Planning for the Neurobehavioral Needs of Individuals with Brain Injury: The State Perspective

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Introduction

A 43-year-old man who experienced two brain injuries, one in childhood and one in adulthood, was “stuck” in a community hospital with no safe discharge options when he came to the attention of the State TBI Program Director. The reason for admission to the community hospital was neurological damage that resulted from being subdued with a taser gun outside of a police station due to his aggressive behavior. This was his fourth interaction with police resulting in formal legal charges. He was well known to the police and human service professionals in his county and considered a major threat to himself and to the community.

He had no natural supports involved in his life, and had a history of aggressive behavior, and a significant seizure disorder. All of these factors were exacerbated by his frequent alcohol use. Since his second brain injury, he had been involuntarily discharged from two nursing homes, a homeless shelter, and a community mental health program. This gentleman remained “stuck” in the community hospital, where he was heavily sedated to manage his aggressive behavior for six months before finally being admitted to a brain injury rehabilitation unit and accessing the state’s brain injury Medicaid waiver program. The reason that he was not initially able to access these needed programs was that he did not meet the admission and eligibility criteria for either program.

His situation was the impetus for change within this state’s service system, which now has more flexible admission criteria that is sensitive to the neurobehavioral rehabilitation needs, as well as the physical and cognitive rehabilitation needs of individuals with brain injury.

Acquired brain injury is a major public health problem and public awareness of the problem has increased with media coverage of sports related brain injury and blast injuries resulting from Improvised Explosive Devices (IEDs), a common combat tactic being utilized against American soldiers involved in the conflicts in Iraq and Afghanistan. While awareness of the cognitive and physical changes that occur after a brain injury and the subsequent rehabilitative needs are becoming increasingly familiar to the public and to healthcare providers, the behavioral changes and challenges resulting from a brain injury remain an under-recognized and under-treated issue. Yet, behavioral deficits are a major impediment to the brain injury recovery process and impact an individual’s ability to engage in rehabilitation, return home to family, return to work, maintain personal safety, and adapt to societal expectations.

Common behavioral challenges include verbal and physical aggression, agitation, limited self-awareness, altered sexual functioning, impulsivity and social disinhibition (National Association of State Head Injury Administrators, 2006). The literature suggests that agitation and aggression develops in 20-49% of children who sustain a TBI and 25-33% of adults who sustain a TBI, usually within one year of sustaining the injury (Kim, et al., 2007 & Baguley, et al., 2006). Risk factors for developing aggression and agitation include frontal lobe lesions, preinjury history of substance abuse, preinjury aggression, multiple brain injuries, and depression.
It has been estimated that approximately three (3%) to ten percent (10%) of individuals who sustain a brain injury require long term, intensive supports because of neurobehavioral issues (Brain Injury Association of America, 2009; McMorrow). While the prevalence is low, the acuity of the problem is high. People with significant neurobehavioral issues can pose a risk to themselves and to others and require specialized supports and services, which do not currently exist in every State. While most States offer neurorehabilitation services that treat physical and cognitive problems associated with brain injury, many states do not have neurobehavioral programs. The safety risks and level of disruption posed by individuals with significant behavioral problems are barriers to accessing neurorehabilitation services, and without the neurobehavioral expertise that is needed, many deficits and symptoms are left untreated. The components of a neurobehavioral program that are often missing include integrated cognitive, behavioral and pharmacological interventions. One of the challenges faced in the development of programs of this unique nature is the availability of resources such as clinical expertise in neuropsychology, behavioral psychology and neuropsychiatry. Other barriers may include lack of adequate physical space with relevant licensures and reimbursement rates that allow for high and adequate staffing ratios.

There are also significant funding constraints that impact appropriate access to care. Payors (private and public) tend to reimburse only for rehabilitation services that are provided initially after the injury but are less likely to authorize payment for needed long-term services. Brain Injury is a chronic but fluid condition and an individual with brain injury experiences many ups and downs throughout the recovery process (BIAA, 2009). Factors such as secondary injury, substance abuse, co-morbid psychiatric conditions and the aging process impact the recovery process and it is not unusual for an individual with a relatively good early recovery to decompensate a year or even decades after the injury yet service systems are rarely flexible or responsive enough to these changes in functioning. The gentleman referenced above is a prime example of the fluctuation in level of functioning during his recovery process. Once he accessed the appropriate brain injury services, he began functioning at a much higher level, eventually returning to work.

The Role of State Government
Historically the role of state government has grown as it relates to the safety of its residents and the community at large resulting in a more critical role in serving those in our communities who are most needy. This philosophy and practice has led to the development of state-supported neurobehavioral systems of care and protection that include both secure and community-based programs.

Specifically the sub-population of individuals with brain injury who experience significant neurobehavioral and neuropsychiatric challenges require specialized and integrated treatment programs designed for those with brain injury, who often present with other co-morbid diagnosis, that do not readily exist in most states. These programs are essential to ensuring the safety of these individuals as well as the communities they live in. Those who reach this level of need have almost always depleted any personal resources they or their family may have and often are not successful when participating in those available services that are not equipped to deal with complex neurobehavioral issues, which are also often coupled with co-occurring mental health and substance abuse disorders. The majority of these individuals therefore become dependent on public resources and state funding to access the neurobehavioral treatment that is needed. When such services are not available within a state, many states resort to paying for specialized services out of state ranging in price from $500-$900 per day.
Although these programs may ultimately lead to improved outcomes they come at a high cost to tax payers eating up a large portion of limited state funds.

Resource limitations, funding constraints, and systemic barriers must be solved in order to improve access to appropriate and necessary services while reducing the spending on ineffective and costly treatment. An increasing number of states (AL, GA, FL and MD) have created taskforces, studies, and neurobehavioral state plans to address the missing points on the state’s service continuum. States have begun to identify the economic and social costs associated with the lack of appropriate services such as high rates of incarceration and hospitalization and homelessness among the brain injured population. The CDC reports that as much as 87% of the prison population in the U.S. has sustained at least one TBI. States have experienced class action lawsuits on behalf of individuals with brain injury who are institutionalized in nursing facilities (MA, FL), some of whom are being managed in secure behavioral units, or state psychiatric hospitals (MD) because of the lack of available resources in the community. Individuals get “stuck” in Emergency Departments and community hospitals because appropriate and safe discharge options are not available.

Over the past two decades State TBI programs across the country have taken the lead in the development of a broad array of services that target individuals with neurobehavioral challenges; however, no state has created the entire menu of service options needed, ranging from early intervention services to secure and/or locked neurobehavioral units. The challenges associated with developing this menu of options by states can be daunting and is driven by many factors including the organizational structure of state government, shifting political climates and priorities, and economic downturns.

For example, TBI leadership within state government may be housed in a variety of different state agencies and differs tremendously from state to state. In some cases, the TBI leadership may be separate from the agencies that provide funding for services. The location of the TBI program staff and the state agency they are housed in often impacts the types of strategies states have utilized to address the gaps in the continuum of care for this population such as Advisory Boards, paid studies, task forces and Medicaid waivers to name a few.

TBI program leaders responsible for States’ Brain Injury programs and service development may also have many different titles and levels of authority within their states’ government structure. They may be directors, specialists, coordinators, council members or grant project staff within the lead agency. The level of authority they have influences their ability to impact change within the state system and to garner support from the Governor’s office, which is necessary for funding and program development.

State funding has always been a challenge to accomplishing what needs to be done for the brain injury community, which is often in direct competition with the resource and funding needs of other aging and disability groups. Legislators decide how state resources will be allocated but they are also elected to represent and serve their constituents. The public needs to be educated about brain injury and why appropriate and timely interventions will lessen the burden on society as a whole and are a good investment of state dollars. This often becomes the role of the Brain Injury Association of America State Affiliates who are important collaborators in any efforts to create solutions through state systems.

Reliance on legislators and therefore politics does not end with public support. Accessing state funding is also dependent on the budget process, which varies from state to state. TBI leaders within state government must come prepared to advocate for the needs of their consumers at
multiple levels of government, especially when the cost is so high. There is a need to be well prepared every step of the way which includes written materials that clearly describe the problem, the consequences associated with the lack of program options, the number of individuals that need assistance (ideally by Legislative District), the strategy being proposed based on experiences and successes in other states and, finally, the estimated costs associated with the proposal. Brain injury professionals have played key roles in defining the breadth of these issues and clinically sound interventions that help to minimize the negative impact on the individual, their family and the community.

Components of Service Delivery Systems
States that have been successful in the development of neurobehavioral services have worked collaboratively and diligently over time with their State Brain Injury Advisory Boards and Brain Injury Association State affiliates that include individuals with brain injury, family members, and providers who are knowledgeable and committed to serving this population. Together these partnerships have created improved identification and screening tools for TBI, identified gaps in the states’ service delivery system, and led to the creation of programs and supports that improve access to and the timely delivery of appropriate services for those with brain injury including those who present with these significant needs.

Administrators of state brain injury programs have come to rely on their counterparts in other states to share their successes and sometimes failures in attempting to design and implement programs for this population. The experiences of other states and the ability to network and provide critical information have been facilitated through the National Association of State Head Injury Administrators (NASHIA). Even with this resource only a small number of states such as MN and MA have developed secure neurobehavioral programs. No state seems to have all the components of a successful neurobehavioral service delivery system.

The ideal system to address neurobehavioral challenges would consist of early intervention approaches, community-based services and structured inpatient programs. Early Intervention practices are needed to prevent the need for more intensive and costly services in the long term. For instance, effective screening and assessment procedures are important. Alaska screens all individuals who seek public behavioral health services for a history of brain injury. Other states (MN, MD) have implemented TBI Screening on a smaller scale at state psychiatric hospital hospitals, correctional facilities and community mental health programs. Screening also needs to be done in nursing homes and other institutional settings. Assessment of needs and risks and development of risk management plans are also needed as a core component of the system.

Training for professionals working in corrections, mental health, addictions, intellectual disabilities, elderly services and long term care facilities is critical as they are already seeing individuals with brain injury who have multiple diagnosis and needs that change over time. These professionals need to develop the skills to appropriately identify and support individuals with brain injury within their programs. MA has developed such a curriculum, which has been used to train other state agency staff such as case managers and clinicians. MD has established a Co-Occurring Supervisor’s Academy that is training senior staff from mental health, substance abuse treatment and intellectual disabilities services agencies on issues of co-occurring disorders, including brain injury, among these populations.

Access to trained case managers/service coordinators/resource facilitators who can assess changes in an individual’s level of functioning, navigate individuals through the service delivery system as their needs change, and advocate for individuals within the various service settings is
critical. These staff must be separate and independent from the service providers to insure adequate monitoring and that service coordination remains in place even if services or funding is lost.

Community-based services and programs are another essential component of an effective neurobehavioral system of care. Services should include: (a) targeted technical assistance to assess and recommend necessary interventions before a situation becomes a crisis (e.g. MA has a formal technical assistance program for school systems that can be utilized when a student with a brain injury begins to exhibit problem behaviors that could result in placement in a less integrated setting); (b) outpatient treatment to prevent hospitalization that includes psychopharmacological and behavioral management, assessment for the need for inpatient hospitalization in times of neurobehavioral crisis, follow-up treatment upon discharge from hospital to the community. Crisis response programs that are mobile and include neuropsychiatric and neurobehavioral expertise are another important resource. These programs may be a component of State’s public mental health system; however, crisis teams typically lack the brain injury expertise needed benefit this population.

In-home supports and family assistance are also critical to preventing institutionalization secondary to behavioral and psychiatric challenges. Initially after sustaining a brain injury, the majority of individuals are discharged home to their families. Services such as respite care in and out of the home, family support programs (MA), and meaningful daytime opportunities for the person with the brain injury (e.g. NY state clubhouse models) contribute to maintaining safety, stability, community integration, and reducing the risk of institutionalization.

Given the incidence of substance abuse within this population and the fact that use of alcohol and drugs can result in more compromised functioning up to and including significant behavioral and psychiatric issues, there is a need to develop specialized treatment programs that build on traditional approaches yet are flexible enough to accommodate the cognitive and pharmacological needs of those with brain injury (MA).

States need structured residential services that provide 24-hour supervision in a provider operated setting. Staff/participant supervision ratios must be adequate to provide cognitive-behavioral interventions. These providers should be able to access and coordinate other necessary clinical services such as psychopharmacology, neurobehavioral interventions, and medical care. These programs are an essential component of the continuum because they offer intensive services in a community based setting and act as a step down program from inpatient services.

Despite the goal of reducing reliance on institutional care that is shared by States, the federal government, and many stakeholders, inpatient programs are an important part of the continuum when individuals are not able to reside safely in the community. Every State should have a locked, or at least secure, neurobehavioral treatment program that is “short term” in nature; provides highly structured programming that integrates cognitive, neurobehavioral and psychopharmacological treatment approaches; has intensive staffing patterns; allows for involuntary admission and leads to improved functioning over time and ultimately community reintegration. Such unit(s) should have the capacity to provide inpatient stabilization in lieu of traditional psychiatric hospitalization for those individuals who require neuropsychiatric and neurobehavioral intervention. States must also have the capacity for chronic and potentially long-term neurobehavioral treatment that keeps the individual safe and eliminates risk to the community for those who impairments cannot be ameliorated.
Specialty brain injury unit(s) are also needed within nursing facility(s) to support the skilled medical needs of individuals with brain injury who present with significant neurobehavioral and/or neurocognitive impairments. The units must be transitional in nature with discharge planning starting at admission and well-coordinated transitions to community settings.

**Summary**

In summary, these programs and services mentioned above constitute the most basic components of a state system of care for those with neurobehavioral and neuropsychiatric challenges. Regardless of what a state is able to create, their neurobehavioral service delivery systems must be coordinated and flexible, person centered and cognitively accessible to the extent an individual is able to participate and able to respond to high risk situations that require immediate crisis management responses. Most importantly states need to work closely with the brain injury community and other human service agencies such as mental health and addictions in order to be successful in meeting the needs of this small but significant number of people whose brain injury has resulted in challenges that are difficult and costly to manage.

**REFERENCES:**


Brain Injury Association of America (BIAA), *Conceptualizing Brain Injury as a Chronic Disease*, a Position Paper, March 2009.


**ABOUT THE AUTHORS:**

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Note: This article was submitted to the North American Brain Injury Society for publication in the Brain Injury Professional, Vol. 7, Issue 4, 2010.