



DEVELOPMENTAL DISABILITIES ALLIANCE OF WNY

TESTIMONY SUBMITTED TO THE NEW YORK STATE LEGISLATURE
Joint Hearing of the Senate Finance and Assembly Ways and Means Committee
2014-2015 Executive Budget Mental Hygiene

Presented By

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Good Morning Chairman Farrell, Chairman Defranco, members of the Senate Finance Committee, Assembly Ways and Means Committee and the Assembly Mental Health Committee and Senate Mental Health and Developmental Disabilities Committee. Thank you for your ongoing interest in these issues and for the opportunity for me to speak with you today. 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 2014-15 Executive budget and in particular the Mental Hygiene portions of the budget.

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

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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."

However, as the United States Department of Justice (DOJ) recently pointed out in finding that Rhode Island was in violation of the ADA, policy statements are not enough. The state needs to provide individuals who want to work, engage in meaningful activities in the community and reside in integrated community based settings with the services and supports that will enable them to do so.

We are concerned that the Executive Budget proposal 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.

Of the \$59 million in additional state funds being made available in the FY15 Executive budget, \$9 million will support the housing needs of individuals with I/DD moving from institutions to community based, Olmstead compliant settings.

Of the remaining \$50 million in additional state resources, approximately \$30 million is committed to the annualization of services and supports provided to individuals who began receiving these services and supports in FY14.

The remaining \$20 million is grossly insufficient to all of the housing, employment, transition to employment, transportation and other day activity needs of those aging out of the education system and those currently receiving services

As DOJ indicated in its Rhode Island findings, the state has an obligation to develop a sufficient quantity of integrated employment, vocational and day services and supports for individuals with I/DD. DDAWNY member agencies are certainly capable of providing services in an integrated settings and additional opportunities can be made available to individuals who capable of receiving services in integrated settings, however DDAWNY believes the Executive Budget fails to provide adequate resources to allow most, if not all, persons with I/DD who are capable to work in integrated settings and engage in integrated day activities in the community.

Unfortunately, as I noted in my written submission on the Education portion of the Executive Budget, New York's current educational system all to often fail to ensure students with disabilities, particularly students with I/DD, are properly educated and trained to enter the workforce.

According to New York Commissioner of Education Dr. John B. King, Jr., as of June of 2012, New York's 4-year high school graduation rate was 74% for all students. Unfortunately, the 4-year high school graduation rate for students with disabilities was only 45%. Even more alarming is that while 35% of all students graduating had graduation test scores correlating with success in first-year college courses and suggest career readiness, less than 5% of students with disabilities graduated with grades that indicate they were either college or career ready.

Moreover, the transition from school based programming to adult services in New York is uneven and poorly coordinated. Just as in Rhode Island, this lack of appropriate support for integrated transition services and the failure to appropriately fund and support linkages between students in school districts across New York State with appropriate post-secondary services and support

***Based upon
June 2012 New
York State
graduation rates
less than 5% of
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indicating either
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like supportive employment and integrated day services, place youth with I/DD in New York at serious risk of isolation and segregation.

Each academic year an ever-increasing number of students transition out of Special Ed programs, many with severe cognitive impairments and critical medical and behavioral challenges. Those with a high level of need whom the educational system has failed to prepare for meaningful employment opportunities require adult community services as well as funded day support services.

Of the 3154 students between the ages of 18-21 receiving Special Education Services in Western New York and the Finger Lakes (Region One) in 2012, 1621 students were assessed between 2008 and 2012 using the New York State Alternative Assessment, which can only be given to students with severe cognitive disabilities.

The State and federal focus on integrated employment options, while laudable, fails to address the very real day habilitation needs of a significant percentage of individuals with I/DD, who because of severe cognitive, physical and behavioral needs will require significant supports and services outside the workforce.

State policy makers need to focus on those who are not qualified to work who have significant day habilitation needs, as well as those found qualified to work.

According to data obtained from OPWDD pursuant to a freedom of information request over 6800 individuals statewide have unmet day activity needs, including 2779 who are seeking day habilitation services and 2200 who need skills training because they are not yet prepared to enter the world of work. Over 1,100 individuals with I/DD in WNY and the Finger Lakes (Region One) have unmet adult day needs, including more than 500 seeking day habilitation and another 550 individuals in need of skills training.

DDAWNY believes the FY15 Executive Budget fails to provide sufficient funding to address the urgent day service needs of individuals with I/DD.

DDAWNY believes an additional \$10 million (\$5 million state share) investment in Olmstead compliant day activity supports, including transportation related supports is necessary in FY15 and strongly urges the Legislature to come to an agreement with the Executive to provide these essential supports and services for Individuals with Intellectual and Developmental Disabilities

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Further, *when it comes to employment services, DDAWNY believes one size does not fit all.*

State policy makers need to understand the diverse interests and needs of individuals seeking jobs and the local businesses that will determine who they will hire. The State must respect a person centered planning process ensuring individuals can make informed choices of the most integrated setting appropriate based upon an assessment of his or her interests, strengths, priorities, abilities and capabilities must be respected by state policy makers.

The State needs to enhance the capacity within the community to provide more regular work opportunities in the community; the State needs to lead by example and provide more employment opportunities within state service and provide incentives for business to hire individuals with I/DD.

DDAWNY urges the State to follow the lead of the Federal Government and enact as state policy a 7% utilization goal for the employment of individuals with disabilities that business and other entities, including school districts and municipalities who contract with the state of New York would be expected to strive to achieve.

DDAWNY also believes the Governor's Youth tax credit proposal (Revenue bill Part U) should be amended to provide that 7% of the credit be made available for business that hire youth with disabilities.

The American Community Survey (ACS) reported that of the 437,229 individuals aged 16-64 "living in the community" with a cognitive impairment about 91,627 (or 21%) were employed in 2011. The mean annual earnings from work for these individuals are only \$22,100.

In New York only 13% of the 69,163 individuals with I/DD supported by OPWDD worked in an integrated employment setting in 2011. Recently the ACS reports that of those aged 16-21 with cognitive disabilities only 14.4% were employed with mean annual earnings of \$5,233. Employment of those aged 22-30 was 27%, but among those young adults served by OPWDD only 15% were employed in an integrated employment setting and earned approximately \$271 per two-week period.

36.4% of people with a cognitive disability are living below the poverty line and of the total number of SSI recipients with disabilities only 4.7% are working.

According to OPWDD, of those employed, 8101 individuals with I/DD are employed in a sheltered work setting, many of these individual are over 50 years

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old, at the same time, OPWDD provides supports and services to 9,934 individuals with I/DD in a supportive work environment and as of June 30, 2013 7,205 individuals with I/DD were receiving a competitive wage at or above minimum wage.

Yet significant number of individuals with unmet employment needs remain. OPWDD indicates, as of November of 2013, over 6400 individuals, including over 1,200 individuals in Western New York and the Finger Lakes are seeking supportive employment services and supports.

DDAWNY believes eliminating current employment-related choices without providing meaningful alternatives is ill advised and arguably a violation of the Olmstead mandate. The State needs to invest additional resources in a full range of employment and pre employment services and must also recognize that without robust transportation options, individuals with IDD, who seldom if ever are able to drive a car, will have great difficulty finding meaningful integrated employment options. The state needs to develop new or alternative transportation capacity in order to support meaningful community integrated employment options.

DDAWNY believes the FY15 Executive budget fails to provide sufficient resources to support the employment needs of individuals with I/DD in an Olmsted compliant manner. In particular the need for appropriate technical assistance, incentives and support from the state is essential if we are to provide more integrated employment services. The Executive Budget fails to provide appropriate resources to allow us to provide sufficient job coaches, job developers, behavioral supports, and very importantly transportation supports, necessary to support the unmet needs of those seeking integrated employment opportunities.

At the same time, the Executive budget fails to support the type of rate structure which will permit providers to retain qualified or trained staff who can serve as community-based employment specialists and fails to provide sufficient resources to ensure individuals with I/DD and their circle of support receive the appropriate benefit advisement services including information about and opportunities to enroll in the Medicaid Buy-in program or to receive benefits planning services to allow them to maintain access to important public benefits, including health care, while earning from work in the community.

DDAWNY believes an additional \$30 million (\$15 million state share) in Olmstead compliant employment supports, including transportation related

supports is necessary in FY15 and strongly urges the Legislature to come to an agreement with the Executive to provide these essential supports and services for Individuals with Intellectual and Developmental Disabilities.

DDAWNY also supports a Worker's with Disability Tax Credit bill (A.8492-B/S.4946-D) modeled after the Governor's proposed Youth Works Tax Credit Bill as part of the Enacted Budget tax cut package.

Similarly, in the context of residential settings, Olmstead requires New York to appropriately fund these important supports and services. The DOJ, in its Virginia findings, has indicated that the ADA's integration mandate applies both to people who are currently institutionalized and to those people who are risk of unnecessary institutionalization. The DOJ pointed out that individuals in the community are at risk of unnecessary institutionalization because of the state's failure to provide sufficient community-based services.

In Virginia, more than 6000 individuals were on a waitlist for residential services, including 3000 individuals on an urgent waitlist-- who generally are individuals in the community, experiencing crisis that put them at risk of entering an institutional setting. In Virginia, the primary reasons for being placed on an "urgent" wait list include an aging caregiver, a primary caregiver who can no longer care for the person, risk of abuse or neglect of the individual, or that the individual's behavioral or physical care needs are putting people at risk.

As of 2012, an estimated 49,673 individuals with Intellectual or Developmental Disabilities (I/DD) live with a family caregiver aged 60 or older in New York

The situation in New York is similar. According to the State of the States in Developmental Disabilities, 2013¹ it is estimated that 306,376 individuals with Intellectual or Developmental Disabilities 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 reside 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

¹ Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2013 <http://stateofthestates.org>

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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 and unnecessary institutionalization 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 the mid 1970s nearly 30,000 individuals with DD resided in 20 state institutions. As a result of the scandal at Willowbrook on Staten Island, New York State shifted the emphasis of care for people with developmental disabilities from institutional care in State-operated developmental centers to not-for-profit operated community residences. Since that time more than 6,200 community homes were developed and 14 institutions have closed, most recently, the West Seneca Developmental Center and an institution on Staten Island for those with multiple disabilities. For the past 30 years these community residences have been the primary method used by the state to address the desire of people with developmental disabilities and their families for long-term living arrangements apart from the family home.

As of January of this year, the 17 counties of the Western Region contained a total of 7626 beds consisting of both IRA and ICF community residences. Of these beds, the state operates 2393 beds and voluntary not for profit agencies operate community residences with a capacity of 5233.

In Western New York there are a total of 3856 community residence beds operated by the State of New York and voluntary not for profit providers. The recent closure of the West Seneca Developmental Center permitted the transition of its remaining 80 individuals into more integrated settings in the community. An additional 3770 beds are located in the Finger Lakes region of the state. As part of a Transformation Agreement with the Federal Government the State has also closed the Finger Lakes and Taconic campus-based ICF/IIDs and has transitioned the 148 residents of these institutions into community-based residential settings

Unfortunately, the waiting list for housing in New York State continues to grow. According to OPWDD, as of April 1, 2013, statewide, 12,057 individuals with developmental disabilities were seeking residential opportunities. 2325 of these individuals reside in the Region One of New York (the 17 counties of Western New York and the Finger Lakes). 980 of these individuals are in the Western New York region and 1,345 individuals are in the Finger Lakes region of the state. In Western New York 451 individuals are seeking housing opportunities immediately or within the next two years. In the Finger Lakes region, 1,065 individuals are seeking housing either immediately or within the next two years.

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In total, 1516 individuals with developmental disabilities are seeking housing now or within two years according to OPWDD data in Region One of New York State.

These numbers continue to grow. In the Western New York portion of Region One, according to August 2013 data, OPWDD now has identified 1002 individual seeking integrated housing opportunities. Moreover, these figures do not include individuals with severe cognitive disabilities who are currently aging out of the State Educational system.

According to data maintained by the State Education Department, statewide 2682 students with severe cognitive disabilities took the New York State Alternative Assessment (NYSAA) in Secondary ELA in 2009. This assessment may only be given to students with a severe cognitive disability and significant deficits in communication/language and adaptive behavior. In order to be eligible to take this assessment, these students require a highly specialized education program that facilitates the acquisition, application and transfer of skills across natural environments and require educational support systems such as assistive technology, personal care services, or behavioral interventions.

According to SED, students eligible for the NYSAA may experience severe speech, language and/or perceptual-cognitive impairments and evidence challenging behaviors that interfere with learning and socialization. These students may also have extremely fragile health conditions and may require personal care, physical/verbal supports and/or prompts and assistive technology devices. Students being given the NYSAA Secondary ELA are assessed at age 16-17, meaning the majority of the students assessed in 2009 are now aging out of the education system.

The population taking the NYSAA is growing. Statewide, 2875 students were assessed using the tool in 2010, 2958 students were assessed in 2011 and 2999 students were assessed in 2012. These students will be seeking to live more integrated lives in the community and away from their family homestead. Unfortunately, current state housing policy fails to address the critical housing needs of these individuals.

Moreover, as part of New York State's Transformational Agreement with the Federal Government, the state must close its remaining developmental centers, and OPWDD is required to provide integrated housing opportunities for most of the nearly 1000 individuals transitioning into the community. The State is also required to transition the residents of most of the over 6300 individuals remaining community-based ICFs to community-based settings. However, the agreement fails to acknowledge or support the critical housing needs of individuals in the community currently waiting for housing and at risk of institutionalization.

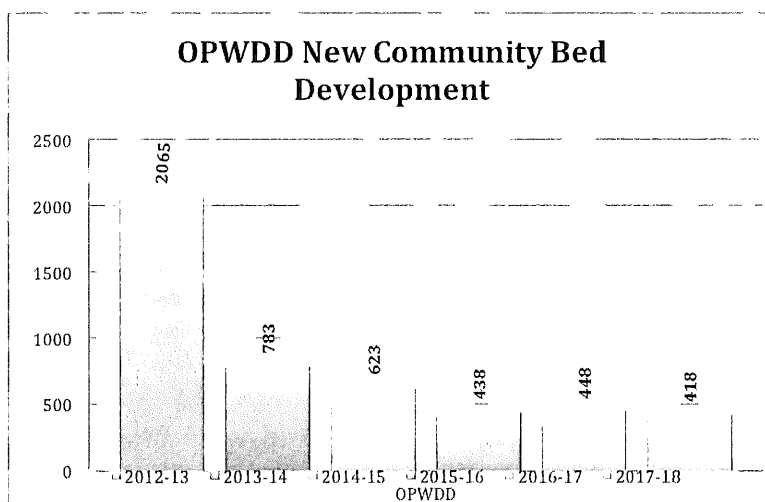
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The current capacity of provider and state run community residences other provider-sponsored housing opportunities is insufficient to meet the growing needs of this population.

Although the Executive budget supports moving 300 individuals from institutional settings into more community settings and provides \$9.1 million in new community services to facilitate the planned downsizing (saving the state an estimated \$10.6 million) the Executive budget fails to address the residential service and support needs of those aging out of the educational system, particularly individuals with complex needs, including the most medically fragile and behaviorally challenging individuals.

DDAWNY strongly supports the move to provide funding for these individuals, however we feel strongly that in order to meet the Olmstead mandate the Enacted Budget must also provide sufficient resources to prevent the unnecessary institutionalization of individuals residing in the community and at risk of institutionalization.

The Executive budget only projects the development of a mere **783 beds** in the current fiscal year, **reducing** bed development to **623 beds** in FY 2015; **438 new beds** in FY 2016; **448 new beds** SY 2017 and only **418 new beds** in FY18.



The FY15 Executive Budget fails to provide sufficient state fund support for those individuals not residing in an ICF but still seeking housing opportunities in the community in an Olmstead compliant manner. The budget needs to provide resources to support the housing needs of individuals on the OPWDD Residential Registry who are seeking housing opportunities in the community,

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particularly those individuals with 24/7 needs who reside with aging caregivers and parents and wish to have choices in the community as to where and with whom they live.

DDAWNY believes an additional *\$80 million (\$40 million state share)* investment in Olmstead compliant residential supports and services is necessary in FY15 and strongly urges the Legislature to come to an agreement with the Executive to provide these essential supports and services for Individuals with Intellectual and Developmental Disabilities

Finally, I would be remiss if I did not point out, there has been no new funding of community supports and services for three years.

DDAWNY appreciates the passage of the bill to restore \$90 million to OPWDD in FY14, which was due to the incredibly immense support of both the Senate and Assembly. **We Thank You.** However, the amount of restoration was based on the amount of savings that private providers are able to accrue through audits and program efficiencies over time. At this time *cuts are continuing to occur* and DOB has not provided any cash spending to support the appropriation.

Meanwhile, the annual expense of providing community based supports and services is being driven up due to the rising cost of living, workers compensation and health care costs, growth in the number of individuals seeking services and the financial impact of the State's intrusive, new, time-consuming, and burdensome Justice Center and Jonathan's Law regulatory requirements on private providers.

The Executive budget provides \$77.7 million to fund the fringe benefit costs of state employees serving in the Department of Mental Hygiene. At the same time, local not for profit providers and the dedicated direct support workers they employ are again denied the \$75.6 million in trends and COLAs we must rely upon to finance these ever-rising costs.

Cost containment strategies contained in the enacted budgets for the last three years (2011-12, 2012-13 and 2013-14) totaled more than \$692 million (\$346 million state share) in savings from cuts to supports and services for people with developmental disabilities. These cuts included elimination of the trend factor and COLA, reduced funding for certain day programs and transportation, moving people from certified residences to non-certified settings, moving people from day programs to employment and cuts to agency administration.

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The FY15 Executive Budget proposes an additional \$39 million in OPWDD state funds to support all of the housing, employment and day activity needs of those aging out of the educational system. An additional \$15 million is being made available using additional Department of Health MRT resources available from under spending under the Medicaid Global Spending cap.

While the State has proposed using Balancing Incentive Program Federal Funds to provide Olmstead compliant supports and services to individuals with I/DD, it is unclear how much, if any of these federal dollars (approximately \$600 million over two and one-half years) may be available for DDAWNY providers in the FY15 Executive Budget.

DDAWNY also believes rates must be actuarially sound and reflect the actual cost of providing supports and services to a diverse population of individuals with wide variation in services needs and support needs. The proposed rate rationalization methodology has a significant adverse impact on most Western New York and Finger Lakes providers. The lack of accurate needs assessment tools and a lack of understanding of the need to deliver services in a person-centered Olmstead compliant manner results in a seriously flawed rate structure.

DDAWNY would propose a \$20 million (\$10 million state share) VAP/Transition Pool to address excessive losses to providers serving more costly high need individuals and ensure, quality, adequate direct support worker compensation and regional parity in the rate reform efforts as a result in flaws in the system design of the current rate rationalization methodology

DDAWNY also supports a proposal to provide \$5 million in recruitment and retention dollars in order to provide funding to support a pilot Direct Support Worker credential ladder program and Article VII language similar to the Direct Support Career Ladder bill recently vetoed by the Governor (A.7313-A/S.5102-A).

Without additional funds, unmet need for community based services and supports will continue to grow. Underfunded, the *totality of need* will reach crisis proportions and threatens to overwhelm an already overburdened system. It will also invite DOJ enforcement activity for violation of the ADA.

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Respectfully Submitted

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