Good afternoon Senators and Assembly Members. I want to thank you for having these important hearings. But, as we conduct these hearings, it is vital that we realize we will not fix nursing homes. We must use this tragedy to shift our thinking to focus on improving services in the community. CDPA provides better services than institutions. It is also much better at addressing many of the health disparities that plague the health care system and society, disparities that led to disproportionate deaths in Black and Brown communities, not just in the community; but, within nursing homes as well.

We know that more than 6,300 New Yorkers who lived in nursing homes have died after contracting COVID-19, a number that does not include those who were transferred from a nursing home to a hospital and died there. Achieving justice for these victims and their families is necessary. But, we cannot be fooled into thinking that these investigations can make nursing homes safe. In most cases, the problems that we've seen from COVID are not new, they have just been exacerbated by this virus.

In the late 1970s, another crisis led to New York becoming a national leader in reforming the way services for disabled New Yorkers are thought of. Today, the word Willowbrook is synonymous with deinstitutionalization. I personally have benefitted from the State's leadership here. Some of you may know that I have epilepsy. Throughout much of the last century, and as recently as 1988, instead of sitting before you here today providing testimony, I could have been at a Colony for Epileptics in Sonyea, NY. I tend to think the decision to reform how we treat epilepsy has worked pretty well for me, and for the State of New York.

To provide justice to the victims in this tragedy, we must again use this crisis as a means to improve the lives of seniors and disabled New Yorkers who want to receive services in their communities so that we can improve the lives of future generations who will need those services.

Nursing homes - Where we send the poor to die

An uncomfortable reality is that through aging, most everyone will experience a decline in their physical abilities and require assistance for some daily tasks. But, we know now that not everyone will go to a nursing home.

As former Albany County Executive Michael Breslin was fond of saying, "I never heard of anyone who said 'I can't wait to go to a nursing home.'"

I guarantee you that Michael Bloomberg will never be in a nursing home. Research is clear, the poorer you are, the more likely you are to die in a nursing home.[1]

[1] Tokar, S. (2010). "Social Support is Key to Nursing Home Length of Stay Before Death." *University of California San Fransisco.*

Nobody wants to go to a nursing home. And if you have to go, you want to go home as soon as possible. There are lots of good reasons why, but at its core - people do not want to go because they know that a nursing home is where you go to die. Alone. The median life expectancy of an individual in a nursing home is just five months - and this was before COVID.[2]

The ability to age in place is a human right. But, it is one that is contingent on being able to receive the services you need to live safely in the community. A person who is otherwise independent but cannot obtain assistance with certain tasks is at risk of injury that could lead to costlier, more invasive interventions down the line. Too often, this means that, for people with means,they find access to home care. For poor folks, they go to a nursing home. But trust me, I guarantee you that Michael Bloomberg will not die in a nursing home.

This is why we saw dramatic disparities in who died of COVID-19 during the pandemic. Black and Brown residents were not just grossly over-represented in community fatalities, the number one factor that determined the extent of fatalities in a nursing home was the number of Black and Brown individuals it held.

As our state ages, we must reconcile that an overwhelming majority of that population will be African-American and LatinX. The majority of those individuals are poor. They will need services. Research shows that nursing homes are detrimental to their health. If we do not fundamentally alter our long-term care system, then we are sentencing them to an early death.

The problems with nursing homes existed before COVID-19

What has occurred over the last several months is nothing short of a tragedy. But, it is important to realize that the problem is not new. The COVID-19 outbreak is not the first instance of a disease disproportionately impacting nursing homes. A drug resistant fungus, Candida auris, ravaged acute care facilities both in New York and internationally as family members watched helplessly[3]. During Superstorm Sandy, there were countless accounts of facility deaths attributed to power outages, and anecdotes abound of neglect and loneliness during routine

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https://www.ucsf.edu/news/2010/08/98172/social-support-key-nursing-home-length-stay-death#:~:text=The%20average%20age%20of%20participants,study%20died%20within%20six%20months.

[2]Kelly, A., Conell-Price, J., Covinsky, K., Cenzer, I.S., Chang, A., Boscardin, W.J. and Smith, A.K. (2010), Length of Stay for Older Adults Residing in Nursing Homes at the End of Life. *Journal of the American Geriatrics Society, 58: 1701-1706.* doi:10.1111/j.1532-5415.2010.03005.x

[3] Richtel, M., & Jacobs, A. (2019, November 13). "New York Identifies Hospitals and Nursing Homes With Deadly Fungus." *New York Times*. Retrieved July 30, 2020, from https://www.nytimes.com/2019/11/13/health/candida-auris-resistant-hospitals.html

times. And, despite the best efforts of policy makers and nursing homes, influenza routinely runs rampant through these facilities, for many of the same reasons that COVID-19 did.[4]

It is clear, nursing homes inherently pose a safety issue for residents - residents we know are more likely to be impoverished minorities. But still, state policy favors nursing homes over home care or consumer directed personal assistance for those on Medicaid. Examine the long term care eligibility and enrollment policies and you will find a bias towards institutional care, even as home care services generally cost less. For instance, in this year's budget, the state enacted a look-back period for home care and CDPA. This policy requires individuals to go through the look-back, which often takes six months or more, before they can receive services. However, when that same individual goes to a nursing home, they receive services *while* the look-back is taking place, and the nursing home decides who to bill - Medicaid or the individual, once the look-back has been completed.

This is just one of the latest policies that favors nursing homes. Whether it is 50 year old policy that has not been changed or new policy from this year's budget, there remains an ableist bias that assumes disabled and the elderly are not capable of living in the community. The result of each policy is the same.

Reimagining long-term care could improve services for all, particularly the most marginalized

It is clear we cannot fix nursing homes. But, just as my future for services is no longer a colony for epileptics, it is time to act and determine if we should. Certainly, for those in nursing homes, the system must do everything possible to keep them safe. However, we need to begin to shift our priorities to care in the community, which is not only higher quality, but also less expensive.

While the average life expectancy in a nursing home is five months, according to the United Hospital Fund's Medicaid Institute, the average amount of time someone receives personal care services (including CDPA) almost five years.[5] The study also found that long-term care costs to Medicaid for individuals receiving personal care was approximately the same before and during their use of personal care services, as the high personal care costs supplanted equally high cost acute care.[6] Thus, in an era of Potentially Avoidable Hospitalizations, personal care and CDPA take large steps in that direction.

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[4] Howley, E. (Nov. 11, 2019). "Vaccination in nursing homes." *U.S. News and World Report.* Accessed on July 30, 20202. *https://health.usnews.com/health-news/best-nursing-homes/articles/vaccination-in-nursing-homes*

[5] Samis, S. and Birnbaum, M. (2010). "Medicaid personal care in New York City: Service use and spending patterns." *The Medicaid Institute at the United Hospital Fund.* Accessed on July 30, 2020. https://www.agingny.org/uploads/1/2/3/0/123049588/2010dec_uhf_medicaidpersonalcarenyc.pdf.

[6] Ibid.

Within CDPA, we know that the results are even more striking. Anecdotal data suggests that those who receive CDPA services from a paid family member or friend often provide substantial value to the state, as services are better and the caregivers provide substantial amounts of informal, or unpaid, care above and beyond what the managed care plan has authorized. As long as family can pay the bills, their primary interest is ensuring the safety and quality of life of their loved ones, not whether or not they are getting paid.

Further, we know that CDPA has the potential to address many of the health disparities that nursing homes, and much of the health care system, fail to address. Because the consumer, or recipient, is the one hiring, they can guarantee that those they hire speak their language. They do not have to worry about whether or not an individual will respect their cultural needs, such as in the way that food is prepared. And, by giving an individual control over how their services are provided and who provides them, we can address many of the institutional concerns that prevent particularly African-Americans from seeking health care - concerns that stem from centuries of institutional racism such as Tuskegee, Henrietta Lax, eugenics, and countless other experiments.

Community-based long-term supports such as personal care and CDPA enhance quality of life and extend the life of individuals. CDPA eliminates many, if not all, of the factors that lead to health disparities. However, these services are also less costly.

According to the New York Department of Health, the average person receiving CDPA receives 37 hours per week.[7] With an average reimbursement of approximately $23 in New York City, the average individual receiving these services costs approximately just under $45,000 per year. The cost of a nursing home to Medicaid in New York City is approximately $155,000 per year. Further, because the state receives an extra 6% in Federal matching funds (FMAP) due to its participation in the Affordable Care Act's Community First Choice Option (CFCO). Therefore, the state costs of CDPA are about $19,500/year. The state-share cost of that nursing home is $77,500, four times more.

Indeed, there is only one cohort of individuals for whom services are more expensive in the community than in a nursing home. That is the individual who receives continuous 24/7 care. At $23/hour, the provision of continuous care costs approximately 201,000 per year. But, when we factor in the additional FMAP the state receives to provide services in the community, the state share cost decreases to $88,400, only ten thousand more than in an institution.

Of course, the state's shift to managed care minimizes the actual savings the state realizes from personal care and CDPA. With the average reimbursement to plans being about $4,800 per month, the state does not realize this savings - the health plans do. As previously noted, these same plans do not have to pay for nursing home care at all. Therefore, the moment a member

[7] Affidavit of NYS Medicaid Director Donna Frescatore. (2019). Provided in the matter of *CDPAANYS, et. al. v Zucker.*

needs more services than $4,800 per month allows at a profit, it becomes the best interest of the plan to force that individual into a nursing home.

Of course, for the individual receiving continuous care services, the switch to managed care has benefitted the state. Instead of absorbing the full cost of that case, the state's exposure is limited to $4,800 per month. The case may push the capitation rate higher; however, while the plan may not earn $26 billion in revenue during the first quarter of the year[8], they will still realize savings due to the fact that the strong majority of individuals receiving long-term supports and services do not receive continuous care.

The Impact of COVID-19 on CDPA

CDPA and home care were also negatively impacted by COVID-19, and there were reports of deaths from consumers and their workers. Often, these illnesses stemmed from hospitalizations on different issues, as was the case with one of our volunteers, who lost her life to COVID-19 early in the crisis after a brief hospitalization. Others contracted the virus while traveling to and from work.

It is impossible to know how many individuals receiving CDPA became infected with COVID-19. The state did not collect this data. But, we know that the factors that led to devastation in the nursing home population do not exist in home care and CDPA. While one nursing home worker can infect hundreds of patients in an institution; in CDPA, that person typically only works with one, maybe two, consumers. Quarantining is much more effective in the community and steps can be taken to minimize the spread of the virus.

The commitment workers demonstrated during this pandemic will be talked about for generations. Many upended their lives, moving in with their consumers to minimize the chance of infection. Others would have three sets of clothes to protect the safety of their consumer and their family, changing on the consumer's front doorstep to avoid contaminants from their ride to work, changing after the shift to avoid contaminating those on public transportation, and changing at their front door to avoid contaminating their family.

But, overwhelmingly, the largest problems stemmed from the failure of Medicaid to provide needed resources.

CDPAANYS surveyed consumers and designated representatives on their experiences since the pandemic began. Across every region of the state, between 70% and 90% of respondents indicated that they were more likely to die if they caught COVID-19. Between 50% (New York

[8] Centene Corp., parent company of Fidelis Health Plan, reported first quarter revenues of $26.025 billion in 2020. "Centene Corporation Reports First Quarter 2020 Results." April 28, 2020. https://investors.centene.com/news-releases/news-release-details/centene-corporation-reports-first-quarter-2020-results#:~:text=ST.,Adjusted%20Diluted%20EPS%20of%20%240.86%20.

City) and 88% (Capital District, Hudson Valley) were worried that they would become infected. However, institutionalization was what most feared, in some cases more than the virus itself.[9]

This fear was partially due to the historic institutional bias. It was due to state policies and "ethics" discussions that centered on whether ventilators should be pulled from vent users to be used on "otherwise healthy" indiivduals in need for COVID. It was due to consumers inability to hire more workers and access personal protective equipment (PPE). Consumers across the state lost workers due to childcare, viral infection, or the worker's own need to remain quarantine due to their own health concerns. Complicating this was the inability to access basic PPE. Despite FIs providing masks to workers, many consumers reported problems obtaining enough masks. Similarly, consumers could not buy gloves, which have traditionally been provided by Medicaid, rubbing alcohol, or other critical supplies. In many instances, these were prioritized to hospitals and other settings, a policy that prioritized the life of those who were in a hospital over those in the community with long-standing needs.

Despite these problems, it is clear that home care, and CDPA in particular, was substantially less dangerous than an institution. But, complicating matters and demonstrating the institutional bias that exists, on June 29, in the face of all evidence to the contrary, Governor Cuomo said to Chuck Todd on *Meet The Press* that, "...So you could argue that they (a senior citizen in a nursing home) are safer than a senior citizen at home."

Conclusion

COVID-19 provides us with a unique moment to analyze our policies, the impact they have, and what we can do to improve them into the future. It is clear that the problems COVID-19 has shone a spotlight on in nursing homes exist outside of COVID-19. It is clear that community-based services like CDPA are not only less expensive, they provide higher quality services and better deal with pandemics, both the unexpected, like COVID-19, and the expected, like seasonal influenza.

As we have this discussion, I'm reminded of an old truism about smoking. It was noted by many that while the healthcare costs for smokers are substantially higher for a brief period of time, they die decades before their non-smoking counterparts, minimizing the long-term expenses they would otherwise experience over that time. Basically, by dying sooner they saved the government money. Despite this, we did the right thing and, over the course of time, have dramatically reduced the rate of smoking throughout this state.

[9] Battista, J and Bryan O'Malley. (2020). "The impact of COVID-19 on CDPA in New York State." https://cdpaanys.org/wp-content/uploads/2020/06/CDPAANYS-COVID-19-Impact-Survey.pdf.

If we do not use COVID-19 as an opportunity to change our policies around nursing homes and long-term care, we are in essence saying that, unlike smoking, we will continue to promote institutionalization because, well, while it costs more in the short-term, the residents die and that saves us money overall.

Thank you for the opportunity to testify today. I look forward to continuing to work with you on this critical topic so that together we can change the way we consider long-term care policy in New York and become a national leader on independence once again.