



HB 1035
House Human Services
Wednesday, January 4, 2023
Representative Robin Weisz, Chair

Chairman Weisz and Members of the House Human Services Committee:

My name is Roxane Romanick and I'm writing as the representative for Designer Genes of ND, Inc., as their Executive Director. 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 is in support of HB 1035 and asks for your consideration of a "yes" vote. The content of HB 1035 was put forth following Human Services Interim work stemming from the passage of SB 2256 during the 67th session.

Our organization was involved in the passage of SB 2256 during the 67th session and have closely followed the work of the Human Services Interim committee, including the work of a study conducted by Alvarez and Marsal. This is a link to their summary presentation during the interim: [North Dakota Developmental Disabilities Study \(ndlegis.gov\)](#). We have been interested in seeing a better alignment between North Dakota's Century Code language and the eligibility determination practice in the field for individuals with developmental disabilities. We have supported previous attempts to assure that children with Down syndrome have a more seamless transition without onerous eligibility requirements when they turn three, resulting in the addition of Down syndrome into the ND Century Code in the definition of someone with a developmental disability ([North Dakota Century Code t25c01.2 \(nd.gov\)](#)).

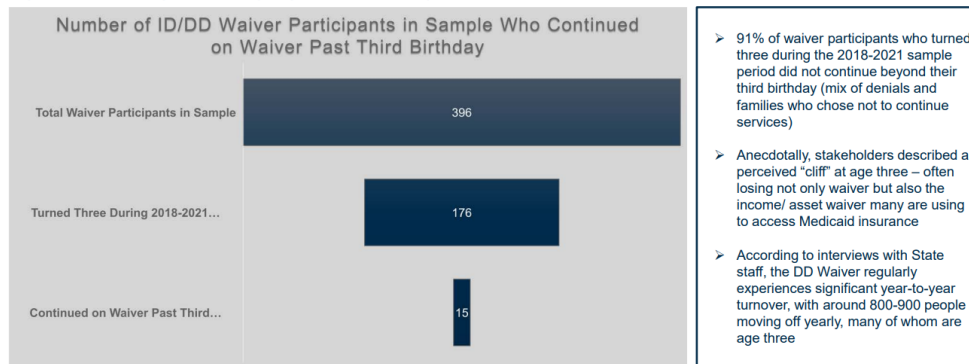
The SB 2256 study was pursued to make the path smoother for families that find themselves caring for a loved one with a special health care needs or a disability like Down syndrome. We have some solid public services in ND but there are cracks that children and adults fall through because they don't meet the eligibility criteria that our state has designed. I see these cracks through my family support work when I'm assisting families to navigate our system of supports.

Section 3 and Section 4 of HB 1035 provides the necessary permissions for the Department of Health and Human Services to move forward to address these system gaps. The Alvarez and Marsal study recommended a three-phase implementation to streamline our current 1915c Medicaid waivers and creating a cross-disability 1915c Medicaid waiver to serve a wider population of eligible children. This work would re-evaluate the eligibility criteria used for children, create more appropriate assessment of need, and assure a more seamless and less confusing transition for children and their families.

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. The Alvarez and Marsal study found that only 9% of the children exiting ND Early Intervention services continued to receive services under a 1915c Medicaid Waiver:

The Opportunity: Improving The Experience for Young Children Ages 3-5

North Dakota's DD Waiver offers strong support for children under three; however, stakeholder interviews and data analysis indicate there is a significant drop-off at age three, when young children still do not yet have access to additional school supports



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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 no longer being 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.

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.

We would also like to offer some possible language for amendments to Section 1. In lines 14 – 17, we suggest that the contracted facilitator work with the department to establish an application and selection process to establish the initial council and that thereafter the council manage membership recruitment and maintenance with assistance from the contracted facilitator. In lines 17 – 18, we believe that the presiding officer should be selected by the seated advisory council. We also suggest that an additional responsibility in Section 1.5 would be to provide feedback to the department on support and service provision to individuals with disabilities.

I'm available for any questions.

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