

To the Committee,

Please allow me a moment of your time and thank you for sharing some of this deeply personal information this letter will impart. My name is Christina DeGennaro. 17 months ago, my husband and I welcomed a child into this world. He came into this world, just like any other baby, shouting and crying, and he was utter perfection. We knew nothing but love. Shortly after the birth of our son, Rory Celestino DeGennaro, our world came crashing down around us. Suspicions were raised of Down syndrome. Suspicions soon confirmed by a karyotype.

The hopes and dreams we had for the future, well they were replaced with fears, concerns, and questions. These are fears, concerns, and questions we had never, ever foreseen in our future. There is no greater shock than learning your child has been born with a disability. Unless you are a parent with a child who has a disability, well then no words I write can ever capture the heartache, the agony. Yet, our son, to us, still represents perfection. Oh if you could see his smile, hear him laugh. But as much as Rory is like any other baby or child--Rory is NOT like any other child. We learned early on that certain things which come easily, no, naturally to so many children--well that wouldn't be the case for Rory. We dedicated our lives to working with Rory, helping him achieve his every potential. He has therapy four days a week, specialists/doctors appointments several times a week--so no, he is not like most children.

So why am I writing? I am writing to object to the language in Proposed Bill #HB 5425. As you know, the language states that the purpose of the bill is "to establish that the burden of proof lies with the party requesting a special education hearing;" The current law states that the burden of proof is the responsibility of the school district to prove it has provided a "Free, Appropriate, Public Education" (FAPE) through the Individual Education Plan (IEP). It is obvious and clear to all that the current law as it exists makes perfect sense...after all, the school districts are in control of the records, staff, and the program. How would the proposed change affect parents who have children with disabilities in Connecticut? Or I ask you on a personal level, how will this change affect parents such as myself? It will hurt. It will create greater hurdles and obstacles than any one parent needs. Please, understand, I have been a teacher for 6 years, but in the past 17 months, I've become something even more--I've become a parent, an advocate. Every day I'm fighting for my son to talk, walk, stand, eat, and do everything that other children do so naturally. I don't want the joy I know to be so overpowered by a lifetime of a further fight which this change would represent.

You don't need me to tell you that history shows, the majority of hearings reviewing the delivery of special education services to students with disabilities, our most vulnerable, and unfortunately underrepresented population, are already decided in favor of the school districts--you know that. This drastic 180 degree change of the burden of proof would make it excessively costly and almost impossible for parents of students receiving special education services to have a fair hearing with any reasonable chance of prevailing. I implore you, please, please don't add to the struggles we know and face every day.

I conclude by saying this; Rory has been the greatest, most unique blessing in our lives. He has taught us much about ourselves, taught us what genuine strength means and is. He makes us better parents and better human beings—all this at 17 months. I need you to know though our struggle is great, this love we feel is great, it is pure, it is unending. I just wanted you to know that important information about our family. When you are making this important decision, I ask you to please think of Rory. Warm Regards, Christina and Douglas DeGennaro 203-641-1622