

Comments for Transformation Panel on September 17th, 2015

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Transforming Everything

Good Afternoon,

I am Elly Rufer, I am the Mother of Katie...who has complex needs...so I have become an advocate, & co-founder of NYC FAIR.

We are here to let the Transformation Panel know our thoughts on the issues they are working on.

I have read the entire Panel's meeting minutes that are posted ...but not all are up. I have thought long and hard about how to narrow down my topic, but I cannot speak about just one thing.

I am actually 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 powerful, cost-effective change CAN happen.

However, it is clear that what is needed when the Panel is considering change in EVERY area of concern is that it is done in **Incremental Steps** to achieve the desired Goal.

Take Residential services for instance...It is absolutely impossible to think that our family members can move from a 24/7 residential setting to anything less supervised without first grappling with the lack of affordable housing in NY and only then can we consider the issue of staffing sufficient to help people learn how to be alone..unsupervised.. for any period of time.....forget about all day.

& EVERYTHING is TRANSFORMING at ONCE.

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, in most cases, the money necessary to execute change.

All this while providers are required to implement the Workforce Transformation, the Code of Ethics and the Core Competencies without the benefit of incremental financial adjustments to initiate new programs.

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All this transformation comes from many, many levels of government ...NYS and Federal too...from people who seem to have their eyes only on the \$\$ sign. They do not comprehend that Katie and her friends have a range of issues.

OPWDD was created because people with Intellectual and Developmental Disabilities are different – there is no cure – there is no rehab – It isn't a medical issue, my daughter isn't "sick", she is a person who needs help with many activities that we take for granted and she will need some sort of help until she dies.

The OPWDD service system was built as a collaboration between parents, government and agencies. Parents knew what their children needed and government listened and together they created a service system 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 any agency representing people with different issues.

It is irrelevant why this is happening, ...why our services are being shrunk to the point of extinction, whatever the reason, the result is that my daughter is being punished for deeds that she had nothing to do with...We, all families, are innocent of any wrong doings – Don't punish us.

Give us incremental steps, financial support and time to implement change 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.