

My name is Laurie Mumley. I live in Shelburne Vermont with my two children. I am here today wearing two hats. First and foremost, I am a parent to an adult with a developmental disability. Second, I am a member of the Developmental Disabilities Housing Initiative (DDHI). I'd like to speak to you wearing each "hat".

My son Joey turned 22 this past May. He loves music, singing, boating, riding his adaptive bike, watching Disney movies and You Tube videos, swimming, and being a part of things. He is very social (although it sometimes doesn't appear that way) and enjoys spending time with his peers. He can be absolutely charming, funny, has an infectious laugh, a beautiful singing voice, and a fantastic sense of humor.

Joey was diagnosed with autism at age 2 1/2. He continues to struggle with compulsive behaviors, multiple sensory challenges, a complete lack of safety awareness, and numerous behavioral challenges (heightened by the fact that he is 6'3" and nearly 400 pounds). He is also minimally verbal and requires assistance with all activities of daily living. He requires 24/7 supervision and needs a high level of structure and predictability.

Vermont schools were unable to meet his needs. He spent 2 and a half years at Easterseals in Manchester, New Hampshire. He loved it and absolutely thrived there but aged out in May of this year. He came home to nothing and went from having 24/7 supports within a structured program tonothing.

As a single parent with zero assistance from my children's father, I cannot work, grocery shop, attend my own medical appointments, or care for my other child (still in high school) if I do not have staff for my son.

His current budget was developed based on his last assessment when he was at Easterseals ALREADY receiving 24/7 supports through the Department of Education. In addition to those 24/7 supports, his budget allows for:

25 hours of community support per week (contracted @ \$30 an hour)

33 hours of in-home supports per week (contracted @ \$30 an hour)

18 hours of respite supports per week (contracted @ \$30 an hour)

Totaling 76 hours per week

PLUS

73 overnight respite days per year

I'd like to note that he has a reassessment scheduled, which his team anticipates will drastically increase his budget.

I have been paying caregivers well above the going rate for years-long before the pandemic and current staffing crises. It was the only way to attract and maintain reliable workers given the intensity of the demands on them (as well as the fact

that they don't receive other benefits). Currently, I pay his respite caregivers \$30 an hour (over DOUBLE minimum wage) and yet he had zero support workers for over four months. Even now, he is only getting 20-30 hours a week. There are 168 hours in a week, and I cover the remainder (138-148 hours per week). This has had a negative impact on my own physical and mental health. He does not sleep well and often keeps me and his sister up all night. She has complained about being exhausted and unable to concentrate at school.

I retired about 5 years ago. My plan had been to take a few months off and return to the workforce. However, my son's needs and the lack of staffing has meant that I cannot work. Obviously, this has created a huge strain on our family finances. We struggle financially, and I often forego things we could once afford without a thought. On rare days like today, my parents are staying with him to allow my testimony here. They are nearly 90 and he can be a lot for them to handle.

I cannot imagine trying to hire someone to work with my son for minimum wage pay. The bagel shop down the street starts their workers at \$25 an hour. McDonald's is just up the road, and starting pay is \$18/hour. I wish I could pay more.

I would like to see a minimum pay rate (for all direct support workers) set significantly higher than minimum wage) I would also want any increases in rates to the agencies to result in a comparable increase in the wages of the people actually doing the work. I absolutely support H.13.

Developmental Disabilities Housing Initiative is an all-volunteer group of over 125 parents across the state who have joined together to push the State into creating safe, stable, service-supported housing options for our adult children with Developmental Disabilities, who receive the Home and Community Based Waiver and have moderate to high support needs. Part of this work is having a stable and skilled workforce, which requires appropriate compensation and professional development.

We (DDHI) recently developed and conducted an informal survey which revealed disturbing patterns.

I will also confess something somewhat embarrassing. I am guilty of NOT completing the survey because as a single mom and 24/7 caregiver, I simply did not have the time. Even though I knew it could be helpful. Even though it wouldn't take that long. Even though I helped develop some of the questions.

When I read the survey results, they resonated strongly with me. The burden of this staffing crisis clearly has fallen directly onto families. Just because no paid caregiver is available does NOT mean that the individual with a developmental disability doesn't need to eat, or use the bathroom, or go to their few activities, or

be supervised for safety. Parents are continuously forced to step in and “fill the gaps”.

18% of the families are receiving ZERO of their budgeted support hours. Families are paying an average of \$23/hour for respite, which means they receive fewer hours of support.

At least 26% of the responding families had to leave jobs or reduce the number of hours they are working to provide care for their adult children due to these staffing shortages. This is a conservative number as the survey did not directly ask this question.

I am attaching the survey to be a part of the official record. The quotes from parents are devastating and demonstrate what this staffing crisis is doing to families.

DDHI supports investment in the direct support workforce by:

1. Increasing Compensation to Direct Support Staff
2. Providing Ongoing Training and Career Pathways
3. Implementing an Annualized Medicaid Rate Review

DDHI supports H13

Laurie Mumley