



March 20, 2018

**TO: BRAIN INJURY ADVOCACY DAY PARTICIPANTS**

**FROM: THE BRAIN INJURY ASSOCIATION OF NEW YORK STATE**

Thank you so much for making the trip to Albany and participating in Brain Injury Advocacy Day.

Today, many of you will be meeting with members of the State Legislature. Each meeting is a valuable opportunity to help a Senator or Assembly member understand how brain injury impacts the lives of New Yorkers, as well as the importance of comprehensive and coordinated services for those with brain injury.

We wanted to share with you a few tips for talking with legislators and their staff members.

- DO thank legislators for their support, and for meeting with you.
- DO tell your personal story about how brain injury has impacted you or a loved one.
- DO keep that story as short as possible – *five minutes or less*.
- DO talk about the challenge of finding and accessing brain injury assistance and the challenge that brain injury brings to coordinating services.
- DO talk about what options you have or don't have if these services are no longer available.
- DO speak passionately from the heart, and be polite and courteous.
- DO be sure that all in your group who wish to speak have a chance to do so.

We also want to share some general information about Brain Injury Advocacy Day

- March is Brain Injury Awareness Month, and today is our Annual Brain Injury Advocacy Day at the State Capitol in Albany.
- Advocacy Day has been organized by the Brain Injury Association of New York State (BIANYS)
- Advocates have traveled to Albany from all over the state to help educate legislators about how services support successful outcomes for New Yorkers with brain injury.

On the reverse of this page, you will find information about legislative issues regarding brain injury. There are brief background descriptions on the topics for you, provided so that you can familiarize yourself with the issues. Additionally, you will see specific requests to pose to legislators at your meetings.

## Legislative Issues: Some Background For You

### **Protect Medicaid Services, Strengthen Protections for People with Brain Injury in the NYS Budget**

- In New York, the transition of the TBI & NHTD Medicaid Waivers into Managed Care will jeopardize the specialized services developed for people with brain injury. The Department of Health has not yet created an appropriate transition plan that protects all participants. The Legislature must hold the Department to their promises to address these issues and require a clear plan for doing so, with adequate time and resources dedicated to ensuring services and participants are protected. To do so, the Legislature must address this issue in the 2018-19 NYS Budget, permanently stopping the transition or delaying it until after the people served under the Office for People with Developmental Disabilities (OPWDD) have been successfully transitioned into Managed Care (slated completion date is 2022).
- New York State implemented an assessment tool, the Uniform Assessment System – New York (UAS-NY) to qualify people for Medicaid Long Term Care Services, including the TBI and NHTD Medicaid Waiver Programs. This tool does not properly assess the cognitive and behavioral challenges that affect the ability of people with brain injury to live independently, and emphasizes physical disabilities at a much higher rate. This puts people with brain injury at a disadvantage, disqualifying them from needed services. To make matters worse, the Executive Budget proposal suggests raising the qualifying score from a 5 to a 9, making an already-inaccessible threshold for eligibility much harder to meet. The Legislature must reject the Governor's proposal to raise the eligibility level to a 9 on the UAS and press the Department of Health to change the UAS-NY. We must ensure that the testing tool is fair for all people in NYS by advocating for a tool that fully assesses the impact of cognitive disabilities on independent living when determining eligibility for Medicaid services.

### **Support the creation of a Traumatic Brain Injury Trust Fund**

Many brain injury rehabilitation and support services, such as cognitive rehabilitation, are not covered by insurance, making them inaccessible to many New Yorkers. The Brain Injury Trust Fund addresses this by letting people with brain injury apply for financial assistance to access these services. Senate Bill 3752 (Golden) and Assembly Bill 0105 (Cahill) would create this needed program.

### How Can Your Legislator Help? Ask Them to Do These Things:

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. **Take action on the TBI and NHTD Waivers in the 2018-19 New York State budget.**
2. The Uniform Assessment System is failing people who need assistance. People with cognitive and behavioral disabilities that impede their ability to live without support are deemed ineligible for services because the UAS-NY fails to take these disabilities into account. **Stop the Governor's plan to increase the UAS qualifying level to 9 in the 2018-19 NYS Budget, and insist that the Department of Health fix the tool.**
3. A brain injury trust fund will help individuals with brain injury access needed rehabilitation not covered by other funding programs. **Support the creation of a brain injury trust fund. Bill number S.3752 (Golden) / A. 0105 (Cahill).**