

Testimony by Donna C. Roberts of Burlington, VT

House Human Services Committee, Montpelier, Vermont

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Good afternoon, esteemed Committee members, fellow parents, friends.

I'm Donna Roberts, and I live in Burlington, Vermont. I'm a member of the parent-led Developmental Disability Housing Initiative

I'm a documentary filmmaker and journalist, hold a master's degree in environmental sciences and am currently pursuing an MFA. But my greatest and most challenging role is being Mother to my 26-year-old son Gabriel.

Gabriel is diagnosed with autism spectrum disorder, generalized anxiety disorder, obsessive-compulsive disorder, and mild intellectual disability. Multiple people have said my son is the smartest person they've ever met. He has a near-perfect memory, along with apparently perfect pitch. He's a musician, plays percussion with tastes ranging from Brahms to Bob Dylan. Gabe was very upset with my husband and me when we failed to produce two of four things on his Christmas list: CDs of Mozart and Bach. Gabe volunteers weekly at Burlington's Salvation Army and rings the red bell during their holiday Kettles' Campaign. Gabriel wants to have his own food truck someday. I'm sure he'll make it happen...with a lot of help from his parents...and support staff...once we have more.

Gabe is also one of the most anxious individuals you could ever meet. He talks about, worries aloud about most everything that passes through his mind. Because of his autism, there's little filter and a lot of repetitive talk. Thankfully, much of the talk involves asking people questions about their lives. But he rarely waits for the answer. Because of his OCD, he repeats rituals that make him feel safe. Like running water in our kitchen sink long after a plate is clean. As an environmentalist, this pains me. I tell my son it's a crime to waste water, that he might not have water to drink when he's older. That just makes him talk about it more loudly as water runs in the background. To interrupt this ritual, one risks being aggressed. It's a risk I often take. Then on comes the garbage disposal. While maddening to me, the sounds and sensations satisfy some sensory need that I can neither understand nor alleviate.

Not just anyone can support our son. People must be patient, calm, energetic, creative, capable of keeping up with Gabe's constant conversation, not getting flustered when he pays more attention to his "worry brain", as he calls his OCD, than the person supporting him. People who can gently redirect his inappropriate banter after he's watched Youtube videos where original characters from Peanuts or Dora the Explorer - at the hands of some IT whiz - become villains with foul language and violent actions. As Gabe said yesterday, "Look, Charlie Brown wants to kill Lucy!" I spent the next 10 minutes explaining how Charles Schultz would never make Charlie Brown kill Lucy, not even for removing that football.

People who support my son deserve to earn a fair wage, a just wage. At this time, they do not. And because they do not earn a decent wage, our family, our son, has just 4 hours of support

per week, despite the State having approved him for 12 hours per week - still far below what we need to be able to fully function as a family. Four hours per week! Four hours every Monday. That's all Howard Center – our designated agency - can provide for our son. Can any of you imagine if you had only four reliable hours in which to do your work, fulfill your obligations, take care of yourself? Unfortunately, most national holidays fall on Mondays, then we have no support.

When I see Howard Center ads on LinkedIn or Indeed, for direct support professionals, offering \$20/hour (\$21 for a vocational coach), I laugh out loud; sometimes I cry. Actually, I a lot...out of frustration at not being able to meet my son's needs not to mention my own. We, as a family, pay a regular respite provider \$30/hour, because that's what she's worth to us.

We moved to Vermont from Pennsylvania in late 2019 for quality of life, for clean air. The clean air, we got. But let me tell you, our quality of life has vastly diminished from what it was in Pennsylvania. Our quality of life is poor and deteriorating by the day. In Pennsylvania, Gabriel had been approved for a space in one of the regions many group homes including 24/7 support. And we gave that up to come to Vermont. Because we knew with Vermont's reputation as a caring, progressive place, our son's needs could surely be met.

Then just when we were starting to integrate, the pandemic hit. Our son's programming halted; there was no more support. We weren't alone, of course. But Gabriel's anxiety and OCD elevated to the point that we could no longer cope. We took him to the UVM Medical Center Emergency Department hoping to get help. Doctors didn't want to keep him there, but a social worker saw our needs, advocated that he be treated. He lingered in the emergency department for two weeks. Finally, a space opened up for our son in one of the very few transitional group homes in our county. He moved into that space in September 2020, with 24/7 support, with house mates who became friends, for three and a half years. It was a tough transition, not the one we imagined when he would eventually move out, with support, our collective goal. But that saved our lives. Our son's group home program ended last May. He came home but the support did not follow. He went from having 24/7 support, to, at first, 16 hours per week, then 12 hours, and now, as I said, we are down to just four hours per week. After continual complaints to Howard Center, an agency social worker said I could speak with someone "higher up" with the state. So I called. That person said, "Your son's needs must have changed. That's the only reason his support hours would change." I assured her that his needs had not changed. The only thing that changed is his address...he came home.

This lack of support means my husband and I have reduced our paid work, our family's income, our livelihoods, to do the unpaid work someone else would be paid to do IF there weren't a staffing crisis, IF there were living wages to pay for that work, that essential service to support the most vulnerable members of our community.

Last March, I resigned my work as Coordinator of the non-profit, Vermont Interfaith Power & Light, because I needed to be more available to support and advocate for my son. Last fall,

my husband, a sales executive with South Burlington-based CallFinder, took a partial unpaid family leave to help *me* support our son. Because I was burning out fast.

While I'm here today, my husband is accompanying Gabe on a tour of a grocery store, Shaw's, hoping to secure paid work for our son. Later today, they'll meet a music therapist. Yesterday, I would have taken Gabe to his psychotherapist who has expertise in anxiety and OCD, but a new medication caused adverse reactions, so we had to stay home. I routinely cancel *my own* therapy appointments because there's not enough time in the week. My husband and I are Gabe's job support, behavior therapists, case managers, life interpreters...we are his support staff 24/7.

But what happens if, when the parents crash? I can tell you our family is in desperate straits, survival mode, and we are just one of many families in our position.

I know of families, including an attorney specializing in supporting our families, who, when at their wits end, took their adult child to the hospital and left them until the agency figured out how to help. Is that the best the State can do? Wait until the worst happens to us to do your best? Can you imagine having to do that for your child or grandchild?

Even though he's a very smart guy, Gabe is also very vulnerable with very little impulse control. He can't manage money, time and, much of the time, his mouth! He needs frequent reminders to stay safe in the community, help with socialization, prompts not to talk to everyone he sees. He loves telling people, "Hello!" and "Have a nice day!" (even at night), but if they don't respond, he can easily get annoyed. "What's wrong with that person?" in an ever-louder voice, is a common refrain.

We are exhausted. We deserve better. And we aren't getting any younger. Families are moving out of Vermont because other states have figured this out. They pay better wages; they have group homes. Why can't Vermont?

Please, support Representative Wood's House Bill 13 and increase wages for direct support professionals. Not just wages to the agency, but wages for the staff who directly support our son. My fellow parents and I request the Secretary of Human Services determine reasonable and adequate Medicaid rates for providers of home- and community-based services, including a process for annual inflationary adjustments....

Thank you for listening. Thank you for caring for your fellow Vermonters. Thank you for taking action to pay better wages to the direct support professionals who save our families lives every day.