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October 7, 2019

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

RE: Independent Living Community's 2020 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 2020-21. New York State can be a champion for the rights and independence of people with disabilities by advancing the below priorities, all of which would help advance the State's Olmstead Plan.

Funding for the below priorities can be allocated from savings to the State 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 2020-21 as recommended 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 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. We are calling on this administration to provide necessary support to the network of Independent Living Centers so they can meet the needs of the over 100,000 people with disabilities they serve by including a \$5 million increase to the network of Independent Living Centers.

- Ensure access to home care, personal care and consumer directed personal assistance for all who need it by:
  - **Addressing the home care crisis by paying home care workers a living wage.** 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.
  - **Providing adequate administrative reimbursement to Fiscal Intermediaries under CDPA.** The Consumer Directed Personal Assistance Program (CDPA) empowers people with disabilities to have full control over their lives and independence by putting the individual in charge of when, how, and by whom their services are provided. CDPA has also often served many people who were not able to be served by traditional home care providers. Yet, the new formula for the administrative rate paid to Fiscal Intermediaries is far below what it costs to provide those services, putting the entire program at grave risk. We are already hearing that FIs are either closing or not accepting any new consumers, leaving counties without CDPA. This budget is an opportunity to work with FIs to develop a rate that achieves savings to the State while still providing a reimbursement that covers the cost to run the program. This is essential to ensure CDPA is an available option to eligible people who need it.
- Preserve and expand consumer assistance programs to ensure the provision of a full range of consumer assistance and advocacy including representation at fair hearings:
  - **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, leaving providers overly reliant on volunteers. The State must increase its share of funding to adequately serve the State's population of people in long-term care facilities.
  - **Increase funding for Consumer Health Advocates (CHA) by \$1.1 million to ensure representation at fair hearings is available.** The CHA program assists New Yorkers, including many people with disabilities, to navigate the complex and ever changing health care system. Both the newly covered and those who have been covered for years need help understanding insurance concepts like deductibles, co-payments, co-insurance, maximum out-of-pocket costs; and filing complaints and appealing plan decisions. Further, there is a real need for CHA to begin doing fair

hearings now that ICAN is no longer permitted to do them. Additional funding is necessary to ensure CHA has the resources to address these unmet needs.

- **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. Investing in Access To Home will help seniors and people with disabilities around the State to remain in their home and out of institutions.
- 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 are doing anything to actually implement these recommendations. As per the report, the TNCs were directed to spend this 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, we are not aware of any of the centers hearing from either company on forming 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. The Office for the Advocate would be an ideal location for such an office.

Finally, the legislature passed three bills this year which we strongly support and would advance the rights and independence of New Yorkers with disabilities. While all three of these bills would have a fiscal impact, the funding would be minimal. We call on Governor Cuomo to sign these bills into law and to allocate any associated funding in the proposed Executive budget.

- **Reactivate the Office for the Advocate for People with Disabilities A.4737 (Steck) / S.1674 (Skoufis).** First created by Governor Mario Cuomo through Executive Order 26, the Office for the Advocate 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). No such advocacy currently exists in state government, despite this office being on the books.
- **Establish a small business tax credit for employing people with disabilities A.7475 (Cusick) / S.5545 (Addabbo).** 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. This legislation, which was updated to address technical issues identified in the previously vetoed proposal, would help small businesses and provide a real incentive for hiring people with disabilities. We urge you to sign this legislation and provide the necessary funding in the 2020 budget.
- **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 A.2493 (Lavine) / S.2424 (Kaplan).** 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, capped at a mere \$1 million annually, would help to ensure that people with disabilities and older New Yorkers are able to afford these modifications and remain in their homes.

We would welcome the opportunity to discuss these priorities further. For further information, please feel free to reach out to Meghan Parker, NYAIL's Director of Advocacy at 518-465-4650, or at [mparker@ilny.org](mailto:mparker@ilny.org).

Sincerely,

*Lindsay Miller*  
Executive Director

*Meghan Parker*  
Director of Advocacy

CC: Paul Francis, Deputy Secretary for Health and Human Services  
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