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Fwd: Decker public comment on Transformation Panel Draft Report

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Fri, Jan 22, 2016 at 2:32 PM

To: NYC FAIR EXEC COMM <nyc-fair-exec-comm@googlegroups.com>, ny-metro-self-direction-community-of-practice@googlegroups.com

My comments on the Transformation Panel Draft Report, for your enjoyment and reference for your own.

Begin forwarded message:

From: Lynn Decker <lynn.decker363@gmail.com>

Subject: Decker public comment on Transformation Panel Draft Report

Date: January 22, 2016 at 2:30:58 PM EST

To: transformation.panel@opwdd.ny.gov

Comment on OPWDD Transformation Panel Draft Report

Lynn Decker, Member of NYC FAIR (nycfair.org)

January 21, 2016

Summary: Largely predetermined conclusions that ignored key panelist input

The Draft Report is disappointing because it is lacking in substance, detail, data, and accountability. Few items are linked to actual policy actions. OPWDD states that the next stage is implementation, but there is very little here ready to be implemented. This is deeply disappointing and leaves this stakeholder wondering whether this was all political theater to create the appearance of engagement.

No track record of managed care effectiveness for non-medical expenditures

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, when it works as promised, relies on population health patterns to deliver preventive services and reduce future expenditures while improving outcomes. There are no pilots demonstrating that habilitative supports demonstrate similar cost dynamics. People with significant cognitive, sensory, communication or mobility impairment, or behavioral disorders have persistently high needs for support which do not predictably decline over time under specific regimens. And there are no value based outcome measurement established for living a meaningful and fulfilling life. A value based payments regimen in this context is an open opportunity for manipulation and abuse.

On the other hand, investment in technologies to automate accurate and complete service

documentation and billing would be a welcome contribution that might relieve administrative burden to agencies and practitioners of self-direction, and this is another thing managed care companies are known for. But this is not the emphasis of the current report.

Correcting public ignorance and social bias against toward disability is a good thing, but is not the primary task of an I/DD services administration

Many of the recommendations prescribe education, explanation and outreach. Embracing the social construction of disability is a positive cultural shift for OPWDD, but it cannot be used as a cover to downplay impairments and the support needs they create. The main problems are bureaucracy, inflexibility, and lack of transparency. Solving those problems requires changes in policy, procedures, services and legislation. Overall, the reliance on healthcare financing drives a standard of service documentation, audit-ability and oversight that may be appropriate to health care services but is wildly out of proportion to the whole of life and fails to deliver on quality improvement. OPWDD should do its first job well before expanding ambitions.

Transparency (macro), redacted data reporting, and transparency (micro)

The OPWDD budget, like much of the NY State Budget, is reported in buckets so large and unspecified that citizens cannot remotely estimate the program level or per capita expense. And this opacity, while by no means unique to this area of the state budget, makes it basically impossible for the legislature and stakeholders to determine whether funding is adequate.

De-identified population, expenditure, setting, and trend data by region and state operated vs. voluntary agency provision was regularly reported in annual strategic plan updates presented for public review annually up through approximately 2010, but is no longer made available. It is not possible for advocates and elected officials to assess the adequacy and effectiveness of programs without such data.

Finally, transparency of expenditures at the individual level is currently non-existent. Medicare sends out quarterly Summary Notices to enrollees of services billed & paid on their behalf. The end users of OPWDD services, the participants and their families, should receive similar statements. This practice would quickly pay for itself in detecting fraud and waste, and would provide program constituents with essential information about the programs they utilize.

Selected responses to actual recommendations, by Category

Residential. I agree that OPWDD should continue “providing more than half of available certified residential opportunities to those living at home”. But not quantities are given to inform the reader or enable comparisons.

And the recommendation on ICF residents is resounding in what it leaves out: ICF settings are being phased out and no mention of a means to choose to maintain current placement is made,

because it doesn't exist. While some ICF's may merely be re-titled as IRAs, many high needs people are going to experience drastic changes in their living arrangements.

Employment & Life in the Community. "Explore on-demand transportation, e.g. linking to existing services like Uber..." is a particularly troubling statement, given the recent campaign against Uber's unwillingness to provide 'accessible' vehicles and refusal to serve patrons with service animals.

Many of OPWDD's participants have a mix of sensory, communication, mobility, or cognitive impairments or behavioral challenges that demand modified transportation services, so putting the focus on a service category that rather famously lacks accommodations for those needs is uninformed at best. And very importantly, there is no transportation marketplace where 'on-demand' services are sustainably priced for the typical incomes & budgets of persons with I/DD. Finally, this recommendation is released at the same time that new regulations from the Department of Health propose to require all contracted program transportation to comply with standards for medical transportation services such as ambulettes, which implies an increased regulation of transportation service rather than a shift toward consumer-grade offerings. This is laughable in its inconsistency.

Instead, recognize that different areas of the state and different participants have varied needs for customization, routes, and frequency of service, and that some folks require a companion for safe travel as well as a driver. Just be person-centered, dammit.

Self-Determination. One major structural weakness in Self-Direction is that the FI agencies, the employer of record for tax and labor standards matters, is decentralized even though all the dollars paid for this work pass through one funding stream, the HCBS waiver. Sixty or more agencies statewide are FI's for almost 3000 individual budgets, and the higher cost of fringe benefits for many small employers erodes the buying power of those budgets. Also, the failure of OPWDD to invest in uniform technology for service documentation pushes that expense down to the FI agencies as well.

Finally, the new billing and documentation regulations for SD requires substantial fronting of expenses other than payroll by the household of the participant. Participants and their families are the people least able to float substantial expenses, particularly as the roil of regulatory changes make repayment uncertain. Many families engaged in SD are feeling hung out to dry.

Supporting Staff. "Urge fair compensation for DSP's and other staff..." The fact that this professionally advised statement of agency priorities cannot use a verb stronger than 'urge' is a powerful statement of the Acting Commissioner's lack of budget authority.

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”. The existing opportunity for family members to become paid caregivers is specific to the CDPAP program in the Department of Health, not in the HCBS waiver’s near equivalent of community habilitation.

Funding and Performance. See comments about Managed Care below. I’m a big fan of transparency as a vehicle for accountability, but the recommendations do not specify frequency, precision, or level of data reporting.

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. Managed Care is a poor fit for delivery of non-medical services to individuals with Developmental Disabilities. To be eligible for OPWDD services, people must have qualifying diagnoses that create substantial impairments that are expected to be lifelong.

Therefore, the objective of supports is not to erase impairments, but rather to help people have full lives in spite of functional limitations. Most individuals served by OPWDD will always 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, among those who requested housing in the past, still needs housing? And this answer will be incomplete because of the spectacularly inadequate the survey was conducted.

Much of OPWDD’s practice around data reporting has been an effort to avoid the appearance of a ‘waiting list’ for services. And that’s an understandable political reality. But no responsible organization can fail to assess current and forecast future unmet needs.

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