



Center for Disability Rights, Inc.

A “Progressive” Agenda Without Progress for Disabled New Yorkers

Response to Governor Cuomo’s 2020-2021 State of the State and Budget

February 13, 2020

INTRODUCTION

Each year, the Center for Disability Rights (CDR) analyzes the Governor’s State of the State Agenda and Budget to identify the effect of these proposals on the Disability Community in New York.

In his 2020 State of the State speech, New York Governor Andrew Cuomo gave an accurate and scathing critique of New York State under his own leadership when he said, “Progressive government is competent and effective. It is about results, not rhetoric. It is not merely the articulation of aspirations but rather the actualization of those aspirations.” The Disability Community and the Center for Disability Rights (CDR) have watched year after year as the Governor’s rhetoric soars while his policies stifle the aspirations and lives of disabled New Yorkers. This year is no different; in a State of the State built around the theme of “mak[ing] progress happen,” the Governor painted a picture of progress for everyone *but* the disabled. In doing so, he manages to avoid even referring to 25% of the population.

The Executive budget goes on to further marginalize disabled people by broadly ignoring the chronic barriers and discrimination we face despite the Governor having been informed by organizations like CDR, year after year. When addressing the needs of disabled people is apparently unavoidable, such as discussions of mental health or Medicaid, the Executive budget “others” disabled people, silos us inappropriately by disability type, or treats us as costs to be contained. Cuomo consistently vetoes bills the Disability Community asks the Legislature to pass. At the same time, despite numerous and persistent recommendations from the Disability Community on ways to address ableism and barriers to community integration, the Governor did not include any in his budget.

Below, CDR responds to both the Governor’s State of the State and his budget from the perspective of disability rights.

Healthcare

Blame-Shifting and Denial

Governor Cuomo recently announced a 1% across the board cut to Medicaid service providers. In his State of the State speech, he indicated more cuts were coming. While railing against

counties not paying their fair share of Medicaid costs he announced that another Medicaid redesign would be needed to bring the State's Medicaid spending into check. He said, "We now face federal cuts and must correct for cost increases incurred when local governments were held harmless by the state for Medicaid increases." Our Governor wants us to shift responsibility for the cost of Medicaid to municipalities, but anyone with even a passing understanding of the extreme financial constraints on most local government will know that the only way the counties will be able to pay a higher share is if the overall spending is reduced. *That means further cuts to key services.*

In his budget Briefing Book, Cuomo says that after the State took on more responsibility in paying for Medicaid, "local governments continued to serve in the role of determining eligibility for certain Medicaid programs, though they no longer had to cover the costs of their decision."¹ He is implying that counties are approving Medicaid beneficiaries for services to which they are not eligible. The Governor is blame-shifting - blaming counties for overspending and blaming Medicaid beneficiaries for the cost of services for which they *are eligible*. The Governor refuses to acknowledge that services covered by Medicaid are critical to the people relying on them. We have a Medicaid program because we must ensure that no one, regardless of ability to pay or significance of disability, will go without the healthcare services we need to survive. Disabled people, in particular, depend on Medicaid; it is the largest insurer of long-term services and supports and provides a measure of safety to people impoverished by high healthcare costs, including those whose services and supports go beyond the modest coverage of Medicare. The necessity of a robust Medicaid program is so apparent to the Disability Community that disabled people put our bodies on the line² to preserve Medicaid federally from the "repeal and replace" assault on the Affordable Care Act in 2017. Treating Medicaid spending as a necessity rather than a problem to be solved would actualize our desire for a progressive government, but adequately funding Medicaid is apparently not "progress."

The factors contributing to the increased State Medicaid spending include an increase in the minimum wage, phase-out of enhanced federal funding, and increased enrollment and costs in managed long term services and supports (LTSS). When the Governor used sleight of hand in moving Medicaid payments earlier this year to address spending above the "global Medicaid cap," it became apparent that the State - not local governments - failed to account for known trends that required increased Medicaid spending, such as the increased demand for LTSS. LTSS not only allow disabled people to live our daily lives but also older adults who are acquiring disabilities. The growth of Medicaid in the State happened not because of or anyone's wrongdoing it happened because there was a need. To borrow another line from the Governor's speech "We don't dictate the needs of the State; we can only dictate our response to those needs."

In his briefing book, the Governor inappropriately identifies one particular LTSS benefit as the culprit for increased spending - the Consumer Directed Personal Assistance Program (CDPAP). "Much of [MLTC] spending growth was driven by the increase in use of the Consumer Directed Personal Assistance Program ..."³ CDPAP enables disabled people to exercise control over the

¹ Briefing Book <https://www.budget.ny.gov/pubs/archive/fy21/exec/book/briefingbook.pdf> p. 65

² See <https://www.thenation.com/article/archive/in-the-fight-to-save-healthcare-the-heroes-ride-on-wheelchairs-and-wear-pink/>.

³Briefing Book p. 65

attendant services we receive; CDPAP “consumers” hire, manage and fire our own attendants. The concept of CDPAP was created by disabled people who wanted choice and control over our attendant services. It is a program that aligns with the ideals of the independent living movement to which disabled people have been subscribing since the 1970s. It contributes to the goals of the Supreme Court’s *Olmstead* decision which requires that disabled people be served in the most integrated setting possible. What could be more integrated than services you direct in your own home that allow you to live the life you want? CDPAP also allows elders to “age in place.” In addition to providing choice and control in the community, the CDPAP is a bargain compared to the alternative, as the Governor acknowledged: “[CDPAP] is designed to divert members from high-cost nursing homes and institutional settings to less costly in-home care that keeps them in their communities.”⁴

More Cuts to Come

Not only did the Governor announce a cost-sharing structure that will put more pressure on county government, the Governor reconstituted the Medicaid Redesign Team to find \$2.5B in “savings.”⁵ He directed the MRT II to develop a plan that “has no impact on beneficiaries.”⁶ This directive will prove illusory; even without specific “cuts” to Medicaid, restructuring the program will no doubt impact beneficiaries, and probably for the worse. On major example is the move to managed care. Disabled people in managed care have had to contend with downward pressure and outright cuts to their services, service authorization denials, delays, and more. A more recent example is the move by the State to whittle down the numbers of fiscal intermediaries allowed to operate in the State. Reducing the number of fiscal intermediaries (FIs) will reduce choice and quality available to CDPAP consumers.

The Governor clearly did not learn from the mistakes of the first MRT because those mistakes are being repeated with MRT II. The first mistake is to start from the premise that Medicaid budget issues will be solved by further and deeper cuts and restructuring. Rather, the process should incorporate plans for increased spending and revenue raising to make sure that LTSS are fully funded and account for the continuing growth of the aging population. A second mistake is the composition of the MRT. On the MRT I, Medicaid consumers were represented by only one advocate – not a consumer – out of 27 members. Other members represented Medicaid providers and labor. The MRT II similarly sidelines the perspectives of the very people who use Medicaid to live and includes only one consumer-advocate member, who also happens to represent a provider.

Beyond the Cuts

In his budget address, the Governor said, “every area gets more,” and “more for every program.” This is simply untrue when it comes to the Medicaid budget. What this area of the budget will get more of is institutionalization and death of disabled people for lack of services. We call on the Governor to take a different approach – fully fund the home- and community-based services disabled people require to be active in our communities, with actualized civil rights and independence. The Governor adds insult to injury by making it harder for people who pay for private long-term care insurance to get LTSS. In the State Revenue part of the Executive budget,

⁴ Briefing Book p. 65

⁵ Briefing Book pp. 10-11

⁶ Briefing Book p. 66

the Governor proposed to cap the long-term care insurance tax credit.⁷

Suicide Prevention

Because the Governor specifically mentioned suicide prevention during his State of the State speech, we should touch on it here. Prevention efforts targeting veterans, law enforcement, correction officers, and first responders were mentioned, but not efforts to reach other high-risk populations like the Disability Community. Numerous barriers exist to adequate mental health services and mental health crisis services for disabled people. Disabled people must be considered among those who need increased attention when it comes to mental health services and suicide prevention.

Housing

The Governor's FY 2021 budget includes the final year of a five-year affordable housing plan. This housing plan has promised a total of 100,000 units of affordable housing and 60,000 units of supportive housing. CDR recommends that the next housing plan avoid this bifurcated way of thinking about what type of housing is needed to best serve New Yorkers. Disabled people need affordable, accessible, *and* integrated housing disconnected from services. The stock of units that meet these requirements is insufficient to meet the need, and disabled people remain institutionalized as a result. Publically funded affordable housing includes only a minimum of 2% and 5% accessible units, for people with sensory and physical disabilities, respectively. Supportive housing must similarly provide accessible units, but supportive housing necessarily requires residents to receive services connected with their housing. In reality many New Yorkers simply need housing that is affordable and accessible. Without increasing the percentage of accessible, affordable and integrated housing units, we are not doing enough to meet the need.

Transportation

Fortunately, the Executive budget deigns to contribute to the Metropolitan Transportation Authority (MTA)'s five-year capital plan, which includes plans to make up to 70 subway stations accessible. Meanwhile, the budget neglects to address specific asks of the Disability Community for years – expanding paratransit service area and addressing transportation network company (TNC) inaccessibility. Last year the TNC Accessibility Task Force released its recommendations for both TNCs and the State. These recommendations must be implemented, and yet no action has been taken by either the TNCs or the State. The Task Force recommended the State create an oversight body as well as incentives for TNCs to add accessible vehicles to their fleets.⁸ Neither recommendation was taken up by the Governor.

New E-Scooter Legislation Continues to Ignore Concern about Access Barriers

The Governor did, however, include the legalization of e-scooters in his budget.⁹ He did so without responding to the specific concerns of the Disability Community. E-scooters too easily become access barriers in public right of way, such as when they are parked on sidewalks and block curb cuts and narrow pathways. They also are a safety concern to those of us with sensory disabilities. The Transportation and Economic Development (TED) section of the budget goes as

⁷ Part E.

⁸ See <https://dmv.ny.gov/forms/tncTaskForceFinalReport.pdf>.

⁹ TED AAA.

far as to explicitly prohibit the operation of e-scooters on sidewalks. This is a modest improvement over previous legislation, which would have permitted local governments more power to determine where e-scooters could be used. However, the Disability Community still has good reason to be skeptical that enforcement of the prohibition would be forthcoming. The proposed budget also explicitly allows the parking stopping, or standing of e-scooters on sidewalks. Again, this emphasizes the potential for additional access barriers on public sidewalks.

Education

Independent living centers expected to do more with less for 15 years running

The independent living centers across the State which provide core services to any disabled person needing assistance achieving their independent living goals have been essentially level-funded for fifteen years. Despite a modest increase in funding last year, the Governor's budget this year returns us to preciously levels. This is unsustainable. Not only are center staff overwhelmed by requests for services, not every center has staff dedicated to systemic advocacy or youth transition. More employment specialists and job coaches are needed to achieve the goals of Employment First.

Deaf kids need LEAD-K for their aspirations

The educational needs of Deaf children in New York have been ignored since before even the founding of the State Education Department in 1904. Deaf kids enter school behind their non-Deaf peers in language acquisition and the gap only grows with time. New York collects no data on the language acquisition of Deaf kids, which would be instrumental in addressing the gap. The Governor said "We need funds to raise those at the bottom." Deaf kids are as close to the bottom as anyone. On average, a deaf student finishes school with a third or fourth grade reading level. This impacts students' ability to graduate, let alone with a Regents diploma. The impact is compounded when these students lose out on the opportunity to benefit from the Excelsior scholarship. The Governor's FY 2021 budget seeks to expand eligibility for students based on their families' income¹⁰; deaf students failed by the system will continue to be left behind.

It is long past time the State began working to understand how to fulfill Deaf students' educational needs. The Governor must pass LEAD-K legislation as part of his budget. This vital legislation has already been passed in states as politically diverse as California, Louisiana, Oregon, Georgia, Hawaii and Kansas. A truly progressive government with a concern for the education of Deaf students would have done this long ago. The Governor needs to take action now.

Access to higher education is more than paying tuition costs

The Executive budget proposes to open up the Excelsior scholarship to more families based on income. But more than financial barriers prevent disabled students' access to higher education. As long as schools put students on the path to receive Individualized Education Plan (IEP) diplomas, they are denying students an opportunity for high education. IEPs were intended to create possibilities within education of disabled students, but they are being used to restrict access. General education diplomas (GEDs) and Regents diplomas are accepted forms of

¹⁰ Education, Labor and Family Assistance Part E.

achievement to then be used to apply for higher education programs; IEP diplomas are not. The Governor must enact systemic reform to develop an education system that actively supports disabled students in getting to higher education.

Once they have that opportunity, the SUNY and CUNY systems still desperately need to address their own curricular, programmatic, and physical barriers. Students cannot take benefit from a scholarship if they cannot access all of the campus, including the online education platform. They cannot get the degree the Governor called “essential to optimize one’s talents and opportunities in life” if a professor refuses the accommodation they need to access and pass the curriculum. For disabled students access is not just the cost of tuition, if the state does also ensure access to hardware and software, books in alternative formats such as Braille or audio, and any other accessible modifications disabled students require.

Finally, accessibility must be central to any new construction on New York’s campuses. Approval of any projects requiring funding from State University Construction Fund, City University Construction Fund, and the Dormitory Authority of the State of New York must first demonstrate how the projects will meet the access needs of all University students.

Labor and Employment

In the State of the State speech, Governor Cuomo talked about the on average low unemployment rate and ignored the persistently high unemployment rate among disabled people. The Governor proposed to extend the Hire-A-Vet tax credit for another two years,¹¹ but refuses to support a small business tax credit to hire disabled employees. He also failed to take action to end the practice of paying disabled workers a discriminatory and demeaning subminimum wage. The practice is permitted under federal law using 14© certificates, but States and municipalities can choose to outlaw the practice themselves. It is shameful New York has not yet done the same.

The sole bright spot in the Governor’s budget regarding employment of disabled people is the proposed expansion of access to sick leave for all employees.¹² Without benefits like sick leave, disabled people in particular can struggle to transition into employment. While not intended to benefit disabled people specifically, it is our hope that an expanded sick leave benefit will help disabled workers.

A Note on Equal Protection

Governor Cuomo’s budget proposes to pass an equal rights amendment to the State Constitution that would add sex, sexual orientation, gender identity, ethnicity, national origin, age, and disability to the list of protected classes alongside race, color, creed and religion. CDR supports and appreciates the effort to broaden the protected classes to include disabled people. Unfortunately, the budgets that have been proposed by Governor Cuomo during his administration leave us doubtful that meaningful change and progress for disabled people residing in New York is forthcoming. Increasing access to LTSS, affordable, accessible, and integrated housing, accessible and affordable transportation, education, employment, and the many amenities that this State has to offer nondisabled people can only be achieved by a strong

¹¹ Briefing book 18 <https://www.budget.ny.gov/pubs/archive/fy21/exec/book/briefingbook.pdf>

¹² Education, Labor and Family Assistance Part J.

disability rights agenda. We have yet to see this agenda.

Accessibility of the State of the State speech and Budget presentation

The Governor's office failed to ensure adequate communications access to both presentations, with access during the budget presentation being notably worse than the access provided during the State of the State speech. Both presentations were live-streamed to provide access to New Yorkers wanting to learn more about how the Executive sees the future of our State. Sadly, deaf and hard-of-hearing New Yorkers are denied the opportunity.

Sign language interpretation was provided during the State of the State speech. The presence of one very competent interpreter was critical, as the second interpreter was not as proficient. Meanwhile, the captioning missed words and was noticeably delayed. It is our hope that the Governor's office would make an effort to provide information to American Sign Language (ASL) interpreters so that they are adequately prepared to communicate what is being said. For instance, the interpreters should have been given the names of people the Governor intends to recognize at the start of his speech. An advance outline of the Governor's proposal - even a copy of his slide presentation - would assist interpreters.

The budget presentation failed by not providing ASL interpretation. The captioning, similar to the State of the State speech, lagged noticeably and was not enabled until after several audio announcements had been made at the beginning of the livestream.

Not only is the Governor doing a disservice to the disabled people trying to understand him, it is disrespectful. CDR has commented on the accessibility of these presentations for years, so the Governor has access to adequate feedback on how to improve them.

CONCLUSION

The absence of any progressive budget proposals that would directly support a disability rights agenda is disheartening and unsurprising. The plans for the State Medicaid program are alarming; home- and community-based LTSS must be adequately funded and accessible. Our enjoyment of housing, transportation, education, and employment, our civil rights, and our lives depend on it. It seems that "the ship of New York will sail on" indeed, while disabled people are left behind, likely stranded in an institution.

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 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.