

February 16, 2018

The Honorable Andrew M. Cuomo
Governor of New York
New York State Capitol
Albany, NY 12224

Re: The 2018 New York State Budget and Priorities for People with Brain Injury

Dear Governor Cuomo,

The Brain Injury Association of New York State is the premier state-wide organization advocating on behalf of the thousands of individuals with brain injury and their families and promoting prevention. We are writing regarding the 2018-19 New York State Budget proposal and the ways that we can work together to improve outcomes for all New Yorkers who sustain brain injuries.

Through our information and resource clearinghouse, family support program, extensive public education and professional training programs, and extensive network of chapters and support groups, BIANYS is uniquely positioned to provide input and insight into the needs of this population. From this perspective, we have reviewed the proposed 2018-19 New York State Executive Budget proposal and would like to provide you with feedback on some of the proposals contained therein, as well as ask for assistance on some issues of importance for this community.

We respectfully request that you take the following steps to assist people with brain injury:

1. Permanently delay the transition of the TBI and NHTD Waiver populations into Managed Care or hold the transition until after the OPWDD population is successfully transitioned into the program to ensure that participants are supported safely until all changes are carefully considered and implemented.
2. Make changes to the Uniform Assessment System - New York State (UAS-NY) to include a cognitive assessment component or identify and implement a tested and qualified cognitive needs assessment tool to assess eligibility for Medicaid services. The UAS-NY has been partially reviewed by an audit that confirmed advocates' concerns about its ability to assess the needs of people with brain injury. The proposal to raise the nursing home level of care eligibility threshold to a 9 on the UAS-NY is unacceptable due to the tool's inadequacy as an assessment tool.
3. Implement reimbursement rates for the TBI and NHTD Waiver programs that allow providers to pay staff a living wage to address workforce shortages across the State.
4. Reactivate the New York State Office for the Advocate for Persons with Disabilities.
5. Work with the NYS Legislature to establish a Brain Injury Trust Fund to help New Yorkers access rehabilitative and independent living services that are not funded through other means.

On the following pages, we have provided details on these issues and the need for action on them. We hope that you will use this input to make decisions on the 2018-19 New York State Budget, as well as on future policy decisions that affect the brain injury community.

Thank you,



Eileen Reardon
Executive Director



Barry Dain
Board President

- 1. Permanently delay the transition of the TBI and NHTD Waiver populations into Managed Care or hold the transition until after the OPWDD population is successfully transitioned into the program to ensure that participants are supported safely until all changes are carefully considered and implemented.**

The Brain Injury Association of New York State has raised concerns about the plan to move participants of the TBI and NHTD Medicaid Waiver programs into Managed Care from the beginning of this process. While the Department of Health has held meetings with stakeholders in the community, in an attempt to address these concerns, those meetings have not led to a complete and thorough transition plan that addresses all of the issues raised by this community and ensuring that the people served by these two programs are protected. This is a vulnerable population and requires a clear action plan.

Now that the TBI Waiver has been approved by CMS through 2022, New York State has more time to fully address issues within Managed Care and ensure that the TBI and NHTD Waiver populations have a safe transition and receive continued support services under Managed Care. **We ask that the TBI and NHTD Waiver transition to Managed Care be delayed permanently or until after the OPWDD population is successfully transitioned into the program.** This will allow the State to carefully assess the Managed Care System and correct issues that have arisen with other populations, and put in place a detailed transition plan that will keep these individuals safe and supported in the community.

Outstanding issues that need to be completely addressed before a transition can occur include:

- The implementation of the Community First Choice Option (CFCO) services into Managed Care. The CFCO State plan services will have a great effect on the service delivery for the Waiver program, yet we have not seen the plan for implementation, nor how it will impact current and future Waiver services.
- Clarification of roles and responsibilities reconciling current Waiver services and services available under managed care. The definition and role of the Service Coordinator as compared to the Care Manager under Managed Care have not been finalized.
- A structured tracking system and policies and procedures to ensure that people currently receiving Waiver services are not institutionalized or dropped from services once Managed Care Organizations oversee services has not been outlined. Similarly, a system needs to be in place that will identify people with brain injury and make sure they also are able to access the services that the current population is guaranteed. This is essential to providing adequate care in the community.
- Eligibility and continuity of services. In conjunction with the other issues raised here, we need to see a clear crosswalk on eligibility requirements for different managed care programs and for the services provided under managed care, to see where gaps exist between the Waivers and these programs and identify ways to reconcile the programs to provide necessary services for these participants.
- Oversight. The proposed drafts of transition plans have provided ideas of how certain oversight will be addressed, but no defined roles and responsibilities. We are open to working with DOH on this issue, but these conversations have not yet occurred, nor have stakeholders seen proposals that DOH has drafted regarding this transition plan. For example, the RRDCs will have oversight roles and provide evaluations, but no further details on how this will work have been provided. The community cannot wait until April 2019 to learn how the transition will be implemented, as it prevents discussion and full discussion to work out details before the transition occurs.

- Reimbursement rates and concerns about institutionalization. Inadequate reimbursement rates for high needs members of this population will lead to decreased services or institutionalization, particularly with the proposal to keep nursing home care outside of Managed Care.
 - Housing. The Department of Health has not established a clear process for the continuation of the TBI Medicaid Waiver's housing subsidy, other than promising that current participants will be grandfathered in. This subsidy is essential to keeping people in homes in the community – new participants will need access to the subsidy, as current housing programs do not meet these needs. We must also ensure that we do not drop current participants from the subsidy, leading to homelessness.
 - The Uniform Assessment System's inadequacies in assessing cognitive and behavioral disabilities resulting from brain injury (see UAS-NY concerns below).
- 2. Make changes to the Uniform Assessment System - New York State (UAS-NY) to include a cognitive assessment component or identify and implement a tested and qualified cognitive needs assessment tool to assess eligibility for Medicaid services. The UAS-NY has been partially reviewed by an audit that confirmed advocates' concerns about its ability to assess the needs of people with brain injury. The proposal to raise the nursing home level of care eligibility threshold to a 9 on the UAS-NY is unacceptable due to the tool's inadequacy as an assessment tool.**

The Uniform Assessment System - New York State (UAS-NY) is inadequate in its ability to assess cognitive disabilities related to brain injury and their effects on the abilities of people with brain injury to live independently. The UAS-NY focuses primarily on physical disabilities, when brain injury has a cognitive and behavioral impacts that threaten the ability of an individual to remain independent. These issues have been outlined and acknowledged by the Department of Health, yet action has yet to be taken to address the problems.

- Many individuals with brain injury have difficulties with iADLs, as opposed to other activities, yet these are underrepresented on the UAS-NY. While the algorithm used to calculate a score is unclear, we do know that there are few areas in the UAS-NY that relate to iADLs. These are limited to meal preparation and medication management. According to the IPRO audit, neither of these questions are included in the algorithm used to provide a number indicating eligibility.
- The Department of Health agreed to address these issues in the side letter agreement with the Legislature during last year's budget discussions, stating that they are committed to regular meeting, including stakeholders, and "generating proposed improvements to the UAS tool."
- The Department of Health's audit of the performance of assessors using the UAS-NY on current Waiver participants (performed by IPRO) indicated serious issues with cognitive assessment by the UAS and recommended a separate cognitive tool be included to ensure that people are properly assessed. It is important to note that the IPRO audit evaluated that consistency of the assessments using the tool, not the tool's ability to assess eligibility.
- The method offered by the Department of Health to address this is a temporary patch, not a real solution to the underlying issue. While we are glad that current participants can access a second assessment by RRDC nurse assessor, with full review of background materials, this is still burdensome, monetarily for the State and emotionally for participants. Additionally, the third step in the process, having a doctor authorize their need for services, is not yet in place.

3. Implement reimbursement rates for the TBI and NHTD Waiver programs that allow providers to pay staff a living wage to address workforce shortages across the State.

We applaud the effort in the Executive Budget's to propose funding for a study of workforce issues in rural Upstate areas and incentives to address the issues, as this is a step in the right direction, but the proposal does not go far enough to address this problem. Across all of New York State, reimbursement rates have to be addressed before this group is put in a position where they are at risk. Reimbursement rates under the current Waiver system and in Managed Care are inadequate to provide services for people with brain injury. The current Waiver system's workforce is dwindling due to better-paying opportunities elsewhere, while reimbursement rates lag behind minimum wage requirements, forcing provider agencies to struggle. We need to address reimbursement rates that allow provider agencies to offer fair wages that keep quality workers available to serve these participants, and provide incentives for increasing the workforce across New York. Under Managed Care, a high needs rate cell is needed to ensure that people with brain injury who require more care are not institutionalized due to the costs of providing services.

4. Reactivate the New York State Office for the Advocate for Persons with Disabilities.

The New York State Office for the Advocate for Persons with Disabilities served an important role in representing people with disabilities in State policy decision-making. Established by Governor Mario Cuomo in 1983 through Executive Order No. 26, the Office for the Advocate was reauthorized by Governor Andrew Cuomo and served as a resource and voice for New Yorkers with disabilities until the establishment of the Justice Center. The Justice Center, however, does not provide the same advocacy functions as the Office for the Advocate performed, and in many cases related to people with brain injury, the Justice Center has no oversight. To ensure that the needs of the brain injury and disability community are reflected in policy decisions, we ask that the Governor reactivate the Office for the Advocate for Persons with Disabilities.

5. Work with the NYS Legislature to establish a Brain Injury Trust Fund to help New Yorkers access rehabilitative and independent living services that are not funded through other means.

Many people with brain injury are unable to access needed rehabilitative services or other necessary elements of independent living because they are not funded through insurance or other programs. For years, the Brain Injury Association of New York State has advocated for the establishment of a brain injury trust fund that would allow people to access funds for services like cognitive therapy or environmental modifications. The Brain Injury Trust Fund would be the payer of last resort for New Yorkers with brain injury, providing a financial safety net to assure improved access to needed services. S.3752 (Golden)/ A. 105 (Cahill) would create this program.