

Testimony on SB 2276  
January 24, 2023  
House Human Services Committee

---

Good day, Chairman Weisz and members of the House Human Services committee. My name is Sarah Carlson. I live in Dickinson, ND and I am writing this, representing my own thoughts and not on behalf of my employers. I am in support of SB 2276.

I have a 10-year-old son, Beckett, who has severe multiple disabilities. He has had these since birth and they are lifelong conditions.

SB2276 allows families, specifically members who reside with the person with the disability to be paid caregivers. For the sake of this letter, I will refer to the dominate role as 'parents,' but this would also include older siblings, multigenerational families, etc.

As a parent to Beckett, every week I must decide how I will juggle his appointments, medical needs, and my work life. I direct services for adults with disabilities and am a critical part of our organization. Not only do I provide leadership to my team of about 75+ staff, I also fill in for staff shortages and work 50+ hours weekly. Leaving my job will only increase the strain on community providers with workforce shortages. This has been something I have needed to consider, though, because of my sons needs and the lack of workforce available to support him. I am grateful that my husband, with a less-demanding full-time job, can be counted on to be home every day after work and adjust to be home if Beckett is ill and I am counted on for my job. He also has not pursued leadership within his vocation because of Beckett's needs and my own leadership role. We make decisions like this daily.

As a parent, I will always be dedicated to my child. But Beckett's needs are extraordinary and the work that I do for him is simply beyond that of typical parents. I will always be "mom," but there are many days that reading, making meals, and monitoring his tablet usage would be simpler. I juggle additional roles of physical, occupational and speech therapist, special education teacher, social worker, medical specialist, pharmacist, etc. A peak year, he had over 200 appointments in a year. As a ten-year old, the department of human services says that he can be left alone for approx. 2 hours. Beckett's supervision needs are beyond that— with his seizure disorder and support needs, we would not be able to do that, nor is that likely in the future. I sleep in the same room as him to monitor for seizures, relying on my light sleep patterns to wake if I hear him starting a seizure. Beckett weighs 75 lbs—we lift and reposition him several times a day as he relies on full support for all movement. These are all adjustments that our lives have adapted to, but speak to the extraordinary hours and dedication families commit to.

The workforce shortage does not meet our needs. We have met the authorized hours with paid caregivers one quarter out of 1 year, out of the 10 years. In the last 5 months, we will have cycled through 3 different staff. Supporting Beckett is challenging, but rewarding work. The economy is an employees arena. Providing self-directed support is not enticing for some staff, as I am unable to provide benefits or a competitive wage. I understand that there are fiscal impacts to commit to provide this for families, but downstream, if we don't do something, we are looking at other fiscal impacts, like children needing to be institutionalized so families can work outside the home.

Thank you for your time and consideration. Please vote in favor of SB2276.

Sarah Carlson  
Cell: 515.450.7378  
scarlson@ablend.net