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Unending Challenges and Unfair Practices Plague System

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Abstract

This case study highlights the experience of a New Jersey family grappling with competing policy priorities put in jeopardy access to the services needed by their adult son, who has multiple disabilities. He requires 24/7 support and resides at Woods Services in Pennsylvania. Federal legislation proposes increased funding but limits where this funding can be used. A severe direct care worker shortage further jeopardizes access to services.

Introduction

In the early months of 1986, we were living a typical suburban life. I was a stay-at-home mom of three active young sons with a hard-working husband who traveled much and did his best to be present for all our family, school, and sports activities. We had a supportive extended family and a wonderful circle of friends.

Our two older sons played competitive soccer and traveling to different venues was a great family experience for us all, as were beach weekends visiting my sister and parents.

But the end of May changed all that when tragedy struck our family. Our youngest son, Drew, who had just turned three, went to bed that night and never woke up. He was diagnosed with bacterial meningitis and spent the next three months at Children’s Hospital of Philadelphia. As Drew lightened from the coma, it was obvious he would not be the playful child that we once knew. Now, he was blind, unable to speak or feed himself, was incontinent, and had severe uncontrolled seizures every day. Drew needed 24/7 care for his diverse needs.

In addition to our anguish concerning Drew’s quality of life, we worried about our two older boys. Although they understood the seriousness of the situation as best as any 7- and 10-year-olds could, we tried our best to keep their lives as normal as possible. However, we all knew life as we had known it would never be the same.

Family and friends stepped in to help and for that we will always be grateful, but suddenly our family needed much more support than we could imagine. We were now very dependent on people outside our comfort zone with Physical, Occupational and Speech therapists, Social Workers and respite professionals coming in and out of our home. To be honest, there were many days I resented the intrusions, but I knew all of this was critically needed for Drew and I slowly learned to embrace them for the angels they are.

As time went on, our two older sons, who were always helpful, went off to college. The realization that Drew was getting stronger and my husband and I were getting older and could no longer meet all his needs was weighing heavy on our hearts. We were encouraged by professionals to consider a residential placement for Drew. He was now almost 19-years old and we were struggling with the reality of wanting the best for him, but not being able to provide it in our home.

The decision to leave our child to the care of someone else was so foreign to us we couldn't process the situation. How could anyone know when Drew was thirsty or how to coax him to eat which was very often an issue? Were they aware that this 19-year-old was incontinent and needed to have his diapers changed throughout the day? Would they protect him during seizures or know how to give him his meds when he refuses them? After all, no one can ever know your nonverbal, multiply-disabled child like mom and dad. Were we now going to be dependent on strangers to care for Drew? So many terrifying questions that, at the time, I was sure were insurmountable. We were physically and emotionally drained.

After dragging our heels for months, we began the search for the appropriate housing and visited Woods Services in Langhorne PA which is only a twenty-minute drive from our home. It was close enough that we could be there quickly in an emergency and was an easy drive to allow us to visit often. We were won over by the bucolic three-hundred-acre campus with swimming pools and equestrian horses, but we were very aware that none of those could take the place of caring and qualified hands-on staff that provide the day-to-day care of our most vulnerable citizens. Once again, I found myself needing to allow strangers into our world and I was stunned by the amount of compassion and dignity the caretakers demonstrated caring for the residents at Woods Services; I have never looked back.

Through the years, Drew has had many wonderful direct care staff at Woods and I have been touched by the devotion and respect these individuals have shown my son. One caretaker, who was a university graduate, passed up several job opportunities due to his commitment to our son. He said Drew was like his brother. But many years later when he made the decision to get married, he realized it would be impossible to continue this job at the current wage rates. Other devoted staff members have made the difficult decision to move on while others remain, but they are deeply concerned about paying their bills and providing for their families. As a result of the inequitable pay rates, there is a workforce crisis in the direct care profession.

Empty shelves at our local stores due to the lack of truck drivers, supply chain issues, and restaurants reducing operating hours because of lack of cooks and servers are an inconvenience, but we can adjust to these annoyances without much hardship. The shortage of direct care services for people with disabilities, however, is not an inconvenience or annoyance, it is a crisis and it's not overly dramatic to say it can be a life threatening one. Unfortunately, good quality care is not a concern for the majority of the population as it isn't on their radar. Quite simply, most people never give this a thought until they need them.

Congress' attempt to address the worker shortage with The American Rescue Plan Act (HR 1319, also known as the Covid 19 Stimulous Package) enacted in March 2021 included funding for pay increases for direct care workers. However, this was short-sighted as it provided a disproportionately larger amount of aid to smaller community-based group homes and in-home care facilities over the larger campus-style facilities like Woods Services. Are the workers at Woods Services any less worthy of a living wage because of the location of their work? Are these workers any less qualified, devoted, and compassionate because of the number of individuals living in the campus style facility? Are the individuals with disabilities living in these facilities any less worthy of care that is appropriately compensated? The answer, of course, is no.

Currently our Legislators are trying to address the wage issues with the Better Care Better Jobs Act (HR 4131, S 2210) which was introduced in June 2021 but, as it stands, it is flawed in that the funding is once again based on the size and type of care facility.

Should the numerous direct care workers, who so devotedly care for my son, and the hundreds like him, be discriminated against because their campus-style facility does not agree with the ideology of our Representatives? Should these hard-working individuals who are entrusted with the care of my precious son be valued any less than others because of a certain philosophy? I think not.

Our House and Senate Representatives are misdirected and need to correct the discriminatory language in this legislation. Perhaps they have been influenced by those who feel the 'one size fits all' type of housing (community group homes, small apartments, etc.) is the only answer. We here in the trenches know that families need choices when making a well-informed decision as to what is best for their loved one, especially where they will reside. We know where our sons and daughters, brothers and sisters flourish. We see it in their happy faces every day.