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Testimony for the New York State Senate Committees on Aging, Health and Labor Tuesday, July 27, 2021

## Maggie Ornstein, PhD, MPH, family caregiver, long-term care researcher & New York Caring Majority member

Senate Chairs May, Ramos and Rivera and Members of the Committees, thank you for holding this important hearing. I am pleased to testify in support of strong investments in health and labor through investments in home care. Care work is essential for older adults and New Yorkers with disabilities to live and age safely and with dignity in their homes and communities. And, so I urge you to support the Fair Pay for Home Care Act.

I write this testimony as a member of the <u>NY Caring Majority</u> and in tandem with my mother, Janet, who 25 years ago 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 years in hospitals and nursing homes, she came home in 2001 and has been receiving Home and Community Support Services through the DOH TBI Medicaid Waiver Program since. We are one of the 500,000 families who rely on home care in the state and without these services and 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 did not have sufficient home care services and so I was forced to make difficult decisions about spending her resources on paid care and delaying my own paid employment. Luckily, her savings and my unpaid care got her through the end of her life. However, adequate care shouldn't depend on luck or exploited labor. Many older adults aren't this lucky.

As one of <u>New York's 2.5 million family caregivers</u>, 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, while also being able to engage in paid employment. Paid and family care goes hand-in-hand and one cannot adequately function without the other. Every day I worry that the precarity of my mother's home care situation will result in a further reduction of services. Despite the significant in- home services my mother receives, I continue to provide care, as well as 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 meet my mother's needs. Without legislation to protect home care workers and increase available services, I will likely be required to give up 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 <u>10% leaving the workforce</u> in order to provide care. Currently, <u>17% of home care positions are unfilled due to staff shortages, and surveyed New York home care agencies have reported 30-58% turnover</u>.

Older adults and people with disabilities are in desperate need of care, but they also provide care to their loved ones. Nearly <u>60% of caregivers of adults over 50 are themselves over the age of 50 and 20%</u> of these caregivers are over the age of 65. With <u>caregiving status being a social determinant of health</u>, we must not expect families to shoulder the full weight of caregiving alone.

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 the Fair Pay for Home Care Act. 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. The Fair Pay for Home Care Act 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. The Act 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 a 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.

Our collective health depends on bold investments in both aging services and labor protections. I hope you will consider our story and understand the necessity of funding the Fair Pay for Home Care Act 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,

Maggie Ornstein

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