



SB 2305
Senate Human Services
Monday, January 20, 2025
Senator Judy Lee, Chair

Chair Lee and Members of the Senate Human Services Committee:

My name is Roxane Romanick and I'm writing as the representative for Designer Genes of ND, Inc. Designer Genes' membership represents individuals with Down syndrome that either live in our state or are represented by family members in North Dakota. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

First off, I'd like to thank you for your work and investment in the concept of paid family caregiving during the 68th legislative session and help to kickstart the current pilot program. I'd also like to thank the Department for their dedicated work to "go live" and make the program a reality for 50 North Dakota caregivers. (Per 12-11-24 Cross Disability Advisory Council Meeting).

Designer Genes is in support of SB 2305 and asks for a "do pass" from this committee. We are asking your consideration of an amendment in Section 1.4 (on page 2), lines 18 – 19 to include the words "developmentally accurate and include a family statement of need". We are also open to a discussion about Section 1.4, lines 19 – 21 because we are still unclear how this affects a family's ability to use other waiver services, such as respite, if they are being paid a daily rate. This language exists in the current law from SB 2276 that you passed last session. When the paid family caregiving option is woven into the Medicaid waivers and being paid for with a Medicaid match, this will become a more critical consideration.

We estimate that there are about 600 individuals with Down syndrome that live in North Dakota and a majority of those individuals are screened to the Individuals with Intellectual Disabilities/Developmental Disabilities 1915c Medicaid Waiver. Quality waiver service options are one of our advocacy priorities and having the paid family caregiver option in our Medicaid waivers is important to our families across the lifespan. Individuals with Down syndrome and their families are able to achieve quality lives in their communities with the formal supports of the Medicaid waivers and State Plan

Medicaid. One thing that is important to note is that families who have children eligible for our Medicaid waivers depend on the service options within the waivers, but also depend on having access to State Plan Medicaid for their children. When they can't use waiver services due to a lack of workforce or quality providers, they run the risk of losing both the waiver service options and State Plan Medicaid. This option can help provide some confidence for families of children with exceptional need that they will not lose coverage.

We are concerned about the current assessment as it does not offer enough information to the Developmental Disabilities Section for children under 8. As you will probably hear in other testimony, the younger a child is, the less items that can be completed on the current assessment. For children with Down syndrome, this is especially concerning as many conditions such as congenital heart defects, gastrointestinal defects, and childhood leukemias may present themselves at birth. These conditions to name a few can cause lengthened hospitalizations, an inability to use typical child care, increased care coordination efforts, trips out of state for medical care, and missed work for parents. While an infant needs total care, the care for an infant with failure to thrive or who is post-surgical looks much different. We've got to figure out a way to "measure" this to assist our families during this time of increased pressure.

We understand the SB 2113 made changes to the Cross Disability Advisory Council (CDAC). Even with those changes, we continue to support Section 1.6 and think that CDAC is an effective method of assuring stakeholder involvement on the paid family caregiver service option.

Please consider the passage of SB 2305 with our suggested amendment considerations. I'm available for any questions.

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