



New York: Consumer Directed Personal Assistance Program

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My name is Maggie Ornstein, PhD, MPH, and I am a Consumer Directed Personal Assistance Program (CDPAP) personal assistant (PA), and daughter of CDPAP consumer, Janet Ornstein. Senators Rivera and Skoufis, thank you for holding this important hearing. I hate that we all need to be here, fighting this fight for the Consumer Directed Personal Assistance Program (CDPAP), but am thankful for having you both on our side. Life is hard enough already, adding the administrative and emotional burden of this transition feels insurmountable. It is mind-boggling that a hearing like this is necessary, given the disgraceful transition of this important and essential program. Advocates warned of the dangers of moving to a private-equity company for third-party financial services, and of Public Partnerships LLC's (PPL) incompetence and illegal actions in other states, but we were ignored. Unfortunately, consumers, personal assistants (PAs), designated representatives (DR) and family caregivers are now living with the dire consequences.

I write this testimony as a family caregiver and PA in tandem with my mother, Janet, who 29 years ago had a near fatal cerebral aneurysm rupture. The catastrophic brain hemorrhage 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 strong investments in long-term home care are.

My mom lived in a nursing home for five years, then came home with the help of home care through the TBI Waiver program. She received 40 hours of home care, but required 24/7 assistance, which I provided. A few years ago, after a new cancer diagnosis, we looked into the CDPAP, as I was concerned that I'd need to quit the part-time paid employment I had to provide for her increasing treatments and frailty. Prior to her enrollment in CDPAP, I was on call for 128 hours of care each week. Yes, you read that correctly- for more than two decades, I worked the equivalent of three full time, unpaid jobs providing care for my mom, which kept her from returning to a costly nursing home. The CDPAP is the *only state program* that helped both my mom and me, as her family caregiver, while increasing consumer choice in services. The program should be expanded and supported, not decimated, as is currently happening. It is a lifeline that is essential to not only the well-being, but very survival of vulnerable New Yorkers.

PPL's operation in other states and now in NY suggests they are incapable of adequately providing care, or even simply payment for 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, which we are now seeing happen in NYS. An estimated 75,000 consumers have already left CDPAP and moved to traditional agency-based home care. Additional evidence suggests that PPL's management failures resulted in individuals "being denied life-critical services". NY legislators must act immediately to protect CDPAP consumers from this dangerous and failed transition.

The past six months have been unbelievably stressful. The enormous administrative burden has interfered with other work, as well as the care my mother receives. We feel neglected and abandoned by the Governor and Department of Health (DOH) and hope they will see the error of their ways in allowing this incompetent company to manage this essential program.

Older adults and New Yorkers with disabilities deserve to live and age safely and with dignity in their homes and communities. PAs and family caregivers deserve adequate support in their dedication to the provision of care. And, so I hope you are able to work with your colleagues to be the checks and balances so urgently needed in response to the Governor's improper handling of CDPAP. We need more of the experienced and trustworthy FIs back and for the DOH to do their job in properly overseeing the program, rather than outsourcing it to a for-profit LLC, who shirks their responsibility and has made the program worse. It is the only way forward to building trust with consumers and ensuring care is adequately provided.

Sincerely,

Maggie Ornstein, PhD, MPH