

HB 1540

Senate Education Wednesday, February 12, 2025 Senator Todd Beard, Chair

Chairman Beard and Members of the Senate Education Committee:

My name is Roxane Romanick and I serve as a representative for Designer Genes of ND, Inc., Designer Genes represents individuals with Down syndrome and their families across the state. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

Down syndrome or Trisomy 21 is highly correlated with learning challenges and need to educational supports to learn and grow. We project that the vast majority, if not all children, youth, and young adults with Down syndrome will be covered by the guarantees of the Individuals with Disabilities Education Act (IDEA) and are served under Individual Education Plans (IEP's) which affords special education services. The provisions of a free and appropriate public education (FAPE) and learning in a least restrictive environment (LRE) with specially designed approaches to learning and targeted adaptations mean that students with Down syndrome have learning opportunities available to them that weren't always historically available to them in the past. As an organization, who is sharply focused on students with Down syndrome, we are in a position of evaluating new initiatives with a lens of protection for students with special education needs and their families.

It is because of this focus that Designer Genes does not support HB 1540. For parents of students with Down syndrome, they will need to relinquish or waive their rights to the protections and services under IDEA as the eligible schools are not required to follow laws, such as IDEA, as noted on Page 6-7, lines 19-29 and lines 1-3. In fact, the bill contains language to help make this clear to parents as they have to sign an agreement with the Department in order to access the funding and reads on Page 2, lines 26-30: "If the participating student is a child with a disability, to acknowledge the parent has received information from the department and understands participation in the education savings account program qualifies as a parental placement of the parent's child under the Individuals with Disabilities

Education Act [Pub. L. 108 - 446; 20 U.S.C. 1412(a)(10)(A)]". In clear disclosure, if this bill passes, we do appreciate the bill sponsors inclusion of this protective language so that families are clear about what will happen if they choose to accept the grant funding and want to assure that this is not amended out of the bill.

Participating schools under this bill may be willing to admit a student with Down syndrome, but generally speaking, our experiences have been that most parents find that schools without additional funding and a broad array of related services are not able to adequately educate their child with Down syndrome. At this time, our agency only knows of one student with Down syndrome being educated in a non-public school in North Dakota. Yes, there is a requirement that non-public schools work with a local education agency or a special education unit to provide some related services, but the offering is not robust enough for the majority of students with Down syndrome, who may require instructional aide assistance, general education accommodations and modifications, and one-on-one skill training in core academics.

We fully understand that we represent a very small percentage of the student population, but we do believe that we represent students who have some of our most significant needs in North Dakota and who serve as a reminder about all students with special education needs. Our students learn from educational systems that have solid general education structures and robust special education features such as is possible in our public schools. We do not believe that HB 1540 adds value to those needs and we ask you consider a Do Not Pass.

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

Roxane Romanick
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