



Testimony on behalf of the Coalition for Self-Direction

Submitted to the Feb 5, 2025 Joint Legislative Budget Hearing on Mental Hygiene

Presented by Jim Karpe on behalf of the Board of the Coalition for Self-Direction

Summary

Self-Direction aims to help people with developmental disabilities live meaningful lives. And it achieves great outcomes. However, we have not yet put in place the services required to sustain those programs after the parents are gone.

Our oral testimony is limited to a few minutes. My personal advocacy is limited to my lifespan, and I aim to be active for another 20 years, by which time I hope we have together created a sustainable collection of services providing the access, equity and supports needed to maintain the autonomy and dignity of people with intellectual and developmental disabilities. There is a lot to do. Let's start now.

Introduction

My name is Jim Karpe. I am the father of two young adults with Developmental Disabilities who use Self-Direction. Today, representing the Coalition for Self-Direction, I will talk about the Office for People with Developmental Disabilities, OPWDD, and the services New York State provides to people with DD.

My Son

My son has a low IQ, somewhere near 50. He is so fortunate. Two generations ago, he would have been warehoused and neglected in a large institution such as WillowBrook. One generation ago, his only choice would have been congregate care— living in a group home, going to a group Day Habilitation program. Everyday being limited to what the group provider offered. Today, he lives a life of autonomy, based on his individual choices. He lives in his own apartment, works at Trader Joes two days a week, and makes his own decisions about how to spend his time—just like any other person.

The difference is a wonderful NYS program for people with intellectual and developmental disabilities, Self-Direction. I plead for your help in preserving, expanding and improving this program. Today my son's wonderful life depends heavily on me, and my ability to navigate an over-complicated. We need to change that, so that my son's wonderful life to continue after I am gone, and so that this kind of life to be available to anyone who wants it— not just those with persistent parents or dedicated siblings.

Self-Direction as it exists today is the result of decades of effort by the parents and other advocates who came before me, people who fought for the creation of a program that provides freedom of choice. They did a great job, and I am grateful every day for what they have carved out. My hope, in the time that remains to me, is to make further improvements that will allow more people to get access to more services and more freedom. We still have a long way to go. We can gauge that distance by looking at what my friend is going through as she tries to create an individualized set of services for her aging brother. Let's call her Martha (not her real name).

Testimony: Coalition for Self-Direction

Martha's Brother

Martha is setting up Self-Directed Day services for her brother, who lives in a group home, a 24/7 supervised IRA. Let's call him Daryl (not his real name either). Daryl is happy with his home, and will continue to live there as long as he can. But he is now in his 70s, and does not want to continue going to the Day Habilitation program every day. The best option seems to be to create an individualized program which mixes certified residential with self-directed day services.

Martha and brother Daryl hope Self-Direction will allow him to finally retire from DayHab. Today, Daryl is still awake at 6 AM every weekday so that he can be showered, dressed and fed in time to be put onto the transport van and sent to six hours of DayHab. Now in his 70s, he wants the option of sleeping in, and going to a place of his choosing at the time he chooses. They did a 'test run' for eight weeks, and it worked well. Some days he went to one of the local senior centers, including one run by his County and another run by his Church. Everyone has been very welcoming to Daryl and his staff member. Sometimes he decided to just stay home for part of the day with his staff. And some days he made the choice to go to Day Hab.

Bottom line for Martha's Brother Daryl

All this freedom of choice and access to opportunities in his neighborhood can be accomplished for less than the cost of sending Daryl every day to the DayHab he has been attending. Based on the two-month test run, Daryl was looking forward to his retirement. Unfortunately, on the verge of success the effort is falling apart.

Three gaps

Daryl's story shows what could be possible. It also illustrates three gaps: Access, equity and support.

Start with access. Martha had to cut a new path to get a Self-Direction program established for her brother. The process was not that difficult, and no one stood in her way. But no one in the system had ever suggested it to her nor was there anyone who could guide her through it. She had to initiate it. Martha knew what to put into place because of her many connections into the SD community. Very few people in Daryl's position have a Martha who can get them access to Self-Directed services.

Equity is the biggest gap. If the budget for Daryl's self-directed day services were 9/10 of the cost of his current DayHab services, he could comfortably retire from DayHab and spend his seventies engaging in as little or as much activity as he wants. Unfortunately, Daryl was given a budget that is much lower than that— 47% of his current Day Hab spend, not the 90% that he needs. Unless something changes, Martha's brother will not be able to retire. There is no way to stretch forty-seven cents far enough to cover Daryl's basic needs.

**Unless the State provides Daryl with an adequate Self-Direction budget, Daryl will not be able to retire from DayHab. The State will go on paying the current costs for DayHab.
Zero savings, zero change.**

The third gap is support. Which is really just another way of looking at sustainability. If Daryl's plan does launch, Martha takes on the task of finding staff and over-seeing them. Martha is getting older herself, and at some point the burden of running her brother's self-direction program will become too much. When that happens, the only realistic choice available will be to have him return to daily mandatory DayHab. Or perhaps he will be 'encouraged' or required to enter a Nursing Home, where his freedom of choice will be even more restricted. The solution to the lack of support is just a little bit more money, to allow Daryl to hire a professional to manage his staff for him. The 90% budget already mentioned was calculated to include the cost of that support.

Testimony: Coalition for Self-Direction

What can be done to make things better

We would like to see something closer to equity between the self-direction budget and the actual cost of care in the certified system. The current formula is based on an opaque calculation and fits you into one of a handful of tiers. There needs to be a way to appeal the self-direction budget. We envision an easy to access forum where you can ask for more money based on the comparison to cost of care in the Certified system, or based on documenting circumstances that require additional spending.

Self-Direction currently saves the system an estimated \$1B each year, and produces good outcomes for my son and for thirty thousand others. As illustrated by Daryl's example, NYS can afford to be a little more generous toward those in Self-Direction. We will still save hundreds of millions. And if we make the changes that enable more people to pursue Self-Direction, the net savings will increase.

Self-Direction enables freedom of choice by people with intellectual and developmental disabilities, assisted by their parents and other supporters. Self-Direction has the potential to produce good outcomes for Daryl as well, if we are willing to have allocate enough money for him to have adequate staff time and support. The changes that benefit Daryl today will also benefit my son when I am no longer here. And tens of thousands like him.

Getting there will require a lot of effort, much of it by the executive. The legislature also has a role to play in monitoring and maintaining the flexibility of Self Direction. As we encounter burdens that can be fixed through changes in statute, the Coalition for Self-Direction will add to the requests listed in our written testimony.

Generally, we ask the Legislature to take a more active role in oversight of the services for people with intellectual and developmental disabilities. Please demand the facts, and dig deep to find the true story. Specifically, one of our requests is to authorize the IDD Ombuds to report directly to the legislature. That Ombuds program launched in December, and the advocacy community has high expectations for a positive impact. A year from now at these hearings next year you could hear from the Ombuds about what they have accomplished. Hear about what complaints they have handled and what obstacles they have encountered. Such a report from the Ombuds could inform us all as we seek ways to improve access, equity and sustainability.

But you will not hear from the Ombuds unless you change the law. Right now, the Ombuds reports to OPWDD, and OPWDD decides what to share with the legislature and the public. We call upon the legislature to draft and pass a bill authorizing the Ombuds to provide quarterly reports directly to the public and to the legislature, without restriction.

In closing

A brighter future lies ahead. It will be a long road to get there— I turn 65 this year, and with luck I have another 20 years of physical health and mental clarity. My goal is that before I am gone, we have created a sustainable collection of services providing the access, equity and supports needed to maintain the autonomy and dignity of all people with intellectual and developmental disabilities.

Testimony: Coalition for Self-Direction

Requested Legislative Action

1. **Sunlight.** Authorize the IDD Ombuds to issue quarterly reports to the public and to the legislature, and to provide any additional reporting or testimony requested by legislative committees.
2. **Community living for people who require medications.** Reform the Nurse Practice Act to allow medication administration by Direct Service Professionals (DSPs). Extend to DSPs the identical pattern of flexibility and oversight that is in place for CDPAP workers.
3. **High Needs Funding.** Earmark money for High Needs Funding. Each year, fewer than 100 people in traditional services qualify for high needs funding. And zero people who are self-directing. We believe that the true need is much greater than this, and the lack of access to higher needs funding is responsible for some of the most intractable problems in our system. We request that the legislature earmark \$40 million dollars for higher needs funding, enough to provide an average of \$40K to each of 1000 individuals, in either traditional services or in Self Direction. Martha and her brother will likely need only \$25k to fund additional hours and the time of a support broker to manage the staff.
Ideally, include authorization for the IDD Ombuds to monitor the application process, assist individuals and organizations in navigating the process, and report the results to the public and the legislature. Supply additional funding for the Ombuds, to staff this added function.
4. **Innovation and Sustaining fund.** In the past decade, special time limited programs like the BIP grants have piloted valuable innovations, which then wither away at the end of the initial grant period. Changes to the HCBS Waiver are inherently slow, and there has been no way to bridge the funding gap between a successful proof of concept and the waiver amendments that codify them. An Innovation and Sustaining Fund will allow OPWDD to support new pilots, and to sustain those that prove worthwhile. This will enable New York State to drive forward with the sort of positive changes that will benefit people with developmental disabilities.