

**ACT NOW TO SAFEGUARD SELF-DIRECTED SERVICES!**

OPWDD will be holding a Public hearing videoconference at sites around the state to gather input for the Statewide Comprehensive Plan 2018-2022, on September 25<sup>th</sup>, from 3-7pm. Anyone can attend, but you have to register if you want to speak. Registration closes September 15, but there are only a limited number of spots. Go to [https://opwdd.ny.gov/news\\_and\\_publications/opwdd\\_news/NEW-DATE-PublicHearing-for-theDevelopment-of-OPWDDsStatewideComprehensivePlan](https://opwdd.ny.gov/news_and_publications/opwdd_news/NEW-DATE-PublicHearing-for-theDevelopment-of-OPWDDsStatewideComprehensivePlan).

But EVERYONE can submit written comments by Sept 25! Keep in mind:

Your comments can be one or two paragraphs only, a few sentences, or just a list of bullet points. A brief story about your family member is helpful, but not necessary.

OPWDD reads all submissions, and tracks the number of comments/recommendations on specific issues. This is your chance to advocate for the issues that are important for people who self-direct.

**Quick Read**

By 2024 almost all OPWDD services will be delivered through managed care. A Care Manager will expand the role of the MSC, and “coordinate” each enrollee’s Medicaid medical, behavioral\*, and other “wellness” services, as well as long term care (this includes self-directed services). The State’s goal is to improve the quality of care, improve health, and lower costs. However, in delivering Self-Directed Services through managed care, there is clear potential for limiting options for people who self-direct.

\*The term: “Behavioral health” refers to what used to be called “mental health”

OPWDD has committed to continuing self-directed services. However, as of yet they have not clearly spelled out how self-direction with employer and budget authority will work under a managed care system operating under the direct authority of the New York State Department of Health. Self-direction’s goal is to maximize individualization and choice: Managed Care Organizations traditionally succeed by limiting options.

For those who use self-directed services, what will managed care mean?

- ! Will there still be room for creativity and choice?
- ! Will managed care organizations steer people into more “cost effective” group settings?
- ! Will budgets be cut, limiting peoples’ options to live outside the family home?
- ! Will we still be allowed to pay staff wages comparable to OPWDD agency rates?

**What can you do today?**

- ! Are you ready to write a brief letter to strengthen self-directed services now? See **Issues to consider for comment** and **Letter Writing** just below. Send your comments to:

[Chris.x.Nemeth@opwdd.ny.gov](mailto:Chris.x.Nemeth@opwdd.ny.gov)

- ! Do you want to see OPWDD's official request for comments?  
Go to [https://opwdd.ny.gov/news\\_and\\_publications/opwdd\\_news/NEW-DATE-PublicHearing-for-theDevelopment-of-OPWDDsStatewideComprehensivePlan](https://opwdd.ny.gov/news_and_publications/opwdd_news/NEW-DATE-PublicHearing-for-theDevelopment-of-OPWDDsStatewideComprehensivePlan).

## **Issues to consider for comment**

### **Self-direction must continue to be a viable option under managed care.**

Here's what's needed:

1. Assessment that is objective and able to document all support needs
2. Adequate funds to support people 24/7, with staff and use of technology
3. Financial support to pay for non-certified housing, and knowledgeable people to assist in the process
4. Sustainability: supports for people who don't have a parent or other caregiver to assist them to self-direct
5. Continuation and strengthening of self-directed supported employment

#### **1. Assessment: Coordinated Assessment System**

Currently, New York State uses a test called the Uniform Assessment System to support care planning and service delivery for all Medicaid agencies except OPWDD. Recently, OPWDD has adopted the Coordinated Assessment System (CAS) which adds 16 domains to the UAS to help identify a person with I/DD's behavioral and medical needs. The goal is to eliminate silos between different departments and to coordinate services. However, its effectiveness is still being evaluated.

People who self-direct are the only group whose supports and services must fall within a dictated budget. Because the budget is determined by the assessment, accurate testing is critical. We have recently become aware of problems with administration of both the currently used DDP2 and the CAS, which will eventually replace it.

Two families recently reported that a DDP2 was administered to their child by someone who didn't know them, without either the parent, broker, or their MSC. An unknown MSC was present. The families found out about this when they got a notice their budget was being decreased. Clearly, this is not how the system is supposed to work.

We have had mixed reports from parent and brokers about the CAS. Some assessors are doing the work thoughtfully, but others are asking multiple direct questions, rather than having a conversation that drives a nuanced understanding of the individual. This especially is an issue for people with chronic intermittent problems, which may easily be swept under the rug when the assessor is not thorough. Because of the way the assessment tool is constructed, a rigid, superficial approach causes fewer domains to be explored, and support needs can go undocumented.

#### **Recommendation**

OPWDD should provide evidence that limiting some questions about health and safety issues to the last 3 days provides valid, predictive information in this population.

Given the importance of a numerical score for people who self-direct, develop a grievance process to address significant disparities between the assessment score and the on the ground assessment from those who interact daily with the person.

As we have previously suggested: Develop a post-assessment feedback form for family/circle of support that will result in actionable data.

## **Supported Employment**

After CSS ended in Oct 2014, job coaching could still be self-directed, but most people could no longer hire a job developer to help them find the right job. OPWDD has suggested, on the basis of a recent review, that people who were self-directing were less likely to be employed, and that SEMP should no longer be offered as a SD service.

After hearing a brief summary of the research, we concluded that the data used was probably flawed, and therefore should not be used as the basis for change in policy.

Currently, in order to access job development services through OPWDD, a person who self-directs is required to use an agency program. This is not an efficient way to deliver services to someone who self-directs:

- ! It can cause a major strain on the budget, and significantly decrease the total amount of an individual's support time.
- ! Much of the "Discovery" part of Pathway has already been done by the circle of support.
- ! A significant number of people who use Self-Directed Services work at integrated, minimum wage jobs, but for only 2-10 hours a week. The "job coach" functions to support the person's interaction with others, behavioral challenges, safety, etc. Innovations job coach training adds little in this setting. If SD SEMP is eliminated, people will continue going to work with their community hab worker, but the hours will not be reflected as integrated employment, a valued outcome.

## Recommendations

Instead of doing away with Self-Directed SEMP, OPWDD should strengthen the program:

- ! A competitive budget line for job developers
- ! A person-centered approach to training requirements for job coaches (e.g., no requirement for expensive and time-consuming Innovations training, if the job coach functions primarily in the role of a community habilitation worker)
- ! If a job coach needs specific task training to support an individual at their workplace, the job coach be funded to be trained in a discrete task or group of tasks.
- ! To gather data about effectiveness, this could be run as a pilot program.

## **Enhanced Broker**

Some people who self-direct are able to take an active role in the long-term and day to day management of their plan, but most cannot. When self-direction was first piloted in the early 90's, it was believed that real community inclusion would result in people developing "natural supports" that would, over time, take the place of some paid direct support and administrative roles. Unfortunately, this goal remains aspirational for most of us. For self-direction to survive as an option for everyone, a structure must be set up to act in the "parent" role when a parent is unavailable.

Broadly, the parent/guardian fulfills three roles in supporting people with I/DD to self-direct.

1. The executive part: hiring and training direct support staff and consultants, setting wages, addressing problems that arise with staff, deciding on the need for medical attention, budget decisions, and more.
2. The hands-on part: arranging for (or filling in as) coverage for people who need 24-7 in both planned (staff vacations) and unplanned (staff illness, car problems, storms) circumstances
3. Paperwork: timesheets, monthly reports, vendor paperwork, etc. (Currently, there's a budget line for "self-directed staff support, but the pay rate is low for the level of responsibility, e.g., ensuring Medicaid compliance).

Currently on Long Island we know of two self-directing individuals with significant support needs who are without family or guardian support. In both cases, brokers have assumed the "parent" role successfully. However, this is the exception, not the rule.

## **Recommendation**

Establish an "enhanced broker" who will close the gap in the service delivery system and enable people to age in place in their communities using self-directed services. This will allow for sustainability.

As the 1115 is a demonstration waiver, this would be worthwhile small pilot program. It could be used both for people who do not have an active parent or guardian, and for those whose parents are unable to fulfill the role.

## **Access to self-direction for people who need 24/7 support**

Currently, when people using Self-Directed Services live out of their family home and require 24/7 support, a family member is required to provide some number of hours of direct care on a regular basis. (We're talking about "You will be covering every Wednesday from 9-3," not, "why don't you come over for dinner tonight, your cousin is visiting").

Some people with I/DD don't have family caregivers, and all caregivers will age and die. Inevitably, emergencies arise for staff, and as people age, their support needs often become more intense or complex.

The cost of people living in a group setting and attending a traditional program far exceeds the cost of supporting a person with I/DD in a community setting in almost all cases. Further, it is well established that many people currently live in more restrictive settings than their needs dictate.

Fairness (and Olmstead) dictate that there should at least be parity: if it costs X dollars for a person to live in a group home, the same amount should be available to live in non-certified housing with all necessary supports and services.

### **Recommendation**

Provide adequate funding and infrastructure to support people who self-direct and require 24/7 support.

### **Housing**

When people move out of their family home or a more restrictive setting they will need assistance to find housing that is right for them, and funding to afford it.

Fairness and the Olmstead decision dictate that if the state will support someone to live in a group home for X dollars, the same amount should be available for someone to live in a non-certified home in the community.

This still leaves the issue for the individual of how to go from wanting to move, either from the family home or certified setting into a home of their choice, with or without roommates.

Seeing this need, OPWDD awarded a grant to NYSACRA to design and implement a “Housing Navigator” curriculum, and a number of people have already completed the program. The goal is for graduates to be “qualified to create housing opportunities for individuals and to develop agency capacity for more housing options.” (From NYSACRA Center for Innovations and Development Training Academy).

This pilot was successful: we believe there should be enough housing navigators to serve anyone who needs one across the state.

### **Recommendation**

Everyone who self-directs and chooses to move into a home in their community should have access to housing navigation which should be a billable Medicaid service usable by people who self-direct

### **Suggested letter writing guidelines**

- ! State you’re a parent or guardian
- ! Describe the issue, and how it affects your child
- ! Offer a potential solution –Your own idea or one we’ve described above

Most important: Don’t let the perfect get in the way of clicking send! They count the responses, and it’s more important to get your opinion out than to make it perfect.

Please bcc us a copy-it will help us to know if the information we send is useful to you.

Questions? Contact us at nyselfd@gmail.com

Do you want more background information? Read the “Deep Dive” below.

### **Deep Dive: Background, and how planned changes could affect SD services**

You will notice that we are repeating some concepts here in the service of clarity, to make sure we're all in the same conversation.

As most of you are aware, over the next 6 years people with Intellectual and Developmental Disorders (I/DD) will follow the rest of NYS Medicaid's 6 million users into managed care, and OPWDD will have less of a voice in the day to day control over services. Our understanding at this time is that OPWDD will continue to be responsible for the Front Door and eligibility determination, as well as oversight and quality assurance, but the program will be run by Managed Care Organizations through the NYS Department of Health.

Now is the time for family members of participants in self-directed services with employee and budget authority to publicly air their concerns so inconsistencies can be addressed and problems can be solved before Care Managers and Managed Care companies and have major roles to play.

Below, we'll give some background, then detail our understanding of the changes that are coming and how they will affect people who self-direct and their families.

#### **What is Medicaid?**

Medicaid was created in 1965 to help with medical costs for some people with limited income and resources. It is a joint federal and state program: in New York the state and federal government each pay half of the costs. Each state sets its own eligibility criteria, and whoever meets the criteria is enrolled. Almost all Medicaid services in NY are currently delivered through managed care; OPWDD services are the last to be included.

#### **How are OPWDD services related to Medicaid?**

Long term services for people with Intellectual and Developmental disabilities are paid for mostly with Medicaid funds through a specific funding stream called a waiver. The waiver allows states to have more discretion over eligibility and services offered. Currently, services for people who use, for example, self-directed services (com hab, support brokerage, job coaching, FI, respite and IDGS) are delivered through a 1915(c) waiver. However, under managed care, all OPWDD services will be delivered through the state's 1115 Waiver. (Note: this does not mean that your family member's services will change; it only refers to how the services are funded).

#### **What is Managed Care?**

Managed Care is a health care delivery system organized to manage cost, utilization, and quality. Medicaid managed care provides for the delivery of Medicaid health benefits and additional services through contracted arrangements between state Medicaid agencies and managed care organizations (MCOs) that accept a set per

member per month (capitation) payment for these services.  
(From Medicaid.gov)

As mentioned above, the vast majority of New York state's Medicaid services are being delivered through managed care, to over 6 million people. In contrast, OPWDD serves over 130,000. Numerically, we are a drop of water in the ocean of NYS Medicaid; however, we do account for a disproportionate amount of the cost.

Although some families are continuing to advocate for a "carve out" of OPWDD services from managed care, we believe that ship has already sailed, and our current goal is to protect and strengthen self-directed services.

OPWDD is planning to transform to a managed care system in two steps. Initially Care Coordination Organizations (CCOs) will take over what has been the MSC role (with the addition of coordinating health services) in 2018 on a voluntary basis in some areas. By 2024 will have moved to a fully capitated system, organized as Health Homes. Initially enrollment will be voluntary, and then mandatory for all eligible groups. Some categories will be excluded from the medical side, for example people who are covered under their parent's insurance and people who have both Medicaid and Medicare. (Note: OPWDD states they plan to allow current MSCs to transition to Care Manager roles, if they wish).

Why are all these changes happening now?

### Federal and State Initiatives

CMS introduced, and New York has embraced, the Triple Aim for health care:

1. Improving the quality of care by focusing on safety, effectiveness, patient-centeredness, timeliness, efficiency and equity.
2. Improving health by addressing root causes of poor health, e.g., poor nutrition, physical inactivity, and substance use disorders
3. Reducing per capita costs

A further incentive for states: Follow the money!

To help states achieve these goals, the Affordable Care Act sweetened the pot with financial incentives, several of which New York is using:

- ! Conflict Free Case Management
- ! Care Coordination Organizations
- ! Health Homes
- ! Community First Choice Option.

Although each of these initiatives has the potential to improve services for people with I/DD, they will result in significant changes. The changes at OPWDD are a just small part of the transformation of the entire Medicaid health care delivery system in New York State. They will bring many advantages but people need to be mindful of how self-directed services may be affected.

What is Conflict-Free Case Management (CFCM) and why is it required?

Recent federal regulations require that an employee of an agency that provides waiver services for an individual (for example, com hab or day hab), must not provide case management or develop the person-centered service plan. The intention of this Federal rule is to ensure that case management services are person-centered and promote the service recipients' interests, not those of the provider agencies. CMS required OPWDD submit a transition plan to comply with the conflict-free standards for service coordination by October 1, 2016

Adapted From OPWDD: "Amendment 01" Overview WebEx Q and A,  
August 2, 2016

### **What is a Care Coordination Organization (CCO)?**

New York State is meeting its obligation for CFCM by creating Care Coordination Organizations. The organizations will be developed by existing I/DD provider agencies and provide care management and coordination specifically for people with I/DD. They will coordinate all Medicaid funded and other community services for enrollees.

Concerns with NYS's plan for CFCM

We strongly support the concept of CFCM. However, most current MSCs work for voluntary agencies that provide direct services, and will continue to work for them as Care Managers although their paychecks will have the name of a different entity on top.

With CMs working for the MCO, and given the pressure from MCOs to control costs, will they be able to act as strong, impartial advocates for their clients who self-direct?

### **What is a Health Home?**

A health home is a Medicaid State Plan Option that provides a comprehensive system of care coordination for Medicaid individuals with chronic conditions. Health home providers will integrate and coordinate all primary, acute, behavioral health and long term services and supports to treat the "whole-person" across the lifespan.

From Medicaid.gov, Health Homes (Section 2701) Frequently Asked Questions.

### **What is a Coordinated Care Organization/Health Home?**

To be able to transition gradually into managed care, OPWDD will first transfer care management to CCOs. CCOs will be paid by capitation, that is, they will be paid a specific amount of money for each person they serve, depending on the individual's support needs. Only the care management will be capitated initially, not any other services.

Over a few years, many CCOs will become full-fledged Health Homes, responsible for coordinating AND providing (within themselves and through contracts with other entities), all of the services described above.

By using conflict free case management through establishment of CCOs, New York will receive increased funding for care coordination. Instead of 50% New York will get 56% federal matching funds (also called fmap).

### **What does that mean for me?**

A major difference is that there is no mechanism to change your CM in the way that you could change your MSC, a potential problem. (On the other hand, the CM will have the resources of the Interdisciplinary Team to provide expertise).

This change is one example of why it will be critical for participants and their families to have access to a neutral advocate, referred to as an ombudsperson in other Medicaid long term care settings.

### **What is the Community First Choice Option?**

The "Community First Choice Option" (CFCO) allows States to provide home and community-based attendant services and supports to eligible Medicaid enrollees under their State Plan. This State plan option was established under the Affordable Care Act of 2010.

This option became available on October 1, 2011 and provides a 6-percentage point increase in Federal matching payments to States for service expenditures related to this option. From Medicaid.gov

Before CFCO the state, people with different diagnoses and long term support needs had access to different services. Now everyone covered under Medicaid is eligible for the same long term care services

CFCO is all about getting people out of nursing homes and other institutions, and keeping them from entering, or as the state puts it "rebalancing" Medicaid funding from institutions to the community. In the rush to reach this goal (a great goal!) we're concerned that DOH may run over self-direction on the way.

Specifically, in trying to "streamline" self-directed services, it's crucial that its customization, flexibility, and creativity not be lost in the name of efficiency and bringing the services to scale.

### **Why is it important to comment on OPWDD's State plan?**

This is our chance to be proactive; it's is an opportunity to clearly and thoughtfully explain what should be preserved and where there's room for constructive change.

