

## Testimony in Support of SB 2305 2025 Legislative Session February 12, 2025

Chairman Dever and Members of the Senate Appropriations – Human Resources Division.

My name is Toby Lunstad and I live in Mandan – District 31. I am writing testimony in support of SB 2305 relating to the Paid Family Caregiver Pilot Program.

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 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.

My testimony highlights the critical difference between typical parental care and the extraordinary caregiving that family caregivers provide. To illustrate this, I want to compare the care my sister provides for her son—who is two months younger than my daughter, Addilynn—to the care I provide for Addilynn in daily activities of eating, bathing, and dressing.

At mealtime, my nephew comes to the table, serves himself, ensures his food is a safe temperature to eat, eats independently, and drinks as needed. In contrast, when Addilynn eats, I transfer her into her wheelchair, make sure the meal is a texture she can safely eat, cut her food to a safe size, and monitor the temperature. She is unable to bring a utensil to her mouth, so I assist with every bite. I also monitor and provide cues so she does not choke or aspirate. Since she cannot reach for her drink, I offer fluids throughout the meal, using the only type of water bottle she can safely drink from.

When it's time to bathe and dress, my nephew needs only a verbal reminder. He completes the routine independently. For Addilynn, I transfer her to the bathroom, regulate the water and room temperature due to her difficulties with temperature control, and complete every aspect of her bathing and dressing. This process is time-consuming and physically taxing for Addilynn, so I have to factor in a time for rest after these routines are completed.

These are just two parts of a typical day, but they illustrate the profound difference between ordinary parental care and the extraordinary care provided by family caregivers.

The impact of family caregivers extends beyond daily tasks. Data from Arizona, where family caregivers are paid, shows that individuals receiving care from a family member have significantly lower hospitalization rates—0.7% compared to 7.7% for those with outside caregivers. This means better health outcomes, less medical trauma, and cost savings for the Medicaid system.

Funding the Paid Family Caregiver Pilot Program is an investment in health, well-being, and financial responsibility. I respectfully request a "Do Pass" on SB 2305 and welcome any questions.

Thank you for your time and service to our state.

Sincerely,

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