

New York Self-Determination Coalition

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Testimony to Joint Legislative Budget Hearing-Mental Hygiene

Good afternoon. Thanks for the opportunity to comment on the budget. I am here representing the NYSDC, a volunteer group which advocates for SDS and mentors families .

Self-directed services represent the most authentic expression of the ADA, the Olmstead decision, and the HCBS Home and Community Settings Rule. Essentially, self-direction allows people with disabilities to live, volunteer, work, and play while getting the supports they need, not just in their communities, but as part of their communities, using an individualized budget based on their level of need.

I bring to this table the perspective of many families, but most importantly that of mom to my 34 year old daughter. Ruth loves, parties, board games, and sports. She also has intellectual disability and bipolar disorder and functions pretty much as a second grader. Because of her poor judgement, she needs continuous supervision. Using self-directed services, she rents a house with a roommate who also gets services. Ruth shops, cooks, cleans, does her laundry, and takes out the trash (reluctantly), with a lot of assistance from staff. Despite all of her challenges, Ruth is living a good life, with friends, a part time job, and volunteering, in the community where she grew up and went to school.

We appreciate that there is a small increase in OPWDD's budget; however, it is inadequate. Children with IDD, are being born every day and living longer. Serving more people with a minimal budget increase has the potential to significantly degrade OPWDD services for everyone. It's not like people have a choice: they don't say, "well, my kid is great, family is fine, let's try to get some services from OPWDD to make us happier." People need these services to live their lives. And this doesn't just affect the person with IDD-it affects the entire family, for example, a mom who can't work because she has to care for her 40 year old son.

At the same time, we understand the need to balance the state's budget.

We urge you to use COVID as an opportunity and NY's financial pressures as an imperative, to right size the system away from an institutional model of care.

Self-directed services give people choice in their lives, and supports them to be productive citizens; in this new age of pandemics, we know they're safer than congregate programs. Relevant here, they are cost effective. In programs, everyone gets the same services; people who self-direct get only the services they need, without wasted money for overhead.

One other imperative: Decisions need to be based on data and consideration of both their short and long term consequences. OPWDD should be required to make public all the data they use for decision making, before making significant changes to how services and supports are delivered.