
2021 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 leads statewide ILC efforts to eliminate physical, communications, attitudinal, and other barriers to all aspects of life. Over the past year, COVID-19 laid bare the dangers of institutionalizing people in nursing homes and other congregate care settings. Never has it been more important for the State to commit to the principles of *Olmstead* by funding vital programs that protect the rights and advance the State's community integration efforts for people with disabilities. Investing in the below priorities would show real leadership from the State in providing safer and more desirable options to seniors and people with disabilities and would help save lives. We urge the Legislature to take legislative and administrative action in the 2021-22 budget as outlined below toward the full integration of New Yorkers with disabilities.

INDEPENDENT LIVING

NYAIL strongly supports:

- Increasing base funding for Independent Living Centers (ILCs) to \$18 million in SFY 2021-22. It is important to note that the proposed Executive Budget proposal does not include the previously enacted \$500,000 increase.

HEALTH / MEDICAID

NYAIL strongly supports:

- Ensuring access to home care, personal care and consumer directed personal assistance for all who need it by paying home care workers 150% of a region's minimum wage;
- Helping address the home care crisis by creating a *Home Care Jobs Innovation Fund* at a mere \$5 million per year for 3 years;
- Funding the Good Neighbor Program at \$500,000/year to assist individuals lacking informal supports transition out of nursing facilities;
- Increasing revenue to protect Medicaid and essential services for people with disabilities in a manner that does not negatively impact them.

NYAIL strongly opposes:

- Extending the Medicaid Global Cap, which has led to harmful cuts and limited eligibility for essential community-based services;
- Reducing recruitment and retention funding by 50% for home care when more needs to be done to recruit and retain quality staff;
- Eliminating provider prevails. The State must ensure qualified prescribers are able to continue to use their best professional judgement regarding which medication their patients require.

AGING

NYAIL strongly supports:

- Increasing the State's share of funding for the Long-Term Care Ombudsman program by \$3 million. The State's commitment to this program is proportionally one of the worst in the country, at a time when residents of nursing homes and other congregate care settings have been most at risk.

HOUSING

NYAIL strongly supports:

- Increasing funding for Access to Home to \$10 million. Funding for this program was cut by 75% several years ago and many legitimate requests to modify housing to accommodate people with disabilities continue to be unanswered;
- Creation of the COVID-19 Emergency Residential Tenant Late Fee Suspension and Security Deposit Utilization Act of 2021.

TRANSPORTATION

NYAIL strongly supports:

- Enacting the recommendations of the Transportation Network Company (TNC) Accessibility Task Force, especially in regard to establishing necessary regulatory oversight over the TNCs.

INDEPENDENT LIVING

- **Increase base funding for Independent Living Centers (ILCs) to \$18 million in SFY 2021-22. It is important to note that the proposed Executive Budget proposal does not include the previously enacted \$500,000 increase.**

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. Further, over the past year, the Independent Living Centers responded to the pandemic by helping form the first line of defense for people with disabilities both in the community and in institutions. Despite being chronically underfunded, ILCs were able to quickly pivot their services to meet the new needs. They immediately shifted focus to individuals who they had transitioned to the community to make sure their needs were being met, including by making wellness checks, delivering meals, and even providing iPads to residents in nearby nursing facilities.

ILCs have been severely underfunded for the better part of two decades while the cost of providing services has increased dramatically, creating a crisis for centers and the people with disabilities they serve. In 2018, the state's network of ILCs served 114,000 people with disabilities, family members and others; an increase of approximately 20,000 in just six 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 communities due to this severe underfunding. There has been strong support in the Legislature and in the final budget the last two years, the ILCs received a modest increase of \$500,000. However, Governor Cuomo's proposed Executive Budget effectively cuts funding to the centers by not including this increase. Centers have already created budgets relying on this increased amount in base funding and taking this increase would further harm the already under-funded centers.

HEALTH / MEDICAID

- **Ensure access to home care, personal care and consumer directed personal assistance for all who need it by paying home care workers 150% of a region's minimum wage.**

COVID-19 highlighted the very real dangers that have long existed in nursing facilities. The State should be prioritizing access to home and community-based services as the answer to the tragic deaths in facilities during the pandemic. NYAIL has long advocated for better wages for home care workers. In many parts of the State, particularly upstate, there is a home care shortage. This is primarily due to falling wages and disparate treatment of women and people of color who comprise most home care workers.

As wages increase in other sectors, such as fast-food restaurants, it is increasingly difficult to find people willing to do this work which is physically and emotionally demanding. 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. NYAIL is a proud member of the NY Caring Majority, which is calling for the State to increase wages for all home care workers to 150% of a region's highest minimum wage.

- **Help address the home care crisis by creating a *Home Care Jobs Innovation Fund* at a mere \$5 million per year for 3 years.**

As New York's home care providers struggle to recruit and retain workers, they unfortunately lack the resources to test innovative solutions to this problem. This year's budget should include funding to support pilot projects throughout the State that would help to increase recruitment and retention of home care workers. NYAIL joins with the NY Caring Majority in proposing that the State allocate a mere \$5 million per year for 3 years to support this effort. The findings from these projects can help determine statewide solutions.

- **Fund the Good Neighbor Program at \$500,000/year to assist individuals lacking informal supports transition out of nursing facilities.**

People in nursing facilities often lose connections to family and friends in the community. When they try to leave the nursing facility, they find that home care agencies, managed long term care plans (MLTCs) and waivers can require that they have a backup caregiver for times when personal care aides do not come. This means people who could otherwise live in the community are stuck in nursing facilities due to the lack of informal supports. The Good Neighbor program, administered by NYAIL, connects these people to Neighbors who provide back-up care as well as connection to the community. This includes visits, check-in calls, shopping and other tasks agreed upon by the person and Neighbor. Neighbors are given a small monthly payment based on region and frequency of contact. This program has been funded since January 2020 by the Mother Cabrini Foundation and has successfully transitioned 10 people, with 15 more already matched to a neighbor. The funding for this pilot program will end in June 2020. To maintain the 25 people who will have transitioned and to transition 25 more people will cost only \$500,000/year. This is a small amount compared to the cost of care in a nursing facility and insignificant when compared to the value of living independently in the community.

- **Increase revenue to protect Medicaid and essential services for people with disabilities in a manner that does not negatively impact them.**

NYAIL understands that the State is facing a significant deficit and funding for the above priorities must come from somewhere. Therefore, we join with many other groups in our support for raising revenue. While we do not have a position on how to go about this, we are adamant that any revenue raised must be done in a manner which does not impact low-income New Yorkers, including people with disabilities. Further, it is imperative the State use that revenue to invest in home and community-based services as the answer to the pandemic.

- **NYAIL strongly opposes extending the Medicaid Global Cap, which has led to harmful cuts and limited eligibility for essential community-based services.**

For the past few years, the State has sought to cut long-term care and limit eligibility to deal with a “budget shortfall” in its Medicaid program. Much of the reason for the so-called budget shortfall is due to spending simply exceeding a self-imposed Medicaid Global Cap. Essential programs and services have already faced significant cuts in recent years as a result of the cap. Just last year, the Medicaid Redesign Team II enacted significant cuts to eligibility for community-based long-term care which will ultimately lead to institutionalization and worse health outcomes for many older New Yorkers and people with disabilities. Now, due to the pandemic, the Medicaid program has grown significantly, providing essential health care and services to hundreds of thousands of additional New Yorkers. The State must reject its current austerity approach to dealing with growth in the Medicaid program and instead spend what is needed to provide comprehensive health care and services to eligible New Yorkers. In order to do so, the State needs to eliminate the Medicaid Global Cap and take factors such as an aging population and growth in the program into account.

- **NYAIL strongly opposes reducing recruitment and retention funding by 50% for home care personal care service workers, certified home health agencies, long term home health care programs, AIDS home care programs, hospice programs, and managed long-term care plans.**

Recruitment and retention funding was established to provide much needed additional support specifically for the purposes of training, recruitment, and retention of home care workers and personal assistants. The Executive Budget proposes reducing this funding by an additional 25% on top of the 25% cut from last year, effectively cutting this important funding stream in half. This has been an important source of funding built into the rates for providers that has enhanced the ability to recruit and retain aides. The State should not be cutting this funding stream at a time when many parts of the State have a serious aide shortage. Many ILCs act as Fiscal Intermediaries under the Consumer-Directed Personal Assistance (CDPA) program. The ability of CDPA consumers to recruit and retain aides has dropped significantly in recent years. This has forced some into institutions and has prevented others from returning home. At a time when there is still a pandemic tearing through these facilities, the State should be investing more heavily in this funding to ensure people have access to vital home care services.

- **NYAIL strongly opposes eliminating provider prevails. The State must ensure qualified prescribers are able to continue to use their best professional judgement regarding which medication their patients require.**

This proposal would repeal an important patient protection in the Medicaid program which restored “prescriber prevails” for prescription 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.

AGING

- **Increase the State’s share of funding for the Long-Term Care Ombudsman program by \$3 million. The State’s commitment to this program is proportionally one of the worst in the country, at a time when residents of nursing homes and other congregate care settings have been most at risk.**

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. The State Comptroller released a report in 2019 on the program and found that many residents in LTC facilities lack representation from an Ombudsman due to lack of volunteers and paid staff. The report found that statewide, there are about half the recommended number of full-time staff. It found that across the State, five of eleven regions require at least three additional staff to meet recommended levels, and in New York City alone, they require 23 more full-time staff. NYAIL urges the State to increase its share of funding by \$3 million to ensure the State’s population of people in long-term care facilities are adequately served.

HOUSING

- **Increase funding for Access to Home to \$10 million. Funding for this program was cut by 75% several years ago and many legitimate requests to modify housing to accommodate people with disabilities continue to be unanswered.**

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. The pandemic has highlighted how vulnerable people are when they wind up in nursing homes and other congregate care settings. Therefore, it is more important than ever that the State invest in programs such as Access to Home which was created to help people avoid institutionalization by making their homes safe and accessible.

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. Investing in Access to Home will help seniors and people with disabilities around the State to remain in their homes and out of institutions.

- **NYAIL strongly supports creation of the COVID-19 Emergency Residential Tenant Late Fee Suspension and Security Deposit Utilization Act of 2021.**

This bill would temporarily allow people impacted by COVID-19 to use their security deposits to make rent payments, as well as prevent property owners from imposing late fees upon tenants who are unable to make timely rent payments until May 2021. Landlords and tenants would be permitted to enter into a written agreement enabling security deposits and any interest to be used to pay any future rent or rent that is in arrears. This proposal would greatly help people with disabilities who have lost their jobs or faced reduced salaries as a result of the pandemic. This financial flexibility and relief from late payments will prevent many from rapidly mounting fees that could ultimately lead to homelessness or institutionalization.

TRANSPORTATION

- **Enact the recommendations of the Transportation Network Company (TNC) Accessibility Task Force.**

Their report was published in February 2019 and included the following two recommendations to the State intended to ensure comparable service is provided to wheelchair users:

- Establish an official governing entity to provide ongoing oversight of TNCs operating in New York State.
- Explore creative ways to provide incentives to increase the number of accessible TNC vehicles statewide. For example, potential TNC drivers could be incentivized through tax breaks or access to low interest loans for the purchase and/or modification of accessible vehicles.

The TNC Accessibility Task Force was created as part of the legislation authorizing TNCs to operate statewide. That legislation mandated that TNCs implement the recommendations of the Task Force. However, there is little to no evidence the TNCs have done anything to implement these recommendations. As per the report, the TNCs were directed to spend this past year working with disability organizations regionally on a plan to provide comparable wheelchair accessible service. NYAIL provided both Uber and Lyft with contacts at Independent Living Centers across the State. Yet, they failed to work with any of the centers to form such a plan. Unless the State creates a mechanism for oversight, it seems very unlikely the recommendations in this report will be implemented, as mandated in the authorizing legislation. This budget is a perfect opportunity to provide funding to help get more accessible vehicles on the road and to create an oversight body to ensure the TNCs comply.

For further information, please contact:

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