

Ralph Warren: Testimony to the Transformation Panel

Ms. Delaney, Mr. Mitchell, and Ms. Bern-Smith OPWDD

Hello I include inline in body of this email my extended testimony for the Public input on the OPWDD Transformation Panel. I include the testimony I submitted in my presentation to the public forum on Long Island on 9-17-2015. I have been informed that public input would be accepted until today 10-10-2015. I will forward this email to NYCFAIR so that they may post my extended testimony to their public website.

I can send you the Word doc version of my extended testimony if you prefer. I have been very stressed with my own medical and OPWDD service problems which are not getting any easier in past few weeks and the version i got in today was very rough.

I do hope that my questions below will be considered and incorporated into OPWDD total response to public comments. I will be submitting a revised version to NY legislators in the next month.

respectfully
Ralph Warren

OPWDD Transformation Panel Public Testimony

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Extended Written Testimony October 10, 2015
PUBLIC TESTIMONY – Presented by Ralph Warren self-advocate

Section 1. Presented in person at Long Island Public Forum 9/17/2015

Hello. My name is Ralph Warren and I receive services from OPWDD with self-direction. I am speaking from the perspective of individuals and families who receive OPWDD services and also from experience and professional and technical knowledge. I will try to maintain a technical way of speaking to maintain focus and avoid the harsher aspects of how changes this year in OPWDD and DOH have already had a harmer impact on me. The only area of good functioning I still have is high verbal abilities in technical areas.

First, years before I obtained these services as an adult while I had private managed care while employed, I was never told a specialist advised evaluation for the diagnosis of the developmental disability that I have. Private managed care in New York should not be the model for Medicaid managed care. I have read through all of the transformation panel minutes, and the discussions on managed care show hiding, disguising or distorting when it comes to key details about managed care for OPWDD. Some key points:

- I get most of my medical care at a Medicaid Medical Home (health home) that now operates under Value Based Payments. My care has there has become worse there this year.
- This in turn created pressure and conflict with my OPWDD Medicaid Service (MSC) provider, and serious failures and misconduct by the MSC provider regarding rewriting my individual service plan (ISP) and the MSC provider not helping me with medical and benefits issues for all of this year. My health and overall functioning have become worse.
- OPWDD has not enforced basic rights and protections with MSC services.
- OPWDD is not enforcing its own regulations on self-direction Fiscal Intermediaries and Support Brokers when it comes to many staffing issues. This places an increasing burden on families and individuals. For some we then can't use our full budgets and this can lead to a downward spiral as managed care payment methods use the prior year service utilization as the base for setting rates of payment.
- There is nothing in the transformation panel meetings that shows:
 - o Useful details on how DOH uses rate setting methods (diagnosis, service utilization and more) and how this will apply to OPWDD
 - o Discussion of the problems that led to a class action lawsuit being filed against DOH last year on several aspects of Medicaid managed care.
 - o There are no quality measures specific to developmental disabilities in the current Value Based Payment contracts, nor any specific plan to do so.
- The distortion and root of the problem with using the promotional slogan "Integrated and Coordinated Care" when it comes to many of us using OPWDD services is simple: There is no medical

professional we can select who is focused on the physiology/biological causes of our problems and who has the power to have the services paid for that we need.

- Specifically to OPWDD leadership, you are delaying and holding back information from us:
 - o On the new assessment tool (CAS).
 - o About quality measures for complex medical conditions related to our disabilities.
 - o About outcome measures for OPWDD services and data that you have that can help families and individuals make decisions in self-direction, data on Support Brokers available to take new cases, and so much more that is withheld.

I am not sure if I will have been able to read through just these simple points today. So consider this submission a bare outline for public comment on the OPWDD Transformation Panel. I will listen carefully to everyone today and take notes and send a more detailed document to you next week for my public comment.

I end with one question: Will you post all public comments from everyone across the state? We need a more complete, open and honest discussion of the facts about managed care and the problems happening this year in OPWDD and DOH programs. We need support for true peer to peer discussion and organizing around these issues. To sum up: We deserve better.

Section 2. Extended Written Testimony sent via email 10/10/2015

First off it is important to note a few broad themes that were covered in the comments of many people who testified at the Long Island Forum on 9/17/2015:

- Families/individuals who get OPWDD services are being divided against each other, and this division flows from partial information or misinformation that comes to us from OPWDD;
- There is increasing disruption in the direct care (direct support staff) workforce and this is happening in traditional agency-based services and self-directed services;
- There is not enough detailed information about OPWDD's plans for managed care being given to families/individuals and this is increasing distrust about many aspects of the service system.

I have waited until the last day possible to submit my extended written testimony because I have been waiting a reply from the Division of Quality Improvement (DQI) about current policies and quality assurance protections for Medicaid Service Coordination and Self-Directed Services. The information has not been forthcoming so I frame my questions and comments without the DQI responses. My questions and comments are based on personal experience, shared discussion among families, individuals and advocates, and from reading various documents from OPWDD (e.g. guidance, policy advisories, etc.) and position statements from provider organizations. I focus my questions and concerns around managed care and how it impacts the Front Door process and self-direction, but my concerns are not limited to these areas. If anything, after speaking to advocates after the Long Island Public Forum on OPWDD Transformation Panel, it is clear that fundamental changes already underway at OPWDD and DOH are driving core problems/disruptions in traditional agency-based and self-directed services for people with developmental disabilities in NY.

I organize my questions and comments along the lines of topics in the Transformation Panel minutes.

I note a Problem Statement and then ask OPWDD staff to respond to Questions. Before starting, I ask that OPWDD present, as part of its responses to public comments, its answers to all of the questions asked by IAC, CPA of NYS, NYSARC, NYSRA, and the Alliance of Long Island Agencies to Ms. Delaney, OPWDD Acting Commissioner in a letter dated July, 20, 2015. In that letter this collection of provider organizations raised important questions about policy changes in prevention and clinical services in Article 16 Clinics. Many of their questions highlight important unresolved issues that can undermine quality of care more generally.

I refer below to Transformation Panel minutes without specific quotes or citations.

Problem Statements and Questions

1. OPWDD states that it has "envisioned a fully integrated benefit package", but it does not clarify what "integration" means in practice. Often the word "integration" is presented to make service system changes sound stronger than the phrase "coordinated care". But really there is nothing in the Panel discussions that make it clear how core OPWDD services (habilitation, family support, etc) would be integrated with medical care in a managed care framework. In the DISCO and OPWDD FIDA models as presented, it is likely that

medical services will remain loosely coordinated, that access to specialty medical services be unduly restricted, and that a primary care clinician would not have “budget authority” to ensure that families/individuals obtain specialist medical care.

Questions:

1A. What will OPWDD do to track access to specialist medical services?

1B. How will OPWDD make this information on access to specialist medical services available to families?

2. DOH’s implementation of DSRPs and valued-based payments this year does not include quality metrics specific to medical problems affecting people with developmental disabilities, and as a result, medical providers have no incentive to provide the primary and specialist medical care that we need. I asked this question to Dr. Pettinger and Ms. Bishop, senior OPWDD administrators, this very question August 4, 2015 at a presentation they did on Long Island about the new crisis service initiatives. Both senior OPWDD staff said that requests had been made to DOH but there appeared to be no movement from DOH to make value-based payments responsive to the needs of people with developmental disabilities.

2A. What requests will OPWDD make to DOH to specifically adjust value-based payment incentives/penalties?

2B. How and when will OPWDD communicate to families/individuals the results of your discussions with DOH with regard to value-based payment methods and contracting?

3. Future Waiver Submissions – It is of great concern that the Panel minutes skip over any real discussion of changes in 1915 or 1115 waivers that would combine waivers affecting the OPWDD population with other Medicaid waiver populations in New York State. People with developmental disabilities have unique needs and the DOH Medicaid redesign efforts (with the DSRP contracting being one facet) are already having a negative impact of actual service delivery to people with developmental disabilities. The Panel minutes are extremely vague where the topic of future waiver modifications was discussed. There was no mention of timelines and for that matter no mention of OPWDD managed care implementation timelines that have been published on the DOH website. Clearly families/individuals need more detailed information here.

3A. What specific proposals have the governor’s office, DOH or other executive agencies presented to OPWDD leadership about the next step in combining waivers across populations?

4. Care Coordination – There was virtually no information presented in Panel minutes about this crucial topic. Care Coordination, as has been presented previously by senior OPWDD staff, is what will replace Medicaid Service Coordination as Managed Care begins. This could happen as early as January 2016. Yet OPWDD has kept families/individuals almost completely in the dark when it comes to how Medicaid Service Coordination will be modified, eliminated or replaced by “care coordination” in managed care. There are many areas under either the DISCO or FIDA models where the role of a care coordinator may face a conflict of interest between and individual participant and their employer (the Managed Care Organization).

4A. What will happen to people’s Medicaid Service Coordination who refuse to participate in managed care?

4B. When and how will OPWDD inform families/individuals about changes to Medicaid Service Coordination?

4C. Will “Care Coordinators” remain responsible for assisting with benefits and ensuring continuity in Medicaid eligibility and benefits?

4D. How will you handle conflicts of interest noted above?

4E. If an individual chooses managed care will they surrender their recourse to the current OPWDD grievance regulations regarding Medicaid Service Coordination (ISPs, and services) and waiver services?

5. Information Technology (IT) – The discussion of information technology is sparse, weak and not useful. There is nothing in the Panel discussion minutes that indicates the current flaws in the roll out of electronic health records in DSRP contracted provider networks or in the managed long-term care (MLTC) plans for all other MLTC populations. Perhaps I missed it but I saw no specifics presented to the panel about OPWDD’s contracting for an OPWDD-wide electronic health record infrastructure. There are too many problems with the current electronic health record roll out to go into here and I will address this in a separate letter. To start here are a few specific questions:

5A. How will OPWDD ensure that individuals/families can get errors in their electronic health records (across any and all MCOs and contracted vendors/providers)?

5B. How will managed care processes impact the writing of Individual Service Plans (ISPs and habilitation plans), the ISP approval process by individuals, and the due process protections regarding the ISP?

6. Coordinated Assessment System (CAS) – The Coordinated Assessment System has been under development and testing for year(s) now. The CAS when it is implemented is supposed to replace the DDP2 and will be used to determine resources available to an individual/family and to determine significant statements of need that will influence service planning opportunities. It is extremely concerning that any real information of the development of the CAS is being withheld from families/individuals until after the start of enrollment into managed care. There is no indication in the Panel discussions that families/individuals will get any meaningful input into the final version of the CAS or its use before managed care is implemented.

6A. What is the status of the CAS and when will pilot demonstration findings be disclosed to the public?

6B. What are the specific components of the CAS that relate to assessing comorbid medical conditions that impact specific subgroups of people with developmental disabilities?

6C. What are the roles of families/individuals in this new CAS process?

6D. What are the due process rights protections applicable to disputing components of the CAS process? In other words, if a family challenges the data or the conclusions of a section of the CAS what recourse to they have to corrective action?

7. Quality Measures Related to Managed Care – The presentation of steps OPWDD will take to ensure proper oversight of managed care and the development and enforcement of quality measures for all programs and services is both vague and lacking in several respects. OPWDD cites the National Council on Disability as a source for developing quality measures but there is no indication in the Panel minutes as to what this really means. It actually gets somewhat absurd in this section of the Panel minutes when we read something like (to quote) “The DISCO is focused on quality management”. Really this sounds like magical thinking or not so well thought out blurb for a web ad. Sorry to be so blunt in tone here but the definition and enforcement of quality measures are the first line of defense for individuals/families when it comes to deficient or harmful services. The current Performance Report Cards that OPWDD uses to evaluate Medicaid Service Coordination vendors/programs are very inadequate and misleading. One simple point should suffice here: there is no consistency to evaluation metrics in sampling the number of people served or MSCs evaluated across vendors/programs. It is impossible to compare one vendor to another vendor in OPWDD’s current web published performance reports. Although it is very positive for OPWDD to remain committed to using the Personal Outcome Measures (POMs), there is great opportunity for misuse of this quality measure. If managed care staff administer this qualitative tool then there is good reason to believe the results will be biased. And the POMs will be used on a small sample of participants. The POMs should be supplemented by a comparable simple survey tool that all individuals/families can use as a quality measure that is completed during an annual ISP review.

7A. What will OPWDD do to implement unbiased comprehensive quality measures for all participants during the ISP annual review process?

7B. Will OPWDD develop a set of quality measures that families/individuals can use to make decisions about selecting key staff in self-direction services? Specifically will OPWDD provide data to families on measures such as: support broker’s available hours and a similar measure of availability for each direct support staff (case load capacity), complaints and firings of specific direct support workers, etc. Note as of today there are no quality assurance processes in place for self-directed services.

This is simply a starting point for consideration. I present a bare outline of a few topics with questions to show that the Panel minutes barely scratch the surface of hard issues and hard questions.