CDPAP Hearing Testimony

My name is Svetlana Jovanovic. I am the personal assistant and primary caregiver for my mother, who lives in NYC and is enrolled in the CDPAP program. She receives 168 hours for 24 x 7 split shift care. There are three other personal assistants, I have also been the Designated Representative. Since Dec 2024, a family friend is the Designated Representative so my mother can have the least amount of caregivers and I can provide the most familiar care. My mother is 94 years old, has Alzheimer's, Diabetes, Aortic Stenosis and requires a wheelchair for outings after she broke her hip under the watch of a home health Aide in the NHTD program. The accident left her with an extreme fear of leaving her home and walking up/down one flight of stairs for outings. I am the only one she trusts to assist her with the stairs. Her care requires consistency, routine, and familiarity—any disruption causes her extreme distress. CDPAP has allowed me to keep her safe at home with trusted caregivers who know her needs. Without it, she would face institutionalization — something that would devastate her and myself, her sole family member.

Commissioner Dr. Jim McDonald has said: "If you're a CDPAP home care user, you can keep your trusted caregiver." But how is that possible if:

- Wages are not paid on time, accurately, or at all?
- Supplemental wage parity benefits are no longer for the PA's benefit?
- Caregivers are forced into PPL's insurance or trapped in the Basic Wellness Plan that does not even cover a doctor's visit?
- Full-time PAs must either accept the useless Basic Wellness Plan or Full coverage insurance with costs at \$212 per month with a \$6,350 deductible — unless they have Medicare? This is the reality for my mother's caregivers and thousands of others.

Wage Parity Abuse & Forced Insurance PPL has reduced wages and increased costs for PAs. Instead of giving them the legal choice to take wage parity in cash — as allowed by law — PPL diverts it into a Flex Card system that restricts how benefits can be used. Categories are chosen without consent, rules change depending on who you speak with, and access to funds is often delayed for months. In my case, I only received my card in mid-August, even though my benefits should have been available with my first paycheck in April. Two of my mother's PAs had health insurance through the Affordable Care Act, but no longer — because PPL now forces them into more expensive coverage. PAs must be able to care for their own health in order to continue caring for consumers. Forcing them into inadequate or unaffordable plans puts everyone at risk.

Payroll Problems Overtime and spread of hours are not paid properly. PPL uses an unusual formula for spread of hours that significantly reduces what PAs are owed. Payments vary week by week, even for the same schedules. This creates instability for workers who already live paycheck to paycheck.

Legal Precedent Attorney General Letitia James and U.S. Attorney Breon Peace recently prosecuted Edison and Preferred Home Care Agencies for defrauding Medicaid and cheating home health aides out of wage parity benefits. Their words bear repeating:

"Home health aides provide essential care to our most vulnerable neighbors and loved ones. They deserve to be paid fairly for their hard work." – Attorney General James "These aides deserve the hard-earned benefits guaranteed them under the law, and my office will ensure they are accurately compensated." – U.S. Attorney Peace

PPL's practices mirror the same abuse of wage parity and must be investigated and corrected.

Human Impact Because of these problems, my mother is under constant threat of losing her caregivers. If they leave, I cannot provide 24/7 care alone. Without CDPAP functioning properly, families like mine will collapse, and elderly New Yorkers will be forced into institutions — at greater financial and human cost.

Conclusion

I urge lawmakers to:

- Hold PPL accountable for wage parity violations.
- Restore caregivers' choice over how their benefits are used.
- Stop forced insurance enrollment that strips workers of coverage they already have.
- Ensure timely, accurate payment of wages, overtime, and spread of hours.

Statement of Experience with CDPAP, NHTD, and MLTC

In 2020, my mother's condition declined rapidly. When I visited from abroad, I was told she needed 24/7 care. The hospital recommended a nursing home. I refused. My mother belongs at home, surrounded by what she knows, not in an institution. I changed the course of my life to make sure she could stay in her home with as few caregivers as possible. My mother lives in a 377 sq ft railroad apartment. Because she could not live alone. I, along with a CDPAP Caregiver, share this small space which has been extremely challenging. My plan was to find housing elsewhere and return to work and my life. But what was to come eliminated any possibility for me to do anything other than care for my mother.

At first, we were approved for 30, then 40, then 80 CDPAP hours. But during the pandemic, no one was available or safe to bring in, so I provided two years of round-the-clock care entirely alone. This was unsustainable—my mother needs overnight care, and I could not go without sleep indefinitely.

When MLTC would not approve the hours her doctors said she needed, we turned to the NHTD (Nursing Home Transition Waiver) program, which was supposed to guarantee 24/7 split-shift care. Instead, it brought disaster: within two weeks of the start of services, my mother and I caught COVID for the first time from an agency aide. After quarantine, my mother broke her hip under an aide's supervision. Before the injury, she could walk several blocks without a walker. Since then, she requires a wheelchair for outings and is traumatized to the point that she will not leave the house without me—even if an aide is present.

*Note: NHTD required me to work 3 hours x 7 days a week in order to get NHTD services, something I was not informed about during the 9 month application process, which blind sided me. I was informed I'd have to pop by weekly or even have someone in my place do so. I lost my German residency, (my retirement plan), and have since not been able to return to take care of my things among other important matters. A year into the program I found out that NHTD was required to have me sign a document for voluntary support if I wanted to provide it, instead I was railroaded into living with my mother in order to get services. I also learned you could do CDPAP in combination, which I eventually applied for but was denied even with the help of a lawyer. It's been five years, and I have not been able to make a trip to Europe to take care of the life I abruptly left due to the chaos and instability of all home care services and the reality of how they actually function, that overburdens the sole family member. All I wanted was help instead I was pulled into the drama of a broken system under the guise of "Care" that in fact is careless with peoples' lives, especially the vulnerable.

Traditional home care failed us. It was chaotic, inconsistent, and not person-centered. Staff came and went, creating upheaval. Some had their own health issues, some stole, destroyed things needed with no remuneration, some were completely unqualified, and one endangered our housing. My mother needs care built around her needs—not whatever agencies decide to provide which from my experience as long as they send a body they've done their part.

Eventually, after constant struggles with CASA, and even outright lies in documentation, they denied 40 hrs of CDPAP in combination with NHTD, and was told to apply again as the case for 40 hrs was closed. With the help of a lawyer, we left NHTD, and applied for the full 168 hours with CASA.

Exactly one year prior to transition to PPL, in Jan 2024 CASA approved CDPAP but only for 40 hrs even though the case for 40hrs was closed. With the help of a lawyer we fought for the rest of the hours, the D.R. and I were able to staff the 5 PAs required for 168 hr care, but there was one glitch, the FI refused to register the PAs as CASA did not send them the authorization. After almost four weeks of waiting 3 of the newly recruited PAs left. Despite this no one was accountable or able to solve the authorization issue, which came in increments. Two more PAs were hired, around the time CASA required a transition to an MLTC. The lawyer worked with us

daily for two weeks to ensure authorization would not be lost, there was a Fair Hearing to ensure this, as still there was no official documentation of the total authorization hours before the transition to the MLTC June 2024. On day ten of the transition to the MLTC the services were mistakenly stopped for 2.5 days. The FI told all PAs not to go to work, leaving my mother without care. As the daughter I took care of my mother and was promised by MLTC that both the PA told not to work and myself who worked, would be paid, we never were paid. Two PAs eventually left after they found other jobs due to the stopped services. The Designated Representative quit. Because in her words "it was just too much". I stepped into the D.R. role, leaving only one PA for 168 hrs, guess who worked all the shifts unpaid?

As a D.R. I had to recruit, train, and manage PAs myself—an unpaid, exhausting process that agencies themselves cannot even handle properly. By Dec. 2024 we were fully staffed. A family friend stepped into the D.R. position, and I was able to return as a PA to provide my mother with familiar care. Through this ordeal, I learned the system is built backward. Instead of supporting families who are keeping loved ones safe at home, it creates barriers, cuts hours, and questions legitimacy—even when all medical documentation proves the need. Meanwhile, the burden of recruiting, training, and replacing aides falls entirely on us, with no acknowledgment of the unpaid labor required to keep things stable.

This was my training for what was to come regarding the transition to PPL exactly one year later in Jan 2025. This is why after hearing many other Consumers and PAs testimonies, we were able to survive and get through many of PPL's ordeals that others could not. I had a year and half of very specific ordeals that gave me the knowledge along with a lot of extra work with the D.R. to help the other three PAs with all PPL administration requirements to ensure they were paid hourly and would stay. However, we are still holding our breath as the supplemental wage benefits, OT, and Spread of hours still need to be sorted out.

Today, I am the "head PA," because no one knows my mother's needs better than I do. I also train the other aides while coordinating with the D.R. Together, we are essentially running a small business—managing staff, compliance, and scheduling—just so that my mother can have the consistent, familiar care that keeps her safe.

This is not only the most humane option for her but also the most cost-effective for the state. My mother does not need the revolving door of traditional home care; she needs stability, routine, and the people she trusts. That is what CDPAP makes possible, if the system allows it.

CDPAP is not a privilege — it is a lifeline for consumers and their families. Please protect and strengthen it before more caregivers walk away and more vulnerable New Yorkers lose their right to live at home with dignity.

Thank you for your attention,

Suethra Junion 8.18.2025

Svetlana Jovanovic, Daughter of Maria Jovanovic, Consumer