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The Honorable Kathy Hochul  
Governor of New York  
NYS State Capitol  
Albany, NY 12224  
Sent via email

RE: Independent Living Community's 2023 budget priorities

Dear Governor Hochul,

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 regarding our top Executive Budget priorities for SFY 2023-24. New York State can be a champion for the rights and independence of people with disabilities by including the below priorities in the Executive Budget, all of which would help advance the State's integration efforts for people with disabilities.

The dangers of institutionalizing people remain ever present following the pandemic which brought them to light. Our community and partners in advocacy continue to encourage systemic reforms in an antiquated system of care that is long overdue for reform. We are seeking your support in addressing access to community-based long-term supports and services (LTSS), which enable people to make the choice to live independently in the community with adequate supports for those who may need them. We are encouraged by the efforts made so far to create an Office of the Chief Disability Officer, an initial investment in increased wages for home care workers, and efforts within state government to partner with our community and membership. We are seeking investment in the following priorities to address our ongoing concerns for older adults and people with disabilities that are living in the community, the many that would like to return home, and those who will be facing challenges if we do not act on making the following investments.

- **Increase base funding for Independent Living Centers (ILCs) to \$18 million in SFY 2023-24 as supported by the State Education Department and Board of Regents.**

Independent Living Centers (ILCs) provide critical services to people with disabilities designed to assist them in navigating the ever-changing service system in order to live independent, fully integrated lives in the community. ILCs provide a wide range of critical services based on local needs, all of which are aimed at addressing the social determinants of health: education, employment, housing, transportation, and other independent living skills. ILCs also employ many people with disabilities statewide and help to elevate them to positions of leadership and governance within the centers. Increased ILC funding will help continue to build future leaders and the workforce of people with disabilities.

ILCs adapted quickly in the early weeks of the pandemic to help meet the needs of people with disabilities in their local communities by providing accessible and culturally competent assistance. Maintaining investment in this response network is essential in being prepared for future events that disproportionately impact those that we serve. Serving new populations experiencing independent living challenges can only be accomplished with renewed levels of investment, like assisting those with long term post-COVID disabilities and older adults who overwhelmingly want to age at home.

ILCs have been underfunded while the cost of providing services has increased dramatically, creating a crisis for centers and the people with disabilities they serve. We are calling on this administration to correct a history of inadequate support to the network of Independent Living Centers so they can meet the needs of people with disabilities they serve annually by increasing their funding to \$18 million.

- **Address the home care crisis by increasing wages for home care workers to 150% of the State's minimum wage, as outlined in the Fair Pay for Home Care Act.**

There has long been an aide shortage in parts of the State, making it difficult for people to obtain home care. However, over the past few years, this crisis has worsened to the point where it is an acute crisis in all parts of the State from Long Island to Buffalo. The home care crisis has surpassed the lack of accessible housing as the primary barrier to transitioning people back home. The State has an obligation under the Supreme Court decision, *Olmstead v. L.C.*, to provide disabled people with supports and services in the most integrated setting, their home communities. Yet the lack of available home care is making this an impossibility for many.

We acknowledge and appreciate the three-dollar wage increase included in last year's Budget but know it will not adequately address the ongoing home care crisis. This work has historically been undervalued by society while the workforce is primarily composed of women and people of color. Other segments of the care workforce already receive higher wages and better benefits from the State while still not being able to adequately fill openings. The stagnant wages which led to this home care crisis are continuing to effectively fall among larger economic pressures and getting people essential care must be structured to account for these changes. In 2006, home care workers earned 150% of minimum wage, a time when people were more readily able to access the hours they were approved for, saving the State money as an alternative to more costly institutional care.

The Fair Pay for Home Care Act would effectively address this crisis permanently, ensuring older adults and people with disabilities are able to obtain home care, while the people who provide their services can get paid a living wage. It would also ensure the providers paying home care workers would get adequately reimbursed, which has been a challenge with last year's increase. NYAIL joins with others in the Caring Majority calling for Fair Pay for Home Care to be included in the Executive Budget and highlighted in the State of the State address.

- **Repeal cuts to eligibility for Medicaid proposed by the Medicaid Redesign Team (MRT) II which makes it more difficult for people to receive vital community-based long-term supports and services (LTSS).**

The Medicaid Redesign Team (MRT) was directed to advance policies that would achieve Medicaid savings without impacting access to services. Yet, multiple proposals were advanced through this process which would make it much more difficult for certain people to receive community based LTSS. In particular, the State raised the eligibility threshold for qualifying for LTSS. Now, people must

require assistance with physical maneuvering with at least three activities of daily living (ADLs) to qualify, or they must have a dementia or Alzheimer's diagnosis and be assessed as requiring supervision for at least two ADLs. This effectively eliminates level I home care, which provided many people with vital assistance with activities such as cooking and cleaning (also known as Instrumental Activities of Daily Living, or IADLs) to remain in their homes, but who did not require assistance with ADLs. It also sets up a discriminatory eligibility standard which bases eligibility in part on diagnosis. This policy, if enacted, would put many people at risk of injury and hospitalization and institutionalization. NYAIL urges the State to repeal this policy in the proposed Executive Budget, as laid out in A.5367 / S.5028.

- **Expand eligibility for New York's Medicaid Buy-In program by eliminating age and asset limits to support the employment of people with disabilities.**

New York's Medicaid Buy-In program allows people with disabilities to maintain coverage for Medicaid while they work part-time or full-time. This is essential for people that depend on Medicaid to maintain independence with support services and would be unable to work without this program.

Unfortunately, the Buy-In program is only available to people with disabilities until they reach age 65. Once a working person with a disability turns age 65, they become unable to maintain Medicaid eligibility through the Buy-In program due to federal regulations within Social Security law. We ask that New York State lead the nation in providing state funded support through the Medicaid program so people with disabilities can continue to work and are not forced to close their businesses or end their careers prematurely. People with and without disabilities are continuing to extend their working years and removing this arbitrary age limit in the Medicaid program will help New Yorkers age in place and continue contributing to their community.

New York's Medicaid Buy-in program eligibility is also asset limited to \$20,000 for a household of one and \$30,000 for a household of two. There are limited exclusions for a home and vehicle. We believe that New York should follow the lead of other states in eliminating the asset limit for the Buy-In program so people with disabilities can fully enjoy the benefits of building wealth through their working years. By eliminating asset limits there is no longer a fear for people with disabilities that they will lose benefits because they choose to work. There are additional benefits of reducing the work and paperwork required to qualify and review individuals while also eliminating the penalty of a household of two people with disabilities living together. Other states have either eliminated asset limits entirely or have much higher asset limits. We ask that New York be a leader in disability employment by eliminating the asset limit for the Medicaid Buy-In program.

- **Increase the State's share of funding for the Long-Term Care Ombudsman program to \$15 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. We saw during the pandemic the need to expand this program to ensure people can access an ombudsman when needed. The State must increase its share of funding to adequately serve the State's population of people in long-term care facilities.

The LTCOP receives federal funding, but it is insufficient to provide adequate services in New York State. Despite this, New York's match is one of the lowest in the nation, leaving providers overly reliant on volunteers. This has become a huge problem as it has become increasingly difficult to

recruit volunteers for the program and it is crucial the program have a presence in facilities across the State. To address this crisis, we urge the State to increase funding to \$15 million. This amount would provide adequate program coverage for every facility in New York State.

- **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, it 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. We urge the State to increase HCR funding to \$10 million for this program, because by investing in Access to Home, older adults and people with disabilities around the State will remain in their home and out of institutions, and the State will more than recoup this investment in other State agency expenditure reductions.

We would welcome the opportunity to meet with you and discuss the above concerns.

Sincerely,



Lindsay A. Miller  
Executive Director

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