

Changes in Delivery of Services for People with Disabilities

OPWDD Transformation: Explanation and Commentary

March 3, 2015

Written by Jim Karpe, Member of the Executive Committee of NYC FAIR

What is going on?

The system in New York is going through a transformational change. We wrote this document to empower you.¹ We want to help you influence the future of disability services in New York State.

The primary state agency responsible for providing and overseeing service, Office of People With Developmental Disabilities (OPWDD), has asked for public comment during the month of March. You can submit your comments at any time before April 1, 2015.

quality@opwdd.ny.gov

With subject line: HCBS Settings Transition Plan comments

-or-

OPWDD Attention: DQI HCBS Settings

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OPWDD has issued "explanatory" documents written in impenetrably dense bureaucra-tese.² There is also a 32-page power-point³ which is slightly better-- but only slightly. For example, the 11th slide of the power-point has 7 different acronyms (with zero explanations).

What is this?

In the paragraphs that follow, you will find out what is at stake, presented in clear and concise language, and almost no acronyms. With the investment of only a few minutes reading, you will get the answer to the question: What is at stake? What is getting proposed? And you can then contribute a comment to OPWDD. Links to the official documents are included, if you have the time to dive in.

Here, we also provide you with our own responses-- on some issues, a blend of multiple responses, since NYC FAIR embraces a diverse group of people who sometimes disagree with each other. Just like any other family. And, we invite you to join our family. There are no dues, no blood test. The only qualification: You care about the issue. Maybe because someone in your family has a disability and you want to advocate for them. Self-advocates are welcome— by definition, you are in your family.

Without further ado, here is what is at stake.

¹ We are NYC Family Advocacy Information Resource (NYC FAIR) a newly formed advocacy group. We are family members of individuals with intellectual and developmental disabilities (I/DD), and concerned others. www.nycfamilyadvocacyinformationresource.org

² The OPWDD documents related to the March 2015 commentary period are listed at www.opwdd.ny.gov/opwdd_services_supports/HCBS/announcement-for-public-content
Direct link to 15-page public commentary announcement: www.opwdd.ny.gov/node/5902
Documents about transition plan: www.opwdd.ny.gov/opwdd_services_supports/HCBS/hcbs-settings-toolkit

³ Direct link to 32-slide powerpoint: www.opwdd.ny.gov/node/5905

OPWDD Transformation: What is at stake?

Overall, what is at stake?

The life our family members will live. Our ability to get them the services they need.

The OPWDD (Office of People With Developmental Disabilities) controls the system which delivers the "ordinary needs of special people":

- Housing
- Transportation
- Recreation
- Jobs

OPWDD is re-structuring the system, in response to demands placed on every state by the Federal Agency in control of Medicaid funding, CMS (Center for Medicare & Medicaid Services).

NYC FAIR Commentary

At first glance, it appears there is an amazing system being put into place. The OPWDD Transformation Plan power point has beautiful language about "person centered planning" and providing choice. However, the reality of OPWDD plans falls short of the rhetoric in the opening remarks. The plan specifies the elimination of several important options, and the "pruning" has already started⁴. Meanwhile, implementation of the new choices has been delayed or bungled. The result is a severe narrowing of options. Offering a choice among unsuitable alternatives is really offering no choice at all.

There are three fundamental problems. The first and most severe, is that the transformation plan eliminates options that are tailored to the needs of those individuals with more severe issues. We have a moral obligation to take care of the most vulnerable. Let's not abandon that obligation by eliminating programs and services-- especially since those changes are not actually required by the Feds. The guidelines from CMS allow for a wide range of housing options and employment programs. The New York State plan calls for dismantling "safety net" options, and thus will reduce choice in the worst way for the most vulnerable.

The second fundamental problem is lack of ways to ensure transparency and accountability—in brief, "no teeth", no actual follow-up. Instead, time after time what actually emerges are more additions to the thicket of rules which prevents delivery of needed services, and a distressing lack of transparency at OPWDD and very little routine reporting about OPWDD activities. The gaps in reporting makes it difficult or impossible to answer even basic questions such as: How many individuals are unemployed? "In God we trust; all others must bring data."

Third, failure to implement the actual service delivery. Sometimes the delivery falls short, sometimes a failure to even get started. One example, the Front Door, a program launched in 2013 to welcome new families to OPWDD, was and is severely under-staffed. Consequently, to many families it appears jammed shut.

NYC FAIR calls upon the OPWDD to expand options rather than prune them, and to practice transparency and accountability—starting with regularly scheduled releases of information about waiting lists and service delivery.

⁴ Example, closures of residences and workshops in Hudson Valley:
northcountrynow.com/news/st-lawrence-nysarc-facing-closure-work-centers-0137255

Housing for people with disabilities

The plan specifies what kind of housing and supports will be funded. OPWDD says it will eliminate funding for all facilities which house more than four individuals.

NYC FAIR Commentary

We want to ensure that each person with disabilities gets the type of housing they need. To achieve that, for real choice, for real person-centered-planning, the system needs to offer a true range of housing options. For example, "clusters" of housing for dozens of individuals can provide specialized medical and therapeutic services, while also meeting all the published criteria for self-determination in housing, such as the right to privacy, visitors, etc. CMS clearly states that "the regulation does not specify size"⁵.

To make sure the system offers appropriate options, we need to have routine transparency and accountability. One simple example: How many people with disabilities are waiting for housing? All we know for sure is that the number is large and growing--probably well over six thousand.

NYC FAIR calls upon OPWDD to expand the range of housing options, including the preservation of settings with more than four individuals.

Employment for people with disabilities

OPWDD has determined that it will eliminate all sheltered workshops-- despite its own assessment that only half of the participants will make the transition to supported employment.⁶

NYC FAIR Commentary

For those who are capable of work, the daily routine provides structure and dignity to life.

We want to provide this to as many individuals as possible. Based on NY State reports⁷, fewer than fifty-five hundred people with disabilities have jobs (supported employment). Another eight thousand are in sheltered workshops. That means no work at all for thousands and thousands of recipients of OPWDD services.

Closing workshops will not magically propel thousands into the workforce. Instead, they will go into group Day Habilitation programs, or worse, into stay-at-home non-programs. Rather than eliminating workshops, OPWDD should transform them. CMS allows sheltered workshops, as long as they are not completely sheltered: "a state could allow pre-vocational services delivered in facility-based settings that encourage interaction with the general public (for example, through interaction with customers in a retail setting)."

NYC FAIR calls upon OPWDD to fix the sheltered workshops, rather than shutting them down. Add retail settings for selling their production, or create other ways to "encourage interaction". An imperfect daily work routine is far superior to no work at all.

⁵ See Question 5 on page 8 of

www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/q-and-a-hcb-settings.pdf

⁶ "OPWDD estimates that 50% of workshop participants could successfully transition", page 7 of www.opwdd.ny.gov/node/4791

⁷ See public reports available from New York Employment Services System www.nyess.ny.gov

Self-Direction

The Federal agency, CMS, urges the expansion of self-direction, and OPWDD proclaims this as one of their initiatives. However, the reality is that less than three thousand families have self-directed plans. And perhaps fewer than two thousand-- the lack of transparency makes it impossible to tell.

NYC FAIR Commentary

Self-Direction (SD) is one excellent option. But it is not for everyone. For starters, as organized today, Self-Direction requires a heavy investment of time from an unpaid advocate-- usually the parents. Further, recent changes in the program have created additional obstacles, including the low rates offered to specialists who are paid through Self-Direction. Even worse, the change in fee structure for Financial Management Services (FMS) has caused agencies to reconsider their involvement in the program. Without a strong network of FMS agencies, there cannot be an expansion of the program.

NYC FAIR calls upon OPWDD to make the many changes required to preserve Self-Direction as a viable option, and then to go further: Make it easier to use.

Staffing

NYC FAIR Commentary

The Transformation Plan does not directly address staffing. But paid staff are the ones who actually deliver the services which provide a range of options and opportunities. Without a trained and stable work force, there is no delivery of anything. And in response to poor pay, trained staff members have to leave for other jobs in order to meet their own needs for food and housing. High turn-over disrupts service delivery, and also creates higher costs for recruiting and on-boarding, including training. The OPWDD plan highlights the problem: "While OPWDD has trained over 2,000 staff of provider agencies in the areas of assessment, planning, job development and job coaching, the turnover of provider agency staff is such that ongoing provider training is necessary."⁸

To create and deliver a wide range of options, we need well trained personnel. And that requires a competitive salary and benefits package, to retain those trained personnel.

NYC FAIR supports a routine annual Cost Of Living Adjustment increase for staff.

⁸ Page 5 of www.opwdd.ny.gov/node/4791