

BRAIN INJURY ASSOCIATION OF NEW YORK STATE 2016 PUBLIC POLICY PRIORITIES

The mission of the Brain Injury Association of New York State (BIANYS) is to promote awareness, understanding, and prevention of brain injury through education, advocacy, and community support services that lead toward reduced incidence and improved outcomes for children and adults with brain injuries and their families. Through our programs and services, BIANYS links individuals with brain injury and their loved ones with services and resources, and advocates for appropriate assistance in the community.

The Brain Injury Association of New York State is the state affiliate of the Brain Injury Association of America (BIAA), and works with BIAA on issues related to brain injury on a federal level. These efforts include ensuring that brain injury rehabilitation is recognized and addressed under federal programs, including Medicare/Medicaid, and legislation like the *Affordable Care Act*, as well as advocating for funding and support for brain injury research.

Within New York State, BIANYS advocates for increased services to support individuals with brain injury and their loved ones. The BIANYS public policy agenda focuses on improving access to treatment and rehabilitation and supporting independent living for all New Yorkers with brain injury, ensuring that they are empowered to make their own decisions and have access to the support necessary to do so. While all areas of advocacy will require input and action by BIANYS, the following public policy areas have been identified as priorities in 2016:

MEDICAID REDESIGN

Since 2011, New York State has embarked on an extensive effort to redesign the Medicaid system. Many of the recommendations have an impact on individuals with brain injury, particularly the move to Managed Long Term Care. There are many unresolved issues and concerns related to the change in systems and how they will affect services for individuals with brain injury.

TBI and NHTD Waiver Transition to Managed Care

BIANYS is engaged in the process of monitoring the development of transition plans to monitor and engage stakeholders, legislators, and regulatory agencies in discussion about these changes. The primary focus is the plan by the state Department of Health (DOH) to transition into managed care those New Yorkers who are enrolled in the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) Medicaid Waiver Programs.

These changes will affect many people with brain injury, both those who receive Medicaid funding and others. The programs and services that serve individuals with brain injury typically include both clients funded by Medicaid and 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 for all New Yorkers with brain injury – not just those whose care is funded through Medicaid.

BIANYS is highly concerned that the transition plan could dramatically reduce the individualized, coordinated services that address physical, cognitive and behavioral issues and help individuals with brain injury remain safely in the community. The transition has been delayed twice due to advocacy from the brain injury community. Most recently, the transition of these two programs was delayed until January 2018 via the NYS 2016 budget legislation. We continue to work closely with brain injury and disability stakeholders and advocates, the DOH, and with members of the NYS Legislature to ensure that any changes to these programs will be fully thought-out and appropriate to the needs of participants.

Uniform Assessment System (UAS-NY)

In addition to the proposed transition of the Waiver programs into Managed Care, NYS is implementing one assessment tool, the Uniform Assessment System – New York (UAS-NY) for all Medicaid programs. The tool is already in place in Medicaid programs, with the exception of the TBI Waiver, to evaluate the level of care for individuals receiving certain services. BIANYS is concerned that this tool does not fully assess cognitive disabilities, impacting individuals with brain injury to a greater extent than individuals with other disabilities. Data gathered by NYSDOH indicates that 28% of current TBI Waiver participants do not meet the level of care to continue receiving services, as measured by this assessment tool.

BIANYS advocates for proper vetting of an appropriate and independently-verified assessment tool to be used to evaluate care needs, to ensure that New Yorkers with cognitive disabilities can access the services they need to remain in the community. BIANYS is working with other brain injury advocacy organizations both nationally and in-state, as well as with other stakeholders on this issue. We are gathering information on the UAS-NY and other assessment tools, providing input to the NYS DOH regarding the needs of New Yorkers with brain injury, and sharing information with our members and the public to educate the community on assessment concerns.

AMEND THE NYS TRAUMATIC BRAIN INJURY LAW

The NYS Traumatic Brain Injury Law (Chapter 196 of the Laws of 1994) was enacted in 1994 and established the NYS traumatic brain injury program, identified the NYS Department of Health as the lead agency, and created the Traumatic Brain Injury Coordinating Council. However, much has changed in the almost 20 years since its enactment, requiring amendments to the law. Chief among the BIANYS recommendations are: establishing an Office for Brain Injury Programs within the Department of Health; reformulating composition of the Council and making it advisory to the Governor; updating the responsibilities of the Department of Health as the lead agency; creating an additional focus on concussion; and making the law more inclusive to all with brain injury. These changes would address the current fragmented nature of brain injury programs and

strengthen the advisory and coordination vehicles resulting in improved services for New Yorkers with brain injury. [A. 1437A (Jaffee) / S.6575 (DeFrancisco)]

STRENGTHENING RESOURCES TO SUPPORT NEW YORKERS WITH BRAIN INJURY ACROSS THE CONTINUUM OF CARE

BIANYS advocates for an increase of services available to all individuals who sustain brain injury in New York State across the continuum of care, so that no New Yorkers are lost in the system, unable to access rehabilitation and support services due to cognitive disability, or due to a lack of adequate funding sources. BIANYS has proposed a continuum of care outreach and assistance project to address the lack of guidance and follow-through for people navigating complex systems of care. With proper support, New Yorkers with brain injury and their loved ones can access the right care at the right time, improving outcomes and lowering costs.

CONCUSSION INITIATIVE

In 2011, the legislature enacted the Concussion Management and Awareness law designed to enhance the identification and treatment of concussion in school athletic activities. BIANYS played a leading role in the enactment of this law and in the subsequent implementation. To respond to great leaps in the identification, treatment, and rehabilitation of concussion, BIANYS has created a Concussion Initiative to address the ongoing needs of New Yorkers with concussion. Among the goals of the Initiative are efforts to provide outreach and training on concussion prevention, identification, and management; highlight areas of legislation that need refinement and/or improvement; and issue recommendations on the best practices in the field. BIANYS will incorporate a youth concussion council made up of young New Yorkers as part of this Initiative.

BRING NEW YORKERS HOME

There are many New Yorkers with brain injury institutionalized in out-of-state facilities due to a lack of adequate community-based resources at home. It is imperative that service networks be developed across the state to provide the support needed to assist these New Yorkers in their home communities. We encourage the State to evaluate the services needed to assist these individuals, what services need to be added, and how we can expand upon existing service delivery systems to return these New Yorkers to their home state.

ESTABLISH A BRAIN INJURY TRUST FUND

There is an acute need for services for individuals with brain injury. Currently, approximately 3,000 individuals receive services through the Department of Health's Home and Community-Based services TBI Waiver. However, the majority of New Yorkers with brain injury are not eligible for this waiver. Nonetheless, many need services which are often beyond their financial means. 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. In addition,

BIANYS proposes that funds be utilized for a public information campaign about brain injury and resources.

ESTABLISH A BRAIN INJURY REGISTRY

There is currently no mechanism in New York State to capture the number of individuals with brain injury. The lack of reliable statistics has a detrimental impact on understanding the scope of brain injury in New York and the development of services to meet the need. In addition, there is no coordinated mechanism in place to link individuals who sustain brain injury and their families with information and services. A registry would provide both improved statistics and a linkage to information, while safeguarding the confidentiality of the injured individuals. This would save countless hours of frustration as individuals and their families search for resources and help.

BIANYS supports the following bills in the current NYS Legislative session:

S. 3419B (Young) / A.2834B (Titone) : Regulates Step Therapy Policies

This bill amends insurance law related to regulation of step therapy and first fail health insurance policies and protocols to ensure access to medication ordered by a physician.

S. 1000C (Funke) / A.5133B (Morelle) : Relates to permanent total disability benefits received by disabled volunteer firefighters

This bill provides a cost-of-living adjustment to benefits received by NYS disabled volunteer firefighters.

S. 7247 (Seward) / A. 9479 (Weprin): Establishes the Office of Community Living

This bill establishes the Office of Community Living in New York State to address the needs of the disability community in accessing community-based services.

BIANYS supports the following bills in the current US Congressional session:

THE DISABILITY INTEGRATION ACT: S. 2427 (Schumer) / H. 5689 (Gibson)

The bill strengthens existing disability integration laws, regulations, and court decisions related to access to community living, with stress on transportation and integrated employment, establishes oversight by the Department of Justice and input from the Department of Health and Human Services, includes nondiscrimination clauses, and legislates that community-based services must be offered to individuals with disabilities prior to institutionalization, with regular updates.

YOUTH SPORTS CONCUSSION ACT: S. 2508 (Udall) / HR. 4460 (Pascrell)

The bill makes it unlawful to sell athletic sporting equipment for which the seller or importer makes deceptive safety claims and authorizes the Federal Trade Commission to provide oversight and utilize existing guidelines with respect to safety benefits.