New York Self-Determination Coalition

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Comment on the Renewal Application for OPWDD’s Comprehensive Home and Community Based Services Waiver

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The New York Self-Determination Coalition is an independent, statewide group of parent volunteers dedicated to promoting participant-directed services as an option for persons with developmental disabilities served by NYS OPWDD.

We applaud the Waiver’s continuing support for Participant Directed Services and New York State’s affirmation that “In OPWDD’s service system, it is assumed that everyone has the ability and the right to direct his/her services.” Appendix E: Participant Direction of Services, E-1: Overview (5 of 13), f, C).

However, to make Participant Directed Services accessible to all, the Waiver must provide all supports and services necessary for participants to fulfill OPWDD’s goals:

 a) to live in the home of their choice

 b) to work or engage in activities that contribute to the community;

 c) to have meaningful relationships: and

 d) to have good health

*Request for a Renewal to a 1915 (c) Home and Community-Based Services Waiver, 2. Brief Waiver Description*

In our experiences speaking with many families and careful review of the Waiver application, we have several areas of concern:

**1.Employment**

Employment of people with developmental disabilities at competitive jobs in integrated settings is a major target of OPWDD’s transformation. However, the waiver does not appear to provide a mechanism for people who self-direct to hire job developers for volunteer positions.

For most people with significant disabilities the only way to learn how to do something is by doing it; explanations and play-acting are often ineffective. Further, they may not be able to transfer skills learned in one environment to another setting.

We believe that the best (and often only) way for many to develop “soft skills” necessary for employment, as well as participate in “job related discovery,” is to work in an unpaid job, as a volunteer or intern, for a period of time.

However, people with significant intellectual/developmental disabilities, who often have accompanying psychiatric diagnoses usually can’t work at an “off the shelf” job. Even a volunteer job needs to be developed or carved out, with the cooperation of the prospective employer: these tasks usually require the skills of a job developer. Further, the job developer can also train the job coach to support the individual on the job, if needed.

To set up a system that denies access to integrated work for people with significant support needs because they need “hands on” practice in a “real life” (but less demanding) setting, before they can do competitive work, would seem to be inconsistent with the Olmstead decision and the ADA.

**Recommendation**

Self-directed individuals should be permitted to hire a job developer to help them find a volunteer job that will let them access the following SEMP allowable activities:

* Job-related discovery
* Training and systematic instruction prior to employment
* Development of soft skills and job retention strategies

The volunteer job developed should be an outcome of person-centered planning (we’re not talking about sitting in a van while staff deliver Meals on Wheels); with the understanding that it is a prelude to competitive work.

There are two acceptable outcomes to delivery of this service:

1. The person’s skills will improve and they can “graduate” to competitive employment, or
2. The person will remain in the volunteer job, with the support of their community habilitation worker, doing work that is meaningful to him or her, takes place in an integrated setting and gives back to their community.

If you do not accept our recommendation in this area, we would appreciate guidance on how to use self-directed funding to find volunteer jobs that can serve as perquisite to work or other meaningful activities.

Further, even when someone already has a competitive job, spending time volunteering at the community garden, the soup kitchen, or a nonprofit office, for example, benefits both the individual and the community. And again, for those with significant disabilities, accessing these opportunities often requires the short-term assistance of a job developer.

Volunteer work in the community embodies OPWDD’s transformation agenda, and is the focus of CMS on community based settings: that people with disabilities should not be visitors, but fully participating and contributing members of the community. The Waiver should further these goals.

**2.Fiscal Intermediary**

“When a person makes an application for self-directed services, the regional office provides information about approved FIs in his or her region among which the person may choose”.

*Appendix E: Participant direction of services*

*E-1: overview (8 of 13)*

*Provision of FMS*

The Waiver clearly states that each person who opts for participant direction of services may choose an FI. It does not state the each FI has the option to choose whom they will serve.

In many areas of the state, individuals with high support needs have reported that some FIs are refusing to accept plans over a certain cost, (usually around $40,000). This ability to “cherry-pick” plans seems inappropriate to us, as these non-profit agencies funded by federal and state dollars are it denying people access to participant directed services.

**Recommendation**

As part of its required oversight process DQI should require that each FI certify that they take all comers, and do not discriminate on the basis of the individuals support needs or the size of their budget.

That said, we understand that FIs are currently under a great deal of fiscal pressure, and recommend that their funding be adequate to support their costs.

**3.People are not numbers; individuals should be able to request a Fair Hearing to exceed the target budgeted amount of the PRA**

We understand the importance of control of Medicaid costs, and the necessity that each individual have a PRA that reflects their need for supports and services. However, we believe that in certain cases, individuals may need a higher level of funding than the PRA. Two factors contribute to our discomfort with the calculation of PRAa:

a. Use of DDP scores

DDP scores, which have been historically used by OPWDD for assessment, are at this time, generally considered to be deficient in addressing the full constellation of needs of people with developmental disabilities; over the next years they will be superseded by the CAS measuring tool. Therefore, the primary tool on which the PRA is established is clearly less than optimal.

b. Source of the numbers

The Waiver states:

Personal resource allocation target amounts were then established by analyzing the variations in Medicaid residential and day billings by the DDP ability levels. However, before the analyses were undertaken, the lowest and highest 2.5% of the billings in each category were trimmed to reduce the influence of extremely low and high expenditure cases.

*Appendix E: Participant Direction of Services, E-2: Opportunities for Participant-Direction (3 of 6), b. ii*

We are not statisticians, and are not privy to the details of OPWDD’s calculations. However, if the highest 2.5% of billings were trimmed, this suggests that there may be some individuals who have support needs that are not being accounted for.

Further, the waiver states:

The State provides the opportunity to request a Fair Hearing under 42 CFR Section 431 Subpart E, to individuals:..(c) whose services are denied, suspended, reduced or terminated.

*Appendix F: Participant Rights, Appendix F-1: Opportunity to Request a Fair Hearing*

Limiting the PRA, for an individual who can document the need for a service necessary to remain in their most integrated setting, essentially amounts to a denial of services. Therefore, we do not understand why the waiver, seemingly arbitrarily, states that

“A participant cannot request a Fair Hearing to exceed the budget target amount.”

*Appendix E: Participant Direction of Services, E-2: Opportunities for Participant-Direction (4 or 6), b. iii*

**Recommendation**

Participants should have the right to request a Fair Hearing to exceed the budget target amount.

**4. Exemption to the Nurse Practice Act**

Background:

Traditionally, people with I/DD who were not reliably able to self-medicate were given their medications by a nurse, or within a certified setting, by someone with special training (AMAP certified). This severely limited the ability of people who need medication or other interventions to spend time in non-certified settings, i.e., anywhere outside of a congregate facility.

Recently, to increase access to the community, an expansion of the exemption to the NPA was approved by the New York State Legislature, and this is a step forward.

However, the rigorous requirements of training and oversight for unlicensed staff to administer medication (See Appendix G: Participant Safeguards, Appendix G-3: Medication Management and administration (2 of 2), c. ii) are based on an institutional model, and are unnecessary for people who live in the community and self-direct.

Current AMAP certification requires knowledge of many medications and techniques, as well as the ability to “pour” medications for a large number of people rapidly. Certification requires 4 workdays of training, two examinations, 3 clinical practicums, and yearly recertification. These may be appropriate requirements for someone who is administering medication to a large number of people, some of whom they have just met, but not for people who self-direct.

In contrast to traditional congregate settings, people who self-direct live alone, or with one or two other people. They have a small, reliable group of support staff who know them as individuals. Direct support staff who would administer these medications do not need the intensive training that becoming AMAP certified requires. They need to be trained in the specific tasks that are required of them for the individual(s) they work with.

Finally, giving individuals and those who support them more responsibility in issues of nursing care is not new to the NYS Department of Health.

 Since the early 1990’s, the Medicaid funded Consumer Directed Personal Assistance Program, (CDPAP) has allowed people to independently recruit, hire, train, and supervise Personal Assistants (PAs). An amendment to the Nurse Practice Act allows PAs to administer medications, as well as perform more complex “nursing” tasks without the requirements required through OPWDD. With this clear precedent, it is difficult to understand why the same provisions cannot apply for people within OPWDD who self-direct.

**Recommendation**

It is essential that the training required for direct support staff to administer medication prescribed by a healthcare professional to people who are self-directed, not be overly broad, but be directed by the needs of the individual(s) they are supporting, as determined by, the individual/family/Circle of support

Some suggestions:

A detailed plan for medication administration can be documented in the “Safeguards” as part of the individual’s habilitation plan. If circumstances change, this can be amended.

OPWDD could design a master template which addresses various areas, (i.e., asepsis, when to call for professional assistance, what happens if someone can’t/won’t take their meds, etc). The MSC and Circle of Support (for FIDA I/DD, their IDT) could choose from the options relevant for the individual, and set up specific training appropriate for the support staff involved, with appropriate oversight as necessary.

5. Protection for people who self-direct in FIDA/IDD

In addition to the lead care manager, the managed care entity will use an Interdisciplinary Team (IDT) that is available to address the specialized planning needs of the person. The FIDA-IDD is responsible to contract members with different expertise and specialty background (e.g., nurse, education specialist, employment specialist, etc.). These members are available to the participant on the IDT as dictated by the enrollee’s care plan needs.

*Appendix D: Participant-Centered Planning and Service Delivery, D-2: Service Plan implementation and Monitoring*

For those participating in FIDA/IDD, the Interdisciplinary Team (IDT), which includes the care manager, will replace the MSC, and also take on other duties that are currently the responsibility of OPWDD. Although we are confident that IDT members will have some awareness of participant directed services, we are concerned that they will not have the experience necessary to help the enrollee make decisions in this more person-centered way to deliver supports and services.

We are aware that individuals can invite whomever they wish to their IDT meetings. However, we feel it is important for the IDT leader to inform the enrollee’s support broker, as well as a designated member of the Circle of Support, when IDT meetings will occur, as well as the agenda, so they are able to plan to attend and contribute their knowledge of both self-direction and the individual.

**Recommendation**

For individuals who elect to self-direct through FIDA-IDD, the Interdisciplinary Team (IDT) should be required to include the broker, unless the enrollee specifically objects. Both the broker and a designated member of the Circle of Support should receive written notice of all scheduled IDT meetings.