



CONSUMER DIRECTED
ACTION OF NYS
BUILDING SELF-DIRECTED POWER

CDANY 2024 Budget and Legislative Agenda

Adequately fund the home and community-based services system by passing and enacting Fair Pay for Home Care. “Fair Pay for Home Care” will address the systemic underfunding of New York’s home care system by investing in services and providing higher wages for workers. While small wage increases have been won, mechanisms to ensure those wage increases can be afforded by providers have failed, as has the wage goal of 150% of the minimum wage. These failures have led to an overall destabilization of the system. Combined with the still inadequate wage increases, this further jeopardizes the services older and disabled New Yorkers rely on. Enacting “Fair Pay for Home Care” will create the investment and accountability necessary to ensure older and disabled New Yorkers have access to the high-quality home care they deserve.

Repeal assessment procedures that limit access to CDPA. A foundational aspect of health care is the relationship between an individual and their doctor. Because of perceived corruption from MLTCs, New York violated this sacred relationship by replacing individuals’ doctors with a private, third-party company called the New York Independent Assessor for home care assessments. This process has had predictable results, as an increasing number of people who had been receiving personal care or CDPA for years are suddenly finding themselves denied for not being “disabled enough.” The state must return the assessment process to one between an individual and their health care provider.

Repeal eligibility cuts to CDPA and personal care preventing access for low-hour individuals. Eligibility cuts to Medicaid at the start of COVID-19 jeopardize older and disabled New Yorkers by limiting access to home care services. By restricting access to personal care and CDPA services to individuals who need assistance for three or more activities of daily living, these cuts will cause harm to older and disabled New Yorkers forced to go without needed services. They will also result in considerably greater spending as without aid, these conditions will worsen, requiring higher hours or institutionalization. These cuts must be repealed.

Reform/Eliminate MLTC. Managed long-term care was meant to provide case management and service integration for dual eligibles. However, care management remains non-existent, and with personal care accounting for 80% or more of the services provided, these companies are essentially managing one benefit. MLTCs take hundreds of millions of dollars out of Medicaid as profit, while forcing cuts to providers, and ultimately beneficiaries. The state should acknowledge this experiment has failed, and focus on new models that can meet the original goals while maintaining high-quality service delivery.

Enact universal long-term care. Paying for long-term care forces people into rapid impoverishment and the depletion of life savings and assets. Younger disabled individuals face forced impoverishment to maintain Medicaid eligibility. For almost 12 million New Yorkers, services like CDPA are not even an option, resulting in gray market services lacking job protections or income tax revenue to the state. Universal long-term care will advance equity while eliminating exploitative gray market services.

Repeal the Medicaid Global Cap. While the Medicaid Global Cap formula was reformed, the changes do not erase the structural issues that lead it to discriminate against older and disabled New Yorkers. The cap has been used to justify eligibility and reimbursement cuts, and continues to be the primary rationale the state uses for its inadequate wages. To ensure equity in the health care system, the global cap must be repealed and policies must be based on priorities and need, not an artificial cap on spending for services for those most in need.

Live-in reform. “Live-in” home care workers are required by law to be paid for 13 of the 24 hours they work, with the remainder technically time off and paid if reported. However, it is rare that these breaks are used, and in the even rarer event they are reported, the agencies must pay for services for which they will not receive reimbursement. This dynamic has led to managed care plans exacerbating this problem, because they can avoid 11 hours worth of costs by exploiting the workers and the agencies that employ them. That this workforce is mainly comprised of Black, LatinX, and immigrant women, many who do not speak English, is particularly troubling given the historic and institutional marginalization and discrimination they have faced. The state must change this system while being careful to guarantee that Medicaid clients who depend on it receive services, specifically by modifying the regulations concerning continuous care to ensure that these individuals who qualify for this level of service receive it.

Adequately fund EISEP - Expanded In-Home Services for the Elderly Program (EISEP) is an important part of the state’s long-term care system, helping alleviate Medicaid costs and delaying costlier and more complex services for older adults living at home. Because the program is administered through county grants and inadequately funded at the state level, it cannot meet its potential and faces long waitlists. This leads to people to forgo services, risking injury and disability. It also increases Medicaid spending, as people rapidly spend down resources to pay for care. A modest increase in investment in EISEP will keep older adults healthier and in their home longer, decreasing Medicaid costs and building communities, through the economic benefits proven by the State Office of the Aging.

Ensure policies prioritize home and community-based settings. New York must work with the federal government to prioritize HCBS over institutional care for people with disabilities and older adults, by using the Master Plan on Aging and Olmstead Planning processes. As part of this, we must::

- Require data sharing for the outcomes of HCBS assessments;
- Repeal the carve-out of nursing home services from managed care; and
- Increase investment in Open Doors, which facilitates transferring people out of institutions.

Fund a CDPA Peer Support Line. Peer support is a proven method of ensuring success in complex programs. To ensure that consumers succeed in CDPA, putting off more expensive institutional services or an increase of hours, the state should help open CDPAANYS’ peer mentoring service to all consumers. This resource allows trained individuals who use CDPA as consumers or designated representatives to provide support to those consumers, new or long-time users, who are experiencing issues.

Increase Revenues by Raising Taxes on the Ultra-wealthy. CDANY recognizes that choices between which state services should be cut inherently harm the same group of New Yorkers in different ways. Through policy choices, including raising taxes on the wealthiest New Yorkers, taxing the homes of Russian oligarchs and others with vacation homes in the state, and taxing some luxury items at a higher level, we can fund all the services New Yorkers need without false choices.

Establish a Budget Authority Model For CDPA. CDPA is a self-directed service and a budget authority model akin to that used by the Office for People with Developmental Disabilities should be an option for all Medicaid HCBS consumers to offer greater control over their service provision.

Increase Affordable Housing Options. The availability of HCBS is contingent on a consumer living within the community. Increasingly, the lack of affordable housing is one of the chief barriers for those in need of services and those who provide services to thrive. The state must fully fund current housing programs such as Medicaid waiver housing subsidies, Housing Choice Vouchers, and public housing; create new housing programs; and require universal accessibility for all new construction.