

Written Testimony of Karel S. Karpe

Public Hearing hosted by New York State Legislators Senator Bill Perkins, Assemblymember Robert J. Rodriguez and Assemblymember Keith Wright

Thursday January 14, 2016

Good evening, my name is Karel S. Karpe. Thank you for providing me with this opportunity to speak to you about issues concerning people with disabilities in New York City.

I am the mother of a 25 year old young man with a rare genetic syndrome. When my son was born, I had no idea about the world I was entering. I already had one child, so I assumed that I would have no problem dealing with the nuances of having a child with special needs. What I didn't know then – and most certainly know now – is that my mothering skills were not enough. This was my reality check. I needed to wear a hundred hats – including being a lawyer to fight for my son's rights; an interpreter so I could understand the hundreds of acronyms that permeate the provision of services to him; a medical doctor so that I could diagnose his needs and find proper care for him; an educator and job coach so that I could help him achieve his highest level of independence; and even a real estate broker to try and negotiate a future placement for him. And really, all I wanted was to be his mother.

I have some hard facts - My son is not going to be able to earn a livable salary. He will rely on public funds for his needs. For all the made for TV movies and even the documentaries showing the capacities and capabilities of young adults with disabilities finding jobs, traveling and moving into apartments – there are the thousands upon thousands of young men and women like my son, who cannot sustain employment and cannot move into apartments without support. This is society's reality check.

My son would like to live in an apartment and he would like to live with his best friend, who happens to be a girl. He will not marry and start a family, so his family will be his friends – a definition not recognized in the housing world (which still only acknowledges nuclear families). He would like to live in his community, which is the area he grew up in, the Yorkville area of Manhattan. He would like to have his dog with him. These are not extraordinary dreams. But for him, given the lack of housing for people with disabilities, given the restrictions on housing for people with disabilities, given the rules and regulations inherent in certified housing for people with disabilities, and given the continued erosion of services to people with disabilities, this dream cannot become a reality.

In the last century, there were significant steps taken to address how we as a society think about people with disabilities. Unnecessary segregation and institutionalization of people with disabilities was met by new laws such as the American with Disabilities Act of 1990, the Supreme Court decision in the Olmstead Act in 1999 as well as the closure of institutional facilities such as Willowbrook in 1987. Today, Developmental Centers continue to be slated for closure. The vision was and is that services and supports would be provided to individuals with disabilities to allow them to stay in a home and in their community.

The reality check is that this is not a fair and true statement. There is no new housing for people with disabilities. There has been no real attempt at seeking new models of housing for people with disabilities. There is not even a waiting list for housing for people with disabilities. There has been

plenty of talk about personhood, individualism, self-direction and community. BUT there is literally no housing for a person with disabilities unless the caregiver parent or family member falls ill, is hospitalized, or dies. There are over 300,000 people with disabilities state wide, the majority of whom are still residing with family members.<sup>1</sup> Without new housing and without new housing options, none of these individuals will receive residential placement or have an opportunity to live outside of their childhood homes until an emergency forces a placement – which placement is usually in a more restrictive and more expensive setting.<sup>2</sup> Housing by crisis is not the solution.

New York City has prioritized housing for other specialized populations. New York City has prioritized housing for veterans, and I applaud this. New York City has prioritized housing for the mentally ill, and I applaud that too. I support all these priorities but now is the time to make housing for people with disabilities a priority.

**There are steps we can take: New York City must prioritize the creation of new housing for people with disabilities. We need to educate housing providers on the needs of those with developmental disabilities, we need the City and State to incentivize them to build and offer apartments to people with disabilities. We need to allow people with disabilities to have choices in housing and have their services follow them. We need real housing options for people with disabilities. And we need them now.**

Thank you again for allowing me to present tonight.

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<sup>1</sup> The New York State Office of People with Developmental Disabilities (OPWDD) provides services to only 128,000 people statewide, so a significant number of people needing services are not even being reached.  
[http://www.opwdd.ny.gov/opwdd\\_about/overview\\_of\\_agency](http://www.opwdd.ny.gov/opwdd_about/overview_of_agency)

<sup>2</sup> Maltby, J., Napierski, C. (2015) “Report to the Housing Task Force”, Albany, NY. NYSACRA