

Choice and Equity in Housing for Those with Intellectual and Developmental Disabilities (I/DD)

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Keywords: experience, systemic discrimination, disability, healthcare, equity

Abstract:

This is a personal story that describes my experience as a mother fighting a deeply flawed and dangerous State initiative that was aimed at those with profound disabilities, medical fragility, and severe behaviors. Our grassroots movement sought to protect their right to live in the residential setting most appropriate for their level of disability while demanding equity and fairness in a system that is failing far too many.

Introduction

As a mom and advocate for the I/DD population for many years, I am sharing our personal story of our journey through a deeply flawed initiative known as Return Home New Jersey (RHNJ).

Our daughter, Kara, is now 33 years old and resides at Woods Services which is a large and comprehensive residential facility in Bucks County, Pennsylvania. Woods is a population health organization that provides life cycle care to meet the lifelong needs of children and adults with intellectual disabilities. It is a unique non-profit model that has both a campus, which serves the most medically and behaviorally frail children and adults with intellectual disability – and also has group homes in Pennsylvania and New Jersey. Kara has lived at Woods since 2008; she was placed there after a failed placement in a similar setting in New Jersey which is where we reside. Kara has very complex needs and is medically fragile. She has intractable epilepsy which has been drug resistant for many years in addition to having severe neurological impairment and dysphagia which requires a restricted diet and much oversight to keep her safe. Kara receives one-to-one direct care staffing during all awake hours as she is at very high-risk for a fall and severe injury from seizures if she is left unattended. Woods has been able to provide comprehensive, wrap-around services which are required to meet Kara's many needs. It is her home and it is where she needs to be.

Around 2013, the State of New Jersey under Gov. Christie decided to ramp up the RHNJ initiative. We were notified by the State of its intent to move Kara back to New Jersey to place her "closer to home" and into "community". The Division of Developmental Disabilities (DDD)

wanted us to believe that they were doing this to make life better for Kara as she would be closer to home and would have the same level of support as she had at Woods. We learned very quickly that this initiative was not about making life better for Kara and for our family, but about the State looking to cut costs on the backs of our most vulnerable.

We were forced to comply with the process of looking at community group homes and relocating our daughter. Failure to comply would have resulted in the risk of having her funding cut off at Woods. It is important to note that Kara had already been through a failed New Jersey placement, one that was far more comprehensive than a group home and still couldn't meet her many needs.

DDD required us to look at the homes they felt would fit Kara's needs, not one of them was anywhere close to our home. Woods is 50 minutes from our home in Central Jersey, yet we were asked to look at homes in Atlantic County, Bergen County, etc., all far more distant than Woods. The first promise of RHNJ to bring her closer to home was broken. There were many more to come.

As we toured these homes and asked questions of the staff, we were appalled and shocked to learn how utterly unprepared they were to meet Kara's needs and provide support equal to her current level at Woods. Kara has 24/7 access to nursing at Woods, while the New Jersey homes we visited only had a nurse that 'travels' amongst several group homes and who could be reached by phone or text if there is an issue. The group homes told us that staffing and budget issues might not allow Kara to continue to have her one-to-one direct support staff which had been established as necessary to keep her safe. Kara's Day Program at Woods is right on campus, she goes there on weekdays with her peers. We were told by one group home that their Day Program was too high functioning for Kara so the alternative for her would be to attend a Senior Center near the group home. My daughter was 25 years old at the time. So much for being with your peers. There was no way that we would allow our daughter to become a victim of such a dishonest, flawed, and dangerous initiative. We knew it was time to fight.

Other families at Woods and at other out-of-state placements were going through the same thing. We knew full well that these group homes were nowhere close to caring for the most vulnerable within the I/DD population. We banded together and formed a grassroots advocacy group to fight this dangerous initiative. We called out DDD whenever they made false statements about RHNJ. We wrote, called, and visited our state legislators to make them aware of what this initiative would do to our loved ones. We testified before NJ House and Senate committees to expose this plan for what it was, a dangerous money grab which would cause immeasurable harm to our loved ones. We went to the media, and newspapers and TV carried our stories. We posted constantly on social media. After years of battling, the Christie administration finally

relented and put an end to the program. This was a major victory for our most vulnerable, their voice had finally been heard.

But our work is far from done. Fast forward to 2022, and not much has changed on the landscape of community group homes for the medically fragile and the most severe behavioral. Placements in community are often not available or they cannot meet the needs of those who require the comprehensive services that a campus setting provides. There is a national movement afoot which calls for 'community' for all. This is a dangerous movement as we proved during RHNJ that the community is not ready to safely house this segment of the I/DD population. We will never stop advocating for CHOICE in housing options for those who are much better served in a placement like Woods. Woods is the definition of community and I'm tired of letting others attempt to define that word for me and my family. We need our government leaders to understand that this population deserves compassion, equity, fairness, and choice in a safe place to call HOME.