

Testimony in Support of SB2305
2025 Legislative Session
January 23, 2025

Senator Lee and Members of the Senate Human Services Committee,

My name is Brenda Schmid. I live in Fargo in District 46 along with my husband and daughter.

I am providing this testimony in support of SB2305 for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service program and cross-disability advisory council. We have a beautiful daughter who is 27 years old who has significant physical and intellectual disabilities along with complex medical needs (extra ordinary care needs). She lives at home with us and will do so as long as we are on this earth together. For 27 years I have been her primary caregiver, and my husband has taken the role of sole financial provider.

Our daughter uses a wheelchair (spastic quadriplegia), has epilepsy, neurogenic bowel/bladder, GJ tube (tube fed), scoliosis and kyphoscoliosis, cyclic vomiting and migraines, congenital tracheomalacia, nephrolithiasis, reflux disease, is nonverbal and has severe intellectual disabilities and has insomnia. She relies on others 100% to live.

I have been participating in the Pilot Program since Spring 2024. It has been life changing. I have attempted to work outside of the home many times over the past 27 years, only to have to resign as our daughter needs me. My husband travels for his work (same company for 33 years) he needs me to take care of our daughter and our home so he can do his job and focus on it to ensure financial support for our family.

My husband and I are in our mid and late 50's. As we enter this chapter of our lives we worry about retirement. When can we afford for my husband to retire? As our daughter will always live with us in our/her accessible home that meets all of her needs, she has her own personal van that enables her to access her community, she has me her Mom who not only takes care of her, I manage all her medical appointments, medications, therapies, socialization, volunteering opportunities, recreation, leisure I make sure she has a beautiful, inclusive life that is meaningful, purposeful and dignified.

My husband and I financially do the heavy lift by providing housing (there is lack of affordable accessible housing), transportation (lack of transportation is a huge barrier for individuals living with disabilities), medical management (countless hours spent managing her care and no one knows her needs better than me) AND quality caregiving (there is a workforce crisis).

I keep a bank statement from the year our daughter was 1 year old, and I was unable to work outside of the home due to our daughter's extraordinary care needs and complex medical needs. We had 11 cents to our name. We never filed bankruptcy, we owned a little house built in 1921, 1 car, we never were on any state or federal funded assistance programs....we made it, through literally, blood, sweat, tears and the good Lord above we made it.

The Family Paid Caregiver Service Program is life changing. First and foremost, for the individual living with significant disabilities (extraordinary care needs) as they can be cared for by their family in their own home. Second, the financial impact. In today's economy dual incomes are necessary for families to pay for the basic necessities. Single parents who are unable to work due to their child's extraordinary care needs need a source of income.

In closing I want to thank you for your time and consideration and am respectfully requesting a "Do Pass" from the committee.

Brenda Schmid
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