

Testimony at OPWDD Transformation Agenda Panel Forum

September 17, 2015

My name is Roy Probeyahn. I am a single parent now, with 3 adult sons with Autism and IDD. Roy jr., Mike, & Glenn, all in their 50s, live with me in our natural home environment as they have done from birth to this very day. We lost our Arleen four years ago.

My wife and I advocated over the years since the Agency was created for as broad a continuum of services as possible for our sons and their peers. We were part of the initial Medicaid Waiver team, which broadened service choices to what we have today. eg. IRAs, ISS, Day Hab, SEMP, Day Hab WW, as well as, maintaining Day Treatment and Workshops as needed, and more recently SD (Self Directed Services).

Under the Transformation Agenda, the Agency is reversing that process by limiting choices. Firstly, by ceasing IRA development for folks living at home. How can we start again to relieve the onerous burden this places on families, particularly those with loved ones having the greatest needs; the medically frail, who have Autism especially with challenging behaviors, or otherwise profound or severe IDD (intellectual and/or developmental disability). Also those in a fragile family circumstance where the individual is best served in one. We have 120 Priority One individuals waiting here for one.

Also by limiting Day Hab. development, which is needed to best serve those with the greatest needs. This virtually forces the utilization of Com. Hab. or SD on all of those we serve regardless of real need. How do we stop making existing Day Habs larger and larger, into congregate care facilities by any other name, to avoid development costs.

Closing down workshops is cruel and inhuman, it destroys the worker's social bonds with friends, in many cases decades long. They deserve the choice to stay or go.

Simultaneously, while this transition to the new agenda takes place, there are no additional family support monies to assist families to avoid complete breakdown,. No new initiatives are being developed. NMSC, Respite and Crisis services are critical needs here.

How can we make the Front Door initiative work better? Parents are told all that's necessary is a phone call for assessment and placement. No agency ever decided on placement and appropriate services based on needs, over the phone, ever ! This needs to be a face to face meeting. The Agency is admittedly marketing SD as the first choice. All services should be offered and explained in detail to the individual and family. Only then is informed choice possible. Follow up is critical to avoid folks falling off the radar.

My family had the first SD type program, under OPTS and we always used an agency for staffing and administrative folderol. We needed to focus our energy on taking care of our family. As I said earlier, SD is not for everyone and it is simply wrong for the Agency to be marketing it to everyone as a be all and end all ! It is wrong to be paying DSPs in SD almost double the pay of DSPs serving the folks with the greatest need. It may attract more workers, to staff the surge in SD services; but shrinks the available workforce for those with the greater needs. The direct care workforce here on L.I. is a zero sum game. Fair is fair!

Job One for the Agency used to be the safety and security of our most vulnerable yet differently abled citizens using PCP (Person Centered Planning) principles. The Agency has lost this vision. Now, forcing families into an often untenable position of accepting less than adequate services or supports either at home or in a day setting regardless of their loved one's needs.

We are headed in the wrong direction. More choices are needed, not less, so that the Agency can truly provide PCP, as well as adequate supports for our loved ones, who are the way they are through no fault of their own.

How can we change the Agency plan to develop DISCOS. DISCOS are a poorly conceived additional layer of bureaucracy. The Discos must NOT use revenues presently being used to serve our folks to support the costs of their operation. The benefit they create would have to be greater than the cost of their operation before any additional revenues to provide service are realized. Any such surplus must be reinvested in improved services, particularly development of IRAs, again, and smaller site based Day Habs.

It is ironic, when the federal government under the Affordable Health Care Act is moving to eliminate the Insurance companies as a middle man and provide direct protection to Americans, this DISCO proposal creates another layer of bureaucracy in the misguided idea it will 'save money' and result in more services with less dollars. If we must use an Insurance Company model, pay for it, just as in Workers Compensation, with state monies.

Please don't misunderstand, I am in favor of offering services in the community in the least restrictive environment. We fought for the closure of the Long Island institution back in 1993. I opposed the development of large ICF units here to replace them back then. I am in favor of ISS programs, and the new Employment initiative to better support our folks in community life and real jobs. I favor of ceasing of new entries into Workshops. I favored every change in day services similarly when their abilities allow for that. My own sons are in Day Hab and Community Hab.

We do need to move to less restrictive residential and day services or work settings, at something less than breakneck speed, but with a rationale to support those individuals with the greater needs and their families; that provides safety and security for our loved ones, in the meantime, and through the transition itself. We need to do better lives depend on it.

As Hubert Humphrey has said;

“The moral test of government is how it treats those who are in the dawn of life, the children, those who are in the twilight of life, the aged, & those in the shadows of life, the sick, the needy, the disabled.”

Thank you,
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