



ONE COMMERCE PLAZA | 99 WASHINGTON AVE  
SUITE 806A | ALBANY, NY 12210  
518.465.4650 PHONE | 518.465.4625 FAX  
INFO@ILNY.ORG | WWW.ILNY.ORG

## **2016 DISABILITY PRIORITY AGENDA EXECUTIVE BUDGET RESPONSE**

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The New York Association on Independent Living (NYAIL) is dedicated to removing barriers to full community integration and safeguarding the civil rights of people with disabilities of all ages. NYAIL represents Independent Living Centers (ILCs) and the people with disabilities they serve. ILCs are disability-led, cross-disability, local not-for-profit organizations that provide community-based services and supports, including individual and systems advocacy, peer counseling, independent living skills training, and assistance with accessing health and long term care, housing, education, employment, transportation and other necessary services that empower people with disabilities to live independent, fully integrated lives in their communities.

The State has made significant progress toward implementing *Olmstead* in New York and ensuring people with disabilities receive services and supports in the most integrated setting appropriate to their needs. Governor Cuomo's Employment First Initiative initiated in 2014 is intended to increase competitive, integrated employment options for people with disabilities. In addition, the State continues its deinstitutionalization efforts across systems as committed to in the 2013 *Olmstead* Implementation Plan, including the commitment to reduce the long term nursing facility population by 10 percent over five years. However, much work is still needed to increase access to essential community based services and supports, break down systemic barriers to community living, and make *Olmstead* a reality in New York.

We urge the Legislature to take action in the 2016-17 Budget to support the State's efforts toward the full integration of New Yorkers with disabilities. NYAIL's priority proposals for legislative and administrative action include:

### **INDEPENDENT LIVING CENTERS**

**NYAIL urges the Governor to increase base funding for Independent Living Centers (ILCs) to \$18 million. This much needed increase of only \$5 million is long overdue and essential to sustaining IL services statewide.**

ILCs are essential community-based advocacy and service organizations that serve as the safety net to ensure people with disabilities have access to services and supports to live independently in their communities. ILCs have been woefully underfunded for the past twelve years and have been losing ground. After receiving level funding for eleven years, ILCs finally received a much needed \$1 million increase in the 2015-16 SFY. This \$1 million increase was intended to provide each of the existing 39 state funded ILCs with a \$25,641 increase. While this amount doesn't come close to making up for eleven years with no cost of living adjustment given the rising cost of doing business - including the costs associated with general operating expenses, health insurance, workers compensation insurance, disability insurance, etc. - it was a start. However, SED used a significant portion of the increase to

create two new centers. As a result, existing centers did not receive the fiscal relief this modest increase was intended to provide.

In 2013/2014, the state's network of ILCs served 91,769 people with disabilities, family members and others; an increase of almost 10,000 in just five years. This demonstrates the pressing need for IL services in communities, and the number served would likely be higher had the IL funding kept up with the capacity needs of centers. ILCs provide critical services to people with disabilities all designed to assist them in navigating the ever-changing service system in order to live independent, fully integrated lives in the community. As the state continues to redesign health care in ways that are intended to increase quality and decrease costs, ILCs play a crucial role. ILCs provide a wide range of services based on the local needs, all of which are aimed at addressing the social determinants of health: education, employment, housing, social skills.

Furthermore, adequate funding of ILCs is essential to ensuring successful *Olmstead* implementation in New York and would result in additional Medicaid savings to the State. Data from the New York State Education Department, ACCES-VR, show that the work of ILCs to transition and divert people with disabilities from costly institutional placements **saved the State more than \$1.8 billion since 2001 as a result of avoided institutional care. ILC transition and diversion activities save the State more than \$9 in institutionalization costs for every state dollar invested in ILCs.** The State has an unprecedented opportunity to utilize New York's Independent Living Centers to assist in implementing *Olmstead* and the Medicaid Redesign Team's reforms impacting people with disabilities, including the transition to mandatory managed long term care and implementation of the Community First Choice Option (CFCO) and the Balancing Incentive Program. The State should invest savings from implementation of CFCO into ILCs over a number of years, ultimately bringing the State appropriation to \$25 million. **NYAIL urges the State to increase IL funding to \$18 million in the 2016-17 SFY.**

### **HEALTH/MEDICAID**

**New York must authorize an exemption to the Nurse Practice Act for advanced home health aides as proposed in the Executive Budget. This change is critical for the full implementation of the Community First Choice Option (CFCO).** CFCO is a Medicaid program made available to the states as part of the Affordable Care Act which incentivizes the provision of long term services and supports (LTSS) in the community by offering an additional six percent federal Medicaid match of spending on LTSS in home and community-based settings. New York has finally received approval from CMS to begin implementing CFCO, effective July 1, 2015. However, the State has failed to date to create the crucial exemption to the Nurse Practice Act which would facilitate full and robust CFCO implementation. This exemption would allow non-licensed professionals, who will be trained and certified as "advanced" aides, to perform assistance with and maintenance of skills necessary for the individual to accomplish health-related tasks. CFCO requires these services to be provided to individuals at the institutional level of care without discrimination as to the type or severity of their disability. At the end of the 2014 legislative session, Governor Cuomo created the Advanced Home Health Aide (AHHA) workgroup comprised of a broad cross-section of impacted stakeholders to provide guidance to the Department of Health as to how this program would be implemented, including the specific advanced tasks that could be performed by home health aides in home care with appropriate training and supervision. As a result of this effort, a broad and diverse number of stakeholders support the creation of an AHHA program as a vital support for this changing system and for older adults and people with disabilities who wish to live in the community. AHHAs must be approved as part of the budget given CMS' approval of CFCO and the urgent need to get the program fully implemented.

**NYAIL strongly opposes prohibiting a spouse or parent from refusing to financially support their child or spouse in order for that individual to obtain Medicaid.** This proposal will eliminate the longstanding right of “spousal/parental refusal” for vulnerable populations such as severely ill children and low-income seniors. As proposed in the budget, the refusal will only be honored and Medicaid be granted if a parent lives apart from their child or if a spouse lives apart or divorces the potential Medicaid recipient. NYAIL opposes denying Medicaid to these vulnerable populations. If this proposal is enacted it will force low income individuals to institutionalize their loved ones purely for financial reasons, creating a discriminatory institutional bias.

**New York must maintain the current Community Spouse Resource Allowance.** NYAIL strongly opposes Governor Cuomo’s proposal to lower the Community Spouse Resource Allowance to merely \$23,844, the minimum allowed by federal law. Currently, New York allows a community spouse to keep the maximum allowed by federal law. As New Yorkers face some of the highest costs of living in the country, this makes sense. Lowering the resource limit to the lowest allowed by Federal law will have dire consequences for the community spouse, who is not on Medicaid and who may require assets in order to pay his or her own medical expenses. By lowering the resource limit, these spouses may end up needing to rely on Medicaid themselves.

**NYAIL strongly opposes eliminating Provider Prevails.** This proposal would repeal an important patient protection in the Medicaid program which restored “prescriber prevails” for several classes of drugs in the fee for service and managed care programs. A prescriber, with clinical expertise and knowledge of his or her individual patient, should be able to override a preferred drug. Different individuals may have very different responses to different drugs in the same class. Sometimes only a particular drug is effective or alternative drugs may have unacceptable side effects. Prescribers are in the best position to make decisions about what drug therapies are best for their patients. NYAIL urges the State to recognize the importance of specific prescription drug combinations and protect Provider Prevails.

**NYS must ensure funding for overtime and travel to prevent a crisis in continuity of care.** The new Federal Labor Standards Act (FLSA) regulations requires attendants be paid for travel time and time and a half for any hours worked over 40 per week. However, this rule did not come with additional federal funding to ensure that attendants would actually be paid more for their overtime hours, and as a result, agencies would be forced to cap attendant hours at 40, putting consumers at risk of unnecessary institutionalization. DOH implemented an across-the-board increase of \$0.34 per hour to both the CDPAS and home care rates, however this is insufficient, particularly for CDPAS as it does not address the degree of overtime variance that Fiscal Intermediaries experience. The State must commit to ensuring that these vital services are not interrupted by changes to the labor law and develop a rate for both overtime and travel within CDPAS.

**Fully fund the Community Health Advocates (CHA) program at \$4 million.** The CHA program assists New Yorkers, including many people with disabilities to navigate the complex and ever changing health care system. Since 2010, CHA has assisted 240,000 New Yorkers to obtain coverage, saving the State \$15 million. Governor Cuomo proposed funding the CHA at \$2.5 million, however the program requires \$4 million to maintain current services. We urge the legislature to ensure full funding for CHA.

**Expand funding to the Independent Consumer Advocacy Network.** The Independent Consumer Advocacy Network or ICAN, is the ombuds program that provides individual, independent consumer assistance services for people in Medicaid managed care who receive long-term care services. The program assists New Yorkers to obtain and use long term care. They also assist some of New York’s

most vulnerable people facing abuse, neglect and other serious violations with minimal resources. NYAIL calls on the legislature to increase funding to ensure the ICAN program can remain operational and to expand as more people join Medicaid managed care.

## **ACCESS TO HOUSING**

**Broaden eligibility to the JP Morgan Access to Home funds.** The JP Morgan allocation plan in the 2015-16 budget earmarked \$19.6 million for Access to Home, a successful program administered by NYS Homes and Community Renewal (HCR) that provides funding for home modifications to allow individuals with disabilities and older New Yorkers to stay in their homes and out of costly institutions. This is significant as the program has been severely underfunded at only \$1 million for many years. Unfortunately, the eligibility for this new funding was limited to veterans with disabilities. This was not the original intent and HCR recommended to the Executive an amendment to the appropriation language in the 2016-17 budget to broaden eligibility. This change is further supported by the fact that HCR only received \$3 million in applications during the 2015 Access to Home for Veterans funding round, despite there being \$6 million available.

As New York continues to implement *Olmstead* and more people continue to transition back into the community, the need for accessible housing will only increase. For many people, the addition of a ramp to their front door makes the difference between being able to live independently and being homebound or forced into an institution. The Medicaid Redesign Team's Affordable Housing workgroup acknowledged the crucial role this program plays and committed to additional modest funds through the supportive housing allocation fund, but it is still severely underfunded. New York should use funds from the JP Morgan Chase settlement to adequately fund Access to Home for all people with disabilities.

**Create a Visitability tax credit.** In the 2015 legislative session, the legislature passed a bill which would have provided homeowners with a modest tax credit to help with the costs of retrofitting their homes to make it more accessible, or to incentivize including visitable features at the time of construction. However, Governor Cuomo vetoed this legislation, stating in his veto memo that "Encouraging the growth of accessible and adaptable housing to help individuals remain in their homes as they age, as well as to help those with disabilities, is an important goal which I strongly support. However, this tax credit will have a significant fiscal impact and should be discussed in the context of the upcoming State Budget." While we appreciate Governor Cuomo's statement that this is a priority for his administration, he failed to include a visitability tax credit in his proposed Budget. This is a priority for the disability community as a tax credit would help keep people in their homes and out of institutions by assisting people with the costs associated with making their homes more accessible. NYAIL calls on Governor Cuomo to include a visitability tax credit in the State Budget.

**Ensure access to shelter for people with disabilities who are homeless.** NYAIL commends Governor Cuomo for proposing to spend \$10 billion to address homelessness and the inadequacies of the shelter system by adding 27,000 new beds and services. Part of this proposal is an audit function including inspection of shelters to address health and safety violations. This audit needs to include inspecting shelters for accessibility. Many people with disabilities face homelessness, yet New York has done a poor job ensuring access to shelters for people with disabilities. Too often people with disabilities are rejected for shelter placement and instead sent to nursing homes as an alternative, even in instances where the individual does not require that level of care. Likewise, supportive housing is too often funded without concern to physical access. The State must ensure that supportive housing is accessible, regardless of whether it is mandated by the Federal Fair Housing Act. We urge the

legislature to support this proposal and to ensure that the audit function include an audit of whether emergency homeless shelters meet the physical, communications and program requirements of the Americans with Disabilities Act Title II and are accessible to people with all disabilities.

### **ADDITIONAL BUDGET PROPOSALS**

**Establish an Office of Community Living.** New York must better align state services in a way that breaks down silos and makes services more responsive to people's needs. The existing system does not provide this, particularly with respect to people with physical disabilities who lack a state agency advocating for their needs. This is also a requirement under the Community First Choice Option, which is designed to serve individuals based on their needs, rather than their diagnosis. The 2015-16 Executive Budget called for a stakeholder process to examine the feasibility of creating an Office of Community Living in New York. This process resulted in a report which identified a number of gaps in existing services and areas for improvement in coordination of service delivery. Unfortunately, the Executive Budget does nothing to advance the proposal further. The state must move forward with the creation of an Office of Community Living in the 2016-17 budget. Such an office would be strongest if it focused on the needs of individuals - regardless of age or disability - to live independently. Given the similarities, we think New York could effectively combine aging and disability services under one State agency to create this new office. At a minimum, the State should create an Office of Community Living with disability and *Olmstead* as the focus. This can be done in a phased approach with the Independent Living Centers and a few key disability programs, such as the TRAID program and Access to Home, as the foundation. New York must not stall the creation of an OCL any longer.

**New York State must fund the proposed minimum wage increase.** Increasing the minimum wage to \$15 an hour without commensurate funding to human services and Medicaid funded programs will gravely hurt people with disabilities and the organizations which serve them. More specifically, Independent Living Centers rely on a State appropriation for operating expenses – including core staff – and are already severely underfunded. With an un-funded mandate such as this, many ILCs would have to cut back on programs which enable people with disabilities to live and receive services in the community.

In addition, increasing the minimum wage without a proportionate funding increase would impede homecare providers' ability to continue serving people with disabilities who rely on these services to remain in the community and out of costly institutions. Current Medicaid reimbursements for home care programs, including the Consumer Directed Personal Assistance program, are so low that these providers would not be able to absorb the increase in wages. This proposal undermines *Olmstead* implementation efforts by putting people's access to critical community based services, including homecare, at risk. While raising the minimum wage is laudable, the State cannot rely on already underfunded not-for-profits and Medicaid funded programs to absorb the increase.

**For further information, please contact:**

Lindsay Miller  
Executive Director  
New York Association on Independent Living  
99 Washington Ave., Suite 806A  
Albany, NY 12210  
Phone (518) 465.4650  
Email [lmiller@ilny.org](mailto:lmiller@ilny.org)