



HB 1466

Senate Human Services

Wednesday, March 10, 2021

Senator Judy Lee, Chair

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 1466 and am encouraging a "do pass" from your committee. I am offering two amendments for your consideration that were not included in the engrossed version from the House. 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.

As I said yesterday in my testimony, our organization cares about two main outcomes in HB 1416 and HB 1466: 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.

Because of that I am requesting your attention to two possible language changes in HB 1466 for your consideration:

1. Page 5, Lines 21 – 22: I would like to suggest that the language "research-based family engagement" be replaced with "**family engagement best practices**". This change allows more flexibility to the four-year-old program staff to engage with parents across a wide range of

practices, like evaluating the times that parent activities are held or using active listening to engage families. The language “research-based family engagement” lends itself to a activities such as offering a set curriculum or model that is stated to be research-based to enhance parenting skill in a certain area, but does little to improve relationships, interaction, and engagement by family members. While “best practices” do not have the rigor of evidence-based practices or research-based programs or practices, they do offer a wider range of strategies that the staff have available to them to make sure families are engaged.

The bill also calls for “10 hours”, my preference would be to see this removed and require the programs to have family advisory councils that would help to develop leadership, engagement, and ownership in the local programs.

Possible language for this section might be:

Incorporates best practices to promote family engagement and shall convene a family advisory committee, consisting of family members of children attending the program, to advise and assist to meet at least three times a year.

2. Page 5, Line 25: Please consider a language change to: **“Is willing to admit any child, no matter their level of functioning across all domains of development, into the four-year old program and be willing to collaborate with the child’s LEA to implement the child’s 504 or Individual Education Plan.”**

One additional concern that I have 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-old’s struggle because four-year-old programs have been developed and you have to be a certain age at a certain time. Or three-year-old’s 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-old’s 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 accepting only 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. 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.

We are supporting this bill (and have supported the current Early Childhood grant program in the past), because these opportunities offer more experiences for children with disabilities to be with their peers, those

children that they are going to continue on with into elementary and secondary school. Language, social interaction, independence, and self-determination are all strengthened when children with disabilities are engaged with their peers.

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

Roxane Romanick

Executive Director

Designer Genes of North Dakota

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