

**Testimony on Behalf of the Brain Injury Association of New York State to the Assembly
Committee on Health, Committee on Mental Health and Developmental Disabilities,
and Task Force on People with Disabilities**

**Public Hearing on Traumatic Brain Injury Treatment and Services
October 8, 2015
Albany, NY**

I thank the members of the Assembly Committee on Health, Assembly Committee on Mental Health and Developmental Disabilities, and Task Force on People with Disabilities for holding this hearing. We thank you for acknowledging the impact of brain injury on the lives of those who sustain injury and their families and friends, and for inviting us here today to discuss the needs of this community. I am honored to read this statement on behalf of the Board of Directors, staff, and members of the Brain Injury Association of New York State.

Brain Injury is a public health issue impacting millions of individuals in New York State. Each year, over 140,000 New Yorkers sustain a traumatic brain injury. This number does not include incidences of acquired brain injuries, such as anoxia, which are not fully tracked. From a teenager sustaining a concussion on the football field to the service member injured by an IED in Afghanistan to the father injured in a car crash on his daily commute, brain injury truly may affect anyone, anytime, and anywhere. While great strides have been made to improve prevention efforts, diagnosis and treatment, rehabilitation, and community resources, there are still many gaps in care across the continuum.

The Brain Injury Association of New York State was founded in 1982 by individuals with brain injury and their family members. For over 30 years, the Association has represented the New York State brain injury community bringing recognition to the devastation that the injury can cause and the challenges faced by an individual who strives to be a valuable and productive member of the community. The Association offers information and resources, training, advocacy, support services, Chapters and support groups. We foster relationships and share resources to work together towards a brighter future for individuals with brain injury and their loved ones.

Brain injury disrupts every aspect of life. Individuals with brain injury are often left with complex problems due to the nature of the injury. Common issues include cognition, memory, and/or behavioral problems as well as possible physical disabilities, making managing life in the community difficult. Added to these difficulties is the issue that brain injury is not widely understood and each individual brain injury is different. It is called the “silent epidemic” because brain injury is often not apparent when looking at an individual, and because stigmas about the injury’s effects limits the openness of people to discuss their injuries. Proper diagnosis, treatment, and rehabilitation, coupled with appropriate coping strategies and community supports, help many individuals with brain injury go on to lead rewarding lives in their communities.

The unique problems that each individual exhibits, combined with the lack of awareness of how brain injury manifests, often makes community reintegration a challenge for many individuals with brain injury. The complex issues resulting from a brain injury can make navigating the confusing structure of different assistance programs and benefit options problematic. Depending on the way they sustain an injury, individuals may be involved in Worker's Compensation, No Fault Insurance, Crime Victim's services, or within their own insurance company to gain access to the best care and assistance. Families are thrown into this new world of brain injury, forced to educate themselves and learn to be an advocate, while grappling with the trauma of this life-changing event. Individuals with brain injury in New York State today struggle to find the proper services in New York State because no clear path connects them to what they need.

In response to the institutionalization of individuals with brain injury and to foster greater community-based assistance, New York State passed landmark legislation in the TBI Act of 1994. This legislation paved the way for the Medicaid TBI Waiver and, later, the Nursing Home Transition and Diversion Waiver. Under these programs, Medicaid-eligible individuals with brain injury have access to a slate of specialized services to best help them remain in the community. These services, which range from Community Integration Counselors to Behavioral Specialists, are part of an individualized plan that supports the specific needs of each Waiver participant. The common service to all participants is a Service Coordinator, who assists the individual with explaining his or her needs and ensures that they are not lost in the system due to a brain-injury-related inability to navigate it. Highlighting the importance of these services, the 2012 NYS TBI Five-Year Action Plan, created by the Department of Health, recommended that Service Coordination be extended to non-Waiver participants and also called for improved access to community-based services.

The Waivers are now slated to be transitioned into Medicaid Managed Care and, like many in this community, we at the Brain Injury Association have grave concerns about the services that will be available under this new program. The Brain Injury Association endorsed the delay of the Waivers' transition to Medicaid Managed Care because a fully-thought out and comprehensive transition plan is necessary. Many aspects of this plan must be carefully determined by experts in brain injury. The individuals currently receiving services under the Waivers and those who will need help in the future deserve to have appropriate services in place when these changes go into effect. Without this attention, the Association fears that pivotal services like Service Coordination may be lost in the shuffle, making access to community-based services unobtainable for New Yorkers with brain injury.

The Association recommends that the information provided to Waiver recipients be clear and easy-to-understand, due to the executive functioning and cognitive issues common after brain injury. We stress the need for standardized training for all providers of brain injury care and services. The transition plan must also address the needs of future individuals with brain injury, including housing assistance. It cannot simply grandfather the services of current Waiver recipients into Managed Care; it must recognize that this will be a need for others going forward. We are actively working with the Department of Health on the creation of a transition plan and hope that it will address these and all needs of individuals with brain injury.

In addition to the issues within the Waivers, there is more improvement needed to ensure that all individuals with brain injury receive the proper services to keep them in their communities. The Waivers have already struggled to provide care for all Medicaid recipients with brain injury, resulting in the out-of-state institutionalization of members of this community. There is clearly an urgency for more community-based services to meet the needs of this population.

For the many New Yorkers yet to sustain an injury, and those who are ineligible for Medicaid, it is imperative that the service gaps be addressed. The Association strongly advocates for increased attention to the specific needs of this population and the establishment of specialized oversight, such as an Office for Brain Injury, to coordinate the disparate entities involved in brain injury care and to ensure the continued support of New Yorkers with brain injury. The Association has also supported legislation creating a Brain Injury Trust Fund, intended to assist individuals with brain injury with funding for rehabilitation and community-based services that are not provided through other means.

We also recommend that New York State establish a statewide registry for brain injury. By organizing such a registry, the State could greatly improve the ability of each person diagnosed with brain injury to access appropriate care and services. Other states have implemented such programs with the goal of reaching each person who is injured and providing resources, assistance, and support.

As we look towards the implementation of the Olmstead Commission Plan developed for Governor Cuomo, we hope that the recommendations issued by it will be combined with the Department's work on the TBI Action Plan to create an appropriate system of support for individuals living with the challenges of brain injury. The Association looks to the Governor and leaders in the Legislature to ensure that the necessary assistance that keeps so many people active in their communities will grow, not shrink.

I again thank you for welcoming me as a representative of the Brain Injury Association of New York State to testify before you today and for your leadership in calling this hearing. On behalf of the many individuals with brain injury and their loved ones in New York State, I ask you to continue to monitor the changes to the TBI and NHTD Waivers by the Department of Health to ensure that no participants are left behind. I also implore you to help those individuals who are served by other mechanisms - or not served at all - by working to strengthen help for individuals with brain injury in New York.

According to the Centers for Disease Control, someone sustains a traumatic brain injury in the United States every 13 seconds. In the time it has taken me to make these remarks, 40 people in the United State sustained traumatic brain injury. With such large numbers of people impacted by brain injury, it is imperative that we ensure that quality services are in place to help them. Together, we can make New York a leader in community resources for individuals with brain injury and ensure that any New Yorker who sustains an injury will receive the best care and support possible.

Thank you.