New York Self-Determination Coalition

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Public Comments regarding OPWDD’s anticipated HCBS Settings Transition Plan and 1915 (c) Comprehensive HCBS Waiver Renewal

Scheduled for Renewal October 1, 2014

The NY Self-Determination Coalition is a group of families who promote self-determined lives for people with developmental disabilities. We are volunteers, and independent of any agency.

We applaud and support the conceptual basis of OPWDD’s transformation agenda: Where people live should feel like their home, paid employment adds value both to the community and the individual’s life, and community integration is a civil right. As citizens, we also understand the need to ensure that supports and services are financially sustainable.

We have reviewed the documents and PowerPoints made available for comment, attended OPWDD briefing sessions, and submitted questions to the Waiver team. However, we have not seen the actual waiver document, and we have all learned “The details are not the details, they make the design” (Charles Eames). Therefore, we are handicapped in these recommendations by our inability to see the text of the waiver to be submitted.

In formulating our comments we have spoken to many people around the state regarding the proposed changes. Everyone contributing ideas to this paper has had hands on, long-term experience using self-directed services, either as a family member or professional.

1. Individual Directed Goods and Services

Individual Directed Goods and Services (IDGS) will be a Medicaid Option 10/1/14

Can be used for items we now call contractor or vendor services, and items like transportation.

From: Consolidated Supports and Services Redesign, April 2014: Individuals and Families Presentation, Slides 19 and 20

IDGS are services, equipment, or supplies that addresses a need in the individual’s service plan, such as: transportation, small kitchen appliances, laundry services, chore services, hippo-therapy, massage therapy, gym memberships, recreational activities, creative arts, other transportation

From: Consolidated Supports and Services Redesign April 17, 2014, for FIs and Brokers Presentation, Slide 23

Self-direction has been successful in great part due to its flexibility in meeting individual needs. We are concerned that putting all of the above services into IDGS and adding a cap will make it impossible to successfully support some people in their communities.

Here are some of the essential supports and services that OPWDD proposes covering under IDGS:

Transportation costs.

Transportation costs for suburban and rural areas for CSS plans often run to $2000-$3000 a year, which goes to reimburse staff members for gas and wear and tear on their personal cars. Will there be sufficient funds for a young man living in western NY to get to his job 20 miles away?

We understand that there may be a plan to put transportation funding into the hourly rate for direct support staff. This approach works for agency programs whose vans often transport people the same amount of miles every day; if routes differ day to day, the costs can likely be averaged out for all of the program participants.

In contrast, people using self-directed services are transported by staff who use their own cars. One day they may travel 10 miles, another day 40 miles. Mileage will vary depending on the person’s schedule. If a person loses a job for example, staff may be driving 10 miles in a day, instead of 40. And if the next job requires a 50 mile roundtrip? There is no fair way to reimburse mileage as part of salary for direct support staff of those using self-directed services. We are concerned that inadequately reimbursing staff for mileage will establish a disincentive to drive people where they need to go, and will also become a problem in staff retention.

Community developer

People with significant intellectual disability, dual diagnosis, and behavior challenges always require intermittent, usually short term, specialized assistance to integrate into the community. The developer needs to know the person and the community, and how to find an opportunity where the person will be successful.

Behavior support:

Over 30% of people with developmental disabilities have co-occurring mental illness, and many more have behavioral challenges. Inappropriate behavior is the greatest barrier to community integration for people with developmental disabilities. Most will not be successful without intermittent or ongoing behavior support. Behavior consultants charge a range of fees, but, for example, if a behavior consultant earns a rate of $75/hr and the individual requires once a week services for 50 weeks, that alone comes to $3750.

Positive behavior support is the glue that keeps many self-directed plans together. This is not a forty minute visit to an office. Consultants go to an individual’s home, workplace, or community center, working with them in the setting where they need support. For individuals to work and play in their communities, consultants must work with them directly and train their support staff in appropriate strategies.

We understand that the IDGS cap is a CMS requirement, but would like to make the point that setting it at an arbitrary level, not individualized to a person’s needs, is not consistent with the principal of budget authority. As long as the person’s supports and services are aligned to their ISP goals, the services are permissible under Medicaid, and the total expenditure doesn’t exceed the person’s PRA, an arbitrary cap becomes an impediment to community integration, and seems inconsistent with the requirements of the ADA and Olmstead.

**RECOMMENDATION**

People should receive any reasonable supports necessary to live and work in the community. If there is an arbitrary limit set for IDGS, there should be alternate ways to fund essential needs, including but not limited to, behavior support, community and job development, technology that makes people more independent, transportation, and other essential goods and services.

2. Circle of Support (COS)

In New York’s current self-directed option, CSS, the Circle of Support is responsible for keeping the focus on the individual receiving services. The circle’s roles include:

Working with the individual to complete the person-centered plan

Creating/Revising the CSS Plan/Budget

Assisting in assuring budget funds are spent appropriately

Assuring that potential support staff are trained

(Adapted from NYS OPWDD Consolidated Supports and Services (CSS Monthly) Plan & Budget Guidance 3/15/13)

The continuation of the Circle of support (COS) is not mentioned in the Redesign PowerPoint. Circle meetings are critical for the success of all people using self-direction, as they act in lieu of the supervision usually provided by agencies.

**RECOMMENDATION**

The COS is critical in supporting an individual who is self-directing, especially as natural caregivers age. COS meetings should be supported by the ability to reimburse staff, and consultants (when appropriate) for attending meetings.

3. Staffing - Paying two or more staff for the same time period

This comes up in three contexts:

1. Paying a behavioral (or other) consultant/vendor and direct support staff person for the same time period.

For example, person with behavioral challenges is having difficulty interacting with coworkers at his paid or volunteer job, and is in danger of being fired. To assist the individual, the behavioral specialist needs to observe the person at the worksite with his job coach and coworkers to assess the situation, develop strategies, work with the individual, and train support staff.

2. Paying a “behavior tech” (i.e., someone whose pay rate falls within the direct support category, i.e., less than $40), and a direct support worker, in the situation described above.

3. Extra staffing for safety. Some individuals, especially those who have spent most of their lives in very restrictive settings, may need two direct support staff when they are out in the community, to keep them and those around them safe.

**RECOMMENDATION**

Adequate support will allow people to become integrated into their communities, and will prevent them from cycling from one failed placement to another.

There should be a mechanism to fund 2 on 1 staff when absolutely necessary; this will ensure the rights of the individual involved, as well as cost less than a more restrictive placement.

4. Staffing - Backup staff

Future choices in Self-Direction: I can arrange my own backup staffing.

From: Consolidated Supports and Services Redesign, April 2014: Individuals and Families Presentation

Access to backup direct support staff for both emergencies and planned absences is necessary for people to continue in a self-directed life. Occasionally “natural supports” can fill in, but for long term sustainability there need to be reliable options for backup. With an increased emphasis on competitive employment it is even more essential for individuals to have reliable support to get to work and keep a job.

**RECOMMENDATION**

Funding must be available for people to obtain back-up staffing when natural support is not available.

There are a number of ways people could obtain trained backup:

1. The individual could contract with the FI to supply cross- trained staff who are available to work as backup.

2. Self-directed plans could have a budget line to purchase staff from a specialized temporary employment agency.

3. If people using self-direction live near each other and enjoy spending time together, one staff person could temporarily support two individuals. (This would not work if a person had paid employment or other obligation). It would be appropriate for support staff to be paid an enhanced rate for the extra responsibility.

5. Staffing - Intentional Staff Sharing

Sometimes people who use self-directed services need to be supervised but don’t require constant one to one support. If two people are friends or romantic partners and wish to be together, plans should be able to build in intermittent capacity for o individuals to be supported by one person. This is also cost-effective.

**RECOMMENDATION**

There should be a flexible funding mechanism to share staff, if that is desired by the participants and their circles.

6. Staffing-Retention

Finding and keeping the right staff is essential to the success of an individual’s plan, and will only become more difficult as we all age.

Access to employer paid health insurance is a major factor in retaining staff. Currently people must work at least 30 hours to qualify for employer offered health insurance. If two individuals use same staff person (on different days), but each individual uses a different FMS/FI how can staff accrue enough hours to qualify employer offered health insurance plan?

**RECOMMENDATION**

OPWDD could require that FIs sign an MOU to contribute proportionally to the health plan of a direct support worker when appropriate.

7. Sustainability, or “and when I die, and when I’m dead, dead and gone”

Lyrics by Laura Nyro

What’s going to happen when parents are no longer able to contribute to the care of their adult child, recruit/train staff, and run Circle meetings? Will people be forced back into congregate settings?

**RECOMMENDATION**

OPWDD should collaborate with families to develop an infrastructure to ensure sustainability of self-directed services.

There should be continued capacity to fund:

A “lead” staff member to coordinate staffing

Someone to submit time sheets and monthly reports

Someone to take responsibility to lead the Circle

8 Brokerage

Budget Template Changes

New way to bill Self-Directed Medicaid funded services-by specific service

Support Brokerage

From: Consolidated Supports and Services Redesign, April 2014: Individuals and Families, Slide 25

Startup brokerage is not listed as a specific service.

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The startup broker explains self-directed services, facilitates person centered planning, helps assemble the circle of support, guides the creation of the plan and budget, and acts as the interface with the DDRO until the plan is launched. He or she needs a broad understanding of waiver services, self-direction, and how to listen to people.

For the rare individual with a clear idea of what they want to do and where they want to live, the broker’s role may be limited, and not require much time. On the other hand, an individual with challenges such as dual diagnoses, inappropriate behaviors, difficulty with communication, or a family unable to fully participate, will often require many, many hours of involvement by the start up broker.

**RECOMMENDATION**

Broker reimbursement should be adequate to support the level of training, competence and time required to do the job. It should be recognized that individuals with complex needs will require a larger time commitment. If necessary, plan developers should be funded by state money.

9. Medication Administration

Self-direction should be an option for everyone. This includes the large percentage of people that take medications, require tube feeding and other everyday medical interventions. This is why we wholeheartedly supported the exemption to the nurse practice act for those served through OPWDD. Current AMAP certification is based on an institutional model, and requires knowledge of innumerable medications and techniques, as well as the ability to “pour” medications for a large number of people rapidly. For people using self-directed services, who live with one or two others at the most, this is unnecessary.

We are concerned that common sense will be ignored and that the new law could create another layer of bureaucracy that stifles independence.

**RECOMMENDATION**

It is essential that the training required for direct support staff in performing daily healthcare needs not be overly broad, but be directed by the needs of the individual(s) they are supporting, as directed by the personal physician/individual/family/COS.

**10 FRONT** DOOR

The New York State Balancing Incentive Program Work Plan, Submitted by the NYS Dept. of Health, November 25, 2013, requires the state to:

9.2. Establish protocol for removing conflict of interest: The State must also describe how it plans to ensure that community LTSS eligibility determination, enrollment, and case management processes are free of conflict of interest. (P.33)

At this time, the “Front Door” is OPWDD’s No Wrong Door/Single Entry Point. Individuals and families are introduced to the system with a 2-hour presentation by their local DDRO, during which a brief explanation of available supports and services is given.

It has recently been announced that due to staffing constraints, Region 5 will no longer be running Front Door introduction sessions; instead several voluntary agencies will be charged with providing this information to families and individuals.

Given the history of voluntary provider agency resistance to self-direction in New York, we believe it is unlikely that they will present unbiased information to families. We consider that this transfer of OPWDD responsibility to those who have a vested interested in agency-funded plans to be a conflict of interest and a dangerous precedent.

**RECOMMENDATION**

Front Door information sessions should not be presented by voluntary service providers: this is a clear conflict of interest.

11 Agency purchased/supported “self directed” community habilitation

Future Choices in Self Direction: Agency Purchased

Purchasing Agency Supported Self-Directed Service:

Individual selects staff

Agency sets salary and provides Backup Staffing, Program Management and Clinical Overview

From: Consolidated Supports and Services Redesign, April 2014: Individuals and Families Presentation, Slide 18

True story: A young woman, Lynne and her family were guided toward using agency purchased “self-directed” community habilitation to support her. Lynne has a significant intellectual disability and uses a wheel chair. There are only a few things that she enjoys doing.

Her mother was concerned that she was spending all her time in the house, sitting and coloring The mother spoke to the direct support person, and suggested she take her daughter to the park, where Lynne always enjoyed watching children play ball. She also suggested they play catch. The staff person’s response was that she wasn’t “comfortable” taking Lynne into the community.

Lynne’s home has a backyard pool, which she regularly uses with her family. When the Mom requested the staff person support Lynne to use the pool for fitness and enjoyment, the idea was rejected, as the worker explained she wasn’t comfortable with that choice either. The mother called the staff person’s supervisor at the agency, who explained that the agency’s policy was that it was “up to the worker” to decide what he or she wanted to do.

We appreciate that expanding options for individuals to self-direct using Employer authority without Budget Authority, is a step forward from status quo, and may be an attractive option for many. However, we are concerned that individualizing services is a sea change for traditional agencies, given that they historically (and currently) deliver primarily congregate services. that people will not get exactly what they believe they signed up for.

**RECOMMENDATIONS**

Self-directed community habilitation, supported employment, and respite should offer people authentic choice and should be realistically described by agencies to families.

OPWDD should issue a clear guidance document, accessible to both agencies and families. When families are given the information they need to understand what they should expect, they can serve as “on the ground” (no cost!) quality control for OPWDD.

12 Preserving a distinct identity for self-directed supports and services with both employer and budget authority.

We recognize that as the system transforms there will be many “self-directed” options and understand that the label Consolidated Supports and Services will change. It is essential that individuals and families be able to clearly distinguish CSS type services (both employer and budget authority) from other options, because there are qualitative differences in the way an individual gets to live his or her day to day life, that distinguish an agency involved and wholly self-directed plan.

It has taken over ten years of outreach and education for CSS to become known to individuals, families, MSCs and, school personnel. Individuals and families won’t be able to make an informed choice if they can’t distinguish between their options. Even with the best outreach and promotion, people will be confused.

**RECOMMENDATION**

There should be a distinct name to identify full budget and employer authority.

The initials CSS must remain. One suggestion: Customized supports and services.

13 Hab Plans

Words have meaning: they create attitudes and influence behavior and perception. We are concerned about the increased use of the term “hab plan” to describe the supports and services chosen by a person with developmental disabilities. Describing the content of someone’s life as a “hab” plan is demeaning, segregating, and stigmatizing. Typical people hire others to support them all the time: if you go to an exercise class and the instructor corrects your posture, you don’t consider they’re providing a “hab” service.

Even if OPWDD is required to use the term “hab plan” in formal communications with CMS, people with developmental disabilities, their families, direct support staff and MSCs need a different term.

**RECOMMENDATION**

The name Hab Plan should be changed to Action plan (this could even be lengthened to Habilitation action plan for communication with CMS).