

Testimony at New York State Legislative Hearing convened by The Honorable Bill Perkins and The Honorable Robert J. Rodriguez on January 14, 2016.

Testimony by Stacy E. Osborne, Esq., 86 Central Parkway, Mount Vernon, NY 10552.

Good Evening Senator Perkins and Assemblyman Rodriguez,

My name is Stacy Osborne and I am the older sibling of a developmentally disabled individual. My brother lives with our mother and I at home and is receiving day habilitation services as well as some respite services. I am also a board member of Arc of Westchester, a non-profit that provides services, including 24-hour residential care, to the developmentally disabled, and a board member of NYSARC which is the statewide agency overseeing the local "ARCs." I am also a board member of GROW, which is a non-profit that advocates for the developmentally disabled. My remarks today are my own personal opinions and do not reflect the aforementioned organizations.

My purpose here today is to advocate for policies and services that allow those individuals with developmental disabilities to participate as fully as possible in the larger community. I would like to focus herein on residential supports and services and leave you with a message about the centrality of residential services to the care and well-being of our loved ones.

When we talk about residential services it is important to understand that RESIDENTIAL SERVICES ARE MORE THAN HOUSING. This is a frequent source of confusion and we have seen it reflected in the deliberations of OPWDD's Transformation Panel and in some of the policies coming out of the Department of Health.

What do I mean when we say RESIDENTIAL SERVICES ARE MORE THAN JUST HOUSING. Well first let us define the special status of the developmentally disabled in the context of the Department of Health. Most services you oversee are aimed at rehabilitation. That is the outcomes are measured by how well the system performs in returning the individual to the state of health they were in before they entered the system.

The system that serves the developmentally disabled is fundamentally different in that its purpose is HABILITATION. As defined by the federal government habilitation means "Health care services that help you keep, learn, or improve skills and functioning for daily living." For the most part our loved ones have conditions that cannot be cured by current medical treatment. Therefore the purpose of all the services we advocate for is to allow the developmentally disabled to participate as fully as possible in our communities.

Residential services must be seen through this habilitative prism. Unlike the rehabilitative system where a person goes to a facility to obtain treatment services and then be discharged; in a habilitative system the residence is part of the treatment. Let me again state this point, IN THE HABILITATIVE SYSTEM THE RESIDENCE IS PART OF THE TREATMENT not merely a place of treatment.

It is the failure to appreciate this distinction that has caused the current system to lose its way. OPWDD and the Transformation Panel talk about “housing.” I see little difference between the current use of the term “housing” and the “warehousing” that was the norm of the now rejected Willowbrook model. Providing every developmentally disabled person with their own apartment, some have even had the temerity to suggest that they should all be warehoused in public, Section 8 housing, would provide no habilitation and would actually be contrary to Olmstead.

Residential habilitation requires that the residence be part of the treatment model. Remember the definition of habilitation “**Health** care services that help you keep, learn, or improve skills and functioning for daily living.” This is the essential difference for the developmentally disabled. The medical habilitation services they receive must be integrated into their environment in order for the services to be effective. How can a person improve their functioning for daily living if they are isolated/imprisoned in an apartment where a stranger occasionally comes by to ask “How’re your doing?”.

In a group home or other properly constituted setting the person is provided with a stable foundation and stable relationships which assist them in reaching their full potential. I know from personal experience that stability in physical surroundings and interpersonal relationships are fundamental in the effectiveness of habilitative treatments.

It makes no sense for the State to provide habilitative services where the residential habilitation service is unstable. For example, we have had instances where young people in transition from school have been placed in residential settings where a group of older adults have been living together for decades. The resulting allegations of possible sexual improprieties that occurred, through no fault of the individuals involved who clearly have qualifying conditions, proved disruptive to the habilitation of all the individuals concerned.

That is the problem with equating “Residential services” with “housing.” Residential services for the developmentally disabled are not like hospital beds. Residential services must be PRESCRIBED/DESIGNED in the same way as a doctor prescribes medication – to ensure the habilitation of the individual.

I am here today to advocate for the participation of participation of parents, guardians, caregivers and self-advocates in the design, implementation and FUNDING of a system of Residential Services which will form the foundation of the entire habilitative system the developmentally disabled are entitled to.

Thank You.