

**Testimony on SFY 26/27 Operating Budget
Senate Medicaid Committee**

Dear Senate Medicaid Committee,

Thank you for the opportunity to share our story. My name is Colleen Clancy, and I am the mother of a 30-year-old son (William) who has spastic quadriplegia, cerebral palsy, and developmental disabilities. In 2018, I had to make 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 near my home in Avon. I was fortunate to find an eight-bed Intermediate Care Facility (ICF) in South Amherst operated by Echoing Hills Village.

I felt like I had 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. Before you increased funding in the last budget, finding people to fill these roles was very hard. Although it has improved, I realize that this continues to be 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 else 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 continues to be my greatest concern, more so than his extensive orthopedic needs.

Staff turnover affects not only my son but also everyone: the other residents, staff, parents, and family members of residents in the house. The ripple effect is significant. 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 of the House, so they don't know normal behavior from 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, it can potentially create a 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 or close to someone working a cash register at a big-box store, and I don't have to describe the disparity between the responsibilities.

I'm worried because the Governor's proposed budget doesn't include more money for Direct Support Professionals (DSPs) working in waiver settings, and there's not a plan to adjust the budget to increase with the cost of living regularly. If you don't act, the workers who provide these services won't get the support they need for years. This means we could end up with the same crisis we had almost just solved.

I firmly believe that a consistent wage increase (as is typical in all business sectors) would positively impact my son Will's House and many facilities like them throughout the State.

Thank you for taking the time to review my letter. I am just a mom who loves her son and wants the very best for him and others with disabilities.

Sincerely,

Colleen Clancy

Colleen Clancy (William's mother)

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