



HB 1318
House Education
Tuesday, January 19, 2021

Chairman Owens and Members of the House Education 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.

We ask for a "do pass" on HB 1318 from this committee. Our organization is often called upon to support parents who are struggling with behavioral issues. Individuals with Down syndrome have made many strides in living in their homes, schools, and communities because of educational advances, public policy, and advocacy efforts. The language in HB 1318 represents a guarantee to North Dakota students with Down syndrome and other disabilities that their educational experience in our public schools will be safe even when their ability to communicate and exhibit desirable behavior becomes challenging.

Dr. David Stein, a leading expert in positive behavioral supports for children with Down syndrome, states that one in three children with Down syndrome experience a behavior problem "serious enough to be diagnosed by a professional (<http://tdsn.org/wp-content/uploads/2017/02/Behavior-Guide-for-Down-Syndrome.pdf>). Health issues, executive functioning challenges, sensory concerns, expressive communication delays, and impulse control factors can add together to result in significant behavioral issues for individuals with Down syndrome. This puts them at a higher risk for behavioral strategies that may include seclusion and restraint practices.

Why are school policies as described in HB 1318 important to parents, students, and teachers? School policies provide a safety net that parents can turn to when relinquishing care and control over to the school of their child. Parenting a child with intellectual disabilities and behavioral concerns has nuances that other parents don't experience. Our children are generally very poor self-reporters and parents with children with diagnoses like Down syndrome typically find themselves information-deficient. Parents have little choice but to trust the adults in their children's schools and yet they are often operating with very little information to do so. Due to most safety protocols and physical barriers, parents wait outside of the school to pick up their child and don't interact with educational staff. Often, instructional aides or paraprofessionals, who may be walking the child out or into school, do not have permission to speak with parents. Teachers are sincerely busy and so parent communication may be reduced to only reporting behavioral incidents or unwanted behavior, leaving parents guessing what the

antecedents or full extent of the consequences looked like. Permission to accompany or observe your child is difficult to obtain. These conditions can create a breeding ground for distrust and break-down of relationships. Policies that insure training, consistent approaches, and communication help everybody on a student's team.

I have had the privilege of observing public school teams tackle some of the most entrenched and undesirable behavioral output from students with Down syndrome. At the core of that work were solid functional behavioral assessments, dedicated resources, ramped-up accommodations and communication supports, ongoing communication and dialogue with the parents, and most importantly, a belief that there was a place at that school for the student.

School policy on seclusion and restraint is protective of everyone. When student behavior that is undesirable happens, the emotional response and reaction is elevated for everyone. In those moments, staff need to rely on robust training and protocol because they will also have to deal with their own emotional responses to what is happening. They have to be focused in real time to help the student regulate and then hopefully acquire other skills for communication and coping for future moments. This takes skill when you, as a teacher, are hurt in some way.

While this example is not school-specific, it exemplifies a mother's message that is so very relevant in dealing with students who have increased needs for communication and behavioral supports. In mid-January of 2013, Ethan Saylor, a young man living with Down syndrome, lost his life in a movie theater because of a prone restraint. He wanted to stay for a second viewing of the movie he had just watched but didn't have a ticket. His support staff had stepped away to go buy tickets for them. He could not communicate this to the movie theater staff or the security officers that were called in to have him removed. His mother, Patti Saylor, has made it her life work to tell his story and to ask all professionals encountering undesirable behavioral communication to stop for a moment and instead of seeing the individuals as the problem to be solved, ask the question: "What are the problems that these individuals need solving and how can we help them?" HB 1318 is a statement that our legislative body has asked this question and is providing guidance to our public schools.

Thank you for your time and I will take any questions that you may have.

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