

Testimony by Kirsten St. Louis

I am here to express my support for changing the way adverse effect is worded in the special education regulations. Vermont is the single state in the country that imposes such rigid interpretations of that and it is preventing huge categories of kids from accessing desperately needed support.

I want to share my experience of frustration in how difficult it is to access IEP supports for my thirteen year old son. My son is extremely smart and has always been driven and motivated and curious. He used sign language to communicate at 6 months, and spoke in sentences at 18 months. He taught himself to read at 2 and was multiplying in kindergarten. As parents we were thrilled....surely our kid would succeed in school and life.....he is so smart and curious. Our experience as he develops and moves through school has been anything but joyous. We quickly realized that along with his intelligence came challenges. He does not interpret the unwritten social cues naturally. He also has extreme sensory challenges and gets overwhelmed easily. He struggles to communicate in writing all that he has inside his head. He also is very self aware that he is different and that has lead to massive anxiety and depression.

School for my son is not the academics.....he can easily learn that in isolation. School for him is learning how to interact, how to be his own advocate, how to manage his materials and time, how to contribute as a team member or member of a class, how to listen, how to speak. For him to be a successful community member, he must learn those soft skills. In class, the absence of those skills is very disruptive to his learning and also to the learning of his peers. His desire to function well is there.....his understanding of how to achieve that is not. He needs supports.

This year alone, even in a small, private, 40 person, k-8th grade school that is highly specialized and accommodating, he has struggled immensely. He has missed 28 days of school, been asked to not participate on class trips and ski days. He has been on a half day program for 2 months in addition to the many late arrivals and days he has been dismissed early. Surely his challenges are affecting his ability to learn, right? However....in trying to access IEP supports for him for high school, I am told that he is most likely not deemed eligible. In testing one on one, he has tested in the top 2%. So, my son, a sweet, big hearted kid who is smart and has high functioning autism as well as anxiety does not qualify for help because he cannot test below 98%. He cannot access an IEP because there is no adverse effect....he can do just fine on the tests.....despite his struggle to simply attend school and focus in class.

My sister is a special education director in Massachusetts and she is in awe that he doesn't qualify for an IEP. In her school alone, there are three different programs he could access with his autism, anxiety and history of absence alone....regardless of him testing in the top 2%. She is baffled at how Vermont could think he can function without specialized help by people trained in this. I am baffled to. Educational performance is more than academic performance. Educational performance is academic, social, emotional, vocational, behavioral, etc. Why is Vermont the only state that only values academic performance?