Witness:
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Testimony

Mr. Chairman and members of the Committee, I am pleased to appear before you today to give testimony regarding one very common type of brain injury that may result in long-term care needs, specifically traumatic brain injury (TBI). Brain injury is not a homogeneous entity; for example, the nature, location, and extent of brain damage differs in trauma (TBI), stroke, and global lack of oxygen to the brain (anoxic brain injury), and thus there are very different recovery patterns and care needs. Today I will speak briefly about TBI, including the magnitude of the problem, the effects on the brain, the types of disability that may result, and long-term health care needs of these individuals.

TBI is a significant public health issue. The CDC estimates that at least 1.4 million people sustain a TBI annually. Of those, 50,000 die, 235,000 are hospitalized, and 1.1 million receive care and are released from an Emergency Room (Langois et al., 2004). The CDC estimates that 80,000 to 90,000 individuals with TBI annually experience permanent disability from their injury. An estimated 5.3 million Americans (2% of the population) are currently living with disability due to a TBI. Because of the nature of the models used here, the CDC suggests that these numbers likely underestimate the problem. The short term and long term effects for those who have sustained a TBI, their families, and society come at an enormous cost. Estimates in 1985 placed the annual cost to the US as $37.8 billion. This includes $4.5 billion in direct hospital and extended care/other medical services, $20.6 billion on work loss and disability, and $12.7 billion on lost income due to death (CDC, 1999; Thurman et al., 1999).

TBI includes both closed brain injury and penetrating brain injury. Both closed and penetrating brain injury can result in widespread (diffuse) and local (focal) brain injury. If one imagines a head striking a windshield in a motor vehicle accident, the gelatinous brain will move forward in the skull at the moment of impact. Acceleration and deceleration forces affect the brain when the moving head strikes an immobile object. The brain, tethered on the brain stem, may also be affected by rotational forces. The brain moves within the skull, cushioned only by a lining of cerebral spinal fluid. The long axons, or the communication fibers of the brain cells, may be stretched, or even torn in severe injury. Patients may be rendered unconscious and may be unable to form new memories for an additional period of time after they regain consciousness. Recovery of the individual depends on many factors, not all of which we currently understand.

Two very important points follow from the manner in which the brain is injured. First, the frontal and temporal lobes, along with their connections, are particularly likely to be injured. The human functions that are affected by these injuries include higher level abilities such as initiation, motivation, planning and problem solving (known as executive functioning), as well as memory, and emotions. Individuals may also experience headache, dizziness, ringing in the ears, and visual changes. To a lesser extent, sensory

and motor functions are impaired.

Secondly, most of the persons with long-term disabilities will be ambulatory patients. These persons may have impaired social and interpersonal abilities which can cause them to have difficulties maintaining work and family relationships. This could render the individual without a job and without previously supportive family members.

Individuals may sustain a TBI in association with other injuries. For example, soldiers who sustain a TBI in addition to a limb amputation may have a more challenging recovery as they are trained with their prosthesis, etc. Patients who incur any polytrauma are likely to have additional problems assisting in the care of their other injuries if they also have sustained a TBI. Evidence from civilian injuries supports this, as it has been demonstrated that TBI in addition to other significant physical injuries (e.g., traumatic amputations, spinal cord injury, etc.) complicates outcome and leads to greater disability (Dimopoulou, et al., 2004; Macciocchi, et al., 2004).

Persons with TBI recover most rapidly in the first 6 months to 1 year after injury. But, improvements can be made up to several years after TBI. We understand these improvements as primarily compensatory gains (learning to adapt better to disabilities) but new research in brain plasticity suggests that improvements may also relate to a strengthening of brain cell connections.

The potential of TBI patients to continue to learn new skills over years underscores the need to have treatment programs available to facilitate their recovery. Unfortunately, these patients are at high risk of “falling through the cracks”. Patients may drop out of our health care systems because of the disability caused by their brain injury. Someone with a “short fuse” who angers easily and has poor memory and organizational skills may be unlikely to negotiate our health care systems to keep appointments, reschedule appointments when necessary, provide the necessary forms when asked, or independently follow-up with treatment recommendations. Because of their brain injuries, these individuals may not even appreciate that they are impaired. They may not trust the health care system, and focus rather on a physical impairment (“All I need to do is to stop having these headaches, and then everything would be fine”). Our health care systems need to have trained providers who can address these patients’ physical and neurobehavioral problems as well as mechanisms to follow patients to ensure they have not dropped through the cracks.

Penetrating brain injury can also affect the frontal lobes. In the well known case of Phineas Gage, an explosion resulted in a tamping iron lodging in his frontal lobes. Though he appeared to be normal, he had severe disabilities in the form of personality changes caused by the injury resulting in his erratic, unpredictable, and inappropriate behavior. While he had previously functioned as a foreman on the railroad, with the ability and skills to supervise others, he was now rendered a pariah due to his behavior. He could neither supervise others nor act responsibly enough to keep any job. Mr.Chairman, I would submit that a person who has sustained such an injury to his executive functions, lost his livelihood, and in essence, is described as a loss of himself

“Gage stopped being Gage” (J. M. Harlow, 1868 quoted in Damasio et al., 1994) has sustained a serious long term disability, despite his ability to walk and talk.

Long term health care needs:
A Scandanavian study of a 15 year follow-up of patients with severe TBI now living at home reported that the most distressing symptoms to their families were not their physical impairments and care needs, but rather their inappropriate behavior and poor social functioning. These behavioral and psychological impairments interfered with the ability of the families to have normal interactions with these persons and with their communities (Thomsen, 1984).

TBI patients with long term care needs include the small number of individuals who do not regain consciousness and others who require institutionalization for ongoing medical and/or behavioral needs and assistance with activities of daily living (ADL’s). However, most TBI patients with long-term needs recover from the majority (and often all) of their physical injuries, yet have ongoing disability from deficits in memory, concentration and motivation, fatigue, and difficulty modulating emotions, including anger.

As such, long term care needs encompass the relatively few who require inpatient comprehensive care and the ambulatory majority whose treatment needs range from supervised living situations to periodic treatment and follow-up as outpatients.

When someone requires inpatient physical care, the treatment needs are clearer. When someone has ongoing cognitive and neurobehavioral problems, the medical care systems often do not reach the patients who need long term outpatient care. Research is needed to see which models of care delivery can provide cost effective care for these individuals. Different patients require different amounts of intervention and have different potentials. Many patients will be able to perform some type of paid or volunteer work while receiving outpatient care.

Certainly not everyone who sustains a TBI has ongoing health care needs. Many of us have experienced a concussion (mild TBI) in the past. Even young individuals who have sustained moderate to severe TBI may have substantial recovery and return to their jobs within one year. (Salazar et al., 2000)

However, a significant proportion of individuals will need ongoing intervention. When TBI patients in Colorado who had required hospitalization were surveyed 1 year after injury, approximately one third of them were still experiencing difficulties due to their disabilities (CDC, 1999). Long-term unemployment rates for individuals with moderate to severe TBI is about 50% (Malec et al., 1995, as cited in Chesnut et al., 1999). Risk factors for poor recovery include severity of injury, complications (e.g., increased intracrainial pressure, a drop in blood pressure, inadequate oxygenation, and infections during the acute period of injury), increasing age of the individual, associated injuries, and previous TBI.

TBI therapies range from inpatient rehabilitation strategies to job coaches and mental

health follow up (specific rehabilitation interventions with the most evidence are reviewed in Cicerone et al., 2000 and Chesnut et al., 1999). It is important for individuals to realize that the emotional or cognitive changes they may experience are related to their brain injury. Fortunately, education regarding the patients' symptoms and expected recovery can help to decrease the number and severity of symptoms seen in mild TBI (Ponsford et al., 2001).

Once again, I thank you for the opportunity to address the committee. I hope this has been helpful in underscoring the large number of ambulatory patients with traumatic brain injury and ongoing health care needs.