

Doris and Sarah Behan

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I would like to share that I am the mom who spent five years working with then-Assemblyman Joe Morelle to pass legislation that allowed parents of adult children with disabilities to be compensated through CDPAP. A change that was crucial for families like ours, ensuring that we could provide care without the added burden of financial strain.

I have been a paid personal assistant for my daughter Sarah for nine years and would like to share our story and experience as I tried to register with the single Fiscal intermediary (FI) Public Partnerships LLC (PPL) to continue services for my daughter with CDPAP.

I started the registration process in January 2025 and was immediately faced with many road blocks. Here are just two examples:

(1) Health Insurance: PPL's inadequate health insurance has forced me out of the program as Sarah's paid caregiver. I am now at risk of losing the very home I fought so hard for her to stay in.

I struggled getting information about the health insurance they were offering. My first inquiry was with Medicaid Director Amir Bassiri in February, 2025 I was told it was going to be a great plan with little to no co-pays. During the month of March 2025 my inquiries yielded four separate answers, The Fiscal Policy Institute said it was a Minimum Value Plan, the manager from PPL said it was the Emblem Bronze Plan, However she didn't know the deductible or premium and thought the effective date would be June 1st 2025 but that was subject to change. And Doh said it would be the Anthem Bronze SSP. And the Anthem Bronze beyond value plan was also put out there. So in the end I didn't know what the plan was going to be.

But I kept holding on to PPL's promise that a dedicated insurance phone number would be available by the end of March 2025 but they kept delaying that information. I needed to make a decision by April 2025 as I would have

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become ineligible to take open market insurance due to income level if I proceeded with registration. Omni/Leading Edge finally sent out emails at the end of May 2025 with contact info and Anthem Bronze Secure Health Plan with a \$6,350 deductible and a monthly premium of \$212.00 is the plan! This insurance plan is not a viable option for me with such a high deductible and high monthly premium and still there is no further information about coverage for this plan.

(2) Memorandum Of Understanding (MOU): Without my or my daughters knowledge, PPL signed off on the MOU for Sarah, who has a designated representative (DR).

On March 4th 2025 I had a zoom visit with Medicaid director Amir Bassiri to voice my concerns that I was unable to move on in the registration process because PPL wanted Sarah to sign an MOU stating she understood the rules of the program and her responsibilities of hiring, firing and timekeeping etc. I explained to him that she has a designated representative for this program, and that Rep should be the one signing off on this, not Sarah. On March 8 2025 I received an email for Sarah stating that her paperwork was complete and PPL would be in touch soon. Neither I nor Sarah had completed the paper work which required checking a box on the MOU confirming a understanding the role of a designated representative. When I looked at the form and registration status I could see that PPL did this. I called Assemblywoman Sarah Clark's office and the manager at PPL. Both the manager and I tried to remove the check mark, neither worked and a ticket was sent to IT with a case number. The check mark was finally removed on March 14, 2025 by PPL. But it took Sarah Clark's office nine days to finally receive a reply from PPL to their inquiry from 3/12/2025 about the MOU. On 3/21/2025 PPL stated it was a mistake and a one off and they fixed it when made aware.

To Governor Hochul and our state legislators, I say this: CDPAP and the ability for parents to be paid caregivers was a hard fought victory that recognized the importance of keeping disabled adults in the comfort of their home being cared for by those who understand them best. It has made the difference between Sarah living at home or being forced into institutional care. Why destroy such an essential and successful program? I am one of thousands of parents, caregivers and consumers who are struggling since the PPL take-over. CDPAP is not just a program- it's a lifeline for those that use it. The impact of this program is profound and personal. It's heartbreaking to see it all fall apart.

Please, I urge you to immediately restore choice to CDPAP and end the PPL monopoly to protect families and the disabled community in New York State.

Thank you,
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