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THE VOICE OF BRAIN INJURY

June 26, 2012

Melanie Bella
Director, Federal Coordinated Health Care Office
Centers for Medicare and Medicaid Services (CMS)
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Cc: Jonathan Blum, Deputy Administrator, Center for Medicare, CMS

Cynthia Mann, Deputy Administrator & Director, Center for Medicaid and CHIP Services

Re: New York State Department of Health's Demonstration to Integrate Care for Dual Eligible Individuals Final Proposal

Dear Ms. Bella,

The Brain Injury Association of New York State (BIANYS) is the premier statewide non-profit membership organization that advocates on behalf of individuals with brain injury and their families, and promotes prevention. BIANYS welcomes the opportunity to comment on New York State's proposal for a pilot program for Fully Integrated Dual Advantage Program (FIDA) for individuals eligible for both Medicare and Medicaid. BIANYS commends the New York State Department of Health (NYSDOH) for responding to many concerns raised and suggestions offered by individuals with brain injury and their families. BIANYS is firmly committed to preserving services currently in place for individuals with brain injury receiving services.

BIANYS strongly endorses the continued availability of all existing TBI Waiver services for individuals currently receiving these services as well as others with brain injury who are in the population of dual eligible individuals. This is consistent with the well-established public policy of the nation and New York State to support individuals with disabilities, including brain injury, to live in or as close to their home communities as possible. BIANYS is hopeful that the FIDA proposal is the first of many steps to provide more comprehensive services for individuals who have sustained a brain injury.

The Brain Injury Association of NYS supports individuals with brain injuries and their families on a daily basis through our helpline, information and referral assistance, prevention programs, support groups and the Family, Advocacy, Counseling, and Training Services (FACTS) program. These individual and community-based activities have shown us firsthand the critical importance of community-based TBI Waiver services to allowing individuals to remain in the community and avoid nursing home or institutional settings while providing cost savings under Medicaid. In view of the effectiveness of these services, we also see the many

benefits of expanding access to these services for individuals who are not currently on the waiver but are dual eligible. Surely, there is no reason to deny essential services and supports to this population.

BIANYS supports the extensive comments submitted by the Alliance of TBI & NHTD Waiver Providers. These comments enumerate in great detail the services currently available under the waiver. Since 1996, the NYS TBI waiver program has been successful in the repatriation and diversion from nursing homes for thousands of individuals who have sustained a brain injury. This program has saved New Yorkers millions of dollars while at the same time ensuring the least restrictive environment for those who have participated in this program. The FIDA demonstration proposal lacks the inclusion of critical services, such as housing, respite, social/non-medical transportation, community transition services, assistive technology and environmental modifications. These essential services must be included in the FIDA program. These services are clearly defined in the NYS state TBI waiver manual and have served as the foundation of success for the individuals served since 1996. The exclusion of these supports jeopardizes the individual's ability to sustain him or herself in the least restrictive environment. The housing component for individuals on the TBI waiver "is" the least restrictive environment, when compared to a nursing home placement. Current TBI waiver participants must be able to have a mechanism that will allow them to access the housing component of the waiver. Now, in order for an individual to participate in the housing program of the TBI waiver, he or she must be a waiver participant. When an individual is enrolled into the FIDA program he or she will no longer be a waiver participant, and subsequently will lose access to housing support. Because the housing component is not a waiver service, a mechanism must be in place to ensure individuals will have and be able to retain access to this support.

While the FIDA proposal seems to include many of the services found in the waiver, there continues to be a lack of clarity regarding how these services will be delivered and operationalized. This is of concern because the delivery of quality services is directly related to the qualifications of those delivering the services and administering then programs. There are no shortcuts to quality. Indeed to think otherwise may undermine the program and jeopardize the individuals receiving services. BIANYS recommends that the proposal include further clarification of the qualifications for service providers, the number of individuals that can be served by one service coordinator, how performance and quality indicators are to be measured, and the way in which types/hours of services are authorized prior to program implementation.

We recommend that the NYS Department of Health work with BIANYS to develop appropriate training standards for individuals assessing and delivering services. A national standardized training mechanism is in place through the Academy of Certified Brain Injury Specialists (www.acbis.pro). BIANYS recommends that NYS Department of Health require use of this certification to ensure competence and training in working with individuals with brain injury, particularly for non-credentialed staff. This will promote standardization of training among providers and, consequently, a more cohesive and higher quality delivery system.

FIDA and other managed care proposed program changes can be confusing for an individual without brain injury, let alone individuals with cognitive deficits. BIANYS has already received many calls from panicked waiver participants who are overwhelmed by what they have heard and are extremely concerned that they

will be losing their services. In the past, program changes have not been communicated clearly and consistently, leading to extensive confusion. It is essential that there be a well thought out communication plan **before** moving forward with this demonstration or any other program changes. The communication strategy must take into account the cognitive challenges for many with brain injury. The information detailing upcoming changes and process must be clear, proactive, and inclusive of collaboration among individuals receiving services and their families, providers, and the BIANYS.

Thank you for the opportunity to comment on the FIDA proposal. On behalf of our constituents, the Brain Injury Association of New York State looks forward to continued collaboration and partnership to ensure that individuals with brain injury live in the community and receive essential quality services! Thank you.

Sincerely,

Marie M. Cavallo, PhD

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President

Judith I. Avner, Esq. Executive Director