

Gina Marie Barbara

WRITTEN TESTIMONY REGARDING THE CONSUMER DIRECTED PERSONAL ASSISTANCE PROGRAM BY GINA MARIE BARBARA

My name is Gina Marie Barbara I am a resident of Wantagh in Nassau County. I submit this as a long time activist with Downstate New York ADAPT. American Disabled for Attendant Programs Today (ADAPT) is a National grassroots community that organizes disability rights activists to engage in nonviolent direct action to end institutional bias. Before I begin, I would like to thank Senator Skoufis and Rivera for arranging this important hearing.

As a 45 year old woman with Cerebral Palsy, I am unable to ambulate and must use a power wheelchair for getting around. I also rely on attendant services for everyday basic daily living skills that others often take for granted. Dressing, toileting, eating, such as cutting my food, meal preparation assistance, reaching items, getting in and out of bed and my wheelchair, housekeeping, laundry and medication reminders. Without this assistance I would be bed bound and unable to participate actively in the community. Although personally I don't receive services through the Consumer Directed Personal Assistance Program, I utilize traditional Medicaid homecare services of approximately 74 hours a week. Although, interest and recommendation pointed out the CDPAP program on several occasions I first would need to establish a team and unfortunately I do not know enough people to build a team so my two agencies assist in coordination of my attendant services. Secondly, I feared that one day CDPAP would become a living nightmare and well frankly, here we are.

Let me establish the main objective of the CDPAP since its inception in 1974. The program was established to give choice to the consumer. It gives the consumer the ability to train, hire, fire, and choose who would provide these intimate services regardless of their relationship to the consumer. Let me be clear this program was designed by consumers for consumers not corporate hedge funds. For several years home care in the state of New York has faced

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changes in eligibility and not paying a living wage to attendants where they can earn more money working at Walmart than helping the individuals that need care.

New York state has claimed they are attempting to weed out fraud and abuse, however have never formally defined these terms. Advocates have warned state officials for years that these terms are nonsensical and furthermore the lack of assistance can prove ultimately to be deadly. Over 800,000 consumers are facing a very critical issue. As of April 1st, control has been stripped from consumers and approximately 800 fiscal intermediaries, down to one fiscal intermediary. Public Partnership LLC has been chosen to be the sole entity. Advocates have been fighting for legislation to take down PPL and to date have not been successful. PPL has been discontinued from at least 7 other states for the very thing the state is trying to cut fraud and abuse. PPL also is still not paying employees, they are forcing employees to leave their insurance plans they have currently and take a less than adequate plan which is minimal with PPL. With pending cuts from Medicaid, Medicare and Social Security it is of the utmost importance to allow consumers to receive the care necessary to live in their communities and not institutions. Hospitals are short staffed, group homes and nursing have extravagant wait lists, leaving people to not receive vital services and die. We must take back control and come up with a plan that is appropriate for all involved. We need consumer control not greedy hedge funds. PPL has failed miserably. We need to find a better solution, not excuses and together protect the rights, freedoms, and liberties of all New Yorkers.