TASC Training & Advocacy Support Center

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Promoting Community Integration for Persons with Brain Injuries: Part 1 – Defining the Scope of a System Reform Initiative

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I. Introduction

Increasing public awareness of the prevalence and impact of brain injuries has resulted in a number of new system reform initiatives designed to address the needs of persons with brain injuries. A central objective of any system reform initiative should be enforcing the right of institutionalized persons with brain injuries to move to integrated community settings.

The Center for Public Representation plans to develop three Q&As, as well as workshops and other training sessions, that address issues related to the unnecessary institutionalization of persons with brain injuries. Each installment will raise critical questions and suggest possible strategies to inform the development of a system reform project. This first installment examines the nature and prevalence of brain injury, the impact of these injuries on individuals' needs and circumstances, and strategic choices in defining the group of persons to be served by any advocacy strategy or class action lawsuit.

II. The Nature and Scope of Brain Injuries

A. Definitions and Distinctions

Acquired brain injury (ABI) is a brain injury that occurs after birth and can be caused by a range of different events, including external force or trauma (traumatic brain injury), problems with blood flow to the brain (stroke), lack of oxygen to the brain (hypoxic or anoxic encephalopathy), and a variety of other conditions. But regardless of the cause, there is one disabling condition called acquired brain injury.[1]

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[1] The Brain Injury Association of America (BIA), the leading national advocacy organization for persons with brain injuries, has adopted the following clinical definitions for both ABI and TBI:

> Acquired Brain Injury (ABI) means an injury to the brain which is not hereditary, congenital, degenerative or induced by birth trauma. An acquired brain injury is an injury to the brain that has occurred after birth. Acquired brain injuries commonly result in a

Much of the local and national data available on brain injury measures the subset of ABI known as traumatic brain injury. As a result, many state and federal programs, as well as model research programs, focus on this discrete group of persons with brain injuries.[2] However, any form of acquired brain injury can result in similar disabling conditions that severely limit functioning, basic skills, and cognitive processing. These injuries also necessitate very similar community-based supports for affected individuals. Thus, a critical issue to consider is whether any system reform initiative should be limited to a specific type of acquired brain injury, like TBI, or whether it should encompass all forms of ABI.

B. Prevalence

1. Traumatic brain injury

The Center for Disease Control estimates that there are currently 5.3 million individuals -- or more than two percent of the U.S. population -- living with a long-term disability resulting from a traumatic brain injury. An additional 80,000 to 90,000 persons are affected each year.[3] When considering an individual's

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change in neuronal activity which affects the physical integrity, the metabolic activity, or the functional ability of the cell. Such injuries may result in mild, moderate, or severe impairments in one or more areas, including cognition, speech-language communication, memory, attention and concentration, reasoning, abstract thinking, physical functions, psychosocial behavior and information processing. Acquired brain injuries include, but are not limited to, brain injuries sustained as a result of stroke, loss of oxygen (anoxia), poisoning (toxemia) or brain tumors.

Traumatic Brain Injury (TBI) means an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment. Traumatic brain injuries are caused by an externally-applied force and can include, but are not limited, to brain injuries sustained as a result of falls, auto accidents, blast injuries, penetrating head wounds, blows or other causes of trauma to the head.

See, www.biausa.org/Pages/types_of_brain_injury.html. More information on the nature and scope of brain injury, advocacy initiatives, and the work of the BIA's 40 state affiliates can also be found through the above website.

[2] The CDC currently funds thirty States to conduct their own surveillance and examination of the impact of TBI. See links to state public health programs at www.cdc.gov/ncipc/tbi/TBI.htm. The National Institute on Disability and Rehabilitation Research funds 17 TBI model systems grants across the country. Descriptions of these system grants and their work can be found at the National Rehabilitation Information Center (www.naric.com/research/pd/type.cfm) and the TBI model system's National Data and Statistical Center at Craig Hospital in Colorado (www.main.uab.edu/TBI/show.asp?durki=56194)

[3] Center for Disease Control, 2006. Brain injury is reported to be the leading cause of death and disability for people between the ages of 15 and 24. It is also increasingly identified in elder populations, who are at risk for automobile accidents and falls. For additional information and

family and circles of support, brain injury touches the lives of approximately one in ten persons in the United States.[4]

Of the 1.4 million traumatic brain injuries every year, 50,000 result in deaths, 235,000 in hospitalization, and 1.1 million in treatment in an emergency room.[5] Traumatic brain injury is more prevalent in the United States than cases of multiple sclerosis, HIV/AIDS, breast cancer and spinal cord injury combined.[6]

2. Acquired brain injury

Because acquired brain injury includes a wide variety of medical conditions and complications that affect brain functioning, like stroke, tumors, and brain damage from related illnesses, the prevalence of ABI is far greater than of TBI. For institutionalized persons, and particularly persons in nursing facilities, the incidence of ABI is often at least a thousand percent greater than TBI.[7] Neither the Federal government nor the States maintain reliable data on the prevalence of ABI, in part because of its elusive and encompassing definition. However, statistical information concerning the broader category of acquired brain injuries is staggering. For example, approximately 700,000 Americans each year suffer a new or recurrent stroke, resulting in the death of over 157,000 citizens annually.[8]

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historical data on cause, demographic and scope of injuries, see www.cdc.gov/ncipc/pub-res/TBI_in_US_04/TBI_ED/htm.

[4] The human costs of brain injury are accompanied by staggering fiscal repercussions. In the U.S., direct medical costs and indirect costs such as lost productivity associated with TBI totaled an estimated $60 billion in 2000. Finklestein E, Corso P, Miller T and associates. The Incidence and Economic Burden of Injuries in the United States. New York (NY): Oxford University Press; 2006. Reference at www.cdc.gov/ncipc/tbi/TBI.htm

[5] Langlois JA, Rutland-Brown W, Thomas KE. Traumatic Brain Injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta (GA): Centers for Disease Control and Preventions, National Center for Injury Prevention and Control; 2004

[6] Brain Injury Association of Massachusetts at www.biama.org/whatis/facts.html. Massachusetts' experience with brain injury mirrors that of the Nation. In 2004, there were 486 traumatic brain injury-related deaths among Massachusetts residents. In fiscal year 2004, there were 4,994 inpatient hospitalizations associated with non-fatal traumatic brain injuries. Approximately 1,750 individuals with brain injuries – more than thirty-five percent of those hospitalized – were discharged to a nursing or rehabilitation facility in 2004. *See* "Maximizing Our Efforts: The Massachusetts State Injury Prevention Plan", Massachusetts Department of Public Health (2006)

[7] For instance, the number of persons with TBI in Massachusetts nursing facilities is slightly over 600, while the number just with stroke and related forms of ABI exceeds 8,000. *See* www.cms.hhs.gov/MDSPubQIandResRep/04_activeresreport.asp#TopOfPage (follow hyperlinks I1cc for traumatic brain injury and I1t for cerebrovascular accident (stroke)).

[8] American Heart Association, *Stroke Statistics* found at www.americanheart.org.

III. The Impact of Brain Injury

A. Acute Treatment and the Rehabilitation Process

Almost all persons who experience serious brain injuries receive acute care at in-patient hospital and acute rehabilitation facilities. After this initial phase of their recovery, they usually require ongoing rehabilitation serves, sometimes for years, in order to regain maximum levels of cognitive and physical functioning and prevent further regression. These services can be provided in a specialized community program, facility, or outpatient rehabilitation center.

When States offer a range of community-based rehabilitation services, this level of continuing care and support can be delivered most effectively to individuals at home and in their communities. When States do not have a robust network of services in place, persons with serious brain injuries are often placed in segregated nursing or other institutional facilities, which can be far from their families and friends.

B. Symptoms and Level of Functioning

Despite the multiple ways in which brain injury can occur, a person with a traumatic brain injury can experience the same clinical problems and the same amount of disability as a person suffering a stroke or hypoxic injury. These injuries can cause a wide range of functional changes that negatively affect an individual's basic life skills including movement, memory, thinking, learning, sensation, communication, and behavior. They can also increase a person's risk for certain medical conditions and other brain disorders including Alzheimer's and Parkinson's diseases.[9]

While individual needs may vary, most persons recovering from serious brain injuries require some level of assistance with personal care and activities of daily living, ongoing speech, occupational and physical therapies, medical and nursing services, vocational training or day habilitation programs, durable medical equipment, transportation, and integrated social and recreational activities. Many also require accessible living arrangements.

C. Risks for Institutional Placement

All of the rehabilitative services required by persons with brain injury are available to some degree in the community and most are forms of medical assistance covered by Medicaid. However, there is often an insufficient capacity

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[9] National Institute of Neurological Disorders and Stroke, "Traumatic Brain Injury: hope through research," National Institute of Health. NIH publication No. 02-158 (Feb. 2002). Available at www.ninds.nih.gov/disorders/tbi/detail_tbi.htm. For additional research citations and to learn more about potential outcomes of TBI, see www.cdc.gov/ncipc/tbi/TBI.htm

and intensity of supports to meet the needs of nursing facility residents and others who no longer require institutional care for their brain injuries. For these individuals, as with all disabled persons, the denial of access to community-based support services has profound consequences. The physical, behavioral, and cognitive problems experienced by persons with serious brain injury are often exacerbated by prolonged and unnecessary institutionalization, leading to deterioration in their functional independence and daily living skills, severe limitations on community access, and negative outcomes for their vocational development and emotional well-being.

The brain injuries experienced by these individuals are profound and life changing, but they need not result in a lifetime of institutional care. Like persons without disabilities, these individuals need "family relations, social contacts, work options, economic, independence, educational advancement and cultural enrichment." *Olmstead v. L.C.,* 527 U.S.581, 600 (1999). Their medical and rehabilitative needs can best be met in community settings, which have been demonstrated to improve skills, promote rehabilitative goals, and facilitate independence for persons with brain injuries and other severe disabilities.

IV. Strategic Choices in Defining the Scope of a System Reform Initiative.

A. Distinctions by Nature and Cause of Injury

An initial, strategic decision for any system reform initiative is how to define the group of persons it will cover. One immediate decision confronting advocates for persons with brain injury is how to address the somewhat artificial distinction between ABI generally, and its subset, TBI.

After the first few months following a brain injury, its cause is of limited relevance to the treatment required to restore the individual to a maximum level of functioning. Instead, the severity and location of the injury are the most important factors in determining the appropriate treatment and the needed rehabilitation services. Nor is the cause of one's injury a relevant predictor of long-term prognosis, ability to live in the community, or the level of functioning that can be regained post-injury. Finally, and perhaps most importantly, the cause of a brain injury has no relevance whatsoever to the need for ongoing institutional care, the effectiveness of rehabilitation programs, or the location of other support and services needed following the acute phase of treatment.[10]

Therefore, while brain injuries can be caused by various events, this fact simply is not relevant to whether persons must be segregated in nursing facilities

[10] *See* Affidavit of Dr. Mel Glenn, director of TBI Model System at Spaulding Rehabilitation Hospital, Boston, Massachusetts, submitted in conjunction with the plaintiffs' Reply Brief on Class Certification in *Hutchinson v. Patrick,* 07-300-84-MAP (D. Mass. 2007), available from CPR.

or whether they would benefit from community support services. As a result, an advocacy initiative to expand community-based care can, and probably should, cover persons with all forms of brain injury, without significantly altering its purpose or the basic nature of a remedy.

However, there are two significant considerations in representing individuals with all forms of ABI: 1) the much larger number of persons affected, and 2) the availability of data to describe the entire population. Advocates should be aware that, by endorsing the principles which support inclusion of all persons with ABI, they will also be dramatically expanding the scope of any advocacy or litigation effort as well as its fiscal impact. Expanded client outreach and identification efforts may also present additional challenges.[11]

B. The Implications of Age

Since brain injuries can occur for a variety of reasons and across an individual's lifetime, persons of all ages are at risk. However, ABI uniquely impacts older persons, since stroke is a common condition among the elder population. As the MDS and other CMS data indicates, the vast percentage of persons with ABI are over sixty-five years of age.

Targeting certain age groups for advocacy, or setting a specific age cut-off for class definitions, can be both arbitrary and likely to exclude large numbers of individuals who could benefit from community living. This reality must be balanced against the significant increase in the number of persons covered by the initiative, and the clinical complexity resulting from the inclusion of older individuals, particularly those who acquired their brain injuries as a result of stroke.[12]

The decision to limit an advocacy initiative or class action by client age may be informed by the extent to which older individuals are adequately served by other state resources or Medicaid waivers designed to transition persons from nursing homes to community living, or to prevent such admissions from occurring. Another factor may be the percentage of younger persons in nursing home settings within your State. Without programs or initiatives that target younger individuals, they must compete with large numbers of older adults for

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[11] Strategies for client outreach will be addressed in more detail in subsequent Q&As. To begin exploring nursing facility admission and assessment information reported in your State, P&As should consult the Minimum Data Set. MDS is a uniform set of elements extracted from the Resident Assessment Instrument (RAI) which is a standardized tool for assessing the functional capacity of residents of long term care facilities. Long term care facilities are required by CMS to complete and transmit MDS data to the designated state agency for all residents as a condition of participation in the Medicare and Medicaid programs. See, www.cms.hhs.gov/MinimumDataSets20

[12] Nearly three quarters of all strokes occur in people over the age of 65. The risk of having a stroke more than doubles each decade after the age of 55. *Center for Disease Control, Stroke Facts and Statistics,* www.cdc.gov/Stroke/stroke_facts.htm

limited placement resources. To the extent these resources are delivered on a first come first serve basis, and operate pursuant to a lengthy waiting list, this younger population of persons with brain injuries could be at greater risk of extended, unnecessary institutionalization.

C. Commonality and Perceptions of Conflict

When analyzing the facts and legal claims in any system reform initiative, it is important to anticipate what real or perceived conflicts might exist amongst those individuals or groups included in the initiative.

Advocates for persons with brain injuries should be prepared for government entities to assert that different causes of brain injury, and corresponding variations in service eligibility, defeat class action requirements for commonality and typicality, while also creating conflicts amongst class members, at least where publicly-funded programs are limited to persons with traumatic brain injury. *See* Federal Rules Civil Procedure 23(a) and (b). These arguments are flawed in several respects.

First, as stated above, the cause of an individual's brain injury is irrelevant to his or her unnecessary institutionalization, the discrimination which results, and the range of remedial services and accommodations needed to facilitate community living. Such arguments misapprehend the purpose of these claims – to challenge the segregation of individuals with brain injuries, regardless of cause, in nursing and rehabilitation facilities, and the failure to make reasonable accommodations to existing programs necessary to facilitate access to integrated community settings. Second, many, if not most, state and federally funded programs are available to individuals with brain injuries, regardless of the cause of their condition.[13] Finally, these arguments ignore decisions by countless federal courts, holding that distinctions in the type, level, and severity of disability, or the services for which various class members may already be eligible, are insufficient to defeat class certification.[14]

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[13] Segregated institutional services funded in nursing facilities and inpatient rehabilitation hospitals through Title XIX are available to persons with all forms of acquired brain injuries. Similarly, Medicaid-funded State plan community services are provided to persons with all forms of brain injuries. These State plan services include, among others, personal care attendants (PCA), home health care, rehabilitative services, various therapies like physical therapy, occupational therapy, and speech and language therapy, durable medical equipment, and physician services.

To the extent that federally-funded programs exclude persons based upon cause or severity of injury, additional claims of discrimination, including discriminatory methods of administration, should be considered pursuant to Section 504 of the Rehabilitation Act. 29 U.S.C. § 794(a) *et seq*. and the ADA. These legal claims will be addressed in more detail in a subsequent Q&A.

[14] Courts have certified classes in numerous disability cases where class members suffered from different disabling conditions, and even different forms of brain injury. *See Hutchinson v. Patrick,* 07-300-84-MAP (D. Mass. September 18, 2007) (all Massachusetts residents who now, or at any time during this litigation: (1) are Medicaid eligible; (2) have suffered a brain injury before the

V. Conclusion

The number of persons affected by acquired brain injury, including TBI, is growing every year. These individuals, and those who care for and about them, are part of an important and rapidly emerging advocacy force. Their work is aimed at understanding the potential for recovery, researching clinical outcomes, and responding to individuals needs. Persons with serious brain injury face many of the same challenges confronted by persons with mental retardation and psychiatric disabilities, and particularly unnecessary institutionalization. As a result, there is a tremendous opportunity, and a tremendous need, to make the principle and promise of community integration a part of their lived experience. Understanding the nature of brain injury, its profound impact on individuals and families, and the needs of those affected is an important first step in contributing to this effort. Developing a system reform initiative that responds to those needs, in as broad a way as possible but with attention to what is manageable and likely to succeed, is the next critical step.[15]

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age of 22; and (3) reside in a nursing or rehabilitation facility or are eligible for admission to such a facility); *Dubois et al. v. Rhonda Medows et al.*, No. 03-CV-107 (N.D. Fla. March 1, 2004) (All individuals with traumatic brain or spinal cord injuries who are unnecessarily institutionalized or at risk of institutionalization who the state has already determined or will determine to be eligible to receive BSCI Waiver Program Services and have not received such services); *Bryson v. Stephen*, No. 99-CV-558-SM (D.N.H. June 26, 2000) (Individuals with acquired brain disorders who are currently institutionalized who are able to be discharged into a less restrictive community setting, or they are individuals who are in the community but who, in the absence of home and community-based services, are likely to be placed in an institution); *Connecticut Traumatic Brain Injury Assoc. v. Hogan*, No. 2:90CV97 (D. Conn. July 6, 1990) (All persons with traumatic brain injury and mental retardation who are institutionalized or may be institutionalized at Norwich, Fairfield Hills Hospital and Conn. Valley Hosp).

[15] Advocates should consider the class definition approved by the district court in *Hutchinson* as a useful model of a very broad definition. A narrower class or system reform initiative might include persons with brain injuries in certain facilities (i.e. public institutions or brain injury units of private facilities), persons with certain types of brain injuries (i.e. TBI), or persons with certain favorable characteristics (individuals with treatment recommendations for community placement). However, each of these limiting conditions has its human costs, as well as management benefits.