

Testimony by Kirsten St. Louis
Special Education/ Adverse Effect
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Thank you for taking the time to listen to my experience in trying to access supports for my son through the IEP process. First I'll tell you a bit about my son. He is a 15 year old sophomore in a public high school in Vermont. He is very smart with an IQ that is in the top 2%. His brain is exceptional in that he embraces thinking outside of the box and can process information at an incredible rate. He is voraciously curious. If you spent time with him the two things you would immediately realize are: he seems awkward because he has difficulty with social interactions and is very uncomfortable with small talk and he is the most empathetic, kind person who cares about what people think.

He used sign language to communicate at 6 months, knew the alphabet by 9 months, talked in complete sentences at 18 months, taught himself to read at 2, and was doing square roots in kindergarten. You may think that I have nothing to worry about...that clearly this kid is going to be successful in life. However, school soon highlighted the challenges that exist with his strengths.

Social Skills - he misses social cues that are inherently understood by others.

Emotional Regulation - he has trouble regulating his emotions and in his words, "I feel things exponentially".

Executive Dysfunction - he has difficulty with executive function which is like the CEO of your brain and it tells you where to place focus, what to ignore, how to plan ahead, how to filter your efforts, how to organize for success. This affects his keeping track of time and materials and priorities.

Anxiety and Depression - he has major anxiety and periods of depression as he realizes that he is different than his peers and life for him requires constant effort for things that are natural to others.

Focus - he also needs to move and fidget in order to focus and process information. He can sit still but it comes at a cost.

In 3rd grade after a tumultuous four years navigating his challenges, we were advised by an educational consultant to consider a local, small, private K-8 school with 5 teachers that has an alternative approach that teaches multiage groups through project based, hands on learning. This nurturing school seemed a better fit as the teachers seemed to be able to adapt to his needs in a smaller setting with more flexibility and ability to differentiate. However, even in this small school with many supports, in 7th grade, his social, emotional, and executive function challenges were more than they could handle. He began to spiral downhill and fast. Academically he was capable, but he was not able to meet the social and environmental expectations and he knew that. He was devastated. By the end of October he had 20 days of absence and was having massive anxiety attacks and depression. His teachers were alarmed and we knew he needed help and support. His pediatrician was meeting weekly with us monitoring his anxiety. His therapist was meeting weekly and everyone encouraged us to contact the public school and ask for an IEP evaluation. Something more was going on and he needed help fast. And this is where my struggle to get him help in the most dire time begins.....

I contacted our local Special Education department in early November and described what was happening at the local private school and asked for an IEP evaluation. In taking my information, his IQ was discussed. I was told that there was no way he would qualify for an IEP with an IQ that high. I was told they just don't serve kids with IQ's that high, that he would not meet the criteria. I explained that he was having panic attacks at school and they couldn't even keep him in class or school so how was he able to access his education? She

told me that she could test him, but not to expect that he would qualify. I waited 6 weeks with no response from the school special education department. In the meantime I was advised by his pediatrician to homeschool him to give him a break from the environmental and social stressors at school. In December I sent him back to school on a modified schedule. I contacted the director of special education to inquire about the IEP evaluation. She apologized as my request had "fallen through the cracks." It was then that we hired an attorney at a cost of \$1500 as I realized that I needed help to advocate properly for my son. Another intake was done and we had a meeting January 27th to discuss his evaluation needs. At that meeting it became apparent that he had significant needs and was failing classes but because he was academically gifted, unless he failed the tests in the bottom 15%, he most likely would not qualify.

My son was struggling to attend school despite his monumental resilience to try each day. He fought panic attacks and endured repeated failure in class. You know that feeling when you are waiting to hear results from your doctor about a biopsy and that call finally comes; your head is spinning, your heart is racing, you can't seem to breathe unconsciously? That is the feeling my son had daily while trying to follow directions, produce written output, engage in the discussions. It is the marathon directed by his developmental challenges and anxiety that his body endured each and everyday. Yet, according to the special education department, he was not struggling in the academic way that is outlined in Vermont standards. He was not functional but he was smart.

Finally, in April (after waiting since November), he completed all the required evaluations. By sheer luck, my son had a panic attack during the written assessment. He hyperventilated and collapsed in a sobbing heap on the floor of the testing room. Luckily for us, this meant he tested in the bottom 15%. I say luckily because one in one in a quiet room with a trusting adult given a single challenging task is something my son relishes. The environment is perfect and he can focus. So luckily, he had a panic attack at that moment and coupled with his abysmal writing samples from the previous few months at school, and a teacher report that he in fact was not able to meet basic expectations for writing in class, he qualified as having met adverse effect in written expression. So, while writing is not the core problem for my son, it was the door that was cracked open ever so slightly to allow him to access an IEP and needed supports for the challenges that make school difficult for him. Given another chance to qualify, my son would not unless circumstances were perfectly aligned for him to repeat his panic attack during the test.

In 9th grade he transitioned on an IEP with amazing services, supports and accommodations from a private school of 40 to a public high school of 1200 students. In 8th grade he missed 32 days and participated in modified half days for 4 months. So far in high school with an IEP, he has not missed a single day, arrived late, or been dismissed early. He made honor roll his 9th grade year and is happy, successful, and challenging himself academically and socially. This was made possible by strong, persistent advocating, \$1500 attorney, and an aptly timed panic attack. Every three years a child on an IEP must be reevaluated to stay on an IEP. The way the law is written makes it impossible for him to re-qualify which is unfortunate considering what a capable student he has proven himself to be with the right supports and instruction.