

**ASSEMBLY STANDING COMMITTEE ON MENTAL HEALTH AND
DEVELOPMENTAL DISABILITIES**
Testimony by Elly Rufer
October 20, 2015

Hello,

I am Elly Rufer. I am the mother of Katie, a young woman who has complex needs. I became an advocate to be sure she got the services that would allow her to develop to her fullest potential. Now I see that the services that helped us, and continue to make a difference in our lives are disappearing. So it is time to get back in the trenches. I got together with Meri Krassner, another mother, to create a new family advocacy organization that would represent all no matter which provider a family is involved with or if they aren't involved with one at all. Our creation is: NYC FAIR, NYC Family Advocacy and Information Resource. NYC FAIR has grown very rapidly because there are many, many, many other families who find themselves having to protect the services that they and their loved ones depend upon.

I am here to let the Committee know what our experiences with OPWDD have been; I speak for myself, Meri, our Executive Committee and other parents.

We have been following the Transformation Panel's work and in addition have spoken with many Panel members.

I have read all of the Transformation Panel's meeting minutes. I have thought long and hard about how to narrow down my topic, but I cannot speak about just one thing.

I am excited to think that the "system" is trying to find creative ways to administer services to Katie. I know that given time and money for development that there is the potential for meaningful, cost-effective change for the better.

However, when change in EVERY area of concern is all it once, it is hard not to be concerned - the changes need to be done in **Incremental Steps** to achieve the desired Goal.

Let's take Residential services for instance...It is ludicrous to think that our family members can move from a 24/7 residential setting to something without that level of supervision without first grappling with the lack of affordable housing in NY. Only then can we consider the issue of sufficient staffing to help people learn how to be alone, and unsupervised for any period of time.....forget about all day.

Additionally for parents who are aging, and who still have their children at home, like Meri, this committee must understand that the idea of residential placement is now a mirage, it is virtually non existent.

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Again, the cost of real estate must be taken into account along with the level of need. At present a crisis is the only avenue to residential placement. Families should be able to **plan** the transition to be the least disruptive for the family – our children are hypersensitive to change and cannot face the loss of a parent together with the loss of a home without tremendous psychological damage. That is the fear that Meri, and others like her live with, and not without reason. Just this last spring a 53-year-old man from Brooklyn ended up in Jacobi Hospital, a city run hospital, for 8 months. He was there because there was nowhere else for him to go after his mother passed away from a long struggle with cancer. There is nothing out there, not now and not in the future either, only beds that become available because the previous inhabitant has left or passed away.

To address the failure of OPWDD to have a realistic plan to deal with residential placement the Legislature asked OPWDD to develop a list of people who will need residential options in the future so that there is accurate information for proper planning. At first OPWDD decided to only survey those on the original New York Cares list, a list that was abandoned years ago.

Of course over time things change - people move, they change their phone numbers so that list is only a suggestion of who is out there. It didn't include those who were not on the original list – and we know many many people who have gone to OPWDD since then asking for residential placement, and many had not. This process is not functioning either. NYC FAIR is collecting stories of what has gone wrong. We can and will elaborate on those difficulties in the near future. A member of our Executive Committee, Chaundra Chauhan, who knew the procedure, had to try many times to get on this list.

And there is talk that some residences that are fully functional are being threatened with closing based on what is, to us, an arbitrary number of people permitted to live together, and a misunderstanding of what “in the community” means.

Moving people without having somewhere appropriate for them to go is far too reminiscent of the time New York State emptied the institutions for the Mentally Ill. It sounded lovely - move them to smaller, more appropriate settings in the community. Now, many of our communities are struggling with a population of desperate people inadequately clothed, fed or sheltered, without even the semblance of appropriate programming. It is heartbreaking.

This cannot and will not be allowed to happen to our loved ones.

The other problem is that EVERYTHING is TRANSFORMING at ONCE.

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Providers have been mandated to switch from a fee-based delivery system to a needs-based system...while dealing with Rate-rationalization that has reduced the funding necessary to run their programs properly and safely. How are they going to be able to execute change?

At the same time providers are also being required to implement Workforce Transformation, the Code of Ethics and Core Competencies **without** the benefit of the necessary financial support and time it takes to initiate new programs.

We understand that this transformation is a result of mandates from both New York State and the Federal Government. These plans have been developed by people who seem to have their eyes **only** on the \$\$ sign. They do not recognize or take into account who my daughter, Katie, and her friends really are, what they can and cannot do – that they are human beings who deserve to have a life, as the Olmstead decision mandates.

We have not given up on what our loved ones are able to accomplish. We simply know from bitter and tear-filled experience that wishing or expecting things to be a certain way does not make it so.

OPWDD was created as a separate agency because at the time New York State recognized that people with Intellectual and Developmental Disabilities are different –It isn't a medical issue with the expectation of a cure, my daughter isn't "sick", she is a person who needs help with many activities that the rest of us can do with ease and take for granted. She will need some sort of help until she dies.

The OPWDD service system was built as collaboration between parents, government and agencies. Parents knew what their children needed, government listened and together they created a service system of voluntary agencies that worked well for decades. Parents are still the best resource for understanding what is going on - they know their family members needs in ways Government never will.

I implore all - families, self-advocates, voluntary providers, NYS representatives, the Governor & the legislature ...please do not let OPWDD be swallowed up by an agency that does not understand the population they will be serving. ID/DD is not equivalent to anything else – and “outcomes” are limited by the realities of the people being served.

Why this is happening is irrelevant. Whatever the reason, it doesn't matter, our services are being shrunk to the point of extinction. What I see is that my daughter and others are being punished for things that they had nothing to do

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with and did not benefit from. The families of OPWDD did nothing more than look out for their family members. They are innocent of any wrongdoing but the punishment is being meted out to us nonetheless.

We...Moms, Dads and siblings are worried and very frightened as outlined in "Services for People with Disabilities: Terrified About the Future" by Jim Karpe for NYC FAIR. Years ago, we would whisper to each other about our innermost fears. Now we are stating them out loud for you all to hear- we fear for their lives. We are so worried about the future of our children.

You know WE will do everything possible to influence you to take whatever steps are necessary to keep us from that dark thought. OPWDD and New York State have a proud history of creating one of the best service systems in the country. Destroying this system is a disaster for families. We see OPWDD becoming a shadow of what it once was, an agency that is no longer able to look out for its constituency. Their failings may have their origins in decisions made by others but this can be corrected with enough time, money and respect for the work they did and can do for our most vulnerable citizens.

Please direct OPWDD to approach making changes in incremental steps, with financial support and time to implement them to achieve a more creative, more cost-effective delivery system that will insure the health and safety of all people with Intellectual and Developmental Disabilities.

Thank you for the opportunity to address this committee.