

## Testimony in Support of SB2305

2025 Legislative Session

January 24, 2025

Senator Lee and Members of the Senate Human Services Committee,

My name is Toby Lunstad and I live in Mandan – District 31. I am writing testimony in support of SB 2305 for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the Paid Family Caregiver Service Option and the Cross-Disability Advisory Council.

I am writing in support of SB 2305 because I am the primary caregiver to my daughter, Addilynn, who requires extraordinary care to live a healthy and happy life. Addilynn is 10 years old and loves music, dancing, Mickey Mouse Clubhouse, and going fast in just about anything. She has a cheerful and sometimes mischievous personality and has blessed my life beyond measure.

Addilynn has a rare genetic disorder called CACNA1A, which has resulted in developmental delays in all areas, Lennox-Gastaut Syndrome (a medication-resistant form of epilepsy), hemiplegic migraines, and the need for specialized care and equipment. Addilynn is currently on the IID/DD Waiver.

In 2020, I was forced to leave my full-time employment as a manager and occupational therapist because her needs were so specialized that we could not find qualified staff to care for her while I worked. As a result, our family lost income, employer-paid health insurance, and other benefits. My husband now works longer hours in an effort to fill the financial gap created by my inability to work outside the home.

Addilynn and I are participating in the Paid Family Caregiver Pilot Program developed through SB 2276 during the 2023 Legislative Session. Participating in this program has reduced the emotional and financial strain on our family. It has provided Addilynn with a consistent, fully qualified caregiver who is deeply invested in her health and happiness.

I support SB 2305 and the provision for family caregiver payments to be set at rates comparable to self-directed direct support professionals. Under the pilot program, caregivers for individuals under 18 years old, like Addilynn, are paid only half the rate of caregivers for adults. Payment rates should be equal regardless of the individual's age and should reflect the skilled care being provided. This recommendation aligns with guidance from the **American Academy of Pediatrics Advocacy Action Guide on Paid Family Caregiving** released in late 2024.

### [AAP Advocacy Guide on Paid Family Caregiving](#)

I also support the bill's language requiring the assessment process to be evidence-based and focused on the unique needs of the individual. As an occupational therapist, I understand that performing daily tasks, such as using the bathroom, involves multiple areas of need. Completing this single task requires consideration of:

- **Transferring:** Is the individual able to transfer to and from the toilet safely?
- **Balance:** Is the individual able to maintain sitting balance while completing toileting? Are they able to maintain standing balance during clothing management?
- **Clothing Management:** Are they able to don and doff clothing or incontinence products?

- **Hygiene Completion:** Can the individual thoroughly complete hygiene to maintain skin integrity and reduce the spread of germs? Are they able to properly dispose of incontinence products?
- **Safety:** Can the individual complete these activities without risk of falling? What equipment is needed for safety and independence? If left unsupervised, does the individual have potential to cause damage to the home?
- **Cognition:** Do they understand and sequence the steps required to use the bathroom? Do they recognize the need to use the bathroom? Are they able to wait if necessary? Can they generalize using the bathroom in places other than their home?

An assessment focused on functional areas of need, rather than skills unrelated to daily care (such as the ability to throw a ball overhead), will more accurately identify individuals who require extraordinary care from their family caregivers.

I also support the inclusion of the Cross-Disability Advisory Council in providing feedback to the department regarding the planning, design, and implementation of the Paid Family Caregiver Service Option. Stakeholder input is essential to ensure the program meets the needs of eligible individuals. As long as the Cross-Disability Advisory Council represents individuals with a broad range of disabilities from across the state and provides opportunities for public comment, it will serve as an effective mechanism for stakeholder participation.

Thank you for the opportunity to express my support for SB 2305 and for your service to our state. I respectfully request a “Do Pass” recommendation from the committee on SB 2305. I am happy to answer any questions you may have.

Sincerely,

Toby Lunstad

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