



HB 1012
Senate Appropriations – Human Resources Division
Tuesday, March 18, 2025
Senator Dick Dever, Chair

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

My name is Roxane Romanick and I here today representing Designer Genes of ND, Inc. Designer Genes’ membership is made up of 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.

We estimate that there are about 600 individuals with Down syndrome live in North Dakota and a majority of those individuals are screened to the Individuals with Intellectual Disabilities/Developmental Disabilities (IID/DD) 1915c Medicaid Waiver. One thing that is important to note is that our families who have individuals 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 loved ones. Quality waiver service and State Plan options are one of our advocacy priorities as 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.

Cross Disability Advisory Council and Waiver (Reference – Sarah Aker’s Medical Services detail):

First off, I’d like to thank you for your work and investment in the Cross Disability Advisory Council and continuing work towards a Cross-Disability 1915c Medicaid Waiver for children who fall through the eligibility cracks of our current waiver system. Designer Genes has been talking about this issue for many sessions because we have families whose children with Down syndrome fall off of waiver services when they turn 3. We appreciate the investment in the study by Alvarez and Marsal in the 2021-2022 interim and their continued work with the Cross Disability Advisory Council during the 2023 – 2024 interim. We support the Governor’s budget request for continued work on the Cross Disability Waiver.

Family Voices of North Dakota Funding (Reference – Kim Mertz’s Healthy and Safe Communities detail):

We are in support of the funding for Family Voices of North Dakota as included in your current version of the bill received from the House. Their partnership is invaluable when supporting and

educating our families. We partner with them on Project Carson, which seeks to support families across the state who receive a prenatal diagnosis. This is especially important for our organization as one of our priorities is to support all new diagnoses of Down syndrome which now are primarily happening pre-birth. We have been active partners in Family Voices Parent Leadership Institute which has helped many of our families to become better advocates for their family member with Down syndrome. We also partner with the Special Health Services Section to place new baby support packages into birthing hospitals across North Dakota. There is no state funding involved with this collaboration, but we appreciate the ability to work with the Newborn Screening team to make sure families have needed information when they find out their baby will have Down syndrome.

Autism Waiver (Reference Sarah Aker's Medical Services detail): While most of our families depend on the IID/DD Medicaid Waiver, never less we are concerned about the loss of \$9 million dollars in the Autism Waiver line item. Any loss of funding for individuals with disabilities is concerning and also leaves a footprint for future funding decisions across disability populations. This decrease was discussed in the House with the Department and it appears that it's due to a lack of providers and utilization. This is concerning, because we know that we have autistic individuals who struggle to remain in their communities and are at-risk for being institutionalized. We have students who are experiencing seclusion, restraint, expulsion and suspension in schools. We have need and there are reported to be 65 children on the wait list. HB 1067 extends the age limit to 21 years of age for the Autism Waiver. It is important to note that if a child can't use a waiver service option, then they are high risk for falling off the waiver and then also losing State Plan Medicaid benefits. The access to Applied Behavioral Analysis services is only through State Plan Medicaid benefits so falling off a Medicaid Waiver is high stakes for many families. North Dakota does have an option for families of children with disabilities to buy-in to State Plan Medicaid, but it is highly complicated to access and presently only 3 families are eligible for this option. This has been in place since 2007.

Thank you for your time and I would stand for any questions.

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