



House Appropriations - Human Resources Division
HB 1012
February 5th, 2025

Chairperson Nelson and Members of the Committee,

My name is Kendra Vander Wal, and I am representing Designer Genes of ND. Designer Genes represents roughly 270 individuals with Down syndrome and their families across the state. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong. My passion in the organization is primarily driven by my background as an early intervention and pediatric occupational therapist and being a mom to a six-year-old son with Down syndrome.

Although individuals with Down syndrome have benefited from support within the Developmental Disabilities Section, there continues to be significant gaps in the areas of early intervention, early childhood services, program management, and home and community-based waiver services. As heard in Tina Bay's testimony yesterday, of the 8,400 individuals served in 2024, 41% of those individuals were under the age of three. Nearly all individuals with either a prenatal or birth diagnosis of Down syndrome, are referred to early intervention (EI) services, which is why program management and EI are key intersections 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 and his EI team, we were able to effectively teach our son sign language and other communication and social skills during his early years, which tremendously decreased his frustration and allowed him to communicate with our family.

Now that he is six, we are witnessing firsthand the workforce shortage of providers through the process of applying for DD waiver-based services. Even though our son didn't have to wait for a waiver slot, for over two months, our family has been on the waitlist for in-home support at multiple provider organizations and therefore we have been unable to receive waiver-based services. Although we could utilize the self-directed services — which over 790 claims were made in 2024 and is a huge win for many families in North Dakota — our family has not been able to dedicate additional time and resources to utilize this option and continue to wait due to the provider shortage at local agencies.

Early Intervention, early childhood services, and in-home support are valuable resources for families. Due to their home-based model and providing services in the least restrictive environment - families know quality providers make an impactful difference. Almost all individuals with Down syndrome are faced with a level of complex feeding, communication, behavioral and motor difficulties making it challenging for families to choose the best childhood support service for their loved one. This is why inclusive child care grants and an inclusion support coach are being requested in the Early Childhood Section executive budget to support facility and program needs. The Inclusion Support Program maintained 97% of all of the child care placements that they supported. This program helps to keep little kids with Down syndrome in their child care placements.

I am also advocating for increased provider wages so that competitive salaries reduce provider turnover and help cover inflation costs as well as improve service quality. The Developmental Disability Section is critical because it supports services that are foundational to the well-being and success of individuals with Down syndrome across their lifespan. Although I have highlighted early childhood and in-home supports, the DD section also covers residential services and day supports for adults. Again, the providers delivering these services are essential, yet provider organizations face significant challenges in maintaining a stable, qualified workforce due to wage disparities. It is why we are advocating for an inflationary increase to 4/3% as aligned with The North Dakota Association of Community Providers (NDACP). Residential and day supports ensure adults with Down syndrome can live meaningful, engaged lives with purpose.

Without sufficient investment in the developmental disability and early childhood sections, we risk service disruptions that can have profound impacts on individuals and families who rely on these supports daily. Our family specifically, has experienced the disruption in services due to provider shortages and therefore are feeling stretched with finding the appropriate community support for our son. Continuing to invest in the Developmental Disability section within our state is not just a budgetary decision; it is a reflection of our state's commitment to its most vulnerable citizens. It acknowledges the importance of these services to help our community thrive as well as investing in the providers to sustain and strengthen services essential to so many individuals with Down syndrome and their families in North Dakota. We know that this work cannot be done alone and Designer Genes is willing to partner in any way that would be helpful.

Thank you for your time and consideration.



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