



SB 2256
Senate Human Services
Tuesday, January 26, 2021

Chairman Lee and Members of the Senate Human Services Committee:

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.

We are keenly aware that public supports for our individuals living with Down syndrome and their families are key to their ability to live with dignity and quality in our schools, homes, and communities. Needing public supports is never easy and our individuals and families are grateful for the assistance they get. One of the many questions I'm asked when I meet a family who is expecting a new baby with Down syndrome is "How will I be able to afford this?" Understanding that they have partners both publicly and privately gives them confidence that they will be able to move forward in raising a child with Down syndrome. My husband and I faced the same news 22 years ago as we found ourselves expecting our daughter, Elizabeth. It brought us great peace to know that we would not be facing someone at delivery telling us her only option was placement in the institution and that, in fact, we were confident that there were great supports waiting for her in the ND Part C Early Intervention system, Bismarck Public Schools and along the rest of her journey.

I am here today to ask your assistance to make the path even smoother for families that find themselves caring for a loved one with a special health care need or a disability like Down syndrome. We have some solid public services in ND and we have some gaps. I see them when I'm trying to assist families with navigating our system of supports.

In the past, you, the Legislature, have heard from parents who have children with Down syndrome, cerebral palsy, and other special health care needs that had amazing wrap-around services until age 3. As eligibility criteria changes, they were deemed no longer eligible for DD Program

Management, de-screened from the IID/DD 1915 (c) waiver and then had no way to access Medicaid, In-home supports, additional therapies, equipment or supplies, or behavioral health support.

I'm asking you to give SB 2256 a "do pass". The gap between our working eligibility processes for Developmental Disability services and our state definition of developmental disability is real. And it starts with children, the youngest of them being just shy of three years old.

I have stood before this committee and Appropriations to ask you for help in addressing the gaps in services for children that have Down syndrome and complex health conditions and find themselves falling off the Intellectual Disability/Developmental Disability (IID/DD) Waiver when they turn 3 years old. Advocates have gotten studies passed but the studies have not resulted in changes that address the issue. In the 65th session, \$500,000 was included in the Department's budget to partially address this issue, but as far as I know, the money was not used to address the gap.

In 2017, the National Association of State Directors of Developmental Disability Services (NASDDDS) was contracted to conduct a study. (<http://nd.gov/dhs/info/testimony/2017-2018-interim/human-services/2018-1-4-handout-nasddds-ta-recommendations-opportunities.pdf>) Entitled "Report to North Dakota: Eligibility, Service Array, and Person-Centered Practices: Observations and Recommendations for Consideration this report outlined recommendations for the state to consider. While there was legislative intent for the NASDDDS study to address eligibility for children, the report did little to further that effort. Very young children (under 3) continue to be subjected to standardized intelligence testing that can result in either false positive or false negative results and thus affecting the eligibility determination. No changes have occurred to address this.

We know that addressing this gap will mean serving additional individuals. But they are individuals that we should be serving. They are individuals with developmental disabilities and our state definition is clear on our responsibility to them.

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

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