

House Bill 1012 – Department of Health and Human Services Budget House Appropriations – Human Resources Division February 5, 2025

My name is Brenda Schmid. I live in Fargo in District 46 along with my husband and daughter.

We have a beautiful daughter who is 27 years old who has significant physical and intellectual disabilities along with complex medical needs. She relies 100% on others to live (nursing home level of care) She lives at home with us and will do so as long as we are on this earth together. For 27 years I have been her primary caregiver, and my husband (of 32 years) has taken the role of sole financial provider. I have attempted to work outside of the home many times over the past 27 years, only to have to resign as our daughter needs me. My husband travels for his work (same company for 33 years) he needs me to take care of our daughter and our home so he can do his job and focus on it to ensure financial support for our family.

The DD waiver is a lifeline to our daughter and our family. The DD waiver enables her to live in her own accessible home (with us) and have access to her community (has her own accessible van) where she volunteers, spends time with her friends, participates in many recreational and leisure activities. She has a beautiful, inclusive life that is meaningful, purposeful and dignified. Her medical needs and day-to-day care are carried out with quality and dignity in her own home.

Through the DD Waiver we participate in the Self-Directed option for in-home support staff and respite staff. Our daughter requires 1:1 care. Due to the caregiving/workforce shortage, providers simply do not have the staff to support her 1:1. Therefore, we elected to participate in Self-Directed where I recruit, hire, train, manage schedules and time sheets. We have 2 caregivers who help support her.

Her caregivers help me shower her, transfer her, provide me with a second set of hands to care for her. In addition, her caregivers provide companionship and help her access her community and do things she wants to do that are meaningful and purposeful to her and prevent her from being isolated.

Another essential piece of the DD waiver are the funds available as the last pay source for durable medical equipment she needs in her home (shower chair, adjustable bed frame that adjusts to help prevent reflux and pressure sores, iv poles and feeding pump, suction machine, standing frame, hoist lift).

The essential funds that are available to be used for modification of a vehicle (van with a ramp or lift for wheelchairs). Funds to make modifications to the home for accessibility (roll in showers, ramps to access the home, lifts to navigate stairs, etc.)

We are asking that all our programs be fully funded. We are also asking for an inflationary increase of 4% and 3%.

As I write this testimony it helps me reflect on the last 27 years of our daughter's life and how far we have come as a state supporting individuals with DD and their families. In 27 years, I have never been this fearful of losing supports and services for our daughter. I am a firm

believer of not living in the past but we do learn from history. The history of disability is dark and disturbing. Individuals with disabilities are now recognized not only equals but as amazing humans who give far more than they receive and are valuable members of their communities.

Thank you for this opportunity to provide testimony to the incredible importance of the DD waiver and disability supports and services. Your time and consideration are greatly appreciated.

Brenda Schmid

Hannah's Mom

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