<u>Testimony- Joint Public Hearing: Consumer Directed Personal Assistance Program (CDPAP)</u>

Wednesday, July 9, 2025

Maggie Ornstein, PhD, MPH, CDPAP 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 and of PPLs 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.

Below, I provide details and examples from notes I've kept, documenting the myriad and ongoing challenges my family has encountered while registering for and participating in CDPAP. 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 Oueens, NY

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Documentation of problems working with PPL

1. Communication, information & contact with PPL

- At the beginning- we were not able to make contact to register and it took months to get a first call back and the website often didn't work or crashed (see Appendix, #1)
- Now- can get people on the phone, but they can't answer questions- need to check with supervisors; answer questions incorrectly (i.e.- telling us we need to have shifts approved in portal in order to get paid, despite submitting paper timesheets, which have approval built in)
- We are often given conflicting information
 - Example 1: Timesheets are considered approved (as per PPL website instructions) when submitted because they are signed by consumer or DR, but we have been told that the hours also need to be approved in the portal within hours of submission. This is redundant, makes no sense and is inconsistent with their own published instructions.
 - Example 2: we were told by PPL representative that overtime is allowed"as much as consumers need", just can't go over authorized hours and
 consumer needs to approve. Then, we receive "excessive overtime"
 warning emails, which seem to be a suggestion for not doing overtime, but
 we don't know the actual rules about this. Very confusing! We can't
 comply, if we don't know the rules.
- When PPL has guidance, they often say they "learned this from a consumer"- we are literally doing their jobs for them!

2. Checking in/out

- We used paper timesheets during court injunction-at times, mailbox was full and emails not accepted (see Appendix, #2)
- o Tried Telephony once the court injunction expired- it didn't work most of the time
 - System was stuck, wouldn't accept our entries, then looked like we had shifts that lasted several days, despite our clocking out- was a disaster with all PAs. Had to contact PPL to fix all the mistakes- see #1 above-communication was impossible and so fixing shifts and getting paid was impossible. This resulted in not getting paid for weeks, until we could reach someone.
- We applied for paper timesheet exception and that was approved. Back to paper timesheets on 6/15 and they have yet to recognize them. None of the four PAs have been paid for the last two weeks of work.
- Communication- didn't receive anything in writing that exception was approvedwe learned this through communication with lawyers at NYLAG. PPL has no process in place for communicating specifics of our case.

3. Shifts & Payment

- One PA has never received paper pay statements
- We can't download or save pay stubs from our portals- information can be changed without our knowledge or any notification from PPL

- o Things change and appear/ disappear in consumer and PA portals
 - Example: shifts that have been approved by DR are no longer there
 - Example: there have been instances of shifts added for only a few minutes (12:01-12:03am), which needed to then be caught and denied by DR. We had no idea where these came from the PA didn't enter them.
 - Example: During registration process "authorized to work" message in PA portal disappeared, which was discovered by mistake. No indication about why or what needed to be done to fix it. This was especially confusing, as the PA had completed all paperwork and thought their registration was complete.
 - Lots of trouble reaching PPL to fix it on their end, then PA was blamed for "not registering", despite doing everything required. In PA portals, it was often impossible to know if documents that were submitted were actually received (see Appendix, #3)
 - O This has been a common theme- PPL and even more troubling, DOH blames consumers and PAs for these problems that are clearly caused by PPL's incompetence.
- There are rules about longer shifts (13 hours or 16 hours), but no guidance has been given to us about them. We have changed how care is provided to keep shifts shorter- this is based on PPL, not my mom's care needs care
 - PPL rep couldn't answer our questions about long shifts
- Ironically, despite rules on long shifts, PPL incorrectly entered a shift for 18 hours that should have been 6 hours, as indicated on the paper timesheet. This is a current issue (6/26), but not yet paid. If they pay me incorrectly, how will I return that money to them? This will cause a problem due to too many hours provided to the consumer. I have no faith that this will be properly resolved, creating problems for the consumer and two PAs, whose shifts are implicated by a data entry mistake by PPL. The time/energy required to keep track of this is enormous.
- None of our pay statements are the same week to week, despite set and consistently worked hours- we don't know how deductions are done or if they are accurate.
 - Several instances of 100% of wages being taken out for "federal taxes"
 - Early Example (April)- first pay statement showed .25 time for training at \$16.50/ hour. All \$4.13 was taken out for "federal taxes" -this has to be a mistake. Also, completed the bank info, but none shows up on my pay stub (see Appendix, #4)
 - Most recent example (mid-June)- make up pay for 2 hours not paid for prior week- 100% was taken out for "federal taxes". This is absolutely wage theft! (see Appendix, #5)
 - When asked PPL about this: "once the pay is taken by the Feds, it's hard to get it back". Me: "but that was your fault". PPL rep- "Yes, it was, but still".
- O Prior to transition, our old Fis caught errors and communicated with us to figure out the problems. They also cleaned up shifts- if we logged in or out a few minutes before or after, they would clean up that data so we were paid only for our hours. We had a 5 minute grace period so not to mess up hours of the next PA

or overall hours the consumer is authorized to receive. This reflected an understanding of the realities of providing care, as well as technology and human error, which PPL has no system for managing, so it all falls on us to sort out. They are not doing their jobs!

4. Unpaid labor -we are all doing PPL's job!

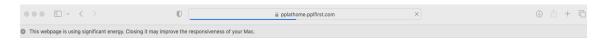
- The initial transition and registration process went so poorly that DOH requested that employees volunteer to help with registering consumers!
- o Elected officials- Senate and Assembly offices have helped constituents with the numerous problems we have been having
- Consumers/ Designated Representatives- the administrative labor required to manage and keep track of all of this has brought complete chaos into already complicated and complex lives.
- O PAs now have to manage an employer who is totally incompetent. I regularly consider how much easier life would be if we were still with our old FI or if we left the program entirely.
- Occollectively, everyone involved in my mom's care have spent countless hours trying to manage and keep track of all of this. I regret not keeping track of the hours I have put into managing PPL since this all started in February. The numbers would be staggering.
- O How can a company that received a \$9 billion contract be so incompetent and still be allowed to operate in our state?
- 5. Wage Parity/Health insurance- Downstate PAs are entitled to Wage Parity, a higher wage than in other areas of the state. Employers are allowed to provide benefits in lieu of wages. PPL is taking full advantage and providing "benefits" that can harm workers by making them ineligible for other health insurance, with no ability to opt out and receive a higher hourly wage.
 - O Prior to this transition, we had a choice of FIs to work with- our family chose an agency that paid ~\$1 more/ hr. because none of my mom's PAs needed health insurance. It was amazing to have this choice- to be able to get health insurance, if needed, or get higher pay. This choice can't be underestimated for low-wage workers. Just \$1.50/hr more per hour would equal \$240/ month or \$2880 additional wages per year. This should be going into the pockets of workers, as intended, not to PPL or its affiliates through scam benefits.
 - o **Anthem-** full-time PAs are forced into a scandalous health insurance policy, even if we don't want it. It will make us ineligible for Marketplace insurance and disrupt any other insurance we have, potentially causing problems in accessing healthcare and increasing out-of-pocket costs.
 - This is administered by Leading Edge, a company who is set up only to exploit loopholes and make profit at the expense of workers. How can NYS DOH stand behind this?
 - This insurance is more harmful than no insurance. Incomprehensible....
 - o Omni Benefit Card- no communication about open enrollment, so we missed it
 - My mom's PAs don't want this "benefit", they all would rather have the \$1.54 per hour more that we are entitled to due to Wage Parity laws. In

addition, these benefits will be lost, if we don't use the funds on our Omni cards by the end of the year. It is another way PPL will profit off the backs of workers by keeping money intended by the state to go to workers.

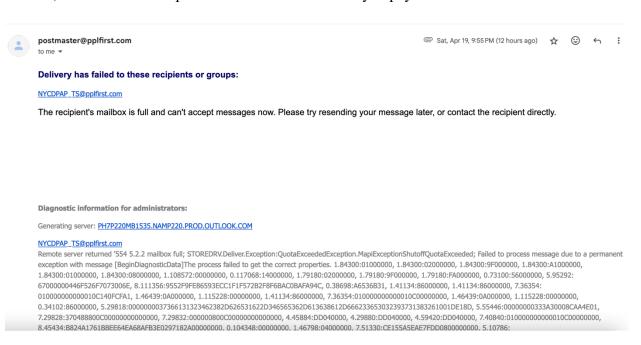
- **6. Technology problems-** not even people who are tech savvy can understand this. People have moved over to traditional home care because the administrative burden here is too great. Who can blame them? However, family caregivers can't legally work within the traditional home care system, so will either work unpaid and at great personal and economic cost or opt out entirely because they need to find other paid work to feed themselves. This creates an impossible "choice".
 - We have faced too many problems to count when trying to check in, such as error messages like these when using Telephony, the phone check in system: "please do not enter time until your consumer has a valid service authorization." There was never an issue with my mom's service authorization and so this was an error, which required much effort to rectify.
 - Telephony is burdensome, and often doesn't work. It takes so much longer to check in/out than with our last FI. With them, it was two steps and done.
 Telephony askes several questions and takes several minutes to complete, interfering with the provision of care.

Appendix

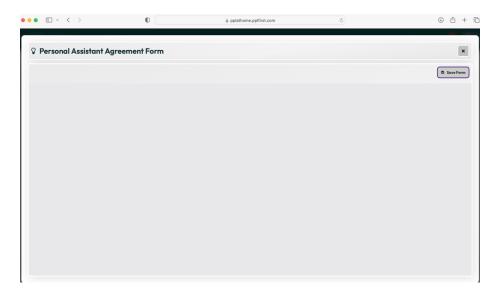
#1- Problem repeatedly encountered with PPL website when trying to register: "this webpage is using significant energy...". We were unable to log on to complete the required paperwork, but were being blamed by DOH Commissioner McDonald for not registering. It was impossible to do so for a long time.



#2- "Mailbox is full" error message when submitting paper timesheet. Unable to document shifts on time, due to PPL incompetence. This resulted in delayed pay for several weeks.



#3- Blank PA form, despite form being uploaded to PA portal, as required for registration. There was no way to know if this requirement was satisfied or not.



#4-Training pay with 100% taken out for "Federal Taxes". This was my first pay statement (4/10) from PPL. It has not been resolved. How many others has this happened to?

Pay Details								
Earnings	Hours	Rate	Amount	Shift	YTD			
Training	0.25	16.50	4.13		4.13			
	0.25 4.13		4.13					
Taxes			Taxable	Amount	YTD			
Federal Income Tax	M-+\$2	25.00	4.13	3.81	3.81			
Social Security			4.13	0.26	0.26			
Medicare			4.13	0.06	0.06			
NYS Income Tax	M-0		4.13	0.00	0.00			
NY Paid Leave			4.13	0.00	0.00			
NY Disability			4.13	0.00	0.00			
NYC Income Tax	M-0		4.13	0.00	0.00			
				4.13	4.13			
Other Info								
Time Off Bala	Balance							
PTO					0.01			

		Stateme	nt Summ	ary	
	4.13				
	-4.13				
	0.00				
	0.00				
	0.00				
	0.00				
	0.00				
Punches	Day	In	Out	Hours	Patient
04/01	Tue	10:00PM	10:01PM	0.25	

#5- This is my most recent pay statement (6/26)-make up for previously unpaid hours, but no pay for the 43 hours I worked that pay period. \$60.30 for 45 hours of work, \$0 deposit! Shows 100% taken out for "Federal Taxes". This has not been resolved. How many others has this happened to? What is the collective amount PPL has stolen from workers with this "mistake"?

		Statem	ent Sumn	nary)
	Gross Pay				
	Federal Taxes				
State and Local Taxes					0.00
Other Deductions					0.00
Net Pay Direct Deposits					0.00
					0.00
Net Check					0.00
Punches	Day	In	Out	Hours	Patient