# CIVICS LEAGUE for DISABILITY RIGHTS

People with disabilities taking action together.



July 3,2025

Testimony of Marcus Johnson Civics League for Disability Rights 169 Madison Avenue, STE 15744 New York, NY 10016 Senate Public Hearing on CDPAP July 9, 2025

Good morning, Chairperson and distinguished members of the committee, My name is Marcus Johnson, and I proudly represent the Civics League for Disability Rights, a coalition deeply rooted in advocacy, independence, and the dignity of New Yorkers with disabilities. Thank you for the opportunity to testify today on an issue that is not only urgent—it is deeply personal.

## First, let me begin with a truth that demands to be heard:

When I speak today, I do so not only in my own voice—but in the voice of 3.9 million adults in New York State who live with disabilities. That's 26.6% of the adult population. Behind that number are elders, veterans, young adults, Black and brown communities, immigrants, and more. We are diverse. We are resilient. And we are outraged.

Outraged because the Consumer Directed Personal Assistance Program (CDPAP)—a program created by us and for us—has been radically altered without our consent, and worse, without our lived experience informing the process.

# Let's be clear about what happened:

Governor Hochul and the Department of Health unilaterally made the decision to transition CDPAP to a single statewide fiscal intermediary under Public Partnerships LLC (PPL). This was not a collaborative process. This was not informed by the wisdom of those who rely on the program every day. Instead, it was a top-down directive, based on narratives shaped by able-bodied decision-makers who do not live with our realities and have never had to depend on CDPAP to remain safely in their homes.

#### Let me give you one example—though I assure you, there are hundreds more:

Just last week, I spent hours—literal hours—on the phone with PPL representatives to address an issue with a so-called "valid authorization." This administrative failure directly impacted my Personal Assistants (PAs), who were unable to be paid through no fault of their own—or mine.

When I had my previous fiscal intermediary, this sort of chaos was unheard of. I never had to log in to a clunky system just to approve hours. My PAs never had to fumble through uploading sensitive documents online. Suddenly, we've all become unpaid HR administrators—a role we never asked for, never trained for, and never agreed to take on.

## The consequences are devastating:

This burdensome system is pushing people out of CDPAP and into traditional home care models that strip away the autonomy we fought so hard to win. Many agencies simply do not understand our needs—nor are they equipped to meet them. Unlike CDPAP, they do not allow us to choose who touches our bodies, who enters our homes, and who supports our daily lives.

And here is a fact that must be emphasized:

CDPAS is the ONLY way some of our community members can remain in the community. People who use ventilators, feeding tubes, or require other complex supports cannot transition to agency care, because agency-based aides are not legally permitted to perform these tasks. There is no alternative. Without CDPAS, these individuals face forced institutionalization—pure and simple. We are talking about a human rights crisis hiding in plain sight.

As a result of PPL's ongoing payroll and processing issues, we are losing our most trusted caregivers. These are people who know our conditions, our routines, and our humanity. These are people who have become family. And when their livelihoods are threatened by a broken payroll system, they're forced to walk away. We are left to fend for ourselves.

## The path we're on is dangerous:

Without reliable access to our chosen PAs, many of us will be pushed into institutional settings—nursing homes, group homes, long-term care facilities—places we fought for decades to avoid. This is not an exaggeration. This is a looming reality for many in our community. For some, it's already happening.

Let me be clear: CDPAP is not just a program. It is a lifeline. It is the difference between dignity and dependence.

## And so today, I say this directly to Governor Hochul and the Department of Health:

Own what you've done. Own it.

You have dismantled a system that once worked—flawed, yes, but functional—and handed it over to a single entity, Public Partnerships LLC, that has utterly failed to meet the scale, nuance, and responsibility

of the role. Their infrastructure is inadequate. Their customer service is non-existent. And their disregard for the needs of people with disabilities is intolerable.

It is time to clean house.

It is time to restore multiple fiscal intermediaries and reinstate choice, autonomy, and oversight. We know what works. We've lived it. And we won't stand by as it's taken from us under the guise of efficiency or modernization.

## In closing:

I urge this body not to underestimate what is at stake. If CDPAP continues down this path, it will cease to be the empowering tool it was meant to be. It will become just another bureaucratic barrier in a system already stacked against disabled New Yorkers.

I thank you for your attention and urge you to act not just with policy—but with courage, urgency, and compassion.

## Respectfully submitted,

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