

My name is Andrea Smith, and I'm from Virginia. My husband, Ethan, and I are parents of two children with autism, one of which is severely affected and attends the private day school Blue Ridge Autism and Achievement Center (BRAAC).

We are grateful for the opportunity to share this story on behalf of our son, Liam Smith. Liam's story demonstrates the immense value of private special education day schools that provide Applied Behavior Analysis (ABA). It also warns of the dangers imposed by conflicting financial interests in special education.

Our story highlights two things that we think that Virginia is doing right for families of children with special needs. First, school districts are not able to alter a child's IEP without parental consent, and second, the unique funding structure provided by CSA/FAPT helps to minimize the conflict of interest that necessarily arises when school districts have both far-reaching authority to dictate what FAPE "Free and Appropriate Public Education" means for a child and direct control over all of the money to fund it.

Liam was diagnosed with autism at age 2 while we were living in Montreal, Canada for Ethan's postdoctoral fellowship. At the advice of several autism professionals, we secured as many hours of genuine ABA services for Liam as possible. The immediate gains that Liam started making astounded us. We were excited for the future ahead of him and saw hope on the horizon.

In the summer of 2012, we moved to Virginia. We were excited because an expert ABA school, BRAAC, had just opened a branch campus in Lynchburg. Upon arriving in Virginia, we called our local school district. He was evaluated and found eligible for special education services under the diagnosis of autism. We went to IEP with the school district with a binder full of data showing that ABA was the appropriate method for teaching Liam. However, the director of special education was unwilling to even have a conversation about the appropriateness of ABA for Liam. He would just interrupt to say BRAAC is off the table.

We could not risk Liam's future. His level of functioning was extremely dependent on the methodology used to educate him. Since Virginia had recently passed its autism insurance reform law, requiring health insurance providers to cover ABA services, we decided to place Liam at BRAAC ourselves without help from the school district. The financial cost was very high for us as a family, and we had to fight hard with the insurance company to get them to pay their part of it.

Liam went to school at BRAAC from Sept. 2012 to May 2014. He made consistent, wonderful progress. At age 3, Liam was potty-trained over the course of just 1 month. He went from speaking single words to the ability to use 5- to 6-word sentences. He could let his needs be known and was sweet and loving. We were a functioning family who could go to church and be part of the community. Make no mistake, he still had autism and nothing was easy, but he continued to learn and grow. We had hope that one day he would live semi-independently, would hold a job at his favorite place "Taco Bell" and live a meaningful, happy life.

We couldn't continue to pay for Liam's placement at BRAAC, so in the summer of 2014, we moved to Howard County, Maryland. This was a very wealthy district with high resources and

special education focus and the reputation of having expertise in serving children with disabilities. We were excited about finally being able to have Liam's needs for ABA met within the public school setting. Unfortunately, we quickly learned how public schools often claim to use ABA but do not invest the necessary resources to do it correctly. ABA programs should only ever be written and supervised by a licensed, credentialed board certified behavior analyst (BCBA) and should only ever be delivered by registered behavior technicians (RBTs) working under the supervision of a BCBA, but of course this is expensive, and school district officials feel pressure to cut corners in the education of such an expensive minority.

The failure of these "in house" ABA programs with the school district is not unique to Howard County Maryland. It has been repeated around the country including in nearby Roanoke, Virginia. Unfortunately, many families cannot talk openly about their experiences because of nondisclosure agreements or fear of retribution from school officials.

Liam regressed terribly while receiving look-a-like ABA services in an "in-house" program in public school in Maryland. He learned to engage in self-stimulatory behaviors (e.g., loud moaning, flicking his fingers in front of his eyes, and tapping his fingers on every surface). His eye contact decreased rapidly as did his interest in people. He lost the ability to perform most every skill that he gained between age 2 and 5. He was no longer able to communicate his most basic needs and desires. All he could do was mumble unintelligible sounds that even we could no longer understand. He became completely withdrawn from the world. He no longer reached for us his parents. While he had never been aggressive before, he was now violent. He lost all toileting skills, and began wetting and soiling his pants as many as 13 times a day. We could barely leave the house with him.

At this point, our hopes and dreams for Liam were shattered. It seemed that he would need continuous, around the clock care as an adult. He would not be semi-independent; he would not hold a job. Rather, he would probably be restrained and would need people to clean him in the middle of the night. The cost of his care would be astronomical. Worse the emotional toll of losing our son devastated us every second of every day. Our family of 4 ceased to function.

Despite Liam's clear downward spiral, the school district was unwilling to place Liam at a private ABA day school. When they finally did agree to private placement, it was clear that their goal was not to see Liam in a setting similar to where he had previous successes. Their goal was to send him where they wanted regardless of its cost or appropriateness for Liam. The Shafer Center, a genuine ABA school that we had identified, was less expensive than the school district's choice, which in fact was unable to meet all accommodations in his IEP, which is illegal. When we confronted the proposed school with this fact, we were told that they would just change his IEP on the very first day in the new school, which in MD they could do without our consent.

We borrowed a lot of money from 4 different family members, unilaterally placed him at the Shafer Center and filed for due process. The cost was high for us as a family and certainly most families wouldn't have the resources for this gamble to stop their child's suffering. Happily Liam began making significant progress again from day 1. I remember later hugging his BCBA and thanking her over and over for giving me my son back. He was connecting with us, loving

us, and communicating with us. We were functioning again as a family. We went to the grocery store, church and had friends over. We began to have hope again for Liam's future: a future that wasn't a scary institution or long stays in the ER.

We have since moved back to Virginia, where coming off of our due process case in Maryland, Liam was placed immediately in BRAAC by the local school. He's been there for a little over a year, and is continuing to make wonderful forward progress. Sadly, Liam has not yet fully recovered from the harm that was done to him in the Maryland public school look-a-like ABA program. However, we have hope for him again.

Our experiences have taught us that unless parental rights are strong and unless at least some of the funding for private day programs is kept separate from school district officials that have the authority to effectively decide what an appropriate education means for a child, there will always be impetus to cut corners and engage in unethical and immoral practices. All the while this most defenseless segment of society will suffer. We believe that CSA/FAPT are part of a unique funding structure in Virginia that can help minimize, though not annihilate, this conflict of interest.

Please understand that the toll of inappropriate education is devastating families. We lose our kids, our ability to hold jobs — to be a part of the community; we lose our health, our lives. While every child should have the right to an inclusive education, it is much more important that they have the right to an appropriate education that actually works for them. These highly specialized autism ABA private day schools are life-giving. Please protect them, and do not throw us back into this suffering, which we know will occur if Virginia goes the road of Maryland.

Again, my name is Andrea Smith. Staff has my contact information, and I would be so grateful to talk to anyone who would like to know more.