

January 29, 2025

Written Testimony to the Joint Legislative Education Budget Hearing on the 2025-26 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, including a \$750,000 increase in the 2024-25 State budget, which brought the total funding up to \$16.75 million for the network of 41 state-funded ILCs. Unfortunately, the Governor's FY 2026 Budget does not include the \$750,000 add into the ILC base funding, resulting in a funding cut from last year going forward. Worse yet, we were troubled to see there was no reappropriation of the \$750,000 from last year. Given that the ILC contracts run October 1st - September 30th, the funding increase certainly hasn't been spent and would need to be reappropriated, as was most of the \$16 million base funding. The decision to not reappropriate last year's add essentially negates it entirely, as if the Legislature never added it. The Governor's lack of support for independent living in the Education Budget is in stark contrast to the praise she has been heaping on our participation in the Consumer Directed Personal Assistance Program (CDPAP). To that end, it is important to highlight that the health budget includes a \$20 million appropriation for the 11 ILCs that serve as Fiscal Intermediaries in CDPAP to provide transitional support to these organizations given their unique role in the program. We strongly support this distinct funding and consider it necessary to ensuring the ILCs continued role in the program, however it does create a vast disparity in state funding between the CDPAP ILCs and the broader ILC network.

We urge the legislature to ensure last year's funding increase is restored and to make further investments into the network of Independent Living Centers to help us achieve a total funding level of \$25 million. In addition, we must ensure ILCs are included in the statutory human services cost-of-living- adjustment statute moving forward, as proposed in (A.8437/S.7793). This will correct a history of inadequate support and help support the needs of people with disabilities and older adults.

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. A recent funding analysis commissioned by NYAIL demonstrates the impact of inadequate and inequitable funding on the network of ILCs and the people with disabilities we are intended to serve. The analysis showed us that nine counties in NYS are not currently served by ACCES-VR or federal IL funding. In addition, the distribution of Independent Living funds does not account for transportation accessibility, cost of living, unemployment rates or economic vulnerability – critical factors to determining need for IL services. An analysis of the necessary costs to establish and operate an ILC found the recommended total annual operating budget to be \$614,817. This amount is higher than the current base funding for basic operations and services at any of the existing 41 state-funded ILCs. The average funding level at centers is only \$390,000, that translates to a deficit of \$224,817. This deficit demonstrates that adequately funding the existing network to maintain basic operations and core IL services is achievable but will require an investment of \$8.25 million in the state education budget.

Our ongoing uphill funding battle is exacerbated by the fact that the human service costof-living adjustment (COLA) statute does not include Independent Living Centers due to our location in the State Education budget. Due to the persistent and ongoing funding challenges, Centers are often faced with the decision to cut services or staff positions in order to cover the rising costs from rapidly rising inflation and expectations for increased wages. This ultimately leads to fewer services and programs for people with disabilities who need them most. Maintaining investment in ILCs is essential to assisting New Yorkers with disabilities in navigating the ever-changing service system (e.g., Consumer Director Personal Assistance Program (CDPAP) and 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.

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. In more recent years post-pandemic the total served has been approximately 100,000. We know the need in our communities for independent living support has never been greater, and the numbers served would certainly 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 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.

<u>New York's Independent Living Centers are asking for the Legislature's support of an</u> <u>additional \$8.25 million to bring the total funding up to \$25 million</u>. A \$25 million total allocation is long overdue and essential to sustaining independent living services statewide, while also delivering significant savings to the State. Data from the New York State Education Department, ACCES-VR, shows that the work of ILCs to transition and divert people with disabilities from costly institutional placements <u>save the State more</u> than \$9 in institutionalization costs for every state dollar invested in ILCs.

We know a \$25 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 \$25 million would enable the 41 Statefunded 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