



2018 DISABILITY PRIORITY AGENDA BUDGET PRIORITIES

The New York Association on Independent Living (NYAIL) represents Independent Living Centers (ILCs) and the people with disabilities they serve. NYAIL is dedicated to removing barriers to full community integration and safeguarding the civil rights of people with disabilities of all ages. This year will mark five years since Governor Cuomo issued the State's *Olmstead* plan, which outlines how the State would advance the State's community integration efforts for people with disabilities. Yet, this year's Executive Budget proposal does little to help achieve these goals. In fact, cuts to Medicaid and level funding for chronically underfunded programs like Independent Living Centers, home care, Access to Home, and the Long-Term Care Ombudsman Program (LTCOP) illustrate a lack of commitment to *Olmstead*. Threats from the federal level means that New Yorkers with disabilities are relying on the State to protect our rights and independence. We urge the Legislature to take legislative and administrative action in the 2018-19 budget as outlined below toward the full integration of New Yorkers with disabilities.

INDEPENDENT LIVING PRIORITIES

NYAIL Strongly Supports/Recommends:

- Increasing base funding for Independent Living Centers (ILCs) to \$18 million as recommended by the State Education Department and Board of Regents;
- Providing a voice for people with disabilities in state government by reactivating the duties of the State Office for the Advocate for Persons with Disabilities.

HEALTH/MEDICAID

NYAIL Strongly Supports/Recommends:

- Establishing a high-needs community rate cell to allow Managed Long Term Care (MLTC) plans to serve those with the greatest needs;
- Addressing the home care crisis by providing a living wage to home care workers;
- Increasing the State's share of funding for LTCOP to \$3 million;
- Fully funding the No Wrong Door system, including an \$8 million annual appropriation for ILCs.

NYAIL Strongly Opposes:

- Requiring a Uniform Assessment Score of 9 to qualify for MLTC;
- Carving nursing facilities out of MLTC;
- Requiring MLTC enrollees to remain in a plan for 12 months;
- Limiting spousal refusal to MLTC members and decreasing the spousal impoverishment resource allowance to the federal minimum.

HOUSING

NYAIL Strongly Supports/Recommends:

- Increasing Access to Home funding to \$10 million;
- Creating 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.

VOTING

NYAIL Strongly Supports/Recommends:

- Ensuring early voting is fully accessible.

Independent Living Priorities

- **Increase base funding for Independent Living Centers (ILCs) to \$18 million in SFY 2018-19 as recommended by the State Education Department and Board of Regents, 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. In 2016/2017, the state's network of ILCs served over 100,000 people with disabilities, family members and others; an increase of more than 20,000 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.

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 in their budget recommendations for the second year in a row. There has been strong support in the Legislature and the Senate and Assembly both included an increase in their one house budget proposals for ILCs last year. However, in the final Budget, these increases disappeared and ILCs received no increased funding once again. The need for a funding increase in 2018-19 budget is critical.

Investment into ILCs actually saves the State money it would otherwise be obligated to spend. 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 \$2.3 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.

- **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.

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.

Health/Medicaid Priorities

- **NYAIL strongly urges the State to create a high needs community rate cell.** The establishment of a high needs community rate cell would provide MLTC plans with sufficient funding to support those with the greatest needs to live in the community. The current capitation rates do not provide for this, and as a result, those with the most significant disabilities may not be able to get the care they require to live at home. Last year's budget included a commitment to explore a high needs community rate cell with CMS. The state must not delay any longer and move forward with this to ensure that people with the most significant needs can get the care they require to live at home.
- **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. The proposed budget includes a proposal for a \$3 million appropriation to assess the home care crisis in rural parts of the state and to increase wages only in fee for service personal care and waiver programs. This is a step in the right direction, but does not go nearly far enough.

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 is set to be implemented by 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

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when compared to other states. NYAIL urges the State to increase its share of funding to \$3 million to ensure the State's population of people in long-term care facilities are adequately served.

- **Fully fund New York's No Wrong Door system, including a \$8 million annual appropriation for ILCs.** As part of the Balancing Incentive Program, the State has expanded its No Wrong Door system to bring together the federally funded Area Agencies on Aging (AAAs) and Independent Living Center networks to create a true single point of entry system for accessing long term services and supports. Ensuring access to comprehensive, accurate and unbiased information about long term service and support options and linkages to services is essential as New York continues to implement major systemic reforms to the State's Medicaid system that drastically change the way long term care is delivered. Over the past year, AAAs and ILCs have been successfully working together and have expanded the program, with numbers served continuing to increase thanks in large part to a successful State advertising campaign. Despite this, the Executive Budget proposes a two-year allocation that is not sufficient to maintain the system as it is currently structured.

In addition to cutting No Wrong Door, the Executive Budget also proposes banning MLTC providers from marketing their services. This proposal further attempts to limit the information available to individuals regarding services they may be qualified for and need.

New York must keep the No Wrong Door system whole by fully funding the program. The funding allocation should include a detailed breakdown and must include an \$8 million annual appropriation for ILCs.

- **NYAIL strongly opposes requiring a UAS score of 9 to qualify for MLTC.** Since the state started its managed care for all campaign, most people who need LTSS have been transitioned into MLTC plans, and other managed care models. Confusingly, the Executive Budget now seeks to limit enrollment in MLTC by changing eligibility and requiring a significant number of people who are at or above the nursing facility level of care (NFLOC) into fee for service. The NFLOC requires a Uniform Assessment System (UAS) score of 5 or greater. Directing new applicants with a UAS score between 5 – 8 to fee for service (FFS) will result in a huge influx of Medicaid participants at the local Departments of Social Services. Most LDSS offices no longer have the infrastructure to handle these cases. In addition, MLTC is intended to provide a certain level of care coordination and requires a person-centered service plan, which is absent in the FFS model. While some of these individuals may qualify for mainstream managed care, that system is not designed to serve those with higher needs and the current rate structure is not sufficient to deliver the level of home care service this population would require.

Further, only under MLTC can family members claim spousal impoverishment. Spousal impoverishment allows people to get on Medicaid without putting their spouse in poverty. This will have a significant impact on many elderly spouses who live on fixed incomes and could result in unwanted and unnecessary institutionalization. The state must keep the requirement for MLTC participation at a UAS of 5.

- **NYAIL strongly opposes carving nursing facilities out of MLTC.** Carving nursing facilities out of MLTC will incentivize plans to push those with the most significant needs, who are the most expensive to provide services for into nursing facilities. In the Governor's *Olmstead* Plan, he prioritized reducing the long-term stay nursing facility population in NYS. This proposal would have

the opposite effect as it will undoubtedly make it more difficult for those with the most significant needs to get care in the community. This is particularly true absent a high needs community rate cell. NYAIL calls on the legislature to reject the proposal to carve nursing facilities out of MLTC.

- **NYAIL strongly opposes requiring MLTC enrollees to remain in a plan for twelve months.** An individual's ability to go to another plan is one of the few protections they have in MLTC and must be preserved. Once individuals are locked into their plans, there is nothing to prevent plans from cutting hours or services they need to remain safe in the community. Additionally, if a person's provider leaves the plan, the person then loses their ability to receive services from the provider that they know and trust. While this proposal contains a 'good cause' clause, there is not enough detail to ensure it will protect individuals' rights.
- **NYAIL strongly opposes limiting spousal refusal to MLTC members and decreasing the spousal impoverishment resource allowance to the federal minimum.** This year's Executive Budget proposes eliminating spousal refusal for those receiving services outside of MLTC. Spousal refusal is a longstanding provision of state law that ensures that individuals can access the Medicaid-funded services and supports they need to live in the community, when their spouses "refuse" to spend down their resources or income to support their spouse. The reality is that with Medicaid income levels below the Federal Poverty Line, all of the couple's income and resources are vital to meet their living expenses, and to prevent the spouse from being impoverished and needing Medicaid as well. The alternatives are to force couples to divorce, live separately, become totally impoverished, or to institutionalize their loved ones purely for financial reasons. Even if spousal refusal is retained for MLTC, it is also critical for those who need the Medicare Savings Program or vital medical care other than home care, and for those who need home care but who are excluded from MLTC. Even those who apply for Medicaid solely to enroll in an MLTC plan need spousal refusal initially, since the proposal would allow it only *after* the individual is enrolled in an MLTC plan, just like "spousal impoverishment."

Similarly, the proposal to decrease the spousal impoverishment allowance to the federal minimum of \$24,000 would force individuals to choose between living in poverty and ensuring his/her spouse can access necessary Medicaid-funded services and supports. Spousal impoverishment protections are available to couples that have one spouse who is eligible for MLTC or a waiver, and it allows the spouse who is not on Medicaid to maintain a certain income while still allowing Medicaid to pay for their spouse's services and supports. The proposal would force many "well" spouses onto Medicaid, who could otherwise avoid it. These proposals would have a disproportionate impact on low-income New Yorkers.

Housing Priorities

- **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 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.

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. Further, after the three-year allocation, much of these funds have gone unspent and could be used to help fund Access to Home for everyone, while still giving veterans a preference. The State must increase funding for Access to Home to \$10 million to help people to leave institutions and move back into the community.

- **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.** Despite strong support from the legislature, Governor Cuomo has vetoed legislation to create a visitability tax credit for the past three years. In the veto messages, the Governor indicated support for the program, but stated that such a proposal would need to be handled during budget negotiations. Despite his stated support for the program, Governor Cuomo has yet again failed to include this tax credit in his proposed executive 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 urges the legislature to include the \$1 million pilot program as proposed in A.5950A/S.2411A of 2017 in the state budget.

Voting Priorities

- **Ensure early voting is fully accessible.** NYAIL supports expanding access to voters by implementing early voting. However, accessibility requirements must be held to the same standard during early voting that it is on Election Day. NYAIL is concerned that language in the bill allows for some polling sites to be inaccessible. Further, there seems to be no provisions ensuring that universally designed Ballot Marking Devices (BMDs) will be available at all polling sites during early voting. BMDs enable people, regardless of their disability, to vote privately and independently. It is critical that the State ensure full access to the polls during early voting by mandating that all polling sites are physically accessible and that they have a BMD available during early voting as required by federal law.

For further information, please contact:

Meghan Parker, Director of Advocacy
Phone: (518) 465.4650
Email: mparker@ilny.org