

January 28, 2021

**Testimony to the Joint Legislative Education Budget Hearing
on the 2021-22 Executive Budget proposal and the
INDEPENDENT LIVING CENTERS saving lives from COVID-19**

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.

The New York State Education Department website describes Independent Living as, "...controlling and directing your own life." Right now, New York's most at risk of COVID-19 can feel so powerless and giving people more control of their own life is the right way to ensure that people with disabilities and older adults have a chance at participating in community living. They have a local point of access for education and assistance services in removing communication, structural, and attitudinal barriers that have been amplified.

Most years, we emphasize the life enhancing benefits of participating in community life and pursuing activities of your own choosing. This year, we want to also share how ILCs are sustaining and protecting people with disabilities. Independent Living is knowing what choices are available and feel safe to you. Letting you select what is right based on your individual situation and needs. Our ILCs now facilitate all this in-person or remotely, engaging in education every day to help people learn and grow as individuals, across the spectrums of disability and age.

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 \(or visit https://ilny.us/covid-response\)](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. Giving 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 the healthcare platform of a video visit 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. It is of note that the number of people who we were able to transition out of nursing homes due to NYAIL's Money Follows the Person program during this time was comparable to the previous year, despite the barrier of not being able to enter nursing homes and meet with individuals face-to-face. (509 people transitioned in 2019 and 527 people in 2020).

ILCs need to grow to provide for the growth in number of people with disabilities, their families, and friends. Our ILCs regularly field calls from people in dire circumstances seeking hope that there is someone that can help and relate to their circumstances. 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 lives. 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 our request for an increase of \$5 million in the 2020-21 State budget, which has been recommended for several years by both the State Education Department and the Board of Regents. The proposed Executive Budget reduces funding to \$13.361 million for the second year in a row. This is a step backwards from the \$500,000 increase provided by the legislature in the last two state budgets and continues the ongoing trend of over a decade of near level funding. An \$18 million total allocation is long overdue and essential to sustaining independent living services statewide, while also delivering \$45 million in projected 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 and potentially deadly institutional placements save the State more than \$9 in institutionalization costs for every state dollar invested in ILCs.

We know a \$5 million increase 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. An additional \$5 million would enable 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.

In 2019/2020, the state's network of ILCs served nearly 117,930 people with disabilities, family members and others; an increase of more than 37,930 in just seven years. We know that the number served would likely be higher had the IL funding kept up with the capacity needs of centers. If staff is not available as quickly, because of large caseloads, then people will not bother to seek services that could be life changing. In fact, with such inadequate funding, 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.

Independent Living Centers take a peer approach and routinely hire employees with disabilities in many different areas within the organizations. As employers, ILCs offer meaningful job opportunities in a competitive and integrated work environment. A handful of ILC staff with disabilities have worked their way up into leading ILCs as Executive Directors. Adequate funding to Independent Living Centers will continue efforts to provide meaningful job opportunities to people with disabilities in a competitive work environment while providing vital services to communities across New York.

This past year was unlike any other in recent history. ILCs across New York have risen to meet the challenge of serving people during the pandemic with additional COVID related supports on diminished budgets and unexpected technology expenses to continue services. Investing in IL funding by a mere \$5 million in the 2021-22 budget will provide Independent Living Centers the resources to continue crucial work, so individuals with disabilities and older adults have more control of their health and lives because they are fully integrated in their local community.

Thank you,

Lindsay Miller

Lindsay Miller
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