

Comment on OPWDD Transformation Panel Draft Report

Note: Not yet approved by full NYC FAIR Executive committee

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What is going on? Time is short!

After eleven months of effort, the Office of People With Developmental Disabilities (OPWDD) has issued a report based on the work of the Transformation Panel convened by the OPWDD Commissioner. Direct link to 20-page document:

www.opwdd.ny.gov/opwdd_about/commissioners_page/transformation-panel/panel_report

OPWDD has asked for public comment during a far-too-short two week period which started January 8, 2016. You must submit your comments by **Friday January 22, 2016** to:

transformation.panel@opwdd.ny.gov

Please contribute your own individual comment to OPWDD—a link to the official OPWDD document and the email address for comments is above. Comments can be of any length. Be counted, even if all you say is: “Comment period was too short.” The most specific part of the Draft Report is the three page list of recommendations in the Appendix starting on page 17. If you like, you can use the attached spreadsheet to collect your own responses to each of the 50 recommendations. You can email that to OPWDD as your comment. Those who have taken this tool on a “test drive” describe it as a valuable but time-consuming process.

Summary: Disappointed

The Draft Report is disappointing mostly because it is not specific, not measureable. For the most part, there are no policy recommendations. OPWDD states that the next stage is implementation, but there is very little here ready to be implemented. This is deeply disappointing.

Managed care is not the solution

The most troubling part of the document is the emphasis on Managed Care as the path forward for delivery of services to individuals with Developmental Disabilities. Managed Care is a great method for prevention and treatment of medical problems. It does not work for delivering meaningful and fulfilling lives. OPWDD’s stated mission is “*We help people with developmental disabilities live richer lives.*”

Ignorance is not the main problem

Many of the recommendations prescribe education, explanation and outreach. These are inarguably good things to do, but there is far too much emphasis on them. The main problems are bureaucracy, inflexibility, and lack of transparency. Solving those problems requires changes in policy, procedures, services and legislation.

Detailed response to actual recommendations, by Category

Residential. We agree that OPW should continue “providing more than half of available certified residential opportunities to those living at home”. But there were no recommendations to increase the supply and variety of housing for the Developmental Disabilities community. The closest was the recommendation that there be a survey of housing availability, to be followed at some unspecified future date by “warranted” increases in investment.

Employment. We should “start identifying skills...as early as middle school.” Some of us would go much further, and recommend providing community placements and training in workplace readiness in middle school.

Self-Determination. The emphasis should be on flexibility and non-traditional services for the many, rather than continuing the valuable but difficult-to-navigate system of SD which so far has been embraced by less than 3% of the individuals served by OPWDD. There is a suggestion of yet-another survey. Please save the surveys for the population which is not currently served by OPW. Those who are in the system can be contacted thru their quarterly interactions with MSCs, or their daily interactions with staff.

One of the best aspects of Self-Direction is that the budget allows for the purchase big-ticket, non-traditional services, like Summer Camp, one-on-one swim lessons, and main-stream dance lessons. One of the worst aspects is the large administrative burden it imposes, and problems with lack of coverage. Under Self-Direction, too much of a parent's time is taken up serving as "Care Coordinator" and "Backup Direct Service Professional".

Our recommendation to OPW: Figure out how to provide all individuals you serve with the ability to pay for non-traditional services without the overhead of Self-Direction. For example, could just provide each person with spending authority totaling ten thousand dollars per year in support of valued outcomes, to be split across no more than 10 items. Roughly one per month. Why not?

Supporting Staff. We agree that there should be "fair compensation".

Supporting Family. We agree there need to be "creative models for...families who choose to pool resources." But this is not a ready-to-implement policy.

Informing families of how to become "paid family caregivers" is endorsed by some of us. Unfortunately, that is not the recommendation. It calls for education about the existence of changes, and no hint of "how to".

Funding and Performance. See comments about Managed Care below. We endorse transparency, and accountability, but the recommendations are still far too fuzzy, with no way to judge whether they have been implemented. "Regular updates" can mean once a quarter, once a year, or once a decade. Tying payment to performance is a dangerous road to go down. Built into the definition of a lifelong disability is the understanding that people do not recover.

Flexibility and Responsiveness. These are wonderful ideas, but the recommendations provide no specifics, no way to judge whether the goal has been reached.

Care Management and Assessment. We think Managed Care is a poor fit for delivery of services to individuals with Developmental Disabilities.

Managed Care can produce innovative solutions to medical problems, when there is good measurement in place. For example, AARP Bulletin recently reported on a "balance training" program for older adults that produced a 20% reduction in hip and leg fractures. Thus the inexpensive activity of Tai Chi classes results in a dramatic reduction in use of expensive emergency intervention following a fracture. A true "win-win" situation. But in the world of Disability Services, there are very few opportunities for this kind of win-win. The point of care is not to solve problems, but rather to help people have full lives. Most individuals served by OPWDD will continue to need supports at home and in the workplace.

OPWDD does not have in place any of even the most basic measurements that would be used to tell what services are needed. For example, OPWDD has embarked on a one-time survey to supply the legislature with the answer to one of the simplest of questions: Who needs housing? And this answer will be incomplete because of the way the survey was conducted.

Our recommendation to OPW: Create the data systems which routinely collect and report out the basic measures.