
2019 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. NYAIL advocates for the civil rights, independence, and full participation of all people with disabilities. This year marks six years since Governor Cuomo issued the State's *Olmstead* plan, which outlined how the State would advance the State's community integration efforts for people with disabilities. Further, last year's ABLE Initiative purported to be aimed at supporting community living for New Yorkers with disabilities. Yet, we have seen little come out of the ABLE Initiative, and 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 ILCs, 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 2019-20 budget as outlined below toward the full integration of New Yorkers with disabilities.

INDEPENDENT LIVING

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:

- addressing the home care crisis by providing a living wage to home care workers;
- establishing a funding mechanism to ensure Managed Long-Term Care (MLTC) plans receive adequate funding to serve those with the greatest needs;
- funding the ILCs role in New York Connects at \$6.5M annually;
- reimbursing the National Diabetes Prevention Program (DPP) for all Medicaid members.

NYAIL Strongly Opposes:

- the drastic changes proposed to the Consumer Directed Personal Assistance (CDPA) program;
- eliminating spousal refusal protections;

- eliminating provider prevails;
- extending the Medicaid Global Cap through 2021.

AGING

NYAIL Supports/Recommends:

- increasing the State's share of funding for LTCOP by \$3 million;

HOUSING

NYAIL Strongly Supports/Recommends:

- making a person's lawful source of income a protected class in NYS Human Rights Law;
- 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:

- funding early voting and passing automatic and same day voter registration to make it easier for people with disabilities to vote.

EMPLOYMENT

NYAIL Strongly Supports/Recommends:

- establishing a small business tax credit for employing people with disabilities.

INDEPENDENT LIVING

- **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, 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 fourteen years while the cost of providing services has increased dramatically, creating a crisis for centers and the people with disabilities they serve. In 2017, the state's network of ILCs served nearly 110,000 people with disabilities, family members and others; an increase of approximately, 30,000

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. The Board of Regents recommended a \$5 million increase to the network of ILCs in their budget recommendations for the third 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. NYAIL is hopeful with new leadership in the Senate that a stronger commitment will be demonstrated, resulting in a much needed increase.

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, shows that the work of ILCs to transition and divert people with disabilities from costly institutional placements saved the State more than \$2.5 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

- **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 is set to be fully implemented by July 2019. 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.

- **Establish 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 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.

- **NYAIL supports funding the ILCs role in New York Connects at \$6.5M annually.**

As part of the Balancing Incentive Program, the State expanded its No Wrong Door system to bring together the federally funded Area Agencies on Aging (AAAs) and ILC 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. AAAs and ILCs are successfully

working together and have expanded the program, with numbers served continuing to increase. NYAIL applauds the State for acknowledging the work of the NY Connects network and adequately funding the program with a separate and increased allocation for ILCs.

- **NYAIL strongly supports the proposal to reimburse the National Diabetes Prevention Program (DPP) for all Medicaid members.**

The national DPP is an evidence-based program focused on helping individuals make positive lifestyle changes, such as eating healthier and getting more physical activity. Adults with disabilities are three times more likely to have diabetes, and nearly half of all adults with disabilities get no aerobic physical activity. Because of these disparities, NYAIL is working as part of a national grant to expand availability of the national DPP to people with disabilities utilizing the Center for Disease Control (CDC) approved inclusive version of the standard curriculum. The funding limits this work to four NY counties – Putnam, Greene, Fulton & Montgomery – but reimbursement through the Medicaid program would help expand availability of this program to people with disabilities in communities across the state.

- **NYAIL strongly opposes the drastic changes proposed for the Consumer Directed Personal Assistance (CDPA) program.**

The Independent Living community was instrumental in designing and implementing CDPA in New York, which empowers people with disabilities to have full control over their lives and independence. It puts people with disabilities in charge of determining how, when and by whom their services are provided. Fiscal Intermediaries (FIs) provide necessary assistance to ensure CDPA consumers are successful and maintain their independence in the community through training, peer mentoring, ongoing support, payroll and other administrative assistance. This Budget proposal threatens to decimate CDPA as we know it.

Limiting FIs - The Governor's proposal would limit the organizations allowed to operate as FIs and allow DOH the power to award a no-bid contract for a statewide FI. ***NYAIL urges the State to use the authorization process that is in the early stages of implementation to weed out FIs that are not running the program as intended rather than make such drastic and harmful changes.*** ILCs are singled out as entities that could apply to remain as FIs, which makes sense. The additional wrap-around services provided at ILCs are aimed at helping people with disabilities live independently in the community, making ILCs uniquely strong FIs. However, under this proposal, no new ILCs would be able to add this important service. Further, existing ILC FIs would have to apply to DOH for approval to continue running their program, and there is no guarantee their applications would be approved. A radical and rapid reduction in FIs threatens existing consumers. Transitioning all CDPA consumers into one or a few statewide FIs is a bad idea. FIs must have a local presence to be successful in their role supporting consumers to manage their own services, and individuals must have choice when selecting their FI.

Reimbursement - The bill also gives the Commissioner of DOH total administrative authority to change the reimbursement methodology, and DOH has indicated its intent to change to a per member, per month fee. An underlying concern with this proposal is that it assumes FIs are nothing more than a payroll processing agency, putting at risk the many additional tasks and wrap-around services FIs provide that help to ensure CDPA consumers are successful and maintain their independence. Further, it shifts the risk from managed care organizations - insurance companies that are set up to receive a monthly per person rate - to fiscal intermediaries whose role is to support people with disabilities managing their own services, and thus creates a disincentive for FIs to serve people with significant disabilities who have larger numbers of attendants, hours and support needs.

The future of CDPA is at stake - Because the proposal repeals the existing CDPA law and replaces it with new law, it allows the Federal Government to control whether these changes will be approved, at a time when Federal approval is anything but certain. ***This puts CDPA in New York at risk.*** Separately but equally troubling, it provides the Commissioner of Health with the unimpeded authority to terminate CDPA if Federal Financial Participation is not “adequate,” even if FFP is available. ***This authorized judgement call, without further Legislative review, also puts the entire CDPA program at risk.*** Both the content and form of this proposal are very dangerous.

NYAIL urges the legislature to reject this harmful proposal that could end CDPA in NY!

- **NYAIL strongly opposes eliminating spousal refusal protections.**

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, or to institutionalize their loved ones purely for financial reasons, creating a discriminatory institutional bias. This proposal would also eliminate the right of “parental refusal” for parents of children with significant disabilities in need of costly services.

- **NYAIL strongly opposes eliminating provider prevails.**

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.

- **NYAIL opposes extending the Medicaid Global Cap through 2021.**

A focal point of the Medicaid Redesign Team's efforts to limit Medicaid spending growth was the creation of a Medicaid global spending cap. While Medicaid growth may have been constrained as a result, essential programs and services have faced significant cuts in recent years. Last year, the Managed Long-Term Care (MLTC) program was targeted with a number of cuts, such as the nursing home carve-out, aimed at limiting growth to the program at the expense of the lives and liberty of seniors and people with disabilities. Further, there is a home care crisis in many parts of the state due largely to the fact that home care workers earn less now than they could make working at a fast food restaurant. NYAIL and other consumer advocacy groups have put forth proposals that would help advance the state's own Olmstead Plan, but they have failed to be enacted due to spending constraints under the global cap. Meanwhile, many programs are carved out of the global cap, and as a result, receive vastly more funding. But somehow, the services and programs that people with disabilities and seniors rely on to live in the community are all subject to this artificial spending cap. In fact, this year's budget proposes carving in the Nursing Home Transition and Diversion and Traumatic Brain Injury Medicaid waivers, two of the few programs for people with disabilities remaining outside the cap. NYAIL calls on the State to end the global cap!

AGING

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

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

NYAIL is extremely pleased that Governor Cuomo included legislation in his Executive Budget proposal to amend Human Rights Law to add lawful source of income as a protected class and to prohibit housing discrimination on the basis of lawful source of income! This has been a priority for the disability rights community for a decade. This is because there is a housing crisis in New York State for people with disabilities due to the lack of affordable and accessible housing. 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.

NYAIL also applauds Governor Cuomo's proposal to cap security deposits at one month's rent. Charging excessive amounts for security deposits has also stopped New Yorkers with disabilities from obtaining housing which would otherwise meet their needs. New York can go a long way to addressing the crisis by supporting Governor Cuomo's proposals and passing them in the budget!

- **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. 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 vetoed legislation to create a visitability tax credit three years in a row. 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 in the state budget.

VOTING

- **Fund early voting and pass automatic and same day voter registration to make it easier for people with disabilities to vote**

NYAIL applauds the legislature and Governor for the voting reforms that have already been signed into law this year, and supports the additional reforms put forward in the proposed Executive Budget, including automatic and same day voter registration. These critical voting reforms will make it easier for everyone to participate in the voting process. However, NYAIL maintains that accessibility for voters with disabilities must be prioritized in all of these reforms. Further, funding for early voting must be included in this year's budget to provide counties with the necessary funding to implement early voting this November.

EMPLOYMENT

- **Establish a small business tax credit for employing people with disabilities.**

There is a dire need to address the extremely high rates of unemployment and poverty among people with disabilities. Governor Cuomo recognized this when he issued Executive Order 136, establishing an Employment First Commission. Included in the Employment First report was a recommendation to create a cross disability tax credit. Legislation which would have established such a tax credit for small businesses was passed by the legislature last session, but the legislation was vetoed. Aside from some technical issues, the administration expressed overall support for the proposal in the veto message, but said it needed to be handled during budget negotiations. And while the proposed budget extends a tax credit for people with developmental disabilities, this broader, cross-disability tax credit aimed at small businesses was not included. This tax credit would provide a real incentive for small businesses to take a chance and hire people with disabilities.

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