



Consumer Directed Personal Assistance Association of New York State

End New York's long-term care institutional bias

It is now known that COVID-19 has accounted for more than twelve thousand deaths in nursing homes. While the sheer numbers are shocking, it is important to note that the problems the virus is merely exploiting long-standing issues in these facilities. Nursing homes have long acted as a petri dish for illnesses. Similarly, the highly reported isolation and exploitation of those in facilities has been at issue for decades. Seniors, those with disabilities, and their families would prefer to have high quality services in the community, but the state has passed consecutive budgets that have reinforced existing bias towards nursing home placement through reimbursement and eligibility cuts. To prevent a tragedy such as this again and learn the lessons COVID-19 seeks to teach, we must invest in community-based services and end policies that favor institutionalization.

Months before COVID-19 was identified in the United States, news outlets were reporting on deadly outbreaks of Candida auris and other drug resistant illnesses. Indeed the common cold and influenza have routinely wreaked havoc in these facilities. Some of the first COVID-19 related deaths in the United States were of nursing home residents, and those numbers soon skyrocketed. New York's initial response was disastrous, including a requirement that facilities take in COVID-19 infected residents, combined with the granting of immunity from liability. While both of those policies were ultimately reversed after much criticism, thousands had needlessly died and disease spread continued.

As the virus ravaged these institutions and the state scrambled to play catch-up, enacting visitation bans. These bans prevented loved ones from visiting and prevented an under-funded ombudsman program from accessing facilities. In doing so, the visitation ban exacerbated existing crises around feelings of isolation in these facilities. Worse, they opened residents up to greater exploitation, a long-standing problem in facilities. The results were secondhand reports of theft of COVID relief payments and harsh penalties to residents who spoke out about what was occurring inside facilities.

COVID-19 presents an once-in-a-lifetime opportunity to reimagine what our society looks like. If we are to take advantage of this opportunity and learn the lessons the tragedies can teach, we must change the focus of our long-term care system to prioritize care in the community. However, doing so means repairing a system that has suffered tremendously over the last decade, particularly with a quarter billion in cuts over the last two years alone. Low wages, a direct result of this neglect, have created a "worst in the nation" workforce crisis that must be addressed. This crisis will prevent the changes that are needed unless wages for this workforce are returned to the 150% of the minimum wage that they were at as recently as 2006.

Without immediate action, seniors and people with disabilities risk injury and institutionalization against their wishes and the state will be unable to act to shift the bias for institutional care. Reimbursement rates should have been increased annually to allow PA wages to keep pace with inflation, but cuts have instead led to reductions in wages in many instances. Nursing homes, already notorious for disease spread and isolation before COVID-19, have been made worse during the pandemic. We must reimagine our long-term care system and champion consumer directed personal assistance and other home care services through equitable funding.

The problems in nursing homes are not new. The state must learn the lessons of COVID-19 and reimagine this system to prioritize community-based services.

CDPAANYS is the only statewide association solely representing fiscal intermediaries, consumers and personal assistants in Consumer Directed Personal Assistance (CDPA). For more information, please contact us at 518-813-9537 or bryan@cdpaanys.org.