This testimony is intended for the purpose of the 250 Broadway **July 9th Senate hearing regarding New York State's CDPAP transition to a single fiscal intermediary**.

I am a New Yorker having lived in Putnam County, the Bronx, the Manhattan financial district, and now for the past 15 years in Tribeca. I am **a contributing citizen** because I work full time as a software engineer, I sing and write music, and I voluntarily advocate for disabled people like myself. **But I only get to attempt living a fulfilling life because I have personal assistants through CDPAP 24/7 who provide me total physical assistance for all activities of daily living**: lifting into wheelchair, showering, using the bathroom, dressing, feeding, positioning my hand onto the table towards the computer, opening doors, going outside, using medical equipment daily, and more.

CDPAP is the only option for me because of how severe my disability is; another type of home care agency would not work or accept me anymore because I require full assistance with my ventilator, full assistance with administering certain bathroom medicines and treatments, and I require existing PAs have to train new ones instead of an unknown home health aide or personal care assistant just coming in. **I have Muscular Dystrophy, I am in a power wheelchair, I cannot move my arms or legs by myself. and I have limited head control.**

CDPAP has successfully supported my life starting in 2007 because I can ensure that all of my daily healthcare needs are covered by choosing who I hire, making sure they get trained properly by another PA as they are onboarding, managing my shift coverage when PAs are sick or using paid time off, and firing a PA who can no longer handle provide me care services. **CDPAP facilitates my independence** despite my physical inabilities that rapidly gets worse to the point where I lose my own functions every year. **CDPAP is my lifeline.**

I am immensely negatively affected by the fact that New York State has decided to eliminate all contracts with every CDPAP agency in the state, move to a single fiscal intermediary model, and - worse - signed a no-bid contract with a single, private company PPL, which has undeniably horrible service and lack of care.

Here are my reasons:

I am forced into a hiring freeze because this FI change removed the "PA to PA" paid hands-on training benefit I rely on. It takes multiple hands-on training shifts for a new PA to observe and try to take care of me the way that my existing PAs do. **PA’s Need to be paid for training** like they have been before this change. Showing others how to do something as simple as moving my sensitive arm is imperative in training. Imagine a more complex task such as transferring me and positioning me in my wheelchair, turning and adjusting my body with my ventilator at night, or pushing my stomach to help me cough or use the restroom. The first thing I asked a PPL representative in February 2025 is whether or not training hours would be paid. The answer was yes, but **little did I know that my definition of training was completely different from PPL's definition of training which is watching their videos about how to use their apps.**

The paid training benefit I lost as a consumer because of the transition also eliminates the ability for existing PA's to train each other which supports me when I have a new device or new symptom that calls for hands-on training across PA's.

There are additional benefits that have been lost and they affect me directly. Since 2020 it's already been extra difficult to hire new PAs as it is, but **now the incentive for a person to become a PA or for my existing PAs to stay providing care for me is not evident**. My longest PA working for me now has been working for me almost 13 years and since March has been without health insurance during the transition, and **the new health insurance is a minimum value medical insurance package anyway. The deductible is $6000! The holiday pay is nonexistent although PPL found a loophole to make it look like they do pay holiday time. The clocking app causes overhead from all of us and takes away time from us.** When trying to address the issues by contacting PPL, they are defensive and accusatory because they live by with the computer tells them. In fact, PPL representatives cannot speak to you without a computer in front of them because they do not think for themselves. **The computer is not accurate most of the time because it accuses me (the consumer) of going over my hours which is impossible since I am authorized for 24/7 care. PPL also harasses my PAs and me with constant notifications warning of going into overtime**, being out of compliance, and reminding us to check the apps constantly. **in a single week, we receive an accumulative amount of at least 30 notifications!** Furthermore, PPL is inconsistent with the physical mail notifications it sends out, causing everyone to wonder when they will receive mail because not everyone gets it in the same month, and sometimes not at all..

I am facing deterioration in stamina ultimately due to the lack of a single case coordinator in the FI. There is tension during shift changes every day that lead to arguments because of the PPL clocking system. This has nothing to do with being out of compliance with EVV. This has to do with the fact that there is no coordinator handling the administration of clocks in and out of shifts, therefore **putting the onus on me and my PAs**. **That is not the definition of Consumer Directed personal assistance, I should be focusing on my care and managing the care I receive - I should not be managing the administrative part nor any human resource related part.** Shift changes have introduced interruptions of my routine, for example **I end up waiting and laying bare in my bed while the PAs worry about clocking** because my schedule involves my night shift PA showering me in the morning and the day shift PA finishing dressing me up. **I have to approve each shift instantly just to provide peace of mind that the worker leaving their shift will be paid for their shift since we do not trust the PPL app based on experiences we have already undergone.** The responsibility of navigating and resolving dire issues raised by PPL has been transferred onto patients like me, who are not meant to handle payroll ourselves. As a result, I have been facing disruption of services and my PAs have encountered unnecessary aggravation that also affects my health.

I am neglected by the state since I no longer have a single case coordinator in the FI. **There is no single person I can physically go to or call on the phone who knows me**, who knows my needs, who handles registration, payroll and health benefits of employees providing our care, who knows the answers to any questions I have, and who lets me know before they are out of the office that they have another coordinator temporarily taking over my case until they return. Furthermore, **there is no single person coordinator who will call me if they ever notice a gap in shifts** to ask me, "who took care of you on this day? For some reason there is no clock in the system and we want to make sure you are okay." My PAs and I need that consistency and customer service, but instead we are coerced in every encounter with PPL that we should empathize PPL for having a large load of consumers and PAs to support. **Every supervisor I meet in person or on the phone does not provide their phone number, only an email address which gives them the leeway to not respond**. In my experience that is not supervisor professionalism. I am neglected because every piece of written press or visual media I have seen of the New York State Governor expressing her response to concerns raised by disabled constituents like myself is accusatory - implicating that I must have some incentive to raise concerns at all. We should be given the benefit of the doubt because this affects our daily lives. In addition, **Governor Hochel's accusations align exactly with PPL's accusations in the website page describing how the protests are trying to steer against PPL for some incentive.** My speculation would suggest that she has some conflict of interest with PPL to have their words come out of her mouth.

Why is the disability community, including myself, being punished for the "rampant fraud" that the Gov. and Department of Health are trying to tackle? There is a correlation between the number of consumers increasing and the cost of services, therefore how can that be fraud? **Someone like myself, severely disabled, could never be left alone without care. That fact alone indicates that I am certainly not fraud** and do not deserve to endure what the state calls "transition hiccups" and I call "foreseeable long-term damage". **The good should not be punished for the bad**, and any investigation into fraud should be plain and simple - ask the consumers and visit our homes to understand the meaning behind the services we value and receive. Rather than actually collaborating with impacted communities or even acknowledging systemic failures, Gov. Hochul and Commissioner MacDonald deflect attention away from their own accountability.

I am in full support of reverting back to multiple FIs to administer CDPAP once again, restoring choice and localized support for consumers. CDPAP was built on the belief that disabled people in New York deserve control over their care so that we can live fulfilling and independent lives just like anyone else. That principle should not be sacrificed in the name of efficiency and saving on costs. New Yorkers deserve a system that works for us, not one that blames them when it fails. **My PAs provide me so much care that you could see it within 5 minutes of being in our presence. My PA's deserve better and I deserve them.**

Thank you.
Tabitha Haly