

Testimony in support of SB 2305

2025 Legislative Session

March 11, 2025

Chairman Ruby and Members of the House Human Services Committee

My name is Toby Lunstad, and I live in Mandan in District 31. I am here today testifying 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 the primary caregiver to my daughter, Addilynn. She is 10 years old and loves music, dancing, Mickey Mouse Clubhouse, and anything that goes fast. Addilynn's cheerful and sometimes mischievous personality brings immense joy to our lives. She receives waiver services via the IID/DD Waiver, and we are participating in the Paid Family Caregiver Pilot Program.

Addilynn has a rare genetic variant on a gene called CACNA1A, which has resulted in developmental delays, Lennox-Gastaut Syndrome (a medication-resistant form of epilepsy), hemiplegic migraines, and the need for specialized care and equipment. She is entirely dependent on others for all aspects of daily living.

Despite being authorized for in-home support services, we have been unable to consistently access them due to an ongoing workforce shortage. In 2020, I was forced to leave my career as a manager and occupational therapist because we could not find qualified staff to meet Addilynn's complex needs, creating significant financial and emotional strain on our family. With the Paid Family Caregiver Pilot Program, families like mine can access the support they need without having to choose between financial stability and ensuring their loved one receives essential care.

It bridges a gap by providing Addilynn with a fully qualified, consistent caregiver who is deeply invested in her well-being. This program is not about paying parents to be parents—it is about ensuring individuals with significant disabilities receive the care they are authorized for, from caregivers who are both capable and committed. Without it, many North Dakotans, like Addilynn, would be left without essential services.

Extraordinary caregiving goes far beyond typical parenting. For example, while my nephew, who is two months younger than Addilynn, eats independently, mealtime for Addilynn requires transferring her to her wheelchair, preparing food to a safe texture and bite size, assisting with every bite, monitoring for choking, and offering fluids in the only bottle she can safely drink from. This is just one of many tasks that require constant vigilance and specialized care.

As a highly trained caregiver, I manage Addilynn's complex medical needs, recognize early signs of medical distress, and provide skilled care that cannot simply be replaced by outside providers. The Paid Family Caregiver Pilot Program ensures individuals receive the care they need from caregivers who are both qualified and committed. This program has helped ease the caregiver crisis by ensuring individuals receive the highly skilled, essential care they need to thrive, maintain their health, and actively participate in their communities.

There are benefits to this program that cannot be measured in dollars. The peace of mind that comes from knowing a loved one is in capable and compassionate hands is invaluable. The security of consistent, high-quality care reduces stress for both the caregiver and the individual receiving support.

Along with my testimony, I have provided a flyer detailing the benefits of paid family caregiving, including improved care quality, cost savings, and better health outcomes. I have also included a list of extraordinary cares compiled by ND Family Caregivers to further illustrate the realities of this level of caregiving.

Thank you for your time and consideration. I respectfully request a "Do Pass" recommendation on SB 2305. I am happy to answer any questions you may have.

Sincerely,
Toby Lunstad
701-595-4386
tobylunstad@gmail.com

