

Elyse Braun
elysebraun@mac.com
914-588-1505

Good Afternoon Acting Commissioner Delaney and Panel Members,

Thank you for providing this opportunity to hear from stakeholders about how the service delivery transformation is impacting families around the state. I am speaking today as a long-time DD professional and as a parent of an adult with autism.

While improvements have been made in developing and executing plans; the process itself is still fragmented, takes an inordinate long time and is inconsistent in its implementation. At any information session, be it for families or professionals, the variety of what a plan includes and how it looks is stunning, as is often the level of misinformation. Identifying “where the buck stops” can be equally confusing (all the way to the top).

To my understanding, there is no consumer redress system in place at any level. From the Front Door on, no defined chain of command or policy is available for individuals or families to express dissatisfaction with a service or agency, state or private. It does beg the question, how is OPWDD about “People First” and an “Agent of Change?”

My daughter’s self-direction plan is about to begin its third year. The good news for her- it has afforded her the ability to pursue activities of interest to her.

Significant challenges do continue for many her and many individuals the panel might consider:

1. **Finding and Keeping Community Habilitation Staff (CommHab)**- Many people who have autism (& other DDs) need an external structure and predictable routine to thrive. The CommHab fills this need when an individual is “out in the community.” Part-time, no benefits, limited pay scale, and no colleagues does not promote this position as a career. This is further impeded by the lengthy process to become employed since each Fiscal Intermediary (FI) has their own system that takes two months to complete.
2. **Fiscal Intermediary/Consumer Choice** - Whether the FI meets your needs or not, if you have staff, changing FIs would mean your staff has to get processed all over again (including fingerprinting) leaving you without staff for two months. This functionally

Elyse Braun
elysebraun@mac.com
914-588-1505

leaves the consumer at the mercy of their FI. Equally frustrating is the continual change to the rules regarding reimbursements.

3. Unending Plan Management/Family Responsibility/Financial Reimbursements -

There is a considerable amount of paperwork to be completed and submitted monthly by a family member. (The obvious question - how does this work if there is no family?) Then there is the staff hiring, training and ongoing supervision, which also falls on the family member. Recalling that this isn't a career job, we are locked in a cycle of regularly replacing staff, so the family member's time commitment is constant. The individual (or the family member) is always having to lay out funds for services, which becomes burdensome with limited income in the first place.

Another Catch-22 is individuals can only be reimbursed if they submit receipts timely and on the correct form...yet what qualifies them for their plan is their inability to complete adult daily activities (such as keeping receipts and being organized). This again means the family member is heavily involved to keep the plan functioning. Lastly, the family member must always be ready to step-in as the de facto CommHab.

4. Community Integration - Participating in community activities is a choice any individual can make, and often chooses to be with like-minded folk. Individuals with DD are as likely to choose activities where they can have peer interaction, as anyone else. The challenge here is: can incentives be provided to "typical" businesses and entertainments so they would accommodate individuals with DD peer groups? Additionally where are the outreach strategies to connect individuals with DD and opportunities available in their communities? This applies to daily living activities, leisure and recreation, as well as employment connections.

Brief anecdote:

When the first CommHab quit (school obligations), it took us nine (9) months to hire a new CommHab (only two ever applied, the other wanted to work with children). After she was hired, it took two months for her to be processed (11 months -no CommHab). Ironically the new staff was already working at another agency and had been OPWDD fingerprinted...yet had to go through the entire process again.

Thank you again for this opportunity to express concerns and ask questions regarding what the future hold for adults with DD, their families and their communities.