Testimony of

Consumer Directed Personal Assistance Association of New York State

to:

Joint Legislative Budget Hearing

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Executive Director

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Good afternoon Chairwomen Krueger and Weinstein, and Health Chairmen Rivera and Gottfried, and all 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), the tens of thousands of disabled and senior Medicaid recipients who rely on it, and the over one hundred thousand workers who provide critical, life-saving and quality of life services to them. As the only entity advocating solely on behalf of Consumer Directed Personal Assistance (CDPA), CDPAANYS' interest lies in serving as a good steward of the program overall, ensuring its integrity, viability, and efficacy. Over the years, we have worked collaboratively with the Legislature, the Executive, and the Department of Health (DOH) to identify and resolve issues with the program. Unfortunately, in the past couple of years, our expertise has not been called upon, and potential issues with the program have led to unreasonable answers that have called into question the continued ability of the program to survive.

Forty years ago, a small group of disabled people in New York City developed the Patient Medical Home Care Program in an effort to take control over their health care and have the independence that recruiting, hiring, training, supervising, and terminating one's own staff provides. Fifteen years later, the Legislature saw the value of this program and made it a statewide Medicaid benefit. As we move into 2020, we celebrate the 25th anniversary of this revolutionary program that started right here in New York. Unfortunately, we do so at a time when the program's future is more in doubt than it has ever been before.

Last year's cuts caused serious, and in some cases irreparable, harm

Last year's budget cut $150 million in funding from CDPA. The Governor proposed this cut, arguing that it would not harm consumers services or worker wages. CDPAANYS, consumer groups, and other associations argued strenuously that this was not feasible. When the cut was enacted, CDPAANYS and others worked with the Department to propose alternative ways to achieve the $150 million in savings and ways to change reimbursement that would achieve the goal of helping push out bad actors while not causing harm to the program and those who rely on it.

We were rebuffed at every turn. Ultimately, one day after the DOH informed stakeholders in a Legislatively mandated workgroup that no new rate methodology was decided on, and they were still very interested in meetings, the DOH published what they determined would be the new rate methodology. CDPAANYS, along with the New York Association on Independent Living (NYAIL), The Health Care Providers of New York State (HCP), and 11 fiscal intermediaries, ultimately sued, contending that the rate was arbitrary and capricious and violated the State Administrative Procedures Act (SAPA).

The judge ruled in our favor; however, the new rates did take effect for six weeks. During that time, every prediction made by CDPAANYS and others bore true. FIs were forced to lower wages to minimum wage and eliminate the ability of consumers' personal assistants (PAs) to work overtime. Facing lower take home pay in a job that was already one of the lowest paying in the state, PAs were often forced to quit just to continue to put a roof over their heads and feed their family. For PAs who did not quit, consumers still went without needed services because of the inability of those PAs to work overtime.

Additionally, we saw that the DOH's laissez faire attitude towards the plans meant that many plans used this as an opportunity to attempt to reap enormous windfalls. We saw Nascentia cut reimbursement by a third, to the minimum wage plus associated fringe costs and a flat administrative payment of $100 per member per month (PMPM). Fidelis was even worse. Their proposed direct care rate for New York City was $21.12, meaning that FIs had only 10.5% above the wage parity level for fringe costs. Upstate, the direct care component was $14.72, which at least allowed a fringe rate of 19.75% over minimum wage. However, most FIs upstate, while unable to meet the higher minimum wage of fast food restaurants, were above the state minimum wage, and 19.75% is insufficient to meet standard fringe costs, which fall at about 21-24%, particularly when the high worker's compensation costs associated with home care are factored in.

But, the portion of the rate changes from Fidelis and Nascentia that were most galling was the per member per month. For instance, Fidelis was offering PMPM payments between $80 and $125. They would tell FIs the direct care component was non-negotiable, but that they would discuss the administrative component. Both plans told FIs that they should just pay PAs minimum wage. That was their intent. This stands in direct conflict with DOH, who said the only cuts would be on administrative rates only, and that wages would not be impacted.

This was all predictable. DOH's hands-off approach to the plans and how they reimburse FIs, combined with a new rate structure based on a lack of both programmatic understanding and data about the true costs within the program, led to a pre-ordained outcome where agencies were forced to dramatically reduce wages and benefits for consumers' workers, and those consumers then went without needed services as a result. Even after the court case was resolved, the problems remained, and the DOH did not see the error. Currently, the DOH is trying to impose the new cuts again, with the same Laissez Faire attitude with the plans. Without Legislative intervention to undo the cuts, there will be substantial harm to the program, and those who rely on it.

The Governor's budget continued, and increased, attacks on this program

Since CDPA was made available in the state, it has been touted as a program that meets modern public health goals: improved health outcomes, increased patient satisfaction, and lower cost of delivery. Because the state recognizes the many benefits the program offers, it has always had a goal of increasing participation. New York Social Services Law 365-f, which establishes the program, contains a directive that anyone receiving home care must be made aware of the option to use CDPA. In 2010, the Legislature and Governor provided $500,000 to increase awareness of the program. And, in 2012, as the state moved the benefit to managed care and managed long term care, DOH urged plans to work with CDPAANYS to gain awareness of the program and how it could benefit the plan, their members, and the state overall.

It has been this administration's efforts that have led to the dramatic growth in CDPA. And CDPAANYS has been proud to be a partner with them in these efforts. We identified problems in implementation of CDPA in MLTC that led to the DOH's development of a guidance policy on CDPA (New York State Department of Health Guidelines for Consumer Directed Personal Assistance Services). We repeatedly

worked to prevent the growth of "bad actors" in the program through the development of credentials for fiscal intermediaries. First in 2012 as the program was shifting to managed care, then in 2015 with a bill unanimously passed by the Legislature but vetoed by Governor Cuomo, and finally in 2017, a slightly amended version of that legislation was enacted as part of the final budget. We supported the inclusion of CDPA in wage parity to close loopholes that encouraged LHCSAs to inappropriate use the program as a form of "home care lite" that allowed them to forego important regulations and contract obligations.

The state has a stake in promoting CDPA to people eligible for long-term services and supports (LTSS). And, over the past several years, we have continually brought new issues and ideas to the state to continue our role as stewards of the program. We do this because we believe the program is a wonderful choice for those who can use it, and it should grow. However, it should not grow as a loophole around rules and regulations meant to protect both those who use services and those who provide them. Nor should it serve as a means for agencies, or managed care plans, to enrich themselves at the expense of workers and consumers.

Unfortunately, in recent years, the DOH has shifted away from relying on our expertise to help address issues in this program. We continue to raise topics of concern; but our phone calls go unanswered. The topics we raise go unaddressed. And, instead of answers to real issues, we see half-baked solutions that do not solve the issues the DOH wants to solve, harm consumers and workers, and, perhaps most concerning, are advanced in the absence of actual data.

Growth, in and of itself, is not a problem

The Governor continues to send mixed messages about the growth of Medicaid, sometimes simultaneously. In his budget address, Governor Cuomo rightly bragged about how almost every person in the state has health insurance. He credited his administration with a 95% coverage rate, or 18 million people out of 19.5 million residents. He then connected this commendable coverage rate to Medicaid, through which six million New Yorkers are insured, as a source of pride. We agree that this is something to be proud of – every person living in New York State needs and deserves to have their health needs met without being forced to sacrifice care because they cannot afford it. The Governor deserves credit for this. He has aggressively pushed to reduce the ranks of the uninsured.

The problem is that even as the Governor cheers about having reduced the ranks of the uninsured, he calls Medicaid growth unsustainable, and focuses primarily on long-term care and CDPA. Long-term care, especially CDPA, costs money. It is a service that is delivered multiple times per week, or even every day, for years. The better it works, the longer someone needs it. Unlike nursing homes, where the average life span is about six months, people remain on personal care for years, sometimes decades. This is particularly true of CDPA.

The Governor's critique of the program seems to be focused on how people qualify, but it does not stand up to examination. In the wake of the scandal in which Visiting Nurse Service of New York, through its MLTC VNSNY Choice, was found to be enrolling perfectly healthy individuals in Managed Long-Term Care, the State contracted with Maximus to create the Conflict Free Evaluation and Enrollment Center (CFEEC). The CFEEC has one job: assess every individual entering a MLTC not already

receiving services to make sure that they actually need those services. Before anyone can enroll in a MLTC to receive long-term care services through Medicaid, they must be assessed by the CFEEC.

After the CFEEC, the MLTC conducts the same assessment. The MLTC, not the FI, determines how many hours a person needs, and what services their workers can do. This is called the consumers plan of care.

This budget blames everyone except Maximus for the growth in long-term care spending, in particular personal care and CDPA spending. The counties are blamed, even though they merely assess potential Medicaid recipients for a factual determination of whether or not the person meets income and asset limits for Medicaid. FIs are blamed, despite the fact that they do not have a role until they receive an authorization of hours from a MLTC. Maximus, the company solely responsible for determining eligibility, has not even been mentioned.

We cannot applaud our efforts to enroll people in Medicaid and then complain about having to provide services they are entitled to when an independent entity determines they qualify. This is the political equivalent of wanting it both ways. The Governor's briefing book notes that New York has been "officially designated the first age-friendly state in the nation by the AARP and the World Health Organization for efforts to support healthy aging across the lifespan" (p.81).

It's easy to agree that such a designation from well-respected entities is a great honor, but we have to recognize that without access to vital services, these are merely words.

The growth of CDPA has kept Medicaid sustainable

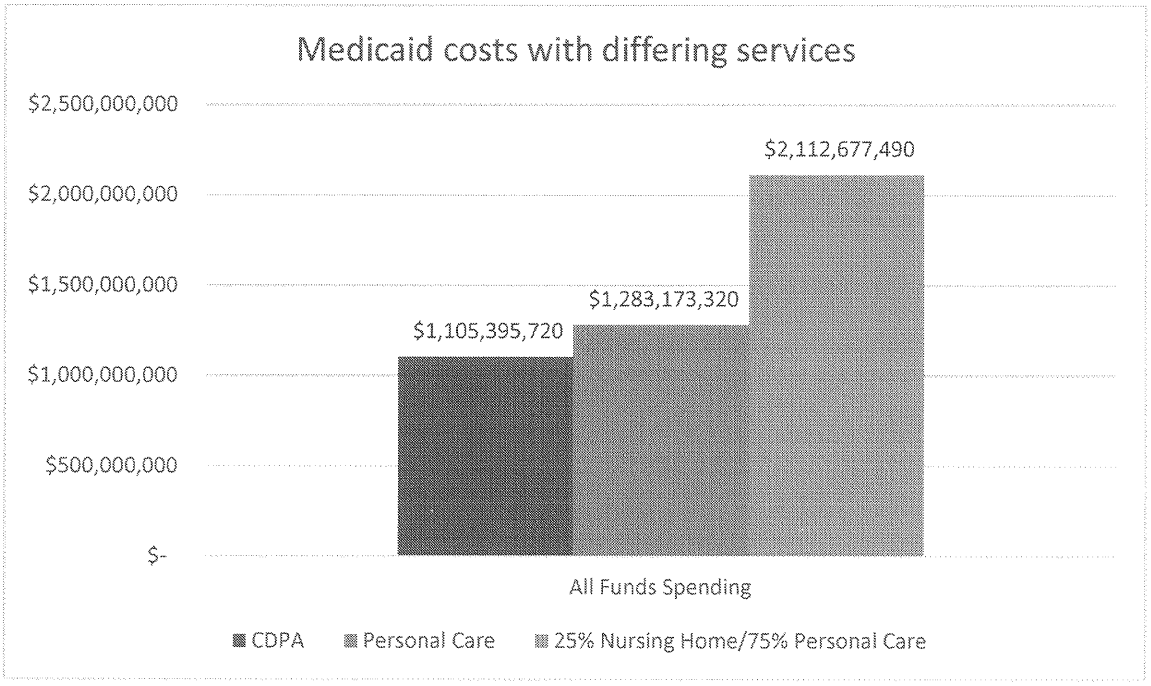
As Medicaid and long-term care has grown, CDPA has been the program that has absorbed much of this growth. This is due to a host of reasons, but not all are negative. That Medicaid long-term care has increased in CDPA, and not traditional means of personal care or through nursing homes, has helped keep the costs of Medicaid down.

The best source we have for the cost of CDPA compared to traditional personal care is the State Plan Amendment (SPA) filed by the state when they sought permission for the Community First Choice Option (CFCO), an option in the Affordable Care Act (ACA) that allowed the state to receive an extra 6% in Federal matching funds for providing services to nursing home eligible individuals in the community. In this SPA, the state said they paid, on average, $2.80 less per hour for CDPA than personal care. While these numbers do not reflect the growth in costs due to minimum wage, we have no reason to think that the difference between the programs has changed at all.

The Budget Briefing Book notes that from 2014 to 2019, CDPAP grew by 88%. Last year, the DOH indicated there were approximately 70,000 people in CDPA. At the identified growth rate, this means there were about 37,500 people in 2014. If the 33,000 people who were enrolled in CDPA instead enrolled in personal care, the cost to the Medicaid would have ballooned.

Based on 37 hours per week, which DOH has said 70% of CDPA recipients in MLTC are at or below, we can conclude that traditional personal care would have cost $5,387 more per consumer every year. With an increase of 33,000 people, this would have cost the state $177.8 million more in one year. The

increased costs associated with personal care do not account for nursing that would be needed for a large number of people. It also does not account for the fact that the home care workforce does not exist to account for this growth. Because of the nursing and workforce issues a total reliance on personal care would present, we also factor in the cost of providing even 25% of these CDPA services in a nursing home. This would lead to an annual increase in spending of over $1 billion.



If the state is committed to ensuring everyone has access to health insurance, we cannot take steps that prevent people from qualifying for Medicaid. However, in helping people learn about Medicaid, they will undoubtedly use the services Medicaid affords them. Unless we want to cut eligibility or access to services, we should be investing in, and encouraging even greater use of, CDPA – not scapegoating and cutting it.

This is one of the reasons why Governor Cuomo's Olmstead Cabinet 2013 report containing recommendations to implement the Supreme Court's *Olmstead* decision contained the recommendation that the state "...offer consumer-directed services as the first option for plan enrollees..." Given that the growth cited by Governor Cuomo began in 2014, it would seem that DOH and the plans were merely seeking to implement the Governor's own Olmstead Plan.

Medicaid jobs are real jobs

The moment in Governor Cuomo's speech that took us, and the consumers and workers who rely on this program, most aback, was when standing in front of a slide with an excerpt from the *New York Daily News,* the Governor read the excerpt, "Medicaid-funded personal care industry added 36,000 new jobs in the first nine months of 2019, making up 75 percent of city-wide private sector job growth." The

Governor read this slide, and repeated the statistic, noting these are jobs paid for by Medicaid – as if this is a bad thing.

The bizarre part of this is that he said in the same speech in which he was trumpeting upstate job growth facilitated by Regional Economic Development Councils (REDCs), which have distributed over $6.9 billion since 2011 to create 240,000 jobs and helped reduce Upstate unemployment by 4.3%. What wasn't mentioned is that when the REDCs spend money, a lot of it goes elsewhere. When we give money to Tesla for a new factory, many of the jobs that were created went to highly trained individuals who moved to the area to take those jobs. They are creating transplants, who gentrify neighborhoods and cost poorer residents their home. The money is invested, and ultimately flows out of the neighborhoods, and in many instances out of the state.

With CDPA and Medicaid, the state dollars invested go to low wage workers. Those jobs go to individuals who live here today. They go to people who are turning around and spending that money on rent, on food, at the local grocer or corner store. The money stays in the community. Further, the individuals who are receiving services are remaining in the community, many of them working. Many of them earning and spending their own money locally. That dollar paid through Medicaid spends much more time in that community, and in New York State, before being transferred out to a large corporation or bank.

With all the talk recently of New York as a donor state, should we not be looking to expand investments that keep our dollars in our communities? Particularly those most impoverished and decimated by historic policies that have created the wealth gap and created communities that were systemically disinvested in as a matter of public policy?

Instead, this budget paints Medicaid jobs, home care jobs, as "less than" the types of jobs that are created by the technology companies we are giving hundreds of millions of dollars in tax breaks to in the hopes of creating a few thousand jobs, with profits returning to their sites of origin in California and Washington. That the work performed overwhelmingly by women, largely women of color, filling an immediate service need, is somehow less legitimate because they are funded by a different form of taxation.

This is why CDPAANYS stands with a coalition called The Caring Majority in calling for the economic development dollars to be invested not in large companies, but in our Medicaid program and other forms of human capital. We can use these investments to offset the costs to counties and the Medicaid program, while improving the quality of the jobs we provide and righting the wrongs of the past.

Growing fast, but not keeping up with demand

Despite the dismissive rhetoric about job growth within Medicaid, there are not enough workers to meet the needs of people eligible for LTSS. The fact is, New York is getting older, and we all know that those seniors who are "healthy and wealthy" leave for warmer climates, while those who are poorer or sicker, two categories that are often interconnected, remain. This has driven the growth of long-term care needs in New York. It is also contributing to, along with stagnated wages, a workforce crisis for

personal care services that has been spreading across the state for the past decade. The Assembly held two days of hearings on the issue in February 2017, in which organizations testified for hours under oath to the extent of the crisis. That same month, CDPAANYS released a report entitled *The High Cost of Low Wages*, based on survey answers from consumers about their staffing experiences. Among key findings, more than 12 percent of respondents could not hire a PA within six months, and more than half took up to six months to staff their hours. Additionally, more than half of PAs who quit reported doing so because of low wages.

Since 2017, the crisis has only gotten worse. The *Albany Times-Union* published a piece in January of this year that examines the impact of a lack of workers in the Adirondacks. It cites the executive director of the largest provider of homecare services in the park, who stated that they have lost 150 workers between 2010 to 2020, and that there are between 700 to 1,000 hours per week of authorized care hours that are unmet. In Franklin County, there is a 96-year-old woman who was authorized for 20 hours of personal care service per week who has still not received a single hour.

Homecare jobs are growing faster in New York than any other state, yet it is the epicenter of the workforce crisis. While the crisis has previously been isolated Upstate, its effects are now being felt hard on Long Island and in Westchester, as per reports in both *Newsday* and the *Journal News*. And, the crisis is now starting to hit New York City. According to a 2018 Mercer Corporation study, New York will be short 20,000 workers in 2022. In fact, Mercer saw the growth that the DOH and Division of Budget say took them by surprise, having estimated in 2018 that the state would need 50,000 new home care workers by 2022.

MRT II: What does the future hold

The Governor's budget reconvenes the MRT, known as MRT II, to look for innovating Medicaid savings ideas. It is possible to lower Medicaid costs without negatively impacting Medicaid recipients or services; but, to do so, we can not rely on budget wonks, hospital and insurance executives, and other industry people. In addition to representatives of long-term care, at least half of the MRT must be comprised of Medicaid recipients and their representatives. CDPAANYS, Medicaid Matters, the Domestic Employers Network, Statewide Senior Action Network, the New York Self-Determination Coalition, legal aid groups, and more must be included.

By including people who live the program, who rely on Medicaid LTSS to remain in the community and their advocates we can get to the list of savings and efficiencies that could improve life for those who rely on Medicaid. In brainstorming with our Consumer Advisory Group, and our provider members, we identified five ideas that, together, could save at least $250 million, increase program integrity, and make the lives of those who use the service better. It is this type of reliance on those who know the system best – the end users – that will help us lower the cost of Medicaid in a responsible manner.

CDPAANYS' ideas would repeal the new funding formula put in place last year, and the draconian cuts that have already caused significant harm to beneficiaries. They would be replaced with the following ideas:

- Make consumer assessments annual, instead of the biannual assessments currently required for MLTC enrollees ($47 million annual in savings);
- Allow PAs to provide transportation for consumers to and from routine medical appointments ($86 million annual in savings);
- Clarify that consumers may only work with on FI to contain growth;
- Formal the process for disenrollment, and for designated representatives to contain growth (jointly, these two ideas result in at least $50 million annually in cost avoidance);
- Create a Minimum Direct Spending Ratio for CDPA (unidentified, as data does not exist; but estimates put savings at a minimum of $75 million)

It is our desire to continue working with you to ensure that CDPA remains available to all New Yorkers who need LTSS, that their PAs are paid fair wages for the underappreciated work that they do, and that the agencies upon which they rely remain intact and capable of coordinating their services and offering support when needed.

Thank you for granting CDPAANYS the opportunity to testify before you today. We are proud of the work that we do and of the program CDPA is today. We ask that you do not look at CDPA in wasted dollars as the Governor would like you to do, but as a lifeline to more than 70,000 of your constituents across the state. I welcome any questions, now or in the future.