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Testimony of Evan Yankey, Advocacy Director,
Brooklyn Center for Independence of the Disabled,
before the Senate Health Committee and
the Senate Investigations and Government Operations Committee's
public hearing to examine the Consumer-Directed Personal Assistance Program
(CDPAP) transition to a single statewide fiscal intermediary

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I testify today as a representative of the Brooklyn Center for Independence of the Disabled (BCID), one of 41 Independent Living Centers in New York State. Founded in 1956, BCID provides services and advocacy for people with disabilities by people with disabilities. We advocate for the right of disabled people to live, travel and work in the community—central to the mission of the independent living movement.

BCID has advocated in support of the Consumer Directed Personal Assistance Program, or CDPAP, since it began as an experiment in giving disabled New Yorkers the power to control their own care in the late 1970s. We are not a service provider for CDPAP or a fiscal intermediary, but we do support people with disabilities to leave institutions and live in the community. In New York, CDPAP has been the program that makes the freedom to live in the community possible for so many of us, including several people on our staff.

Unfortunately, the State has failed to protect CDPAP. Instead, it has engaged in what we can only describe as a systematic attempt to make CDPAP significantly less available to the disabled people BCID and other Independent Living Centers work to support. This reduces the ability of disabled New Yorkers to manage

their own care and to live their lives as they wish. As we discuss below, the state must end its contract with PPL and take a new approach that protects the hundreds of thousands of disabled people who rely on CDPAP, and their workers.

In 2024, the state decided it would hire a single, out-of-state fiscal intermediary, Public Partnerships, LLC (PPL) and end the agreements it had long held with not-for-profits, including many independent living centers, among many other companies. The independent living centers had decades of experience in making sure the people in CDPAP got the homecare they needed; they also made sure workers got paid and were treated fairly.

BCID and our Independent Living Center colleagues, whether they were fiscal intermediaries or not, warned that the loss of expertise and the short transition period to a single fiscal intermediary would result in disaster.

Unfortunately, as the April 1 deadline for the transition to PPL loomed, we began to hear from the people we work with about the tremendous problems they were having making the transition to PPL. Eventually, BCID joined with other disability advocates and individuals in <u>Engesser et al v. McDonald</u>, which sought to delay the transition to a single fiscal intermediary because we saw that the transition was putting people, through no fault of their own, at risk of losing staff and services.

Last week, Federal Judge Frederic Block approved a settlement in that suit, which forced the state Health Department to drastically increase its outreach to people who used the program, including home visits if necessary. The lawsuit preserved the right to CDPAP and other home care services for thousands of New Yorkers who might otherwise have lost them.

Despite our settlement, CDPAP participants and their workers still are encountering major hurdles with PPL's administration of CDPAP. While we know our lawsuit helped New Yorkers, we are under no illusion that PPL will ever have

the capacity to run CDPAP effectively or in a way that protects the rights of the thousands of New Yorkers who use the program or work as aides in it.

We testify to support CDPAP and the extraordinary role it has played in keeping disabled people in the community and free from institutions. For the CDPAP program to continue, which is essential, it must return to its origins as a program administered by trusted not-for-profits, including Independent Living Centers and others, who maintain trusted relationships with those in their communities who use the program.

We also testify, for reasons outlined below, to ask the state to end their contract with PPL. The experiences of the many people with disabilities who we serve and represent presents no way forward with PPL administering a program intended to keep people out of institutions and living in the community. Continued administration by PPL will mean the failure of the CDPAP program and ongoing punishment and neglect for people who depend on it.

## The Transition to PPL

New York State has a successful track record of supportive transition within some of its health and support programs. The OPWDD transition from Medicaid Service Coordination to Conflict-Free Case Management was given several years, as was the return of Medicaid Eligibility after the end of federal Maintenance of Effort requirements. It remains inexplicable to us why the state in this instance chose to give so little time for the transition to a single FI.

For us, the months leading up to the mandated transition to PPL was a flood of calls, emails, texts, and visits to our office asking for help. BCID has never been a CDPAP FI, but people came to us desperate for support because they could not get through to PPL. People with disabilities, including our own staff, spent hours, days, weeks, months trying to get in touch with PPL with no success. When people faced barriers to registering because of their disability, or questions, there was no answer from PPL.

One of our own staff who uses CDPAP services found herself unable to get in touch with PPL during the registration period. She eventually got through on a Spanish-language phone line and was directed to an in-person office in Manhattan. When she arrived, with her CDPAP staff, at the office, it was closed and empty. When she called through to PPL again she was directed to an office far away in the Bronx. Upon arriving at the Bronx office the people there made an attempt to poach her CDPAP staff by trying to trick them into signing up for traditional homecare. If failures like this happened for experienced, knowledgeable users of the program, what happened for those with less resources?

As the transition date hit, many of those who had been reaching out to us, trying in vain to register with PPL, still remained unregistered. We had few answers for people whose staff were not being paid, who were unable to even log hours, who still could not get contact with PPL. PPL's channels of communication are impossibly narrow, especially if you or your staff speak a language other than English. Their apps are inaccessible. Their staff are untrained and unhelpful.

What did this mean for people who had previously been using the CDPAP program successfully? It meant long hours trying to fix their own services. It meant paying staff out of their own pocket, or losing staff completely. It meant New Yorkers were at risk of going back into nursing homes or other institutional settings.

We still are hearing from users all across the program about the barriers they are facing with PPL. The experiences we hear make it clear that even far past the transition date, PPL continues to fail at providing CDPAP FI services, and people with disabilities are left struggling to stay in their homes.

## **Barriers for CDPAP going forward**

Based on our experiences hearing from a wide representation of people using CDPAP through the transition, it is our belief that there is no path forward with PPL. The previous system of CDPAP fiscal intermediary administration included Independent Living Centers and other trusted nonprofits who knew people using CDPAP well and were well-known by the people receiving FI services. PPL has no interest in developing these relationships or knowledge base, and we are concerned they are motivated to encourage the release of high-workload cases.

Not-for-profit FIs in our previous system were motivated by their organizational missions while PPL, a private-equity funded for-profit corporation, is motivated by financial returns. They will always seek to limit their costs and increase their profits, and for CDPAP users that will mean a struggle to stay in the program.

PPL has made clear that their path for administering the program runs through an app-ification of their services, pushing as many people as possible away from person-to-person contacts and into inaccessible app-guided neglect. This is the opposite of the person-centered supports that New York has successfully used to keep people out of institutional settings.

PPL also faces significant barriers in workforce retention. There are large populations of CDPAP who have already left the program through frustration with PPL, and for many that we hear from, convincing potential new staff to sign up with PPL's punishing systems has been a serious struggle. Many support and care systems in New York are facing a workforce crisis, and allowing PPL to continue driving workers away is inevitably going to amplify that crisis.

For us, one of the strongest signs that PPL is not equipped to move forward with the program is their inability to acknowledge the problems that are occurring and in most cases, caused. PPL's public statements insist on a widespread satisfaction that is disproven by the flood of contacts and complaints our organization and many others have received. Their inability to appropriately weigh nervous consumers clicking "satisfied" on an app or email survey versus the same consumers spending hours on the phone trying to get their staff paid is a

roadblock to them being able to confront serious problems. They don't know the problems, because they don't want to know. They've assembled a business based on ignorance.

We know that PPL is not capable of justly and effectively administering this program because the same outcry of complaints and requests for help reaching out towards our organization at the beginning of the transition have continued. PPL is not learning or improving, only maintaining a system of neglect and abandonment.

## New York's path towards keeping people in the community

Even before federal changes to Medicaid and social welfare programs begin to devastate New York, our state is at serious risk of our institutional settings filling with people driven out of the CDPAP program. The sooner we end PPL's contract and return to administration of the CDPAP program by Independent Living Centers and other trusted not-for-profits, the better chance we will have of preserving our state's successes in community living.

Many of the trusted previous FIs remain capable of leveraging their long-term relationships with CDPAP consumers to serve as FIs again. Limiting FI administration to Independent Living Centers and other trusted nonprofit subcontractors of PPL would eliminate the participation of profit motives in the CDPAP system. These organizations are best positioned to end this nightmare through an orderly transition.

By ending PPL's contract, New York state can make a statement that the government and its not-for-profit partners care for the people of New York, and that the social welfare of New York's citizens will not be left in the hands of corporations.

As generations change and age, as families find it harder to care for loved ones, as rents and costs for care rise, what will New York say is our future? Will we tell

New Yorkers they are on their own? Will we force people to quit jobs to care for their loved ones? Will the people who can't find care be sent to overcrowded institutions? Or we return to a system of people working together with nonprofits in their communities to keep people in their own homes.

It is our hope that this hearing today will be the beginning of a path forward that works for everyone.