**The Brain Injury Coalition of Central New York**

We appreciate the opportunity to respond to the Transition Plan for the Nursing Home Transition and Diversion (NHTD) and Traumatic Brain Injury (TBI) 1915c Medicaid waiver programs move to managed care.  As a group comprised of individuals with brain injuries, family members, service providers and supporters we will keep our response focused on the needs of the brain injury community.

Michael Paul Mason in his book, *Head Cases* writes, “Since the mid-eighties, the United States, along with the rest of the world, has seen a dramatic reduction in the number of specialized rehabilitation beds available to the brain injured…… Most state officials, however, blame lopsided legislation that ignores the special needs of brain injury survivors and instead confuses them with the mentally ill or the developmentally disabled.”

In New York, we have benefitted from a program specifically created to meet the needs of people with brain injuries. We believe that the NYS DOH HCBS TBI Waiver was a brilliantly crafted person- centered program which has at its core a rehabilitation model. In order to function with the utmost efficacy each plan must be carefully monitored for clearly written goals with achievable outcomes. It is a program written for the specific needs of individuals with traumatic brain injuries and provides opportunities for skill acquisition in demonstrated need areas including but not limited to: Service Coordination, Community Integration Counseling, Independent Living Skills Training, and Positive Behavior Intervention and Supports. Goals written in these areas should be measureable and have achievement levels set within specific timeframes. Unfortunately, this has not always been the case and perhaps some funding has been unproductively spent. However, the Department of Health will be making a serious mistake if it offers any less of a specialized person-centered program for individuals with brain injury.

It is well believed that the trajectory of recovery from brain injury has the majority of its momentum within the first year from the onset of injury. If a stay in an acute rehabilitation facility is limited from to two to four weeks…how can we as a just society propose that we are treating these individuals and families fairly?

In its report to Congress the CDC wrote: These injuries have both short-term and long-term effects on individuals, their families, and society and their financial cost is enormous. According to one study, the annual economic burden in the United States was approximately $37.8 billion in 1985.

For the estimated 5.3 million Americans who live with a TBI-related disability, the financial cost is only part of the burden. The long-term impairments and disabilities associated with TBI are grave and the full human cost is incalculable. Yet because these disabilities are not readily apparent to the public--unlike a broken leg, for example--TBI is referred to as the invisible epidemic. These disabilities, arising from cognitive, emotional, sensory, and motor impairments, often permanently alter a person's vocational aspirations and have profound effects on social and family relationships.

(http://www.cdc.gov/traumaticbraininjury/pubs/tbi\_report\_to\_congress.html)

So, is the Department of Health of the State of New York now going to “silence the voice” of the people affected by this “invisible epidemic”? Please hear us….. We are not chronically mentally ill, we are not developmentally disabled and we are not (in most cases) suffering from a chronic and worsening health condition. We have brain injuries that may impact our cognitive, sensory, emotional and physical abilities, and we

have skills and abilities that we can use to contribute to society, if society will only invest in us.

The Brain Injury Association of America in its position paper, Conceptualizing Brain Injury as a Chronic Disease (March 2009) summarizes,

Presently, more than 3 million individuals in the U.S. are disabled due to the myriad of sequelae of a TBI (Zaloshnja E, MillerT, Langlois JA, Selassie AW. Prevalence of long-term disability from traumatic brain injury in the civilian population of the United States, 2005.*The Journal of Head Trauma Rehabilitation 2008*;23(6):394-400.) Their brain trauma has resulted in a condition that is disease causative and disease accelerative. As a result of their brain trauma, these individuals now have life-long brain injury disease. Their disease should be reimbursed and managed on a par with all other diseases. Only then will the individuals with this disease get the medical surveillance, support and treatment they deserve. Only then will brain injury research receive the funding it requires.

This is the time when the New York State Department of Health can provide individuals with Brain Injuries the medical surveillance, support and treatment they deserve. Now is the time to give people in New York living with Brain Injury the funding their condition requires in order to live fully in the communities of their choosing.

Will the New York State Department of Health consider keeping the TBI Waiver in with its present constellation of services? The plans can continue to be managed by the service coordinators presently in place. All goals can be re-written in specific, measurable, achievable, relevant and time-bound (SMART) format. The service coordinator will assist each provider re-write goals with the input of the individual. The RRDS and the Service Coordinators will work closely together to monitor the cost effectiveness of each plan. Service Coordinators will use data and objective information to assist program participants to understand why services may need to be adjusted or discontinued due to lack of progress toward stated goals.

With a recommitment to a modified version of the program the expectation is that the RRDCs will provide education that the DOHHCBSTBIWAIVER program is now considered a community based rehabilitation model program and the expectation is that the individuals receiving services will attain the skill set being focused upon within a time limited period with a functionally based community goal as the outcome. Data will be collected each month and summarized quarterly. Team meetings will take place bi- annually to ensure progress toward addressed goal(s). The data will be collected across the state. Experts in the field of Brain injury including Physiatrists, Neuropsychologists, Rehabilitation counselors, Rehabilitation nurses, Physical therapists, Occupational therapists, Speech-language pathologists could come together as a ***volunteer clinical review panel*** or as a ***clinical advisory board*** to advise on the program’s effectiveness. Possibly these review panels could be formed regionally across the state .Thereby adding a level of increased surveillance and clinical programmatic support to the TBI waiver program. The provision of ongoing consultation and training with the RRDSs could add enrichment of the clinical aspects of the program while interfacing with the administrators at the Department of Health will assist in ensuring access to ongoing Medicaid funding.

We request that the NYSHCBSTBIWaiver Program continue as it has with minor modifications, as a unique program structured to meet the needs of uniquely changed New Yorkers and their families. It has the infrastructure and we have the means to provide continuous quality improvement. Through the implementation of the **multidisciplinary expert panel** we can ensure the practices are **evidence-based and measure individual outcomes related to the goals of the person-centered service plan**.

The most common problems associated with individuals with brain injury are deficits in cognition and behavior. Cognitive functioning encompasses thinking, understanding, reasoning, and memory leading to the attainment of information and knowledge. Issues related to memory affect attention, concentration, storing and retrieving information and understanding communication. Executive functioning refers to a set of cognitive abilities that control and regulate other abilities and behaviors. Executive dysfunction often occurs due to injury to the frontal lobes of the brain which affects a person’s ability to plan and organize, and impacts flexible thinking, multi-tasking, solving problems, self-awareness, decision making, motivation, controlling or regulating emotions, concentrating and taking in information, impulse control (e.g. curbing inappropriate language or behavior), and integrating past experience with present action.

These cognitive issues affect a person’s ability to initiate, organize, and carry out the most basic functions of activities of daily living (ADLs). While a person may be able to make a sandwich, he or she may not remember the order to make a sandwich (bread on top and bottom) or to even remember to make the sandwich to eat. Accommodations, including cueing**, *are critical***to assist people to remember to take their medications, which medications to take; to buy groceries; to eat; to bathe; and so forth.

Brain injury may also affect motor functions, such as impaired coordination and balance; sensory, such as hearing, vision, impaired perception and touch; emotions, such as depression, anxiety, aggression, impulse control, and personality changes; and other physical problems such as fatigue. Seizures may also occur after a brain injury. Individuals with brain injury may also have co-occurring problems associated with substance use disorders or mental health conditions. Staff assessing persons with brain injury should take all these issues into account in determining how they impact the person’s ability to live independently without supports and how without supports, they may be faced with few other alternatives than institutional levels of care, even correctional facilities or being homeless. (***Medicaid Balancing Incentive Program: Recommendations for Core Assessment Tools for Individuals with Brain Injury, June 2015, National Association of State Head Injury Administrators)***

The Brain Injury Coalition of Central New York implores the New York State Department of Health to realize that the proposed transition plan is too complicated and does not provide the necessary supports to adequately assist individuals with TBI to move from their 1915 (c) Waiver programs to the Managed Care environment. Further, newly injured individuals with brain injury and their families will also be overwhelmed by the complexities of the program, especially when the individual and family are in the early stages of adjustment to the castrophic and life altering event that has impacted their lives.

For instance, the roles of the Managed Care Providers, the RRDCs, the Care Managers and the Service Coordinators have duties and responsibilities intermingled like a ball of yarn which only the most “savvy cat” can unravel. Why do people with brain injuries require a service system structured by multiple layers of gate keeping?

If the nine Regional Resource Development Centers are presently operating without contracts and a new Request for Proposal (RFP) is necessary to fund them? Perhaps the Department of Health might conceive of an alternate means to administer the transition of the 1915c TBI/NHTD waivers to managed care. Or at least open the RFP to other regional agencies who have worked with individuals with brain injuries. We do not have confidence in the structure of the RRDCs or that they have ***ever*** adequately fulfilled their responsibilities to develop services for individuals with brain injuries. The ability of many of the RRDCs to adequately serve as technical assistance and service assessment centers to the managed care plans and members is also doubtful. We are concerned regarding the RRDCs ability to assist the providers of brain injury services with interfacing with the managed care plans.

We also have concern about the ICAN system’s ability to help persons with brain injury. Many of us are easily frustrated and have difficulty expressing our thoughts and feelings, wants and needs with clarity. We cannot talk on the telephone for long periods of time. It is often hard for us to understand what someone is saying and what they are meaning when we cannot see them. We need someone beside us to partner with us as we navigate the complexities of the service system. We need more than a service coordinator and far more than a care manager.

Thank you for the opportunity to provide our comments.