Testimony of

Consumer Directed Personal Assistance Association of New York State to:

Joint Legislative Budget Hearing

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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). Over 75,000 seniors and disabled folk rely on Medicaid's consumer directed personal assistance program (CDPA). Those individuals employ over 110,000 people who provide critical services that empower them to live safely at home and be active members of their communities. In many cases, those 110,000 workers were the only people preventing the people employing them from becoming just another COVID statistic. As the only entity solely advocating on behalf of CDPA, it is our express mission to foster and promote the program so that it not only continues to serve those currently receiving services, but is also available to any New Yorker that needs it. We are a grassroots organization providing a means for consumers who use this program to strengthen it while also ensuring programmatic integrity.

CDPA was first conceptualized 41 years ago by a small group of people with disabilities living in New York City, then known as the Patient Medical Home Care Program, who envisioned a system in which individuals receiving long-term care had greater control over their services. Those who use CDPA, referred to as consumers, have the responsibility of recruiting, hiring, training, supervising, and terminating their own staff, called personal assistants (PAs). This allows for greater independence than traditional home care, where agencies hire and schedule the staff that provide services in private homes. Taking on the aforementioned tasks in place of an agency not only allows greater flexibility in scheduling, it ensures that services are provided in a culturally appropriate manner by nearly eliminating linguistic and cultural barriers that pervade the health care system. However, the state's worst in the nation workforce crisis is increasingly jeopardizing the ability of current and future consumers from recruiting the staff they need to remain independent and out of nursing homes. And unfortunately, recent policies have made this situation worse.

Last year, we celebrated the 25th anniversary of CDPA. Our jubilation was quickly replaced by dread and anguish in early 2020, as the COVID-19 pandemic reached our state and began to exponentially claim lives. Early reports of outbreaks and deaths within nursing homes did not prepare us for the disproportionate toll of fatalities within these facilities: to date, nearly 15,000 residents have died, as the disease continues to ravage institutions. After Onondaga County requested and released data from regional hospitals, it was revealed that two out of three COVID-19 deaths in a peak period of infection within the county were of people in nursing homes. We have recently found out that this was, tragically, the case across the state.

Institutional bias: a death sentence

The mounting COVID-19 death toll from inside nursing homes received a lot of attention for the staggering numbers. But the shocking statistics and the astonishing death toll obscured a more basic fact. The COVID-19 pandemic did not create the conditions that allowed for devastation of this scale, it merely placed the spotlight on them. Disease spread and congregate residential facilities have always been inextricably tied. A concentrated medically vulnerable population and a highly contagious and deadly virus created a volatile combination. However, before COVID-19, "routine illnesses" like the flu and common cold would routinely ravage nursing

homes despite the best infection control measures. So, too, would lesser known drug-resistant infections endemic to medical facility settings, such as Candida auris, who's destruction the New York Times chronicled over five months in 2019[1]. Even if COVID-19 had never entered nursing homes, more than 30,000 hospital patients and nursing home residents would have died from these types of illnesses[2].

Isolation and exploitation of nursing home residents were also existing problems heightened by the pandemic. It has been nearly a year since nursing homes across the country began enacting visitor bans. While these bans have been horrid for the institutionalized as well as their families, for so many in nursing homes, "visitors" prior to the pandemic meant volunteers who visited the nursing home out of charity to provide company. This isolation causes depression and anxiety residents. It has become worse during COVID-19, but it has always been there.

Further, without an ombudsman and family to provide oversight and accountability, many nursing homes have new opportunities to exploit residents. One study from the Office of the Inspector General found that, nationally, 85% of nursing homes reported at least one allegation of abuse or neglect[3]. Unfortunately, this is not novel behavior. Disabled people know all too well that arguing for your rights will often lead to punishment, highlighted in repeated news stories about people having wheelchairs removed or being denied visitation or even services.

The bottom line is that nursing homes are not, and have never been, safe places to live. The proposals in the 30-day amendments are critical. We must make sure that those who are already in nursing homes are safe. But, we cannot stop there.

If we are serious about protecting the lives of seniors and people with disabilities, we must reimagine our entire long-term care system. It does not take an expert to know that the best way to avoid dying in a nursing home is not to enter one to begin with; but our policies do not reflect that truth. The status quo is biased towards institutionalization, and recent policies have only made that bias worse.

Changing this bias will require commitment. We must change our way of thinking so that everything possible is done to ensure people can receive the services they need in the community and that we can delay, or completely prevent, institutionalization. We must rethink everything from the way we finance Medicaid, to program eligibility, to how we value those who perform the critical work that keeps seniors and disabled folk safe.

Properly funding Medicaid is key to preventing institutionalization

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[1] Richtel, M., & Jacobs, A. (2019, November 13). New York Identifies Hospitals and Nursing Homes With Deadly Fungus. New York Times.
[2] Richtel, M., & Jacobs, A. (2019, November 13). New York Identifies Hospitals and Nursing Homes With Deadly Fungus. New York Times.
[3] Levinson, D. R. (2014). *NURSING FACILITIES' COMPLIANCE WITH FEDERAL REGULATIONS FOR REPORTING ALLEGATIONS OF ABUSE OR NEGLECT* (Rep. No. OEI-07-13-00010). Washington, DC: Department of Health and Human Services.

One of the policies most responsible for furthering the institutional bias over the past decade has been the Medicaid global cap. Conceived of and implemented during the first Medicaid Redesign Team (MRT) as a tool to reign in medical spending, the global cap placed an arbitrary limit on the Medicaid program's growth by using the ten-year index of the medical component of the consumer price index (CPI). While this measure was a seemingly neutral approach, it had two fatal flaws: it did not account for new services also required by the MRT and it did not allow for enrollment growth based on need.

When the MRT enacted the global cap, they also implemented mandatory Managed Long Term Care (MLTC) for most individuals seeking to access CDPA and other community-based long term care services. As a result, the state pays billions of dollars in premiums to insurance companies to manage Medicaid benefits, a role that used to be handled by counties for a fraction of the cost. These plans are allowed to, and do, take up to 15% of the Medicaid dollars they receive to pay for profits and administrative services, referred to as the "Medical Loss Ratio". This amounts to an increase in expenses of billions of dollars that occurred without a formulaic adjustment, leaving fewer dollars available for actual medical services.

The global cap also fails to allow for growth in the Medicaid budget due to growth in the program, despite the Constitutional obligation of the state to provide healthcare for everyone. This problem has been exacerbated over the past year, as COVID-19 has put additional pressure on a Medicaid budget already pushing against the bounds of a flawed cap.

The health and economic impacts this pandemic make it impossible to keep spending within the cap without shortchanging critical programs. Record unemployment rates have left hundreds of thousands of New Yorkers reliant on Medicaid. This has led to 13.4% Medicaid enrollment growth from March to September 2020[4]. As the state continues to face the worst public health crisis in a century, and the economy falls to levels not seen since the Great Depression, there is no methodology that makes this artificial spending cap functional, it must be repealed and the Governor and Legislature must once again determine the fiscal constraints of this program based on need, through negotiation in the budget process.

Cuts disproportionately impact seniors and the disabled

The global cap has caused harm throughout the Medicaid program; but, that harm is disproportionately felt by seniors and the disabled. While these populations only comprise 22% of the state's Medicaid consumer population, they account for 63% of Medicaid spending[5]. As New York's population rapidly ages, with much of that population being poor and facing long-term health needs that stem from poverty, the long-term care sector has borne a

[4] Lina Stolyar, E. (2020, December 01). Growth in Medicaid MCO enrollment during the Covid-19 pandemic. Retrieved February 09, 2021, from https://www.kff.org/coronavirus-covid-19/issue-brief/growth-in-medicaid-mco-enrollment-during-the-covid-19-pandemic/#:~:text=Among%20the%2030%20states%20reporting,the%20median%20growing%20to%2010.9%25.

[5] Medicaid in New York. (2019, October). Retrieved from http://files.kff.org/attachment/fact-sheet-medicaid-state-NY

disproportionate brunt of cuts. These cuts have manifested in two ways, eligibility cuts and reimbursement cuts. Both have led to further the institutional bias of New York Medicaid policy.

Eligibility cuts: Violating civil rights and encouraging institutionalization

Nowhere was the disproportionate impact of the global cap on those requiring long-term supports and services exemplified better than in the MRT II process last year. Of the budget year reductions in the SFY 2021 budget, 46% of the cuts were to long-term care. This did not include the impact of the additional 0.5% across-the-board cut to providers. For perspective, the next largest cut sector was hospitals, with less than half the amount of cuts that long-term care endured. For those who rely on CDPA and personal care, the effect of these cuts was a violation of their basic civil right to live in the least restrictive environment.

MRT II dramatically cut eligibility for community-based long-term care services and overhauled the assessment process. The effect of these cuts was a “Goldilocks” approach to Medicaid, as hundreds of thousands were suddenly “too disabled” to receive community-based supports, and hundreds of thousands of other folks were “not disabled enough.”

Most of these individuals could still receive services in a nursing home.

Eligibility for CDPA and personal care was changed to require individuals in need of services to require assistance with three or more activities of daily living (ADL), such as bathing, toileting, transferring, or getting dressed, unless they had Alzheimer’s disease or dementia, in which case they only required assistance with two. For thousands of disabled New Yorkers, this meant they would not qualify for critical services that prevented them from decompensating and needing higher levels of care. It meant that, if they did not end up in a nursing home, they would ultimately need much higher levels of care when they did finally qualify.

For those who could still qualify, the process made it dramatically more burdensome to receive services. The new laws drastically changed the assessment process, implementing onerous new requirements and completely removing the knowledge and perspective of an individual’s health care provider. Those seeking services could no longer use their own practitioner to receive an authorization, but instead be examined by a Maximus employed doctor who was not even required to review their old medical records. This process not only removes the expertise of the person most familiar with the person’s medical history, it also creates a strong potential for a bottleneck as Medicaid recipients wait for the limited pool of providers to perform their medical assessment.

The rules went a step further though, and created an arbitrary new “safety review” for individuals authorized to receive twelve hours or more of services per day. Despite no clinical evidence that this population is at greater risk in the community and multiple safety reviews already embedded in the assessment process, those “too disabled” for services would require yet another independent medical review to determine if they are “...capable of safely remaining in the community.” The Department of Health maintains that this is necessary to ensure people are receiving the proper level of care; however, draft regulations implementing the rule prevent the

review from requiring higher levels of service. Instead, they may only say whether or not someone is “safe” from their perspective.

These rules are not merely bad social policy that violate the civil rights of seniors and disabled folks in need of CDPA or personal care, they are also bad economic policy. The rules jeopardize hundreds of millions of dollars in Federal funding. Under the Affordable Care Act’s community first choice option (CFCO), the state receives an extra 6% in Federal matching funds for most long-term care services delivered in the community. However, this additional funding comes with conditions, one of which prevents discrimination based on the type or severity of a person’s disability[6]. Clearly, these rules violate that provision, and the state could forfeit approximately $300 million per year if this is implemented.

Reimbursement cuts: exacerbating the workforce crisis

Most of the cuts over the past two years were to reimbursement. These cuts have resulted in lower wages for PAs and personal care aides (PCA), meaning jobs that were a potential path to middle income now are the lowest paid jobs in our economy.

While all of the cuts were harmful, one stands out most, and it is repeated in this year’s budget. That is a cut to “Home care workforce recruitment and retention.” This funding, which is a supplemental payment in fee-for-service and added into rates through managed care, must be spent on PA and PCA wages and benefits. Last year’s budget cut this funding by $45 million, or 25%. This year’s budget doubles the cut, bringing the total reduction to $90 million, or 50%. To cut wages and benefits for these frontline heroes as they risk their lives to provide services in a pandemic is appalling enough. But, the rationale used for the cuts is even more shocking. The sponsor’s memo for the budget states that the cut is necessary to better align spending with need. Given that New York is the epicenter of the national home care workforce crisis, this rationale is unfathomable.

If these cuts stood alone, they might not cause an impact. But, the workforce and recruitment cuts are merely the tip of the iceberg. Rates for FIs have been systemically cut by hundreds of millions over the past several years. Across the board Medicaid cuts have combined with reductions in administrative payments, which were often used to subsidize inadequate payments to account for overtime and other services.

While in the past, those cuts would have resulted in the elimination of overtime, that can no longer happen. The Department of Health arbitrarily and without discussion changed an almost 30 year old policy when it released the request for offers (RFO) for a limited number of state contracts to be required to continue administering FI services. One of the many conditions FIs had to agree to if awarded a contract was that they could no longer limit overtime. An FI may not even limit someone from working 24 hours a day, seven days a week - something that is clearly not humanly possible.

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[6] Community First Choice Option, 77 § 1915(k)(3) (2012).

Consequently, agencies have no choice but to lower worker wages when possible. In fact, Fidelis, who was cutting their reimbursement to FIs by substantial margins, would openly tell agencies that their rate only worked if agencies were paying workers minimum wage, though it did not even work under that scenario. Their parent company, Centene, did however realize profits of $1.8 billion, a 38% increase over their 2019 report.

Underfunding CDPA through reimbursement cuts puts the service out of reach to thousands of Medicaid consumers who need it. It is a cruel cycle: providers are not paid sufficient rates and in turn cannot pay PAs a fair wage. This leads PAs to seek other employment to support themselves and their families, decreasing the supply of available workers while demand increases. Consumers, unable to recruit or retain workers, go without needed services, exposing themselves to increased risk of injury. This injury potential increases the risk of hospitalization and, ultimately, institutionalization paid by Medicaid, driving up costs for Medicaid even further and ultimately resulting in more cuts, which starts the process all over.

An easy solution: Fair Pay for Home Care

The workforce crisis driven by the cycle of underfunding has been well established. Legislative hearings four years ago led to two days of testimony where everyone except the Department of Health spoke to the harm being caused by the crisis. National workforce experts from Mercer Consulting released a study in 2016 that identified New York as the epicenter of the home care workforce shortage, predicting a need for 50,000 more workers than will be available at the current rate by 2023[7]. Mercer published another report on the topic in 2018 that paints a more dire picture, projecting a shortage of 83,000 workers by 2025[8].

The shortage of home health aides is so severe that new home care cases cannot be opened in many upstate counties. Managed long term care plans will routinely authorize more hours if someone utilizes CDPA, not because they prefer the service but because they know that home care companies cannot staff cases at the hours required. The same limitations apply in CDPA, but the onus falls on the consumer themselves, the plan is not accountable.

In April 2020, CDPAANYS' updated our 2017 report *The High Cost of Low Wages*, which used consumer survey results to examine the ability to hire and retain PAs based on the frequency of advertising. Almost a quarter of respondents reported posting an advertisement more than six times pers year and more than a third advertised three to five times per year. Consumers reported that 61% of PAs cited low pay for the reason they quit[9]. This means that a majority of consumers are in a near perpetual state of recruitment because wages are insufficient. In any other industry, that would be considered a failure of management. In New York's Medicaid system, it's been viewed as a rationale for cuts.

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[7] Narlock, J., PhD, & Stevenson, M., PhD. (2016). *Healthcare Workforce 2025 Part II* (Rep.). Mercer.
[8] Stevenson, M. (2018). *Demand for Healthcare Workers Will Outpace Supply by 2025: An Analysis of the US Healthcare Labor Market* (Rep.). Mercer.
[9] P. (2020). *The High Cost of Low Wages: The disregarded impact of balancing a budget on the backs of the disabled* (Rep.). Albany, NY: CDPAANYS.

The High Cost of Low Wages demonstrates what should be simple logic, but unfortunately is often lost: people are not taking jobs and/or are quitting because of low wages. The obvious solution is to increase wages.

Home care workers today earn a median annual salary of about $22,000[10] per year, a mere five dollars per week, about the price of one gallon of milk in New York City, over the Federal poverty level for a family of three. This wage is more than $13,000 less than the median annual cost of a one bedroom apartment in New York City[11], and $8,000 less than the legally mandated salary of a full time-fast food employee. These workers provide critical services to consumers and also have their own families to support. To survive on these wages, more than 50% of workers are themselves on Medicaid, as well as other public benefits.

The workforce crisis is only going to continue to worsen. Despite the fact that home care, and CDPA in particular, is the fastest growing sector of the workforce in most parts of the state, current demand for workers far outweighs supply[12]. The state's senior population continues to increase, and the "healthy and wealthy" retire to warmth and sun while those who remain are impoverished, dealing with the comorbidities that stem from poverty, and reliant on Medicaid.

The New York State Office for the Aging estimates that by 2030, 25% of the state's population will be people aged 60 or older[13]. As people age, the likelihood of developing a disability rises. More than half of individuals who are 65 years old now will need long-term supports and services in their lifetime[14]. If there is no one available to provide these services in the community, an individual is at imminent risk of institutionalization; extrapolating from this data we can expect that tens of thousands of people will be placed in nursing homes despite their wishes if the workforce crisis is not addressed.

The answer to the crisis is easy. Fair pay for home care would require home care workers in Medicaid programs, including CDPA, be paid 150% of the highest minimum wage in the region in which they work. This would restore wages to approximately the level they were at in 2006, in relation to the minimum wage.

A report from the CUNY School of Labor and Urban Studies report estimates that the $4 billion investment necessary to make this happen would generate increased taxes and savings of $7.6 billion. The benefits are not limited to the home care workers themselves, either. They note that

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[10] Jabola-Carolus, I., Luce, S., & Milkman, R. (2021). *The Case for Public Investment in Higher Pay for New York State Home Care Workers Estimated Costs and Savings* (Executive summary). New York, NY: CUNY School of Labor and Urban Studies.

[11] Ricciulli, V. (2019, June 03). NYC one-bedroom rents Hit $2,980/MONTH, an all-time high. Retrieved February 12, 2021, from https://ny.curbed.com/2019/6/3/18650949/nyc-rent-prices-zumper-report

[12] David, G. (2019, August 05). Home health care drives job growth. Retrieved February 22, 2021, from https://www.crainsnewyork.com/greg-david-new-york/home-health-care-drives-job-growth

[13] Older adults: An economic powerhouse. (2019, November 19). Retrieved February 09, 2021, from https://aging.ny.gov/news/older-adults-economic-powerhouse#:~:text=New%20York%20State%2C%20with%20more,percent%20of%20the%20state's%20population

[14] Nguyen, V., MPA. (2017). *Long-Term Support and Services* (Fact sheet). Washington, DC: AARP Public Policy Institute.

the investment will generate significant revenue from increased sales taxes and provide economic stability for entire neighborhoods as these workers spend their increased wages on food, transportation, rent, and other goods and services - including many of the sectors hit hardest over the past year by the COVID-19 pandemic.

The report estimates that the increased spending will generate 20,000 jobs per year for the next several years within the home care sector and that the increased spending by these home care workers would generate another 17,500 jobs per year in the broader economy. This net increase of 38,000 jobs per year for the foreseeable future far outpaces even the most ambitious economic development program and would quickly eliminate the workforce gap identified by Mercer.

Aside from the health and economic considerations, this is an issue of gender and racial equity. More than 85% of home care workers are women, 62% are people of color, and 31% are immigrants[15]. We are tasking this workforce with some of the most physically and emotionally difficult work, trusting them with the well-being of our loved ones, while paying them poverty wages that allow many of them to qualify for Medicaid themselves. These are people who have their own families to care for, some of whom may also rely on these workers for their own unpaid care needs. It is a system that has its roots in institutionalized racism and sexism, and it dates back to slavery. It is imperative that we treat these workers with the respect they deserve. We cannot wax philosophical about racial justice while we refuse to lift people of color performing this work out of poverty.

New York's long-term care system has reached a fulcrum point. If we hope to retain the infrastructure for community-based services, we must overhaul the practices that prioritize institutionalization, and it begins with ensuring the workforce is paid fairly. Guaranteeing home care workers a wage of 150% of the minimum wage is the only way to accomplish this. We have seen this tidal rushing towards us yet continued to ignore it. Action must be taken now: we must reimagine our approach to long-term care and enact Fair Pay 4 Home Care.

Next steps

As you craft your one house budgets, there are a number of measures to take to make Medicaid work for the people you represent.

- **The global cap must be repealed.** This is a basic and necessary to appropriately fund a program on which one out of three New Yorkers rely, particularly seniors and people with disabilities, whose care costs are disproportionately higher than the general population of Medicaid consumers.
- **Repeal the CDPA and personal care assessment overhaul and eligibility cuts in the budget before they are implemented.** These cuts reinforce the existing institutional bias and put community-based care out of reach for thousands of people who will still be eligible for nursing home placement. This is wrong in the best of times, but in light of the devastation of the COVID-19 pandemic, it is a death sentence for thousands of people.

[15] *Direct Care Workers in the United States Key Facts* (Issue brief). (2020). Bronx, NY: PHI.

- **Invest in CDPA through Fair Pay for Home Care.** This includes:
    - Ensuring home care workers, including consumer directed personal assistants, earn 150% of the highest minimum wage in a region. This will eliminate the workforce crisis. Current and future consumers will be able to hire and retain enough workers to live safely at home and tens of thousands of workers will be lifted out of poverty, benefitting their families and local communities. It is a matter of economics, equity, and justice that cannot be delayed.
    - Ensuring that managed care and fee for service Medicaid rates are sufficient to account for all of the costs providers incur, and that plans face accountability for unjustified cuts that do not meet this threshold.
    - Creating a dedicated overtime rate. This will offer immediate relief for consumers facing staffing shortages and FIs who cannot afford to provide overtime under the current reimbursement structure, even as DOH changes a decades old rule to prevent FIs from limiting overtime in any way.

Thank you for granting me the opportunity to testify today. I look forward to working with you through the budget process and remainder of the legislative session to make these proposals a reality. I am happy to answer any questions you may have now or in the future.