

Testimony to Assembly Ways and Means
and
Senate Finance Committees
Joint Legislative Budget Hearing on Health/Medicaid

February 28, 2023

Thank you for the opportunity to submit this testimony on behalf of Independence Care System and the Civic League for Disability Rights. This testimony is being submitted by Regina M. Estela, President and CEO for Independence Care System (ICS), the first and only Health Home for People with Physical Disabilities in New York State and by Sharifa Abu-Hamda and Marcus Johnson, Co-Directors of the Civic League for Disability Rights (CLDR). CLDR is a group of New Yorkers with disabilities advocating for equal access and justice for people with disabilities.

It is well-established that people with physical disabilities suffer the consequences of fragmented, complex health systems. They live shorter lives because they have unequal access to health care services and support than their non-disabled peers.

People with disabilities have turned to ICS for more than 20 years because of our expert, disability-competent staff, who help them improve their health and avoid hospitalizations, achieve goals, improve their quality of life, and be active members of the community. Our foundational pillars —health, mobility, and independence — support health equity for people with disabilities so they can thrive while receiving the quality care they deserve. We represent over 2,000 adults with disabilities living in Manhattan, Bronx, Brooklyn, and Queens. All our members are Medicaid recipients; more than half are people of color, women, and wheelchair users.

The Governor’s proposed budget devastates the community of adults with physical disabilities. Guaranteed a right to live in the community by the Olmsted decision in 1999, this budget significantly undermines the supports needed by the community of people with disabilities to live the full lives they desire.

The Governor’s budget proposal is particularly harmful to the Health Home program using her proposal to “Recalibrate the Health Home Program to Improve Care Management for Vulnerable Populations” For our population, the proposition that people should be stabilized and “graduated” to another care model is simply impossible. People with physical disabilities have permanent conditions that do not improve over time.

This approach is rash and dangerous for our members and leaves our organization in a precarious financial position because we serve a population with unique needs and high costs that are forced to navigate a health care and social service delivery system that is complex. This proposal would again threaten the ability of consumers with high costs and high needs to live at home in their communities and threaten the knowledge and expertise we have built up over 20 years to support people with physical disabilities.

The Health Home program has successfully garnered significant cost savings by reducing hospitalizations and Emergency Department use. We are punished for our success with this proposal suggesting our members are better served with short-term, fragmented interventions. Our staff was also denied the cost of living increase granted to other programs. We support the request of the New York State Health Home Coalition that the Governor amends her Cost of Living increase proposal to include the Health Home staff for an 8.5% cost of living increase.

For the past five years, New York State's plan for people with disabilities seems to be to eliminate specialized, community based, member-centered services while simultaneously promoting person-centered care and health equity.

A 2022 report from NYLAG (New York State Managed Long-Term Care: Data Transparency Project) showed that "A relationship between high-hour care and high Medical Loss Ratio is apparent. Of the four plans with MLR's above 100%, meaning that they spent more than 100% of their revenue on services, three (Guildnet, United Healthcare and Independence Care System (ICS)) provided relatively high hours of home care services (PCS and CDPAP) to more members, and less nursing home care, than many other plans. This means they were serving more high-need members in their homes rather than in nursing homes, helping the state meet the federal goals of rebalancing long term care. **Instead of being rewarded, they were forced to close.**" The closure of ICS's MLTC Plan and the other plans named here left a huge gap in the MLTC program's ability to meet the needs of people with physical disabilities who need high-hour care to remain independent in the community.

This year's original 1115 Waiver proposal was submitted without mentioning people with physical disabilities. It was only when advocates called attention to the omission that people with physical disabilities were included.

New York State cannot address health equity without addressing disability. Disability appears in every population and is overrepresented in people of color, women, and people who are poor. **It is past time that we recognize that this is a population with unique needs that cannot be served in the general population.**

The Governor's budget proposal suggests that people in Health Homes can get their care elsewhere after graduation. This is a costly and dangerous assumption. Thirty-one years after the Americans with Disabilities Act, our members still struggle to find primary care providers with an accessible scale, a table that can go up and down to facilitate a transfer, and a provider well-versed in the needs of people with physical disabilities. A recent study showed that over 70 percent of wheelchair users were examined in their chairs, and only 41% of physicians surveyed reported feeling "very confident" about their ability to provide the same

quality of care to people with disabilities as those without disability and more than 36% of survey participants reported knowing little or nothing about their legal requirements under the ADA. **There is no place to send an adult with physical disabilities after graduation**, and the system does not have a place for our members.

Added to this issue are the continued attacks on the systems supporting people with disabilities. The Governor's proposal eliminates a raise for home care workers and parity for consumer-directed aides. Both these moves will make it harder for people with disabilities to secure workers to remain in the community. Recent changes to the assessment requirements to get services in an MLTC means newly disabled people cannot ensure the services they need in a timely fashion.

The only increases in the budget are directed toward nursing homes, assisted living facilities, and hospitals. **With her budget proposal, the Governor demonstrates a bias toward institutional care instead of community based services that allow New Yorkers with disabilities to live at home and in their communities.**

While there were nods to the disability community in the Medicaid income eligibility expansion for people with disabilities and older adults, raising their eligibility from 84% of the Federal poverty level to 138%, the same as the level for other adults we have seen this change negatively impact our members as they scramble to understand the implications of the change on their other supports like food stamps and housing. This requires disability expert care coordination to support our members in balancing out their long-term supports, income, and financial needs.

We applaud the Governor for including the expansion of the Medicaid Buy-In for Working People with Disabilities (MBI-WPD) in this year's proposed budget. The MBI-WPD has been a godsend for many of our members and staff. It allows people to work, earn a competitive wage, and maintain the Medicaid-funded supports that facilitate living in the community. However, without specialized care coordination and disability-competent providers, many people with disabilities do not have the time to work as they spend hours and hours appealing service denials, waiting 90 days or more for wheelchair repairs, or fighting for the quality and quantity of supplies that they already know work for them.

The time to build a disability-competent care model for adults with physical disabilities is past due. We urge this committee to question the wisdom of the proposed graduation policy and urge the Governor to rethink this misguided policy for Health Homes. It is a bad policy that will put our members and organization at risk.

We see the state's application for the 1115 Waiver as an opportunity to build a care system for adults with physical disabilities that: invests in preventative care, addresses the unique needs of people with physical disabilities, establishes a rate based on quality measures specific to this population, builds a network of disability expert care providers all while improving health outcomes, quality of life and preventing costly hospitalizations and Emergency Department use.

We are ready to roll up our sleeves and do the work. We hope the Governor will rethink her budget proposal to fulfill the promise of the Olmstead decision and build a disability-competent, inclusive program that includes the voices of people with disabilities, addresses health equity, and improves the lives of New Yorkers with disabilities.

Sincerely,

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