



Center for Disability Rights

Response to Governor Cuomo's FY2022 Executive Budget

February 2, 2021

Disabled New Yorkers are the Acceptable Losses and Collateral Damage in Governor Cuomo's War on COVID

Governor Cuomo spent a considerable amount of time in both his State of the State and his Budget address talking about “winning the war on COVID”. Yet beyond vaccination, he is almost exclusively focused on the economic rather than the human cost of the pandemic.

To be fair, the Governor is trying to develop a State Budget with great uncertainty around the availability of federal funding. Much like the ‘choose your own adventure’ books many of us read as children, the Governor’s Budget is highly dependent on whether the State receives \$6 billion or \$15 billion in federal aid. Still this does not excuse the limited approach the Governor employs in his War on COVID, which 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.

The plan, however, fails entirely in addressing the impact that the COVID-19 pandemic has had on elderly and Disabled New Yorkers who have died in unprecedented numbers. As a State, we can – and need to – do better.

Health/Long Term Services and Supports

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 13,000. Historically, New York has had about 100,000 residents in our nursing facilities, which means over the last year, more than **one of every eight 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.

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 Governor and State legislature to increase Open Doors funding by \$2.25 million to double the program’s capacity.* This, combined with our recommendations to bolster the Olmstead Housing Subsidy and the Rapid Transition Housing program will allow our State to transition 1% of the institutional population each year back into the safety of our communities.

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

Critical to addressing this moral issue is resolving the workforce crisis in home care. 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 Governor's 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 State 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.

The Governor and State legislature must 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 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 Governor Cuomo and legislature to ensure that all homecare workers are paid no less than 150% of the regional minimum wage.*

Reduce State Reliance on Nursing Facilities

With the significant reduction in the nursing facility population, New York State has the opportunity to significantly reduce its reliance on institutionalization in nursing facilities. Instead of repurposing nursing facility beds and potentially creating another pipeline of individuals to be institutionalized, *the New York State Department of Health should reduce the number of authorized beds in these facilities. The facilities that have had the most significant numbers of deaths from COVID-19 should be shut down with their residents given the opportunity and resources to return to community living.* These defunded facilities can then be repurposed, much in the same way the Governor is proposing to repurpose other space that has become vacant due to the pandemic.

Medicaid Cuts and The Global Cap

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.*

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. *We urge the State 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.*

Housing

Expanding Affordable, Integrated, and Accessible Housing

The Disability Community has repeatedly expressed the need for more accessible, affordable, integrated housing. Over the years, considerable resources have gone into supportive housing options, which link services to an individual’s housing; however, options that allow Disabled New Yorkers to live independently in the community have been far more limited. Supportive housing – which requires residents to use the services that come with the housing – is better than institutional placement, but still undermines a Disabled individual’s right to control their daily lives, which continues the insidious nature of institutionalization in a different form.

The State has spent billions on housing programs, while failing to address the needs of elderly and Disabled individuals who want to leave or avoid nursing facility placement. As a result, elderly and Disabled New Yorkers are literally locked away in nursing facilities. This year’s Executive Budget is no different, even as a deadly pandemic has killed more than one in eight nursing facility residents in New York.

Investments in transition programs require similar investment in housing to give elderly and Disabled New Yorkers a viable alternative to a death sentence in a nursing facility. Consequently, CDR calls on the State to expand two key housing programs: the State's Olmstead Housing Subsidy (OHS) and Rapid Transition Housing (RTH) programs. These two programs have shown considerable success in placing people in affordable, accessible, and integrated housing while ensuring both their independence and their well-being. To support the transition of only 1% of the nursing facility population a year, the State would need to invest \$9.6 million in operation of these programs (\$4.4 million for OHS and \$5.2 million for RTH), as well as \$3 million to double the OHS subsidy.

As discussed in the Health section of our analysis, New York State has historically spent \$7 billion on nursing facility placement. The deaths of 13 percent of these residents will likely reduce Medicaid spending by over \$900 million, with State share savings of approximately \$450 million. CDR's recommendation re-invests less than 3% of that back into the housing services to save elderly and Disabled New Yorker's lives.

Access to Home

Access to Home grants make residential units accessible for low- and moderate-income persons with disabilities. These grants, while underfunded, have offered a means for elderly and Disabled New Yorkers to modify their homes, allowing them to either return, or continue, to live in the community. The Governor's Budget maintains the program at \$1 million, but if our State is serious about winning the war on COVID-19 for elderly and Disabled New Yorkers, by giving them the tools needed to leave or avoid institutionalization, the program must be significantly increased to a minimum funding level of \$10 million. The State should also address the inequity in the program eligibility which makes veterans eligible if their income is 120 percent of area median income while non-veterans must have incomes below 80 percent of area median income.

Repurposing Commercial Space for Housing

CDR applauds the Governor's plan to repurpose underutilized hotel properties in New York City for housing. It is a significant step in addressing housing needs in New York City; however, the Governor has not addressed whether this housing will be affordable for, and accessible to, people with disabilities. Projects funded under this initiative must be developed in partnership with disability-led organizations like Independent Living Centers, with at least 10% of the units accessible to people with mobility disabilities and 4% accessible for persons with hearing or visual disabilities. Because Disabled New Yorkers have historically often been priced out of much "affordable" housing, at least 20% of the units funded under this initiative should be affordable to people with disabilities living on Medicaid and other benefits. And finally, none of these projects must require that a Disabled individual receives support services from any specific provider.

Tenant Supports Are Good, But More Still Must Be Done

CDR supports the Governor's efforts to prohibit charges or fees for late rent payments and to provide payment options to tenants facing financial hardship. These protections can be a lifeline, particularly for Disabled New Yorkers. Temporarily allowing tenants to use their security deposit to pay the rent is a limited solution. The State must do more to offer people housing stability.

The Budget allocates \$1.3 billion to protect tenants who are at risk of facing homelessness. We are pleased to see that this includes a hardship fund for undocumented immigrants, but this program is not likely to assist elderly and Disabled New Yorkers who may be forced into nursing facilities because current guidelines do not consider institutional individuals to be homeless. *The State must extend these protections to anyone who is at risk of facing homelessness, explicitly including elderly and Disabled individuals who may be forced into a nursing facility or other institution.*

Education

Independent Living Funding Must Increase

As was mentioned earlier, while COVID was raging through nursing facilities like an unchecked wildfire, the State's Independent Living network – through its New York Open Doors program – has helped more than 500 people find the safety of the community in the last year alone. Our State's Independent Living Centers (ILCs) do much more. This network of disability-led organizations provides members of the Disability Community across the State with individual and systems advocacy services, adaptive equipment, peer supports, housing services, employment supports, youth transition services, and a variety of other supports. Over the last 20 years, the ILCs have saved the New York State more than \$2.5 billion. Even so, the State has continually underfunded these centers.

Last year, the ILC network received a modest \$500,000 increase. This year, the Executive Budget eliminated that increase, bringing the funding level for the entire IL network down to \$13.36 million. At this time when independent living is the best defense against the devastation that has torn through congregate settings, cutting these services makes no sense. *CDR calls on the legislature to restore those funds and increase base funding for ILCs in FY 2022 to \$18 million with the long term goal of increasing the State appropriation to \$25 million.*

Support Deaf Students and Pass LEAD-K

For several years, CDR has worked with a coalition of organizations to pass LEAD-K legislation in New York. LEAD-K stands for Language Equality and Acquisition for Deaf Kids. Deaf children consistently come into the education system behind their non-Deaf peers, and the education system, as it currently exists, only exacerbates these gaps.

All evidence points to language acquisition being central to these disparities, but currently there is little data on language acquisition for kids aged 0-5. LEAD-K legislation gets the data, and puts in place mechanisms to use it to inform the educational system, as they try to craft early intervention and other educational responses.

The Governor is rightly proud of his Excelsior Scholarships. Providing people with the ability to access higher education is something that should be afforded to everyone. Unfortunately, without LEAD-K, Deaf students will continue to graduate on average with a third or fourth grade reading level and will not be able to pass the Regents Exam needed to qualify for the Excelsior Scholarship. We call on the State to include LEAD-K the Budget, and begin to give the Deaf Community the same educational opportunities as afforded New Yorkers who are not Deaf.

Public Safety

The Governor's Crisis Stabilization Centers Solve Nothing

As part of his Budget, the Governor proposes to create behavioral health crisis stabilization centers 'to streamline stabilization and reintegration' of individuals experiencing a mental health crisis. These centers would accept all admissions without referral, including drop-offs by law enforcement and other first responders. There are numerous problems with this proposal. Its reliance on institutional care to 'stabilize' individuals, as well the involvement of police, ignores the prevailing wisdom that community-based responses to mental health crises are not only more effective, but also are far less likely to result in the death or injury of the person in crisis or anyone elseⁱⁱⁱ.

Any involvement by police with people in mental health crisis is a concern to us. By some estimates, more than 50% of fatal police shootings involve Disabled people. The risk of a person with a mental health disability being killed when they are approached by police in the community is 16 times higher than that of a nondisabled person in the same situation^{iv}. These differences are even more extreme when looking at shootings involving Disabled People of Color. Police violence is a problem that has garnered attention nationwide, and institutional racism involved cannot be understated, but the contributing role of ableism is rarely reported. In Rochester, this past year we saw both at work in the violent murder of Daniel Prude. Police involvement in Prude's mental health crisis, and their escalation in response to it, directly led to his death.

If New York State is serious about police reform and addressing mental health crises in ways that do not endanger the lives of those in crisis or others in our community, we must invest in community-based responses to mental health crises. This includes investment in, and utilization of peer supports and interventions in the form of crisis prevention, and warm lines to help de-escalate, and peer led diversion programs aimed at keeping people from being pushed into institutional settings.

Transportation

MTA Accessibility

The highlight for the Disability Community once again is a plan to bring 70 more Metropolitan Transit Authority (MTA) stations into compliance with the ADA. While this is something we can all applaud, it must be noted that this is not a new plan. It was part of last year's Budget.

We hope this means that one day New York City will no longer be home to the most inaccessible mass transit system in the country. This, however, is far from enough. By the Governor's own admission, after these stations are complete, 40% of passengers will still face inaccessible stations. The Americans with Disabilities Act was signed into law nearly 32 years ago and Disabled New Yorkers are still waiting for access. *The Governor must work with the legislature to take all necessary steps to ensure that 100% of MTA services are accessible to people with disabilities.*

Disability Community Still Waits on Access to Transportation Network Companies

Two years ago, the Governor's own taskforce released a series of recommendations for transportation network companies (TNCs) and the State to improve accessibility. These recommendations included creating a body for oversight of the TNCs and offering incentives to the TNCs to add accessible vehicles to their fleets. To date, recommendations have not been implemented and nothing was included in the Executive Budget. *New York State must implement the Taskforce's recommendations to ensure that Disabled New Yorkers are not left behind.*

Invest in and Expand Public Transportation and Paratransit

As TNC's have come into the State, we have seen public transportation use decline and transit authorities attempt to reshape their service area in response to this. This has the potential to devastate the paratransit system, as transit authorities must only provide "comparable" service. If public transportation contracts, so does paratransit. Although ambulatory individuals may make the shift from public transportation to TNCs, Disabled New Yorkers – particularly those who use motorized wheelchairs – do not have that option. Reductions in public transit and, by extension, the paratransit system leave Disabled New Yorkers stranded without access to any transportation. Given the lack of affordable, accessible, integrated housing, it can be impossible for people with disabilities to quickly respond to these changes in transportation systems. Some transit authorities have simply ignored the concerns of their Disabled constituents about this issue. Until another solution can be found, *CDR calls on the State to expand paratransit services by doubling the size of the corridor in the State used to determine where paratransit services must be provided, and funding this expansion of services with a tax on the TNCs.*

Transportation Infrastructure Needs to Go Beyond Basic Accessibility

As part of his State of the State Address and Budget presentation, the Governor announced several multi-billion dollar proposals to add to the transportation infrastructure, including developments of Midtown West, Penn Station, The Port Authority Bus Terminal, and extensions of the Highline. Accessibility must be a priority in all these projects. These projects offer the State an opportunity to go much further than basic access. At times, the Cuomo administration has failed to provide even the most basic level of access for Disabled New Yorkers and needed to be sued, which raises doubts about whether these projects will be accessible. If the Governor truly wants these facilities to be world-class hubs, true Universal Design must be at the center of all of these projects. The State must add a contractual requirement that all of these projects be developed with consultation from disability-led organizations who are experts in accessibility, so they are models of accessibility and inclusion.

Revenue

The Governor has focused a great deal on the State's Budget shortfall. His primary hope is receiving \$15 billion from the federal government. Should this fail, austerity will rule and across-the-board cuts will follow. He also has a very odd proposal seemingly aimed at placating those calling for raising taxes on the ultra-wealthy. He wants to enact a temporary income tax surcharge for high-income taxpayers in which they have the option to prepay three years of their taxes and get it all back in the fourth year. Rather than raising taxes on the wealthy, the Governor is getting what amounts to a loan from them. CDR opposed this short-sighted approach.

To address the State's Budget shortfall and ensure the many programs that Disabled New Yorkers depend on to live their lives in the community are funded, we call on the Governor to incorporate The Invest in Our New York Act – a package of six State bills that raises \$50 billion by ending tax breaks for the wealthiest – into his Budget. This would raise the taxes of billionaires, ultra-millionaires and hedge funds that can afford it rather than realizing a small portion of those saving by cutting the services Disabled New Yorkers need to survive during these deadly times.

About the Center for Disability Rights

The Center for Disability Rights (CDR) is a disability led, not-for-profit organization headquartered in Rochester, New York, with satellite offices in Geneva, Corning, and Albany. 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 the 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.

For more information, contact our Director of Advocacy & Development, Gregg Beratan, at gberatan@cdrnys.org.

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>

ⁱⁱⁱ <https://www.vera.org/behavioral-health-crisis-alternatives>

^{iv} <http://www.treatmentadvocacycenter.org/overlooked-in-the-undercounted>