



Testimony on behalf of The Coalition for Self-Direction Families “Yes, and...”

We need money, and also free choice

Mental Hygiene Joint Legislative Hearing, February 13, 2024

Introduction

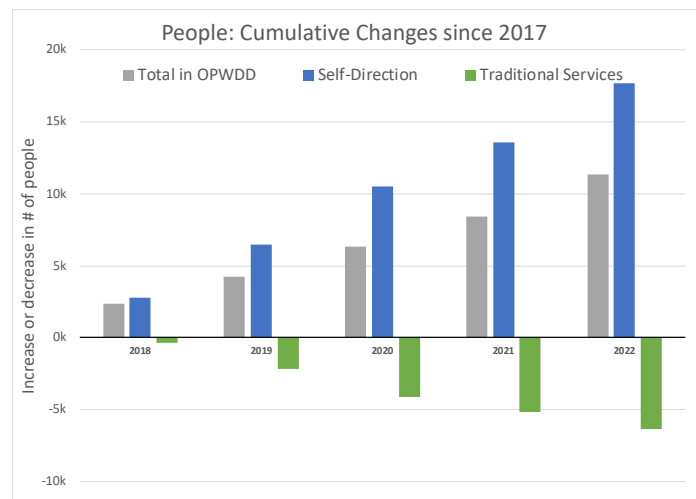
Thank you for your time and attention.

Unfortunately, New York State policy with regard to people with developmental disabilities remains mired in the patterns of the past, with far too much emphasis on a care-taker mentality. The system today offers a strictly limited set of options to this incredibly diverse group of people. Attempts at innovation are stifled, based on some unknown combination of

- sincere desire to protect people;
- equally sincere desire to assert State control;
- fear of
 - the NYS Office of Medicaid Inspector General,
 - and of the Federal Authorities.

Our hope is that we can move to a different stance, one based on a commitment to serving the full range of people with developmental disabilities. Some will want the traditional services, which emphasize protection. However, it is undeniable that the people entering the system today want something different. Over the past five years, Self-Direction has grown rapidly. Meanwhile the number in traditional services has shrunk modestly. The traditional system continues to serve almost one hundred thousand people and needs to be supported. The Direct Service Professionals, who are the heart and the hands of the system, **deserve a living wage.**

And, the people who pick Self-Direction also need your support. We deserve the freedom of choice which the State has promised, which the Federal authorities endorse, and which is the fundamental birth right as New Yorkers, Americans, humans.



On the following two pages, please find my written testimony with regard to the FY 2025 budget for the Office for People With Developmentally Disabilities. Following that, I attach a proposal that the Coalition for Self-Direction Families submitted last year to the Governor’s office for specific regulatory changes in one vital area of Self-Direction. This proposal aligns with Federal guidance which puts [outcomes and the quality of the individual’s experience](#) at the center of decisions regarding Home and Community Based Services (HCBS). Unfortunately, New York’s policy on Community Classes remains focused on “what they are not”.



Summary

We are the recently formed Coalition for Self-Direction Families. Our requests, for the FY 2025 budget for OPWDD, the Office for People with Developmental Disabilities:

1. DSPs deserve a **living wage**. A decade ago, the starting salary was 40% above minimum.
2. Support innovation in general. Start with the **Self-Direction** movement which seeks to expand freedom of choice for people with DD. In the past five years, the number of people choosing Self-Direction has tripled to thirty thousand.
3. Support specifically the flexibility provided by the **exemption to the Nurse Practice Act** proposed in part EE of the Governor's Mental Health bill. This proposed change makes it easier to support, in a home of their own, people who have a routine need for light-weight nursing tasks, such as help with medication administration.
4. **Reject MLTSS**, Managed Care for Long Term Supports and Services. Managed Care would consume up to 12% of the budget for OPWDD, leaving even less money for a living wage.

Support for Living Wage for Direct Service Professionals

The Coalition for Self-Direction Families fully supports the request for a 3.2% COLA and a four thousand dollar wage restoration. The Direct Service Professionals who work for certified non-profit providers deserve a living wage, and this proposal is a good start toward restoring DSPs to the economic status they deserve

More than money—Innovation and freedom of choice

And, our area of human services needs more than just more money. We also need greater flexibility, an expansion in the ways that services get delivered. Some of you are already familiar with the freedom we seek. For others this might be a new request:

- Please, support our movement to expand freedom of choice.

In this brief testimony we touch lightly on what that means. For in-depth discussions, the family members at the core of the Coalition for Self-Direction Families are available to be full participants in consideration of trade-offs, risks, federal oversight, and fiscal impacts.

For today, right now, we want you to understand that certified providers are just one way to provide services. The complete continuum of options must be fully supported—and today is not. Our Coalition has multiple active [initiatives](#) to make this a reality, and we are continuously working with our community to define the next set of [priorities](#).

Right now, unfortunately, there is an on-going attack on our ability to choose “non-certified” services. We are passionate about this, because these non-certified Community Classes provide people with relevant activity. That is, activities which the person has decided are relevant to them. Under Self-Direction, people with developmental disabilities select what they want to do, from a growing array of options provided by JCCs, Ys, sports leagues, non-profits, and newly formed businesses. The system of traditional services has a shortage of meaningful activity. Community Classes are part of the solution, **expanding the capacity of the system to create lives of purpose and worth and full participation.**

The attack on Community Classes is an attack on the things that make lives meaningful.



Certified and Non-Certified

We have used the terms certified and non-certified. Think of Certified settings as being similar to hospitals, while non-certified settings are roughly equivalent to the full range of non-hospital settings for care, ranging from neighborhood Urgent Care centers to doctors offices to tele-medicine to the home.

In the range of physical medical care, New York State acknowledges the value of this range of options, and the practical need for overlap. Hospitals can stitch up people with open wounds, but the Department of Health does not therefore forbid a doctor's office from treating cuts. They don't call it a "duplicative service", and refuse to pay for the service of putting on bandages at the doctor's office. In New York State, we don't direct Medicaid recipients to go to the hospital for every cut.

No overlap allowed!

Unfortunately, NYS does something different when it comes to DD services and supports. People using Self-Direction frequently are told: "You can't do that, it is a duplicative service." The claim is false, just as false as it would be to say that a doctor's office is the same as a hospital. There are overlaps in what happens in those two places, but it would of course be ridiculous to go item-by-item and forbid doctors from doing what hospitals do, and vice versa.

In DD services, New York State has decided to go through item-by-item. The result: People with Developmental Disabilities do not have a full range of options to choose from. People get pushed into certified settings by official regulations and habitual practices and shadow policies. We need to make changes in our system, changes which allow a full range of services from which people can choose. The Coalition for Self-Direction Families will be glad to meet with you to discuss further.

Reminder: more money

I finish by coming back to the opening theme: more money for DSPs at certified non-profit providers. The starting salary for a DSP used to be substantially higher than minimum wage. Then came a decade of neglect, a decade without any Cost Of Living Adjustments. By the end of that time, DSP compensation had sunk down to minimum wage.

Consequently, we now have the situation which my son deals with every week. My low-IQ son works at Trader Joes two days a week. His hourly wage is twenty dollars and seventy-five cents. The job coach who assists him earns less than \$16 per hour. As a direct consequence of this low pay, the average duration of a job coach has been twelve weeks. They are just getting to know my son, and then they quit working for the certified provider. They get a 25% raise by going to work at Trader Joes themselves.

In Closing

On behalf of the Coalition for Self-Direction Families, I have four requests--

1. move the DSPs toward **a living wage**.
2. Support innovation, start with our movement to **expand freedom of choice** for people with DD.
3. Support **part EE of the Mental Health Title VII bill**, which extends to DSPs the flexibility to perform some nursing tasks, and thus supports "Access to More Independent Living Settings".
4. **End the authorization to explore Managed Care for Long Term Supports and Services**. We have been exploring for a dozen years, and have not managed to come up with evidence that Managed Care brings benefits to Long Term Supports and Services. We do know that Managed Care would consume up to 12% of the OPWDD budget, leaving less money for services.

Thank you for your time.

Coalition for Self-Direction Families

2024 Community Class Policy

Our North Star

The 1999 Olmstead decision of the United States Supreme Court ruled that people with disabilities have a right to live and receive services in the most integrated setting appropriate.

Ten years ago, the 2013 report of the Olmstead Cabinet closed with the promise to:

“Safeguard the fundamental civil rights of New Yorkers with disabilities to lead integrated lives.”

We call upon New York to keep that promise.

Community Class Policy

Our overall request to the Governor and OPWDD: Restore freedom of choice in Self-Direction.

In the long run, we want to get as close as possible to achieving:

The only criteria for a Community Activity is **the individual’s desire to attend**.

A Community Activity is one the individual is choosing to participate in, and for which OPWDD is not responsible. The individual, assisted by their Circle of Support, chooses to embrace the dignity of risk by participating in these non-certified activities. New York State does not have a role in restricting the choices made by the individual. There is a role for the State in identifying and prosecuting fraud. It is not appropriate to delegate this policing to Fiscal Intermediaries.

Restore and Enhance Community Classes

We call upon OPWDD to **issue a Self-Direction Administrative Directive Memorandum (ADM)** which

- a. states that the only valid criteria for refusing a community class are the **six exclusions** specified on page 24 of OPWDD's [Self-Direction Guidance for Providers](#), and updates those exclusion criteria as detailed below;
- b. brings the rules for class content into alignment with Federal policy expressed by CMS;
- c. restores the Fiscal Intermediaries to their proper role of support for the individual, rather than the recent focus on compliance.

Six exclusions, updated

The ten unofficial red flags are inappropriate, subjective, and in many cases illogical.

OPWDD should repudiate them, and restore the official Self-Direction Guidance for Providers.

The six exclusions on page 24 should be updated to remove subjective judgements.

Update the Rules for Class Content

Page 24 includes a description of class content. This description should be updated to match with CMS policy.

Restore Fiscal Intermediaries

The unfortunate trend over the past few years has been to convert the Fiscal Intermediary into a Field Investigation force. The waiver specifies that with regard to Medicaid compliance, the FI’s responsibility is to support the person who is self-directing, which should mean helping them color within the lines of what is described in the Waiver and the six criteria listed in the Self-Direction Guidance for Providers.

Revisions to Self-Direction Guidance for Providers

Update page 24 to read as follows. Text shows ~~strikeouts~~ and **additions**, and in addition the criteria have been numbered for ease of reference. See [Self-Direction Guidance for Providers](#) for original text.

Criteria #1 and #5 have been altered to remove subjective judgements. #5 might seem unobjectionable, but in practice it has been used to shut down activities where self-selection by people without disabilities has resulted in a setting that is accessed only by people with IDD. Think for a moment of the absurdity of it being unlawful for a hair salon to operate, if the only people who choose to purchase its services are women. All we ask for people with IDD is the freedom to choose.

The text below the list of exclusions details the appropriate role of the Fiscal Intermediary, as a support for the individual.

Last, the existing text on specialized classes has been updated to allow classes that are solely of interest to people with special needs. For example, a class which teaches non-verbal people how to use an electronic communication device.

Updated text for page 24

Each of the following are excluded from being funded with the IDGS as a Community Class:

1. Classes that ~~duplicate any Medicaid State Plan or HCBS Waiver service~~ or are conducted by an entity that delivers such **Medicaid State Plan or HCBS Waiver** services;
2. Classes where participation is restricted solely to people with intellectual/developmental disabilities (I/DD);
3. Classes where there are not established published fees;
4. Classes that are credit bearing for matriculating students;
5. Classes in ~~a setting accessed only by people with I/DD (not including paid staff support)~~, including all certified settings; and
6. Classes that do not adhere to the standards identified in the broader IDGS rules and standards (e.g. experimental therapies).

The FI fully discharges its duty by documenting that the person self-directing is

- aware of the criteria, and
- **the person has determined those criteria are met.**

Participation in specialized classes that take special needs, such as physical limitations or beginner level learning, into consideration are appropriate as long as those specialized classes are open to the broader public. **Participation in classes teaching skills which are solely of interest to people with special needs are also allowable.**

Background

Background on Red Flags

A [November 2022 OPWDD](#) training specified ten unofficial red flags. This training has had a disproportionate impact. The verbal listing of the ten flags was combined with statements which caused Fiscal Intermediaries to fear they would be in financial peril if any payouts were later found to be invalid based on those unofficial red flags. FIs were told how much investigation they were responsible for:

"The only real answer for that is all of it. All of it. All of it."

Background on the role of the Fiscal Intermediary

According to page 98 of the current approved [HCBS waiver](#), the FI is meant to support the individual who is self-directing.

The most typical set of tasks that the FI supports the individual self-directing is with billing and payment of approved goods and services, fiscal accounting and reporting, ensuring Medicaid and corporate compliance, and general administrative supports.

The core of self-direction is individual choice. The role of the FI is to help the individual make informed choices. The waiver does not specify that they are to be Medicaid police, and they do not want that role.

Fiscal impact of Policy Changes

The above changes would have no direct fiscal impact.

As an indirect impact, the changes remove barriers that prevent individuals from spending the Community Class portions of their budgets, which are capped at \$32K per person.

In addition, these policies would make Self-Direction even more attractive, and would likely result in accelerated growth of Self-Direction. Based on our analysis of the available data, the impact of more individuals moving into Self-Direction would be a net **savings** in Medicaid expenditures, on average. This savings should be reinvested in the system.

That savings **might** be counter-balanced by the earlier entry of children with IDD into the system, attracted by the features of Self-Direction. These are people whose parents would have eventually applied for the waiver, but not until years later. In the past five years, thousands of school-age children have entered the OPWDD system. It is not clear how many more, if any, will enter due to this specific easing.

Long term, early entry will likely lower overall costs. It is almost a tautology: Early access to services that increase independence will result in an adult population that is less dependent on services.

Last, for the sake of completeness: These policies will result in higher budget expenditures when compared to the immoral and discriminatory alternative of erecting barriers to access. Zero delivery of services results in a lower budget—but a much higher cost in the degradation of our society. In the words of Daniel Patrick Moynihan

*The ultimate test of a moral society
is the kinship it expresses with the disadvantaged.*
