

Testimony in Support of SB 2305
2025 Legislative Session

Dear Senator Lee and Members of the Senate Human Services Committee,

My name is Amanda Burner (I am a caregiver/parent to my son Kaden who is 22). I live in Minot ND and am part of district 5.

I am writing this testimony in support of SB 2305 for an act to amend and reenact section 50-24.1-47 of the ND Century Code, related to the paid caregiver service program and the cross disability advisory council.

The reasons I believe this bill (SB 2305) is so important are many, but I will try and keep it brief. I have had the privilege to be a part of the paid caregiver pilot program. It has been a true life altering program for my family. Our adult son Kaden has a rare disease called Leukodystrophy. This disease has come with so many challenges including profound cognitive disability (he cannot talk, do any of his own cares, feed himself, or walk), seizures, and being immune compromised. Due to all of these factors I have only been able to work minimum and sometimes not all leaving all the financial responsibility on my husband. We have done it and made it work, but it has been mentally exhausting. Once we became a part of the pilot program things changed drastically for the better. We were able to breath a little. It took the heaviness of financial issues off the table and allowed for some peace in that area. I even had my son's social worker and others comment to me that I seemed much less stressed and more at peace. It made me realize that just having the program made such a positive difference in our lives. For that we are so grateful. The mental load on parents and families of profoundly disabled children is something so hard to describe. We do the job because we love our child and want his quality of life to be the best it can be, but it is a heavy job. It has been so wonderful to get the recognition for doing this intense job from the start through this program. It has made me and my family feel less invisible and created less stress, thus improving the quality of all of our lives. For that I thank you! I respectfully request a Do Pass from the committee. From my family to you all thank you for helping us to improve the quality of our lives.

Respectfully
Amanda Burner

Minot ND