

March 23, 2018

Hello Chair Baruth and Senators,

My name is Miriam Stoll. I appreciate having the opportunity to speak today. I would like to start by acknowledging the work this committee did to develop and pass S. 229. That was a tangible, positive step for children with disabilities in Vermont, and I truly thank you.

I am a member of the Vermont Developmental Disabilities Council (VTDDC). Today, however, I am speaking primarily in my role as a parent. My oldest daughter, Eva, has Williams Syndrome, which is a neuro-developmental disability present at birth. I'm guessing you remember Eva as she spoke to this committee sharing her views of how important it is for private schools to accept students with disabilities. As you saw, Eva has a gift of being able to express herself and speak from the heart. Yet, she has difficulty with many other activities -- academic and otherwise. Eva did not lift her head until she was 10 months old, did not smile until she was close to a year and at 6 she entered kindergarten -- a year later than her peers -- she struggled to learn to count, hold a crayon, and master basic fundamental school readiness skills. In 4th grade, on top of Williams Syndrome Eva battled cancer. But I am not here to focus on the hardships and challenges. Just the opposite, I am here to tell you how, despite many obstacles, Eva at 18 is a young woman who can read, text, understand and discuss current events, bake luscious desserts, and who, as you experienced, contributes mightily to her community.

A critical factor in Eva's ability to become the young person she is has been her Individual Education Plan. Her IEP, as is required by the Federal Law through the IDEA, has provided her with FAPE -- a free and *appropriate* public education -- in the Least Restrictive Environment, which for her has been the Burlington public schools. Through her IEP Eva has had a variety of excellent supports -- Physical therapy, occupational therapy, speech and language services, intensive reading and writing interventions, alternative math programs, and para-educator support to help with social and adaptive skills. These supports were not "extras" but were pivotal to her ability to access her education and to learn.

Having lived the journey with Eva I can attest that the way IEP supports are determined, planned and implemented is not perfect, certainly there is much room for improvement. I also am well aware that these supports are costly. But here's the thing...it is the mandate of public schools to serve *all* children, and for Eva and children with other types of disabilities this means providing an *Individualized*

Education Plan – not providing a minimum level of services or providing a capped dollar amount of services. It means IEP's are a funding priority, and is not relegated to what money is “left over” after others students' needs have been met.

Today I am here to address H 897. My concern is that H 897 *drastically* reduces the resources available to serve our most vulnerable students – those on IEP's (a subset of whom research tells us also live below the poverty line). Early intervention is important and schools should provide more robust support to all children who struggle through an MTSS system or other model. But to do this by shifting resources from children on IEP's without explicit, detailed plans as to how FAPE and LRE will be maintained is heartbreaking....and not acceptable.

This bill, if enacted as currently written, sharply cuts the school resources for children with disabilities in two ways: First, beginning in 2021 it caps and then *reduces* the funds available to children with disabilities, regardless of the needs of children on IEP's at the time or any upcoming students. Second, there is no stipulation that the remaining funds, which will be provided through a census grant allocation, be used to support children with the greatest need – those with diagnosed disabilities who are served by Individual Education Plans (IEP's). H. 897 goes into detail regarding how base census grant amounts will be determined and what the reporting relationship will be between the State Board and the AOE but gives very little, if any, guidance regarding what Districts should use their census grants for. It appears that the plan enables Districts to use these funds however they like, including for children without disabilities and even for school repairs or administrative salaries. Let me be clear, H.897 has no protections for children served by IEP's nor does it even provide guidance to Districts that funds first be allocated to cover the costs of IEP's. This brings into question whether with H 897 Districts can or will uphold their statutory responsibility to their most vulnerable students. Finally, the advisory committee that is tasked with working out critical implementation details does not include adequate representation -- by that I mean more than 1 --from the disability community. The only recourse available for children with disabilities and their families will be through litigation, which puts an undue burden on parents of children with disabilities and is fundamentally inequitable.

I would also like to share a more personal note about how it feels to be a parent of a child with a disability reading this bill. Individuals with disabilities are often put in the role of outsider, viewed as different and “less than” others. Every parent of a child with a disability has had the experience of hearing others grimace or seeing eyes roll when “special ed” costs are brought up. Every parent who has sat in an IEP meeting advocating for their child experiences doubt and even guilt when faced with

a team of professionals, some of whom are clearly weighing how much it costs to educate your child and how that takes away resources from non-disabled students. H. 897 and the thinking behind it, though perhaps not meant to, once again stigmatizes, blames and devalues children with disabilities. And that hurts.

IEP services are currently funded in Vermont through a reimbursement model, which definitely has disadvantages. The census model that is the base of H. 897 could be worthy of further study as it may provide remedies to some current challenges. However, if the legislature seeks to change the payment structure for special education it has a responsibility to ensure that first school districts have been provided with time, resources and practical support to fully implement best practices for serving children with special needs -- such as those recommended in the District Management report -- and that these practices are consistently implemented across the state.

My daughter, Eva, and I thank you for your time and consideration. This committee cares about equity and inclusion – that was made clear in your recent work on S229. I ask you to take the same careful approach here. The decisions you make regarding special education practices and funding are critical to families like ours, and will make a real difference in the lives of children with disabilities -- it will matter every day when our children attend school and will impact what our children, all Vermont's children, can and will do with the rest of their lives.

Thank you very much for your time.

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