

January 26, 2022

**Testimony to the Joint Legislative Education Budget Hearing
on the 2022-23 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 across New York State. ILCs are cross-disability, locally administered not-for-profit organizations, run by and for people with disabilities.

ILCs exist to ensure that 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 that touch all points in a person's life, and our centers do see people return as they need assistance with new challenges. For younger people with disabilities, we provide help to transition from school to employment, and this is now one of the core services provided to communities and 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, and with youth, time is crucial in addressing issues early to prevent devastating impacts down the line.

Throughout the COVID pandemic the Independent Living Centers have 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 rural residents with disabilities who do not have transportation – food, hygiene items (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.

In 2018/2019, the most recent data available by ACCES-VR, the state’s network of ILCs provided core ILC services to nearly 114,000 people with disabilities, family members and others; an increase of more than 34,000 in just six years. We know that the number served would likely be higher had the IL funding kept up with the capacity needs of centers.

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 that need us. We want 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.

We are thrilled to see a proposed funding line of \$16 million for Independent Living Centers in this year’s Executive budget, an increase of \$2.6 million. This is the first time a Governor has proposed an increase for ILCs in the Executive Budget, undoubtedly

in part a result of the strong legislative support in recent years. While \$2.6 million sounds like a substantial increase to the base funding, it is important to note that there are 41 state funded centers in New York, resulting in approximately \$65,000 per center, barely enough to fund 1 FTE. **New York's Independent Living Centers are asking for the Legislature's support of the Governor's increase of \$2.6 million and requesting 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. The center network is funded at less than it was in 2008, but now with more centers. 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 that 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