

February 1, 2024

**Testimony to the Joint Legislative Education Budget Hearing
on the 2024-25 Executive Budget proposal and**

FUNDING FOR INDEPENDENT LIVING CENTERS

Thank you for the opportunity to provide testimony on behalf of the New York Association on Independent Living (NYAIL). 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 appreciate the strong support from the Legislature for Independent Living, resulting in an increase in funding of \$2.6 million since 2020, including the first ever increase from the Executive in 2022. After decades of stagnant or reduced funding, this has been very helpful to the center network whose operating expenses have increased exponentially in the same period. Unfortunately, this year's Executive Budget proposes level funding once again for the ILC network. This uphill funding battle is exacerbated by the proposal to provide a 1.5% cost of living increase to human service agencies which **does not** include Independent Living Centers due to our location in the State Education budget. We continue to urge the state to increase the total funding line to \$18 million and to ensure a statutory cost-of-living adjustment to ensure funding keeps pace with the ever-rising cost of doing business. This addition of just \$2 million would be divided among the 41 centers statewide.

Independent Living Centers are the only statewide network of disability-led organizations. We provide critically important services which help Disabled New Yorkers to navigate the ever-changing service system to live independently in the community. The ILC network has been historically underfunded while the cost of providing services has increased dramatically, creating a crisis for centers and the people with disabilities they serve. ILCs were not included in the 2023-24 state budget 4% Cost of Living Adjustment (COLA) given to other human service organizations, which amounts to a de facto cut in funding. Centers, with level funding, will be forced to cut services and staff positions in order to cover the rising costs from rapidly rising inflation and expectations for increased wages. This will ultimately lead to fewer services and programs for people with disabilities who need them most. Maintaining investment in ILCs is essential to being prepared for events like COVID resurgence or a declining economic outlook which disproportionately impacts the consumers 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. In addition,

ILCs also employ many people with disabilities statewide and help to elevate them to leadership positions and governance within the centers. They work with businesses to understand their responsibilities to hire and support employees with disabilities. Increased ILC funding will help continue to build future leaders and the workforce of people with disabilities, supporting the Administration's efforts to make New York State a model employer and increase employment rates within the disability community.

ILCs exist to ensure people with disabilities have a chance at participating in community living and have assistance in removing communication, structural and attitudinal barriers in all parts of New York State. The New York State Education Department website describes Independent Living as, "...controlling and directing your own life. It means taking risks and being allowed to succeed and fail on your own terms. It means participating in community life and pursuing activities of your own choosing. Independent Living is knowing what choices are available, selecting what is right for you, and taking responsibility for your own actions." Our ILCs facilitate Independent Living, engaging in education every day to help people learn and grow as individuals, across the spectrums of disability and age.

We have services touching all points in a person's life. Our centers see people return as they need assistance with new challenges. For younger people with disabilities, we provide help to transition from school to employment, which is now one of the core services provided to communities that needs investment. Parents of a child with a disability will contact our centers overwhelmed when faced with the challenges presented to them by complicated systems that are not always designed to accommodate differences. We always do our best to help with addressing the root causes and connecting the right pieces. With youth, time is crucial in addressing issues early to prevent devastating impacts down the line.

During the COVID-19 pandemic Independent Living Centers helped form the first line of defense for people with disabilities both in the community and in institutions. [Click here to view our flier highlighting some of this work done by ILCs](https://ilny.us/covid-response) (or visit <https://ilny.us/covid-response>). Despite being chronically underfunded, ILCs were able to quickly pivot their services to meet the new needs. We immediately shifted focus to individuals who we had transitioned to the community to make sure their needs were being met. Given that many food programs were closing or under tremendous demand, our ILCs provided doorstep drop offs of food, medical supplies, DME, PPE, cleaning supplies and even provided iPads to residents in nearby nursing facilities, as well as to consumers in the community who had no internet service or equipment.

In rural New York, our ILCs brought essential items to residents with disabilities who do not have transportation – food, hygiene items (e.g., toothpaste, soap), and phone cards. ILCs ensured continuation of services remotely by subscribing to a video visit healthcare platform. ILCs did whatever was needed to make sure the individual could remain in their home and not return to a nursing home where infection with COVID was a significant risk. ILCs also continued to serve individuals in nursing homes through whatever remote means were necessary, successfully transitioning over 500 individuals back to the

community in 2020 – comparable numbers to previous years, despite the barrier of not being able to enter nursing homes and meet with individuals and nursing home staff face-to-face.

Pre-pandemic, in 2018/2019, state's network of ILCs provided core ILC services to nearly 117,000 people with disabilities, family members and others; an increase of more than 34,000 in just six years. We know the number served would likely be higher had the IL funding kept up with the capacity needs of centers. In more recent years post-pandemic these numbers have dropped due to funding and program restrictions associated with other IL funding streams, further straining the core operations of ILCs across the state at a time when we know the need in our communities for independent living support has never been greater.

ILCs need to grow to provide for the growth in number of people with disabilities, their families, and friends. Our ILCs are fielding calls from people in dire circumstances seeking hope that there's someone that can help. We want to continue to be there for those who need us. We need to provide faster services for people facing deadlines while in crisis. People call us wanting an appointment as soon as possible because they are losing housing, being discharged from a hospital with a new disability, need help navigating the system to get accommodations for their child, or someone wants to change their life situation and try working while keeping a support system of benefits. ILC staff are experts at helping people navigating the vast systems that can shape their futures. Connecting them to ILC services and coordinating plans with local non-profits, schools, county, state, and federal liaisons to deliver results for people that needed help yesterday but did not know where to turn. ILC staff and the people who have been through the process will tell you it is life changing.

ILCs currently provide a range of critical services, including independent living skills training, peer counseling, individual systems advocacy, information and referral, assistance with housing services, benefits advisement, transitioning from or avoiding unnecessary institutionalization, youth education transition services, transportation assistance, and more. ILCs also assist ACCES-VR meet their mission by providing consumer-driven and community-based wrap around services that complement the Vocational Rehabilitation services provided by ACCES-VR, acting as a dedicated referral source and valuable resource to counselors. The size and scope of these services are ultimately decided by available funding.

New York's Independent Living Centers are asking for the Legislature's support of an additional \$2 million to bring the total funding up to \$18 million. An \$18 million total allocation is long overdue and essential to sustaining independent living services statewide, while also delivering \$45 million in projected annual savings based on current data from the New York State Education Department, ACCES-VR, showing that the work of ILCs to transition and divert people with disabilities from costly institutional placements save the State more than \$9 in institutionalization costs for every state dollar invested in ILCs.

We know a \$18 million total allocation is warranted beyond potential savings to the state given the rising cost of doing business - including the costs associated with general operating expenses, health insurance, workers compensation insurance, basic adjustments caused by inflation, and the need to keep experienced and trained staff members. ILCs are being forced to let staff go —many of whom are people with disabilities because people with disabilities make up the majority of our workforce.

Increasing Independent Living Center funding to \$18 million would enable the 41 State-funded ILCs to maintain staff and expand services determined to be in the greatest need for each individual center. Centers use a disability-led planning process to identify the most pressing needs in their communities which inform the services these centers provide. Through these planning processes, centers have identified pressing needs they do not currently have the funding to offer. For each center the needs of the community may vary, but all communities have unmet needs which the State's network of Independent Living Centers could address with additional funding.

We appreciate your strong support of Independent Living. We hope you will help us to achieve our funding goal and ensure that all New Yorkers have access to essential Independent Living services in their community.

Thank you,

Lindsay Miller
Executive Director