



HB 1012

House Appropriations – Human Resources Division

Monday, January 25, 2021

Rep. Jon Nelson - Chairman

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

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. **Payments for providers** – We stand in support with other advocacy efforts and the recommendation to award providers within the Developmental Disabilities system up to a 3%/3% increase. 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.

- b. **Eliminate the \$11 million in state cost savings to the adult services providers** - This cut to our providers is devastating. The provider system has been stressed due to COVID, recruiting and maintaining staff, and assuring health and safety for everyone that they serve. These challenges put individuals at risk of institutionalization and instead of helping more individuals to move out of the Life Skills Transition Center, we will see the reverse happening.
- c. **Restore and reallocate \$100,000 Experienced Parent Funding** – In the 65th session, a number of advocates worked with legislators to secure an amendment on HB 1012 for \$100,000 in state general funds and \$160,000 in designated funds from the federal Part C grant to support the Experienced Parent program within the ND Part C Early Intervention system. In her January 20, 2021 budget detail testimony, Tina Bay, Director of the Developmental Disabilities Division, reported that this funding (both state and federal grant) would be cut as part of the state’s cost saving plan.

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. Our organization for one 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 need other families to connect with 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. I am requesting that upon restoring the \$100,000 cut from the DD budget that it is reallocated to the Children and Family budget and passed on to Family Voices of North Dakota. (See below). Family Voices will put this money to work from Day 1 for the citizens of North Dakota and has the resources to do so.

2. Children and Family Services

a. Restore \$100,000 to Family Voices and Reallocate \$100,000 from DD

I am requesting that \$200,000 be restored and given to Family Voices of North Dakota. They currently have \$175,00 in the 2019-2021 biennium and have been told that \$100,000 is being eliminated due to the cost savings plan. With your restoration and reallocation, they would have \$275,000 to continue, plus expand the work they do to help families navigate and access a variety of service delivery systems. Believe your

money will go to work. Without an amendment from your committee, our North Dakota families will have lost \$200,000 in critical supports.

3. 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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