

Testimony for the New York State Joint Legislative Hearing on the Budget

Proposal: Health/ Medicaid

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Senate Chair Rivera and Members of the Committee, thank you for holding this important hearing. I know many of you are staunch supporters of Fair Pay for Home Care (A.6329/S.5374A) and I am pleased to testify in support of strong investments in health through increased investments in home care. Home care workers are essential for older adults and New Yorkers with disabilities to live and age safely and with dignity in their homes and communities, but for too long have been underpaid and exploited, lacking dignified working conditions. And, so I urge you to support Fair Pay for Home Care.

I write this testimony as a member of [JFREJ](#) and [Hand In Hand: The Domestic Employers Network](#) and in tandem with my mother, Janet, who 26 years ago this month had a cerebral aneurysm rupture, which left her in a coma and minimally conscious state, and on life support for nearly five months. At the time we lived with my grandmother, then 90 years old and with increasing care needs that fell to me, due to the unavailability of adequate home care. **I was 17 years old.**

Against all odds, my mother survived and after five long years in hospitals and nursing homes, she came home in 2001 and has been receiving Home and Community-Based Services through the DOH TBI Medicaid Waiver Program since. Ironically, we were lucky that my mother didn't have a well paying job or health insurance. As a poor, uninsured New Yorker, she was immediately eligible for Medicaid. Given the extensive in-patient treatment and long-term care she received in the five years after her injury and the subsequent decades of home care she continues to receive, Medicaid was the only option. I am certain private insurance would have denied services and who knows where that would have left me, a teenager, trying to navigate insurance claims while coping with a dying mother and attending school. We are one of the [500,000 families who rely on home care](#) in New York State and without these services, which are heavily supplemented with my care, my mother would not be able to live at home. She enjoys a relatively good quality of life, but without significant 'behind the scenes' support from my husband and I and her wonderful home care worker, she would be unable to live in the community and would, against all of our wishes, be forced to live in a nursing home, which would be a violation of the Olmstead Decision.

My grandmother died at home at 102 years old. She had too many assets to be eligible for Medicaid, but nowhere near enough money to pay for home care services in the last years of her life and so did not receive sufficient home care services. As a result, I was forced to make difficult decisions about spending her resources on paid care and delaying my own educational and employment opportunities. Luckily, her savings and my unpaid care got her through the end of her life. However, this "choice" isn't one families should have to make. It is bad for families and costs the state, as people forego paid employment

to provide care. Adequate care shouldn't depend on luck or exploited labor. Many older adults and people with disabilities aren't as lucky as we were.

As one of [New York's 2.5 million family caregivers](#), I know first hand how important investing in our caregiving infrastructure is. Paid home care has been essential in order for me to continue to provide care at home for the past two decades, while also being able to engage in paid employment outside of the home. Paid and family care goes hand-in-hand and one cannot adequately function without the other. Every day I worry about the precarity of my mother's home care situation. Despite the significant in-home services my mother receives, I also provide care and supervise the formal care she receives for what equates to the hours of *three full-time jobs*. My mother receives 40 hours of paid care a week. This sounds like a lot and is much more than many people receive, but even with so many hours, my husband and I are on call during the other 128 hour each week, including nights and weekends, with no time off. We are very lucky, but underserved and without sufficient home care to fully meet my mother's needs. In theory, my mother is eligible for 24/7 care, but I know too well the reality. [With 25% of home care patients being unable to find home care workers](#), due to worker shortages, I'm acutely aware that I will be forced to provide more care as my mother ages and as her health and mobility decreases. Without legislation to protect home care workers, create dignified wages and working conditions and increase available services, I will likely be required to give up even more paid work to care for her as she ages. Without a reliable paid workforce, family caregivers' jobs are that much more difficult, with as many as [10% leaving the workforce](#) in order to provide care. Currently, [17% of home care positions are unfilled due to staff shortages, and 42% of New York's home care agencies have reported high turnover](#). Without legislative intervention this dire situation will only get worse. If I can't work, I will likely end up on Medicaid myself in the future when I need care. Fair Pay for Home Care will provide a stronger foundation for home care, allowing family caregivers to engage in paid employment, having greater financial security as we age.

With seniors and people with disabilities struggling to find home care workers, due to low pay and lack of labor protections and benefits, we need to support Fair Pay for Home Care. As New York faces an economic recession and a global pandemic, we need to create new jobs, keep New Yorkers safe and stave off widespread unemployment. Fair Pay for Home Care would move our care and financial economies in the right direction. The Act would raise home care wages to 150% of minimum wage - on average this would raise wages from \$22,000 to \$35,000 a year. CUNY's School for Labor and Urban Studies [new report](#) found that The Act would *generate* \$5.4 billion for the state economy through new income and sales tax revenue, economic spillover, and reductions in Medicaid and social assistance. Importantly, this is an issue of racial and gender equity and an opportunity to create prospects for dignified work in home care. Fair Pay for Home Care will overwhelmingly improve existing jobs and create new ones for women and people of color: currently, [New York's care sector is 91% female and 77% people of color](#). As the country and state wrestle with historic racial injustice, along with the disproportionate impact of COVID-19 on communities of color, Fair Pay for Home Care is an investment in equity, and would lift up an historically underpaid and exploited workforce. We need to correct current unjust labor practices, which effectively impoverish the next generation of older adults as we allow both those who need care and

those who provide care to age into poverty. This would be a win/win/win for paid and family caregivers and the older adults and people with disabilities they care for.

The institutional bias in long-term care must end. How is it that Medicaid will pay ~\$400/ day for nursing home care, but not an equivalent amount to care for people in their homes and receive better care? When my grandmother broke her hip at 99 years old and refused surgery, we were sent home, receiving homecare for only a few hours a few times a week for a very limited period of time. The “standard of care” would have paid for surgery, a rehabilitation facility, etc., but provided very little of the care she needed at home. Instead I was left to figure it out on my own. Had I not had the privilege I have to fall back on, this would have been catastrophic for our family. We would have lost our home, had to institutionalize my grandmother and suffer the indignity of losing everything at the end of one’s life. My mother and I would have been homeless, which would have resulted in my mother’s institutionalization as well. Given my age at the time, I can imagine a variety of poor outcomes for me, none of them good.

Our collective health depends on bold investments in long-term home care. I hope you will consider our story and understand the necessity of funding Fair Pay for Home Care to support people like my mother, family caregivers like me and the care workers we so desperately depend upon. If I can be of further assistance, please do not hesitate to contact me.

Sincerely,

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