



**SB 2012**  
**House Appropriations – Human Resources Division**  
**Thursday, March 9, 2023**  
**Representative Jon Nelson, Chair**

Chair Nelson and Members of the House Appropriations – Human Resources Division:

My name is Roxane Romanick and I am here today as the Executive Director for Designer Genes of ND, Inc. 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 a variety Department of Health and Human Services (Department) services extending across several sections. Below I'll outline the points that are relevant to those specific sections:

**Developmental Disabilities Section's (DD):** We estimate that over 90% of the individuals with Down syndrome that we are connected with are 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. These services are all made possible by the state's Individuals with Intellectual Disabilities/Developmental Disabilities (IID/DD) Medicaid 1915c Waiver. Living in the community with quality is dependent on these services whether individuals live on their own, in congregate situations, or with family members. **It is for that reason that we are asking you to consider the ask from the North Dakota Association of Community Providers for an increase to their rate structure.** Over and over, we are hearing the stories about individuals and families going without services. The underutilization in DD is evidence that services that are authorized are not getting delivered. We have to stay competitive with the wages that we are offering to our direct care staff.

North Dakota's Part C Early Intervention (EI) system 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 March 7, 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.

Developmental Disabilities Program Managers served almost 8,000 children and adults in SFY22.



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.

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.

Both the state employee and provider inflationary 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. **The Department asked for additional FTE’s for DD Program Management, as well as one administrative FTE that will assist with this program. Due to the increases that continue in this area and the importance of the work to act early, we ask for your support on this request.**

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.



**Children and Family Section:** Our organization is specifically concerned with funding within the Child and Family Section of the Department of Health and Human Services (Department) budget that is targeted to family to family supports. The funding contained in the 2021-2023 budget is contracted to a non-profit partner, Family Voices of North Dakota. Family Voices also serves as our state’s Family to Family Health Information Network as well as our Parent-to-Parent organization. Designer Genes values our collaborative partnership with Family Voices. Because of their robust outreach effort, they can easily get information out statewide and can partner on a variety of projects to meet the needs of families. **This funding was restored in the engrossed version of SB 2012 and we ask for your support to keep this funding in SB 2012.**

**Early Childhood Section:** Last but not least, I’d like to ask for your continued support for the Inclusion Support Program (<https://www.nd.gov/dhs/services/childcare/inclusion.html>). The Inclusion Support Program has two main components to assure young children with disabilities can be supported in a typical child care setting. These are a grant program for child care providers for additional staffing, equipment, supplies, and/or facility modifications and inclusion specialists to help stabilize, maintain, and enhance placements of children with disabilities. Designer Genes wants to know that there is a strong continuum of opportunities for our youngest members who have Down syndrome and the Inclusion Support Program is critical to that work. Presently, the funding for this bill is built into the Department’s budget and in engrossed SB 2012. **We ask that you continue this funding.**

**Developmental Disabilities/Medical Services Sections: Please restore the language of HB 1035 into SB 2012 as you move the work forward.** HB 1035 established permission for the Department to move ahead on developing a cross-disability waiver for children and redesigning their eligibility system. We are in support of this work because our families find the eligibility for DD services to be highly onerous and difficult to navigate. It is the hope that streamlining our waivers and the eligibility will assist families in accessing services.

I’m in this work because of my personal and professional experiences and I’ve been at it a long time and experienced many trends. While the public support that you have legislated in the past has always been very important, we are now at an unprecedented time where we you’re your urgency and action. We know that none of us can do this work alone and Designer Genes is willing to partner in any way that would be helpful.

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

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