



Center for Disability Rights, Inc.

INTEGRATION, INDEPENDENCE, CIVIL RIGHTS

Center for Disability Rights Response to Governor Hochul's 2024-25 Executive Budget

Each year, the Center for Disability Rights (CDR) reviews and responds to the Executive's Budget. CDR's response focuses on the proposed Executive Budget's impact on Disabled people and, more specifically, how the Budget affects the rights of Disabled New Yorkers and the ability of people with disabilities to live independently in the community.

Governor Hochul's third Executive Budget signals that Disabled New Yorkers are an important part of New York; however, in many ways, this year's budget does not go far enough to expand the services and supports we – as Disabled New Yorkers – need. In a difficult budget year, the Executive Budget has proposals to applaud, such as making efforts to tackle the mental health crisis, providing funding to protect those covered by the Justice Center and other vulnerable New Yorkers, providing funding for special education, and addressing unemployment among disabled individuals. Additionally, we recognized that Governor Hochul understands the need to ensure that people with disabilities receive services in the most integrated setting and has allocated funding to develop an Olmstead plan. This funding is a significant commitment from Governor Hochul to Disabled New Yorkers, a welcome departure from previous administrations.

While we applaud these efforts, we believe more can and needs to be done to ensure Disabled New Yorkers can access the services and supports needed to live independently in the Community. The governor's budget does not include reversing eligibility cuts to home and community-based services, expanding access to accessible housing and paratransit, or increases to funding for the State's only network of disability-led organizations, Independent Living Centers.

The Center for Disability Rights looks forward to working with the Executive, Legislature, and other stakeholders on the following areas related to the health budget.

Health and Long-Term Supports and Services

Managed Care Reforms

The Executive Budget contains several proposals surrounding the State's delivery of Medicaid via managed care organizations. Among these is a proposal to require the State to procure Medicaid managed care benefits from Medicaid Managed Care (MMC) plans, Managed Long Term Care (MLTC) plans, Medicaid Advantage Plus (MAP) plans, and Health and Recovery Plans (HARP) plans. Additionally, it would authorize the Department of Health to impose liquidated damages for managed care organizations that fail to comply with the model contract.

We all recognize that managed care for Long Term Services and Supports (LTSS) is not working in New York. Insurance companies have developed mechanisms to enrich themselves while denying services needed by Disabled individuals to live in the community. Instead of raising attendant wages, funding during the pandemic, which supported bonuses of \$20,000 or more to direct care workers funded by other state agencies, went into the bank accounts of the managed care companies. After the Disability Community secured funds to increase attendant wages, fiscal intermediaries complained that those funds never reached them.

CDR strongly supports Governor Hochul's proposal to have Managed Care Organizations (MCOs) competitively bid for the opportunity to provide managed care in our State. From the beginning, CDR opposed how Managed Care was implemented in New York State. By having many managed care companies or plans, the base of people served by each plan was significantly smaller. The capitation model incentivized serving people with less significant disabilities, while people with the most significant disabilities were seen as unsustainable outliers. Consequently, plans reduced rates and services so that individuals with significant LTSS disabilities were forced to go without assistance and/or were institutionalized.

CDR supports the Executive's proposal and looks forward to working with the Governor, Legislature, and the Department of Health to implement it. We believe that this proposal has the potential to be a bold and transformative initiative and address years of problems in that system. Governor Hochul's predecessor never used managed care as a mechanism to promote community integration of people with disabilities and, in fact, did the opposite by implementing initiatives in managed care and acknowledging they would promote unwanted institutionalization. Governor Hochul can change that.

CDR is eager to work with the Hochul administration and the Department of Health to advance this initiative in a manner that promotes the ability of Disabled New Yorkers to live in freedom. As the State develops the Requests for Proposals (RFPs), it should include components demonstrating an MCO's commitment to Disability competence and community integration. In the RFP, plans should be expected to demonstrate experience:

- Ensuring that the services provided by their network are accessible and Disability-competent;
- Maximizing the use of home and community-based services to avoid institutionalization;
- Funding transition services to people leaving nursing facilities and other institutions; and,
- Contracting with Independent Living Centers and other disability-led organizations as providers in their networks.

The state can also use the RFP and the contracting process to significantly change how services are delivered. The state could use the RFP process to:

- Establish a high-need community-based rate cell which would ensure that plans are adequately funded to support individuals with the most significant disabilities in the community rather than "cherry picking" to serve people with far less significant disabilities;
- Improve transparency by requiring plans to publish the rate of institutionalization of the people they served;
- Establish person-centered planning as a fee-for-service funded by the managed care organizations rather than embedding this service within the plan structure;
- Require that plans contract with non-profit, Disability-led providers to the greatest extent possible; and,
- Reduce institutionalization by establishing a penalty for plans when people are institutionalized or implementing some other mechanism that ensures that plans cannot offload high-cost individuals with significant disabilities.

CDR calls on Governor Hochul to work with the Disability community to identify eligibility criteria necessary for the RFP, change policies that will facilitate a smooth transition and continuity of services, and monitor and evaluate the implementation of this transition.

Extension of the Global Cap

The proposed budget would extend the two-year Medicaid Global Cap through FY2026; this would keep overall Medicaid spending within capped levels, which are indexed to the five-year rolling average of Medicaid spending projections within the National Health Expenditure Accounts produced by the Office

of the Actuary in the Centers for Medicare & Medicaid Services. While we acknowledge the need to keep spending down in the face of a difficult fiscal future, we are concerned that keeping Medicaid levels capped results in a deficit of services provided to Disabled New Yorkers. CDR is gravely concerned that continuing the global cap – even with these changes – will perpetuate ableist budget policies that are weaponized against New Yorkers with disabilities. CDR opposes the extension of the Global Cap.

Eliminate Prescriber Prevails

The Executive Budget proposes eliminating prescriber prevails, which ensures that people will be able to access medications specifically prescribed instead of cheaper alternative medications. This proposal threatens the bodily autonomy of every elderly and Disabled New Yorkers, and Governor Hochul should understand that a person's body is something they should have the right to make choices over. The State is saying that you and your doctor are not competent enough to make medical decisions for yourself. In some cases, specific medications are needed because cheaper ones may have side effects. In other cases, an individual may need their medication to look a certain way (shape/color) to recognize it. Changes can have serious consequences. CDR vigorously opposes this invasive proposal and warns the State that it has no business inserting itself into the medical decisions made between a patient and their healthcare provider.

Transition the Special Needs Assisted Living Residence (SNALR) Voucher Program from a Pilot Program to a Permanent Program

While we agree with the need to help more New Yorkers age in place, the Governor's priority to transition the Special Needs Assisted Living Residence (SNALR) Voucher program to serve individuals with Alzheimer's and dementia who are not eligible for Medicaid to age in place from a pilot program to a permanent program misses the mark.

While funding absolutely must be provided to ensure the most at risk are able to receive services, the continued subsidization of institutions must end. Studies have shown that independent living supported by increases in home care services is more cost-effective than institutionalization. A higher quality of life would also be provided for these individuals by allowing them to age in their homes while saving the State money. CDR calls on the Governor to divert funds targeted for nursing facility reforms to transition and independent living services.

Medical Debt Protections

Vulnerable New Yorkers should not fear receiving medical attention. Disabled individuals often incur higher medical bills and at a faster rate. The Governor's Executive Budget proposes to limit the ability of hospitals to commence legal action related to the recovery of medical debt or unpaid bills from patients earning less than 400 percent of the Federal Poverty Level (\$120,000 for a family of four). The proposal would also expand hospital financial assistance programs for low-income New Yorkers, limit the size of monthly payments and interest charged for medical debt, and implement other protections to improve access to financial assistance. The proposal would also amend the Public Health Law to add a new definition of "underinsured" and require hospitals to extend financial assistance to both uninsured and underinsured persons. CDR supports these steps in ensuring that Disabled New Yorkers are not financially penalized for seeking access to care.

Unallocated cuts to Long-Term Care and Medicaid

In lieu of more specific cuts, the Executive Budget includes a \$200 million unallocated State share reduction outside of community-based long-term care services, which will be achieved through one or more savings proposals developed in consultation with the healthcare industry and other stakeholders. Additionally, the Executive Budget also proposes \$200 million in unallocated Medicaid Savings.

We are extremely concerned about funding cuts that provide essential services and supports that underpin the health and freedom of Disabled New Yorkers. While we understand the need to balance the budget, we do not support unspecified cuts and trust that these cuts won't undermine home and community-based services for Disabled New Yorkers. The state should not continue the practice of balancing its budget by sacrificing the lives and freedom of its Disabled citizens.

Independent Living and Home Care

Olmstead Plan

The FY 2025 Executive Budget includes \$250,000 for New York's Most Integrated Setting Coordinating Council (MISCC) to issue an Olmstead Plan. Such a plan would help ensure that people with disabilities live and receive services in the most integrated setting. Under the Office of the Chief Disability Officer and the new Olmstead Director, this plan will be inclusive of people with all types of disabilities, addressing the needs of people with physical, sensory, developmental and/or intellectual, mental, and behavioral disabilities. CDR supports funding this important development and looks forward to working with the CDO and the Olmstead Director on the State's Olmstead Plan.

Stop Defunding the Consumer Directed Personal Assistance Program and Home Care Workers

We are disappointed in the continued attacks on the Consumer Directed Personal Assistance Program; our home care workers deserve better. The proposal to eliminate wage parity for personal assistants is another shameful attack that will further de-incentivize an already underfunded workforce. Wages for home care workers need to be increased, not decreased.

Stagnated reimbursement rates and the increase in the State's minimum wage have created an unprecedented crisis in community-based long-term services and supports (LTSS), and more specifically, in home care. A decade ago, programs like Consumer Directed Personal Assistance (CDPA) paid well over minimum wage. Although these workers were underpaid, consumers were able to attract and retain workers so they could live independently and safely in the community. Although limited progress has recently been made, the situation remains at a crisis level. This week, an individual CDR is advocating for only receiving eight hours of assistance a day even though the agencies serving her were authorized for 24-7 coverage due to a decubitus ulcer, putting the individual's health at serious risk.

We expected better from Governor Hochul, whose predecessor balanced his budget on the backs of New Yorkers with LTSS disabilities. The wages paid to personal assistants have lagged behind those paid to other Direct Service Providers in the developmental disability and behavioral health systems. Last year's enacted budget provided 4% COLAs for these other providers, further widening that gap.

CDR calls on the Governor to include a proposal in her budget amendments to not only reverse these attacks on wages for home care workers but to fund permanent wage increases for home care workers to ensure that all home care workers are paid no less than 150% of the regional minimum wage.

Additionally, not included in the Executive Budget is the proposal to repeal eligibility restrictions to access home care services, which increase the number of activities an individual needs assistance with to be eligible for home care. These harmful restrictions are part of the cuts to community-based long-term services and supports (LTSS) proposed by the Medicaid Redesign Team (MRT) II, enacted in the SFY2020-21 budget, and set to take place in 2024. While these restrictions were enacted in the SFY2020-21 budget, they were temporarily delayed due to the COVID-19 pandemic. CDR calls on the Governor to repeal these restrictions and make it easier, not harder, for Disabled individuals to receive services that are needed to enable them to exercise their rights to live independently in the community.

Cost of Living Adjustments

Unfortunately, not all human services programs are treated and respected equally. The Executive Budget puts forth a proposal to provide a 1.5 percent Cost-of-Living Adjustment (COLA) for certain human services programs. These programs are the same programs that received a 4% COLA in last year's enacted budget. Left out of this COLA are programs in the Independent Living Centers Program. Independent Living Centers (ILCs) are the only statewide network of disability-led organizations that provide integral services to help people with disabilities live independently in the community. ILCs have been underfunded for many years, leaving many struggling to provide services to Disabled New Yorkers so they can continue to pay staff.

It is not lost on us, that organizations run by Disabled people for Disabled people are treated differently than those run by nondisabled folks. We understand that ILCs don't have the same clout that these other organizations have. That's because Disabled people, in general, are seen as broken and treated as tokens. Instead of reinforcing the ableist bias that keeps our community under the thumbs of nondisabled people, New York should be investing in organizations run by Disabled people. We understand that in a difficult budget year we may not see investments in our network to address these long-standing inequities, but we should have – at a minimum – been treated equally. We continue to call for increasing ILC funding to \$18 million and establishing a statutory COLA for Independent Living Centers.

Support Access to More Independent Living Settings for OPWDD Providers

The Governor's proposal would allow greater flexibility for the performance of certain nursing tasks by unlicensed employees of providers certified by the Office for People with Developmental Disabilities (OPWDD) in community-based settings that are not certified by OPWDD. This would increase the availability of nursing task services outside of certified residential settings, allowing more people with developmental disabilities to remain in or transition to more independent settings, which could decrease the reliance on certified residential settings, such as group homes or intermediate care facilities (ICFs).

While this proposal would increase the availability of nursing task services outside of certified residential settings and allow more people with developmental disabilities to remain in or transition to more independent settings, the state still hasn't implemented the statutory changes made in home care years ago to allow advanced home health aides to perform nursing tasks. Consequently, years after the policy was addressed in statute, a self-directing CDR consumer who receives traditional home care services is still unable to get basic medication because their aides cannot put it in their mouth. CDR supports this proposal but calls on the state to implement the previously approved policy changes that would allow Disabled New Yorkers to get the medications they need.

Expanding Hospital Services Outside of a Healthcare Facility

As part of our quest to ensure all New Yorkers are able to live fully integrated and independently in the community, we support all measures to provide care in home and community settings. The Governor's proposal to expand hospital services outside of a healthcare facility by expanding existing home care collaboration models and making it easier to involve multiple types of licensed entities, including hospitals, home care agencies, and emergency medical services, would be a positive step towards achieving these goals.

Building on the "Acute Hospital Care at Home" demonstration program from the federal Centers for Medicare and Medicaid Services (CMS) during the COVID-19 public health emergency, this proposal would authorize general hospitals to provide care in patients' homes without obtaining a license as a home care agency. Additionally, this proposal would enable authorized organizations to operate paramedic urgent care and expand healthcare access through telehealth services while complying with licensing and practice standards. CDR supports this measure.

Mental Health

Make Flexibilities for Demonstration Programs Permanent

We support efforts to expand services to people with mental health disabilities, with the understanding that there is not a one-size-fits-all approach and that Disabled New Yorkers – including those of us with mental health disabilities – must be supported and empowered by our services. The Governor has proposed allowing the Office of Mental Health, the Office of Addiction Services and Supports, and the Office for People with Developmental Disabilities to utilize flexibilities to develop new methods of services through demonstration projects. It is critical that individuals with disabilities and lived experience be involved in these efforts. This is particularly true of people with mental health disabilities who are often unfairly stigmatized by people’s ignorance and ableism. CDR supports this proposal and calls on the Governor to allow other agencies and departments to utilize flexibility to develop new methods of services through demonstration projects.

Require Minimum Commercial Insurance Reimbursement Rates for Behavioral Health Services

The Governor proposes to require New York State-regulated insurers to reimburse providers licensed by the Office of Mental Health (OMH) and the Office of Addiction Services and Supports (OASAS) at or above the Medicaid rate for outpatient behavioral health services. When providers are not reimbursed appropriately, they lose money, and when they lose money, they stop providing services. Across many sectors and throughout the State, individuals cannot access the services they need because providers are limited in their ability to provide services. CDR supports this proposal and calls on the Governor to require all reimbursement rates to be no less than the Medicaid rates for covered services.

Protections for Vulnerable Populations

Clarifying the Justice Center’s Obligation to Refer Reports of Abuse or Neglect to OMIG

The Justice Center has primary responsibility for receiving, investigating, and/or reviewing abuse and neglect allegations at certain facilities and programs that are operated, certified, or licensed by the following six agencies: OMH, OPWDD, OASAS, DOH, OCFS, and the SED. The Executive Budget includes an investment of \$1.3 million into the agency’s Investigations Unit to support an additional 18 full-time employees across six different titles. This expansion will address the anticipated need for investigative services driven by mental health investments, improve cycle time for investigations, and shorten the time staff accused of unsubstantiated charges are out of work. The costs of this expansion are supported by federal Medicaid reimbursement.

CDR supports this proposal, but policymakers need to understand that the Justice Center does not protect all Disabled New Yorkers. Over the last year, CDR has worked with a Disabled woman in Rochester whose services were illegally terminated by the University of Rochester Medical Home Care. In terminating her services, the agency left her without any assistance. URMH argued that they didn’t have staff even though they were not recruiting for home care aides at the time, and that they lacked the funds to support her even though URMH could afford to run a Super Bowl ad. Ultimately, the agency was forced to restore some services, but their nurses would leave the individual without assistance, laying in feces for up to nine hours at a time. Because she receives the “wrong” type of services, this woman was not protected by the Justice Center. CDR supports this proposal and calls on the state to expand the scope of the Justice Center and adequately fund it so that all Disabled New Yorkers are protected and have recourse when abuse and neglect occurs.

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 lives. 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.