



**Testimony Submitted by the Brain Injury Association of America
Before the
Social Security Administration
Public Hearing on Compassionate Allowances
November 18, 2008**

Good afternoon. My name is Greg Ayotte, and I am the Director of Consumer Services for the Brain Injury Association of America (BIAA). The Brain Injury Association of America was founded in 1980 by individuals who wanted to improve the quality of life for individuals who had sustained brain injuries and their families. Today, the Association encompasses a nationwide network of more than 40 state affiliates sharing in the mission of creating a better future through brain injury prevention, research, education and advocacy.

On behalf of BIAA, its nationwide network of state affiliates, and the millions of Americans affected by brain injury, I want to express sincere appreciation for the opportunity to speak before you today.

BIAA applauds the Compassionate Allowances Initiative, and the Social Security Administration's (SSA) desire to identify information to help better determine when a child or adult with a brain injury is most likely to meet the SSA disability standard. BIAA also applauds the openness of the Social Security Administration in proactively seeking information about how its disability determination process can be improved for individuals with brain injury.

A traumatic brain injury (TBI) is a blow or jolt to the head arising from blunt or penetrating trauma or from acceleration/deceleration forces in the skull that result in a decreased level of consciousness.

According to the Centers for Disease Control and Prevention, each year, at least 1.5 million civilians sustain a traumatic brain injury (TBI), and TBI is the leading cause of death and disability in children and young adults. Males are twice as likely to sustain a brain injury as females, but people of every age, race, gender and socioeconomic status are at risk for brain injuries. Brain injuries are caused by falls, motor vehicle crashes, assaults, sports/recreation accidents, and most recently, blasts from improvised explosive devices.

The Rand Corporation's Center for Military Health Policy estimates that 320,000 members of the U.S. Armed Forces have sustained a TBI while serving in Iraq and Afghanistan, and I know that the earlier session this morning devoted special attention to this specific population of heroic men and women.

All in all, with a new injury occurring every 23 seconds in the United States general population, TBI clearly ranks as a public health crisis.

Brain injuries can lead to physical, cognitive, and psychosocial or behavioral impairments ranging from balance and coordination problems to loss of hearing, vision or speech. Fatigue, memory loss, concentration difficulty, anxiety, depression, impulsivity and impaired judgment are also common after brain injury. Even so called “mild” injuries can have devastating consequences that require intensive treatment and long-term care.

Often called the “silent epidemic,” brain injury affects people in ways that are invisible. The injury can lower performance at school and at work, interfere with personal relationships and bring financial ruin. The annual estimated cost to society exceeds \$60 billion, and consumers mistakenly believe employer health plans or the government will pay for needed services in a health crisis. In reality, insurance policies are geared to wellness and routine care, strictly limiting the type, amount, and length of rehabilitation and post-acute brain injury services available to most people.

BIAA state affiliates regularly work with individuals with brain injury who encounter obstacles in trying to access important public programs, including Social Security disability benefits. Obviously, it would be impossible for me to recount every type of challenge that these individuals have faced, and for this reason – and because these voices are so important to hear - BIAA has circulated news of today’s hearing to all affiliates and is actively encouraging individuals to submit their personal accounts in the form of written testimony to the Social Security Administration.

I would, though, like to highlight a few themes which have emerged as BIAA has heard from, and worked with, individuals with brain injuries who are struggling to gain access to Social Security disability benefits.

As you well know, Social Security disability determinations rely in large part on medical information. Perhaps the biggest challenge when it comes to medically addressing brain injury is the fact that the brain is infinitely more complex than any other organ or organ system in the human body. Add to that the fact that every brain, and every brain injury, is unique, and it is easy to understand why it is often said that “there is much more that is unknown about the brain, (and brain injury) than is known.”

This “unknown” surely plays a complicating role in the Social Security disability determination process in cases of brain injury. However, even as we await further advances in diagnostic and prognostic technology, a substantial amount of expertise in identifying and treating brain injury has developed within the past few decades. It is critically important that clinicians and other professionals involved in Social Security disability determination process in cases of brain injury have specialized experience in brain injury. As one brain injury professional recently noted to BIAA, “It has been my experience that, without proper training as to how to read the pattern of results obtained through an assessment patients are often undiagnosed or misdiagnosed as to the severity and nature of specific deficits.”

Similarly, it would be ideal if all Social Security examiners making disability determinations in brain injury cases had training resulting in a strong working knowledge of the unique aspects of brain injury. Many individuals with substantial disability resulting from brain injury have reported that their application for disability benefits was rejected, and that they were told they should be able to hold down some kind of job, even after they detailed and documented extensive evidence of impairment. Many of the characteristics of brain injury impairment are not obvious or familiar to the general public, likely including Social Security examiners. Such characteristics include balance problems, car sickness, sensitivity to bright lights and visual stimuli, irritability, fatigue, sensory overload related to difficulties filtering out background noise, inability to initiate or to follow through on tasks, and quite commonly, a lack of self-awareness of one’s own cognitive deficits. It is important that those making the disability determination truly understand the impact that these various impairments can have on the lives of individuals with brain injury, as well as the implications such impairments can have for employability and ability to participate in the workforce.

In addition, the unique cognitive and other impairments associated with brain injury pose an intrinsic challenge for individuals with brain injury attempting to navigate the Social Security disability system.

BIAA has heard from numerous individuals wishing to implore the Social Security Administration to better take into account the immense challenges faced by applicants with cognitive deficits and fatigue related to brain injury. Process improvements could better take into account these challenges, and thus, make the Social Security disability system more accessible to individuals with brain injury. Such improvements may include allowing more time for individuals with brain injury to be able to complete paperwork. Flexibility, clear processes for extensions, and advance warning of deadlines for planning purposes could be helpful to this end. One brain injury survivor who has successfully obtained SSDI benefits noted that “letting people know ahead of time that they will need to plan time to submit required paperwork would be helpful.”

Several brain injury support professionals and case managers communicated to BIAA that the individuals with brain injury that they were working with would not have been able to complete the paperwork necessary to apply for benefits without their assistance. This poses a difficult problem in terms of bureaucratic hurdles, but it is the reality for many individuals with brain injury. One individual with a brain injury noted that, “the lawyer asked me to bring records of some events. He did not consider that record keeping is one of my most difficult tasks and I am unlikely to find most of the records he requested within the next two days.” Another brain injury survivor likened asking a person with injury-related cognitive impairment to navigate the Social Security disability benefits eligibility process to “asking a person with a badly broken leg to run to get help. Except that the person with a damaged leg would know that they couldn’t run, which is more than many people with brain injury may be able to do.”

One case manager stated, “The process of applying for disability benefits with the Social Security Administration for patients with brain injury needs to be refined to consider the cognitive deficits more, and to expedite the approval and appeals processes.”

One theme above all is quite clear – for both children and adults, obtaining SSI/SSDI benefits serves as a gateway, facilitating access to additional, much needed health care and support services. The Brain Injury Association of America looks forward to continuing to work with the Social Security Administration to making the Social Security disability system more accessible to individuals with brain injury who meet the eligibility criteria.