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Thank you to Senators Rivera and Skoufis for holding this hearing. These last six months have been a bit rough for consumers of CDPA.

Public Partnerships, LLC, is lying when it says it has and is the CDPA program. They are not. Nothing about them is consumer-directed. They are a business. They are swindling the people of New York State. We must not allow this to continue. They must be kicked to the curb and they must be held accountable for their misdeeds.
First, some critical background history.

The program that we call consumer-directed personal assistance (CDPA) began in New York City in 1977. A group of disabled people who were living in a hospital came up with the idea. They didn't need healthcare workers to meet their basic needs to live independently. They were able to arrange a meeting with state officials to negotiate the creation of a program to give these people complete authority and control over all aspects of operation. Running alongside the independent living movement which swept America in the early 1970s, they called themselves consumers. They named their program consumer-directed personal assistance.

Word of what they did spread across the region and New York State. CDPA grew in popularity and demand. Disabled people do not want to be forced to live in institutional settings. When Medicaid was established in 1965, there was a section written for long-term care. It mandated all states and territories using Medicaid to cover long-term care in hospitals and nursing homes. All other services state governments might want to create and provide were optional. Anyone serving in government at any level in any branch has the greatest desire to save money. The vast majority of anybody serving in government in any branch at any level does not have the experience of living with a disability. Disabled people didn't start to have political movements affecting change in the community until the second half of the 20th century. The institutional bias for long-term care is deeply ingrained in western culture. Legislators and executives think of disabled people as a population subgroup completely separate from them. They know nothing about living with disability. It scares them. They don't like to spend much time thinking about it. For the most part, they do what is easiest. They do what is mandated. Anything that is optional is not important to them. It is not personal to them. It doesn't mean anything to them. The easiest justification they have for not wanting to do anything else is cost. If they don't have to do it, they just don't do it.

In the 1970s, disability advocates were able to convince the state that in-home care is better for them. They don't want to live in nursing homes. There they don't have freedom to go anywhere or do anything. They are told when to eat, they are told what to eat, they are not given any choices, the quality of the food is horrible, and they can't enjoy it because it tastes bad. They haven't committed any crime, but they are held prisoner. They have to wear gowns and are not allowed to dress casually or fashionably. The institution and society as a whole does not treat them equally or respectfully. They all have a right to live independently in their own homes of their own choosing if they had assistance. The advocates understood and used as their bargaining chip the fact that the service they need and want costs much less than keeping people unnecessarily in institutions.

When the group of disabled people broke out of the hospital and created CDPAP, they were taking the movement for disability rights a step further. The in-home service was built by government officials who sought information by consulting medical professionals. Medical professionals think about all things that are done in a medical way. From their perspective, long-term care is a treatment. They are taught in medical school that disabled people need to have medical professionals decide what is needed. It is as if disabled people are incompetent or incapable of making their own informed decisions. The state built a system of in-home personal care by contracting the service out to agencies. The services are strictly regulated according to medical guidelines about what the professional consultants consider to be the proper ways to to care for disabled people. Their knowledge suggests that there are only the ways they consider to be the proper ways that trained professional assistants should carry out the tasks they have to do for their job. Think about it. Having lunch isn't medical. Showering in the morning and getting dressed isn't medical. Cleaning the house isn't medical. Paying the phone bill isn't medical. Charging a wheelchair battery isn't medical. Taking the bus isn't medical. Going to work isn't medical. Yet, having personal assistance is necessary for millions of people who need it just to get up out of bed and go to work. Or to a club to listen to a band.

Agency service is okay. It is way better than institutionalization. It is freedom. Almost. Agency service is restricted. Trained PCAs are not allowed to do many ordinary things like handing out medications or cutting fingernails. There is fear that a consumer might get injured and file suit to hold the agency liable in a court of law.

CDPA was created to make a political and social policy statement: that fully informed disabled people are fully capable and fully competent to make their own decisions. Each consumer is a director in their own right. They demanded to be allowed to recruit, hire whoever they want, control who comes into their homes and touches their bodies, train them not out of a generalized textbook to meet their own individualistic personal needs their way, manage them, direct them, supervise them, pay them with Medicaid long-term care funding money, discipline them if necessary, and terminate them when necessary. The state agreed. By doing so, consumers assumed all liability. Each individual consumer takes full responsibility for all aspects of the program. Policies, practices, and procedures were accepted and agreed to by all parties involved, including the state health department. They have been in effect with minor adjustments for 48 years, including the implementation of electronic visit verification.

The original program in New York City became a not-for-profit corporation called Concepts of Independence. The state created pilot programs in the 1980s in Syracuse and Utica in response to demands for expansion statewide. They followed the example set by Concepts. The pilot programs were authorized to operate for three years. In the third year, they were renewed for another three years. In 1992, advocates got together in Albany again to demand that the program be expanded statewide and made permanent. The director of advocacy at the Capital District Center for independence invited me to that conference as a consumer with a consumer point of view. That is when I met those advocates. Later that summer I was hired to be a staff advocate at the same center. Three years later, the legislature and Governor Pataki made it law. The system was set up copying the example of Concepts as a fiscal intermediary. The independent living centers originally were intended to run the program, covering all counties with the program.

The president and the executive director of Concepts met with my boss and me. They told us why CDPA is the best program and a winner for the consumers, the assistance workers, and the state. At that time Concepts had 410 consumers. In fiscal year 1993, the cost comparison between CDPA and the agencies was in the aggregate $10 million. I did some quick calculation. If we got 10,000 people into the program, that $10 million savings could be in the hundreds of millions. That is tremendous savings. We could save the state so much money with our freedom that could be used for infrastructure upgrades, servicing long-term debts, and lowering taxes. Not by a little, but by huge amounts. Just from one little line item in the budget.

As a staff systems advocate for CDCI, I was a member of the team of five consumers, one county official, and one state official, helping us setting up the program we were going to run for Albany and Schenectady counties. I wrote the bulk of the proposal. A year later, CDCI ran into financial difficulties. The CDPA program was much too important in its embryonic stage for us to be a threat to it if the organization was in danger of going bankrupt. It incubated the program into a separate not-for-profit corporation to stand on its own. It took the name Consumer Directed Choices. It thrived and grew along with Concepts and all the other independent living centers. By definition, CDPA is run at all levels by consumers for consumers. There are consumers who use the program on their boards of directors in the majority and on their staffs.

It is understandable that our governor and our state health department want to keep costs under control. So do we, the consumers. We want the best service from the best workers we hire who are paid a respectful, decent living wage. CDPA has grown tremendously because it is so much better because consumers are in full control of their own lives. We are the users. We are the customers. We have plenty of ideas to improve the service to make it meet our needs even better than they already are. Those improvements include having all government officials understand that consumer-direction is the best service at the lowest cost, the most cost-effective, and the biggest bang for the buck. When it is done right, CDPA makes 280,000 consumers and over 400,000 PAs very happy here in New York. That is how it has been from 1977 until the end of 2025.

Governor Hochul announced in 2024 that because CDPA has grown so big, it is too costly. She made a decision. She said there were 600 companies acting as fiscal intermediaries. She decided to reduce them. Not by half. Not to 100. Not to how we started in the beginning with just the independent living centers. She decided it would only be one. A monopoly. No competition in a fair market. She didn't choose any of the existing ones already established within the state. She decided to contract with an out-of-state corporation. She did not work with us consumers. She did not talk to us. She did not ask us. Like we don't matter.

PPL is partially owned by a for-profit private equity firm. It is not owned by consumers in the program. It violates the very definition of CD. It has many practices and procedures that are very different from the way they have been done by all the other FIs for the last 48 years. You are hearing testimonies today from many other consumers who have been having hardships and nightmarish experiences since the transition to PPL began in January of this year. Just like all those other agencies who horned in on CDPA who were misleading by calling its provision of the service consumer-directed when it really wasn't, PPL is doing the same thing. It is trying to fool government officials by claiming it is consumer-directed when it doesn't even meet the definition as it does not have consumers on its board of directors. It has its own procedures and policies that take full control, duties, and responsibilities away from consumers. It is no longer consumer-directed. Consumers are being exploited for profit.

The PAs are underpaid. They are blamed with phony reasons why they are underpaid. You will hear plenty more of that from other consumers testifying today. The happiness that we had before this year started now is gone. Our PAs are very unhappy. It gets worse every day. They were not paid the holiday rate on Memorial Day and the Fourth of July. They had always been paid holiday rates going back even before we had CDPA in New York in 1995. PPL is finding new ways to take more money that was never taken before for the policies they are creating to squeeze profit. Members of my crew have already told me if they are not

going to be paid the holiday rate for Thanksgiving, they are not giving up their family time to work for me that day. Another member of my crew has been contributing for many years to 401K. That investment did not roll over when PPL took over. She has no access to it now.
PAs are leaving to find better jobs. Without them, consumers cannot live independently. This is a threat to each and every one of us. We have gone for 48 years without any threat. Now with PPL as the only provider of this service in New York State, we are all under constant threat. We could lose our service. We could be coerced into changing which type of service we use. If that happens, we will be forced into a higher level of service that ends up costing more, not less. That is the exact opposite of Governor Hochul's stated intent to lower costs. They have us at their mercy. The state has taken away our freedom. We were not given a choice. Not even so much as the courtesy of open debate. That is tyranny. PPL is not telling the truth when it says it is providing CDPA. They took over on April 1 of this year. Before that day, the Medicaid money flowed smoothly. Consumers and assigned staffers at local offices worked very well together so that all practices and procedures were done easily and promptly. Since April 1, there has been a never-ending flow of complaints to the state health department, the department of labor, disability rights advocacy organizations, and the news media. Consumers and PAs are very unhappy. And very angry.

It is encouraging for us to see the legislature starting to take action. Since home care started in the 1970s, New York has been the world leader in independent living. Industries which exploit disabled people using stereotypes and outdated customs are competing with us. They want profit. We want freedom. When Governor Hochul said CDPA was too costly, she was not looking at the bigger picture of the entire long-term care options. The greatest cost savings will always come from moving and keeping people out of nursing homes. That should always be the goal! Government officials never listen to us. They want to save money. At least, they say they want to save money. So do we. They don't listen to us. They don't work with us. They don't ask us. They listen to other people who contribute to political campaigns. They do TO us, then split. They believe wrongly that they are doing good things for us. That is appalling. They won't work with us. They won't hear any of our ideas, any of our requests, any of our suggestions. We are part of the public. We must be served equally. What is happening over the last six months is not service. That is tyranny. Under these unfair conditions, the state is subjecting us to purposeful unequal treatment on the basis of disability in violation of the Americans with Disabilities Act, and because there is federal money involved, section 504 of the Rehabilitation Act.

The state legislature must take action that restores CDPA to the way it was before December 31, 2024. As before, consumers must have full control. It should be written in statute that when it comes to long-term care, the consumer-directed personal assistance program should be the first option, not the last one and not an afterthought.
Especially if everybody involved wants to save money and maintain freedom.