



HB 1416
House Human Services
Tuesday, February 2, 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.

I am here today to provide testimony on HB 1416 and am encouraging a "do pass" from your committee. Beyond the general and typically known early childhood experiences, like child care, North Dakota's infants, toddlers, and preschoolers with Down syndrome and their families are additionally supported with our North Dakota Part C Early Intervention system (birth to 3) and special education supports (3 – 5). This gives Designer Genes good reason to care about this bill.

When I say "care", I mean that the main focus of testifying and watching the process of this bill is to make sure that the smallest individuals with disabilities and delays are not left out of the conversation nor are they in any way negatively impacted. Our organization cares about two main outcomes in this process: **1) that all early childhood experiences in North Dakota are inclusive and 2) that families are supported to help their children, in their own unique ways, to learn, grow, and be healthy.**

I have to be honest with you, when I read that HB 1416 gave the Department of Human Services the authority to act "on behalf" of the Department of Public Instruction to administer "Part B of the Individuals with Disabilities Education Act (IDEA)", I almost fell off my chair. Section 3 of the bill which creates a new subsection to 50-06-05.1 holds both promise and concern for me. Let me explain.

A position statement created by the Division for Early Childhood and the National Association for the Education of the Young Child states: *“Early childhood inclusion embodies the values, policies, and practices that support the right of every infant and young child and his or her family, regardless of ability, to participate in a broad range of activities and contexts as full members of families, communities, and society. The desired results of inclusive experiences for children with and without disabilities and their families include a sense of belonging and membership, positive social relationships and friendships, and development and learning to reach their full potential. The defining features of inclusion that can be used to identify high quality early childhood programs and services are access, participation, and supports.”* (DEC & NAEYC, 2009) <https://www.decdocs.org/position-statement-inclusion>. The very youngest of children with Down syndrome as well as other children with special health care needs and/or disabilities benefit from high expectations and inclusive practices. Actually that’s true for all the children. The bill has the potential to recognize that children with disabilities and delays will be included and will not be an afterthought as so often can happen. I have been actively engaged in early childhood advocacy from a disability perspective since 2000 when my daughter turned one, and I have not seen comprehensive top-down action and legislative initiative like this bill represents. I want to acknowledge those of you that crafted the language of the bill. If you, our legislative body, and our agency leaders value inclusion, then you can drive change. This holds promise for me.

Our children (ages 3 – Kindergarten entry) with Down syndrome and other disabilities will need you, our legislative body, our agency leaders, as well as our local school districts to remember and honor the obligations under IDEA. Today, we have well-intentioned leaders working on this legislation, but we will all change places with someone coming along behind us who does not share the same institutional memory. Critical issues such as funding streams, monitoring requirements, teacher credentialing, and adhering to procedural safeguards all hang in the balance. I am requesting that the committee explore alternate language in Section 3 that better represents the operations that will need to take place between the Department of Public Instruction and the Department of Human Services to deliver IEP supports to our preschoolers who qualify. A possible change may be (Page 2, Line 28) “To act **in conjunction with** the department of public instruction...”.

One of the concerns that I have had is that not all three-year-olds on IEP's are receiving services in an inclusive, developmentally appropriate setting with a robust set of special education supports decided in collaboration with their family. In particular the three-year-olds struggle because four-year-old programs have been developed and you have to be a certain age at a certain time. When there is a preschool-like experience provided, our three-year-olds often miss out on inclusive experiences because only children with IEP's are included in a classroom. Current licensing regulations make it prohibitive for a school district to include other three-year-olds not on an IEP. Attending private preschools may be out of the question because the child is not potty-trained or needs an instructional aide for supervision and other reasons. Advocating for IEP services that are tailored to meet the child's needs is difficult for families and families face having to take what they are offered. Often the only service offered is for them to bring their child in during school hours for discrete skill training that can be developmentally inappropriate and definitely does not promote inclusive interaction with other children. First of all, young children do not learn well in this environment and most working parents face difficulty transporting their child during the day. I desire a comprehensive approach that will fix the above issues and it will take your attention and the work of DHS and DPI to make it happen.

My final point is around the promotion of family engagement. From Head Start, Early Head Start, home visiting programs to Part C Early Intervention, family leadership and partnership are inherent to the work. Early Childhood experiences happen with and in partnership with families whether that be child care, skill-based parenting supports, development and delivery of Individual Family Service Plan supports in Part C, or preschool experiences. The federal Office of Head Starts recognizes family engagement as "...a shared responsibility of families and staff **at all levels** that requires mutual respect for the roles and strengths each has to offer. "<https://eclkc.ohs.acf.hhs.gov/family-engagement#:~:text=Family%20engagement%20is%20a%20collaborative%20and%20strengths-based%20process,the%20roles%20and%20strengths%20each%20has%20to%20offer.>) Both my daughter and myself are products of our early childhood experiences. I am the advocate that I am today because I was nurtured to take the reins by her professionals in Early Intervention.

In this spirit, I am also asking the committee to consider amending the language on Page 6, Lines 7 and 8) to substitute "The parent..." with "Three parents..." in each line. Yes, this will increase the number serving on the Council, but it will move to equalize family voice with the 18 professional voices that are

appointed. Please consider other ways that family engagement can be emphasized as you discuss the bill. Other options might be strengthening the bill to partner with community family support entities, build in parent-to-parent supports, as well as leadership opportunities for families. Presently, roughly \$370,000 dollars have been cut in the Department of Human Services budget to directly support families' competence and confidence through family-based family support. \$260,000 of that is specifically in the area of early learning (Part C Early Intervention). Requests have been made to House Appropriations – Human Resources Division to restore this funding. Your support of this effort as it aligns to the need for family engagement in early childhood would be deeply appreciated.

I wholeheartedly believe that Elizabeth Romanick is a product of her earliest experiences. As we engage in a discussion about early childhood investments, we will be talking about outcomes. As we do, keep Elizabeth in mind. From a first year of significant health concerns, including open heart surgery and a seizure disorder, to present, which finds her attending a joint post-secondary effort between Minot State University and Dakota College of Bottineau to take early childhood classes herself. I regularly get texts with apartment listings and plans to “move out” as soon as she is done at Minot. Our work through her early years and beyond was to mitigate the impact of having a diagnosis of Down syndrome and increase her independence and self-determination as much as possible. I may be biased, but I think that her life is a testament to the positive outcomes that can happen when we engage early with children and families.

Thank you for your time and I look forward to your questions.

Roxane Romanick
Executive Director
Designer Genes of North Dakota, Inc.
701-391-7421

