

Downstate New York ADAPT

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Image description: "Downstate NY ADAPT" text over & under image of PWD in wheelchair with arms raised, breaking handcuffs' chain overhead, under arching text "Free Our People"

Oral Testimony of Downstate New York ADAPT; Nina Bakoyiannis Hearing on CDPAP and PPL – August 21, 2025

My name is Dr. Nina Bakoyiannis, here today on behalf of Downstate NY ADAPT. Let me be absolutely clear: nothing in all the years of CDPAP has been as stressful, as chaotic, or as traumatic as this.

When private-equity backed PPL took over, we were dropped. The promise of continuity was not lived. On April 1st, everyone I know had service disruptions. Consumers were left for days without care while waiting for PPL to get their act together. This wasn't a transition to PPL—there was no bridge, only a gap we were forced to drag ourselves and our PAs across. People were scrambling, people were scared.

DOH claimed services wouldn't be lost, but "on paper" *IS NOT* reality. DOH's weekly press releases boasted that most consumers had "*started or completed*" *registration*, "*started or completed*" *registration* – it meant nothing. It didn't mean PAs were actually onboarded. It didn't mean service authorizations were in place. It didn't mean care was delivered.

Even as the dust settled, support remained diminished under PPL. Before, we had a timekeeper or coordinator with our FIs who knew our case. Now, every time we call PPL, it's a different person. There's constant turnover, no extensions, no accountability, no continuity. Agents lie, pass the buck, and make things up. Problems go unsolved. The DOH literally had to create a hotline just to deal with PPL's failures.

We, consumers, are no longer co-employers, nor are we "joint" employers like the PPL contract states. Instead, we are treated like PPL's commodities. There were no materials from PPL to even explain how to hire a PA through this new system – which is so fundamental to CDPAP. We don't know what "benefits" we are supposedly able to offer our personal assistants. Health insurance? PTO? Nobody can tell us. There is no handbook. PPL keeps changing their website, so even when we think we have an answer, it changes overnight.

Our FIs, who once supported us, were turned into PPL's pawns. They were forced to help us onto PPL's ship, but once we were out to sea, they couldn't help us with our PPL problems. Weeks later, they were instructed to harass us about our PAs working overtime (which PPL is not

even allowed to restrict under NYS law). Suddenly, PPL claims to care about PAs' "health and safety"—a laughable statement given the history of wage theft and apathy.

We were left in the dark. Activists, lawyers, policy analysts, who always know what to say, now having to admit, "I don't know," because nobody could get a straight answer. PPL phone lines went unanswered. We had nowhere to turn. We received WHAT? A letter and maybe a phone call with some vague reason as to why all our FIs shut down. What "joint employers" endure watching their agencies shut down WITH NO ABILITY TO GIVE FEEDBACK? And THEN get forced to sign a contract under duress when told not signing would jeopardize CDPAP coverage. Our ability to use the bathroom. To eat. To shower. Ask yourselves: are any HUMANE public health policies ever built on coercion?

The technology is clunky and inaccessible. The Time4Care app is a nightmare. Glitches, clock-out errors, deleted shifts. Our personal assistants have their own logins and passwords, and we can't even see what's in their account. We can't help them troubleshoot or problem-solve. This separation undermines the relationship at the heart of CDPAP.

In the middle of a work force crisis, nothing guarantees more turnover than not paying workers on time. PAs have gone unpaid, a clear case of wage theft. At least two lawsuits over wage theft have already been filed. Our PAs were stripped of pensions, 401(k)s, and accumulated leave. They face health insurance that has a \$6K deductible.

PPL's entire model is inappropriate for New York. Their system is designed for other states' waiver programs, models that are incompatible with NYS CDPAP. Ours is supposed to be the equivalent of a home care agency where consumers are in charge. PPL does not fit.

So no, we don't accept that this was in the "best interest" of our community. This plan was crafted by people who have no real understanding of what it's like to have the State—or now a private equity firm—control something as basic as using the bathroom, taking a shower, or eating. The authority, dignity, and respect that CDPAP was built on are steadily eroding.

And we become the <u>scapegoats</u>. They've painted us as abusers of the system to justify gutting our programs, while the real waste flows upward. Press releases and op-eds track how much it "costs" the State for us to get out of bed in the morning, while some healthcare executive lounges on a yacht, paid with taxpayer dollars.

New York State has pushed agendas no one asked for, manufacturing crises while shielding bureaucrats. This "reform" of CDPAP was everything about us, <u>WITHOUT</u> US, which is never the way a consumer-directed program should be run. We're here today to fight to rebuild CDPAP around the people, not PPL.