

Testimony on SB 2305  
January 27, 2025  
Senate Human Services Committee

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Good day, Madam Chair Lee and members of the Senate 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 2305.

I have a 12-year-old son, Beckett, who has severe multiple disabilities. He has had these since birth and they are lifelong conditions.

SB2305 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 son's 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 honorary 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 twelve-year old, the department of human services says that not only can he be left alone, he can babysit and be responsible for other children. Beckett's supervision needs are far beyond that—with his seizure disorder and support needs, he is in our line of sight almost always, and leaving him alone for any period of time does not happen, nor is that likely in the future. I sleep in the same room as him to monitor for seizures and apneic episodes, relying on my light sleep patterns to wake if I hear him starting a seizure or pauses in breathing. Beckett weighs about 100lbs—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 hours available for Beckett to receive support through self-directed service, but there are not workers available. The last person that we interviewed was a nursing student currently working as a CNA at a long term care setting. He declined the job: it was too much work. Supporting Beckett is challenging, but rewarding work. The economy is an employee's 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 SB 2305.

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