

## **BIANYS Comments on DOH Transition Plan for TBI and NHTD Waiver Programs**

In June 2016, the NYS Department of Health issued an updated version of a transition plan for moving the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) Medicaid Waiver Programs into managed care. The Brain Injury Association of New York State is the premier advocacy organization in the State advocating for individuals with brain injury. We strongly stress the special needs of this population and the importance of developing the most thorough and complete transition plan for any changes to this program.

The TBI and NHTD Waivers have served this population for many years, providing the specialized services necessary to support participants' independence. The person-centered structure of the program and focused services based on the needs of those with brain injury have successfully supported participants for years. Changes to this structure may endanger the independence of current participants and future eligible people. The Brain Injury Association of New York State would like the Waivers to remain in their current structure outside of managed care, to ensure the best outcomes for participants. While we recognize the need for improvement within the program, the concepts and intent remain intact. We will continue to advocate for the continuation of this person-centered program addressing the unique needs of the community for anyone who sustains a brain injury and requires assistance to remain in the community. To that end, if any changes are made to these programs, they must be well-conceived and within a consistent structure that protects these individuals and their much-needed services.

We have significant concerns about the ability of this plan to meet the needs of this community, particularly in conjunction with other changes to Medicaid services in New York, including the implementation of the Community First Choice Option, as well as the continued issues with transitioning of other populations into the programs. While the transition of the Waiver populations has been delayed until 2018, we have seen repercussions from earlier transitions that indicate problems that could arise over time. We implore the Department to heed these concerns, even if the result is a further delay or carve-out of these programs, so long as that outcome will best help the people who rely on the programs for assistance in their daily lives.

Below are the itemized responses of the Brain Injury Association of New York State to the current version of the transition plan.

### **1. Issue: Transition plan does not include a high-needs rate cell to incentivize community-based services.**

Without a high-needs rate cell to provide the services that Waiver participants are currently receiving, participants of the TBI and NHTD Waivers and people who would be eligible in the future will lose services and become institutionalized due to financial incentives to institutionalize. Data cited by a Long

Island provider shows via a sample of 26 downstate Waiver participants that Waiver participant average costs are about \$9,737 a month. This figure is much lower than the proposed \$4,000-\$5,000 per member per month rate provided under Managed Care.

This rate issue would greatly impact the ability of Managed Care Organizations to provide care for these participants, as they would be losing a significant amount of money on a monthly basis. Nursing facility reimbursement rates are much higher, leading to a higher risk of institutionalization to provide services that participants were receiving in the community under the Waivers.

These populations are particularly vulnerable for multiple reasons, the most significant being the higher long-term cost for services and the challenges of assisting people with cognitive disabilities and behavioral issues. Brain Injury is better conceptualized as a chronic disease than as a singular event, as explained by the Brain Injury Association of America's Conceptualizing Brain Injury as a Chronic Disease<sup>1</sup>. Individuals with these injuries may require higher levels of supportive care for a longer period of time than other populations. Funding rates that accurately cover the costs of providing services are necessary to ensure continuous community-based services for these individuals.

## **2. Issue: Methods of oversight and tracking are not clearly defined in transition plan.**

The transition plan states that "NYSDOH is committed to track waiver participants at the time of the transition, in order to identify any future nursing home admissions or institutional placements" (page 23, paragraph 4). A clearly outlined plan to track outcomes after transition must be put in place prior to the transition, with a concise monitoring system to ensure that current participants remain living in the community with the services they need and that future eligible individuals also have access to these services.

The recently-released Medicaid Matters report, "Mis-Managed Care: Fair Hearing Decisions on Medicaid Home Care Reductions by Managed Long Term Care Plans," highlights the issue of Managed Care Companies unjustly reducing hours of service.<sup>2</sup> For many Waiver participants, understanding their rights and taking action to fight such a decision is a struggle without the services provided under the program. This is both an example of the need for a strong and independent Service Coordinator with expertise in this population and the ability to advocate for the services their clients need, and for strong tracking mechanisms that would highlight changes in care and prompt the NYSDOH to step in.

Suggestion: The implementation of a strong monitoring and tracking system with checks and balances for the alteration of services and/or institutionalization for the population qualifying for the TBI and NHTD Waivers.

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<sup>1</sup> Masel, B. Conceptualizing Brain Injury as a Chronic Disease. Vienna, VA: Brain Injury Association of America, 2009. [http://biausa.fyrian.com/\\_literature\\_49034/Brain\\_Injury\\_As\\_a\\_Disease\\_Position\\_Paper](http://biausa.fyrian.com/_literature_49034/Brain_Injury_As_a_Disease_Position_Paper)

<sup>2</sup> Medicaid Matters. Mis-Managed Care: Fair Hearing Decisions on Medicaid Home Care Reductions by Managed Long Term Care Plans. 2016. [http://www.legal-aid.org/media/205410/managed\\_longterm\\_care\\_fair\\_hearing\\_monitoring\\_project.pdf](http://www.legal-aid.org/media/205410/managed_longterm_care_fair_hearing_monitoring_project.pdf)

### **3. Issue: Implementation of Community First Choice Option altering the structure of Waiver services**

The Community First Choice Option provides similar services to many Waiver program services. It is not clear from this transition plan how that implementation will affect participants receiving these services as they exist today. The transition plan states that these services will be available to Waiver participants, however, there are qualification requirements to accessing these services, some of which include a UAS-NY score indicating nursing home level of care.

The Department of Health must address how the services provided under the Waivers will transition not only to Managed Care, but also any changes that might occur if CFCO is expanded to cover new services. Specific questions include:

- HCSS is being moved to CFCO, how will the guarantees of the transition plan be included under that program?
- Independent Living Skills Training (ILST), Positive Behavioral Interventions and Support Services (PBIS) and Structured Day Programs (SDP), all significant programs in the provision of services for people under the Waivers, may be included as CFCO services. What protections will be in place for current participants to ensure continuity of care?
- How can participants be sure that their services will remain accessible under this new program?

Suggestion: The Department must clearly define transition plans for all of the services that will change and include all of these in a tracking and monitoring system to protect against the loss of care. The Department must clearly indicate qualifications for those services and create safeguards for this population related to any assessment tools or other qualifications that may unintentionally inhibit the ability of Waiver participants to access services.

### **4. Issue: Limits on Community Integration Counseling**

The transition plan defines Community Integration Counseling as provided on a short-term basis, but does not define this term. Current Waiver definition of the service does not limit its provision, leaving decisions on length of counseling to be decided by the qualified professional providing the care. Additionally, before the plan is in effect, we have heard that the Regional Resource Development Center in Long Island has stated to providers that CIC is only to be approved for a 6-month term.

We are strongly concerned about arbitrary limits on services. Brain Injury may cause ongoing emotional issues and cognitive/memory impairment may result in the need for more assistance/longer duration than someone without cognitive impairment may require. Additionally, there is a danger in asserting a hint of a limit without clear definition, as requiring additional services may result in the determination that the participant would require institutionalization.

Suggestion: Remove reference to short-term basis and allow professional trained in counseling and brain injury to decide on length of treatment needed on a person-centered basis.

## **5. Issue: Independent Living Skills Training (ILST)**

The definition of Independent Living Skills Training in the transition plan includes the statement “primarily targeted to those individuals with progressive illnesses to maintain essential skills” (page 5). Does this mean that brain injury will be categorized as a progressive illness? If not, this may undermine access to ILST services.

In the existing TBI Waiver manual, ILST services are stated to include assistance “with ‘real world’ paid or unpaid (volunteer) employment.”<sup>3</sup> This is not included in the new definition.

The current TBI Waiver manual stresses the significance of the assessment for this service, highlighting certain aspects of it and their relation to this specific population. “It is the responsibility of the ILST provider to conduct a comprehensive functional assessment of the waiver participant ... The assessment if the basis for developing an ILST plan that describes the milestones and interim steps necessary to attain these goals ... must also include a determination of the participant’s manner of learning new skills and responses to various interventions.”<sup>4</sup> The transition plan does not specify anything about the assessment, including a statement on who performs it.

Suggestions:

- Clarify statement on population needs primarily targeted to ensure that the importance of this service for people with brain injury continues to be stressed to providers
- Clarify whether ILST will continue to be provided as an assistance to employment when other services to assist with employment cannot assist the individual. This aspect of ILST services is significant to meeting the specialized needs of this population.
- Specify role of ILST in assessing the needs of the individual, in particular their manner of learning, to ensure that the assessment is properly performed by a qualified provider.

## **6. Issue: Service Coordination Roles and Conflicts of Interest**

The transition plan includes the new conflict of interest requirement that a Service Coordinator cannot be employed by a provider who provides other services to the Plan member. This is a significant change from the regulations under which providers are currently operating. We understand and applaud efforts to reduce conflicts of interest, however, putting this requirement in place with the transition will lead to complications in the services consumers currently receive. How can service continuity be guaranteed with this fundamental change?

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<sup>3</sup> NYS Department of Health. Home and Community-Based Services Medicaid Waiver for Individuals with Traumatic Brain Injury Program Manual. NYS Department of Health, 2009, Section VI, p. 9, para 5.

<sup>4</sup> Ibid. Section VI, p. 9, para. 1.

What is the Department's transition plan for ensuring this change is managed in the least disruptive manner and to assist people to access appropriate services in all areas of the state?

Additionally concerning is that the new definition of Service Coordinator does not include the statement that they are an "effective advocate" for the participant. This description is key to the role that the Service Coordinator plays in helping the participant manage their life in the community.

Suggestions:

- Adjust the definition and/or title of Service Coordinator to include the "effective advocate" role and stress that the Coordinator bridges gaps in services between systems and has a hands-on role in assisting the participant with all matters of community living in a real person-centered manner.
- It is possible that a change in title and inclusion of the "effective advocate" role may adjust the duties of the position enough to exempt the service from the conflict of interest issue, thus remedying the issue of substantive changes to the overall structure of the program, which would result in onerous changes to both service providers and participants.

## **7. Issue: Regional Resource Development Centers and Referrals/Assessments for Services**

The transition plan states that the RRDCs will continue to provide coordination of services, but it is unclear what level of coordination will fall under their purview. It is imperative that this "Enhanced Benefits Service Assessment" be able to fully provide assessments and recommendations for the services that provide a lifeline for participants.

Many people with cognitive disabilities may find this system challenging and are unable to recognize their right to request this assessment in addition to the services they are receiving via the Care Manager. Some may not even recognize that they may need these services, due to problems with self-assessment and understanding of their limitations. Safeguards must be in place to ensure that these individuals have access to the RRDC assessment process and can access these services.

If the MCO/Case Manager decides who will be assessed and also makes the final decision on whether the recommendations are followed, there is a grave danger that people may be denied these services. As mentioned earlier in this document, the Medicaid Matters review of fair hearing decisions revealed efforts to save costs by denying home care services. These enhanced services come at a higher cost and are therefore at higher risk of being denied.

Additional questions arise when considering the new RRDC structure. It seems that the qualifications for the organizations seeking these contracts must also change with the new roles. We stress the need to ensure that roles and responsibilities are clearly identified and that measures are in place to reduce the risk of conflicts of interest. To fully ensure a conflict-free program, RRDCs should not have roles in providing services or be a MCO. BIANYS also stresses the need of anyone providing services or assessments to have training and knowledge in brain injury and the needs of this population.

**Suggestions:**

- Strengthen the role of the RRDC in issuing service recommendations for participants to ensure that MCOs do not simply ignore this recommendation and deny services. Add a role for the RRDC in appealing authorization decisions by MCO.
- Develop clear conflict of interest policy in the guidelines for the RRDCs, ensuring that an RRDC is not run by an MCO, nor has conflicting interests as a provider of services.
- Include a mechanism to track assessments, recommendations, and authorizations for these enhanced services to evaluate the effectiveness of this process and track any unintended issues arising from this process.
- Create specific guidelines for MCOs and Care Managers with triggers that will prompt them to send people for assessments and let them know that they may request it themselves. This will help direct people to these assessments.
- Determine if additional mechanisms to send people for assessments for enhanced services are available or applicable. We must ensure that anyone who needs these supports to remain independent is able to access them.

**8. Housing**

The transition plan does not address the housing needs of this population. We understand that because this document is to be submitted to CMS, and no Medicaid funding may be applied to housing, the Department has not included this issue. However, because housing is so important to community living, it is vital that it be addressed as part of this transition planning.

The current TBI Housing Subsidy provides needed assistance with rent and utilities. Without this assistance, many participants would not be able to live in their communities. While the Department has indicated that the subsidy will continue for current participants, dependent upon funding by the Legislature, it will not be available for any new individuals who meet the same qualifications as current participants.

The TBI Housing Subsidy program was developed in recognition that housing is an integral part of community living, and one that is very difficult for members of this population. The program was created to meet the special needs of this population. There are other programs that assist with housing services, including Section 8. However, often these programs are full, leaving participants on a waiting list or unable to even apply until more funding is available. These complex systems support the need of this population for an advocate, often a Service Coordinator, who can track application dates and deadlines and ensure that support programs are in place to keep these people in their homes. Even with the addition of a special Olmstead housing subsidy program, these vulnerable people will still become lost in a larger system.

BIANYS has concerns that the subsidy itself will be in jeopardy if the TBI Waiver program is dismantled, since the funding allocation relates specifically to that program. Recent problems with contracts that resulted in nonpayment of rents also raise questions about proper management and oversight of the

subsidy. Despite these concerns, the subsidy is a lifeline for participants of this program. Many areas of the State are currently in the midst of housing crises, in which many people cannot access affordable housing. For someone with a cognitive disability, tracking rent, utility bills, and benefit programs is a struggle. Adding a search for programs to assist them with housing services, and navigating a complex web of housing programs is a daunting prospect.

Suggestions:

- Support the continuation of the TBI Housing Subsidy for all current and future individuals with brain injury.
- Ensure that the advocate role of a Service Coordinator in assisting individuals with brain injury is protected, to ensure that they have assistance in all aspects of their independent living needs.

### **9. Issue: Brain Injury Training**

Under the TBI Waiver program, as detailed in the TBI Waiver Manual, training and expertise in brain injury is a required qualification for all providers. If these programs move into a larger system serving many individuals with other disabilities, the impetus to fully understand the challenges of brain injury may be lost. While some training has been recognized in the transition plan and elsewhere, the specifications of brain injury knowledge are adjusted in the provider qualifications to make them more open to interpretation. People with brain injury and cognitive disabilities have unique challenges and should not need to train their staff in the best ways to approach those challenges. We stress the need to include a strong training component across-the-board to establish high-quality service for all people with brain injury.

Suggestions:

- Require standardized training in brain injury for staff of all entities working with individuals with brain injury, including MCOs, RRDCs and provider agencies.
- Utilize experts in brain injury to develop a standardized training to meet the needs of all of these organizations. The Department has worked with BIANYS in the past to create a train-the-trainer program, *Understanding Life with Brain Injury*, which could be adapted to fit all of the roles of these organizations. BIANYS is ready to work with the Department and all entities involved in the provision of services to people with brain injury, to better educate them on the needs of this community.

### **10. Issue: UAS-NY Assessment Tool**

The Transition Plan continues to state that the UAS-NY assessment tool will be used to determine eligibility for services under Managed Long Term Care. BIANYS has consistently raised questions regarding the suitability of the UAS-NY for assessing level of need for people with cognitive disabilities. According to NYS DOH tracking numbers, the UAS-NY has determined that 28% of individuals currently served by the TBI Waiver program will be deemed ineligible for these services. We continue to state that this is an unacceptable outcome.

The Department has indicated interest in ensuring that the tool is properly assessing people with brain injury and we appreciate that. However, it is necessary to state that the UAS-NY in its current state is not properly assessing the issues related to brain injury and will cause harm to people relying on Waiver services to remain safely independent in the community. It has been stated that the tool was tested on a very small group of Waiver participants early on in this process, but it is clear from the percentage of current participants receiving ineligible scores that not enough has been done to ensure that the tool is truly taking into account all of the issues related to brain injury.

A challenge of these cognitive disabilities is that an assessment that focuses on physical disability and activities of daily living frequently misses the complex issues that are compromised after brain injury and vastly affect the ability of these individuals to live independently. BIANYS has been participating the interRAI/University of Michigan collaboration to explore these concerns, and commend the Department on their actions on this.

The Department and interRAI have stated that the interRAI tool was studied in people with TBI, pointing to a study published in 2015 in the *Journal of Head Trauma Rehabilitation, A Profile of Patients with Traumatic Brain Injury within Home Care, Long-Term Care, Complex Continuing Care, and Institutional Mental Health Settings in a Publicly Insured Population*.<sup>5</sup> However, this study does not analyze the use of the tool to assess qualification of participants into a program. Instead, the study utilized assessment results for participants already accepted into facilities, to analyze the clinical and demographic data contained therein. The authors stress that the tool provided an insightful way to analyze the population, but, again, the purpose was not to assess qualifications for the program, but to utilize previously-gathered data to learn more about the population with TBI.

The study may still be used to examine the tool, as the authors did note many important issues. The authors note that “it is therefore important to understand the dynamics of TBI in order to improve the instruments used to assess and diagnose this condition”<sup>6</sup> and that “these clinical and behavioral complexities require health policies advocating for tailored and more attentive care for people with TBI.”<sup>7</sup> Additionally, in a statement that echoes a point raised with interRAI/University of Michigan, the authors mention that the tool does not clearly identify people with TBI, stating that:

Low sensitivity from the diagnostic check box items in interRAI data may be considered too vague, leading to underreporting. Hence, it is likely that TBI is underdiagnosed in the study’s population, particularly among older adults, where communication limitations resulting from TBI may affect reporting of symptoms.<sup>8</sup>

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<sup>5</sup> Colantonio, A., Hsueh, J, Petgrave, J. Hirdes, J, & Berg, K. A Profile of Patients with Traumatic Brain Injury within Home Care, Long-Term Care, Complex Continuing Care, and Institutional Mental Health Settings in a Publicly Insured Population. *Journal of Head Trauma Rehabilitation* 2015; 30 (6): E18-E29

<sup>6</sup> *Ibid.* p. E27, para. 3.

<sup>7</sup> *Ibid.* p. E28, para. 2.

<sup>8</sup> *Ibid.* p. E28, para. 2.



The study supports concerns that the brain injury community has raised regarding the use of the UAS-NY for people with brain injury and cognitive disabilities. The specialized needs of this population require trained providers who know how brain injury differs from other disabilities and that it can be challenging to identify these needs in a general assessment tool. We hope that the Department will heed these concerns and develop a tool or tools that better assess these needs.

In June 2015, the National Association of State Head Injury Administrators (NASHIA) issued a report on assessment tools with recommendations on their use with this population. NASHIA had gathered a workgroup to determine which would more fully meet the needs of states seeking a standardized tool and also assess those needs of individuals with brain injury. From the summary of that report:

the workgroup was unable to identify any tools that are valid and reliable that would address the five domains required by BIP requirements for individuals with brain injury and also adequately assess the areas of cognition and behavior to accurately reflect the functional abilities of an individual with a brain injury and accurately drive service planning. Several of the assessment tools found on the COMBI website adequately assess behavior and cognition, but do not address the other three BIP domains: ADLs, IADLs and medical conditions. They could be used by States to supplement a tool that lacks detail related to behavior or cognition.<sup>9</sup>

BIANYS stresses that in order to best serve people with cognitive disabilities, it may be necessary to implement a tool designed to identify cognitive issues that can result in an inability to live completely independently. The Department should be open to this possibility, to protect the lives of those who can benefit from the services provided under the Waiver, without subjecting them to undue difficulty accessing programs.

#### Suggestions:

- Continue the process of evaluating the UAS-NY versus the existing assessment tools to learn how many people will potentially lose services if the tool is put in place. Utilize this data to create a better understanding of the complex needs of this community and to ensure the continued safety and support of these individuals.
- Reach out to experts in the field of brain injury and other cognitive disabilities, including neuropsychiatrists, neuropsychologists, Independent Living Skills Trainers, Behavioral therapists, Community Integration Counselors, and other qualified care providers to gain insight into participants' needs and to highlight the issues involved in assessment.
- Evaluate other tools used to determine Mayo-Portland Adaptability Inventory (MPAI) or the assessment tools provided by the Traumatic Brain Injury Model Systems Center for Outcome Measurement in Brain Injury,<sup>10</sup> tools created to evaluate the needs of people who have sustained brain injury.

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<sup>9</sup> NASHIA. Medicaid Balancing Incentive Program: Recommendations for Core Assessment Tools for Individuals with Brain Injury. 2015. [https://www.nashia.org/pdf/revised\\_bip\\_recs\\_assessment\\_june\\_2015.pdf](https://www.nashia.org/pdf/revised_bip_recs_assessment_june_2015.pdf)

<sup>10</sup> Center for Outcome Measurement in Brain Injury. <http://www.tbims.org/combi/>