

**New York State Senate Standing Committees on Health and Investigations & Government
Oversight Joint Public Hearing July 7, 2025
Consumer Directed Personal Assistance Program**

TO: Senator Gustavo Rivera, Chair, Senate Standing Committee on Health
Senator James Skoufis, Chair, Senate Standing Committee on Investigations &
Government Operations
FROM: Brian Flannery, Coordinator of Policy and Advocacy, Independent Living, Inc.
DATE: July 3, 2025

Dear Chairman Rivera,
Dear Chairman Skoufis,

We appreciate this opportunity to submit written testimony regarding the experience of Independent Living, Inc.,¹ a former fiscal intermediary (FI) operating in the State's Consumer Directed Personal Assistance Program² (CDPAP) and current facilitator working to support the ongoing implementation of the State's transition of the program to a single FI,³ PPL, as well as our former consumers, designated representatives, and personal assistants. We share concerns about the rollout of this transition's impact on consumers, and PPL's engagement with its facilitator partners.

Founded in 1987, ILI is a consumer-directed, cross-disability advocacy and service organization dedicated to enhancing the quality of life for people with disabilities. Having served the Orange County and the greater mid-Hudson region for nearly 40 years, ILI is a center for independent living (CIL) authorized and supported by the Rehabilitation Act of 1973,⁴ and has also become the regional leader in the provision of Peer services.

¹ Independent Living, Inc. (ILI) participated in the State's Consumer Directed Personal Assistance Program (CDPAP) as a fiscal intermediary (FI) through Independent Home Care, Inc., a separately incorporated sibling entity sharing senior leadership with ILI, and, more important, sharing ILI's overarching mission, vision, and values, as well as its commitment to New Yorkers with disabilities. All references to ILI throughout this testimony incorporate and refer to Independent Home Care, Inc.

² See generally N.Y. Soc. Serv. L. § 365-f.

³ See, e.g., Amended Prelim. Inj., *Engesser v. McDonald*, No. 25-cv-1689 (E.D.N.Y. June 27, 2025), Dkt. 118. The injunction extends earlier court-ordered provision for the purported class of CDPAP consumers whose own or their PAs' registrations with PPL are not yet fully complete to continue receiving FI services through their pre-April 1, 2025 FI. Accordingly, although Part HH of chapter 57 of the New York Session Laws of 2024 anticipated full and complete transition to a single "statewide fiscal intermediary" by April 1, 2025, as a factual matter this has still not yet occurred. 2024 N.Y. Laws, ch. 57, pt. HH.

⁴ See Rehabilitation Act of 1973 §§ 721-727, *codified at* 29 U.S.C. § 796f.

Steeped in the tradition of the independent living movement, which gave rise to the current disability rights movement in middle of the last century, ILI is committed to its vision of barrier-free society with opportunities for all people to achieve their maximum potential.

Indeed, ILI's current leadership was instrumental in bringing the consumer-directed program model to the State almost three decades ago, and ILI has remained a stalwart champion of the consumer-directed approach to facilitating the independence, securing the dignity, and preserving the autonomy of New Yorkers with disabilities since its own founding.

Impact on Agency

ILI began providing CPDAP FI services in 1997, and in the period since, has served over 2,000 of our neighbors and community members with disabilities, ensuring that these individuals have been able to remain in the communities they call home and continue contributing to public and community life. We view the loss of a single individual from CDPAP to an institutional setting as a tragedy, and the attrition CDPAP participants to more costly and less effective levels of home care to be a needless indignity. This transition has already led to the latter and needlessly risks the former. Among ILI's modest share of program participants alone, around 10% appear to have attrited to Personal Care Services,⁵ a variant of Medicaid-funded home care that de-centers the consumer, restricting their choice of care provider and the scope of tasks those providers are permitted to perform.⁶

Under the consumer-directed model, participants are able to, with limited exceptions,⁷ select any personal of assistant of their choosing and train them to perform precisely the tasks that consumer needs in exactly the way that best suits the consumer's particular impairments, needs, and preferences, but these are significant deviations from the requirements of alternatives.⁸ CDPAP's approach centers the autonomy and expertise of the consumer with respect to their own needs, and echoes and reinforces the objectives of the disability rights movement *writ large*. Under PCS and other agency-driven home care arrangements, "responsib[ility] for hiring, training, supervising and providing . . . home care worker[s]" shifts from the consumer—who best

⁵ See N.Y. Pub. Health L. § 3600 *et seq.*

⁶ See 18 N.Y.C.R.R. § 505.14(a)(5).

⁷ N.Y. Soc. Serv. L. § 365-f(3); *id.* (A CDPAP "[consumer's] spouse or designated representative may not be the personal assistant for the eligible individual; however, a personal assistant may include any other adult relative of the [consumer]."); *accord* N.Y. State Dep't of Health, Consumer Directed Personal Assistance Program (CDPAP) https://www.health.ny.gov/health_care/medicaid/program/longterm/cdpap/ (last visited July 3, 2025) ("CDPAP[] is a New York State Medicaid program that allows Medicaid members to choose and hire their own personal caregiver, or 'personal assistant,' . . . includ[ing] a friend or family member . . .").

⁸ See, e.g., N.Y. Edu. L. § 6903(1)(a)(iii) (exempting CDPAP PAs from otherwise applicable licensure requirements).

knows their own needs—to the agency.⁹ Such arrangements’ de-prioritization of individual consumers serves to undermine their dignity and personhood, and throws into sharper focus the stakes of any disruption to the continuous delivery and receipt of CDPAP services.

In addition to lying at the center of ILI’s commitment to the community, its provision of CDPAP services has contributed substantially to our growth into a key social services agency offering over 35 distinct programs and services to New Yorkers with disabilities in seven counties—often the only provider of certain services in a given geography. While ILI will strive to continue serving the expansive geography of its service area with the broad ranges of critical services, the loss of CDPAP complicates that picture.

Having spent the last 28 years as a leader in the provision of home care services for individuals with disabilities in the mid-Hudson region, ILI was loath to lose the close connections we had forged with our 352 then-current consumers on April 1 of this year. It was only on the strength of ILI’s reputation and relationships with our CDPAP consumers that, in the period between the announcement of the transition in late 2024 and its intended completion date of April 1,¹⁰ we saw only a 5% reduction in our consumer base. Feeling the risk somewhat more acutely, our PAs left at a rate of approximately 7%. Indeed, the designated representative of one of our former participants reported, after long experience “work[ing] with a lot of FIs” on behalf of two of her uncles, that “hands-down, ILI is a cut above. They truly are.”¹¹ All the same, we would fervently have preferred to preserve these consumers’ home care, and lament even this 5% reduction in the dignity and autonomy conferred by participation in CPDAP.

ILI remains gratified by New York State’s explicit recognition of the irreplaceable value CILs such ILI represent in the provision of CDPAP. The same enactment that required the State to transition to a statewide FI also requires that FI to “subcontract” with the 11 CILs been had been providing CDPAP FI services prior to the transition.¹² We continue to believe firmly that CILs have a central place in the provision of CDPAP services in New York, and look forward to continuing to support their provision under any guise we must adopt. Accordingly, ILI enthusiastically entered into its current arrangement with PPL as a facilitator.

⁹ New York State Medicaid Plan, Attachment 3.1-A, Supplement New York 3(d)(i) (effective as of July 1, 1991), available at

https://www.hcrapools.org/medicaid_state_plan/Attachment_PDF_PROD/attach_3-1a_supp.pdf

¹⁰ Office of the Governor of N.Y., Governor Hochul Announces Next Steps in Plans to Strengthen Home Care Services for New Yorkers (Sept. 30, 2024)

<https://www.governor.ny.gov/news/governor-hochul-announces-next-steps-plans-strengthen-home-care-services-new-yorkers> (last visited July 3, 2025).

¹¹ Partial transcript of July 2, 2025, phone conversation available upon request.

¹² 2024 N.Y. Laws, ch. 57, pt. HH



Having subcontracted with PPL under relevant statutory terms to support the State's transition of the program, ILI requested to carry a roster of 10,000 consumers (hereafter 'facilitatees') in our new, more limited capacity as a facilitator under the statewide FI, and hired seven additional staff to meet the promised demand. As the process has unfolded, ILI never carried more than 1,344 facilitatees on its rolls. Finding its added capacity underutilized, ILI's consistent requests for additional facilitatees have gone unheeded. As of this writing, our total facilitatee-base has diminished to 1,186—not only a far cry from requested 10,000 but itself a nearly 12% diminution over the course of the transition.

PPL's intervention into the CDPPA ecosystem appears to be accelerating our participant attrition by roughly 100%. Accordingly, ILI is growing concerned about PPL's commitment to furnishing the number of facilitatees it will take to make whole reductions suffered by the loss of full FI status, and, more important, the number commensurate with our documented ability and repeatedly-articulated desire to support. Eventually, we had to eliminate over 70% of our additionally-hired staff for lack of facilitatees to support in transition and engagement with CDPAP.

Irrespective of the foregoing, our chief concern remains with our former consumers, and all CDPAP consumers relying the program around the State.

Impact on Consumers and PAs

While we share certain key information regarding this transition's organizational impact on ILI, we leave to our colleagues at the New York Association on Independent Living (NYAIL) and other former-FI CILs the elucidation of structural issues ripping across NYAIL's network of CILs, particularly the 11 former-FI CILs. We endeavor instead to use this testimony to center certain representative or significant experiences of our former consumers and PAs.

The designated representative (DR) of one of ILI's former CDPAP consumers shared her experience working with PPL to transition her aunt, who receives 168 weekly hours of home care, or 24/7 support.

I have written 3 emails to PPL and have received NO response with the exception of the "auto-response" informing me that they did receive my email. I have given up on that approach. . . .

It has been 3 months since the conversion to PPL and the Time4Care application. The transition has been an ongoing cause of stress and anxiety for me and my caregivers and my aunt (as I am consumed with working with caregivers to unravel and address payroll issues and not visiting with her). It is so frustrating and so sad. Characterizing the "errors with payroll processing" as "too numerous to list," this DR has "had no choice but to up-front over \$5,000 in personal funds for caregivers to draw from" to ensure they "be made whole on their pay each week," and further shared a detailed note "outlin[ing] the shifts that have still not been paid"—this note identifies fifteen unpaid shifts for just one of this

DR's aunt's PAs. As of a July 2, 2025 phone call, this DR could not confirm whether her aunt's PAs had received any back-pay at all.

Moreover, this same DR has taken to jury-rigged workarounds to reach PPL staff regarding the litany of issues she has described above. "I finally found that the only way to talk to someone at PPL was via the Spanish line." Through that route, she found that "[o]ne person was helpful in giving me the steps on what I needed to do to resolve an authorization issue." However, she also reported that the issue in question was "created by PPL's lack of informing consumers of new requirements." In another instance, "the PPL representative promised she would correct a problem with my 'In Review' timesheet," but "[i]t never happened."

Added Urgency

Now more than ever, New Yorkers who rely on CDPAP grow more vulnerable to the vagaries of federal policymakers, and require the affirmative and robust protection of the state DOH, Medical Assistance Plan, and coordinated protection schemes. With today's passage of H.R. 1 and the Supreme Court's near-simultaneous erosion of § 1983 causes of action to vindicate rights secured under Spending Clause legislation, already-vulnerable populations face ever-greater precarity, with consumer of CDPAP services no exception.

Medina v. Planned Parenthood's curtailment of 42 U.S.C. § 1983's provision of causes of action to vindicate erstwhile statutory rights secured by Spending Clause legislation casts the Legislature into a newly central role in preserving the rights of Medicaid members.¹³ This past Friday's decision risks cutting off access to judicial remedy when states violate rights protected by the Medicaid Act. Left without full recourse to federal court, Medicaid members are relying more urgently on State mechanisms of intervention to protect their access to this critical home care program and make good on New York's commitment to upholding the promise of *Olmstead*.¹⁴

Indeed, with respect to the State's rollout of the ongoing transition of CDPAP to a single statewide FI, courts have already affirmatively intervened on the basis of actions brought under § 1983. Federal District Judge Frederic Block was sufficiently persuaded that the balance of the equities in this transition sufficiently favor affected CDPAP consumers and that they stood a sufficient likelihood of success on the merits of their claims that he issued a preliminary injunction preventing the Department of Health from enforcing a provision of the Social Services Laws that

¹³ No. 23-1275 at 3-4 (2025) ("[F]ederal statutes do not confer "rights" enforceable under §1983 "as a matter of course. That is particularly true of statutes, like Medicaid, enacted pursuant to Congress's spending power.) (internal citations omitted).

¹⁴ *Olmstead v. L.C.* 527 U.S. 581 (1999) (holding that states' unnecessary institutional segregation of people with disabilities amounts to impermissible discrimination under the Americans with Disabilities Act, 42 U.S.C. § 12101 *et seq.*)

would require all pre-April 1 FIs to cease operations.¹⁵ This case proceeds on just such a theory likely to be affected by *Medina*.

We believe the foregoing to be sufficient reason for the Legislature to consider intervention for the benefit of CDPAP consumers, and reconsider the current approach to provision of CDPAP services—as, indeed, it has striven to do through the leadership of Senator Rivera, among others.¹⁶

This is uncharted territory and we look forward to the State taking up its familiar mantle as critical bulwark against any incipient return to “the regrettable reality where [certain] state instrumentalities could not or would protect federal rights.”¹⁷ As ever, ILI will be with the State as it does.

We appreciate your consideration of these important matters.

Respectfully,
Brian Flannery
Coordinator of Advocacy and Policy, Independent Living, Inc.

¹⁵ Amended Prelim. Inj., *Engesser v. McDonald*, No. 25-cv-1689 (E.D.N.Y. June 27, 2025), Dkt. 118.

¹⁶ S.1189; S.7954.

¹⁷ *Health & Hospital Corp. of Marion Cty v. Talevski*, 599 U.S. 166, 177 (internal quotation marks omitted).