Transformation Panel Report Comments

The New York Self-Determination Coalition is an ad hoc group of parent volunteers dedicated to promoting self-determination as an option for persons with developmental disabilities who require support through New York State’ s OPWDD HCBS Waiver program. While we are supportive of many of the recommendations described in your report, *Raising Expectation, Changing Lives*, we offer the following comments:

We strongly support the adoption of guiding principles, as they will help frame the solutions to any issue that may arise. However, we recommend an additional criterion.

One of the key priorities of the panel, under outcomes, is “living and working in the community while directing their own services and supports.” For consistency, an “essential question” should include:

Does it facilitate the opportunity for people to choose self-direction?

This clarification will become even more critical to specify, given the transition to managed care, for as many have pointed out, managed care - by definition - limits options, while self-direction increases them.

1. Self-Determination

Discussion of Self-Determination (p13):

 It is curious to us that in an overwhelmingly optimistic document, the first sentence of the description of SD is “Self-direction may not be the right service delivery option for everyone, but all of us like to have some control over our lives.” We have two specific comments on this sentence.

This comment contains a value judgment about self-direction, which many do not share. The recommendations must show stronger support for Self-Direction, as reflected in OPWDD’s pronouncements and in the mandate of the HCBS Waiver:

1. “Self-Direction is a central tenant of the OPWDD transformation agenda” appendix E, E1, Overview (1 of 13)
2. “the waiver is designed to afford every participant (or the participant’s representative) the opportunity to elect to direct wavier services. Alternate service delivery methods are available for participants who decide not to direct their services. Appendix E; Participant Direction of services, E-1:

Overview (3 or 13)

In the recommendations, self-determination seems to be equated with self-direction. Self-determination is a philosophy , while self direction is a specific way to deliver services. Also, as many who read this document will not understand the nuance, self-direction with budget and employer authority should be clarified.

We offer the following new language for your consideration:

*All of us like to have some control over our lives. Making sure that self-direction with budget and employer authority is an accessible option for everyone we serve moves our system away from a regimented approach to one that offers individuals meaningful opportunities to exercise control over their supports and services, and live a self-determined life in the community*

We strongly support the recommendation that the system should “ensure that funding is sufficient for individuals with greater needs to self-direct their services, maximize flexibility in how budgets are used, and ensure sufficient reimbursement for FIs servicing those with greater needs.”

1. Care Management and Assessment (p.19)

There is a recommendation to: “Begin managed care demonstrations with community based supports and services, but consider initially not including certified residential services in funds paid to managed care entities.”

This recommendation brings up several questions:

Would this approach incentivize adherence to the residential settings rule, as well as OPWDD’s stated goals of more integration and community inclusion?

And, more broadly, given the large amount of money tied up in residential holdings, how would this affect available funding for other services? Will this not create an overwhelming disparity between those who reside in legacy settings with those who wish to choose more integrated settings?

We suggest that everyone should have a PRA (i.e., a budget that they can spend for their services), as was discussed years ago when OPWDD was contemplating submitting an 1115 waiver. Put another way, the money should follow the person. People should be funded according to their support needs, not the program they access.

As we all know from history, services follow the funding. Just as the HCBS waiver moved people from nursing homes to the community by funding community services equivalently, OPWDD’s transformation should fund self-directed services at a rate equivalent to that for traditional services. This should include housing as well as other funding. This is the only way for services to be individualized and flexible, both goals which are repeated emphasized in the transformation recommendation

1. There is no mention of ombuds services by individuals trained in the needs of people with in I/DD in the report. This is a glaring omission. The report needs to include the a recommendation about ratio of Ombudspeople to participants, how to measure satisfaction with services performed by Ombudspeople, how to measure comprehension of participants with available options, service delivery, remedies, and redress. Also how will participants, and their family members and advocates, learn about Ombuds services?
2. Employment and community life

Although paid employment should be the default option for people served by OPWDD, we suspect that the majority of people who get opwdd services will not be able to sustain full time work (That is what makes them eligible for SSI). People with high support needs may be able to spend some hours a week working, but also need to be involved in volunteer projects in their community. This doesn’t happen by chance; someone who knows the individual, and is able to approach a volunteer group needs to be paid for that essential service.

Recommendation: For people using self-direction, job-developers should be allowed to develop volunteer jobs (that might lead to paid employment in the future).

1. Nurse Practice Act: There is no recommendation in the report about amending the Nurse Practice Act so that people using self-direction services can live, work and recreate in the community.
2. Housing-

It seems clear to us that the most efficient way to find housing for people is to support them in their efforts to find non-certified housing. -Everyone who rents needs to pay one month rent and one month security deposit as they sign their lease. Currently, FIs are not reimbursed for this money until after the lease is signed. This is a “catch 22” that prevents people from accessing non-certified housing and

can be easily solved.

Other areas that need to be addressed to safeguard access to self-direction, include ensuring that care coordinators under managed care are educated about self-direction, making sure that there is adequate availability of support brokers and Fiscal intermediaries in all parts of the state, supporting paperwork and community mapping, and making sure that self-direction with Budget authority is robustly offered to maximize service hours.

To summarize, we believe that the Transformation Panel has the opportunity to use *Raising Expectation, Changing Lives* to demonstrate a commitment to making the option to self-direct services truly available to everyone seeking support from OPWDD. In that way, the report will be a true reflection of its title.