

## **TESTIMONY: TRANSFORMATION PANEL, 9/17/15**

My name is Lynn Decker, and like other members of NYC FAIR, I want to share what keeps me up at night. We're going to submit written comments on all the Transformation Panel's agenda items, but I'm going to put a face on one concern – staffed residential development and the lack of public data necessary to have informed conversations about that.

I am the mother of two of an estimated 30,000 New Yorkers with autism who will reach adulthood in the next decade and require a wide range of supports to lead healthful and productive lives.

My two are among those with severe impairments who'll require 24/7 supports at home and in the community, and structured environments with staff supervision to work, volunteer, or exercise productively and safely. For my sons and their closest peers (with and without Autism), the current policy mandate for total integration favors a largely optical social inclusion rather than advancing a balance of integration with supports that address specialized needs.

Public attitudes about disability are not the sole or even the largest obstacle to inclusion for some you serve, as failing to meet my guy's particular needs can lead to behaviors that put them at risk for injury to self and others, property damage, and encounters with law enforcement. For some, absence of care is itself neglect.

So the biggest thing that keeps me up at night is worry that one of my sons will elope from care and drown, be hit by a car, or die of exposure. Or next, that a socially inappropriate act in the community will lead to placement in the Correctional system. Or, that an underfunded, short-staffed program will achieve 'safety' through excessive medication. Or that inadequate exercise & poor nutritional decision-making will lead to obesity and chronic illness.

I read the newspaper and the research, and these are all evidence-based fears, some pieces of which we've already experienced.

So what I want this panel to recommend is this:

For the last several years, there have been nonstop change initiatives touching almost every part of OPWDD operations.

But what we haven't seen in quite a while are comprehensive descriptive statistics on settings, supports, and persons served or expenditures by category, demographics, etc. Everyone knows OPWDD knows, or can know, such information.

It's not even public how many residential school age-out and out-of-state persons are considered Priority 1 for residential development in a given year, though again this must be known. One can't begin to assess the adequacy of the 'new programs' portion of the state budget without that information. And the fact

that the legislature specifically allocated a million dollars to verify the broader Residential Request List speaks for itself.

Government cannot plan and citizens cannot advocate for sufficient resources or efficient service delivery without data. We're like the parable of the blind men surrounding an elephant, and the result is a constituency full of suspicion, resentment, and distrust.

Please recommend the development & release of meaningful statistical reports to enable informed discussion and make it possible for our legislators to know whether they are meeting their obligations to this constituency under Article 17 of the NY State Constitution, the Americans with Disabilities Act, the Olmstead Decision, and their consciences.

And consider borrowing a practice from Medicare, which sends out quarterly Summary Notices to enrollees of services billed on their behalf. Adopting this practice would introduce needed transparency at the individual level while honoring privacy. Your organization's end users, the participants and their families, can't see what's being spent on their supports, so can't assist you to correct inaccuracies or detect fraud, let alone be informed of the cost of supports they or their family members receive.

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