



HB 1012

**Senate Appropriations – Human Resources Division
Tuesday, March 18, 2025
Senator Devor, Chair**

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

My name is Kendra Vander Wal and I am the Executive Director for Designer Genes of ND, Inc. Designer Genes' mission is to support individuals with Down syndrome and those who support them to earn, learn, and belong across our state. I stand before you with a unique perspective as a representative of Designer Genes, an early intervention /pediatric occupational therapist, as well as a mom to a 7-year-old son with Down syndrome.

At Designer Genes we estimate that there are over 270 individuals with Down syndrome living in North Dakota and a majority of these individuals benefit from State Plan Medicaid and the 1915 (c) Intellectual / Developmental Disability HCBS Waiver. These supports have been critical in ensuring that individuals with Down syndrome and their families have access to person-centered services that promotes independence, inclusion, and quality of life in their community.

Designer Genes works closely with individuals ranging from newborns, who may experience NICU stays or early intervention needs, all the way to adulthood. Starting from our youngest members, nearly all individuals with either a prenatal or birth diagnosis of Down syndrome are referred to early Intervention (EI) services. The impacts of EI services span far, as heard in Tina Bay's testimony, there were over 3,400 children served in EI between July 2023 - June 2024. Early intervention is often a family's first opportunity to help their child thrive which is why program management and EI supports are key intersection within the continuum of services available to individuals with Down syndrome and their families. Our family has experienced the importance of EI and its foundational impact from birth. Thanks to skilled speech therapists, his case manager, and EI team, we were able to effectively collaborate together to come up with goals that met our family priorities. Because of quality providers, we were able to teach our son sign language and other communication strategies and social skills during his early years. This decreased his frustration and allowed him to communicate with our family and peers in a childcare setting.

As families transition from EI supports after the age of three, robust case management, in-home and respite supports, and Home and Community-Based Services all support individuals and families throughout our state. Investing in these services not only uplifts individuals and families, but also ensures quality care and the amounts of services available for every person is based on the supports they need to live meaningful and engaged lives. Individuals with Down syndrome may face different challenges throughout the lifespan, some of which include



communication and language delays or difficulty with independence in daily routines. That is why we are committed to advocating for high quality providers that are supported, trained, and equipped to help the many individuals and families they are serving. Designer Genes is advocating for an increase in provider rates of 3% and 3% to continue to support high-quality services and to better align with federal inflation levels.

Our family is experiencing workforce shortage of providers through the process of applying for DD waiver-based services. Even though our son did not have to wait for a DD waiver slot, for over two months our family has been on the waitlist for in-home support at a few provider organizations. Therefore, we have not been able to receive waiver-based services. Although our family could utilize the self-directed services – which there are currently over 580 self-directed providers as heard in Tina Bays testimony and is a huge win for many families in North Dakota – we have not been able to dedicate additional time, energy, and resources to utilize this option. Therefore, we continue to wait for in-home and respite care support at local provider agencies.

Continued investment in the developmental disability section and Medicaid supports are important for many individuals in ND. It is not only a budgetary decision, but a decision that has significant impacts on the many families who rely on these services daily across our state.

Thank you for your time and I welcome any questions you may have.

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