

Our very bright, curious and kind 9-year-old Autistic child with a Pathological Demand Profile and Generalized Anxiety Disorder has been struggling in our local school district since he started kindergarten. From the beginning I was consistently asked to come to the school to help “support” him, essentially becoming his unpaid 1 on 1 adult support. We then put him on an abbreviated day for the latter part of kindergarten. There is no way he was going to be able to remain in school without 1 on 1 support, so I worked hard to try to make that happen. I wrote letters and advocated on his behalf, however it seemed to be an almost impossible task. Day after day of school trauma, consistently being asked to come “support” him in the classroom, many school suspensions, and the abbreviated day finally became too much and we made the decision to put him in a Social Emotional self-contained classroom. The impact of the lack of support the school district provided made it impossible for me to go back to work. I am trained as a Special Education teacher and do not see a time when I will ever be able to go back to my profession. This seems quite ironic to me, given the teacher shortages in Special Education.

Once we made the decision to move him to an SES classroom, Covid shut schools down and he received 15 min a day of online “schooling” which consisted of the teacher reading one story from a social emotional book to him alone. He had zero access to peers online.

The following fall he was moved to another SES program because the one he started in shut down. While learning through Covid was challenging, we managed it ok as a family. Although again, it would have been impossible for me to go back to work.

While things settled somewhat, he continued to struggle in 3rd grade and this is when the restraints and isolation started occurring on a more regular basis. During this time, we did not receive any official documentation related to these restraints. We did get an occasional phone call or email indicating the teacher had to “hold him a few times” or put him in the “peace room” (this is what they call the de-escalation or isolation room). There was a short respite from the restraints and isolation while the teacher went on an extended leave that year.

In 4th grade things continued to worsen. He started refusing to go to school and when he did agree to go, they would call me to go pick him up, many times only after only a couple of hours. Sometimes it was officially called a suspension and sometimes it wasn't. More instances of undocumented restraints and seclusion. He was being traumatized in a place where he was supposed to feel safe. I asked for more support, I asked for a school employed BCBA (Board Certified Behavior Analyst) to do an observation or if that couldn't happen, for our own private BCBA to come observe, I asked for an updated FBA (Functional

Behavioral Assessment) to be done, I asked for meetings where the whole IEP team would be present. The only thing that was done was that the teacher allowed our BCBA to come to do an observation, but this is only after the teacher told us it wasn't possible and we had to go higher up the chain to find out that it was in fact a possibility. None of our other requests for help were met.

I still cannot understand why more wasn't done to try to figure out what was happening for him in the school setting, especially given the amount of times they had to restrain him, put him in isolation, or physically transport him. For the record, the teacher told us in a meeting that the reason my son had to be restrained was mostly for behaviors that were dangerous to himself NOT because he was being aggressive towards anyone else. Of course, once they restrained him he would sometimes become verbally or physically aggressive towards them in that moment. I'm not sure who wouldn't under those circumstances. It might be helpful to also point out that we never use restraints or any form of isolation in our house, as it is completely unnecessary. It was ultimately decided that my son would be moved to the most restrictive setting in the district. They told us it would take two weeks and it's now been over 3 months. There are no spots available in the setting THEY placed him in. We agreed to the placement only because we thought he would get more support. He has not been in school since October. These are the obstacles we are facing. How could I possibly find a job, especially in the field I'm trained in, that would have the flexibility to accommodate my schedule and my son's support needs.

In a small light at the end of this dark tunnel, he finally started Home Instruction two weeks ago and it's been a very positive experience. It's only 5 hours a week but we'll take it. He can learn in a setting where he feels safe while we wait to find out what happens next. I know many stories of other families who have gone through similar situations and it's devastating. The lack of support has caused so much angst, trauma and exhaustion to our family, and families like ours over the years. I know the federal education laws regarding a student's right to a Free Appropriate Public Education (FAPE) in the Least Restrictive Environment (LRE) and I know that in my child's case they were not being followed. My hope is that school districts are held accountable for NOT following the laws outlined by our federal government and that more is done to help support these students and their families as well as the educators who work alongside them. Our children deserve to go to school and to feel safe and secure while there.

Thank you,  
Emily Pirkle

