



155 WASHINGTON AVE | SUITE 208
ALBANY, NY 12210
518.465.4650 PHONE | 518.465.4625 FAX
INFO@ILNY.ORG | WWW.ILNY.ORG

October 10, 2018

The Honorable Andrew M. Cuomo
Governor of New York
NYS State Capitol
Albany, NY 12224
Sent via email

RE: Independent Living Community's 2019 budget priorities

Dear Governor Cuomo:

The New York Association on Independent Living (NYAIL) is a Statewide membership organization of Independent Living Centers (ILCs) across New York State. ILCs are cross-disability, locally administered not-for-profit organizations, run by and for people with disabilities. We are writing in regard to our top Executive Budget priorities for SFY 2019-20. It is critical to the disability rights community that they be included in the Executive Budget proposal in January.

Almost 30 years after the passage of the Americans with Disabilities Act (ADA), people with disabilities are still facing lower educational attainment, lower levels of employment and wages, greater social isolation, worse health outcomes and greater levels of poverty than their nondisabled counterparts. Further, threats at the Federal level are putting our rights and the services we depend on at grave risk. However, New York State can be a champion for the rights and independence of people with disabilities by advancing the below priorities.

As a result of CFCO implementation, the State is receiving hundreds of millions of dollars annually from the enhanced federal match, which New York State committed to allocating toward Olmstead implementation. As such, the funding should go toward the following proposals, all of which are designed to promote community integration for New Yorkers with disabilities. Our priorities are:

- **Increase base funding for Independent Living Centers (ILCs) to \$18 million in SFY 2019-20 as recommended by the State Education Department and Board of Regents the past two years, with the ultimate goal of increasing the State appropriation to a much needed \$25 million.**

Independent Living 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, transportation, and other independent living skills.

ILCs have been severely underfunded for the past thirteen years while the cost of providing services has increased dramatically, creating a crisis for centers and the people with disabilities they serve.

Over the past few years, the Board of Regents and the Legislature have all acknowledged that ILCs are essential providers for some of their most vulnerable citizens, yet have not been able to meet the needs of their local community's due to this severe underfunding. The Board of Regents recommended a \$5 million increase to the network of ILCs as part of their budget recommendations for the past two years, and the Senate and Assembly both included an increase in their one house budget proposals for ILCs. In the final Budget, these increases disappeared and ILCs received no increased funding once again.

After eight years in office, this Administration has not once included a funding increase for ILCs in its proposed Executive Budget. We are calling on this Administration to show a commitment to Independent Living and the over 100,000 people with disabilities we serve annually by including a \$5 million increase in this year's proposed budget.

- **Provide a necessary voice for people with disabilities in state government by reactivating the duties of the State Office for the Advocate for Persons with Disabilities, as established by former Governor Mario Cuomo in 1983 through Executive Order No. 26.**

The disability community desperately needs a voice in state government that represents all people with disabilities. Reinstating the Office for the Advocate for Persons with Disabilities is a critical first step. This concept has been championed by the Assembly's Task Force for People with Disabilities and supported by members of this Administration.

Governor Mario Cuomo originally established this Office to advocate for people with disabilities in State government. This Office was responsible for advising and assisting the Governor in developing policies designed to help meet the needs of people with disabilities and serving as the State's coordinator for the implementation of Section 504 of the Federal Rehabilitation Act of 1973 (this would now include the Americans with Disabilities Act and Olmstead).

As one of his first acts in office, Governor Cuomo continued Executive Order 26. However, despite the existence of the Office on the books, any advocacy function in State Government disappeared when the Justice Center reorganized itself without any advocacy functions.

A new home for advocacy and independent living must be established. At a minimum, and immediately, the responsibilities of the Office for the Advocate must be activated. We urge you to include this proposal in your SFY 2019-20 Budget, and highlight it in your State of the State Address.

- **Establishing a funding mechanism to ensure Managed Long-Term Care (MLTC) plans receive adequate funding to serve those with the greatest needs.**

New York State's FY 2019-20 Executive Budget must ensure that MLTC plans are adequately incentivized so that their members with the greatest needs have the services they need to live in their home communities. Previous years' Budgets included a commitment to explore a high needs community-based rate cell with CMS. It is our understanding that New York based its proposal on the cost of providing services, and CMS denied this request. If that is accurate, we recommend a revised proposal to CMS based on functional needs in combination with the cost of providing services. DOH is collecting better data on the services being provided to populations that typically have the greatest needs as part of New York's new risk adjustment process. This data should be optimized to strengthen a revised submission for approval by CMS, and increase the likelihood that it would be approved.

- **Address the home care crisis by providing a living wage to home care workers.**

People with disabilities who require home care are having a harder and harder time getting the care they require to remain in their homes and out of costly institutions. In many parts of the state, particularly upstate, people are unable to get care at home because not enough people want these jobs due to the low pay. The State has a legal obligation under Olmstead to ensure people have access to appropriate care in the most integrated setting, their home communities. The State needs to provide a living wage to home care workers in order to attract people to work in that field.

One way to address the home care crisis would be to ensure home care workers are paid equivalent rates to those of providers under OPWDD. The State is obligated to rationalize rates across systems in the approved State Plan Amendment (SPA) for the Community First Choice Option (CFCO), which began implementation in April, 2018. Given the timeline for CFCO implementation, the State needs to address the disparity between rates in this year's Budget. By increasing rates for home care up to the funding levels of OPWDD providers, the State will truly help address the current home care crisis by offering essential home care workers a living wage.

- **Increase the State's share of funding for the Long-Term Care Ombudsman program to \$3 million.**

The Long-Term Care Ombudsman Program (LTCOP) serves as an advocate and resource for people living in nursing facilities and other institutions. The program is intended to promote and protect residents' rights as well as their health and safety by receiving, investigating and resolving complaints made by or on behalf of residents. The LTCOP receives Federal funding, but it is insufficient to provide adequate services in NYS. Despite this, New York's match is one of the lowest when compared to other States. The State must increase its share of funding to adequately serve the State's population of people in long-term care facilities.

Currently, LTCOP downstate providers are extremely overburdened, relying heavily on volunteers. In New York City, about 52% of nursing home residents are being served by volunteers. CMS recommends 1 FTE per 2,000 nursing home beds. In NYC, they would have a staff of 26 staff members, but currently only have six. This results in LTCOP staff members spending a disproportionate amount of time recruiting and training volunteers. The State can address this by increasing the State share of LTCOP funding to \$3 million.

- **Increase funding for Access to Home to \$10 million.**

Access to Home is an important 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. For many people, the addition of a ramp to their front door makes the difference between being able to leave the house and being homebound. Access to Home was cut by 75% several years ago. Ever since, Access to Home has been funded at a mere \$1 million Statewide, leaving many parts of the state without the program and resulting in years long waiting lists. While the State did allocate \$19.6 million over three years to the program in the 2015-16 SFY from the J.P. Morgan settlement funds, those funds were limited to veterans with disabilities. This meant that the vast majority of low income families who needed home modifications to remain at home, couldn't access them.

While the State has invested in programs designed to help people leave nursing facilities, such as Open Doors and the Olmstead Housing Subsidy, without adequate or associated funding for home

modifications, many people still can't leave the nursing facility. The State must increase funding for Access to Home to \$10 million to help people to leave institutions and move back into the community.

- **Make a person's lawful source of income a protected class in NYS Human Rights Law.**

There is a housing crisis in New York State for people with disabilities due to the lack of affordable and accessible housing. People with disabilities who are on fixed incomes, or who have low wage jobs are unable to afford to rent without a subsidy. In fact, more than a third of people with disabilities are severely rent burdened, spending more than 50 percent of their income on housing. A modest one bedroom costs an average of 133 percent of a person's SSI in New York State. Avoiding institutionalization or homelessness depends on having a housing rental subsidy. Yet, landlords turn down prospective tenants who have rental subsidies. This results in a situation where even with a subsidy, people with disabilities are often unable to find housing.

New York can address this barrier to housing by making a person's lawful source of income a protected class in NYS Human Rights Law. Governor Cuomo championed this issue during the 2018 legislative session by introducing Program Bill #23. We urge the Administration to incorporate this important legal protection into the 2019 Executive Budget and ensure necessary enforcement activities by the Division of Human Rights.

- **Create a Visitability tax credit to help homeowners retrofit their homes to make them more accessible, or to incentivize including visitable features at the time of construction.**

Due to the high cost of home modifications, many people cannot afford to make changes to their homes to make them more accessible, or to move to a more accessible home. Most prefer to remain at home rather than move to nursing facilities or different, more accessible housing as their needs change. However, many are forced out because their homes are no longer safe or practical for them to live in. The Visitability Tax Credit would help to ensure that people with disabilities and older New Yorkers are able to afford these modifications and remain in their homes.

Despite strong support from the legislature, who has passed it for three years in a row, this bill has been vetoed each time. The veto messages have lauded the goals of the legislation but stated it needs to be handled in the Budget, but it has never been proposed and/or supported by this Administration in the Executive Budget. Given Legislative support for this issue, we urge the Cuomo Administration to include this program in the 2019 Executive Budget and make this incentive a reality.

We strongly urge this Administration to make the integration and equality of people with disabilities a priority in this year's Budget.

Sincerely,



Lindsay Miller
Executive Director

CC: Paul Francis, Deputy Secretary for Health and Human Services
Megan Baldwin, Assistant Secretary for Health
Shelly Weizman, Assistant Secretary for Mental Hygiene
Kerri Neifield, Assistant Secretary for Human Services
Jamie Frank, Assistant Secretary for Education