

Dear Members of the House Committee,

Thank you for taking the time to listen to our story about our family and struggles with adverse effect in the state of Vermont. My husband and I are parents of a wonderful, intelligent, warm, inquisitive, and often hilarious nine year old boy. We moved to Vermont almost four years ago for my husband's job as a scientist and professor while I continued working as a graphic designer. We were so excited to come to Vermont, a beautiful state with job opportunities for both of us and a state we could finally settled down in and make our home. Our son was five years old at the time and we were moving from Maine. While in Maine, our son was first diagnosed with a speech and language delay and sensory processing disorder at age three and then finally diagnosed with Autism Spectrum Disorder at age 4. We were a little frightened at the time but then educated ourselves quickly about the disorder and realized that with the right support and understanding on our part and society's part, our kid was just like any other kid—he just had a brain and body that worked a little differently. The state of Maine gave us all the support and education we needed immediately. He entered preschool in the Maine school system that year with an IEP and started occupational therapy, continued speech therapy, and was quickly assigned a special educator to help him with social skills and how to understand his emotions and other people's emotions. At the end of preschool, his team recommended continuing his IEP with supports in speech therapy, occupational therapy, and social skills to continue our son's progress in all those areas—areas that he will need help with the rest of his life.

Before we arrived in Vermont, I contacted the district regarding our enrollment in their school system and sent them all the paperwork with his IEP and his therapists recommendations. When we met with the school and district in August of that year, we sat down expecting to go over his existing IEP and talk about the services he would be getting. Within minutes of the meeting, we were told our son wouldn't qualify for an IEP here in Vermont because he wouldn't meet adverse effect requirement. My husband and I were really confused. What about all the progress our son had made? Research shows that people with autism spectrum disorder are more successful in life and work with earlier intervention of services such as speech, occupational therapies and social skills. We both work full time and do not have any immediate family here—are we supposed to quit our jobs to give him the therapies and support he needs? How can we even afford to do that? A special educator explained to us the Vermont law required students to be 2 standard deviations below the mean or bottom 5% in testing of any one area to qualify at age 5. Our son's test scores from Maine had him at 1.5 standard deviations below the mean for speech and language. He was taken off the IEP by December. Most adults could not understand what he said when he talked. He was slow to process multi-step verbal questions or demands, he had a hard time writing, he struggled with talking to his peers and making friends, and his sensory needs were through the roof.

By the next summer entering first grade, we were relieved because our son was having the same teacher as Kindergarten, although Kindergarten and first grade were going to be combined. We assumed he wasn't going to need a lot of support in his transition because he had the same classmates and same teacher. And since he wasn't on an IEP, we didn't have a team to discuss his transition so we were on our own. We brought him to school on the first day and he seemed nervous but got in the car like usual. We parked at the school and open the

doors to the car but our son refused to get out. He said he couldn't go and said he rather hurt himself instead of go inside the school. We didn't know it at the time but he was having a panic attack because his routine was interrupted and there were new people in his classroom. We ended up having to physically bring him in the school and have the teacher restrain him so he wouldn't run away. He cried and miss half of his day while being with one of the support staff. We found out that this happened because he needed visual supports and this transition broken down into steps. He needed people at the school there to receive him who he had met previously and could visualize. We wonder, did we have to go through this if he had these supports on an IEP plan?

By the latter half of 1st grade our son still needed more time than his peers to process information, had a hard time writing, struggled to orally process directions and even just to articulate his own words. The school was finally able to provide limited speech services off of an IEP. We were very thankful for that assistance but it was still limited a fraction of what had been recommended by his earlier IEP. Our family also started providing outside services to help with social skills, anxiety, and sensory processing.

Over the last 2 years he has had a couple of evaluations to look at his oral expression and speech language development. Our son tested 2 standard deviations and 1 standard deviations in a couple different areas with independent testing. One evaluator even noted how his speech and language skills had actually gone down since he arrived in Vermont. However because the law states that tests alone cannot qualify a student even when they test below the standard deviations—in-classroom work and other vague interpretations by the schools can be used to contradict the testing— so therefor, he does not have to be put on an IEP.

And so here we are today with a wonderfully intelligent son who is wired differently than his peers but is expected every day to keep up with them without much extra support. As his parents, we are so proud of him because of everything he has achieved. But I see his struggles every day and I see the limited services he gets. For the services he is getting, the state of Vermont is not even getting reimbursed for those expenses from the federal government because he is not on an IEP. I also see him behind in 3rd grade with information and work assignments getting longer and more complex.

We wonder if we are doing the right thing by living here in Vermont. If we never left Maine, would our child would have the supports he needs? Do we need to move out of state so that he can have the supports he needs as he grows and learns to become a successful man who can contribute to society and live and work independently?

The adverse effect law requires students not only fail but fail so much below their peers that it damages so much more than their test scores. This stringent definition of adverse effect does not exist in any other state. We strongly believe this should change for the benefit of our son, for the benefit of all families with children on the spectrum, and for the benefit of Vermont's future.

Sincerely,
Carolyn Crowley and Glen Ernstrom