Members of the Senate Finance Committee and the Assembly Ways and Means Committee:

My name is John R. Drexelius, Jr, and I am the Government Relations Counsel for the Developmental Disability Alliance of Western New York (DDAWNY).

DDAWNY is a collaborative group of member voluntary agencies that provide services and supports, including educational services to people with developmental disabilities in the Western and Finger Lakes regions of Western New York. DDAWNY member agencies employ over 22,400 individuals in the seventeen Western and Finger Lakes counties of New York State providing supports and services to over 33,000 individuals with developmental disabilities and their families and/or circle of supports.

In 2011, DDAWNY member agencies had combined revenues of over $737.1 million and combined expenses of over $737.2 million. Revenues are derived from various governmental and non-governmental programs, including programs funded by the State Education Department, the Department of Health, the Office of Mental Health, the Office For People With Developmental Disabilities, the Federal Department of Housing and Urban Development, foundation fundraising activities and contributions from various charitable and related religious institutions.

DDAWNY is pleased to provide comment to the Joint Fiscal Committees on the 2015-16 Executive budget and in particular the Health/Medicaid portions of the budget.

OLMSTEAD and the ADA

The State of New York is currently seeking to transform its delivery of supports and services to persons with I/DD. The State is seeking to ensure, consistent with Title II of the Americans with Disabilities Act (ADA) that individuals with I/DD are not unlawfully discriminated against and that services, programs and activities are provided in the most integrated settings appropriate to the needs of persons with I/DD.

Title II of the ADA prohibits discrimination in all “services, programs, or activities of a public entity.” 42 U.S.C. § 12132. The ADA establishes a broad mandate, including that citizens with disabilities have the right to live integrated lives. Based on Title II and its integration mandate, the United States Supreme Court held that “unjustified isolation” of persons with disabilities by State and local government constitutes discrimination under Title II. Olmstead v. L.C., 527 U.S. 581, 597 (1999). The United States Department of Justice (DOJ) has

interpreted this to mean that the civil rights of persons with disabilities are violated by unnecessary segregation in a wide variety of settings, including in segregated housing, employment, vocational, and day programs. It is the State's obligation to fulfill this mandate on behalf of its citizens, whether they receive services during the day or in residential settings at night, and regardless of the severity of their disabilities.

In guidance on how the Federal government will enforce this integration mandate, DOJ has indicated that "Integrated settings" are those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities. According to the DOJ, Integrated settings are located in mainstream society; offer access to community activities and opportunities at times, frequencies and with persons of the individuals choosing; afford individuals choice in their daily life activities; and provide individuals with disabilities the opportunity to interact with non-disabled persons to the fullest extent possible. In contrast, DOJ has indicated segregated settings include, but are not limited to… settings that provide for daytime activities primarily with other individuals with disabilities.

DDAWNY strongly supports the goals of Olmstead and was pleased with the proposals contained in Governor Cuomo's Olmstead Plan intended to assist in transitioning people with disabilities from segregated settings to the community. Governor Cuomo has stated that "people with disabilities have the right to receive services and supports in settings that do not segregate them from the community; it is a matter of civil rights."

We are concerned that the Executive Budget proposed fails to provide the level of funding we believe is necessary to ensure the state meets the promise of the Governor's Olmstead plan and more importantly complies with the ADA as interpreted by the Supreme Court in Olmstead and the United States Department of Justice, which is charged with enforcement of the ADA's integration mandate.

PARTNERSHIP PLAN WAIVER AMENDMENT - TRANSFORMATION AGREEMENT

In an effort to comply with these Olmstead goals, New York State and the Centers for Medicare & Medicaid Services (CMS) have identified a series of shared goals that will improve opportunities for individuals with developmental disabilities in the areas of employment, integrated living, and self-direction of services. These goals are captured in a transformation agreement, which was incorporated as an amendment to New York State's current Section 1115 Partnership Plan Waiver and effective April 1, 2013. The purpose of the amendment was to expand the objectives of the current Partnership Plan Waiver

to support NYS' transformation of the Office for People With Developmental Disabilities service delivery system.

. They include:

- Developing new service options to better meet the needs of individuals and families in a truly person-centered way, including allowing for more self-direction of services;
- Creating a specialized managed care system that recognizes the unique needs of people with disabilities, and is focused on a habilitative model of services and supports;
- Ensuring that people live in the most integrated community settings;
- Increasing the number of individuals who are competitively employed;
- Focusing on a quality system that values personal outcome goals for people, such as an improved life or access to meaningful activities; and
- Working to make funding in the system sustainable and transparent.

The amendment seeking to transform its developmental disability system and provided federal matching dollars for the period of April 1, 2013 through March 31, 2014 was contingent upon the state meeting milestones outline in Special Terms and Conditions (STCs).

In particular STC 62 requires permits NYS to claim Federal Financial Participation (FFP) for expenditures made for certain designated state health programs (DSHP) beginning April 1, 2013 through March 31, 2014. Up to $250 million in FFP was authorized to pay for DSHP costs during this period. These program expenditures include funds expended by the state to support programs operated by the Office of Mental Health, the Office of People with Developmental Disabilities and the Office of Alcohol and Substance Abuse Services. During this period the state is also required to submit several deliverables to demonstrate that the state is successful in its efforts to transform its health system for individuals with developmental disabilities.

BALANCED INCENTIVE PROGRAM

As part of this transformation agenda, the state also agree to develop a work plan to support approximately $600 million the State was awarded as part of the Federal Balancing Incentive Program. The State indicated it intended to use the new federal resources to build on current efforts to rebalance the delivery of long-term services and supports (LTSS). The BIP work plan submitted in November is intended to create a more balanced and effective LTSS system that will ensure essential services are provided in the least restrictive setting.

The BIP program implementation included:

- Creating a No Wrong Door/Single Point of Entry (NWD/SEP)
- A Statewide Core Standardized Assessment
- A Conflict-free case management system and
- Rebalancing Activities leading to the delivery of LTSS in the least restrictive environment

Over the course of two and a half years, the Federal government is expected to provide NYS with $600 million. Of that amount, $371.4 million is dedicated to the I/DD population and of this $50 million is still pending federal approval on how the funds can be spent. In addition there is at least $111.3 million available to all affected populations (I/DD, Behavioral Health/Mental Health and Aged, Blind Physically Disabled) that may in part be available to support the needs of individuals with I/DD to support the goals of rebalancing.

The state has been claiming the enhanced FFP associated with the BIP since April 1 of 2013, and has accrued significant federal resources. The FY16 Executive Budget uses these cash resources in FY16, providing a significant one-time benefit to the State fiscal plan and to Department of Mental Hygiene agencies in particular. These Federal resources are considered Department of Health resources in the fiscal plan. However, these resources are no longer available to the State once BIP funding ends September 30, 2015

DDAWNY is happy these one-time Federal resources are available, but is concerned the Executive Budget fails to address how these essential supports and services will be funded in the final two quarters of FY16.

DDAWNY is particularly concerned proposed SEMP Medicaid rates DOH has submitted to CMS may not sufficient to cover all of the additional costs associated with transitioning people from traditional day services to employment. In the event these new rates do not allow New York State to meet its Employment First Transformative goals, DDAWNY believes additional non-Medicaid state funds should be available to assist those seeking competitive employment.

DDAWNY is also concerned the proposed $50 million Community Fund has not yet received federal approval and providers may not have access to this essential resource. This funding, along with a BIP funded $65.2 million Transformation Fund, which provided funding to support community-based care that increased offerings, choice or access to non-institutional LTSS, including self-directed options, employment and community housing options, is expected to permit providers, advocates and local government with the resources necessary to meet the transformational goals of people with Developmental Disabilities as outlined in the Partnership Plan Waiver agreement.

DDAWNY would urge the Legislature to continue funding similar to the Transformation Fund and the Community Fund in order to expand the availability of community based residential, day and support services, including transportation, once Federal BIP resources are no longer available. DDAWNY believes reinvestment savings related to the Community First Choice Option could be used to address this funding need.

DDAWNY is pleased that the Executive Budget provides State fund support for some current BIP funded programing. These programs include enhanced funding of high need individuals leaving institutions (Template Funding), funding to continue the Electronic Health Record initiative, funding for Environmental Modifications and Family Care as well as funding for the START crisis respite program. (State funds for continuation of these important programs are proposed in the Mental Hygiene portion of the state budget)
.

MENTAL HYGIENE STABALIZATION FUND

DDAWNY supports the Executive Budget proposal to provide $915 million under the Medicaid Global Cap to support programs and services provided by voluntary not for profit providers of Long Term Supports and Services (LTSS) under contract with OPWDD. Last Year, the Enacted Budget included $715 million under the Medicaid Global Cap to support this spending. The Mental Hygiene Stabilization Fund (MHSF) permitted the state to manage a $1.1 billion reduction in federal support to LTSS delivered in institutional settings and related community settings under a CMS approved methodology no longer permitted by the Federal Government. This funding protected vital community based residential, day activity, clinic and family support funding for individuals with I/DD. DDAWNY would urge the Legislature to maintain this critical funding source.

DOH RATE RATIONALIZATION

DDAWNY supports a rate rationalization methodology that is fiscally neutral, regionally fair, supports the delivery of quality service by appropriately compensated staff and accurately reflects the LTSS needs of a very diverse population residing in Olmstead compliant integrated community settings. DDAWNY remains concerned the current rates fail to reinvest savings from the methodology to address quality, acuity of need and support for direct care workers.

The development of the new rate setting policy has demonstrated that our population's unique needs are not well understood by DOH. We have heard throughout that people with developmental disabilities would receive "managed long-term care with a DD add-on" – this sentiment reflects a lack of understanding of the population we serve.

DOH staff and others continue to indicate that a similar methodology was used for nursing homes and "it worked well". Certainly from the Western New York perspective, there is strong disagreement with this statement. The nursing home rate methodology does not work well for Western New York providers.

More fundamentally, the concept of using a institution-based model, which may work in some crude fashion for a 120 bed nursing home and applying it to a cluster of four or six bed homes, where Olmstead/ADA guidance and federal HCBS regulations require that individuals be integrated into the community, empowered, using a person centered planning process, to make meaningful choices among activities they freely seek to engage in, including the right to go out every day to either a work or day program and participate fully in society and in their community, a completely different home and community based model of delivering long term supports and services, is not at all similar to the nursing home model and the two should not be equated for rate setting purposes.

Unlike in a nursing home, staff cannot "float" among a geographically widely dispersed cluster of homes that are blocks and miles away, each with individuals who have different levels of support and service needs and where each individual, having though a person centered process, had those service and support needs tailored to the unique and different life choices and plans of the individual. Quality suffers, as providers cannot cover the cuts to hours and reimbursement for staffing the current rates require. DDAWNY believes the current rates are having an adverse impact upon the quality of the services delivered, on the lives of the individuals being served and on the dedicated care workers who provide these services.

In an effort to improve regional fairness, account for the fact that current acuity tools used to assess need fail to accurately measure actual need and to address the unique nature of an Olmstead compliant residential settings, including the quality of the services provided and the need to support the direct care workers who provide these services, DDAWNY would urge the Legislature to provide funding for a VAP/Transformation Fund in the amount of $20 million to address excessive losses to critical safety net providers, adverse impacts driven by the current flawed Needs Assessment which is being used to score acuity of need, the quality of LTSS being provided and regional parity issues as a result of the flaws in the current rate methodology. Similar to Education Bullet aid, this aid could be targeted to those hurt by the current rate methodology.

SUPPORT EXPANSION OF THE NURSE PRACTICE ACT EXEMPTION

One of the areas of focus for Governor Cuomo's Olmstead Cabinet was the need to increase opportunities for people with disabilities to live integrated lives in the community. One critical legal issue identified by the Olmstead Cabinet

as inhibiting community integration is access to health-related task assistance for individuals with developmental disabilities.

These health-related tasks include medication management, medication administration and other home health treatments. Recognizing these barriers, current law only authorizes people with disabilities served by certain programs to receive assistance with these tasks from non-nursing personnel.

The FY15 Enacted budget allowed for an expansion of the exemption from the Nurse Practice Act for medication administration to individuals in non-certified OPWDD settings, subject to an MOU with the State Education Department. Unfortunately concerns raised by State Education officials have delayed this important initiative, which will allow individuals to live more integrated lives in the community. The FY16 Health and Mental Hygiene Article VII bill contains language aimed at meeting these concerns and DDAWNY strongly supports the Executive proposal. DDAWNY would suggest some technical modifications to the proposed waiver authority language are required to address our concerns regarding the needs assessment process, due process requirements and the development of quality standards related to an outcomes based quality standard.

SUPPORT RESTORATION OF THE MRT 2% CUT AND RELATED ARTICLE 16 UTILIZATION CAPS

The FY15 Enacted budget included restoration of the MRT 2% across the board cut. DDAWNY strongly supported this restoration and understood at the time the restoration would eliminate the utilization limits imposed on Article 16 clinics that serve individuals with developmental disabilities.

While OPWDD's Medicaid supports and services were supposed to be exempt from the MRT process and are not currently included in the Medicaid Cap or reinvestment, DOH determined that OPWDD's Article 16 clinics would be cut. Rather than a 2% across-the-board cut, as with other Medicaid providers, DOH decided that in an Article 16 clinic environment where OPWDD had already set utilization limits for clinics and our providers had operated under those thresholds, DOH would target people with developmental disabilities who received more than the average number of long term therapies in a month, regardless of diagnosis or medical condition. The clinics, which provided services to individuals who required more than the average number of therapies, were expected to absorb the cut. As a result, DDAWNY member agency providers with clinics who serve patients with more complex medical needs and physical disabilities were cut significantly, while Article 16 clinics serving individuals who are physically healthy and whose physical or medical condition do not require long term therapies above the average received no cut at all. Therefore, providers serving the most vulnerable are given the choice of either not providing

the services as prescribed by their physician or continue to be penalized and have their clinic payments cut. That sort of public policy does not make sense on many levels, particularly when services provided to maintain function will reduce costs to the Medicaid system so that patients do not regress and present in a higher cost service setting.

While the 2% ATB cut is in the process of being restored to Article 28 clinics, DOH has refused to reverse the utilization cap for Article 16 clinics. DDAWNY would urge the Legislature to include budget language requiring the Commissioner of Health to eliminate the Article 16 utilization caps imposed as part of the MRT 2% ATB cut which is in the process of being restored.

SUPPORT MRT BHO/HARP AND MRT SUPPORTIVE HOUSING FUNDING AND INCLUDE INDIVIDUALS WITH /I/DD IN THESE PROPOSALS

DDAWNY supports the MRT proposals regarding Medicaid funding supporting the integration of physical health and behavioral health services within a managed care environment, through Behavioral Health Organizations and Health and Recovery Plans as well as the additional funding available for affordable housing contained in the Executive Budget. However DDAWNY strongly urges that these MRT proposals explicitly acknowledge and include individuals with I/DD who need access to Mental Health services and affordable housing.

- *MRT BHO/HARP*

Individuals diagnosed with a developmental disability who also may have a co-occurring Serious Mental Illness (DD/SMI) comprise approximately twenty percent (20%) to one-third (33%) of the individuals served by DDAWNY member agencies. These individuals are particularly troublesome as silos between mental health systems and developmental disabilities systems prevent the type of cost-effective collaboration essential to provide quality services and current needs assessment tools fail to appropriately identify the support and service needs of these individuals. According to national studies, individuals with DD/SMI represent a very high cost Medicaid population. DDAWNY believes the integration of behavioral health and physical health services must also address the behavioral health needs of individuals with I/DD receiving services with a diagnosis of developmental disabilities.

- *MRT SUPPORTIVE HOUSING*

According to the State of the States in Developmental Disabilities 2013, it is estimated that 306,376 individuals with I/DD reside in the State of New York. 64% or 195,388 reside with a family caregiver. 67,807 or 22% reside in a supervised residential setting and only 14% or 43,181 live alone or with a

roommate.

Of the estimated 195,388 individuals living with family caregivers, 39% or 77,173 live with caregivers who are under the age of 41. At the same time 68,542 individuals (35%) live with family caregivers who are between 41 to 59 years of age. **Of great concern are the 49,673 individuals with developmental disabilities living with caregivers aged 60 or older.** These individuals, representing 25% of those living with a family caregiver in New York, are most at risk of homelessness should their family caregivers pass away. Moreover of the estimated 195,388 individuals with DD being cared for by family caregivers only 27% or approximately 52,630 individuals are provided with supports or assistance by the State or provider agencies in the community.

In its Partnership Plan amendment with the Federal Government, New York State has agreed to increase its utilization of supportive housing options, including "nontraditional housing models" such as "Home of Your Own", Family Care, Shared Living, Customized Residential Options and Assets For Independence/Matched Savings programs. However, the combination of the over 12,000 individuals already seeking appropriate and affordable housing who have registered with the State as part of the NYS-CARES waitlist, the 3,000 to 5,000 students currently transitioning out of New York schools on a yearly basis and seeking an integrated setting in the community and the roughly 6700 individuals the state has agreed to transition to community-based settings threatens to overwhelm current supportive housing models.

DDAWNY believes the MRT supportive housing funds can be one of several options that will assist individuals with I/DD reside in Olmstead compliant settings and live a fully integrated life in the least restrictive environment possible. DDAWNY supports this important MRT investment.

SUPPORT INCREASED CAREGIVER SUPPORTS AND FUNDING OF A COMMUNITY MOBILITY STUDY

DDAWNY supports the Executive Budget proposal to provide $25 million to support increased funding for caregiver respite services as well as $750,000 to hire a transportation management expert to perform a cross-agency mobility management needs assessment designed to improve transportation options for the elderly and individuals with disabilities.

SUPPORT COMMUNITY FIRST CHOICE OPTION & REINVESTMENT OF SAVINGS INTO OLMSTEAD INITIATIVES

The Community First Choice Option (CFCO) is a Federal Medicaid funding initiative that allows states to more widely provide long-term supports and services to people in their homes and communities, rather than institutionally

based settings for which they are eligible. States that elect to implement the CFCO receive an additional six percent in Federal Medicaid share.

The FY16 Executive budget includes an exemption from the Nurse Practice Act for Advanced Home Health Aides, increasing the availability of personal on the ground to fully implement the CFCO. It is expected adoption of this proposal by the State will lead to CMS approval of the state's proposed Medicaid state plan amendment for CFCO which has been pending since December 2013.

The FY16 Executive Budget would authorize the state to reinvest savings associated with implementation of the CFCO, estimated to be approximately $300 million annually, into initiatives that will further the state's Olmstead Plan. DDAWNY strongly supports language that directs that reinvestment into community supports that facilitate independence support the community based residential, day and support services needs, including transportation of individuals with developmental disabilities. DDAWNY believes the reinvestment savings can and should be used to support services and supports for which Federal BIP resources sunset in the second quarter of FY16.

SUPPORT PROPOSED OFFICE ON COMMUNITY LIVING

DDAWNY supports the FY16 Executive budget proposal to establish a planning commission for the creation of a state Office on Community Living (OCL). DDAWNY believes a dedicated state agency with the sole purpose of working to ensure community integration for seniors and people with disabilities can breakdown system silos, which currently exist in New York particular in relation to SOFA, OMH, DOH and OPWDD funding models.

OPPOSE "SPOUSAL/PARENTAL REFUSAL" FOR VULNERABLE POPULATIONS

The Executive Budget includes Article VII language that will eliminate the long-standing right of "spousal/parental refusal" for children with severe illness and other vulnerable populations, including certain children with developmental disabilities. DDAWNY opposes the proposal and questions whether the savings expected will be achieved are actually valid.

Currently the refusal law applies to any "legally responsible relative" including parents of minor children. Although a waivered program, which does not count parents' income, covers some children and others will benefit from the Medicaid expansion under the ACA, there are still some children with serious illness, including children with developmental disabilities who will be denied Medicaid without parental refusal. For a parent of a developmentally disabled child receiving crucial Medicaid home care services and not enrolled in an

OPWDD waiver program, the potential loss of LTSS can be catastrophic. If a parent, who previously was on Medicaid, loses Medicaid because of a job promotion, the only way to ensure a child with developmental disabilities who is not enrolled in an OPWDD waiver program receives Medicaid LTSS is to exercise "parental refusal" while awaiting enrollment in the OPWDD waiver program. The wait times for enrollment in the OPWDD waiver program including the necessary assessments that are now being performed as part of the "Front Door" process by state agency personnel exceed nine months. Without "parental refusal" children with developmental disabilities will be denied important and life sustaining Medicaid LTSS.

DDAWNY urges the Legislature to reject this thoughtless proposal and retain current law.

Respectfully Submitted

John R. Drexelius, Jr.
DDAWNY Government Relations Counsel
Law Office of John R. Drexelius, Jr.
PO Box 141
Buffalo, NY 14223
(716) 316- 7552
Fax: 716-875-7552
jrdrexelius@gmail.com