



A·DOWN·SYNDROME·SUPPORT·NETWORK

SB 2256

House Human Services

Tuesday, March 9, 2021

Rep. Robin Weisz, Chairman

Chairman Weisz and Members of the House 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 receive. 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 an institution and 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 but there are cracks where children and adults fall through because they don't meet the eligibility criteria that our state has designed. I see these cracks in my family support when I'm assisting families to navigate 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 a robust system of wrap-around

services until age 3. Annually, North Dakota serves roughly 3000 children and their families in our Part C Early Intervention program for infants and toddlers with delays and disabilities. We have maximized the use of the federal Medicaid match for this program, so close to 100% of the children can be eligible for state plan Medicaid as well as being screened to our Individuals with Intellectual Disabilities/Developmental Disabilities (IID/DD) 1915(c) Medicaid waiver. Children with conditions like Down syndrome are essentially automatically eligible for this program based on their diagnosis. At age 3 however, all of the children face more stringent eligibility criteria both for school-based special education services as well as continued support under the IID/DD waiver. While it is very appropriate for many of these children to find their delays mitigated, we have children whose special health care conditions continue and their needs don't stop. As eligibility criteria changes, they face being no longer eligible for Developmental Disabilities Program Management, de-screened from the IID/DD waiver and then have no way to access Medicaid, In-home supports, additional therapies, equipment or supplies, or behavioral health support. In the past, I have testified that this includes toddlers with Down syndrome.

I'm asking you to give SB 2256 a "do pass" with the proposed amendments. One example of why this study is needed is the stark differences between our working eligibility processes for Developmental Disability services and our state definition of developmental disability as found in NDCC 25-01.2-02. As I noted earlier, these differences leave young children at the age of 3 with physical disabilities, significant health issues, undiagnosable intellectual disabilities, and developmental delays without the supports that they were receiving the day before their third birthday.

In the past, 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. This bill is different from previous studies, because it directs our attentions to

our North Dakota's century code and the language of "appropriate treatment, services, and habilitation for those disabilities in the least restrictive appropriate settings".

We acknowledge 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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