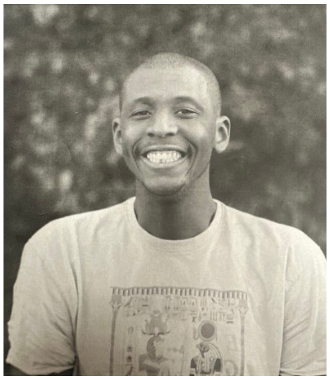
Testimony for Mental Hygiene Budget Hearing

February 4, 2025



I am Dr. Natalie Ferguson, and my main qualification for being here today is that I am the mother of a young man with Autism, IDD, ADHD and Tourette's. I am also a health professional, supervising the nursing staff at SUNY Downstate Medical Center.

New York can be justly proud of what our Self-Direction program makes possible for people with IDD. Now we just need to make it easier for more people to get on-board, and easier to use once you are on-board.

To accomplish that, we need MORE oversight-- not of what people are doing to provide services, not of what families are doing for their loved ones. What we need is visibility into whether the system is preventing access to services. I am requesting that the legislature improve their oversight of the system of services for people with developmental disabilities.

As the legislature, you can flex your oversight muscle, and demand to know more about what is going on in the service system.

How much is actually getting spent for housing subsidies, for family support services

What is the rate of refusal for....

How long does it take to get...

OPWDD will tell you that they cannot collect this information, that they are fully occupied with other important activities.

I can tell you, as a supervisor of nurses, that no one likes having to report on the outcomes of their activities. And so they come up with lots of reasons why they can't. But I know that without situational awareness, it would be impossible for me to do my job of maintaining and improving the quality of nursing services.

There is so much that is being done right, and there is so much to be done. The legislature needs information

As the single mom of a young man, I am deeply concerned about the future of the system of services. Will my child's individualized services continue after I am not here to do all the administrative work required to keep it going?

As a health professional, I am even more deeply concerned about the families that I see coming in for emergency care. I routinely see people with developmental disabilities who are not getting the services they need.

When I was getting started seeking services for my child, no one told me about Self-Direction. It was not offered to me as an option, and the other members of my community were not doing it. So it came as a welcome surprise, when I learned that there was such a thing. I am thrilled with the benefits that it has brought to my child's life. We need to be doing more, to make this accessible to more people in more different communities.

Getting OPWDD eligibility… that was a protracted battle. It felt like running a marathon. Barefoot. On broken glass.

The journey from getting approval for HCBS, to launching your SD budget, can be months. By the time someone has HCBS approval, they have already gone through months or years of vetting and checking. They have hacked their way through the forest of obstacles. And then they have to fight some more for Self-Direction, and wait for months to get their budget approved. There is no justification for making them wait any longer.

When I was seeking eligibility for my son, I could not get anyone to answer emails or calls. By the time they got back to me, the evaluations had expired. It felt like the whole ordeal was designed to get me to throw my hands up in the air and say "I am done".

And, I know families who HAVE given up. They come into the hospital where I work. When they do, I get the call. That is because, after working through my shame and guilt, I finally started to talk about my son and our journey to services. Everyone at Downstate knows that I am the one to call in. For example, one day I got a call from security, that there was a woman who was lying on the floor and screaming.

When I arrived, the woman was screaming "I cannot take it anymore", while her son watched from his wheelchair. I was able to calm her down. She shared with me "I have no support, I am so exhausted... He hurts himself, he bangs his head on the floor. I cannot take it. Sometimes I wish I could just run away and leave him-- and then I feel horrible about having that urge."

I told her: You are not a bad parent, you are just overwhelmed. You have no help, and we all need a break sometimes.

And then I started to ask her about services, and she had never heard of self-direction. She had no idea what I was talking about.

And then I explained to her about respite, and she was sitting there, and I saw this whole...

eureka moment. It just opened up for her, and she was like, well, how do I do it.

I said, listen, it's not going to be easy, it will be a fight, you will feel like you want to give up.

But don't give up. If you don't fight for your son, no one else will. And you need to take care of yourself. Do not feel bad about accepting the fact that you need a break. It's not that you love him less, it's just a fact that if you do not recharge your batteries, then you will not be able to fight for him.

When she left that day, at least she had some hope.

So that is good.

The bad news that ten months later, she is still in the approval process.

We can do better than this. I am so glad that I had people to help me along the way. Frankly, I did not find them until I moved out of the neighborhood that SUNY Downstate serves. No one in that community was using Self-Direction, no one could guide me. They did not even know that it existed.

And even today I hear about Care Managers who are not adequately trained. Just last week a family told me that their Care Manager spent months trying to convince them NOT to pursue self-direction. She kept telling them it was difficult to access services, that they would not get the benefits that were promised.

We can celebrate the continued growth of Self-Direction. Between June 2023 and June 2024, there were almost eight thousand families who joined that program. Each one of those eight thousand might be one more mom who is no longer despairing, or one fewer child banging their head on the floor because they have absolutely nothing to do. I hope you will join me in celebrating that growth.

And most of all, I hope that you will do everything in your power to make it easier to get services, to make it faster, more equitable and more comprehensive.

I am a one-woman band at SUNY Downstate. We need a more comprehensive outreach program. Printed materials in 20 different languages will be great, but what we really need is more community outreach. A small squad of people to go to schools, community centers, churches, homes, and tell people about what is possible. It will not need to be a permanent squad-- after a few years, there will be a robust network of parents in every community who are helping to spread the word. But we absolutely need something in the short term to accelerate our progress. In 2023, there were twenty thousand more people in self-direction than there were in 2018, which is great. And two thousand of them are African-Americans, which is wonderful-- almost four-fold growth. But to get to equity, it would have had to be eight-fold.

We need your help. Earmark funds for outreach to under-served communities. People like me are doing this as a side gig. Right now, we need more than that.

And one of the things we need: It has to become easier to access these services. The recent growth in families who choose to self-direct has come despite the obstacles and delays. In some cases, it has come even in the face of active discouragement. Self-Direction continues to be the choice of younger families, and will soon be the choice of half the people who qualify for the Home and Community Based Waiver.

That Care Manager who discouraged the family was partly right-- it is too difficult to get services:

- The approval process for Housing Subsidies is typically close to 8 months.
- Families need to pay out of pocket for services, and then wait months for reimbursement, even for things that have been pre-approved.
- Fiscal Intermediaries are fearful of facing financial penalties, and so they say 'no' far too often. There is a thumb on the 'no' scale.

The solutions include:

- The legislature needs to demand information on actual spending, on rates of approval, on the real time from starting eligibility to getting services. Also, how many people give up along the way? Without information, we will never be able to tell whether things are getting better or worse.
- New York State must make self-direction available to anyone in the HCBS waiver who wants it, and give them a 'quick start'. They should allow people to start off with the default smallest budget, about $20K a year, while the real budget approval. This will allow people to get started on accessing services within days, rather than months. New York State is proud of not having any wait lists, but as everyone knows, there are lots of people waiting around for services. And while they are waiting, they are regressing, they are cut off from the community and the growth that they desperately need.
- Provide low interest or no interest loans to Fiscal Intermediaries, so that they can immediately reimburse families who submit valid reimbursement requests.
- We need more outreach. Not documents in a dozen different languages-- though those are nice to have, they are not the solution. We need outreach specialists, who are going out to the schools, to the community centers, the food banks, the churches, to tell people about the services that they can access. We don't need a permanent army of these people, we just need a small squad for a couple of years-- and then a natural community will grow up.