

Hello, and thank you for taking the time to read my comments!

I attended the Transformation Panel meeting in Albany on Tuesday evening, and I have to say that I wish I had been able to attend more of them. I also wish that I had prepared my own comments for the evening, but I'm glad that you have made yourselves available for additional comments through email.

My son has autism, and I'm sure I don't have to tell you how devastating it is to hear that your child will never have what is known as a "normal" life. He will never date, never get married, never drive, never vote, never....well, you get the idea. I think that one of the most damaging things that has ever happened to the "A" population is the inclusion of "higher functioning" and "Asperger's" into the definition of the autism spectrum. Unfortunately, too many people have gotten it into their heads that ALL people on the spectrum can be "cured", and those who still need round the clock care MUST have been raised by parents who just didn't try hard enough. Those are the people who make me understand what it must have felt like to be called a, "Refrigerator Mother", decades ago.

One of the comments I heard the other night came from a member of the panel. Please forgive me for not remembering his name. I think it would have been helpful if there had been hand-outs available so that we would know how to contact the panel personally. His comment was something I take to heart, having been raised in the days when the horrors of Willowbrook were just coming to light. The comment concerned moving forward from the days on institutional placement to something less restrictive. While I applaud the concept of giving our children more freedom, you must understand that not all of them would be able to survive, if not for the round the clock care they receive. My son is a resident at The Anderson School for Autism in Staatsburg, and while he has made tremendous progress, he will never be able to live on his own, and is slated to go into an IRA shortly. I thank God for Anderson, and for the fact that there is placement available for him in their agency. They are truly one of the best, and I am very grateful to be a part of their "family".

Speaking of Anderson, I was very disheartened to hear that more of my son's "senior" staff will be leaving. Some have said that if the minimum wage is increased and THEY don't see any benefit from it, they have no choice but to move on. Why spend your days working THAT hard when you can get the same pay working retail or flipping burgers? It just doesn't make any sense. Please address that issue, and make it a priority. We need our staff ~ especially our EXPERIENCED staff ~ and MUST find a way to be able to compensate them properly. Additionally, please examine the current practice of paying direct care staff in residential schools LESS than the salary they would receive if they worked with the more "moderate" population in a school district. That is something that has never made sense to anyone, and should be changed as quickly as possible.

One of my other concerns is the fact that, unfortunately, when it comes to OPWDD, the old saying is true. The left hand really DOESN'T seem to know what the right hand is doing. Long Island parents are being told different

information from those of us who live in the Hudson Valley. This cannot continue. Families of children with disabilities have it tough enough without having to wonder if the information they are being given is true, or if it is going to change before the ink is dry on the copious number of forms they have just finished signing.

The most heartbreaking testimony the other night came from the parents who have been waiting years for placement for their children. These families are in crisis, and the idea that one child (adult) has been on a list for SEVENTEEN YEARS is unconscionable and unacceptable.

And what about the middle of the road population? The ones who would do well in an apartment house type setting, with roommates, someone to check in on them, trained medical help on-site, and a 24 hour concierge? I know several individuals who would benefit from a setting like that, as it would give them the freedom they want and deserve, while still preserving the level of supervision and care they NEED.

Closing sheltered workshops? Why? No brick and mortar day habs? Why? Close respite houses to create "emergency" housing? Why? While these things may look good on paper, these changes are crippling our community, and need to be reinstated.

As my friend mentioned at the meeting the other night, it is very disheartening to know that OUR services (along with services for our veterans) are being cut, while more resources are being given to those far less deserving. Those of us who are parents with young adults fought long and hard for services while they were in school districts ~ why take them away when they turn 21? And why give OUR money away to those who have no business taking them in the first place? I would like to leave you with one final thought, and that is, "If you know one person with autism, you know ONE person with autism." Please don't try to paint all of them ~ or ANY of our disabled ~ with a broad brush. Services are NOT "one size, fits all", and each and every one of our children deserves to be treated with respect, to be protected, cared for, and loved. WE will take care of the LOVE ~ it's up to YOU to make sure they get the rest!

Thank you for this opportunity to share my thoughts with you.

Good luck!

Carol Antonoff