Testimony of the
Center for Disability Rights
to the

SENATE STANDING COMMITTEE ON HEALTH

SENATE STANDING COMMITTEE ON INVESTIGATIONS AND GOVERNMENT OPERATIONS

Transitioning CDPAP to a Statewide Fiscal Intermediary

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Thank you for the opportunity to speak with you today.

The Center for Disability Rights is a Disability-led non-profit membership organization. We are a Center for Independent Living, providing services to people with disabilities and advocating for systems change promoting the full integration, independence, and civil rights of people with disabilities. We over the course of a year serve approximately 9,000 people with disabilities across New York State.

Our comments are based on our experience as disability rights advocates who worked to establish consumer directed personal assistance services as a statewide program in the early 1990s, a disability-led nonprofit that served as a fiscal intermediary for 25 years, and a contracted IL facilitator under PPL.

I am sharing copies of my testimony and a copy of the 200-page policy report, Early to Bed/Late to Rise, which was written by volunteers and published in 1993.

It is critical that the legislature understand this issue from the perspective of Disabled people who are living it.

- Importantly, Disabled people see ourselves as a marginalized community who experience oppression which we describe as “ableism”. That oppression is similar to other forms of oppression. It can be interpersonal, institutional, structural, and internalized.

- Due to systemic ableism, Disabled people are not included or represented among the policy-makers who have an extraordinary impact on our daily lives. Consequently, we must rely on allies to understand and advance our interests.

- Disabled people live in a world of double-speak where the oppression we experience is often framed as “care.” This can include being taken from our homes and locked away solely because we are Disabled.

- When we raise concerns or objections as Disabled people, we are dismissed and our concerns minimized as “not understanding” which leverages ableism against us individually as well as against our organizations.

It is critical that the legislature understand important historical background about the development of CDPAP – which was originally called “Patient Managed Home Care”. This program was developed BY Disabled people FOR Disabled people.

- The model was originally created in NYC in the 1970s, and we owe a debt of gratitude to Sandra Schnur, Marilyn Saviola, Victoria and Ira Holland, Muriel and

Vincent Zgardowski, Daniel Ginsburg, Gertrude Schleier, and Ed Litcher for their groundbreaking work.

- In 1990, because people with significant disabilities in Rochester were being forced into institutions because they could not get home care services that would effectively support their independence in the community, members of CDR – who were all volunteers – wrote a policy report titled Early to Bed/Late to Rise.

- This report was researched and written by John Belanger, Debbie and Joe Bonomo, Adele Carlson, Patricia Carpenter, Teresa Carroll, Peggy Gorrow, Carmen Hernandez, Janine Lawson, Ann and Julian Kaplow, Nancy Salazar, Judy Sandler, Sherry Shaw, Susan Stahl, and myself – Bruce Darling.

- Early to Bed/Late to Rise was completed/published in 1993 and served as the basis for the advocacy which established CDPAP as a statewide service in a single legislative session. The reason this policy moved quickly was that the program increased the independence of Disabled New Yorkers while at the same time it was much more cost-effective than traditional home care.

Initially, CDR chose not to become a fiscal intermediary, but when the program was not implemented locally, our board recognized that "if Disabled people want something done right, we need to do it ourselves".

- Our program model was developed in partnership with Disabled individuals who used attendant services, including Carmen Hernandez, Steve Kasper, and Vivian Mangan.

- We followed the lead of Sally Johnston – a Disabled woman who spearheaded the model in Syracuse – and worked closely with Constance Laymon a personal assistance user who established the program in Albany.

- CDR maximized individuals' control over their services by clearly recognizing that we were only an employer of record and not a joint employer.

- CDR also recognized that every manager needs support and that as a fiscal intermediary our role was to provide the support and training. Over 25 years we found this was essential to the success of individuals managing their services.

- We developed specialized training – built on the lived experience of local attendant service users and Alfred DeGraff who wrote an exceptional book on the topic of his lived experience of using attendant services. This training became the basis for our onboarding of all CDPAP consumers.

As a Disability-led, membership organization, CDR not only maximized Disabled people's control over their own services, but we also maximized control by Disabled people of the organization itself and reinvested what would otherwise be "corporate profit" into the Disability Community.

- CDR developed and self-funded a nationally recognized model for transitioning people out of institutions and into the community. We stopped tracking our impact after we had trained people from 37 states, territory of Guam, and the District of Columbia.

- CDR developed and self-funded DeafBlind Support Services in Rochester.

- CDR advocated for federal and state policies that advanced Disability Freedom, including the creation of the federal Money Follows the Person Program and the Community First Choice Option – which have brought billions of dollars into New York State – as well as the state's Nursing Home Transition and Diversion Waiver, Olmstead Housing Subsidy, and Open Doors Program which have given thousands of Disabled people the kind of freedom everyone else takes for granted.

- And we saved Medicaid and Obamacare in 2017, only to lose that ground in 2025 because we were consumed by this state-level disaster.

The root cause of the problems in New Yorks approach to Long Term Services and Supports is that, instead of creating a rational system where care is coordinated, implementation of managed care created perverse incentives and unintended consequences.

- The Cuomo administration never accounted for the basic principles of capitalism in the privatization of Medicaid – that a privatized managed care system would seek to increase its customer base.

- When they could not market themselves directly, MCOs began using CDPAP fiscal intermediaries to expand their customer base. They incentivized adding lower need/lower cost individuals who could help the MCO maximize their capitation.

- Lack of regulation and oversight has created and fostered opportunities for backroom deals which divert funds from the Disability Community into private equity and corporate bonuses.

The public messaging is very different from the actual intent and policy of establishing a Statewide Fiscal Intermediary (SFI).

- The SFI proposal was advanced by 1199SEIU at least as early as 2017 as a way to centralize the workforce and make it easier to organize this large group of home care workers.

- The SFI was (and still is) publicly being touted as addressing fraud, but it was never about fraud as it is commonly understood. When staff in House Minority Leader Jeffries' office were told that there is very limited fraud in CDPAP and that the authorizations and billing were all legal, they responded with "Fraud isn't always illegal. We are addressing legal fraud." That's Orwellian doublespeak.

- Scapegoating the former FIs – including the Independent Living Centers – is intentional misdirection, diverting attention away from the harm being done to Disabled New Yorkers. That's Trumpian-level misdirection.

The transition was a nightmare.

- The April 1st deadline was established to avoid giving the legislature an opportunity to rethink this decision when problems arose. It was unworkable.

- PPL's system was not designed to accommodate facilitators. They didn't appropriately control access to people's personal data. This meant people's data was available to organizations they did not work with. To compensate for that PPL locked down data, but that interfered in the work we were trying to do.

- During the transition, it was openly acknowledged that some Disabled people would "attrite," but there was no regard for the impact on the lives of Disabled New Yorkers. There was no recognition that people would be left without services, be institutionalized, or worse. Policy makers didn't express any concern that people like Jensen Caraballo – and others – would die.

- There was no recognition that the plan would violate the rights of Disabled Medicaid recipients to notice and due process. This required the Disability community – and our most appreciated allies – to go to court and sue the state to secure a plan that complied with the law.

- There is an unfounded rumor in Albany that CDR and the other ILCs withheld consumer data to delay the transition. That isn't true. CDR vehemently disagreed with the state's expectation that we hand over confidential consumer information without people's individual consent. Confidentiality and consent were not tactics. They are deeply held beliefs.

- Disturbingly, the transition established precedent and policy that state government should be able to direct healthcare organizations to hand over what would otherwise be considered confidential information. This doesn't end with us. When you think about the state's right to direct the release of confidential healthcare information, look beyond "disability" and please consider the implications for reproductive healthcare. This is dangerous precedent.

- CDR identified a process to expedite enrollment while ensuring that individuals actively authorized the release their personal data. Although PPL agreed to implement the plan and assign specific customer service staff to CDR, they reported that the Hochul administration forbid them to implement our mutually agreed upon plan. The rationale for the decision was never explained to us.

Frankly, NYS has done more to support an out-of-state for-profit corporation backed by private equity than it ever did for the non-profit Disability-led organizations that originally developed the program.

- NYS has funded and continues to support a significant – and frankly ableist – public relations campaign supporting PPL.

- NYS appears to have "relaxed" some of the rules that it would have otherwise vigorously enforced, including documentation requirements under Medicaid and labor law, timely payment of wages, and compliance with the Obamacare mandate.

- NYS also interceded with managed care in the contracting process to establish a system of pre-payment to PPL for services when we – non-profit organizations – needed to scrape the funds together to pay the workers and wait for reimbursement which MCOs would regularly delay and deny. For the record, Constance Laymon – a quadriplegic woman who founded Consumer Directed Choices in Albany – mortgaged her own home to accomplish this. CDR's bank expected me to do the same thing.

- NYS appears to have given PPL flexibility allowing direct care and training funds to be used to support PPL's administrative operations.

The change to PPL as a statewide fiscal intermediary has not addressed the issues it was supposed to address.

- Although the change has been touted as advancing consumer direction, PPL selected partners that aligned with its corporate model and were not respected by the Disability Community. As an example, PPL partnered with Angels in Your Home, a for-profit, upstate home care agency that was fined for losing control of their confidential consumer and attendant files when they were stolen by Angels' former CEO and staff. The agency was known in the community for not supporting true consumer direction.

- There is still room for backroom deals. PPL facilitators have been instructed to secure preferred provider agreements with MCOs as a way to increase their referrals, and these facilitators are using lists apparently provided by MCOs to involuntarily transfer consumers from the ILCs and other facilitators.

- This change was supposed to save taxpayer money, but a significant number of Disabled people moved into more expensive programs to preserve the agency and personal connections that were important to them, wiping out any projected savings. We warned the administration that this would happen but were ignored.

Even with all of their corporate backing, PPL's systems are less sophisticated than the infrastructure we – as Disabled people – developed.

- CDR developed a system that for almost 25 years prevented anyone on our staff from fraudulently creating hours in the system for payment or diverting these funds to themselves. PPL didn't manage to avoid this during its first four months of operation in New York.

- CDR's systems kept people's personal information confidential – both consumers and workers. PPL's system allows people to see each other's information.

- When authorizations expire, attendants can't clock in to work and be paid. This is a termination of Medicaid services. For decades, CDR accommodated regular delays in authorizations which never impacted people's services.

- The problems continue. Just yesterday, CDR had to escalate yet another situation where workers haven't been able to clock in for a month because of problems with PPL's system.

This change has undermined the services Disabled people use to stay in the community. This particularly impacts the ability of people with the most significant disabilities to live in the community – particularly those who are most marginalized and have the least amount of personal resources or support.

- Before managed care, CDR staff would meet regularly with counties to review concerns and develop a plan to provide training and support to foster success. Despite the focus on care management, we have never had such a meeting with an MCO.

- Recognizing that workers need their pay in a timely manner, CDR could immediately issue a check if there was a problem. That no longer can happen.

- Disabled individuals worked with a CDR support specialist who was assigned to them. This resource would know the individual personally and could identify support needs. The PPL system is an app and call center model which may be "efficient" but eliminates this level of support.

- CDR would make a variety of reasonable accommodations for individuals, including alternative formats and language accommodations. Under the current system, PPL drives individuals who require higher intensity support to the IL facilitators while keeping others for themselves which means we don't have the resources to effectively meet people's needs.

- The situation is even more perilous upstate where there is not an effective alternative to CDPAP for in-home assistance. Traditional home care doesn't accept "must-fill" cases, doesn't cover authorized and needed hours, and actively discharges individuals with significant disabilities.

We appreciate the legislature's intention and commitment to preserving the Disability-led Independent Living Centers in the state law establishing the SFI, but that is not what is happening.

- Instead of centering Disabled people and the organizations we run in this system, PPL has not utilized or effectively leverage this non-profit, mission-driven, Disability-led network. In fact, despite clear legislative intent, we are being side-lined.

- CDR submitted a capacity plan to PPL when we signed our contract with PPL. Our capacity plan for July 2025 was 11,000 consumers; we are only serving 1,006 – less than 10% of CDR's capacity plan.

- Although PPL is required by that signed contract to refer consumers to CDR and the other ILCs in order for us to meet our capacity plan, they are not doing that. When we notified the Hochul administration that the ILCs are struggling under this system, they took a "hands off" approach and indicated that our only recoyrse is to address the issue with PPL.

- Even though the ILCs negotiated a contract that avoids PPL's original gag order, PPL has repeatedly communicated its concerns that the ILCs – and our state association who is not a party to any contract – have disparaged PPL. They have indicated that referrals will not be forthcoming until we comply with their expectations on messaging. This is a clear effort to silence our voice and advocacy on behalf of Disabled New Yorkers.

- The message is clear. The ILCs will only get what PPL is willing to give us. Compliance – not competence – will be rewarded.

- The State of New York has forced the Disability-led Independent Living Centers out of a system we developed to meet vital needs in our community. We have been relegated to a subservient role to a private-equity-backed, for-profit corporation whose primary interest is its bottom line and investors.

The legislature needs to take action.

- Reinstate the 11 ILCs as full fiscal intermediaries and ensure that these non-profits are treated equitably in the system they developed and not disenfranchised by preferential treatment being given to PPL.

- Establish a process that centers the Disability Community – specifically people who utilize Long Term Services and Supports – in the redesign of the state's system for providing those services and supports.

Final words.
I will take you back to the beginning of my testimony. Consider the Disability Community as a marginalized and oppressed community.

We recognize that our country has a long history of enriching people with power and privilege at the expense of the marginalized and oppressed. From our perspective, doing this to the Disability Community is not fundamentally different from doing it to any other marginalized and oppressed community.

Our siblings in the fight for social justice should take note, and ask themselves, "Where does this end?"

I will ask you, as members of the NYS legislature, will you take action to address this injustice or will policy makers in Albany allow state government to divert resources away from marginalized communities by selling off segments of our healthcare system to for-profit corporations backed by private equity?

Personally, I think the choice – and call to action – is clear.

Thank you.