

My name is Colleen Clancy and I am the mother of a 28-year old son (William) who has spastic quadriplegia cerebral palsy and developmental disabilities. In 2018, I made the difficult but necessary decision to find placement for Will where he could gain some independence, where his daily needs would be met and that was in close proximity to my home in Avon. I was fortunate enough to find an eight-bed Intermediate Care Facility (ICF) in South Amherst operated by Echoing Hills Village.

I felt like I won the lottery — Will's house, Renouard House, is fifteen minutes from my home. It's exceptionally clean, organized and very well run by a loving staff of Direct Support Professionals (DSP). They care for Will and his seven housemates with the utmost compassion and love — they bathe, toilet, dress, assist with feeding and mobility, engage him in conversation, plan outings and recreational activities, and comfort him when he's sad or anxious. They anticipate his every need, just like a mom would. I like to think that no one cares for their child like a mother, and while I believe this to be true I have to admit that the staff at Renouard House come in a very, very close second.

This brings me to the reason for my testimony: staff retention. I realize that this is a national issue; however, few people are more affected by change than individuals with disabilities. They rely on structure and consistency. My son Will grows very attached to the DSPs at his home, as you can imagine someone would who is dependent on someone for their every need. DSPs become just like family — he loves them. Will calls me daily from his Alexa Show, and I can always tell when there has been staff turnover because he perseverates on a random topic and won't stop — he becomes very anxious. He becomes very sad. My son's mental health is my greatest concern at this point, more so than his extensive orthopedic needs.

Staff turnover not only affects my son, it affects everyone: the other residents, the staff, parents, and family members of loved ones in the House. The ripple effect is large. DSPs have to take on more hours to cover shifts and are frequently left exhausted. This alone creates a desperate situation. Newly hired DSPs have to get to know my son and the other residents of the House and this can take months. Newly hired DSPs don't know my son or the other residents so they don't know normal behavior versus abnormal behavior. My son is verbal and can let someone know when he's not feeling well, but some residents can't and they rely on DSPs to understand their behavior. This takes time and again creates a potentially desperate situation.

In my experience and observation, nearly every DSP who left, did so for a higher paying job, not always in health care. I have talked to a few DSPs before they left and they were sad to leave because they loved their job and the residents, but they had families to take care of too. It's unconscionable to me that DSPs hourly wage is less than someone working a cash register at a big-box store, and I don't have to describe the disparity between responsibilities. I implore you to support higher wages for Direct Support Professionals by increasing the developmental disabilities' rates in the State budget. I firmly believe that an increase in wages would have a positive impact on my son Will's House and many facilities like them throughout the State.

Lastly, thank you for allowing me to speak today — I am just a mom who loves her son and wants the very best for him and others like him with disabilities.

Thank you.