

Services for People With Disabilities: Terrified about the future

Report from the OPWDD Transformation Panel Forums

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As parents of adult children with disabilities, we hear beautiful words of a future with a wide range of individualized services. Meanwhile the actual system in place today continues to disintegrate before our eyes. Programs and supports have been discontinued before alternatives have been developed. The negative impacts we see are the result of poor planning or lack of planning. Or perhaps there is an evil plan, but most likely our adult children are the victims of incompetence. The distinction does not matter to those individuals whose lives have been damaged by the gap between words and reality.

In Transformation Panel forums on Long Island and in Manhattan on September 17th, dozens of parents and self-advocates testified about the real obstacles to care they are facing. Our population is so diverse, with a wide range of issues and challenges. Yet over and over we heard the same thing from those different perspectives: The system has stopped working, is un-raveling, has let us down, has abandoned us. There is no monitoring, and there is no place to voice our dissatisfaction.

We also heard from OPWDD Acting Commissioner Kerry Delaney at the forums. We heard Ms. Delaney acknowledge the need for transparency, but we continue to get very little data. We heard acknowledgement that "one-size does not fit all", but we continue to have policies which shut down the "fitting" options for the most fragile. We heard that the transformation is "not about taking away services, instead about responding to actual needs and being sustainable." But meanwhile we watch the dismantling of the supports which were in place. Individuals are getting pulled out of sheltered workshops where they feel valued and needed, and are instead "out in the community"—walking aimlessly around a mall, losing hope and regressing. Other individuals are losing their homes of 20 or 30 years, since those homes are now alleged to be harmful "institutions". And those individuals capable of greater independence find that the Self-Directed programs of OPWDD have thickets of restrictions and forests of paper work. The promise of Self-Direction was "you control your own budgets." The reality is that we can spend money only within narrow, non-overlapping categories. It's like the choice offered by the Model-T Ford: "You can have any color you want, as long as it's black."

People With Disabilities are getting forced out of options which were working—which did fit. No one should be limited to sheltered workshops as their only option for activity. But neither should anyone be forced out of a sheltered workshop that they treasure and which works for them. Our actual needs are the same as every one else—housing, transportation, education, jobs, friends. A full and meaningful life.

The fears, the concerns, and the stories were the same on Long Island and in New York City. I'm confident they are the same in Upstate NY as well. Ronnie, a plain-spoken self-advocate in Manhattan, captured the spirit of us all with his simple message to OPWDD: "You are not doing your job."

This situation is not the fault of Olmstead. That landmark Supreme Court decision has at its heart the right of the individual to choose the level of community integration they desire. The fundamental issue instead is lack of courage. For decades, New York State siphoned Medicaid funds to help balance the State budget.

(See www.nytimes.com/2012/10/24/nyregion/new-yorks-medicaid-program-is-at-the-mercy-of-washington.html)

That has ended, and in the aftermath:

- Federal bureaucrats are punishing NYS for past fiscal sins, as the federal Centers for Medicare & Medicaid Services (CMS) puts in place regulations that restrict choice,
- State officials have abandoned OPW, now that it is no longer a profit center,
- With no political backing to fight for the individuals who need services, the Office for People With Developmental Disabilities (OPWDD) has become the Office for CMS Compliance.

Fundamentally, OPWDD needs to start advocating for People With Disabilities. Has to stop falling over themselves in their rush to comply with every CMS edict. Sadly, when they fall down, it is our kids who get bruised. OPWDD needs to stop adhering to CMS regulations which damage fragile individuals. And they need to stop going beyond those regulations! New York State is putting in place policies and procedures which go far beyond what is required by CMS.

It comes down to us: Parents and self-advocates. Our state officials must support our population, and must support OPWDD-- and if needed, pressure OPWDD. The appropriate response to many of the CMS regulations is not "Yes sir", but "No way!" Tell your legislator, tell the governor, and tell OPWDD itself, that we need to put People back into the center of the process. **Say no to serving CMS, and say yes to serving People.**