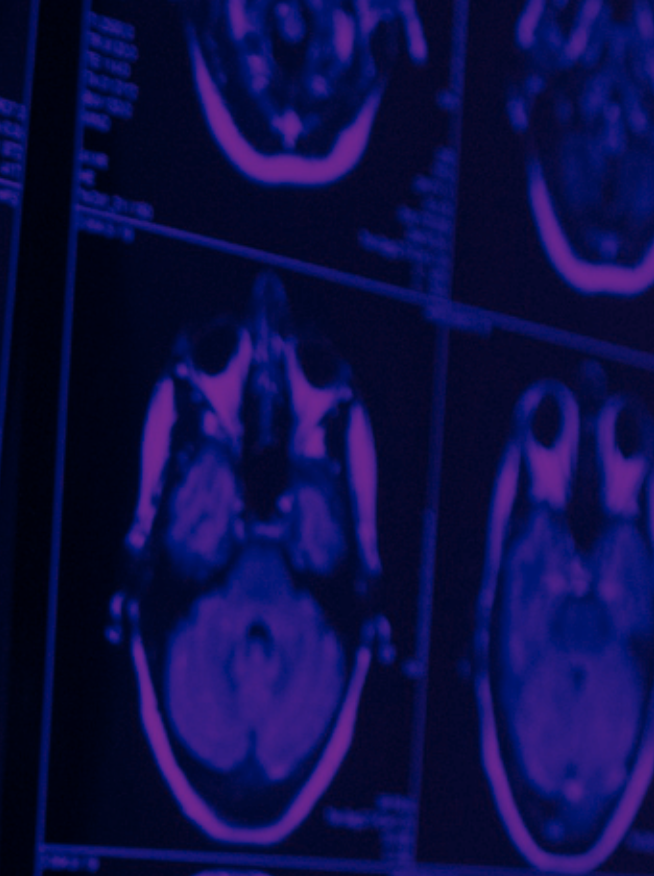
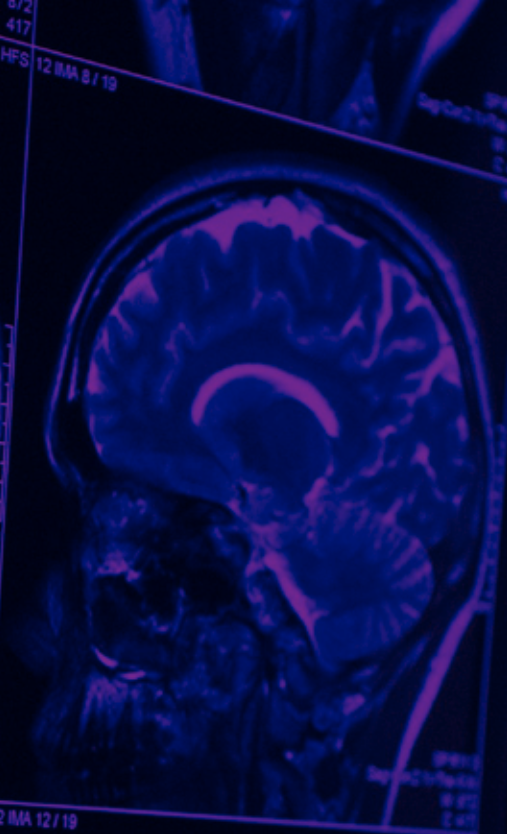
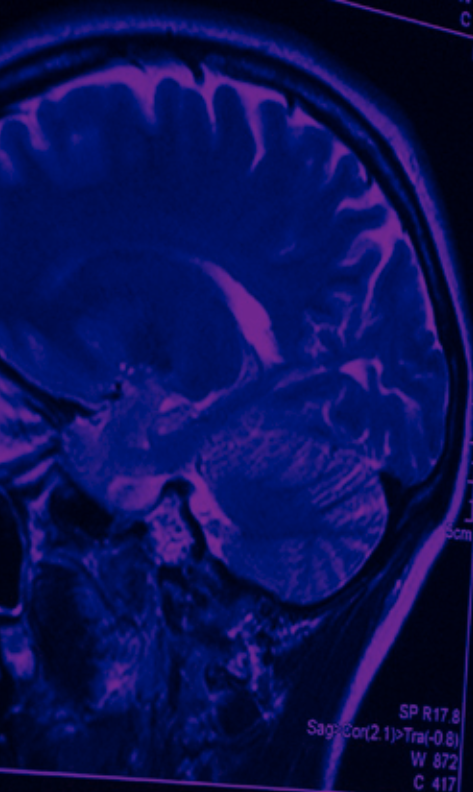
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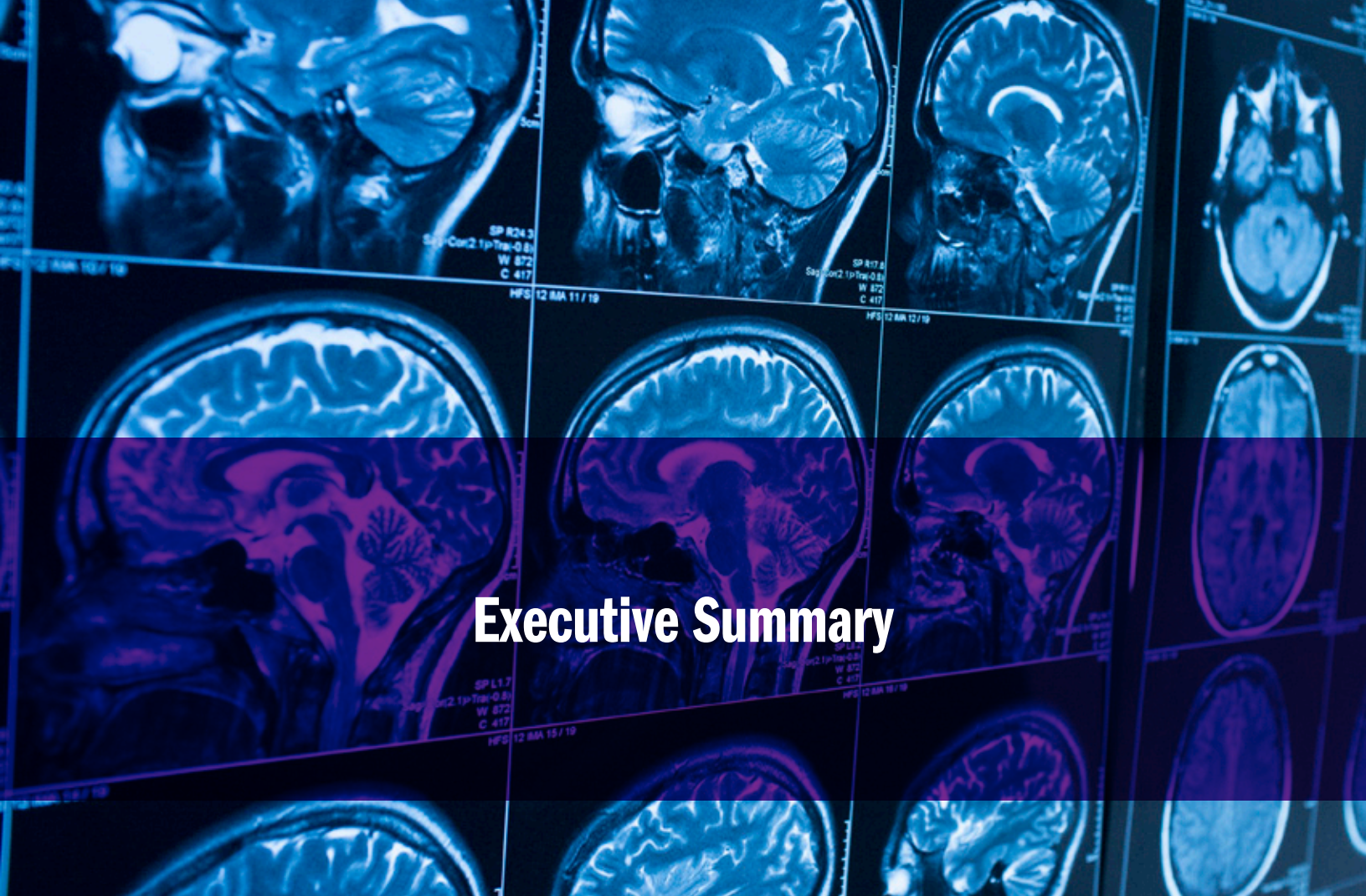
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## Executive Summary

The Traumatic Brain Injury Act of 2008 authorized research and public health activities related to traumatic brain injury (TBI). The goal of public health related to injury prevention is to reduce the burden of injury at the population level by preventing injuries and ensuring care and rehabilitation that maximizes the health and quality of life for injured persons. The purpose of this report is to review what is known about TBI in three areas:

### **TBI BURDEN**

- Describe the incidence of TBI, including trends over time;
- Describe data on the prevalence of TBI-related disability;

### **TBI OUTCOMES**

- Review the adequacy of TBI outcome measures;
- Describe factors that influence differential TBI outcomes;

### **TBI REHABILITATION**

- Assess the current status and effectiveness of TBI rehabilitation services.

## Introduction

A TBI is an injury that disrupts the normal function of the brain. It can be caused by a bump, blow, or jolt to the head or a penetrating head injury (Marr and Coronado, 2004). Explosive blasts can also cause TBI, particularly among those who serve in the U.S. military. In 2010, the Centers for Disease Control and Prevention (CDC) estimated that TBIs accounted for approximately 2.5 million emergency department (ED) visits, hospitalizations, and deaths in the United States, either as an isolated injury or in combination with other injuries. Of these persons, approximately 87% (2,213,826) were treated in and released from EDs, another 11% (283,630) were hospitalized and discharged, and approximately 2% (52,844) died. However, these numbers underestimate the occurrence of TBIs. They do not account for those persons who did not receive medical care, had outpatient or office-based visits, or those who received care at a federal facility, such as persons serving in the U.S. military or those seeking care at a Veterans Affairs hospital (Faul et al., 2010). Those who serve in the U.S. military are at significant risk for TBI as Department of Defense data revealed that from 2000 through 2011 235,046 service members (or 4.2% of the 5,603,720 who served in the Army, Air Force, Navy, and Marine Corps) were diagnosed with a TBI (CDC, NIH, DoD, and VA Leadership Panel, 2013).

## Classification

The severity of TBI can be classified as mild, moderate, or severe on the basis of clinical presentation of a patient's neurologic signs and symptoms. The symptoms of TBI vary from one person to another, and although some symptoms might resolve completely, others, especially as a result of moderate and severe TBIs, can result in symptoms that persist, resulting in partial or permanent disability.

The assessment of TBI-related health effects is vital for the delivery of medical care, for discharge planning, inpatient treatment, and rehabilitation. Some health effects of TBI in children, such as deficits in organization and problem-solving, might be delayed, and not surface until later. As a result, for both adults and children, TBI is being recognized more as a disease process, rather than a discrete event, because of the potential it presents for non-reversible and chronic health effects (Masel and DeWitt, 2010).

## Public Health Impact

A TBI can adversely affect a person's quality of life in numerous ways, including cognitive, behavioral/emotional, and physical effects that affect interpersonal, social and occupational functioning. In addition to the impact of TBI on the individual, TBI can negatively impact families, communities, and the economy. Although data are limited, estimates based on data from two states indicate that 3.2 million–5.3 million persons in the United States are living with a TBI-related disability (Selassie, et al., 2008; Thurman, Alverson, Dunn, Guerrero, and Sniezek, 1999; Zaloshnja, Miller, Langlois, and Selassie, 2008). Additionally, adolescents and adults affected by moderate or severe TBI who were discharged from rehabilitation facilities were more than twice as likely to die 3.5 years after injury compared to persons in the general population of similar age, sex, and race (Harrison-Felix et al., 2012). Also, among adolescents and adults who received rehabilitation for TBI, 2 in 10 will have died at 5 years post-injury, and nearly 4 in 10 will have declined in function from the level of recovery attained 1–2 years after their injury (Corrigan, et al., 2014). These findings point to the chronic health effects of TBI that can affect a person's health and social environment long after acute medical treatment and rehabilitation.

In the United States, children aged 0–4 years, adolescents aged 15–19 years, and adults aged 75 years and older are among the most likely to have a TBI-related emergency department visit or to be hospitalized for a TBI (Faul et al., 2010). Adults aged 75 years and older have the highest rates of TBI-related hospitalizations and deaths among all age groups. The leading causes of non-fatal TBI in the United States are falls (35%), motor vehicle-related injuries (17%), and strikes or blows to the head from or against an object (17%), such as in sports injuries (Faul et al., 2010). The leading causes of TBI-related deaths are motor vehicle crashes, suicides, and falls (Coronado et al., 2011).



## TBI Health Effects

A TBI can result in health effects that vary in intensity, length, and clinical manifestation. These health effects can persist and contribute to potential impairment, functional limitation, disability, and reduced quality of life (Riggio and Wong, 2009; Walker and Pickett, 2007). Disturbed cognition is the hallmark symptom of TBI but the injury also can affect behavior, emotion, and motor function. Cognitive disturbances can lead to difficulties with memory, attention, learning, and coordination. Other signs and symptoms include headaches, fatigue, and sleep disturbances. In addition, secondary neurologic disorders such as mood disorders and post-traumatic epilepsy can occur following TBI and disrupt health-related quality of life (Rosenthal, Christensen, and Ross, 1998; Hart, Brenner, Clark, Bogner, Novack, Chervoneva, Nkase-Richardson, and Arango-Lasprilla, 2011; Lowenstein, 2009; Agrawal, Timothy, Pandit, and Manju, 2006). The scientific literature also suggests that TBI increases the risk for neurodegenerative disorders, such as dementia. However, a majority of persons, particularly those with mild TBI, will generally experience one or more of these health effects for a short time following the injury. Repeated TBIs, though, can have prolonged and long-term effects. Finally, TBI can negatively affect families. Adverse family effects can include caregiver distress, depression, and deterioration of family functioning after a TBI (Aitken et al., 2009; Wade, Carey, and Wolfe, 2006b).

## Effectiveness of TBI Outcome Measures

TBI outcome measures can be broadly defined as instruments or scales that assess physical and cognitive ability, as well as psychological functioning, after the injury. There can be a wide range of short- and long-term outcomes resulting from a TBI. Accurately measuring these outcomes is critical given the important purposes for which measurement results are used. First, outcome measurement helps assess the status of recovery and effectiveness of rehabilitation. Second, measurement results can be used to monitor the progress of treatment in the clinical setting and demonstrate treatment progress to a third-party payer. Finally, these outcomes undergird research on the effectiveness of TBI rehabilitation and better inform future clinical interventions and recovery.

The TBI Outcomes Workgroup of the Common Data Elements (CDE) Project identified the critical outcome domains for TBI outcomes research (Wilde et al., 2010) as follows:

- Global Outcome
- Recovery of Consciousness
- Neuropsychological Impairment
- Psychological Status
- TBI-related Symptoms
- Behavioral Function
- Cognitive Activity Limitations
- Physical Function
- Social Role Participation
- Health-Related Quality Of Life
- Health-Economic Measures
- Patient-Reported Outcomes

The TBI CDE Outcomes Workgroup also identified a set of recommended measures within each outcome domain. These recommended measures were those with the strongest level of research support. However, these measures require several hours to implement. One of the current goals of the National Research Action Plan (NRAP), a federal interagency group that is charged with coordinating TBI research, is the development of a shorter but comprehensive assessment tool that is sensitive across the range of TBI severities. In addition, the authors of the NRAP have acknowledged that the limited effectiveness demonstrated by previously conducted intervention studies, including those in rehabilitation, have been caused in part by the limited number of validated assessment tools that are sensitive enough to detect treatment effects. The TBI CDE Outcomes Workgroup also identified several measures within each domain that are promising and that have the potential to surpass the currently recommended measures. The TBI CDE Outcomes Workgroup indicated that these measures require additional study to warrant inclusion as a recommended tool to assess a particular element within an outcome domain.

A separate pediatric workgroup identified additional CDEs and associated measures for children, specifically related

to academics, adaptive and daily living skills, family and environment, language and communication, and social cognition (McCauley et al., 2012).

The taxonomy developed by the TBI CDE Outcomes Workgroup has the potential to bring greater consistency to TBI-related outcomes that will improve the quality and comparability of TBI research.

Finally, a multicenter study, Transforming Traumatic Brain Injury Research and Clinical Care (TRACK-TBI), evaluated the feasibility of implementing a wide range of the TBI CDEs in a single study of adults with TBI. This study found that assessing a large number of TBI CDEs was feasible. However, several gaps in the study were identified, including the need for validating additional outcome measures for TBI patients living with higher levels of disability and the need for validating additional outcome measures among non-English speaking patients.

## Factors Influencing Outcomes

Intervening factors that have been shown to influence outcomes must be considered when interpreting research examining the effectiveness of rehabilitation. Aside from the type and severity of a TBI, and the medical care received, recovery from TBI is influenced by factors including individual patient characteristics, social-environmental factors, and access to rehabilitation services.

Individual characteristics, such as age and pre-injury functioning, can influence outcomes after TBI. The degree to which they influence outcomes depends upon the severity of injury. Social-environmental factors (e.g., socioeconomic status, social support, caregiver and family functioning) also can influence outcomes after TBI. Finally, access to rehabilitation services can be negatively impacted by a lack of specialty providers, particularly in rural areas, as well as a lack of financial resources available to a person with TBI. The availability and level of insurance coverage are especially important.

## Effectiveness of TBI Rehabilitation

Following hospitalization for a TBI, persons can receive rehabilitation care and services in various settings. Post-acute rehabilitation is provided following an inpatient hospital stay and is typically indicated for persons whose medical condition requires continued skilled nursing

care. Some settings in which this level of rehabilitation is available includes inpatient rehabilitation facilities, long-term care hospitals, and skilled nursing facilities. Persons who no longer require skilled nursing care are usually discharged home and may receive rehabilitation care provided by outpatient and community service centers. However, the type of rehabilitation care or setting selected is also based on a person's level of functional recovery, independence, geographic availability, and financial resources—including insurance coverage.

For persons living with TBI-related health effects, rehabilitation goals are structured to improve their independence in activities of daily living, social functioning, quality of life, and ability to participate in the community. They typically focus on the recovery of motor function, cognitive function, self-care skills, and community participation. A person's pre-injury functioning and personal goals are fundamental in determining the best rehabilitation treatment plan, as well as the eventual outcomes. No single TBI rehabilitation program will work for all patients; rather, the goals and methods of rehabilitation must be individualized to each person.

TBI rehabilitation consists of therapies broadly categorized as cognitive and physical. Cognitive rehabilitation (CR) consists of a group of therapies used to manage deficits in thought processes and behavior (e.g., comprehension, perception, and learning). Physical rehabilitation focuses on enhancing different forms of mobility by improving physical factors such as strength and endurance, as well as providing assistive devices that facilitate independence.





## Cognitive Rehabilitation

The Cognitive Rehabilitation (CR) Task Force of the American Congress of Rehabilitation Medicine (ACRM) Brain Injury Interdisciplinary Special Interest Group evaluated 370 studies and found that CR is effective during the post-acute period—even 1 year or more after injury (Cicerone et al, 2000, 2005, 2011). Further analysis of the scientific literature suggests that CR is effective in patients with moderate and severe TBI (Rohling et al., 2009). However, an Institute of Medicine (IOM) committee concluded that the evidence was insufficient to provide practice guidelines, particularly with respect to selecting the most effective treatments for a specific person (IOM, 2011). The insufficiency of the evidence was largely attributed to limitations in research designs for rehabilitation evaluation studies. And yet, empirical support for CR is growing with the strongest level of evidence for the following interventions (Cicerone et al., 2011):

- Direct attention training accompanied by metacognitive training to promote development of compensatory strategies and generalization;
- Interventions to address functional communication deficits and memory strategies for mild memory impairments;
- Meta-cognitive strategies for executive function deficits; and
- Comprehensive holistic neuropsychological rehabilitation.

Preliminary evidence supports the effectiveness of group-based rehabilitation treatment of pragmatic communication disorders. However, research that demonstrates the effectiveness of cognitively based treatments for listening, speaking, reading, and writing, in social, educational, occupational, and community settings is lacking (Turkstra et al., 2003).

## Physical Rehabilitation

Evidence supports the general effectiveness of physical rehabilitation (Bland, Zampieri-Gallagher, and Damiano, 2011; Betker, Desai, Nett, Kapadia, and Szturm, 2007; Irdesel, Aydiner, and Akgoz, 2007; Mossberg, Amonette, and Masel, 2010; Scherer and Schubert, 2009; Shaw et al., 2005). With respect to specific interventions, regularly scheduled passive range-of-motion exercises and body re-positioning are techniques that are commonly used with positive effects (Winkler, 2013). Equipment, such as standing frames or tilt tables, can be used to maintain bone structure, elongate shortened muscles, challenge endurance, and stimulate the minimally conscious person. Body-weight-supported (BWS) gait devices and knee-ankle-foot orthotics can be used with manual assistance to initiate standing postures. BWS devices can lead to improved cardiovascular function and assist with the beginning of walking training (Mossberg, Orlander, and Norcross, 2008; Wilson and Swaboda, 2002).

Gaming and virtual reality-based treatment methods are emerging as an adjunct to physical therapy standards of practice for treating persons with TBI (Betker et al., 2007; Scherer and Schubert, 2009). One study demonstrated the effectiveness of improved goal-oriented, task-specific training with the use of a gaming system to promote practice of short sitting balance control for persons with TBI. Another method used a game-based training tool that yielded an increase in practice volume and attention span, and furthermore, improvements in dynamic sitting balance control (Betker et al., 2007). Certain evidence indicates that virtual reality and other methods to improve vestibular function and balance result in improvements in both gait and gaze stability of persons with TBI sustained during blasts (Scherer and Schubert, 2009). However, approaches such as motor interventions, proprioceptive muscle training, and neurodevelopmental treatment have been used in clinical practice with limited research on their effect on functional outcomes.

## Recommendations

The following section lists recommendations to address gaps identified in each of the major sections in this report. The full report provides additional background and describes the critical gaps that are addressed by the following recommendations:

### Section I. Epidemiology and Consequences of TBI in the United States

- *Improve TBI incidence and prevalence estimates to include patients with TBI who are treated in non-hospital settings and those with TBI who are not receiving medical care.* Develop or identify sources of non-hospital TBI incidence data, such as data from physician offices and other sources of outpatient medical encounters, to improve estimates. Similarly, develop or identify data sources that capture information from persons who might have experienced a TBI but did not seek medical care for their injury.
- *Generate state-specific TBI estimates.* Collect and compile health care administrative data in all states to quantify and examine state-level variations in TBI burden. In addition, state-level TBI estimates can be used to inform decisions related to the allocation of preventive and rehabilitative services that are made at the state level.
- *Better understand injury mechanisms and their effect on sub-populations.* Examine trends in TBI incidence by injury mechanism and within population subgroups (e.g., children, older adults, and others) by using data systems such as Healthcare Cost Utilization Project (HCUP). This can help target prevention resources to populations at greatest risk for TBI.
- *Enhance monitoring of sports and recreation concussions.* Develop and implement a concussion surveillance system that captures the full range of sports- and recreation-related concussions. Current surveillance systems capture only emergency department visits or injuries experienced in organized high school sports, collegiate athletics, and some professional leagues.
- *Produce population-level estimates of TBI-related disability.* Add TBI-related disability to large, existing national health surveys, and analyze large-scale claims or administrative datasets to produce population-level estimates.

## Section II. Effectiveness of TBI Outcome Measures

- *Develop comprehensive outcome measures that enable measurement of treatment effectiveness specific to the TBI population.* It is essential to develop tools that are sensitive to changes associated with treatment and rehabilitation regardless of TBI severity.
- *Increase validation of outcome measures in sub-populations.* Conduct validation studies of outcome measures among particular sub-populations in which validity, reliability, and sensitivity have not been assessed previously. This practice is critical to expand scientific knowledge of outcomes and establish best practices for sub-populations, such as children, where evidence is still developing.
- *Better leverage health information technology (IT).* Examine the expanding use of electronic health records as 1) a method for tracking patient progress from one level or system of care to another and 2) as a way to better examine the effectiveness of TBI interventions.
- *Create additional outcome measures that can be administered readily to non-native English speakers.* The TRACK-TBI study found that a number of the measures recommended by the TBI CDE Workgroup could not be administered to non-native English speakers.
- *Test and adapt the CDEs for children and adolescents.* Similar to how the TRACK-TBI study examined the feasibility of implementing the CDEs in adults, a need exists for examining the feasibility of assessing the full range of CDEs among children and adolescents.
- *Assess promising Common Data Element Outcomes measures.* Conduct additional studies of the measures the TBI CDE Workgroup identified as promising to determine whether they might warrant inclusion as recommended measures.
- *Enhance involvement of patients and families in assessing rehabilitation outcomes.* Increase inclusion of patient- and family-centered outcomes in research studies to better document the real-world utility of rehabilitation.

(continued on next page)

## Recommendations (continued)

### Section III. Effectiveness of TBI Rehabilitation

- *Improve understanding of optimal rehabilitation protocols.* Conduct research studies to better examine the optimal timing, intensity, and dose of rehabilitation interventions.
- *Study rehabilitation effectiveness among sub-populations.* Conduct research studies to determine the effectiveness of TBI rehabilitation services among groups in which effectiveness has not been specifically examined, such as children. Examining effectiveness among specific sub-populations can help to identify ways in which rehabilitation might be tailored to the particular needs of sub-groups to optimize effectiveness.
- *Create service models for parents and caregivers to optimize rehabilitation services.* Develop and evaluate service models that will assist parents to better navigate the post-acute rehabilitation setting, ensuring that needed services for children with TBI are received.
- *Strengthen understanding of TBI continuum of care after acute inpatient rehabilitation.* Conduct research studies to examine the effectiveness of rehabilitation services following acute inpatient rehabilitation, such as community-based rehabilitation and vocational rehabilitation.
- *Further assess the cost benefit of TBI rehabilitation to enhance understanding of cost effectiveness.* Conduct studies examining the cost-benefit ratio of TBI rehabilitation interventions and examine how the cost-benefit ratio is related to the dose, duration, and intensity of rehabilitation. Beyond demonstrating the health-related effects of rehabilitation, the effectiveness of TBI rehabilitation can also be supported by documenting the resulting economic benefit.
- *Further assess the need to increase use of alternative sources for delivering rehabilitation services, such as telemedicine, tele-health, mobile services, and the use of lay health advisors.* Evaluate the effectiveness and cost effectiveness of alternative delivery models—especially those that might overcome barriers to rehabilitation access caused by factors that include rural residence and lack of transportation.
- *Implement integrated systems to support the ongoing follow-up of persons affected by TBI.* Develop healthcare models that integrate medical and community services that support the lifelong needs of persons affected by TBI.
- *Expand use of promising technologies for use in rehabilitation interventions.* Increase widespread dissemination of emerging practices such the use of web-based consultation, as well as global positioning system devices, paging systems, and smartphones to aid with cognitive rehabilitation.

## Conclusion

Understanding the epidemiology of TBI, its associated consequences, and the availability and effectiveness of rehabilitation interventions are crucial to improving the quality of life of those with a TBI. The most recent estimates of the burden of TBI suggest a decrease in TBI-related deaths, likely related to fewer motor vehicle-related TBIs. In contrast, TBI-related emergency department visits have increased, although this may be due in part to increased awareness of concussions among the general public. Nevertheless, the public health and economic burden of TBI is substantial and primary prevention remains the key public health strategy to reduce the burden of TBI. However, because preventing all TBIs is impractical, an imperative for those in public health practice, clinical practice, and research is to design and evaluate effective strategies to mitigate the health effects of TBI. Maintaining a comprehensive and coordinated system of rehabilitation interventions is critical to achieve this end. Substantial progress has been made in identifying effective rehabilitation interventions after a TBI, but considerable work remains to be done.

CDC was asked by Congress to address the need for evidence-based guidelines for TBI rehabilitation. Although previous research has demonstrated the broad effectiveness of a number of TBI rehabilitation services, additional research is needed before evidence-based guidelines can be developed. The heterogeneous nature of TBI injuries and TBI rehabilitation imposes challenges to identifying the specific conclusions that can be translated into recommendations for clinical use. These challenges must be addressed to improve the evidence base before embarking on guideline development.

Signs of extensive progress in TBI rehabilitation research are evident. Chief among these are the efforts of the TBI Common Data Elements Project and the TRACK-TBI study, as both are steps forward in improving the quality and comparability of future TBI outcomes research. Such coordinated effort is required to move the evidence base forward to better help persons with TBI to lead more healthy and productive lives.







## Background

“The brain is more than an assemblage of autonomous modules, each crucial for a specific mental function. Every one of these functionally specialized areas must interact with dozens or hundreds of others, their total integration creating something like a vastly complicated orchestra with thousands of instruments, an orchestra that conducts itself, with an ever-changing score and repertoire.”

— *Oliver Sacks*

*Physician, author, and professor of neurology*

## Introduction

The Traumatic Brain Injury Act of 2008 [P.L. 110-206 (S. 793, H.R. 1418); U.S. Government Printing Office, 2008] authorized research and public health activities related to TBI. Part J of Title III of the Public Health Service Act (42 U.S.C. 280b et seq.) was amended by inserting section 393C-1 entitled *Study on Traumatic Brain Injury*. This section authorized CDC to conduct a study in collaboration with the National Institutes of Health (NIH) and other appropriate entities to complete the following, subject to the availability of information:

1. Determine the incidence of TBI and prevalence of TBI-related disability and the clinical aspects of the disability in all age, racial, and ethnic minority groups in the general population of the United States;
2. Report national trends in TBI;
3. Identify common interventions used for rehabilitation and determine their effectiveness;
4. Analyze the adequacy of existing measures of outcomes and knowledge of factors influencing differential outcomes;
5. Identify interventions and therapies that can prevent or remediate the development of secondary neurologic conditions related to TBI; and,
6. Develop guidelines for patient rehabilitation after TBI.

The first section of this report describes the epidemiology of TBI, including incidence and trends (Items 1 and 2 from above). The second section examines TBI outcomes measurement and the factors that have been associated with differential outcomes (Item 4 from above). The third section describes TBI rehabilitation interventions and their effectiveness (Items 3 and 5 from above). Finally, the Conclusion section outlines the critical gaps that impede the development of evidence-based guidelines for rehabilitation after TBI occurs.

## Purpose

The goal of public health related to injury prevention is to reduce the burden of injury at the population level by preventing injuries and assuring care and rehabilitation that maximizes the health and quality of life for injured persons. The purpose of this report is to review what is known about TBI in the following three areas:

### TBI BURDEN

- Describe the known incidence of TBI, including trends over time;
- Describe data on the prevalence of TBI-related disability;

### TBI OUTCOMES

- Review the adequacy of TBI outcome measures;
- Describe factors that influence differential TBI outcomes;

### TBI REHABILITATION

- Assess the current status and effectiveness of TBI rehabilitation services.

In this report, critical gaps and challenges related to these topics are described and recommendations for addressing these gaps are identified.





## Method

In October 2011, CDC convened a panel of specialists in TBI rehabilitation to devise a plan for addressing the language within the TBI Act of 2008 related to the *Study on Traumatic Brain Injury*. Participants included psychologists, physical medicine and rehabilitation physicians, physical and occupational therapists, speech-language pathologists, and federal specialists and representatives from CDC, NIH, Department of Defense (DoD), Department of Education (DOE), and Department of Veterans Affairs (VA). Additional authorities served as consultants and subject matter experts during the review process (Appendix A).

Panel participants concluded that two recently published systematic reviews—one by the Institute of Medicine (IOM) on cognitive rehabilitation and one by the Agency for Healthcare Research and Quality (AHRQ) on multidisciplinary post-acute rehabilitation (Brasure et al., 2012; Institute of Medicine [IOM], 2011)—contained supporting information for at least some of the questions

posed. In addition, the panel decided that their work should focus on building upon these and other publications (e.g., Gordon et al., 2006).

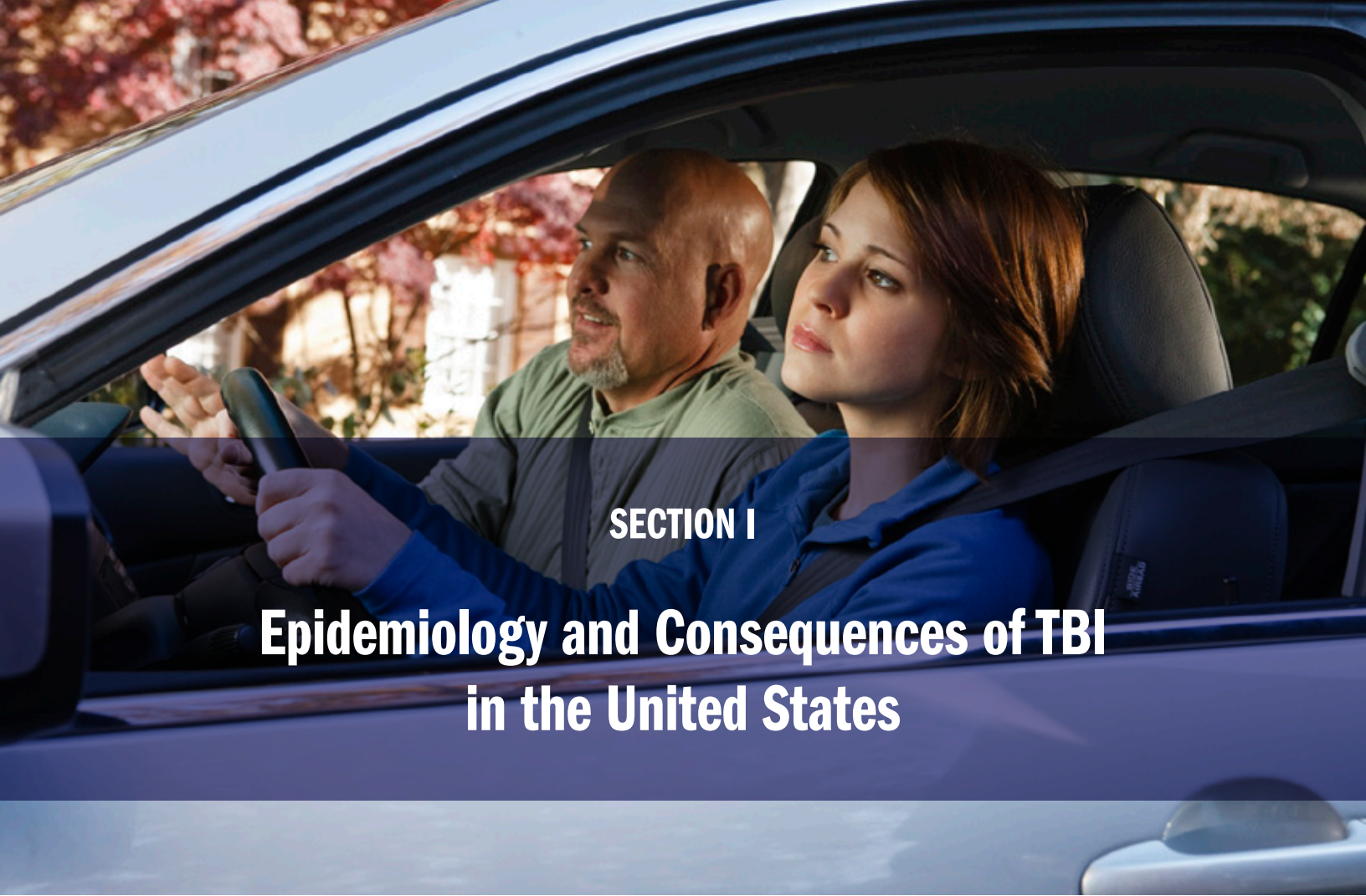
As a result, the methodology employed was a broad-based review of the literature. This methodology included studies that might not have met the criteria used in systematic reviews, such as literature examining emerging and current “best practices” in TBI rehabilitation.

The panel conducted its work through working groups composed of CDC staff and external panelists. The panel developed the initial outline of the report and working groups were formed to focus on the following topics: special populations, TBI outcome measures, delivery of TBI rehabilitation services, and the effectiveness of TBI rehabilitation practice. Both CDC staff and panelists contributed to identifying and reviewing literature in each of these areas.

This report reflects CDC’s synthesis of these activities.







## SECTION I

# Epidemiology and Consequences of TBI in the United States

## Definition of TBI

CDC defines TBI as a disruption in the normal function of the brain that can be caused by a bump, blow, or jolt to the head or a penetrating head injury (Marr and Coronado, 2004). Explosive blasts can also cause TBI, particularly among those who serve in the U.S. military. Observing one of the following clinical signs constitutes an alteration in brain function (Menon, Schwab, Wright, and Maas, 2010):

- a. Any period of loss of or decreased consciousness;
- b. Any loss of memory for events immediately before (retrograde amnesia) or after the injury (post-traumatic amnesia);
- c. Neurologic deficits such as muscle weakness, loss of balance and coordination, disruption of vision, change in speech and language, or sensory loss;
- d. Any alteration in mental state at the time of the injury such as confusion, disorientation, slowed thinking, or difficulty with concentration.

Not all bumps, blows, or jolts to the head result in TBI. Additionally, not all persons who experience a TBI will have behavioral effects or a TBI-related disability (Corrigan, Selassie, and Orman, 2010). However, the combination of several factors—trauma from the head striking or being struck by an object, an object penetrating the brain, acceleration/ deceleration movement of the brain not caused by direct trauma to the brain, and the presentation of signs and symptoms of TBI either immediately or shortly after the suspected event—is sufficient to classify a person as having sustained a TBI (Corrigan, et al., 2010).

## Characteristics of TBI

Classification of TBI based on patterns and types of injury is important to ensure proper treatment and long-term therapy. However, the complexity of TBI and limitations of available assessment tools make this challenging (Marshall et al., 1992). A primary brain injury occurs immediately after impact and is a direct result of mechanical trauma. Depending on the injury mechanism and severity, the initial event might cause direct, primary physical alterations of the brain tissue. A secondary brain injury can occur hours or days after the initial traumatic event and can arise from complications initiated by the primary injury such as inflammation, cell receptor-mediated dysfunction, free radical and oxidative damage, and calcium or other ion-mediated cell damage (Graham, Gennarelli, and McIntosh, 2002; Greve and Zink, 2009; Werner and Engelhard, 2007). Cerebral edema, or brain swelling, is a common secondary brain injury and a frequent cause of brain death in persons with severe TBI (Plesnila, 2007).

As in other tissue injuries, an inflammatory reaction to TBI can occur. Inflammation is involved in the repair of brain tissue after injury, but it also can contribute to secondary brain damage. Secondary injury also might result from other systemic events related to multiple injuries in other organs or body parts.

TBI can appear as a focal (localized) or diffuse (widespread) injury. Some persons exhibit both. A focal injury results when bleeding, bruising, or a penetrating injury is isolated to a portion of the brain. A diffuse brain injury occurs when brain tissue suffers more widespread damage, often resulting from acceleration and deceleration forces. Impact of the head against another object can cause focal brain injury under the skull at the site of impact and at a site on the opposite side of the head (Adams, Mitchell, Graham, and Doyle, 1977). The most common form of TBI is caused by a combination of impact and acceleration/ deceleration forces, such as those occurring in high-speed motor vehicle crashes (Kotapka et al., 1991; Adams, Graham, Murray, and Scott, 1982).

Certain regions of the brain are particularly vulnerable to the external forces that cause TBI (Bigler, 2007). External forces that initiate brain movement can stretch and disrupt the integrity of brain tissue and cause the brain to impact bony protuberances within the skull. The frontotemporal lobes of the brain are particularly susceptible to this phenomenon because these regions are situated above

bony surfaces in the skull where brain tissue can be easily injured with impact or forceful movement. For this reason it has been hypothesized that the susceptibility of the frontotemporal lobes are the basis for the cognitive and behavioral symptoms commonly experienced after a TBI (Bigler, 2007).

**Table 1. Glasgow Coma Scale**

Ability	Score
<b>Eye opening (E)</b>	
Spontaneous	4
To voice	3
To pain	2
None	1
<b>Motor response (M)</b>	
Normal	6
Localized to pain ( <i>purposeful movement toward site of pain</i> )	5
Withdraws to pain	4
Abnormal flexion to pain ( <i>an abnormal posture that can include rigidity, clenched fists, legs held straight out, and arms bent inward toward the body with the wrists and fingers bent and held on the chest</i> )	3
Abnormal extension to pain ( <i>an abnormal posture that can include rigidity, arms and legs held straight out, toes pointed downward, head and neck arched backwards</i> )	2
None	1
<b>Verbal response (V)</b>	
Normal conversation	5
Disoriented conversation	4
Words, but not coherent	3
No words, only sounds	2
None	1
<b>Score: Eye score (E) + Motor score (M) + Verbal score (V)= 3 to 15</b>	

*Teasdale and Jennett, 1974*

## Injury Severity Classification of TBI

Although several injury indicators exist for the classification of TBI, the Glasgow Coma Scale (GCS) is the most widely used (Malec et al., 2007; Teasdale and Jennett, 1974). The GCS is a neurologic scale consisting of three components: eye opening, verbal response, and motor response. The component scores are added to create an overall score to determine a patient's level of consciousness (Table 1). The GCS was originally developed in 1974 to assess coma and other impaired levels of consciousness based on observed clinical signs and symptoms (Teasdale and Jennett, 1974), but was later adopted to assess TBI severity (Jagoda et al., 2008). However, the GCS has some limitations. Factors not necessarily related to the injury might affect the GCS score and lead to misclassification of TBI severity. Some of these include factors that can independently alter consciousness such as medical sedation, alcohol or drug intoxication, and organ system failure.

TBI severity can be misclassified when the GCS is used alone. Because of this, additional criteria are used in clinical practice and research (Boyd, Tolson, and Copes, 1987; Cooke, McNicholl, and Byrnes, 1995; Stein, 2001).

These include duration of altered mental state or loss of consciousness and duration of post-traumatic amnesia. Imaging techniques, such as computed tomography (CT) scans, also can be used to identify structural damage that might contribute to the assessment of injury severity. In research studies, the Abbreviated Injury Scale (AIS) score for the head and neck region (Baker, et al, 1974; Brasure, et al., 2012) can be used to classify TBI. The AIS ranks injuries on a six-point scale based on mortality risk, with "1" indicating minor injury and "6" indicating a non-survivable injury. The relationship of these measures to classification of TBI severity as mild, moderate, or severe, is shown in Table 2. However, as with the GCS, each of the severity criteria has limitations and might not be an accurate predictor of TBI severity and outcome when used alone.

**Table 2. Criteria used to classify TBI severity**

Criteria	TBI SEVERITY		
	Mild	Moderate	Severe
<b>Structural imaging</b>	Normal	Normal or abnormal	Normal or abnormal
<b>Loss of consciousness</b>	<30 minutes	30 minutes to 24 hours	>24 hours
<b>Post traumatic amnesia</b>	0-1 day	>1 and <7 days	>7 days
<b>Glasgow Coma Scale score (best available score in 24 hours)</b>	13-15	9-12	3-8
<b>Abbreviated Injury Scale score: Head</b>	1-2	3	4-6

Source: Brasure et al., 2012



## Health and Other Effects of TBI

TBIs can lead to a spectrum of secondary conditions that might result in long-term impairment, functional limitation, disability, and reduced quality of life. Health effects associated with TBI can be broadly categorized into cognitive, behavioral/emotional, motor, and somatic symptoms (Riggio and Wong, 2009; Walker and Pickett, 2007). Given the high frequency of frontal lobe injury, cognitive impairment is the hallmark injury of TBI; however, combinations of these health effects are frequently experienced. The evolution of secondary symptoms following TBI will vary across persons and is dependent on the injury location, injury severity, and medical history before the injury (McAllister and Arciniegas, 2002; Silver, McAllister, and Yudofsky, 2011). Although not an exhaustive list of potential TBI-related health effects, common cognitive, behavioral/emotional, motor, sensory, and somatic signs and symptoms associated with TBI are presented in Table 3.

Psychological and neurologic disorders also can develop following TBI, which also might contribute to varying degrees of long-term impairment, functional limitation, or disability. These include mood disorders, (e.g., depression), and post-traumatic epilepsy (Rosenthal, Christensen,

and Ross, 1998; Hart, Brenner, Clark, Bogner, Novack, Chervoneva, Nkase-Richardson, and Arango-Lasprilla, 2011; Lowenstein, 2009; Agrawal, Timothy, Pandit, and Manju, 2006). Post-traumatic stress disorder (PTSD) and dementia also are conditions of concern for persons affected by TBI. Considerable gaps in understanding exist with regard to the overlap and specific relations among TBI and these conditions (Bryant, 2011; Wang, Lin, Sung, Wu, Hung, Wang, Huang, Lu, Chen and Tsai, 2012).

Adverse health effects also affect work-related behaviors, and these include difficulties with social interactions, organizational obstacles caused by an acquired disability, health and safety concerns, and challenges with work attitude, skills, behavior, and performance (Tyerman, 2012). For working-aged adults, the return to work, school, and other pre-injury activities after TBI are key elements for life satisfaction. Failure to achieve a self-perceived productive role in society after TBI comes at personal and economic cost to injured persons, their families, and society (Selassie et al., 2008). However, gainful employment for a person affected by TBI has positively influenced outcomes and contributed to self-reported life satisfaction (Corrigan, Bogner, Mysiw, Clinchot, and Fugate, 2001).

**Table 3. Health effects associated with TBI**

Category	Description
<b>Cognitive</b>	Deficits in: <i>attention; learning and memory; executive functions like planning and decision-making; language and communication; reaction time; reasoning and judgment</i>
<b>Behavioral/ Emotional</b>	<i>Delusions; hallucinations; severe mood disturbance; sustained irrational behavior; agitation; aggression; confusion; impulsivity; social inappropriateness</i>
<b>Motor</b>	<i>Changes in muscle tone; paralysis; impaired coordination; changes in balance, or trouble walking</i>
<b>Sensory</b>	<i>Changes in vision and hearing; sensitivity to light</i>
<b>Somatic signs and symptoms</b>	<i>Headache; fatigue; sleep disturbance; dizziness; chronic pain</i>

Sources: Anstey et al., 2004; Asikainen, Kaste, and Sarna, 1999; Clinchot, Bogner, Mysiw, Fugate, and Corrigan, 1998; Dikmen, Machamer, Fann, and Temkin, 2010; Granacher, 2005; Katz, White, Alexander, and Klein, 2004; Meares et al., 2011; Orff, Ayalon, and Drummond, 2009; Riemann and Guskiewicz, 2000; Riggio and Wong, 2009; Rogers and Read, 2007; Schmidt, Register-Mihalik, Mihalik, Kerr, and Guskiewicz, 2012; Silver et al., 2011; Williams, Morris, Schache, and McCrory, 2009; Ziino and Ponsford, 2006; Nampiarampi, 2008.

## Burden of TBI

### *Incidence and Epidemiology*

Each year, approximately 30 million injury-related emergency department (ED) visits, hospitalizations, and deaths occur in the United States. Of the injury hospitalizations, approximately 16% included TBI as a primary or secondary diagnosis. Of the injury deaths, approximately one-third included a TBI as a direct or underlying cause of death. In 2010, CDC estimated that TBIs accounted for approximately 2.5 million ED visits, hospitalizations, and deaths in the United States, either as an isolated injury or in combination with other injuries. Of these persons, approximately 87% (2,213,826) were treated in and released from EDs, another 11% (283,630) were hospitalized and discharged, and approximately 2% (52,844) died. These figures, however, underestimate the occurrence of TBIs, as they do not account for those persons who did not receive medical care, had outpatient or office-based visits, or those who received care at a federal facility (i.e., persons serving in the U.S. military or seeking care at a Veterans Affairs hospital) (Faul et al., 2010). Department of Defense data revealed that from 2000 through 2011 235,046 service members (or 4.2% of the 5,603,720 who served in the Army, Air Force, Navy, and Marine Corps) were diagnosed with a TBI (CDC, NIH, DoD, and VA Leadership Panel, 2013).

In the United States, children aged 0–4 years, adolescents aged 15–19 years, and older adults aged ≥75 years are the groups most likely to have a TBI-related ED visit or hospitalization (Faul et al., 2010). Adults aged ≥75 years have the highest rates of TBI-related hospitalizations and deaths among all age groups. Overall, males account for approximately 59% of all reported TBI-related medical visits in the United States (Faul et al., 2010).

As shown in Table 4, during 2002–2010, the leading causes of TBI-related ED visits were falls, being struck by or against an object, and motor-vehicle traffic crashes. The leading causes of TBI-related hospitalizations were falls, motor-vehicle traffic incidents, and assaults. For TBI-related deaths, the leading causes were motor-vehicle traffic incidents, suicides, and falls (Coronado et al., 2012). The proportion of TBIs occurring during sports and recreation-related activities is undetermined because of limitations of the data source. However, according to

the National Electronic Injury Surveillance System – All Injury Program, during 2001–2009 (CDC, 2011) the activities associated with the greatest estimated number of TBI-related ED visits were bicycling, football, playground activities, basketball, and soccer among persons younger than 19 years.

### *Incidence of TBI-related Disability*

In the United States availability of data related to the incidence of TBI-related disability is limited. The few national-level estimates that have been reported are based on extrapolations of state-level data from South Carolina and Colorado. These extrapolations suggest that 3.2 million–5.3 million (Selassie et al., 2008; Zaloshnja et al., 2008; Thurman et al., 1999) persons were living with a TBI-related disability at the time of those studies.

**Table 4. Estimated average annual numbers of traumatic brain injury-related emergency department (ED) visits, hospitalizations, and deaths, by external cause, United States, 2002–2010**

Mechanism of injury	ED visits	Hospitalizations	Deaths
Falls	658,668	66,291	10,944
Struck by or against an object	304,797	6,808	372
Motor vehicle traffic	232,240	53,391	14,795
Assault/Homicide	179,408	15,032	5,665
Self-inflicted/Suicide	*	*	14,713
Other	122,667	25,478	4,990
Unknown	97,018	113,172	0

\*Estimate not reported because of small numbers

## Trends in Traumatic Brain Injury

Figure 1 illustrates the annual age-adjusted rates per 100,000 persons in the United States for TBI-related ED visits, hospitalizations, and deaths. Since 2007, for every 100,000 persons in the United States the rate of total TBI-related ED visits, hospitalizations, and deaths have increased 45%, from 566.7 to 823.7. This increase in TBI-related medical encounters is primarily driven by an accompanying increase in the rate of TBI-related ED visits, which have increased 56%, from 457.5 in 2007 to 715.7 in 2010. In contrast, TBI-related hospitalizations and deaths have not increased similarly. Specifically, the rate of TBI-related hospitalizations has been relatively stable since 2007, as evidenced by an identical rate of TBI-related hospitalizations in both 2007 and 2010 (91.7 per 100,000 persons). TBI-related death rates decreased from 18.2 to 17.1 per 100,000 persons from 2007 to 2010. The reason(s) for an increase in ED visits and a

decrease in TBI-related deaths is not known. However, one plausible explanation is that a continued reduction in motor-vehicle crashes (the leading mechanism of TBI-related death) has reduced the TBI-related death rate. The increase in TBI-related ED visits might be related to an increased awareness about TBI resulting in more persons seeking care. Awareness of the health risks from TBI have been driven by increased media coverage of sports-related concussions, state-level legislation that requires coaches to receive training related to recognition and management of sports-related concussions, and public education campaigns (e.g., CDC’s HEADS UP) targeted to athletes, parents, coaches, health care providers, and educators. Lending support to the role of sports-related concussions affecting the rate of TBI-related ED visits, one study determined that during 2001–2009, the number of sports and recreation–related ED visits for TBI among persons aged ≤19 years increased 62% (CDC, 2011).

**Figure 1. Annual age-adjusted rates of TBI-related Emergency Department (ED) visits, hospitalizations, and deaths—United States, 2001–2010**





## Unique Considerations for Specific Populations

TBI can pose challenges for all persons, regardless of age, sex, geography, military status, or other distinguishing characteristics. Although the risk factors, health effects, and long-term implications of TBI vary for each person, some persons require special considerations (e.g., pediatric and older adult age groups, residents of rural geographical areas, military service members and veterans, and incarcerated populations).

### Children (Aged 0–19 Years )

Approximately 145,000 children and adolescents aged 0–19 years are estimated to be living with substantial and long-lasting limitations in social, behavioral, physical, or cognitive functioning following a TBI (Zaloshnja, et al., 2008). However, these numbers likely underestimate the true consequences of pediatric TBI, given the underreporting of mild TBI (mTBI) or concussion, and abusive head trauma (Theodore et al., 2005).

A TBI experienced by a child can contribute to physical impairments, lowered cognitive and academic skills relative to developmental expectations, and deficits in behavior, socialization, and adaptive functioning, depending on the presence of factors that influence outcomes (see *Factors Influencing Outcomes*) (Anderson et al., 2006; Yeates et al., 2004; Yeates and Taylor, 2006). Some studies suggest that even children with mild injuries are at risk for disability (Rivara, et al., 2012). Children with a TBI can experience specific impairments in language, memory, problem-solving, perceptual-motor skills, attention, and executive function (Anderson et al., 2006; Gerrard-Morris et al., 2010; Taylor et al., 2008).

In pediatric populations, some effects of a TBI may not be present initially, but can emerge later in a child's development. This delay of onset can manifest itself in later academic failure, chronic behavior problems, social isolation, and difficulty with employment, relationships, and, in some cases, difficulty with the law (Ewing-Cobbs et al., 2004; Gerrard-Morris et al., 2010; Hendryx and Verduyn, 1995; Williams, Cordan, Mewse, Tonks, and Burgess, 2010). Unlike other injuries with chronic consequences, the physical effects of TBI in children are often difficult to recognize. For this reason, common behavioral manifestations of TBI in children and adolescents, such as lack of inhibition, difficulty reading

social cues, and emotional lability, might be mistakenly attributed to other causes ranging from lack of motivation and laziness to bad parenting (Wade et al., 2010).

### Older Adults (≥75 Years)

Current studies estimate that approximately 775,000 older adults live with long-term disability associated with TBI (Zaloshnja et al., 2008). The TBI sequelae of older adults are often attributed to the aging process rather than an injury, preventing affected seniors from being accurately diagnosed and treated. Older adults affected by TBI have a higher risk for mortality (Thompson, McCormick, and Kagan, 2006) and worse functional outcomes following injury than younger patients with similar injuries, regardless of initial TBI severity (Cifu et al., 1996; Susman et al., 2002). The societal and medical-care costs of TBI also are more extensive for older adults than younger patients. When compared with younger patients, older adults had longer hospital stays and slower rates of functional improvement during inpatient rehabilitation (Cifu et al., 1996; Miller and Pentland, 1989). Preexisting medical conditions, (Mosenthal et al., 2004), also were found to increase the length of stay among older adults in outpatient rehabilitation (Yu and Richmond, 2005).

### Rural Geographical Residents

Data indicate that the prevalence of TBI-related disability in rural geographical areas is higher than urban and suburban areas (24% compared with 15% and 14%, respectively) (Kaye, 1997). Persons affected by TBI in rural areas are less likely to have access to specialized trauma care and rehabilitation professionals (Johnstone, Nossaman, Schopp, Holmquist, and Rupright, 2002; Murphy, 2004). Fewer resources exist in rural communities to support independent living after a TBI, such as long-term rehabilitation facilities or community-based services (Sample, Tomter, and Johns, 2007).

Transportation limitations further restrict service delivery in rural communities. Rural residents travel two to three times further for specialty care, attend fewer medical visits even when community resources are available, and have less access to medical specialists (Chan, Hart, and Goodman, 2006; Sample et al., 2007). Primary care physicians are more likely to be the single source of care of persons with TBI-related disability in rural areas, and are less likely to

have received advanced training in the management of TBI. (Lishner, Richardson, Levine, and Patrick, 1996). Finally, persons affected by TBI who are enrolled in vocational rehabilitation services in rural geographical areas are more likely to discontinue services and have considerably worse employment outcomes when compared with vocational rehabilitation clients in urban areas (7% compared with 24%, respectively) (Johnstone, Reid-Arndt, Franklin, and Harper, 2006).

### **Military Service Members and Veterans**

Since the beginning of Operation Enduring Freedom (OEF) (Afghanistan) and Operation Iraqi Freedom (OIF) in the early 2000s, public health and health care communities have become aware of increased rates of TBI among active duty U.S. military personnel. In response to these public health and medical concerns, Congress passed the Traumatic Brain Injury Act of 2008. The Act required CDC and NIH, in consultation with DoD and VA, to determine how best to improve the collection and dissemination of information related to the incidence and prevalence of TBI among persons who were formerly in the military. In addition, the goal was to provide recommendations for CDC, NIH, DoD, and VA collaboration on the development and improvement of TBI diagnostic tools and treatments. (For more information about TBI specifically related to military populations, please see CDC's *Report to Congress on Traumatic Brain Injury in the United States: Understanding the Public Health Problem among Current and Former Military Personnel* ([http://www.cdc.gov/traumaticbraininjury/pubs/congress\\_military.html](http://www.cdc.gov/traumaticbraininjury/pubs/congress_military.html)).

Military service members and veterans from recent conflicts and combat are a population of special concern. However, of all new cases of TBI among military personnel, approximately 80% occur in non-deployed settings. In addition to motor-vehicle crashes, falls, sports- and recreation-related injuries, and assaults—military members also might sustain TBIs during training activities (DVBIC, 2013) (Reference for military external causes of injury: MSMR, 2013).

The combat situations that cause TBI in conflict zones might contribute to other problems (e.g., post-traumatic stress disorder [PTSD]). Recent research suggests that a history of mild TBI might place persons at increased risk for developing PTSD even after adjusting for type



of injury (Bryant et al., 2010). Moreover, those with both PTSD and mild TBI are at greater risk for various post-concussive symptoms following injury than those with either PTSD or mild TBI alone (Brenner et al., 2010). PTSD, pain conditions, mood disorders, and substance-use or misuse can yield symptoms similar to those of mild TBI (e.g., difficulty sleeping) making differential diagnoses challenging. Growing awareness of the problems facing service members and veterans has illuminated the need for rehabilitation research that is focused on evidence-based interventions for mild TBI, TBI complicated by psychological conditions like PTSD, and best practices to facilitate the transition from military to civilian life.

### **Incarcerated Populations**

Incarcerated populations are another population heavily affected by TBI. It is estimated that the prevalence of TBI in imprisoned populations is 60.3% (Shiroma, Ferguson, and Pickelsimer, 2012). This suggests that in many cases the illegal acts leading to incarceration, as well as non-compliant prison behaviors and subsequent recidivism, may be at least been partially influenced by the effects of a TBI. In addition, data from a statewide sample of prisoners in South Carolina indicated that approximately 65% of men and 72% of women reported a TBI (Ferguson, Pickelsimer, Corrigan, Bogner, and Wald, 2012). However, how and when incarcerated populations experienced a TBI or the circumstances surrounding the injury remains unclear.

## Gaps in Determining the Incidence of TBI

CDC provides annual updates on the national incidence of TBI. However, the limitations of the available TBI data create barriers in fully describing the incidence of TBI in the United States. National estimates of TBI in the United States are based on health care administrative data describing the number of TBI-related hospitalizations, ED visits, and deaths. Consequently, persons who do not seek care for a TBI or seek care at a physician's office, urgent care center, or other non-emergency outpatient department are not included in these estimates.

Data sources that have been used to capture TBIs diagnosed during these health care encounters have not had sufficient sample sizes to produce reliable yearly estimates. Adding to the problem is the likelihood of multiple visits from the same patient for the same injury, making it difficult to generate an accurate count of TBI incidence. In addition, surveillance is not in place to determine how many persons might have had a TBI but did not seek medical care. As a result, TBI incidence estimates are likely undercounted. Another gap involves a lack of uniform race and ethnicity data in TBI data-systems, which makes examining trends in TBI incidence by race/ethnicity difficult. Finally, although CDC has funded 20 states to produce state-level TBI incidence estimates, TBI incidence data is limited in states that have not been funded.

Until recently, trends in the national incidence of TBI by demographic subgroups and mechanism of injury have been difficult to assess. Data sources used to examine TBI-related hospitalizations and ED visits have not had sufficient sample sizes to produce single-year estimates by demographic subgroups and mechanisms of injury. As a result, multiple years of observations had to be aggregated to examine the overall incidence of TBI in subpopulations. CDC has recently developed a new strategy to examine TBI-related medical encounters by using data from the Healthcare Cost and Utilization Project (HCUP). These data will enable CDC to generate single-year estimates of TBI incidence by demographic subgroup. These HCUP data sources are more widely sampled than the previously utilized data sources and allow for estimates of population subgroups without aggregating multiple years of data. This step forward will allow CDC to provide a more fine-grained understanding of how TBI incidence varies over time.

Gaps exist in the surveillance of TBIs that occur in sports- and recreation-related activities. TBI-related

health care visits are defined by diagnostic codes from the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM, for hospitalizations and ED visits) and Tenth Revision (ICD-10, for deaths). And yet, little information is available that describes the mechanism of injury - particularly information related to whether the injury occurred during a sport or recreational activity and the particular sport or recreational activity that was being engaged in at the time of the injury. Persons who experience a TBI while participating in sports and recreational activities, and who seek care at an ED, are included in the overall incidence estimates. However, they are included in broad external cause-of-injury categories, such as falls or being struck by or against an object—rather than being identified as having been injured in a sports or recreational activity. Using current data systems it is not possible to describe sports- and recreation-related TBIs as a separate category for those who are hospitalized or die as the result of sports- or recreation-related TBI.

Current surveillance systems that can capture sports- and recreation-related concussions are based on data collected during ED visits or injuries experienced in organized high school or college sports leagues. Consequently, these systems do not capture the full range of sports- and recreation-related concussions. Specifically, these systems miss out on sports- and recreation-related concussions that do not result in an ED visit and/or concussions experienced outside of organized sports at the high school level or higher. Also, these systems do not routinely collect a person's concussion history, use of personal protective equipment such as a helmet, and other circumstances of an injury.



## Gaps in Determining the Prevalence of Persons with TBI-related Disability

Currently, ongoing surveillance of TBI-related disability does not exist. The only nationally representative estimates of TBI-related disability are based on extrapolations of one-time state-level estimates of lifetime TBI-related disability (Selassie et al., 2008; Zaoshnja et al., 2008). The limited data available result in the following limitations: no true national-level estimates; no 12-month prevalence

estimate of TBI-related disability; an inability to examine state-level variation; no recent estimates; an inability to monitor trends; and an inability to examine variation in TBI-related disability by important demographic subgroups such as race/ethnicity or military status.

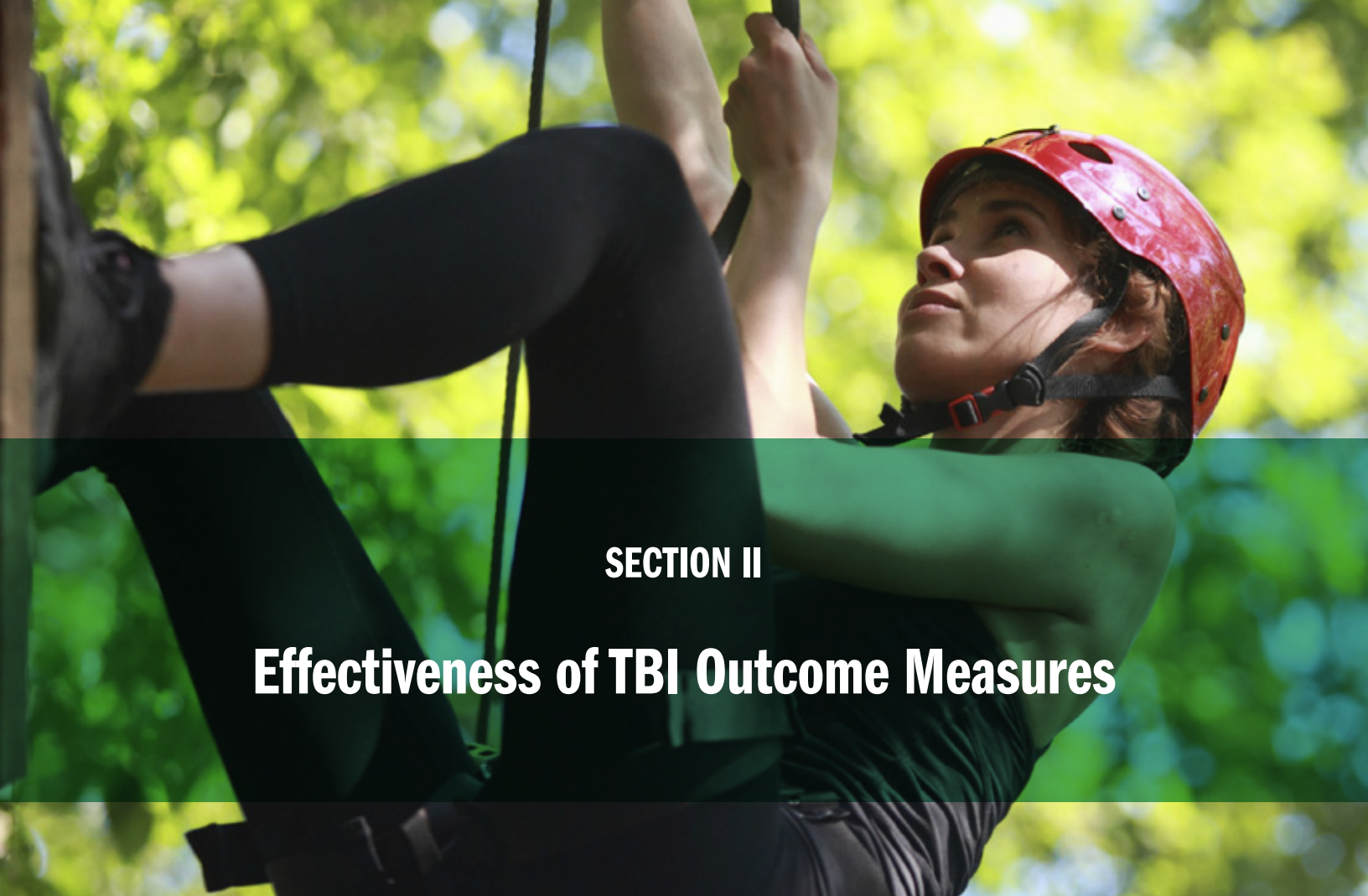


## Recommendations

Recommendations to fill gaps in understanding the epidemiology and consequences of TBI include the following:

- *Improve TBI incidence and prevalence estimates to include persons with TBIs who are treated in non-hospital settings and those with TBIs who are not receiving medical care.* Develop or identify sources of non-hospital TBI incidence data, such as data from physician offices and other sources of outpatient medical encounters, to improve estimates. Similarly, develop or identify data sources that capture information from persons who might have experienced a TBI but did not seek medical care for their injury.
- *Generate state-specific TBI estimates.* Collect and compile health care administrative data in all states to quantify and examine state-level variations in TBI burden. In addition, state-level TBI estimates can be used to inform decisions related to the allocation of preventive and rehabilitative services that are made at the state level.
- *Better understand injury mechanisms and their effect on sub-populations.* Examine trends in TBI incidence by injury mechanism and within population subgroups (e.g., children, older adults, and others) by using data systems such as HCUP. This practice can help target prevention resources to populations at greatest risk for TBI.
- *Enhance monitoring of sports and recreation concussions.* Develop and implement a concussion surveillance system that captures the full range of sports- and recreation-related concussions. Current surveillance systems only capture emergency department visits or injuries experienced in organized high school sports, collegiate athletics, and some professional leagues.
- *Produce population-level estimates of TBI-related disability.* Add TBI-related disability to large, existing national health surveys, and analyze large-scale claims or administrative datasets to produce population-level estimates.





## SECTION II

# Effectiveness of TBI Outcome Measures

### Importance of Outcome Measurement

The range of short and long term effects from a TBI is varied. Beyond TBI mortality, various elements related to outcomes must be characterized: physical, neuropsychological, psychiatric, behavioral, functional, and quality-of-life outcomes. The primary goal for TBI rehabilitation is to assist the injured person in achieving an optimal level of functioning. Outcome measurement helps us assess the status of a person's recovery and rehabilitation. This information can be used to monitor the progress of treatment in the clinical setting and to demonstrate treatment progress to a third-party payer. More broadly, these outcomes undergird research on the effectiveness of TBI rehabilitation and better inform future clinical interventions.

### The Common Data Elements Project

Recently, the Common Data Elements (CDE) Project served to better classify the key domains for TBI rehabilitation outcome measurement. The CDE Project was a joint effort of the National Institute of Neurological Disorders and Stroke (NINDS) and several co-sponsoring federal agencies. The goal of the CDE Project was to develop data collection standards for clinical research. The work was divided into workgroups comprised of specialists focused on problems related to the quality of TBI research data, including workgroups focused on PTSD, biomarkers, neuroimaging, and outcomes (Wilde et al., 2010).

The TBI CDE Outcomes Workgroup was convened to identify the core elements and a common set of outcome measures needed for TBI rehabilitation research (Wilde et al., 2010). The workgroup examined multiple outcomes potentially affected by TBI and identified measures that assess the range of short- and long-term outcomes for all severities of TBI (Wilde et al., 2010).

Descriptions of the outcome domains identified by the TBI CDE Outcomes Workgroup are provided in Table 5.

**Table 5. Outcome domains and descriptions for TBI common data elements**

<b>Domain name</b>	<b>Domain description and relevance in TBI</b>
<b>Global outcome</b>	Global outcome measures summarize the overall impact of TBI and incorporate functional status, independence, and role participation.
<b>Recovery of consciousness</b>	Duration of coma, level of consciousness, and rate of recovery contribute significantly to functional outcome and play a key role in treatment and disposition planning.
<b>Neuropsychological impairment</b>	Objective measures of neuropsychological functions such as attention, memory, and executive function are very sensitive to the effects of TBI, and often affect everyday activities and social role participation.
<b>Psychological status</b>	Psychological issues associated with TBI that affect outcomes include adjustment problems, personality changes (e.g., impulsivity), or mood disturbances. In addition, substance use disorders are prevalent among persons with TBI and can have a substantial impact on long-term outcomes.
<b>TBI-related symptoms</b>	TBI-related symptoms include somatic (e.g., headaches, visual disturbances), cognitive (e.g., attention and memory difficulties) and emotional (e.g., irritability) symptoms. They are commonly reported after TBI or concussion and may persist in some cases at all levels of TBI severity.
<b>Behavioral function</b>	Behavioral dysfunction (e.g., aggression, childlike behavior) is commonly reported following TBI and may contribute to difficulties in returning to work or school, personal relationships, and social functioning.
<b>Cognitive activity limitations</b>	Cognitive activity measures describe the impact of neuropsychological impairments on cognitively loaded real-world tasks such as instrumental activities of daily living, functional communication, and health and safety-related behaviors.
<b>Physical function</b>	Individuals with TBI (particularly severe TBI) may manifest difficulties in physical or neurological functioning, including cranial or peripheral nerve damage, impairment in motor functioning, strength and coordination, or impairment in sensation. These impairments may contribute to difficulties in performing day-to-day activities safely and independently.
<b>Social role participation</b>	Participation is defined by the World Health Organization (WHO) as “involvement in life situations” (World Health Organization [WHO], 2001) and commonly includes engagement in endeavors within one’s community. TBI affects many areas of participation including work or productive activity, recreation and leisure pursuits, and social and family role function.
<b>Perceived generic and disease-specific health-related quality of life</b>	TBI may create significant limitations in multiple areas of functioning and well-being, often reducing perceived quality of life with regard to multiple generic and disease-specific dimensions.
<b>Health-economic measures</b>	Health-economic measures to assess the cost benefit, e.g., the most cost-effective therapeutic procedure in terms of cost per Quality Adjusted Life Year.
<b>Patient-reported outcomes (future multidimensional tools)</b>	No single measure to date can adequately capture the multiplicity of difficulties that individuals with TBI may face. This domain includes emerging large-scale measurement tools for patient reported outcomes across several domains for generic medical populations, neurological compromise, and TBI-related complaints.



The TBI Outcomes Workgroup assessed the properties of each recommended outcome measure to account for its relevance in the identified domains. The workgroup recommended specific measures based on evidence demonstrating the reliability, validity, and other relevant properties. The effectiveness of the recommended measures is informed by the following criteria (Wilde et al., 2010):

- Sufficient representation in the scientific literature and/or widespread use in the TBI clinical and research communities;
- Evidence of adequacy, including construct validity, internal consistency, sensitivity to change, test-retest reliability, intra-/inter-rater agreement;
- Well-established normative data;
- Applicability across a range of injury severity and functional levels;
- Availability in the public domain;
- Ease of administration;
- Brevity.

Each measure has strengths and limitations and their respective results must be interpreted accordingly. For example, the Disability Rating Scale (DRS) is a global outcome measure that can be used to track general functional changes over the course of recovery. It has been shown to predict employment fairly well, particularly for persons with moderate to severe TBI. However, the DRS is relatively insensitive to subtle neurological deficits that might only be noticed by the injured person. The development of CDEs provides researchers with standardized measures that are both reliable and valid. Although each of the measures also has been examined for sensitivity to change, expected changes from rehabilitation might be subtle and outcome measures might fail to identify clinically meaningful changes. This is noted above in the discussion of the DRS, but might also be true for other global outcome scales when not used with detailed assessments that can take hours to implement (Shukla, Devi, and Agrawal). As a result of these concerns, agencies involved in the development of the TBI NRAP (Department of Defense, Veteran Affairs, Health and

Human Services and Education, 2013) included as one of its goals for immediate action: “Develop efficient, affordable, comprehensive, valid, and sensitive tools for assessing functional outcomes and quality of life over time” with the intent to “improve clinical assessment and enable measurement of treatment effectiveness specific to the TBI population”.

A complete list of the recommended outcome measures and their individual properties has been published elsewhere (Wilde et al., 2010).

## TRACK-TBI Study

A multicenter study, Transforming Traumatic Brain Injury Research and Clinical Care (TRACK-TBI), funded by NIH-NINDS, sought to validate the feasibility of implementing a broad range of TBI-CDEs in a prospective observational study. Patients were recruited through four study sites, including three acute care sites (San Francisco General Hospital, University of Pittsburgh Medical Center, and University Medical Center Brackenridge in Austin, Texas) and a rehabilitation center (Mount Sinai Rehabilitation Center in New York City). Although this study concluded that the implementation of the TBI CDEs is feasible, TRACK-TBI researchers identified several gaps related to the outcome-related CDEs for adult TBI (Yue, et al., 2013).

These gaps included the identification of a lack of validated outcome measures for TBI patients living with greater disability. In addition, while the TBI CDE Workgroup considered the availability of outcome measures validated among non-English speaking patients as a factor in recommending specific measures, TRACK-TBI found several measures that could not be administered to non-English speaking patients (Yue et al., 2013). The researchers recommended validating additional TBI CDE measures in languages other than English and including nonverbal memory tests, which can be useful irrespective of the language spoken by the patients (Yue et al., 2013). TRACK-TBI has been expanded and is now an ongoing study designed to establish more precise methods for TBI diagnosis and prognosis, improve outcome assessment, and compare the effectiveness and costs of tests, treatments, and services. Harmonized data collection with a parallel study funded by the European Union, Collaborative European Neurotrauma Effectiveness Research (CENTER-TBI) will add to its value.

## The Pediatric Common Data Elements Project

Although the effects of TBI cut across developmental stages, outcomes frequently manifest differently in a child than in an adult. For example, temper tantrums might be an indicator in children whereas belligerence might be an indicator in older adults. Consequently, measuring TBI outcomes in children can be difficult and presents an ongoing data challenge. Because children have a higher prevalence of executive function impairments (Anderson, Bigler, and Blotter, 1995; Levin, Goldstein, Williams, and Eisenberg, 1991), determining whether results in clinical settings correspond to real life situations can be difficult (Eslinger, Biddle, and Grattan, 1997; Wilson, 1993). Therefore, a parallel attempt by the Pediatric CDE Workgroup was initiated to address the particular complexities involved in pediatric TBI research. Convened in 2011, the Pediatric CDE Workgroup was charged with modifying the adult TBI CDE research recommendations to include domains of functioning appropriate for children and adolescents. The workgroup emphasized the need for multiple outcome measurements across developmental stages—such as the transition from elementary school to middle school. Outcome measures spanning developmental age groups were given preference, and attention was given to assessing domains for infants and toddlers (McCauley et al., 2012). The pediatric CDEs include all of the domains identified as important for

adults. In addition, the domains of academics, adaptive and daily living skills, family and environment, language and communication, and social cognition were included to reflect the importance of these domains for children’s every-day performance. Measures validated among infants and toddlers were identified as an additional domain. A complete list of these recommended outcome measures and their individual properties contributing to effectiveness has been published (McCauley et al., 2012).

To better allow for comparisons across study types (e.g., epidemiology, long-term outcome research, and clinical trials), the adoption of the CDEs and the use of common outcomes measures is critical. Accumulating information from multiple studies can be used to improve the identification of persons at risk for persistent complications, for assessment of the short- and long-term effects of TBI, and management of persons from the stages of early care to long-term care and re-integration into society. The CDE workgroup’s recommendations for outcome studies for adults are highlighted in a series of published articles (Kaloupek et al., 2010; McCauley et al., 2012; Nash et al., 2010; Whyte, Vasterling, and Manley, 2010; Wilde et al., 2010).

Table 6 contains the outcome domains unique to the pediatric population.

**Table 6. Outcome domains and descriptions for TBI common data elements unique to pediatrics**

Domain	Description
<b>Academics</b>	Children with TBI have been found to have significant academic difficulties characterized by school failure and deficits in academic achievement, such as reading, math, and written language.
<b>Adaptive and daily living skills</b>	Adaptive and daily life functioning consists of multiple domains and involves the ability to adapt to and manage one's surroundings to effectively function in home, school, and community life. This domain also includes children's functional activity and activity limitations.
<b>Family and environment</b>	This domain includes moderators of outcome related to family and environment, as well as the consequences to family.
<b>Infant and toddler measures</b>	Childhood and adolescence represent a wide range of developmental levels, and most pediatric measures are inappropriate for infants and toddlers. Therefore, limited special measures are included for this age range.
<b>Language and communication</b>	Deficits in language comprehension and expression and in speech articulation are common after TBI. Measures of language use in context (pragmatics) are particularly sensitive to TBI effects.
<b>Social cognition</b>	Social cognition refers to the cognitive processes necessary for successful social interaction. A growing body of literature has documented impairments in this domain after TBI, in some cases independent of other cognitive impairments.

Source: McCauley et al., 2012

## Factors Influencing Outcomes

Recovery from TBI is influenced by classes of factors such as individual patient characteristics, social-environmental factors (e.g., family support systems), and barriers to rehabilitation access. The following sections outline some of these specific factors.

### Individual Characteristics

Individual characteristics, such as age and pre-injury functioning, can influence outcomes after TBI. These characteristics differentially influence outcomes based upon the severity of injury. For example, children who sustain a moderate-to-severe TBI before the age of 7 years have substantially worse short- and long-term outcomes than children who suffer a similar injury at an older age (Anderson, Bechara, Damasio, Tranel, and Damasio, 1999; Barnes, Dennis, and Wilkinson, 1999; Dennis, Wilkinson, Koski, and Humphreys, 1995; Ewing-Cobbs et al., 1997; Taylor and Alden, 1997; Verger et al., 2001). Behavioral changes and problems in adaptive functioning (i.e., coping skills) are the most persistent negative impacts of TBI in children (Anderson, Morse, Catroppa, Haritou, and Rosenfeld, 2004; Chapman et al., 2010; Fay et al., 2009; Schwartz et al., 2003). Older adults who sustain a TBI have lower survival rates and less favorable outcomes than those who sustain a TBI during young and middle adulthood (Frankel et al., 2006; Hukkelhoven et al., 2003).

Pre-injury functioning also is related to various cognitive and behavioral outcomes. Persons with higher levels of pre-injury cognitive functioning often preserve more functional capacity after TBI (Kesler, Adams, Blasey, and Bigler, 2003). This hypothesis suggests that a person might be able to use cognitive resources post-injury that were not needed or used before the injury. Finally, growing evidence of the role of genetic influences on outcome suggests that some alleles, or gene variants, might confer neuro-protection to some and vulnerability to others post-TBI (Zhou et al., 2008).

### Social-Environmental Factors

Social-environmental factors, such as socioeconomic status, caregiver and family functioning, and social support influence the effectiveness of rehabilitation treatments (Sander, Maestas, Sherer, Malec, and Nakase-Richardson, 2012). Returning to participation in pre-injury social roles also is an important aspect of functioning for adults following a TBI. The ability to function in social roles is

related to psychological and neurocognitive outcomes, but can also be influenced by other factors such as caregiver and family support, independent of TBI severity (Hart et al., 2010). Social-environmental factors, such as the ability to live independently, maintain employment, or be involved in meaningful interpersonal relationships such as marriage, also can influence outcomes for persons affected by TBI (Sander and Struchen, 2011; Struchen et al., 2011).

Family-level factors are critical social-environmental influences on outcomes for children following a TBI (Gerring and Wade, 2012). Family-level factors can include caregiver distress or depression, and deteriorating family functioning (Aitken et al., 2009; Wade, Carey, and Wolfe, 2006a). Aspects of the home environment, such as parental responsiveness, negativity, and discipline practices, are linked to a child's behavioral recovery (Wade et al., 2011a; Wade et al., 2002). Economic and social disadvantage have been associated with poor cognitive and academic outcomes following severe TBI (Taylor et al., 2002; Yeates, Taylor, Walz, Stancin, and Wade, 2010). Well-functioning caregivers and available financial and social supports contribute to better recovery and outcomes (Sander et al., 2002; Sander et al., 2009). In fact, family-centered interventions have been shown to be beneficial. Research has shown improved behavior of pediatric TBI patients and improved family functioning from this type of intervention (Wade et al., 2003; Wade, Walz, Carey, and Williams, 2009). Studies also have demonstrated that cognitive-behavioral, problem-solving therapy can improve several pediatric outcomes, including executive function skills, behavior, and caregiver distress (Wade et al., 2006a, 2006b, 2006d, 2010, 2011a; Wade, Michaud, and Brown, 2006c; Wade et al., 2011b).

### Access to Care after Hospitalization

Persons with TBI who transition from acute injury care often are discharged home or admitted to one of various rehabilitation programs or facilities. Discharge disposition is influenced by both clinical and non-clinical factors. These factors frequently influence the type and quantity of rehabilitation care received, which can affect TBI outcomes. In some instances, adults with moderate to severe TBI are discharged home where the level and intensity of rehabilitation is not well defined (Cuthbert et al., 2011). For persons who do not immediately return

home, the decision to discharge patients to inpatient rehabilitation (i.e., post-acute rehabilitation) or outpatient rehabilitation programs (i.e., sub-acute rehabilitation) is complex because the decision is frequently influenced by age, comorbidities, concurrent injuries, financial resources, and injury severity (Cuthbert et al, 2011). Outpatient rehabilitation programs are less intense, and are composed of fewer total hours of therapy, on average, compared with inpatient rehabilitation.

Type of insurance coverage also is a predictor of discharge disposition (Buntin, 2007; Chan, Doctor, Temkin, MacLehose, Esselman, Bell & Dikmen, 2001; Cuthbert, Corrigan, Harrison-Felix, Coranado, Dikers, Heinneman & Whiteneck, 2011). For example, the Centers for Medicare & Medicaid Services (CMS) established specific criteria in regulation for inpatient rehabilitation admission in order to fulfill statutory coverage requirements that inpatient rehabilitation facility claims are for reasonable and necessary services. A patient's condition must require active and ongoing therapy by at least three separate disciplines, and the patient must be capable of participating in at least 3 hours of therapy, 5 days per week

or 15 hours during a 7-day period (Centers for Medicare & Medicaid Services, 2012). In addition, a patient must also be reasonably expected to actively participate in, and benefit significantly from, the intensive rehabilitation therapy program. Further, face-to-face supervision by a rehabilitation physician is required at least 3 days per week, and an intensive and coordinated interdisciplinary team approach to the delivery of rehabilitative care is also required. Patients who do not meet these criteria are discharged home or to sub-acute rehabilitation. Also, research suggests that patients with Medicare are more likely to be discharged to inpatient or outpatient rehabilitation (vs. home) compared with patients who pay out-of-pocket (Cuthbert et al., 2011). Outcomes for persons with TBI can be influenced by any of these external factors regardless of injury severity. Additional research is required to understand predictors of discharge disposition for persons with moderate-to-severe TBI and the subsequent bearing on outcomes.



## Gaps in TBI Outcome Measurement

Outcome measurement plays a key role in identifying effective interventions. Research demonstrating effectiveness can then guide the targeting of interventions and the allocation of resources for persons with TBI. Outcome measurement also plays a key role in clinical rehabilitation settings, both as a way to monitor the progress of individual patients and as an indicator to third-party payers that a patient is making progress. Given the important functions of outcome measurement, the quality of outcome measures—validity, reliability, and sensitivity—is of paramount importance. These properties describe a measure’s ability to detect real changes in a particular outcome domain. Measures that are valid, reliable, and sensitive can be trusted to produce an accurate and reproducible assessment of the effects of an intervention and can help avoid inaccurate interpretations of intervention effectiveness. The potential for missing the identification of promising practices or the promotion of an ineffective intervention (Bagiella et al., 2010) can occur in the absence of validated measures.

The recent work conducted by the CDE TBI Outcomes Workgroup represents a step forward in identifying the key domains of outcome measurement and the identification of valid, reliable, and sensitive measures within those domains. By identifying outcome domains and outcome measures, based on criteria that support their effectiveness for use in research, the CDE TBI Outcomes Workgroup sought to bring consistency to outcomes measurement that will improve the quality and comparability of TBI outcomes research.

However, a number of challenges are not adequately addressed by the recommended outcome measures (Wilde et al., 2010). For example, some measures require self-report. This can be problematic for persons with TBI who have cognitive and other deficits that impede communication. In these cases, a proxy might be used but more research is needed to determine the validity of proxy reports. Additionally, more representation of vocational and developmental outcome measures is needed. Also, some outcome measures have only been validated in limited



populations (e.g., pediatric vs. adult, moderate/severe vs. mild) and some have been validated primarily outside of the TBI context (e.g., attention deficit hyperactive disorder [ADHD], stroke). Lastly, standard measures are still needed to account for various outcomes that are important for employment, community participation, and childhood development after a TBI.

There has been a recent trend toward examining patient-centered outcomes based on the provision of feedback by patients and their care-givers related to treatment outcome. This has been helpful in ensuring that rehabilitation progress translates to improvements in the day-to-day life of patients. However, more studies are needed to validate patient-centered outcome measures.

The efforts of the CDE TBI Outcomes Workgroup primarily addressed the need for a common set of outcome measures for research. However, administration of some CDE recommended outcome measures might not be feasible in clinical practice settings. For example, social role participation can only be assessed following inpatient rehabilitation discharge when the affected persons attempt to re-engage with their community.

Most clinical assessments measure global outcome domains during inpatient rehabilitation. This is in contrast to individual specialties that might use discipline-specific indicators of therapeutic progress that do not have a

comparable level of research support. Although the CDE TBI Outcomes Workgroup has made progress in identifying key outcome domains and valid outcome measures within the research context, a similar need exists for agreement regarding the measurement of outcomes in the clinical context. This will aid in comparing outcomes across clinical settings and improving the utility of clinical data for outcomes research.

The TBI CDE Workgroup also identified several measures within each domain that have the potential to surpass the currently recommended measures. However, the measures identified did not have a comparable level of research support and were identified as promising. The measures identified as promising are good candidates for future research that could help improve current practices.

The TRACK-TBI study examined the feasibility of administering a broad range of TBI CDEs for adults, but no such large-scale effort has been made for the pediatric TBI population. Pediatric CDEs assess a broader range of outcomes, including academic outcomes, so a similar undertaking could identify particular challenges related to examining the CDE domains among this population. Some of this work has begun and one example is the NIH-funded Approaches and Decisions in Acute Pediatric TBI (ADAPT) study which utilizes a number of the pediatric CDEs in a pediatric population that has experienced a moderate to severe TBI.



## Recommendations

Recommendations to address the gaps in TBI-related outcome measurement include the following:

- *Develop comprehensive outcome measures that enable measurement of treatment effectiveness specific to the TBI population.* It is essential to develop tools that are sensitive to changes associated with treatment and rehabilitation regardless of TBI severity.
- *Increase validation of outcome measures in sub-populations.* Conduct validation studies of outcome measures among particular sub-populations in which validity, reliability, and sensitivity have not been assessed previously. This is critical in order to expand scientific knowledge of outcomes and establish best practices for sub-populations, such as children, where evidence is still developing.
- *Better leverage health information technology (IT).* Examine the expanding use of electronic health records as 1) a method for tracking patient progress from one level or system of care to another and 2) as a way to better examine the effectiveness of TBI interventions.
- *Create additional outcome measures that can be readily administered to non-native English speakers.* The TRACK-TBI study found that a number of the measures recommended by the TBI CDE Workgroup could not be administered to non-native English speakers.
- *Test and adapt the CDEs among children and adolescents.* Similar to how the TRACK-TBI study examined the feasibility of implementing the CDEs in adults, a need exists to examine the feasibility of assessing the full range of CDEs among children and adolescents.
- *Assess promising CDE outcomes measures.* Conduct additional studies of the measures the TBI CDE Workgroup identified as promising to determine whether they might warrant inclusion as recommended measures.
- *Enhance involvement of patients and families in assessing rehabilitation outcomes.* Increase inclusion of patient- and family-centered outcomes in research studies to better document the real-world utility of rehabilitation.







## SECTION III

# TBI Rehabilitation

## Goals and Purpose of TBI Rehabilitation

TBI rehabilitation is the medical and therapeutic services designed to improve and maintain cognitive, sensorimotor, and psychosocial functioning in persons with TBI. Ultimately, rehabilitation should “promote and optimize the activities, function, performance, productivity, participation, and/or quality of life of the person served” (CARE, 2013) and thus reduce the likelihood of TBI-related disability.

## Effectiveness of TBI Rehabilitation Practices

### *Types of TBI Rehabilitation Services*

Persons with severe TBI are more likely to suffer cognitive and physical impairment compared with those with mild TBI (Dikmen et al., 1986, 1995; Gentilini et al., 1985; Gronwall and Wrightson, 1974). Multidisciplinary teams commonly provide coordinated care for those with severe TBI (Brasure, 2012; Sander and Constantinidou, 2008; Wertheimer et al., 2008). The composition of a multidisciplinary team can include specialists trained in psychology, occupational therapy, physical therapy, speech-language pathology, therapeutic recreation, rehabilitation nursing, and case management. The inpatient rehabilitation team is typically under the direction of a physiatrist. This is a physician whose specialty is physical medicine and rehabilitation. The continuum of care is broad and ranges from inpatient rehabilitation to outpatient and community rehabilitation (Table 7).

Practices and interventions within each rehabilitation discipline address the specific health effects of TBI—each contributing to the overall effectiveness of rehabilitation. TBI rehabilitation consists of therapies broadly categorized as *cognitive* and *physical*. Cognitive rehabilitation (CR) consists of therapies used to manage deficits in thought processes and behavior, which

includes comprehension, perception, and learning. Physical rehabilitation focuses on enhancing different forms of mobility by improving physical factors such as strength and endurance.

### Special Considerations for Rehabilitation Among Children with TBI

Children who are acutely disabled following a TBI are a vulnerable population. As a result, they might receive both inpatient and outpatient medical rehabilitation therapies—including occupational therapy, physical therapy, and speech-language therapy. However, long-term medical rehabilitation services often hinge on availability of financial resources to pay for care. The most frequently reported unmet health care need by parents is for cognitive services for their child. Thirty-one percent of parents report an unmet need at 12 months post-injury because of a lack of physician recommendation, lack of provision by school, or expense (Slomine, et al., 2006).

Adding to the complications, frequently a gap occurs between the need for pediatric rehabilitation services and the receipt of needed services. This might be affected by the level of parents’ understanding regarding the need for therapy and educational services after their child is discharged from acute medical care (Gfroerer, Wade, and Wu, 2008; Slomine et al., 2006; Taylor et al., 2003). This disconnect can influence children’s receipt of both behavioral and academic or cognitive services. Typically, children who receive inpatient rehabilitation services are tracked after they transition out of inpatient rehabilitation. However, children who need services, but do not meet the requirements for inpatient services, might not be tracked. This can negatively affect whether they receive those needed services.

Families of children who are affected by TBI face the challenge of negotiating two different service models following their injury: the medical model and the school-based model. Both models have different mandates for service access and varying delivery and funding considerations (Haarbauer-Krupa, 2009, 2012). In the medical model, rehabilitation services are provided based on assessment of medical necessity and injury recovery. In contrast, the school-based model provides services for TBI under the Individuals with Disabilities Education Act, which is based on medical documentation of the TBI and assessment results demonstrating learning needs.

**Table 7. TBI Rehabilitation programs and settings**

Type of care	Description/Eligibility/Funding
<b>Skilled nursing facility/Sub-acute rehabilitation</b>	In a separate setting than the hospital. Individuals require multiple therapies that are delivered at less intensity. Length of stay average 30–60 days.
<b>Long-term care hospital (LTCH)</b>	Individuals have a medically complicated status requiring ongoing pulmonary and cardiac support. Length of stay approximately 25 days.
<b>Home health</b>	Individuals are medically stable, seen in their homes, requiring more than one therapy service. May have slower recovery and not able to participate in multiple therapies.
<b>Comprehensive inpatient rehabilitation</b>	Can occur in acute hospital rehabilitation floor or specialized brain injury unit. Individuals are medically stable and can benefit from 3 hours of therapy per day. A support system for discharge is in place. Length of stay 19-30 days.
<b>Day treatment/Home/Community-Based services</b>	Can occur in a hospital or community-based setting. Individuals are medically stable and can participate in 5 hours of therapy per day.
<b>Outpatient rehabilitation</b>	Delivered in a hospital facility or non-facility private practice. Individuals are medically stable and can participate in a single service.
<b>Post-acute residential</b>	24/7 care for therapeutic behavioral monitoring based on individualized need for cognitive and behavioral support.
<b>Neurobehavioral</b>	24/7 care for severe neurobehavioral symptoms. Able to participate in 5-6 hours of treatment per day. Length of stay based on type of services utilized.
<b>Independent living</b>	Delivered in a variety of locations, including the home, group homes, or supported living programs.
<b>Vocational rehabilitation</b>	State and private services for career counseling, training, and placement.

*Adapted from Zasler, Katz, and Zafonte, 2013*

This has resulted in under-identifying affected students for educational support services (DiScala and Savage, 2003; DiScala, Osberg, and Savage 1997; Glang, Todis, Thomas, Hood, Bedell, and Cockrell, 2008; Hawley, 2004). Although return to classroom protocols have been developed based on expert consensus, adoption of these protocols has been limited due to a need for more education for school personnel regarding how to best implement a return to the classroom (Dettmer, Ettl, Glang, & McAvoy, 2014; Halstead, et al., 2013).

Although most medical rehabilitation therapies are discontinued within the first year post-injury, the effects of pediatric TBI on cognition, behavior, and adjustment frequently persist and can worsen over time. However, a service delivery gap often exists because few children receive special educational services in schools (Glang, Tyler, Peason, Todis, and Morvant, 2004). Only 50.9% of pediatric TBI patients receive hospital-to-school transition services (Glang et al., 2008). Equally troubling, the need for special education services is not identified among 33% of children (Glang et al., 2008). Obtaining the appropriate frequency and intensity of services in the school can be affected by a lack of understanding by staff regarding the need to integrate medical and school services (Haarbauer-Krupa, 2009).

Reports of unmet health care needs and under-identification of children affected by TBI in schools are partly related to the difficulties parents face in navigating the continuum of services following TBI. In addition, students who sustain less severe injuries, concussions or mild TBIs, often fail to receive school accommodations despite recommendations that accommodations be made available for several weeks to months post-injury (Gioia, Kenworthy, and Isquith, 2010). As a consequence, both parents and school personnel can become frustrated and discouraged by a child's continuing difficulties and disruption to their normative development (Chapman et al., 2010).

## Overview of Knowledge and Practice in Rehabilitation

The following sections review the current state of knowledge and practice regarding the effectiveness of cognitive and physical rehabilitation for TBI. This section is followed by a description of longer-term approaches that might be employed, including community-based rehabilitation and vocational rehabilitation.

## Cognitive Rehabilitation

### Definition, Methods, and Goals

Cognitive rehabilitation (CR) focuses on improving cognitive deficits and the effects of cognitive impairment on interpersonal communication, behavior, emotions, community participation, and academic and vocational functioning. Services are directed to achieve functional changes by (1) reinforcing, strengthening, or reestablishing previously learned patterns of behavior, or (2) establishing new patterns of cognitive activity or compensatory mechanisms for impaired neurological systems (Harley et al., 1992).

CR is a collection of treatments tailored to cognitive impairments and psychological health. It is also a core component of TBI rehabilitative care for those persons with moderate and severe TBI (Cicerone et al., 2005). It is provided in approximately 95% of all TBI rehabilitation programs in the United States (Mazmanian, Kreutzer, Devany, and Martin, 1993). The scope, duration, timing, and intensity of CR services for post-acute rehabilitation are often affected by the availability of financial resources, including the level of insurance coverage available to an individual patient (Katz, Ashley, O'Shanick, and Connors, 2006).

CR for TBI is rooted in one of two basic models: *restorative interventions* and *compensatory skill development*. Restorative interventions are designed to improve cognitive functioning through practice. The cognitive skills practiced are targeted in a hierarchical fashion, from less sophisticated to more complex components of cognitive functioning. Compensatory skills development involves the teaching of skills for adaptation to impaired cognitive functioning. Within the medical model, CR is administered through the disciplines of neuropsychology, speech-language pathology, and occupational therapy. However, CR for children is rarely delivered in medical settings. Instead, it is delivered through schools with a focus on acquisition of academic content (Haarbauer-Krupa, 2009).

Various technological approaches can be employed as part of CR. For example, specialized training with external assistive devices (e.g., personal data assistants [PDAs], global positioning system [GPS] devices, paging systems, and smartphones) can be implemented to make it easier to perform activities of daily living. For example, pager reminders can prompt patients to take medication, get up

in the morning, and perform daily housekeeping tasks (Wilson, Scott, Evans, and Emslie, 2003). Therapist guidance is required for selecting a device that best suits cognitive capacities, as well as support for programming and maintenance of the device (LoPresti, Mihailidis, and Kirsch, 2004).

### **Effectiveness of Cognitive Rehabilitation**

Several scientific reviews have synthesized the existing literature on CR interventions to determine their effectiveness in improving cognitive functioning (Cicerone et al., 2000, 2005, 2011; Institute of Medicine [IOM], 2011; Rohling, Faust, Beverly and Demakis, 2009). For example, the Cognitive Rehabilitation Task Force of the ACRM Brain Injury Interdisciplinary Special Interest Group evaluated 370 studies and found that CR is effective during the post-acute period, even 1 year or more after injury (Cicerone et al, 2000, 2005, 2011). Further analysis combining results from a subset of these studies (Rohling et al., 2009) concluded that the scientific evidence supports the effectiveness of CR in patients with moderate and severe TBI.

However, an Institute of Medicine (IOM) committee concluded that the evidence was insufficient to provide practice guidelines, particularly with respect to selecting the most effective treatments for a specific person (IOM, 2011). The insufficiency of the evidence was largely attributed to limitations in research designs for rehabilitation evaluation studies. Flaws identified included the lack of operational definitions for different forms of CR therapy, small sample sizes, the wide range of outcomes targeted, and lack of testing for treatment moderators. Taken together, the limitations identified suggest the need for more research to determine the effectiveness of specific CR therapies and the circumstances in which they confer the most benefit.

And yet, some studies do support the effectiveness of specific CR interventions. Direct attention training and instruction in the use of a memory notebook or problem-solving strategies have been found to be effective in promoting the development of compensatory strategies (Cicerone et al., 2011). Also, metacognitive (i.e., self-awareness) training has been shown to improve attention and alleviate executive function deficits contributing to poor self-monitoring and self-regulation of behaviors (Cicerone et al., 2011). Evidence also is sufficient to

support the effectiveness of interventions and cognitive-linguistic therapies designed to improve functional communication deficits after TBI (Cicerone et al., 2011; Demir, Altinok, Aydin, and Koseoglu, 2006).

In summary, the literature suggests that CR is effective in teaching those affected by TBI to learn and apply skills to compensate for cognitive limitations, although there is currently an insufficient body of evidence that demonstrates the effectiveness of this method in treating the underlying cognitive deficits caused by a TBI (IOM, 2011). However, insufficient evidence does not mean that CR treatment is not effective, but rather that not enough research of high quality has demonstrated positive outcomes. Specifically, research is needed to identify the patient and treatment factors that contribute to successful outcomes while addressing methodological concerns (Cicerone et al., 2011; Rohling, et al., 2009). Finally, additional studies are needed to evaluate therapies used to restore attention and memory (IOM, 2011).

### **Physical Rehabilitation**

#### **Definitions, Methods, and Goals**

Physical rehabilitation addresses the effects of TBI on sensory and motor systems. Therapy sessions include the use of physical modalities (e.g., massage, exercise, or applied heat or cold), therapeutic exercise, adaptive equipment, orthotics, and medications. As persons with TBI progress through recovery, a greater emphasis is placed on activity level, conditioning, and participation in community activities. Psychiatrists, physical therapists, and occupational therapists are most often involved in physical rehabilitation. Other disciplines also can be involved in motor skill acquisition. Therefore, having an interdisciplinary treatment team in place is essential (Sullivan, 2007).

For persons at a more advanced stage of recovery, the primary goal of physical rehabilitation is to improve muscle strength, balance, motor control, and functional ability. Adjusting the rehabilitation session to the individual person is essential during this stage (Crisis Prevention Institute, 2005). For persons who receive treatment in inpatient or outpatient rehabilitation programs, treatment progresses and incorporates strategies to promote independence in self-care activities. These strategies include addressing functional mobility, such as walking and climbing stairs. Additionally, various interventions can be



used to address specific impairments (Acker and Linder, 2004; McCulloch, Blakley, and Freeman, 2005) such as disturbances of balance and equilibrium (Shumway-Cook, 2007).

### ***Effectiveness of Physical Rehabilitation***

Evidence supports the general effectiveness of physical rehabilitation in improving TBI outcomes (Bland, Zampieri-Gallagher, and Damiano, 2011; Betker, Desai, Nett, Kapadia, and Szturm, 2007; Irdesel, Aydinler, and Akgoz, 2007; Mossberg, Amonette, and Masel, 2010; Scherer and Schubert, 2009; Shaw et al., 2005). Persons who have little or no response to stimulation (i.e., comatose, vegetative or minimally conscious state) benefit from activities that prevent involuntary muscle contraction or muscle shortening and skin breakdown. Regularly scheduled passive range-of-motion exercises and body positioning are techniques that are used to positive effect (Winkler, 2013). To assist with physical rehabilitation, casts or devices are helpful in treating muscle shortening at the knee, ankle, wrist, and elbow (Singer, Jegasothy, Singer, and Allison, 2003). Progression from lying down to being able to sit up allows the physical therapist to monitor and promote responsiveness, head and trunk control, and improved pulmonary function. Assistance in unsupported sitting and a proper wheelchair seating assessment also are beneficial for contraction and skin-breakdown prevention. Equipment, such as standing frames or tilt tables, can be used to maintain bone structure, elongate shortened muscles,

challenge endurance, and stimulate the minimally conscious person. Body-weight-supported (BWS) gait devices and knee-ankle-foot orthotics can be used with manual assistance to initiate standing postures. BWS devices can lead to improved cardiovascular function and assist with the beginning of walk training (Mossberg, Orlander, and Norcross, 2008; Wilson and Swaboda, 2002).

Evidence supports the treatment efficacy for several specific physical rehabilitation methods. Gaming and virtual reality-based treatment methods are emerging as an adjunct to physical therapy standards of practice for treatment of persons with TBI (Betker et al., 2007; Scherer and Schubert, 2009). One study demonstrated the effectiveness of improved goal-oriented, task-specific training with the use of a gaming system to promote practice of short sitting balance control for persons with a TBI. Additionally, a game-based training tool yielded an increase in practice volume and attention span, and furthermore, improvements in dynamic sitting balance control (Betker et al., 2007). Certain evidence indicates that virtual reality and other methods to improve vestibular function and balance result in improvements in both gait and gaze stability of persons with TBI sustained during blasts (Scherer and Schubert, 2009). However, approaches such as motor interventions, proprioceptive muscle training, and neurodevelopmental treatment have been used in clinical practice with limited research regarding their effectiveness.

Pharmacologic intervention for reduction of involuntary muscle contraction, a common physical effect of severe TBI, is a growing field. Chemo-neurologic agents can be administered locally in order to target specific muscles. Orally ingested medications can also offer relief from involuntary muscle contraction. However, those persons who most often need intervention for muscle contraction are sometimes the most sensitive to the cognitive side effects of pharmacologic interventions, particularly in the area of attention (Esquenazi et al., 2012).

## Rehabilitation Services Following Acute Rehabilitation

### Community-based Programs

Although numerous persons with TBI are able to return to their communities when discharged from the hospital or inpatient rehabilitation, a portion will continue to require therapy services and support for independent living, family life, work, and leisure activities. To meet this need, community-based programs help persons affected by TBI reclaim a presence in the community that is “meaningful, satisfying and socially productive” (Volpe, 2012). Community-based rehabilitation programs also are known as Community Integrated Rehabilitation (CIR; Trudel, Nidiffer and Bartg, 2007), Community Integration Programs (Glenn, Goldstein, Selleck and Rotman, 2004) or Post-Acute Brain Injury Rehabilitation Programs (Malec and Basford, 1996). Unlike medical rehabilitation

programs, CIR programs often form partnerships with state agencies, brain injury support groups, and volunteers. Such programs can be described as either supportive—providing assistance to persons with TBI to maintain their current status—or more intensive, with goals related to improving health and functional abilities, and returning to work and/or community participation (Malec, 2012). Home-based rehabilitation, telephonic or web-based counseling focused on helping a person with TBI identify needed and available outpatient services, is one type of community-based program that might be funded by medical insurance (Phillips, et al., 2012). Types of community-based program models are described in Table 8. Eligibility for community-based programs is determined by 1) program requirements for funding and services offered and 2) individual level of functioning and funding resources.

Some states provide support for community-based rehabilitation programs. Consequently, funding levels and the availability of programs vary by state. Because of the heterogeneity of these programs, effectively describing their admission eligibility criteria, composition of services, and other key characteristics is difficult. As a result, research on community-based program outcomes is limited. Despite limitations with respect to research support, community-based program development continues in state and local communities because of the recognition of the chronicity of needs for persons affected by TBI.

**Table 8. Types of community-based programs in the United States**

Type of program	Description	Participant characteristics
<b>Neurobehavioral</b>	Residential setting, intensive behavioral management	Severe behavior disturbances that require 24-hour supervision
<b>Residential community</b>	Residential setting with full community integration, comprehensive clinical team treatment	A holistic milieu-oriented environment for individuals who require 24-hour supervision
<b>Comprehensive holistic</b>	Day treatment programs, integrated multimodal rehabilitation; outpatient programs	Need for immediate services; benefit from improved awareness
<b>Home-based</b>	Education and advisement; telephonic and web-based support; counseling related to availability of outpatient services	Ability to reside at home and direct self-care
<b>Club house</b>	Participants as members of a community who have decision-making rights; key features promote community participation	Ability to take responsibility for building own capacity

Source: Malec et al., 2012; Trudel et al.; 2007; Volpe, 2012

## Vocational Rehabilitation Services

For persons affected by TBI, vocational rehabilitation (VR) is a treatment option that offers assistance with career planning and achievement of career goals. VR rehabilitation can include assessment, counseling, guidance, training and education, and on-the-job training. Because of the range in severity and types of difficulties among persons affected by TBI, person-centered and individualized planning is needed to comprehensively address the goal of returning to work. The models of VR and a brief description of each are provided in Table 9. Models of VR program implementation vary by state, but primarily address three areas of concern: work preparation, work trials, and supported employment (Tyerman, 2012). Evidence indicates that VR clients who are successfully employed can substantially increase their income and decrease their reliance on public support (Johnstone et al., 2006; Zuger, Brown, O'Neill, Stack, and Amitai, 2002). No comprehensive systematic research on access, use, and effectiveness of state-based VR programs is available; thus, understanding their organization and effectiveness is limited. However, certain research has established that receipt of VR services is a better predictor of vocational success for persons with moderate-to-severe injuries than injury, psychological, or demographic factors (Johnstone, Vessell, Bounds, Hoskins, and Sherman, 2003). In addition, on-the-job training, vocational counseling, supported employment, and case-management services have been identified as predictors of positive employment outcomes (Chesnut et al., 1998; Johnstone et al., 2006).



**Table 9. Models of vocational rehabilitation (VR) following traumatic brain injury in the United States**

<b>Program-based vocational rehabilitation</b>	A program-based approach offers intensive individualized cognitive and work skills, guided work trials, and assistance with placement.
<b>Individual placement model of supported employment</b>	This model involves job placement, on the job training, job coaching, and long-term support.
<b>Case coordination approach</b>	In this approach, VR is a part of an overall model of care that includes other rehabilitation services. Focus is on early intervention and continuity of care across time.
<b>Consumer-directed approach</b>	Described as the “Clubhouse Model,” individuals with brain injury play a major role in running the program. Professional staff are involved “opportunistically” according to members’ goals, preferences, and activities. Those with requisite skills receive support for community-based employment.

Source: Fadyl and McPherson, 2009; Tyerman, 2012

## Gaps in Evaluating the Effectiveness of TBI Rehabilitation

Evaluating the effectiveness of TBI rehabilitation is a challenge because of the complexity of TBI pathophysiology, limitations of common research methodology, and the diversity of rehabilitation therapies and settings (Brasure, 2012). TBI can have numerous health effects that manifest differently in each person. As a result, therapies must be tailored to the individual person. This also has a bearing on research because finding a sizeable study population with similar attributes for outcome studies is challenging. In addition, pre-injury factors such as age, pre-injury functioning, socioeconomic status, caregiver and family functioning, social support, and access to care, can influence the recovery of a patient. Also, qualities such as the timing, duration, and intensity of treatment can have a bearing upon treatment effectiveness. Further, these critical characteristics of treatment can be heavily influenced in the real world by the level of insurance coverage available to a person.

Methodological concerns remain in the area of conducting and interpreting research on the effectiveness of TBI rehabilitation. Although considered the gold standard,

randomized control trials (RCTs) are challenging and costly to implement. Also, RCTs are frequently conducted in an ideal environment and might not generalize to the inherent complexity of TBI treatment in the real world. Related, the content of therapy sessions in research and practice might not always be well-defined, which results in variability among different facilities and practitioners. Some have called for increased efforts to manualize treatment (i.e., develop and adhere to specific treatment instructions) to enhance the comparability of treatment across treatment sites and research studies (Gordon, 2010). However, it may be premature to focus too many resources on RCTs, as some have suggested the need for a better description (and testing) of the theoretical basis for rehabilitation, and the identification of the foundational components of effective rehabilitation (Gordon, 2010).

Among the foundational questions that remain, the current body of evidence does not permit the identification of the optimal dose or intensity of therapy, the ideal timing of therapy in the recovery process, or the necessary modifications for subpopulations. The available evidence is





frequently limited to crude measures of dose (e.g., length of stay or number of hours spent in physical, occupational, or speech therapies). Also, with regard to the intensity of rehabilitation, a growing body of research on TBI and recovery has demonstrated benefits of high-intensity intervention, even during later stages of recovery (Turkstra, Holland, and Bays, 2003).

Scientific reviews indicate that a higher dose of therapy is associated with better functional outcomes (Kennedy et al., 2008; Sohlberg et al., 2003). Related to the timing of rehabilitation, evidence suggests that intensive intervention in the very acute stage of motor recovery (less than 2 months post-injury) is not advantageous and can actually exacerbate deficits (Dromerick et al., 2009; Kleim and Jones, 2008). Addressing the need to better understand questions related to dose, intensity, and timing of rehabilitation will require coordinated effort by several facets of the rehabilitation research community to develop usable and meaningful models for classifying and measuring rehabilitation interventions.

Robust research methods are needed to resolve these gaps within each discipline or specialty of rehabilitation (i.e., cognitive, physical, community-based, and vocational).

More definitive answers to these questions could have a substantial effect on the policies of third-party payers and better ensure that sufficient levels of treatment are covered.

Increased evaluation of alternative delivery models of rehabilitation and long-term medical care for TBI is needed. For example, the use of tele-health and web-based technologies that provide access to expert consultation via the telephone and internet can help to overcome barriers to rehabilitation access, such as geographic residence and lack of transportation. Also, the need to develop and evaluate service models must be addressed so that patients will have the assistance to better navigate the post-acute rehabilitation setting, ensuring that needed services for children with TBI are received. Furthermore, TBI can affect a person throughout their lifespan and additional medical conditions might develop such as neurodegenerative diseases. Therefore, it is important to establish integrated healthcare models that support ongoing treatment, community integration, and cognitive-behavioral support of persons with TBI.

Comparative effectiveness studies are needed to examine the cost-benefit ratio of rehabilitation for TBI, and to determine how the cost-benefit ratio is related to the



length, duration, and intensity of treatments. Beyond the impact of rehabilitation on health outcomes, the effectiveness of TBI rehabilitation also can be supported by documenting the overall economic benefit of rehabilitation. These types of analyses are critical as they can be powerful drivers of decisions made by funders, government agencies, and managed care organizations. Attempts should be made within all rehabilitation outcomes studies to measure the economic impact of particular interventions.

Inclusion of patient- and family-centered outcomes in research studies should be continued and expanded to better document the real-world utility of rehabilitation. Persons with TBI and persons who provide support, such as family and friends, can offer critical insights about the real-world effects of rehabilitation.

Research is lacking relative to the effectiveness of rehabilitation services following acute rehabilitation, such as community-based rehabilitation and vocational rehabilitation interventions. Program models for these types of rehabilitation vary by state, creating challenges in characterizing and evaluating the effectiveness of these

types of programs. Research examining promising models of post-acute rehabilitation might be a good place to begin in demonstrating effectiveness. Despite the ongoing needs of persons with TBI for services after acute rehabilitation, less insurance coverage is typically available for these types of services. Demonstrating the effectiveness of post-acute rehabilitation services would likely be helpful in expanding coverage for these services.

In sum, the field of TBI rehabilitation has progressed considerably within the past 20 years. Evidence suggests that rehabilitation services can improve a person's quality of life and can improve the likelihood of achieving community integration, including returning to work or school, living independently, and enjoying social and leisure activities. More work is needed to understand the specific factors related to the achievement of improved outcomes for TBI. Researchers and practitioners must collaborate to identify and pursue opportunities to strengthen the rehabilitation system and coordination of care, so that appropriate resources are available.



## Recommendations

Recommendations to address the gaps in understanding the current state of rehabilitation for TBI and the effectiveness of various rehabilitation approaches include the following:

- *Improve understanding of optimal rehabilitation protocols.* Conduct research studies to better examine the optimal timing, intensity, and dose of rehabilitation interventions.
- *Study rehabilitation effectiveness among subpopulations.* Conduct research studies to determine the effectiveness of TBI rehabilitation services among groups in which effectiveness has not been specifically examined, such as children. Examining effectiveness among particular sub-populations can help to identify ways in which rehabilitation might be tailored to the particular needs of sub-groups to optimize effectiveness.
- *Create service models for parents and caregivers to optimize rehabilitation services.* Develop and evaluate service models that will assist parents to better navigate the post-acute rehabilitation setting, ensuring that needed services for children with TBI are received.
- *Strengthen understanding of the TBI continuum of care after acute inpatient rehabilitation.* Conduct research studies to examine the effectiveness of rehabilitation services following acute inpatient rehabilitation, such as community-based rehabilitation and vocational rehabilitation.
- *Further assess the cost benefit of TBI rehabilitation to enhance understanding of cost effectiveness.* Conduct studies examining the cost-benefit ratio of TBI rehabilitation interventions and examine how the cost-benefit ratio is related to the dose, duration, and intensity of rehabilitation. Beyond demonstrating the health-related effects of rehabilitation, the effectiveness of TBI rehabilitation can also be supported by documenting the resulting economic benefit.
- *Further assess the need to increase use of alternative sources for delivering rehabilitation services, such as telemedicine (including web-based consultation), mobile services, and the use of lay health advisors.* Evaluate the effectiveness and cost effectiveness of alternative delivery models—especially those that might overcome barriers to rehabilitation access caused by factors such as rural residence and lack of transportation.
- *Expand use of promising technologies for use in rehabilitation interventions.* Increase widespread dissemination of emerging practices such as the use of global positioning system devices, paging systems, and smartphones to aid with cognitive rehabilitation.
- *Implement integrated systems to support the ongoing follow-up of persons affected by TBI.* Develop healthcare models that integrate medical and community services that support the lifelong needs of persons affected by TBI.





## Conclusion

Understanding the epidemiology of TBI, its associated consequences, and the availability and effectiveness of rehabilitation interventions are crucial to improving the quality of life of those with a TBI. Prevention is the key public health strategy to reduce the burden of TBI. However, because preventing all TBIs is impossible, an imperative for those in public health practice, clinical practice, and research is to design and evaluate effective strategies to mitigate the health effects of TBI. Maintaining a comprehensive and coordinated system of rehabilitation interventions is critical to achieve this end. Considerable progress has been made in identifying effective rehabilitation interventions after a TBI, but much work remains to be done. This report outlines many of those opportunities from understanding the TBI burden better to improving TBI rehabilitation.

CDC was asked by Congress to address the need for evidence-based guidelines for TBI rehabilitation. The development of guidelines is a systematic process in which a panel of experts assesses the scientific literature to produce practice recommendations. Ideally, any guidelines developed will help clinicians to make evidence-based decisions supported by research.

Although previous research has demonstrated the effectiveness of a number of TBI rehabilitation services, much more research is needed before evidence-based guidelines can be identified. The complex nature of TBI injuries and TBI rehabilitation makes it challenging to identify the type of specific conclusions that can be translated into recommendations for clinical use. The heterogeneous nature of TBI-related injuries and a large set of rehabilitation services are just some of the particular challenges that make TBI rehabilitation research difficult. These challenges must be addressed in order to improve the evidence base before proceeding to guideline development.

Some of the specific challenges include the following:

- *Dose, Intensity, and Timing of Rehabilitation:* The current body of evidence does not permit the identification of the optimal dose or intensity of therapy, the ideal timing of therapy in the recovery process, or the necessary modifications for subpopulations.
- *Relevance of New Technologies:* To help overcome barriers to rehabilitation access such as geographic residence and lack of transportation, alternative delivery models of rehabilitation (e.g. tele-health and tele-medicine technologies) must be evaluated.
- *Continuity of Care and Service Delivery:* There is a need to develop and evaluate alternative service models that can assist parents and other caregivers in better navigating the post-acute rehabilitation setting.
- *Comparative Effectiveness and Cost of Rehabilitation:* Comparative effectiveness studies examining the effectiveness and benefits of TBI rehabilitation are lacking. In addition, studies examining the relationship between the cost-benefit ratio and the length, duration, and intensity of rehabilitation services are needed.
- *Post-Acute Rehabilitation Care:* Research that focuses on the effectiveness of rehabilitation services following acute rehabilitation, such as community-based rehabilitation and vocational rehabilitation interventions is lacking.

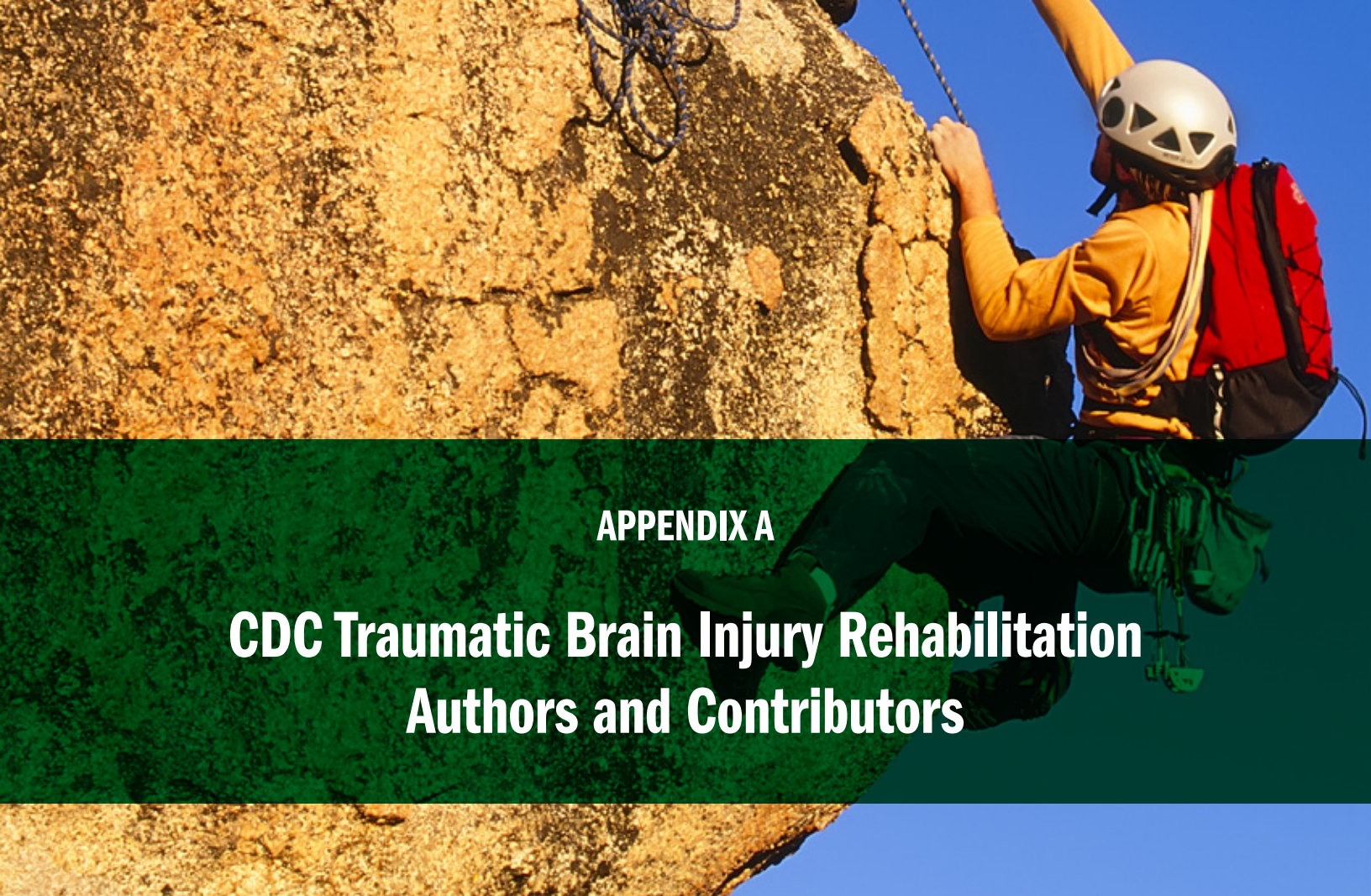
Although key gaps are evident in TBI rehabilitation research that present challenges in identifying practice guidelines, signs of substantial progress are also evident. Chief among these are the efforts of the TBI Common Data Elements (CDE) Project. The recommendations made by the TBI CDE Workgroup will bring much needed consistency to TBI research and will be helpful in improving study design and comparability between studies. In addition, the TRACK-TBI study established the feasibility of implementing a broad range of TBI CDEs in a single study. Efforts such as these are critical examples of the type of coordinated effort that is required to move the evidence base forward to better help persons with TBI to lead more healthy and productive lives.











## APPENDIX A

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## **Dedication**

We dedicate this report to the memory of E. Lynn Jenkins, PhD, who served as a senior editor of the report. She passed away unexpectedly in January 2014. Lynn had a distinguished career in injury and violence prevention with standout contributions in a variety of areas including workplace violence prevention.

Her stewardship was critical to the completion of this report.

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