

Testimony for the New York State Legislative Budget Hearing on Health

Tuesday, February 11, 2025

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Chairpersons Krueger, Pretlow, Rivera, Paulin, and members of the Senate and Assembly Health and Finance Committees, thank you for holding this important hearing. I am pleased to testify in support of strong investments in health through investments in home care through the Consumer Directed Personal Assistance Program (CDPAP). Older adults and New Yorkers with disabilities deserve to live and age safely and with dignity in their homes and communities. Paid and family caregivers deserve adequate support in their dedication to the provision of care. And, so I urge you to take action to protect the 280,000 home care recipients and 425,000 home care workers who use the CDPAP and receive care in their communities.

I write this testimony as a family caregiver, a member of the [NY Caring Majority](#) and in tandem with my mother, Janet, who 29 years ago had a near fatal cerebral aneurysm rupture, which left her in a coma and minimally conscious state, and on life support for nearly five months. As one of [New York's 2.2 million family caregivers](#), who contributes to the nearly \$40 billion worth of unpaid care provided across the state, I know first-hand how important investing in our caregiving infrastructure is.

My mom lived in a nursing home for five years and I was with her nearly every day, doing the jobs of overburdened workers. When she came home nearly 25 years ago, I was responsible for all of her care. **I was 22 years old.** At the time we lived with my grandmother, then 92 years old and with increasing care needs that fell to me. I received no assistance, financial or otherwise, as an unpaid family caregiver. I alone had to figure out how to maintain our household so we wouldn't all be homeless and work for pay in order to have health insurance, all while managing the complex care of two people. After my mom came home, I was saving NYS taxpayers ~\$300,000 each year by providing care at home, as opposed to the costly and poor care found in nursing homes.

My grandmother died in my arms at home at 102 years old. She did not have access to home care services through Medicare or her private health insurance and so I was forced to make difficult decisions about spending her resources on paid care, delaying my own education and reducing my 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 family labor.** Many older adults aren't this lucky. A [new report by the Center for an Urban Future](#) paints a sobering picture of the dire financial insecurity faced by older adults throughout NY State. Decades of unpaid caregiving, which has limited my paid employment makes me fearful of how I will provide for my own care needs as I age.

A few years ago, my mother was diagnosed with cancer. It blindsided me- how could we add cancer to her brain injury? How would I cope with the new realities of the care she will need as she approaches the end of her life? What if I need to give up my part-time employment because of her increasing needs? It felt time to seriously look into the CDPA Program as a means of financial support for me, as I continue to provide care, which will only increase as she nears the end of her life. In 2023, after difficulty finding accurate information and dealing with the eligibility process, my mother was approved for the CDPAP. It has been life changing for both of

us. She now has more paid care, provided by people of her choosing, and I am receiving pay for some of the hours of care I provide. Prior to this program, I was solely responsible for and on call for *128 hours of care each week*. I donated the equivalent of three full time jobs worth of hours each week to care for my mother, saving NYS and taxpayers millions of dollars over decades. **Family caregivers across NYS deserve support for these countless hours. CDPAP is that support.** For the first time, I can breathe a little better knowing I have some element of financial security due to the ability to be paid as my mother's caregiver through CDPAP.

CDPAP is *the only program in NYS* that supports older adults and people with disabilities *and* their family caregivers. It should be expanded and supported, not jeopardized or reduced! It is a lifeline that is essential to not only the well-being, but very survival of vulnerable New Yorkers. I urge you to consider the absolute urgency and need to protect and strengthen this unique and valuable program. It is clear that this transition plan is already a failure- we have yet to hear anything from our existing fiscal intermediary (FI) about the transition or from PPL, who was handed this contract, despite [an undisclosed conflict of interest](#) that could have prevented them from securing the contract. In addition, PPL's operation in other states suggests they are incapable of adequately providing care through the CPDAP. In Pennsylvania, the transition to PPL was deemed "[a disaster](#)". Mismanagement cost the state an extra \$7 million a year when consumers had so much difficulty they switched to a more expensive model of care. Additional evidence suggests that PPL's management failures has resulted in individuals "[being denied life-critical services](#)". NY legislators must protect CDPAP consumers from this dangerous transition.

We need to block the transition from going further and pass legislation to build a home care system that works for recipients and the paid and family caregivers who care for them, rather than for profit insurance companies. To that end, please support the Fiscal Intermediary Licensure Requirement bill ([S.1189/A2735](#)), which would replace the handover to PPL with a more responsible approach that would provide additional oversight of FIs while protecting the home care that so many New Yorkers have come to rely on. For the longer term, The Home Care Savings & Reinvestment Act ([S.2332 /A2018](#)) would stop NYS from giving insurance companies billions of dollars meant for the home care sector and ensure consumers get the care management they need.

Our collective health depends on bold commitment and investments in health for people who need care, as well as all of those who provide it. I hope you understand the necessity of protecting CDPAP 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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