



HB 1416
Senate Human Services
Wednesday, March 10, 2021
Senator Judy Lee, Chairperson

Madam Chair 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.

I am here today to provide testimony on HB 1416. 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. While I am in support of the concept of HB 1416, I do hope for some amended changes to the bill which I will discuss below.

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 NDCC 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. 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. This is the potential and promise I see in the bill. 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 like this bill represents.

Now to address my concern which is specifically around language in Section 3. 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 for services under the Individuals with Disabilities Education Act (IDEA) who are 3 to 5 years-old. A needed change is to **amend the language** on Page 2, Line 6, **“To act in conjunction with the department of public instruction...”** vs **“to act on behalf of...”**. I don’t believe that IDEA Part B allows a relinquishment of responsibility to any other agency outside of the state education agency. I do not believe that the engrossed bill from the House which added the language “Section 619” to Section 3 was helpful because all provisions of IDEA are relevant to any student on an IEP no matter their age. Our North Dakota public school districts are responsible for serving three through five-year-old’s who have IEP’s. Section 619 of IDEA is best known as the 3 – 5-year-old provision in the federal law, but it really only outlines federal discretionary spending for this age group. Critical issues such as funding streams, monitoring requirements, teacher credentialing, and adhering to procedural safeguards all must be attended to in this redesign.

I'm also requesting that you please consider a **language change** on Page 2, Lines 22 – 23 from “Has documented the provider's willingness to admit children of all learning abilities into the early childhood education program” to **“Has documented the provider’s willingness to admit any child, no matter their level of functioning across all domains of development, into the early childhood program and be willing to collaborate with the child’s Local Education Agency (LEA) to implement the child’s 504 or Individual Education Plan.”** It is usually not the “learning ability” of a child that get in the way of them being admitted or maintaining a typical early childhood experience. It is usually things like being potty trained, undesirable behaviors, and need for increased supervision. It is also important that push-in services from the LEA are allowed and welcomed.

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.>)

In this spirit, I am also asking the committee to consider **amending the language** on Page 6, Lines 2 and 3 to substitute “The parent...” with **“Two parents...” in each line. I also think that a parent representative that has a child in the new Four-Year-Old program should be included.** Yes, this will increase the number serving on the Council by three, but it will move to equalize family voice with the 21 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 \$290,000 dollars have been cut in the Department of Human Services budget to directly support families’ competence and confidence. \$260,000 of that is specifically in the area of early learning (Part C Early Intervention). Requests will be made Senate Appropriations to restore this funding. Your support of this effort as it aligns to the family engagement 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. It’s hard to know what savings have occurred in just her case, but if she’s able to work in the early childhood community, become a tax payer and give back to her community then I think we can say that the investment was worth it.

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

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