

Carolyn Wember

My name is Carolyn Wember and I live in Brooklyn, NY. I have a disabled adult daughter who has been using CDPAP for over 15 years. My daughter has severe physical disabilities and is authorized for 24/7 "split shift" CDPAP services. She currently has five CDPAP Personal Assistants (PAs), and I am one of them. I'm writing to share how devastating the PPL transition has been for my daughter and for our entire family.

In addition to her CDPAP services, my daughter receives HCBS Waiver services from OPWDD, and is therefore excluded from MLTC enrollment. She has fee-for-service Medicaid, which means she receives her CDPAP authorizations from her Local Department of Social Services -- which is the NYC Human Resources Administration (HRA). Since the PPL transition began, we have been living at the "intersection" of the preexisting dysfunction of HRA, and the inexcusable dysfunction of PPL.

For many years, my daughter used Concepts of Independence as her Fiscal Intermediary (FI). We already lived through one involuntary CDPAP transition in 2017, when Concepts of Independence lost its contract with HRA, and my daughter was forced to choose a new FI. She was one of approximately 400 consumers who were forced to transition to a new FI at that time. Significantly, she was offered a choice of several FIs, and opted to sign up with the Chinese-American Planning Council (as did many of that group of 400 fee-for-service CDPAP consumers). This time around, almost 300,000 consumers were forced to transition, and there was no choice of FI.

Back in 2017, Chinese-American Planning Council did everything possible to make the transition easy for us, and we were 100% satisfied with them all these years. Governor Hochul and her Health Commissioner did their best to smear our former FIs as greedy "middlemen" who were siphoning Medicaid funds away from disabled consumers, while providing nothing of value in return; but their shameless media campaign couldn't be farther from the truth. With Chinese-American, my daughter had an assigned case-worker who knew us by name and was readily available via phone or email. We had a "consumer relations" specialist, who was also readily available to help us work out any kinks along the way. Perhaps most important of all -- Chinese-American never stopped approving and paying for shifts for my daughter's PAs, even when HRA got seriously behind in processing CDPAP reauthorizations.

As a result of the Covid pandemic, HRA was frequently late in completing CDPAP consumers' annual assessments and reauthorizations. My daughter's reauthorization that should have been completed by the end of 2023, wasn't completed by HRA until mid-way through 2024. Despite that lengthy delay, Chinese-American was able to work something out behind the scenes, so that my daughter didn't lose services due to the bottleneck at HRA. Similarly, my daughter's reauthorization that should have been completed by the end of 2024, was still in process when PPL took over this past April. We soon realized, to our horror, that PPL would not allow PAs to enter time in their system if the consumer didn't have a current service authorization on file. After somehow getting through the arduous sign-on process with PPL (which I'm sure you'll hear plenty about from other folks) -- we were terrified that at the last minute, my daughter's PAs would be unable to enter their time or to get paid, all because of HRA's chronic delays.

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As you've probably heard, HRA issued "emergency" authorizations to a large group of their fee-for-service CDPAP consumers, so that those consumers' PAs could get paid by PPL. Hundreds of those emergency authorizations ran for a truncated 3-month period, from April 1 through June 30 -- instead of the customary one year period. Needless to say, HRA has still not caught up with their CDPAP reauthorizations -- and we are once again in a state of anxiety over whether my daughter's PAs will be able to access PPL's payment systems after June 30. If not for the intrepid team at NYLAG, CDPAP consumers who receive services through HRA would be left to fend for themselves against the faceless PPL bureaucracy. With PPL, there is "no there there." The company appears to be staffed by robots reading from scripts. No one at PPL cares whether consumers lose their services or whether PAs go unpaid -- and our Governor obviously couldn't care less, either. As of this writing, HRA has supposedly committed to issuing yet another round of "emergency" authorizations for consumers whose CDPAP authorizations are expiring on June 30. As far as I know, there is nothing in writing to document this commitment by HRA. Is this how vulnerable fee-for-service consumers in NYC are supposed to live now? In a constant state of anxiety and uncertainty, not knowing whether their CDPAP services will continue from one month to the next? Our former FIs would never have allowed that to happen!

My understanding of the REAL reason for handing over CDPAP to PPL, is that it was a dirty, back-room deal between our Governor and 1199SEIU, to enable the unionization of CDPAP in exchange for 1199's electoral support. The thriving CDPAP eco-system has now been destroyed by PPL, which is essentially a criminal enterprise. Consumers and PAs have been thrown to the wolves. We have lost our trusted FIs, with their staff who knew us and were a phone call away, in exchange for anonymous call-center workers who won't even reveal their last names. Our governor has lied to us and betrayed us. I'm a lifelong Democrat, but I would never vote for her again.

To end on a hyper-personal note, my daughter has actually lost her job because of the PPL transition. For the past 5 years, she worked as a part-time Peer Mentor for CDPAANYS. She worked from home, fielding calls from CDPAP consumers (and potential CDPAP consumers), helping them navigate the complex world of consumer-directed home care. She performed a valuable service, and it was a perfect job for someone with her degree of disability, who can't easily travel to an office. The Peer Mentor program was funded by dues paid to CDPAANYS by their member FIs. Now that the FIs have been put out of business, CDPAANYS has no funding to pay the Peer Mentors and had to lay them off. It's a loss for CDPAP consumers, who have lost a source of human support at the worst possible time. It's also a devastating loss for my disabled daughter, who was a model employee, but whose future employment prospects are extremely uncertain.

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