

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"

July 3rd, 2025

Senator Gustavo Rivera

Chair, Senate Standing Committee On Health

Senator James Skoufis

Chair, Senate Standing Committee On Investigations and Government Operations 250 Broadway,

New York, NY 10007

Contact: Ms. Lequela Steen, MPH

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Re: July 9th, 2025 NYS Public Hearing to Examine the Consumer-Directed Personal Assistance Program (CDPAP) transition to a single statewide fiscal intermediary

These comments are submitted on behalf of Downstate New York ADAPT, a chapter of the nation's largest grassroots, non-hierarchical community of disabled people that fights for our right to live and fully participate in the community. We are not a provider organization; we are a coalition of disabled Consumers of Medicaid home care services and our allies. We rely on these services for our survival.

On behalf of more than 250,000 disabled New Yorkers who rely on consumer-directed personal assistance (CDPA), we are writing to express our deep concern about the reckless and dishonest manner in which the State of New York pursued and implemented the transition of the program to a single Statewide Fiscal Intermediary (SFI), a decision that has fundamentally altered our services and threatened our health. As a result of this transition, which was largely hatched behind closed doors, more than 600 trusted FIs, many of which employed people with disabilities, have been shuttered and our care has instead been placed in the hands of Public Partnerships LLC (PPL), a behemoth private-equity company not even based in our state. We ask NYS to roll-back on the Single-FI arrangement, for the following reasons:

First, we were not afforded an adequate opportunity to participate in a proper public comment period, as required.

The secrecy with which the New York State Department of Health (NYS DOH) sought the State Plan Amendment (SPA) authorizing the single-FI plan subverts the most basic tenets of democratic policymaking. The public notice about the SPA was published on New Year's Eve, but the actual text of SPA #25-05 was not posted online until it was submitted to CMS on March 28, 2025, which State of New York officials know does not follow typical protocol and probably violates the law. For DOH to not post in time the actual text of what is, by every measure, a major change to New York State's Medicaid program is not a careless oversight, but an

intentional choice to keep Consumers and our personal assistants in the dark about changes that alter the very fabric of our lives. These failures by New York State denied New Yorkers', including us Consumers', right to proper notice and opportunity to provide public comment, a clear violation of our rights to due process, which is a fundamental principle of administrative law that ensures transparency and public participation with respect to significant policy changes such as this change.

It is disingenuous for DOH to report that they received no public comment on this matter (last page here), since DOH never posted the actual text, never stated a timeframe within which to submit comments, nor complied with other notice requirements with respect to submitting comments. Moreover, the many attempts by activists to raise concerns and objections about this policy have been dismissed by the DOH and the Governor's office. Our valid critiques have been touted to the public simply as a scheme encouraged by disgruntled former FIs instead of legitimate concern by the very individuals who rely on these services to survive.

(For a list of some organizations that have joined us in speaking out about this matter – including AARP, the NYS Senate Republican Conference, and various public officials – please see the end of this letter.)

It is further disingenuous for DOH to claim that the public was able to appropriately engage in discussion around this change. On page 24-25, they wrote that the NYS "legislative process provides opportunities for all stakeholders to lobby their concerns, objections, or support for various legislative initiatives." However, this bill was added into the State Budget with push from the Governor's office at the eleventh hour behind closed doors. Further, the protocol in our State is for the NYS Senate and Assembly to vote "yes" or "no" to an entire fiscal budget that the Governor can add Bills into at whim. There was even added pressure to pass the Budget as a whole given that it was late, further eroding appropriate time for the Senate and Assembly to try to understand this deeply nuanced program and metabolize feedback from the public.

The model of "Self-Direction" that this plan seeks to impose is inappropriate in NYS.

New York's CDPAP program is operated quite differently than other states, and does not use the same kinds of Medicaid "authorities" that are imagined here. The single statewide FI, PPL, came in and superimposed the model of "self-direction" that they are used to in other states (namely 1915(c)), where there are "Support Brokers/Support Coordinators", where there is "Budget Authority" built into the model so that consumers may choose their Personal Assistants' wages, benefits, etc. This is NOT how NYS's CDPAP operates, and thus the Single-FI scheme is asking for permission to use a fiscal framework for admin/direct care costs in CDPAP that the state does **not** yet have the infrastructure for, nor necessary CMS and HHS approvals and safeguards that come with 1915(c), 1915(j) or 1915(i) for. See #02, #07, #08 here: https://pplfirst.com/wp-content/uploads/2024/02/10-reasons-why_selfdirected-care-3-18-2020-1.pdf

Given that Consumer direction is at its core about autonomy and choice, the complete lack of regard for Consumer input in this decision is callous, disrespectful, and deeply contrary to the spirit of CDPA as well as a violation of the laws of New York State and the United States.

While the Governor and her team have routinely dismissed public outcry, we assure you that the chaos and incompetence playing out before our eyes is very real. It is alarming and outright deceitful for DOH to write that, "this change has no impact on service delivery, it only enables the State to streamline the administrative needs of the program to a Statewide contract." (*In the SPA #25-0005 submission to CMS on the last page here*). Significantly, our FIs are more than simply a payroll system. This dismissive oversimplification belies a fundamental disregard for or total lack of familiarity with how CDPAP functions for Consumers and PAs. More disturbing is that this callous and abrupt execution has paralyzed and, in effect, dismantled our care system since April 1st in a manner entirely consistent with what we as advocates publicly predicted all along. We refuse to sit silent and helplessly witness the very care system our lives depend on be upended and dismantled before our eyes.

The State's assertion that the transition of all services to PPL has been smooth and successful is false and fails to account for the State's utter and complete failure to comply with the law and the factual reality of the numerous documented problems experienced by Consumers and personal assistants "on the ground." For instance, many Consumers have experienced being placed on hold for hours only to receive inadequate responses to their questions. So too, many Consumers who request callbacks never receive them, and personal assistants (PAs) who inquire about health insurance documents remain empty-handed. It is outright fraud and incompetency by the State to award a nearly billion dollar contract to a company, here PPL, which the evidence has proven is not equipped to handle the massive caseload. It is fraud and incompetency for PPL to have entered into a contract knowing it could not properly and competently perform. In fact, this past month, state workers were asked to "volunteer" to assist with the PPL transition despite PPL's alleged expertise in managing such programs. Aside from being an indicator of PPL's lack of capacity, the involvement of state workers also raises concerns about patient privacy being violated under federal and state laws including the Health Insurance Portability and Accountability Act, also known as HIPAA, as consumers did not consent to their personal information being shared with people outside of PPL. It is clear that PPL is not prepared to serve a state as large and diverse as New York. Attempting to superimpose other states' models on New York simply will not work, as evidenced by the ongoing struggles of CDPA families.

In general, having only one FI system is foolish.

For instance, our previous FIs were local businesses embedded in our community. They were able to meet our needs on a personal level. Consumers had built years-long relationships with their FIs, with many receiving cultural services and language support not available from a huge and largely faceless entity like PPL. Now with PPL, phone calls are hardly returned, and when they are, it is a new person each time with a different understanding of CDPA.

Our FIs truly respect the consumer-driven model. Many of our FIs honored the consumer directed nature of CDPA by having a minimum of 50% of their Board be consumers of CDPA.

¹ Justin, R. (2025). State workers asked to volunteer to assist with CDPAP transition.Retrieved from https://www.timesunion.com/state/article/state-workers-asked-volunteer-assist-cdpap-20242202.php

Now we are stuck with PPL - a for-profit company that does not care for this arrangement. PPL is not *truly* consumer directed.

Further, many now-closed FIs served elders who are not technologically savvy or lack reliable Internet service. PPL's insistence on the use of the glitchy Time4Care app and the equally glitchy PPL @ Home website disadvantages older adults and those living in low income neighborhoods and clearly violates laws such as the Americans With Disabilities Act. The app's ability to keep accurate records is questionable.

Consumer Kathleen Downes, 32, who has used CDPAP for more than eight years, said that her "PA's shifts sometimes disappear from the app entirely, or the consumer side and the PA side show incongruous information for no obvious reason." She calls her attempts to seek help from PPL "fruitless," describing the phone exchanges as "something of a ping pong between human resources and payroll." Yet, there is no way to speak with payroll directly, raising questions about whether a resolution process for payroll errors even exists which can only lead to violations of labor laws and other laws as well as possible outright fraud by PPL.

PPL has a terrible track record of service provision. When this transition to PPL occurred in states like Pennsylvania, almost half of the program enrollees were lost in the process. It was clear to us from the start of the award of this contract to PPL that PPL would not have the foundation to handle a program as large and complex as we have in New York State. However, our concerns were ignored by New York State and we have had to witness this occur in our home state. This has jeopardized our wonderful CDPA program which the independent living movement fought hard for.

Thousands of Consumers have already fallen through the cracks during this transition in just the first few months of its implementation and this has resulted in a federal lawsuit. Service disruptions have been far and wide since this was implemented, with consumers reporting that the April 1st deadline was not enough time. Paperwork was not processed by PPL in time, our PAs were not fully onboarded, and our service authorizations were not in the system. This resulted in thousands of New Yorkers having their care disrupted. We raise concern that this has violated the Olmstead Decision's mandate to have care firstly available in the least restrictive setting by pulling our care out from under the rug. Moreover, it resulted in unnecessary injuries and hospitalizations to Consumers.

To add insult to injury, the DOH released a statement on April 4th 2025 claiming that "93% of CDPAP consumers have started or completed onboarding with PPL." This is a misleading statement. All that means is that people have made contact with PPL — not that they're actually in the system and ready to receive care, with staff ready to receive pay. The fact that that was being shared as *good news* speaks volumes to how little this administration values consumers and care workers and how easily they can contort information. To save face, they celebrated thousands of us being forced to wait in limbo — without care — simply because they prioritized cost-saving and appearances over human lives. This entire disaster has resulted in multiple lawsuits, both at the Federal and State levels, many of which are ongoing. Some of the lawsuits

include Jeannot et al v. New York State (1:24-cv-05896), Engesser et al v. McDonald (1:25-cv-01689), and Calderon v. Public Partnerships (1:25-cv-02320).

We witnessed wide-ranging wage theft of our PAs' pay. According to a recent survey by Caring Majority Rising, 70% of surveyed PA's went unpaid at the first pay cycle and 57% still went unpaid at the second.² Not only is this a violation of the law in the form of wage theft, but it increases the likelihood of staff resignations in the midst of a historic care crisis. According to PPL, addressing this matter is asking "leading questions", but we just want to know if our PAs got paid. Payment delays have left Personal Assistants with no choice but to leave their jobs, which puts the lives of an estimated 280,000 Consumers at risk. This includes the risk of hospitalization or nursing homes placement, which just increases the cost to taxpayers, costs that could have easily been avoided.

There are numerous individuals and organizations whose concerns have and continue to be ignored by NYS. Please review some additional letters opposing the Single Statewide-FI:

- New York State Senate Republican Conference letter (August 14, 2024)
- NYS Assembly letter (October 1, 2024)
- Richie Torres letter to Gov. Hochul (December 8, 2024)
- **Health Plans 1st** letter to Hochul (Jan 7, 2025)
- Medicaid Matters NY letter (Jan 8, 2025)
- Ritchie Torres letter to Inspector General of the US Dept of HHS (Jan 15, 2025)
- **Health Plans 2nd** letter to Hochul (Feb 21st, 2025)
- Assemblymember Amy Paulin letter (March 5, 2025)
- AARP Letter to Gov. Hochul (March 17, 2025)

<u>Ultimately, we believe the only reasonable way forward is to give Consumers real choice</u> and eliminate the Single-FI model. Without such, we will continue to watch NYS' home care infrastructure crumble before our eyes.

PPL's practices and procedures which began on April 1 fundamentally changed our beloved program. Procedures and duties that have always been the responsibility of every consumer since the program was created in 1977 have been taken away by a single Statewide Fiscal intermediary, PPL. We are being steamrolled and the Governor and the DOH continue to cheer.

Governor Hochul's stated intent was to save money. One way she could have accomplished her goal is to eliminate for-profit managed care companies who have mismanaged Medicaid. Instead, she chose to attack the very foundation of our care by first violating laws with respect to providing due process when proposing a major change to a New York State's Medicaid program and second, in not complying with the law and awarding a contract to an out of state private

² Khafagy, A. (2025). Immigrant caregivers say state-backed home care agency stole their wages. Retrieved from

https://documentedny.com/2025/04/29/immigrant-caregivers-home-care-agency-cdpap-ppl-wage-theft/#:~ :text=But%20according%20to%20a%20survey.caregivers%2C%20and%20home%20care%20workers.

equity company, PPL, that clearly cannot properly perform the contract. **DOH has turned our FIs into a corporate conglomerate and is treating us like commodities for the benefit of a corporate system. This has decimated the very foundation of the Consumer-Directed model and put our lives at risk.**

We are asking for your assistance with this matter and for the chance for our concerns to be meaningfully considered.

Thank you for your time, **Downstate New York ADAPT**