

Everything is changing at once

Testimony for January 14th, 2016

Good Evening Senator Perkins and Assemblymember Rodriguez,

Thank you for giving us the opportunity to speak to you directly.

I am Elly Rufer. I am the mother of Katie, a young woman who has complex medical and support 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 help us, are disappearing. Given the current circumstances, it is time to get back in the trenches.

I am here today to protect my daughter Katie.

OPWDD wants 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.

That's exciting.

However, what is incredibly frightening is that change in **EVERY** area of concern is coming all at once. Every new initiative seems to be of the all or nothing variety. Programs are being dismantled without other services in place. Change needs to be done in **Incremental Steps** to make sense and keep Katie & others safe.

For us, we are dealing with the fact that the lease on my daughter's residence has not been renewed and the agency has been looking for a new place for them to live for over 5 years but the state's housing allowance rate is from 2007. *They need a reality check on the cost of housing in NYC.* So far there is nowhere for them to go.

Additionally, parents are aging, and there are those who still have their children at home. **The NYS legislature must understand that for them the idea of residential placement is now a mirage, it is virtually non-existent.**

Again, the cost of real estate must be taken into account along with the level of need. At present the only avenue to residential placement is a crisis. 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 and the loss of a home without tremendous psychological damage. That is the fear families live with, and not without reason. There is nothing out there, not now and not in the future either, the only beds that become available are because someone dies or moves away.

Now there is talk that some residences are being threatened with closing based on what is, to us, an arbitrary number of people permitted to live together,

dictated by CMS, 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, except they never built those smaller settings. 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.

OPWDD was created as a separate agency because at the time New York State recognized that people with Intellectual and Developmental Disabilities ARE different –They don’t have 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.

Please do not let OPWDD be swallowed up by an agency, the Department of Health, 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.

We Moms, Dads and siblings are worried and very frightened. 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 that worried about the future of our children. *Where ill they go? How will they providers who take care of them survive? With horror, we do think that perhaps it is better if our loved ones pre-decease us.*

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 the best service systems in the country.

Please direct the legislature, the Governor and OPWDD to approach making changes in incremental steps, with financial support and time to implement those changes 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. Elly Rufer, Parent, Advocate