

Testimony in Support of S.B. 2305

2025 Legislative Session

March 8, 2025

Chairman Ruby and members of the House Human Services Committee,

My name is Jennifer Restemayer and I live in West Fargo, ND. My husband Jim and I are the primary caregivers to our young adult daughter Allison who just celebrated her 24<sup>th</sup> birthday. I am writing to you in support of SB 2305 and to share with you how being able to participate in the Paid Family Caregiver Pilot Program has been a benefit to our daughter and to our family.

Allison was diagnosed at the age of 2 with a rare genetic disorder called Mucopolysaccharidosis type 1. Allison requires daily meds as well as a 6 hour weekly I.V. infusion of an enzyme replacement therapy (ERT), and she also has multiple therapies throughout the week. Allison's disorder is progressive and degenerative, when she was diagnosed we were told that she would be bedridden by 8 and dead by the age of 10 without treatment. Allison has now had 1133 weeks of her ERT infusions. The progression of Allison's disorder has led to her currently being unable to walk or stand on her own, she is legally blind and has a profound hearing loss. Her ability to verbally communicate is her greatest strength, however she needs someone with her constantly to narrate the environment in a way that she can hear and understand. Allison's anxiety level is high due to her impairments.

Our ability to participate in the Family Paid Caregiver Pilot program has allowed us to provide the care that Allison needs without the revolving door of respite staff that we have had in the past. Our family has utilized respite staff, but when COVID shut things down, our respite staff who were all college students at the time, left the area. Since Covid, Allison's needs have intensified, and we have not been able to find suitable staff to train and hire. I know that being able to provide the care for Allison has been a huge benefit to her health as there have been fewer hospitalizations for her, fewer major illnesses, and her mental health has shown improvement.

My husband and I have had to adjust our work schedules to accommodate Allison's needs. This is nothing new as I have needed to do this since Allison was 2 years old and newly diagnosed. The pressure my husband has felt to be the primary breadwinner, maintain our health insurance and continue to assist with Allison's care has been overwhelming at times. I have always had to find a way to continue to be part of the workforce in taking very

flexible part time jobs that would allow me to drop everything if needed to be there for Allison. The shortage in the workforce of qualified caregivers with the willingness and knowledge of how to care for a medically fragile child/ young adult has been something our family has had to navigate for years. The Family Paid Caregiver pilot project allows me to continue to be a part of the workforce and be there for Allison in a way that benefits my whole family.

Thank you for taking the time to read the impacts this pilot project has had on my family and for considering a “do pass” recommendation on SB 2305 so more families in our state are able to contribute to our workforce as paid caregivers to our most precious resource, our children.

Jennifer Restemayer

630 23<sup>rd</sup> Ave W

West Fargo, ND

[Jennifer\\_restemayer@yahoo.com](mailto:Jennifer_restemayer@yahoo.com)

701-471-8714

