

February 27, 2023

To Whom It May Concern:

All of the slots to testify before legislators were filled before I had the opportunity to sign up for one. I hope you will take the time to read my written testimony.

I am the 68-year-old parent of a 33-year-old daughter with severe medical and cognitive challenges. She has lived in our home for all of her 33 years and been part of the state's high tech program for 27 of them.

I say that I am grateful for the many ways the state of Vermont has helped our family care for our daughter over the years not to "win" your ear(s), but because I am sincerely grateful. Your help made it possible for us to keep our daughter out of a residential setting—a setting which I am convinced (mostly due to perpetual staffing shortages) would have led to her decline and probably an untimely death. Your support has made it possible for us to provide our daughter with a decent quality of life both in our home and in the community. She is generally an emotionally well-balanced, happy, engaged (in her own way) young woman. Your support has enabled us to purchase an accessible van with which to transport her into the community. Your support made it possible for my husband to continue working full time for two decades. And your flexibility in supporting self-managed budgets for families allowed us to take fuller advantage of resources—for a time.

This being said, there is a significant "but" to our happy story. The past ten years have seen our daughter move from pediatric to adult support. These years have also ushered in a steady decline in support. Due to a narrowing of qualifying criteria (our daughter's medical neediness has not changed, but the criteria for defining "neediness" has), the state purposed to take away all of the shifts provided by nurses. I had to fight in 2017 and 2018 to retain nursing support for our daughter, which I was able to do—agreeing to reduced hours.

Since that time, information used to supplement the assessment tool used to determine qualification for nursing have not only restored nursing hours lost in the 2017/2018 struggle, but increased them. But nurses, it turns out, are not to be found. I am convinced Covid was not the cause of our current home health care crisis, but the event that threw it into our faces—and yes, exacerbated it. Over recent years (even before Covid) the nurses we had, left our home for better paying clinical positions. One of our best workers without a medical background could not afford to live in Vermont on even the decent wages we were paying her (no medical benefits could be provided). She enrolled in nursing school and now works in a clinical setting and makes livable wages. I had to leave my part-time work as a teacher. My husband was forced to apply for part-time employment at his place of business so that he could help me at home. We feel that his need to work part-time led to him being laid off. My older daughter, seeing that we were in trouble, quit her full-time job at a memory care center in town to work full time with her sister (yes, she is paid with respite monies but is doing the work of a nurse without being paid the wages of a nurse and must secure her own health benefits). For nearly two years (during the onset of Covid), my daughter and I provided all but 7 hours of the 24/7 hour care my younger daughter requires. My husband, who has developed a cognitive disorder since his forced retirement, no longer participates in her care. Suffice it to say that my older daughter and I were burned out from two years of almost no feet-on-the-ground support. This past summer, we made the heartbreaking decision to leave the state of Vermont for Indiana (likely in May of this year), where my son and daughter-in-law have offered their support. We are under

no illusions that the state programs in Indiana will provide much-needed staffing support, but we know our son and his wife will be there for us in many ways.

I have heard from attending “informational meetings” in our state that Vermont is now looking more and more to “natural supports” to help solve the home health care worker shortage. Please consider what leaning on natural supports has cost our family already. I think it’s important to ask yourselves, would you be content having to sacrifice to the extent our family has had to sacrifice to make up for worker shortages?

What is the answer? I think it starts with an unwavering—and I mean unwavering—commitment to supporting one of (if not **the**) most vulnerable populations in Vermont, knowing that it is and will always be extremely expensive but extremely rewarding in the end to support this community. There is no way around the huge monetary output involved in providing that support. If you, the legislators, are not convinced, how will you convince your constituents? In my opinion, you won’t.

One of the great needs is to support the work force for this population with livable wages. A governor’s budget that supports level funding is not going to turn around the crisis in finding and retaining home health care workers.

One of the other great needs is to reject the notion that saving money in supporting people with developmental disabilities can be had by employing less and less skilled people to provide the services. I will make my point by using an analogy—which will resonate best with those of you who have children. I am a retired teacher, but for the sake of my analogy, imagine that I was still employed and your child had been assigned to my kindergarten or first-grade classroom for the year. You arrive the first day of school with your child, and discover that I am not there. You learn, in fact, that I do not plan on being present. The person who will be providing instruction to your child is someone with no teaching background and no teaching degree just hired by the school district for minimal wages. When you race to the administrator’s office—which you learn is off campus in another part of the town to prevent conflict of interest—you are told, “No worries. We have found that anyone, really, can be taught to teach your children. The head teacher has provided the needed training but will not visit the site (to prevent conflict of interest).” After inquiring about the extent of the training, you are not reassured.” The administrator continues, “We have a few ‘instructional assistants’ on site that will provide episodic visits to the classroom to make sure all is going well. Oh, and the head teacher will be available by phone for emergencies on an as-needed basis.” You learn that this head teacher is the emergency contact for a number of classrooms, not just the one your child will be attending. When you express concern, the administration tells you that you can lean on ‘natural supports’ as an alternative, i.e. you can always homeschool your child.

You may think this analogy ludicrous. But in my opinion, just as ludicrous is providing the state’s most vulnerable population (much like kindergarteners and first graders) with underpaid, undertrained staff. In my opinion, you will not attract and retain the caregivers/workers you would like to employ without money for decent wages and adequate training.

Feel free to contact me for a further discussion, should that be helpful. Even more helpful, if I might be bold, would be to spend a day in the homes of people with developmental and intellectual disabilities—in the home living, group living, shared living, or mostly independent living with support situations in which they have been placed/placed themselves—and in their places of employment, if they are supported in those places.

Best,  
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