CONSUMER DIRECTED ACTION OF NYS

BUILDING SELF-DIRECTED POWER

The proposed SFY 2025 budget contains devastating provisions that, if enacted, would undermine original intent of and completely destabilize Medicaid's consumer directed personal assistance (CDPA) program. The changes would drastically reduce the number of agencies providing service so severely it could potentially eliminate fee-for-service CDPA in New York City; cut eligibility to over 100,000 children, seniors with Alzheimer's disease and dementia, adults with severe developmental and neurological disabilities, people with traumatic brain injury, and those who are unable to communicate because they are nonverbal or face language barriers; impose a 12% pay cut on workers, bringing compensation in New York City to the lowest levels since 2018; and corrode the basic tenets of self-direction. These cuts will not only devastate CDPA, they will further overwhelm the entire health care system, overrunning capacity at nursing homes, intermediate care facilities, LHCSAs, hospitals, and other sites as those desperate for services are forced to turn to systems already struggling with critical shortages themselves. **These cuts to the CDPA program must be rejected.**

CDPA Related Budget Proposals Must Be Rejected

1. **Carving CDPA out of wage parity (Part G)** - The Executive seeks $200 million in state savings via wage and benefit cuts of over 12%, or $2.54/hour in New York City and $1.66/hour in Long Island and Westchester. Annualized, counting Federal matching funds, the cut totals **$800 million**. This 12+% cut means PAs in New York City would receive compensation at the lowest amount since 2018, undoing two years' worth of efforts to improve wages and driving thousands from a workforce already in crisis. Since the removal of wage parity only applies to CDPA, personal assistants (PAs), who like most home care workers are predominantly Black, Latina, and immigrant women, will receive a message that they are second-class home care workers, unworthy of compensation equal to that of their peers, despite being able to perform nursing tasks their peers cannot.

2. **Removing designated representatives (DRs) from CDPA (Part HH, Sec. 14-17)** - The Executive seeks to end a provision that goes back to the beginning of CDPA allowing individuals called Designated Representatives (DRs) to self-direct CDPA services on behalf of consumers who cannot do so themselves. Approximately 40%, or 100,000, of CDPA consumers use a DR and would lose eligibility on October 1 of this year. These include medically fragile children; about 6,000 people who use CDPA to complement OPWDD services; seniors with Alzheimer's and dementia; those with traumatic brain injuries; and those who are nonverbal or face other language barriers. This cut would overwhelm all other aspects of the healthcare system, as those losing eligibility for CDPA are forced to costlier LHCSAs, nursing homes, Intermediate Care Facilities, and hospitals, themselves all already facing their own financial and workforce crises.

3. **Undoing the negotiated procurement and imposing arbitrary limits on the number of FIs (Part HH, Sec. 1-7) -** The Executive again seeks to repeal the procurement process insisted on by DOH in 2017, issued in 2019, and renegotiated with the Legislature in 2021. Even though awards have been announced and DOH could issue contracts, they propose to again change the process to one primarily set in emergency regulations. While reworking the authorization process, DOH also proposes to place arbitrary and undisclosed caps on the number of fiscal intermediaries that managed care plans and counties would be able to contract with via emergency regulation.

4. **State-mandated training and daily and weekly hour limits for PAs (Part HH, Sec. 7)** - CDPA is premised on the foundation of self-direction, of which two core components are that consumers train and schedule their own PAs. The Executive's budget undermines these foundational aspects of the program by mandating PA training and by placing undisclosed daily and weekly hour limitations on PAs, both via emergency regulations. Training requirements add significant new costs to CDPA while increasing the risk of harm to the consumer. Those who

use CDPA often have very specific needs as it relates to their service delivery, meaning the cost of training will be wasted as consumers are forced to retrain the workers. Worse, if PAs ignore consumer training in favor of the state imposed training, it could cause significant harm due to the specific nature of the disabilities. This is one of the primary reasons the disability community fought to train their own workers in a self-directed program. With data consistently showing self-direction having better outcomes, this is a solution in search of a problem.

Limitations on hours worked also have the potential to cause very real harm. In a workforce crisis, limiting weekly hours undoubtedly will result in consumers going without needed services. Meanwhile, particularly for consumers with the most severe disabilities and in need of the highest level of services, daily hour limits pose an entirely different risk. Because these consumers are most at risk during shift changes, when PAs may be delayed or unexpectedly not arrive, many consumers will schedule shifts in blocks of 12 hours or more, up to the 16 currently allowed by law, limiting the potential of going without services.

5. **Disallowing licensed home care service agencies (LHCSAs) from providing FI services (Part HH, Sec. 8)** - Since the beginning of CDPA, some agencies serving as FIs have also been LHCSAs. This has benefited consumers who may choose to use both CDPA and agency-based home care services because they are not comfortable directing specific tasks, have short-term needs better met by an agency, or prefer LHCSA care but use CDPA to fill gaps where the workforce shortage prevents full coverage. In addition to preventing consumer choice, the proposal could leave New York City, where every FI that HRA contracts with is also a LHCSA, in a potentially dire scenario, unable to offer Fee-For-Service CDPA. The added benefits accrued by having some FIs also operate as LHCSAs make it difficult to understand what problem the budget seeks to solve.

6. **Cuts to Fiscal Intermediary Per Member/Per Month payments (Admin) -** In 2021, DOH implemented a three-tiered per member/per month (PMPM) payment system to cover the administrative component of payment for FIs. While precedent pointed to regionally-based payments to account for differences in expenses for staff, rent, and other costs, the PMPM was uniform statewide. Since the PMPM was implemented, we have experienced record inflation; however, instead of adjusting these rates to account for that inflation, the Executive proposes to cut rates for the two lowest tiers of services, while raising the highest, and smallest, tier (associated with cases over 16 hours per day, but not live-in cases). This action primarily harms FIs in fee-for-service, as managed care plans do not use the PMPM system. Instead, the PMPM should be codified and based on regional rates adjusted annually based on inflation.

THERE IS A BETTER WAY

Enact The Home Care Savings and Reinvestment Act - The experiment of managed long-term care (MLTC) has failed. These plans promised comprehensive services and using care managed to coordinate with Medicare and improve outcomes. Instead, services offered by the MLTCs have consistently been stripped away. First, social adult day care was removed unless other benefits were also used. Then nursing homes. On March 1, transportation services were removed. Even service assessments for personal care and CDPA have been contracted to the New York Independent Assessor (NYIA).

Now, over 80% of the benefits paid for by MLTCs are related to personal care. Plans use incentives to drive growth in low hour cases. Care management has never come to fruition. Consumers routinely report rotating care managers with incorrect information about their services, or phone numbers that place them into voicemail to wait 24-72 hours for a call. All of this means MLTCs receive between $4,500 - $5,000 per month to manage, essentially, one service.

Independent analysis by New York's former Budget Director found eliminating MLTC would save at least $900 million in plan profits and overhead. A new system would return personal care and CDPA to state payments through fee-for-service, eliminating pressures from plans to drive growth and reinvesting the MLTC profits to bring these rates to levels at least equivalent to the baseline when developing MLTC rates. The NYIA will continue with assessments and organizations experienced in working with older and disabled individuals will actually coordinate care, improving outcomes while increasing transparency and accountability for all.