



HB 1012
Senate Appropriations
Thursday, March 11, 2021
Senator Ray Holmberg - Chairman

Chairman Holmberg and Members of the Senate Appropriations:

My name is Roxane Romanick and I'm representing Designer Genes of ND, Inc., as their Executive Director. Designer Genes' membership represents 260 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.

Individuals with Down syndrome have made many strides in living in their homes, schools, and communities because of educational and medical advances, public policy, and advocacy efforts. Public investments in early intervention, family support, public schools and special education, post-secondary school options, and home and community-based services do make a real difference for people with Down syndrome. The vast majority of our membership are living in home and community-based settings. Thank you for your important part in opening up these opportunities.

My daughter, Elizabeth, and our family are an example of the positive outcomes of this investment. Elizabeth has been a consumer of services from the first day of her life when her Early Intervention staff visited her in the hospital until the present with support from Vocational Rehabilitation and the Minot State Access Disability Services and the ASTEP program. Her education was supported by special education and general education from 2002 to 2018. A number of her job experiences have been supported by Vocational Rehabilitation. As a family, we have been supported by Family Voices of ND as well as the connections we've made through Designer Genes and the rest of the Down syndrome community across a wide arena of areas. All of these services and supports poured into a reservoir that she is depending on as she works on an Early Childhood Paraprofessional Associates from Dakota College of Bottineau. Who would have thought?

Our organization has interest in a number of areas of HB 1012 and this single piece of testimony is presented to draw your attention to those areas:

1. Developmental Disabilities Division

a. Restore the Experienced Parent Program Funding

The Experienced Parent Program has been a part of the North Dakota Part C Early Intervention system for close to 25 years. The program provides funding to hire parents who had children in Early Intervention to support and mentor other parents in

the Early Intervention system. Originally, the funding was contracted out through our Human Service Centers.

In the current baseline budget, the program was been funded with \$100,000 of state general funds and \$160,000 of the federal Part C grant through the Department of Education. This funding was secured in the 65th session. This past December, Tina Bay, Director of the Developmental Disabilities Division, informed the North Dakota Interagency Coordinating Council that the \$100,000 of state general funds would be cut. This was understood to be part of the Department's savings plan. In addition, it became known that the \$80,000 was no longer included in the budget for the federal Part C grant, nor is it in the one for FFY '21. This leaves the program unfunded and thus eliminated. **I am asking that this loss of \$260,000 for family support in our state be restored.**

Family-to-family support, parent support, peer support – call it what you want - is a critical element in sustaining the confidence and competence for families who have children with special health care needs. While we don't receive any state and/or federal funds, to offer an example, Designer Genes is designed expressly with that purpose in mind. In a 2005 research study of postnatal support of mothers of children with Down syndrome ([mere 43 304.196 212.tp \(brianskotko.com\)](http://www.brianskotko.com)), the vast majority of mothers reported a desire to be connected to their local down syndrome organization “which can provide practical knowledge in addition to establishing the beginnings of a long term support relationship.”

Our families who are raising children with special health care needs depend on connecting with peers who have lived experience either through their own experiences or through helping other families. We need structured approaches to matching families with other families like Family Voices of North Dakota does through their Parent-to- Parent program.

In this same spirit, we are asking for a full restoration of funding for family support that are in Children and Families as well as Behavioral Health. A total of \$30,000 is being cut from agreements with Family Voices of North Dakota and Federation of Families. In total, this would be a loss of almost \$300,000 for the very programs that keep many of our families on requiring deeper end services.

- b. **Payments for Developmental Disability Services** – We stand in support with other advocacy efforts and the DD provider system to ensure that HB 1012 has the necessary funding for Developmental Disability Services. Our individuals across the life span from infants and toddlers in our Early Intervention (Infant Development) to our oldest individuals with Down syndrome rely on this system. We agree that a 3%/3% provider

increase is needed to address wage pressures and workforce shortage. Every dollar makes a difference in our communities, so we also ask that the Department continues to pay the accreditation costs.

2. Vocational Rehabilitation

- a. **Restore state general funds for the Centers for Independent Living** – If anyone should be testifying on this section, it's my daughter, Elizabeth. Through Dakota Center for Independent Living (DCIL), she was able to get her driver's permit. DCIL's active engagement on the Bismarck-Mandan Mayor's Committee on People with Disabilities helped her to know about their scholarship program, of which she's been awarded funding the last 3 years. Probably what she would tell you about the most though is their Youth Empowering Social Status (YESS) movement and the opportunities that she's had to develop leadership, speak publicly, and connect to other youth and young adults with disabilities and without. Sustaining our four Centers for Independent Living is another piece of assuring individuals with disabilities in our state live quality lives.

Thank you for your time and I will take any questions that you may have.

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