Testimony of

Consumer Directed Personal Assistance Association of New York State

to:

Joint Legislative Hearing on the

New York Health Act

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Good afternoon Health Chairs Rivera and Gottfried, and all of the Legislators here today. Thank you for the opportunity to provide testimony on behalf of the Consumer Directed Personal Assistance Association of New York State (CDPAANYS) in support of A.5248/S.3577, known as the New York Health Act (NYHA). NYHA would provide community based long-term care options to all New Yorkers through single-payer health coverage, which is almost entirely funded through either Medicaid or private pay currently.

CDPAANYS is the only statewide association solely dedicated to Consumer Directed Personal Assistance (CDPA). We advocate behalf of both consumer and fiscal intermediaries. CDPA offers an alternative to nursing homes and traditional agency-based home care by empowering consumers to self-direct their services, including the recruitment, hiring, training, scheduling, supervising, and if necessary, termination of their own personal assistants (PA).

Everyone deserves long-term care, without going bankrupt in the process

CDPA was created by the disability community, for the disability community, in 1979. At the time, the institutionalization of people with disabilities was the default standard of care. Tested as a pilot program in New York City and Syracuse, CDPA was established by law and became available statewide in 1995.

While popular among a core group of people with disabilities, the program began to grow rapidly once it became known within the senior community. As the population of New York has aged, so has the demand for community based care options increased. Unfortunately, CDPA is only available to Medicaid consumers. While those who are wealthy can hire caregivers, often under the table, those in need of long-term care who are middle class cannot avail themselves of this program. CDPAANYS receives several calls each week from those who wish to utilize this approach to long-term care but, because they are not on Medicaid, are denied.

Indeed, those in need of long term supports and services who are not Medicaid eligible must spend their life savings and bankrupt themselves. For people who have spent their adult lives working and saving for retirement, this is an often unexpected and alarming reality. Entire industries have sprung up helping these individuals hide their money so that they can qualify for Medicaid without giving their life savings, which they hoped to pass on to their children, to a home care company or nursing home.

New York Health eliminates this dilemma.

By ensuring that every New Yorker who needs long term supports and services has access to them, people can work knowing that the money they earn and save will help them in their golden years. It will help them live a higher quality of life, being able to experience and live life while still receiving services they need. It will also keep them healthier, as they receive nominal services when they need them, rather than forgoing care until they injure themselves, ending up imprisoned in a nursing home for the remainder of their days.

Nobody should have to be poor to live

For people with disabilities who need community based long term supports and services to get out of bed, go to the bathroom, or even just breathe, there has always been a cruel fate. No matter how smart, or highly qualified, or able, they have been forced to live at or near poverty in order to receive basic services they need to not only lead the productive lives they desire; but, to survive. Since Medicare and commercial insurance do not cover long term supports and services, the disabled must rely on Medicaid in order to get the services they need.

This has created a system of forced impoverishment. It has created a system where disabled people will forego marriage to those they love, because it will place their Medicaid services and the economic well-being of their partner in jeopardy. This reality creates an institutionalized level of discrimination that ensures the disabled will always be viewed as a liability and a drain; because society does not afford them the services they need to fully function in society.

While the Medicaid buy-in option for people with disabilities does allow the working disabled some ~~ability to both work and receive the services they need, it still fosters a discriminatory practice. Because~~ the program caps an individual's annual earnings at $63,492 and their assets at $20,000, regardless of which region of the state they reside in or their qualifications, the disabled are often forced to take salaries lower than their peers. In many instances, people with disabilities will make less than those they supervise because of the need to stay under the cap.

Under Federal law, the buy-in covers people up to age 64, the age of Medicare eligibility. At that point, one must meet the traditional means-based requirements to stay on Medicaid. Retirement savings, pensions, and assets earned over one's lifetime are nearly all subject to this ceiling. For someone who has followed conventional advice and handled their finances the "right way" in preparation for retirement, it can be like the rug being pulled out from under them. The only options to retain services uninterrupted is to forfeit these assets or submit them to a specialized trust that will be transferred to the government upon the person's death, rather than their loved ones. This final act of discrimination is one of the largest insults to a community who is used to them.

Medicaid managed care is wasting valuable state resources that should go to health care

Medicaid the largest entitlement programs in New York and accounts for almost half of the state budget. Attempts to reign in spending invariably lead to pitting differing groups against each other in a Dickensian race to the bottom. However, for decades, one of the largest, if not the largest, expense in the Medicaid program has been premium payments for managed care. These premiums are paid whether or not a recipient requires services, which has led managed care companies to seek out healthy individuals who require no, or almost no, medical coverage. At the same time, these companies make life miserable for those who actually require care in an effort to convince them to switch plans.

This problem was exacerbated in 2011, when Managed Long Term Care (MLTC) became a requirement for every Medicaid recipient in need of community based long term supports and services or nursing home care. In what to most appears as an obvious conflict of interest, it is the managed care companies, many of whom are for-profit and publicly traded, that determine the amount of long term supports and services an individual qualifies. Consumers too often receive too few hours in their initial plan of care, or routinely have their hours reduced, so that the plan will make money. Even not-for-profit plans pay their executives exorbitantly high salaries, with Father Frawley, the former CEO of Fidelis, making $5.5 million in 2017. Of course, the true tale of how much money there is to be made from the state in managed care is the fact that Centene, a for-profit publicly traded managed care company, bought the not-for-profit Fidelis for a jaw dropping $3.75 billion.

With so much money to be made from managed care, you would think the plans would be happy. However, they were not content. In 2013, Visiting Nurse Service's MLTC, VNS Choice, was found guilty of stealing from the state coffers by enrolling perfectly healthy individuals in no need of long term supports and services. They were forced to pay the state over $35 million in restitution. However, their crimes did not stop them from continuing as an MLTC. Instead, they are now one of the largest programs in the state. Meanwhile, the costs of their crimes continue to rise for the state, as it was forced to hire for-profit Maximus to screen everyone looking to enroll in a MLTC to ensure they qualify in what is known as the Conflict Free Evaluation and Enrollment Center, or the CFEEC.

Instead of paying executives millions, and paying companies millions (or billions, nobody knows as the contract with Maximus is proprietary) to ensure those other companies do not steal from taxpayers, New York Health would entrust our health care with the state. While fee-for-service Medicaid certainly had, and still has, its flaws; denying care for profit, exorbitant CEO salaries, and financial incentives to enroll people who do not need services are not among them.

New York Health must improve reimbursement to be viable

As it stands, Medicaid is actually a terrible payer, even for those, like FIs, who cannot bill anyone except Medicaid. Fee-for-service Medicaid is reimbursed not based on actual costs, but "ceilings" imposed by the Department of Health. There is a direct care ceiling, which covers the cost of providing services to those who need them. There is then an administrative and general, or A&G, ceiling, which until recently had been 18% in CDPA.

In 2009, the trend factor, which allowed those ceilings to grow with the cost of inflation, was ended. Therefore, for a decade, the direct care ceiling has remained flat. This has led to costs outpacing the cost of services. Almost every FI in the state operates at a loss when it comes to Fee-for-service reimbursement. This is true of providers across almost every spectrum and it has resulted in service shortages, as wages have been largely frozen because of the stagnant rates. Indeed, throughout most of Upstate New York, wages for personal assistants in CDPA are now over $1.50 less than the minimum wage for fast food. Home care is the lowest paid job in our economy, and it is because of Medicaid reimbiursement rates.

Home healthcare jobs constitute the fastest growing job sector in New York City. According to a report released by the city's Independent Budget Office (IBO) earlier this month, two out of every three jobs created in 2018 were part of this category. The IBO also estimates that 64,000 of these jobs are paid through CDPA. New York has seen the fastest growth in home health care jobs in the United States, while it simultaneously represents the epicenter of the home health care workforce crisis. A 2018 study released by the Mercer Corporation projects a shortage of 20,000 workers by 2022.

Of course, the failures of Medicaid are not limited to inadequate reimbursement in fee-for-service. This year, the budget took aim at CDPA as a whole, targeting the program for $150 million in cuts that it claimed would not affect consumers. To achieve this, a new policy was enacted to restructure FI reimbursement costs from a percentage of direct care rates to a flat, per-member, per-month rate (PMPM), to take effect July 1, 2019.

DOH has yet to announce finalized PMPM rates, but has released to stakeholders potential figures, tiered by case hours, that it has indicated are likely to become policy. During a meeting with DOH and the Governor's office in May we learned that miscommunications had led to a dramatic misunderstanding of what these rates would be. The proposed rates will lead to 9-10% cuts to every FI; but, as the cuts are limited to administrative services, it will cut those funds by 70-80%. It is akin to telling someone that they must save 9% in their monthly household budget; but, they can only take the cut from groceries. It is impossible.

Not a single FI in any region of the state can remain operational if these rates take effect, causing a de facto end to CDPA. The sudden cessation of a community-based long term care program upon which 70,000 seniors and people with disabilities rely would create chaos and spell disaster for these consumers and their families. More than 100,000 jobs in the fastest growing employment sector in the state would be lost, to the detriment of local economies. Further, it would immediately put New York out of compliance with the Supreme Court's *Olmstead* decision, which mandates that people with disabilities have a right to receive services in the least restrictive setting possible, as agency based home care is unavailable in several counties.

It's evident that the planned cuts to CPDA, despite being aimed at administrative spending, can occur without negatively impacting consumers. In making these cuts, the state has overlooked the significant price of contracting these services through managed care organizations.

Of course, the reason reimbursements are so low in Medicaid, and the reason we can cut critical services to the point where they will cease to exist, is easy to determine. It is for poor people and marginalized populations that have faced historic discrimination. If the Legislators on this panel, myself, and our parents were using the program, we would never tolerate this level of reimbursement for the services we use, or this appallingly low wage for those who provide them.

Medicare has reimbursements that doctors accept willingly and is often deemed the best payor in the health care system. It is not because the Federal government is that much better than New York's. It is because the mothers of members of Congress, and many members of Congress themselves, use the program. It is because Medicare is open to everyone. Michael Bloomberg gets Medicare. Jeff Bezos will.

The entirety of the working class gets Medicare. There would be riots if reimbursements were so low that doctors and nurses were forced to rely on minimum wage.

By placing every New Yorker in a singular health care plan, not only can we get health spending under control, we will do so in a manner that improves services and improves the quality of life of those who work in health care. The public will not stand for their providers to be paid appallingly low wages, and the government will be forced to act.

Moving to a single payer system has been an increasingly popular idea in state legislatures across the country and on the national stage. What has been considered an impossible policy shift since Truman has adopted a level of gravity from academics and economists on all sides of the political spectrum. Even the Koch brothers determined that a single payor health plan such as New York Health would save money and lead to better health care, albeit accidentally in a failed attempt to prove just the opposite.

Health care, including long term supports and services, is a human right. New York Health will guarantee its availability for all New Yorkers. This makes New York Health not only good policy; but, a moral mandate. CDPAANYS strongly urges the Legislature to act as soon as possible to fulfil that mandate.

Thank you for allowing CDPAANYS the opportunity to testify before you today. We strongly support NYHA and its inclusion of long-term care. It represents a commitment to the rights of people with disabilities and seniors to live independent lives in their communities and pursue their educations and careers. I welcome any questions, now or in the future.