

## **New York State Report - June, 2021**

By Hugo Dwyer

As a resident of New York City, but not having a family member in the DD System in New York State, my exposure to the challenges met by families in the state are observational, not personal. There are plenty of families that could paint a very different picture, based on their experience.

The Acting Commissioner of NYS Office for People With Developmental Disabilities (OPWDD) is Dr. Ted Kastner. Dr. Kastner has experience in both the public and private sector, ICF and group home, and has worked with Kevin Walsh contributing papers for VOR showing cost comparisons between ICF and HCBS settings and dispelling some of the claims that everything costs less in “the community”. Dr. Kastner is in the unenviable position of trying to do the right thing in a system that has never been properly funded or governed and has a record of having failed many of those who have relied on its services, dating back to, infamously, the Willowbrook State School on Staten Island.

NYS got rid of its public ICFs years ago, and replaced them with Individualized Residential Alternatives (IRAs), which essentially allowed the state to convert ICFs to HCBS services. Many IRAs are large congregate settings, housing up to 14 residents, though some have been reported to actually house more.

Last year, New York State was totally unprepared for the COVID-19 pandemic. We received little support from the federal government, and did not have sufficient hospital beds, PPE, or personnel to handle such a large scale medical emergency. Governor Cuomo appeared daily on television, trying to assure the public that he would help get the situation under control.

Unfortunately for elderly people in nursing homes, and, as we later found out, for people with I/DD in group homes, Governor Cuomo failed. New York had too few hospital beds available, so people who were no longer critical were sent back to their group homes or nursing homes while they were still contagious, affecting everyone else in the facility. COVID spread among residents and staff, and since many staff worked at multiple facilities, it spread further outside of the affected area. Much of this had been covered up until earlier this year.

On a brighter note, VOR’s Debbi Napolitano has been working for years on a bill in the state legislature to increase coverage for Applied Behavior Analysis (ABA), a therapeutic program proven successful for many people with severe autism with aggressive or self-injurious behaviors. The legislators had previously passed a law that required insurance companies only to pay for ABA when individuals had a diagnosis of autism. Debbi, an ABA practitioner and trainer, was determined to extend the law to force insurance companies to cover people with other intellectual disabilities, including Cerebral Palsy and Down Syndrome. The insurance companies fought hard to prevent this bill from passing. Debbi knew that my member of the State Assembly was the head of the committee for this bill in the assembly, and the state senator from my district was another key vote in that chamber. Since I do participate in local politics, and both of these people knew vaguely who I was, or at least recognized my face from larger gatherings, I was able to get them to agree to sign on to the bill, which did pass this year.

I take no credit for this. It was Debbi who pushed this, and who pushed me. I don’t even take credit for having swayed either vote, or having brought it to their attention. I do know that this would not have become law without Debbi, and that thousands of people will receive therapeutic services that they would not have previously been able to receive.