



Center for Disability Rights

Testimony for Joint Legislative Public Hearing on 2021 Executive Budget Proposal: Topic Health/Medicaid

My name is Gregg Beratan and I am The Director of Advocacy at the Center for Disability Rights. I would like to thank you for the opportunity to testify today concerning the Executive Budget Proposal for the FY 2021-2022 Health and Medicaid Budget. The Center for Disability Rights (CDR) is a disability led, not-for-profit organization headquartered in Rochester, New York. CDR advocates for the full integration, independence, and civil rights of people with disabilities. CDR provides services to people with disabilities and seniors within the framework of an Independent Living Model, which promotes independence of people with all types of disabilities, enabling choice in living setting, full access to the community, and control of their life. CDR works for national, state, and local systemic change to advance the rights of people with disabilities by supporting direct action, coalition building, community organizing, policy analysis, litigation, training for advocates, and community education.

Proposed Budget Treats Disabled People as Acceptable Losses and Does Nothing to Prevent Future Tragedies!

We are still in the middle of a Pandemic which has hit the Disability Community particularly hard. Recently updated numbers now show that more than 15,000 nursing facility residents have died from COVID-19. Unfortunately, the approach to “Winning the war on COVID” laid out in the Executive Budget proposal can be boiled down to “Vaccination” and “Economic Recovery.” There is nothing wrong with either of these being a part of the Governor’s plan; both will be needed but they do little to prevent future loss of life, and there are still other indications that all of wrong lessons have been learned.

The Nursing Home Model is Beyond Repair

The state must end its reliance on the deeply flawed nursing home model. The Cuomo administration’s reporting of COVID-19 nursing facility deaths has consistently been taken to task for its flawed and incomplete data, which excludes nursing facility residents who were taken to the hospital and died. Following a report from the State Attorney General highlighting the inaccuracy of the State’s reporting, the NYS Department of Health quickly updated the number of COVID fatalities in nursing facilities from about 8,000 to nearly than 13,000 (The number is now estimated at more than 15,000). Historically, New York has had about 100,000 residents in our nursing facilities, which means over the last year, roughly **one of every seven nursing facility residents in New York has died from COVID-19.**

This is a broken system that – even before the pandemic – shortened people’s lives. Disability rights advocates have long known that Home and Community-Based Services (HCBS), which allow people to age in place and stay active in their communities, are safer and healthier than institutional placement. The pandemic has now provided the evidence to prove thisⁱ.

Researchers compared the infection and death rates of people in Connecticut nursing facilities to those receiving services in the community, and demonstrated that people receiving HCBS were 11 times less likely to get infected with COVID-19 and die than their nursing facility counterparts. Although some may assume that the COVID-19 deaths in nursing facilities and other institutions were unavoidable or exacerbated because people in institutions are “sick” and “frail,” the research told a different story. The researchers found that – after infection – the death rates in the community and in the nursing facilities were comparable, which means the nursing facility residents were not, in fact, more “frail” than their peers in the community. In summarizing their findings, the researchers noted that “the main distinction between groups was their living situation. It is likely that living in the community, versus a congregate setting, accounts for the significantly lower infection rates.”

Throughout the pandemic, disability rights advocates have desperately tried to persuade the Governor to leverage HCBS as a way to allow residents to leave institutions and save their lives.ⁱⁱ For nearly a year, Governor Cuomo and his administration have stonewalled these advocates. The Governor does so again in his Executive Budget. Instead of expanding the availability of HCBS, which has withered under Medicaid Redesign and implementation of managed care, Governor Cuomo focuses on “Enhancing the Nursing Home Quality of Care.”

He is operating under the assumption that nursing facilities can be fixed through a series of regulatory and administrative changes. They cannot. The model on which they are built, one in which disabled people are warehoused in congregate settings requiring minimal supports and cut off from the community, has always been flawed. Not only is this what people do not want for themselves – as all evidence points to people wanting to age in place, in their communities – this model is now being recognized as an enormous threat to public safety in the midst of a pandemic. The spread of the virus in nursing facilities and Black, Indigenous, and People of Color (BIPOC) communities are connected with the virus spreading among nursing facility residents, and then out into BIPOC communities by the facilities’ workers.

Even with a vaccine, it is understood that the virus will continue to mutate and new strains will break out. It is reasonable to assume that nursing facility residents, other institutionalized individuals, and communities of color will continue to bear the brunt of future outbreaks. State policy makers must ask themselves how many more elderly and Disabled New Yorkers must die before our State recognizes that it must reduce its reliance on institutionalization.

In 2012, Governor Cuomo established an Olmstead Cabinet and produced a plan (released in 2013) for the State to integrate people with disabilities into the community. Although disability rights groups were allowed to provide feedback on the plan, most felt it fell short, but believed that “something was better than nothing.” Since publication of the plan, community members of the Most Integrated Setting Coordinating Council have continually sought information on the

State's progress. During the pandemic, they finally got information, showing that the Cuomo administration had failed to meet even their own limited goals. The State's greatest failure was in its efforts to reduce the State's reliance on nursing facilities and transition nursing facility residents into the community. Representatives of the State agency responsible for addressing this goal – the New York State Department of Health – and the Governor's office have steadfastly refused to meet with the Disability Community on this issue.

Even so, there are models that work. The single best weapon we have currently at our disposal to get people out of nursing facilities and into the community is the 'Money Follows the Person' program, which operates in New York as the 'Open Doors' project. 'Open Doors' is administered across the State by the New York Association on Independent Living in partnership with our State's Independent Living Centers. Over the last year, despite the COVID-19 pandemic, the program has helped more than 500 New Yorkers return to the community. At CDR alone the program has been able to transition 126 people into the community.

Although this model is successful, due to funding limitations 'Open Doors' has not yet come close to meeting the needs in the State. There are many more people across the State who could be safe in their own homes if the program had greater capacity. The number of transitions we saw during the past year could easily be doubled with adequate funding – increasing funding of the program by \$2.25 million per year.

The failure of the State to comply with the Supreme Court's Olmstead decision and implement an effectively working plan to transition people with disabilities into the community – on its own – is reason enough to take action. However, in the age of COVID-19 and the massive loss of life associated within New York State nursing facilities and other institutions, addressing this is even more of a moral imperative. *The Center for Disability Rights calls on the legislature to increase Open Doors funding by \$2.25 million to double the program's capacity.*

Funds exist to do this critical work. New York State has historically spent \$7 billion on nursing facility placement of about 100,000 people. CDR estimates that the deaths of 13 percent of nursing facility residents will reduce Medicaid spending by over \$900 million, with State share approaching a half-billion dollars. Instead of treating these deaths as a budgetary windfall, hidden somewhere in the Executive Budget, the State should be investing these funds into community reintegration efforts – particularly those that target nursing facility residents.

CDR recognizes that there are far too many groups that benefit from the continued institutionalization of Disabled New Yorkers, including those that own and operate these facilities, managed care organizations, and the unions that represent institutional workers. It will be imperative that the State not allow these voices to continue to drown out the voices of the Disability Community, who have been trying to address the injustice of institutionalization for over three decades. The State simply cannot treat the deaths of Disabled New Yorkers as acceptable losses in the Governor's War on COVID.

Address the Workforce Crisis in Home Care

One of the most significant barriers to reducing our reliance on nursing facilities is the crisis level workforce shortage in home care. This is not news to this legislature, two years ago Rates in these programs which have stagnated for a decade or more, combined with the increase in the State's minimum wage, have created an absolute crisis. A decade ago, programs like Consumer Directed Personal Assistance (CDPA) were able to pay wages that were considerably higher than minimum wage. They were able to attract a quality workforce to provide the services and supports Disabled New Yorkers need to live in the community. Today, those workers are being paid minimum wage, and there is little incentive for them to continue in this line of work when they could make the same money – or in some instances, better money – in other jobs.

As an example, the State requires that fast food workers receive higher wages than individuals serving elderly and Disabled New Yorkers. In July, the State will require that fast food workers in upstate New York be paid \$15 an hour; in comparison, personal assistants providing Consumer Directed Personal Assistance Services will only get paid \$12.50 an hour. Although they may do complex health-related tasks, typically only done by nurses, which allow elderly and Disabled New Yorkers to live in the community, these workers will receive \$2.50 an hour LESS than the person taking your order at McDonalds.

Instead of increasing funds for home care, the Executive Budget proposes to extend the elimination of Medicaid inflation factors for home care and personal care providers for two more years. *It also cuts the workforce retention and recruitment fund by 50%. This follows on last year's 25% cut.* The Executive Budget does include \$2 billion in funding to cover the cost of required minimum wage increases for Medicaid-funded services provided by home care agencies, nursing facilities, hospices, hospitals and other providers reimbursed through the Department of Health. This underscores how the Governor's Budget locks these workers into minimum wage by State policy, rather than investing in our workforce. *As a starting point, we urge the legislature to restore the inflation factors and reverse both worker retention and recruitment cuts* at a time when we need every tool to fight the war on COVID-19 and save the lives of elderly and Disabled New Yorkers.

Despite the deliberate stagnation of home care wages for more than a decade, the State has continued to increase wages for direct care workers in other State agencies which has further eroded the workforce that keeps (and gets) elderly and Disabled New Yorkers out of death-trap nursing facilities. It is imperative that the legislature realize that efforts to fund direct care workers have not helped home care workers – the majority of whom are Black women and other women of color.

Like healthcare workers, the people providing in-home services and supports have put their lives on the line everyday throughout this pandemic, providing a lifeline for elderly and Disabled New Yorkers. Disturbingly, they could have made more money receiving

unemployment payments. The \$600 a week federal payment – alone – was \$128 more each week than upstate home care workers received working 40 hours.

We urge you to recognize how these policies are not only ableist, but also racist, and how State policies have amplified the interlocking systems of ableism and racism. There is no doubt in our minds that if home care workers were typically white men working with people whose lives were seen as intrinsically valuable – instead of mostly black and brown women and immigrants working with our elderly and Disabled – State policy would be very different.

Perpetuating this unacceptable situation may be even more deliberately insidious. Disability advocates are now questioning whether State inaction on this issue has been orchestrated to give the unions fertile ground for organizing these workers. The stagnated wages combined with the consolidation of home care agencies and fiscal intermediaries that provide these services has significantly changed the landscape in favor of organizing efforts. While we support the right of workers to organize, if this is the case, we cannot help but ask how many elderly and Disabled New Yorkers lost their freedom and their lives as collateral damage to such policies. To stop these needless deaths, *CDR calls on the legislature to ensure that all homecare workers are paid no less than 150% of the regional minimum wage.*

Incorporate New York Health with Long Term Care

For New York to truly rebuild after this pandemic, healthcare needs to stop being a weight around people's necks. Our current health care system is a cash cow for the managed care plans, but offers little to the average New Yorker, and even less to Disabled New Yorkers. In the New York Health Single Payer legislation authored by Assemblymember Richard Gottfried and Senator Gustavo Rivera, we have a solution that would provide a real foundation for New Yorkers striving to rebuild their lives after the pandemic. Not only does this legislation provide health coverage for 100% of New Yorkers, it builds in long term services and supports and prioritizes home and community-based services in ways the Governor's abandoned Olmstead plan should have but never did. *We urge the Legislature to incorporate NY Health into the Budget and build the COVID recovery on firm ground in which no New Yorkers have to deal with healthcare uncertainty.*

Medicaid Cuts and The Global Cap = Rationing Healthcare

The proposed Budget reflects a one percent across-the-board reduction to Medicaid payments; however, the Executive Budget indicates that this cut and other cuts would be eliminated if the State receives its full federal funding request of \$15 billion. The Executive Budget also extends the Global Cap through FY 2023. It is grossly inappropriate to maintain the global cap while we are navigating the worst public health crisis in a century. In the current environment, the global cap amounts to rationing

health care, and as we have repeatedly seen, when governments ration health care it is always Disabled individuals who lose out.

We have good reason to fear medical rationing. Members of our community – like Michael Hickson – have been denied lifesaving treatment because his disabled life was not deemed worthy of the resources that would have been needed to save it. Here in New York, Governor Cuomo is being sued to overturn a policy that would allow hospitals to confiscate someone’s respirator if they determine that someone else might benefit from it more. We are also using a standard known as Quality Adjusted Life Years to determine drug pricing and availability. The rationing of medical care is a very real threat to the Disability Community, and the Global Cap only adds to the pressure to limit the use of medical resources. To ensure that New Yorkers are not pitted against each other in some twisted version of ‘The Hunger Games’, *CDR opposes extension of the Global Cap.*

Thank You

I thank you for the opportunity to submit this testimony, if you have questions about anything in this document or our positions on housing, transportation, education, public safety or revenues, please do not hesitate to contact me. I can be reached at:

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ⁱ [https://www.jamda.com/article/S1525-8610\(20\)31050-1/pdf](https://www.jamda.com/article/S1525-8610(20)31050-1/pdf)

ⁱⁱ <https://ilny.us/latest-news/378-disability-advocates-respond-to-governor-cuomo-via-letter-on-covid-19-policies-for-people-with-disabilities-living-in-congregate-settings>