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2022 Mental Hygiene Joint Legislative Budget Hearing Testimony

Good afternoon. My name is Susan Platkin. Thanks for the opportunity to comment on the budget. I am here representing the New York Self-Determination Coalition. We are an independent, group of volunteers who have been advocating for self-directed services for people with intellectual and developmental disabilities at the local, state, and federal level for over ten years.

I appreciate the proposed increase in funding to OPWDD. However, there is more work to do.

OPWDD's Self-directed services represent the most authentic expression of the Americans with Disabilities Act, the Olmstead decision, and the recent HCBS Home and Community Settings Rule. As an example, my daughter Ruth 35, has used self-directed services since finishing high school. Despite being challenged by a rare genetic disorder causing significant intellectual disability and hard to treat bipolar disorder, which require her to have 24/7 support, she lives in a regular house with a roommate. With the help of staff she shops, cooks, cleans, does laundry, takes out the trash, says hi to her neighbors -just like the rest of us. Despite all her challenges, Ruth is living a good life, with friends, a part time job, and hobbies, in the community where she grew up and went to school.

1. Pay staff a living wage

To live safely and productively, people with IDD need assistance. Even as most peoples' lives now are starting to open up, many people with IDD are still in virtual lockdown, without staff to support them. NYS needs to pay a living wage to all direct support staff, including home care workers hired through the CDPA program.

2. Increase the ISS Housing subsidy

Parents of neurotypical children worry about where they'll go to college, will they find love. Get any group of parents of kids with IDD and ask them their worst anxiety; it's where will my child go when I can't take care of them any longer. For parents over 60 this is the fear keeps us awake at 3am.

In the past, the solution was "get your child into a group home," but we've moved on from there for most people with IDD.

We applaud the proposed increase in the ISS housing subsidy in the Governor's budget.

The long overdue increase will allow people with various support needs to afford to live where and with whom they want. People will no longer have to give up living in neighborhoods they know, and where people know them. This will also help relieve pressure on the OPWDD housing wait list, and it's a lot less expensive for the state to provide housing subsidies than build more group homes.

3. Amend the Nurse Practice Act

The Department of Health's Consumer Directed Personal Assistance program allows consumers (or their representative) to recruit, interview, hire, train and supervise staff to do health related tasks.

However, people who use OPWDD self-directed services are unable to use their direct support staff to perform these tasks. That means, if someone needs assistance taking medicines, or insulin shots, for example they must live with their parents or in certified housing; they have no other options.

These are not highly technical tasks; they are things typical people usually do for themselves. There is no medical reason not to extend what has been working so well for personal care to people with IDD who need the same services by amending section 6908 of the Nurse Practice Act.

4. Ombudsperson needed

More than any other group, people with I/DD need an independent ombudsperson. Because of their disabilities, people with I/DD are even more challenged to deal with these complex and often inefficient systems.

Such a program would:

Provide individual assistance to people with I/DD, their family members, and advocates,

Be available statewide,

Advise and advocate on individual cases and concerns, and

Provide accessible education on various aspects of state programs and CCO services.

Thank you.

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