

March 23, 2016

**TO: BRAIN INJURY ADVOCACY DAY PARTICIPANTS**

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 how services currently address specific needs.
- DO talk about the challenge of coordinating services.
- DO talk about what options you have if those services are no longer available.
- DO speak passionately from the heart.
- DO 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 Awareness Day and how the plan to move New Yorkers with brain injury into managed care programs could lead to dramatic service cuts for these individuals.

- March is Brain Injury Awareness Month, and today is the first-ever 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.
- We will also work to help legislators understand how a New York State Department of Health (DOH) plan to move individuals with traumatic brain injury (TBI) into Medicaid managed care programs could lead to dramatic service cuts.
- This issue is especially important right now, as the 2016-17 state budget is being negotiated, because the budget is expected to include a determination regarding how to provide these needed services to New Yorkers with brain injury.

**MANY STATE LEGISLATORS SHARE ADVOCATES' CONCERNS**

- We are grateful for the support of the State Senate and Assembly. We thank the members of both houses who share our concerns and have encouraged action.
- In their one-house budget proposals, both the Senate and Assembly include measures to ensure continuity of care, service quality and protections.

- Apart from the budget process, matching legislation has been introduced in the Senate and Assembly to protect New Yorkers with brain injury and ensure that services for are maintained at current levels – either by creating a “carve out” to maintain existing waiver programs that allow these individuals to be served outside of managed care settings or by ensuring that managed care includes the current level and range of individualized and coordinated services.

***CONCERNS ABOUT MANAGED CARE FOR NEW YORKERS WITH BRAIN INJURY***

- BIANYS and other advocates have determined that, compared with the existing waiver programs, managed care will significantly reduce the level and quality of care for individuals with brain injury.
- For many people, brain injury profoundly affects their physical and cognitive abilities and makes it extremely difficult or impossible to live their lives the way they did before the injury.
- Brain injury impacts family dynamics, community activities, employment and social life.
- Behavioral changes that occur as a result of brain injury can be especially challenging, because they can have a significant impact on the ability to interact with others and conform to the rules and structure of our society.
- Service coordinators, independent living skills trainers, positive behavioral intervention supports and other services address the complex needs and challenges of New Yorkers with brain injury by offering individualized structure, support and assistance to help them live as independently as possible in their home communities.
- Individuals with brain injury who are unable to be productive, law-abiding members of their communities are much more likely to face institutionalization, homelessness, or incarceration – at far great cost to taxpayers than community-based services.
- The concerns of BIANYS and many others in the brain injury community regarding the transition to managed care have been described in detail to officials from the state Department of Health (DOH).

***SERVICES ARE AT RISK FOR ALL NEW YORKERS WITH BRAIN INJURY***

- Not all New Yorkers with brain injury receive services funded by Medicaid.
- The TBI waiver program fostered the creation of services focused specifically on the complex needs of individuals with brain injury, making these services available for Medicaid recipients as well as others with brain injury.
- The programs and services that serve individuals with brain injury typically include clients funded by Medicaid as well as those funded through other sources.
- Without the clients funded by Medicaid at current levels, some of these programs may no longer have adequate resources to continue to operate, potentially creating gaps in services even for those who care is not funded through Medicaid.