NYS Public Hearing – CDPAP Testimony from Geralyn (Geri) Pinciaro Mariano Thursday, August 21st, 2025 ~~ 10:00 AM

To: Honorable Gustavo Rivera

New York State Senator, 33rd District Chair. Health and Investigations Committee Chair, Government Operations

Honorable James Skoufis New York State Senator, 42nd District

Thank you, Senators Rivera and Skoufis for your invitation to speak today. I thank, too, all other members here in person and listening in. I am honored and humbled by this opportunity to speak of what I think has been a most disastrous transition of NY's Consumer Directed Personal Assistance Program known as "CDPAP" to the Single Fiscal Intermediary ("FI"), Public Partnership, LLC ("PPL").

As I know time is limited, I respectfully request you read my full written testimony provided here today. And I ask, too, you please forgive any stumbles when I speak as this fiasco has caused no end of stress and anxiety since it was passed last year that all NY's CDPAPs, over 600, would be switched to just one akin to 600+ lanes of traffic coming from various directions being merged into one single lane to cross a bridge with a new and untested toll system.

INTRODUCTION

My legal name is GERALYN PINCIARO but to most of the world, I am GERI MARIANO. I was born in October 1967 (yes, I will be 58 this year!) with the genetic condition Diastrophic Dysplasia/Dwarfism and was left behind at White Plains Hospital by my biological parents. I became a ward of the state through Westchester County Department of Social Services ("DSS") - of which I remain under the purview of some 57 years later. Brave case workers decided I should not be hidden away but should live out in Society years before the Olmstead Act or ADA would come along. After my baby photo appeared in the local paper, applications were made, and DSS decided upon Doris and William Mariano to be my foster parents. In March 1969, after over a year spent at Blythedale Children's Hospital ("Blythedale"), I went home as Geri Mariano, as Bill and Doris would then on introduce me as their daughter with no FOSTER adjective. In the early 1970s, Bill worked with lawmakers to get a bill he drafted passed allowing disabled foster children to be adopted and not lose Medicaid, with Mom even bringing the toddler me up to Albany as Exhibit A. Sadly, it was not passed and I was never formally adopted. But since I was never considered as merely a foster child, after turning 18, I was not shown the door as countless foster children usually are.

Because I was raised to be independent and I had always dreamed of being self-sufficient, I never asked for more assistance than was necessary. I only became a Consumer in the self-directing Consumer Directed Personal Assistance Program ("CDPAP") in 2003, after a several months stay in rehab following left hip replacement surgery; Social Workers insisted that I could use the extra help and so I started with a few hours each week. With additional surgeries causing progressive physical decline along with age, I have needed more and more assistance, up to 15 hours daily in 2015 following two major spinal surgeries that did not go well.

I now have 24/7 home care with four personal assistants ("PAs") each working three or four 12-hour shifts for a total of 14 shifts weekly.

PPL taking over as NY CDPAP's sole statewide FI is jeopardizing my future to continue living in the community, and if I'm no longer able to, my life, such as it is, would be over.

ABOUT ME AND THE IMPORTANCE OF CDPAP

Without knowing it, I was basically living a life of being part of a CDPAP without actually having personal assistance until 2003. I was living in the community, attending public schools -- in fact I'm one of 4 organizing my Byram Hills HS Class of 1985's 40th Reunion this September. Incidentally, it has been said that I'm the glue that holds our class together. I attended summer camp for several years. I graduated from Smith College in 1989. Last year I was elected Class President. I received my MS Ed from Lehman College in 2007 (with a 4.0 GPA). I became a Certified Therapeutic Recreation Specialist in 2010 and looked forward to making my own way until a second hip operation started a downward spiral which then led to my needing daily assistance.

CDPAP has been transformative for so many of us like me who would not be able to continue living in our communities without it. Though I was an in-patient at Blythedale for my first year plus, I have no memory of institutional living. I have known no other life just as Social Workers wanted for me in 1968/9. By the end of 2015, I would have absolutely ended up in a nursing home following those disastrous spinal surgeries, that left me unable to sit up under my own power, without CDPAP. And if I had ended up in a nursing home, my life would've ended as surely as both my parents' lives did that year.

TRANSITION TO PPL

PPL taking over as NY CDPAP's sole statewide FI has honestly been a disaster since they were given this 9 billion dollar contract.

I never received any written information about the transition or welcome packets from PPL as apparently everything is online. CDPAP deals with a population that is elderly or has disabilities, many of whom cannot use technology. Why is everything now subject to being online? It's absurd how many Consumers and even PAs are not able to use computers or smart phones. Look at my hands. I cannot hold an iPhone. My fingers are short and stubby. Though it's still quite painful to be sitting up, I've had two surgeries in the past year to address the situation and I'm hoping that in short time that sitting up will become easier and less painful. Regardless, I'm old school and I believe in documentation that I can hold and read from! And, in fact, one of my full time PAs cannot communicate with PPL online at all.

Though there were months to prepare for the start of transitioning, PPL was completely unprepared as of January 1st. Why was there not an advisory council of Consumers, PAs, and former FIs/Facilitators to work with the PPL team on the transition of this consumer-directed program? Instead, we all got stuck in a horrible "traffic jam" as people who do not know our program jammed 600+ lanes of former FIs into one consolidated lane of PPL. Just imagine the George Washington Bridge with hundreds of lanes

coming from various highways all of a sudden having to be crammed into one with a new untested EZPass system?

The chaos started for me when I first called PPL on January 6th to verify that my ladies were counted in the system, as I had been previously advised. I was put on hold numerous times and then basically was told yes, my PAs were listed, everybody is fine. Fast forward to March 1st, and all of the sudden my ladies have to be enrolled ASAP. So why was I told something different on January 6th?

PROBLEMS WITH TRANSITIONING PAS AND MYSELF

Getting my four full-time and two fill-in PAs registered by the April 1st deadline then became a frantic rush. And as it turned out, PA information was added incorrectly by PPL staff! They had both dates and other information wrong, despite passports and drivers licenses being sent to PPL directly by PAs. One PA whose information was entered wrong by PPL had submitted her enrollment submitted by fax as she could not upload anything on line. I was not involved in transitioning my PAs at all. Previously, I had been involved whenever a new PA enrolled, by signing and confirming each paper form and confirming with my FI.

I was connected with one specific PPL representative by mid-March who also kept telling me my Medicaid authorization had to be put through as of March 28th, because that was the *deadline*. But guess what? My authorization was not received by the deadline – and there was no answer as to why it wasn't. I was not the only one in this predicament either. The PPL rep had no answer for why the deadline had come and gone without the required authorization. The finger pointing went back and forth between PPL and DSS until finally the authorization was received by April 1st and there was no worse case scenario which would have meant my PAs hopefully showing up to work according to PPL. Things didn't get any easier, however, once my PAs were all finally and officially registered. I won't bore you with countless details of the many roadblocks and phone calls. My most pressing concern was that my PAs were not fully compensated for all of their respective shifts for three months following the April 1st transition. The fourth payroll as of May 1st 2025 showed that my PAs were missing numerous shifts through end of pay week April 26th, 2025!

To be fair, I believe that as of July 3rd, ironically or not, just prior to the original hearing date of July 9th, all of my regular and fill-in PAs have finally been paid – and I can't say for sure because of the lack of PAPER PAYSTUBS that had always been sent with each payroll. I still have not done a full reconciliation with each of them. Only one of my four full-time PAs has confirmed that she has been fully paid from April 1st on. And regarding paper paystubs, I had been repeatedly told and even chastised and bullied, that paper paystubs were no longer available, period – but that was a blatant lie. Apparently my PAs were opted out of paper paystubs without their knowledge. My Facilitator (former FI) unchecked the OPT-OUT box re paper pay stubs, which was verified by PPL reps subsequently. When I was continuing to prepare this statement early in July, we were still waiting to see if the paper paystubs would arrive at PAs' own homes. This is another way we Consumers are being shut out – we used to distribute paychecks and paystubs.

CONCERN FOR PAS AND STAFFING ISSUES

To be quite frank, when faced with a second surgery in less than a year, on May 7th, I honestly hoped that I wouldn't wake up post-op, as my ladies/PAs could then be free to gain steady employment with steady pay elsewhere. As my PAs were then not fully paid, I was frantic that they may not return to work for me upon my release from rehab. And if I didn't or don't ever have sufficient staffing, DSS may need to exercise its oversight and strip me of CDPAP services. I remain so anxious that my PAs are properly compensated for the work they perform with such concern for my well-being, that I often think it might be better if I'm no longer around. This is what I face day in and day out now. When my dear friend Tom passed away after only a three month battle with cancer on June 8th, I honestly thought - "Why him and not me?" - same as what I wondered when my sister died in 2021 – "Why her and not me?"

CONTINUING CONCERNS

When prepping this testimony on June 30th, I received just that day, a phone call from my former FI, now Facilitator subcontracting with PPL, which was requested to call consumers such as myself who have PAs approaching 40 hours a week with the reminder that PPL wants PAs to stay under 40 hours along with a warning about "burnout." I immediately responded that I am approved for 24/7 care with two 12-hour shifts a day, and my PAs have always been allowed to work a maximum of 4 12-hour shifts weekly. My current schedule is 2 PAs work 4 shifts weekly for a total of 8 shifts and two additional PAs work 3 shifts weekly for a total of 6. 8 and 6 = 14 shifts which is the two a day I need. And after having 24/7 care for a number of years, I believe I'm more than familiar with potential burnout. This is really rather insulting. Couldn't the Facilitators be assigned as our case workers as they once were? Weren't we promised no reduction of services?

Crazily, too, the Telephony (seriously, that's the name?) system that PAs use to clock in and out of is not working for all 4 of my full time PAs. One PA has not been able to use since mid-April when the system had her erroneously clocked in for over 24 hours. Though I have repeatedly called attention to this issue from the get go, PPL has not been able to wipe out the time after 4 months! I want all my PAs to clock in and out from my home landline. This is the best way to avoid fraud, I believe. And the clocking in and out takes far too long, over two minutes; the inefficiency and redundancy is astounding.

Throughout all this transition and ongoing, I feel that I am working for PPL without actually getting paid. I have to call numerous times, take notes, write follow up emails, schedule sometimes weekly calls, check for missing pay, etc. And now I have to approve time that once was automatic with my previous FI's automated telephone clock in and out system. And if ever there were an issue, the FI knew immediately and we were contacted to correct. Oh and when I went for surgery in May, I had to be concerned about approving my PAs for pay from my hospital bed. One PA also was applying for affordable housing through Westchester County and paystubs were required which she didn't have. I made daily calls from rehab to my elected officials with me often in tears trying to help her!

IMPACT AND CONCLUSION

Honestly, was the Governor's mandate for PPL to reduce the number of consumers living in the community under CDPAP? This is how I have felt – that I'm being driven to want out, like the 80,000 consumers who have already left the program since the transition. How could they not fully pay my PAs for months following the April 1st switch? And really, who thinks a huge transition should take effect on April Fool's Day? This is the farthest thing from a joke! And how ironic that my choice of something as

important as a FI was taken away from me just as we were celebrating the 35th anniversary of the ADA last month.

Furthermore, I and my PAs contribute to the local economy: we buy gas; we buy groceries; and we order pizza and Chinese food every once in a while. I own my own car. I pay insurance through a local insurance company out of Mahopac. I have EZPass that I pay for. I do not use Medicaid transportation or anything else because it's too uncertain and quite frankly it's dangerous to my body because my body bounces around so much more than when I'm in my own van. Why would NY want to take me out of CDPAP where I am contributing, maybe not as much as my wealthy neighbors in North Castle, to the local economy? I'm not asking for Medicaid or any other State assistance more than necessary, believe it or not. My parents raised me to be independent and it's only because of bad surgeries gone awry since 2010 that I have become now completely dependent on 24/7 home care. Do folks know Maslow's Hierarchy? I studied that in Grad School and I firmly believe in its tenets, that being part of a community and being self directing is key to a person's happiness and fulfillment in life. Additionally, are not my rights, as outlined in the Declaration of Independence which we will be celebrating the 250th Anniversary of next year, to *life, liberty and the pursuit of happiness* also in jeopardy if I'm constantly fretting about being taken from my home? Having my own home is a blessing for sure as I also still feel connected to my family with treasured items such as my Mom's needle point of NYC's skyline pre 9/11.

Switching to PPL was a shortsighted decision, I believe, to address issues that are valid about fraud, but instead of going after the bad perpetrators, the entire CDPAP was subject to an overhaul that was completely unnecessary and now has proved to be fraught with problems and danger to Consumers and PAs. Additionally, more fraud has occurred because of wage theft that has been exposed by a PPL worker but also, I believe, because 12-hour shifts are being paid out in 13 hours in a split shift. It's crazy that I have to explain this, but 2 12-hour shifts means that one shift is overnight, but PPL is splitting them into two shifts, the first part from 7:30 PM to11:59 PM and the second part from 12 midnight to 7:30 AM. I don't understand how this is the new protocol. And how is PPL outsourcing arranging annual physicals to a third party without Consumer oversight not potentially troublesome? Why can't the Facilitators arrange these as they once did?

Westchester County Social Workers wanted me to live with a family back when rather than being hidden away. With PPL taking over CDPAP, my freedom of choice of FI was taken away. The loss of freedoms is decried by many on the national level. I thought the Empire State still believes it to be a beacon of hope as is our beloved Statue of Liberty, the last stand against loss of liberty. Why, then, is NYS specifically always threatening MY liberty?

The fact that my PAs may have finally been paid in full doesn't diminish the difficulties they faced while getting underpaid, or the chaos that still exists for countless others who may not have the ability to advocate and push for correction! I'm somewhat embarrassed that I do know who to call for assistance. I have asked State Senator Mayer and Assemblymember Burdick's offices for help too many times, often several times a day from January through July. Though countless questions are still unanswered, I do have a specific PPL person I can still reach out to. Yet I feel a tremendous responsibility for all Consumers who don't know who to call for help because randomly calling PPL's 800 number is demoralizing.

And while pay seems to be steady now, it does not allay my fears that my PAs won't finally have enough of the uncertainty and take off for other steady pay opportunities. If my ladies leave, I can't imagine being able to find others leaping at the chance to work for a program whose FI, PPL, has such a horrible

reputation. I still don't know if I can offer training hours! Without PAs, I will not be allowed to stay in CDPAP... and what a slap in the face to Social Workers from 1968/9 and to Bill and Doris Mariano who willingly gave me a home when my birth parents left me behind. I feel like I can be left behind again now by PPL and NYS. THANK YOU.