



**SB 2012**  
**Senate Appropriations – Human Resources Division**  
**Tuesday, January 24, 2023**  
**Senator Dick Dever, Chair**

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

My name is Roxane Romanick and I am writing as the representative for Designer Genes of ND, Inc., as their Executive Director. Designer Genes’ membership represents 230 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.

Designer Genes represents a group of individuals and families who are frequent users of the Department of Health and Human Services (Department) Developmental Disabilities Section’s (DD) services. You will find individuals who have Down syndrome receiving services, such as In-Home Supports, Residential Habilitation, Day Supports, Equipment and Supplies, Infant Development, and Supported Employment across the lifespan and across our state.

I’d like to spend my time this morning focusing on North Dakota’s Part C Early Intervention (EI) system which supports infants and toddlers with delays and disabilities (Birth through 2) and their families. The budget for this program is contained within the DD Section budget. In Tina Bay’s testimony from January 17, 2023, she included this slide showing 3179 children under 3 being served in SFY 22 under Program Management. It is likely that the vast majority of these children are enrolled in the EI system.



Most babies with Down syndrome and their families, whether diagnosed before or after birth, are referred to North Dakota’s EI system. For these families and their new babies, this service provides them with service coordination through the DD Program Management system, access to a

family income and asset disregard for Medicaid for the child, screening to the Individuals with Intellectual Disabilities/Developmental Disability (DD) Waiver so that they can receive the Infant Development program services from a regional provider and any other relevant waiver services. The Infant Development services are provided through a home visiting model, bringing the services to the infant/toddler where they are at and works in partnership with the family to support the child's development. Professionals such as physical therapists, occupational therapists, and speech and language therapists deliver the services designated through an Individual Family Service Plan (IFSP). North Dakota has braided the needed requirements under the Individuals with Disabilities Education Act (IDEA) Part C with the wrap-around supports under our DD waiver to assure a robust approach for our youngest children with disabilities and delays.

Both the state employee and provider increases that you are considering affect this program as an eligible child in EI and their family will be supported by a DD Program Manager and a DD licensed provider. We ask that you consider a rate increase for the provider system that is the same as state employees. This will benefit not just our infants and toddlers with Down syndrome, but all of our individuals receiving DD services across the life span.

The ND EI system described above is funded through a mix of a federal discretionary grant, Medicaid and state general funds. Other critical components of the system include a developmental screening program called Right Track, training and technical assistance, and peer supports for families. Because I have not seen the Department's detail, I am unaware of the funding status for these other EI activities in the Governor's budget, but would urge the committee to maintain the funding that is in place for this current biennium.

I remain a committed advocate of the ND Part C EI system because I truly believe that I do what I do today because of the supports I got when my daughter was young. I also believe that my daughter, who has Down syndrome, had the right start from ND EI to graduate from high school, go to college, and become an employee of our local school district. I think that she's living proof of your return on investment.

Thank you for your time and I'd answer any questions.

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