

Chairman Wieland and members of the committee

I am Isaac's grandmother, Luann. He came to live with my husband Pete and I at age 8 because of challenges he was facing in his mother's home which included an abusive stepfather and trouble coping with living with three younger siblings all under the age of three. The noise and chaos that comes from living with three babies was beginning to take a toll on Isaac.

From age 4, our family knew Isaac wasn't developing like other kids his age. We started taking him to doctors to find a reason for his behaviors. This was the beginning of the many tests and evaluations that Isaac would go through to try and find a reason for his unique and challenging behaviors. Over the next twelve years, we saw many different doctors and were given many different diagnoses. Some of the diagnoses he received included: mood disorder; depression; ADHD; Obsessive Compulsive Disorder; Oppositional Defiance Disorder; Bi-polar; Borderline Personality Disorder. With each new diagnosis, Isaac's medications were changed. Unfortunately, these new medications each had side effects and few, if any, benefits. At times Isaac was taking 3-4 meds a day, sometimes causing adverse reactions. Looking back now, I can see that these medications may have been masking symptoms that could have more easily been seen, allowing us to reach the diagnosis of Asperger Syndrome much sooner.

We read articles and searched the internet for some answer as to what Isaac could be experiencing. That is when I found information about ASD. When Isaac was 13, I asked his doctor if he could be on the autism spectrum. The physician said that while Isaac did have some features and symptoms of a spectrum disorder, he didn't meet all the criteria. At this point in his life, Isaac was retreating to his room sitting in the dark alone playing video games, scratching his face and arms, banging his head on the floor and his sleep patterns changed drastically. The search for answers became crucial.

By this time, Isaac was no stranger to being hospitalized at Prairie St. Johns for depression and suicidal thoughts. After another unsuccessful inpatient stay at Prairie, my husband and I decided to admit him to the Dakota Boys and Girls Ranch for treatment for safety reasons and 24 hour counseling and medication monitoring. After spending one year at the residential center and not seeing any improvement, I again asked the doctor and his counselor at the treatment center if Isaac could be assessed for Asperger's. I was told by the attending doctor at the Dakota Boys and girls ranch that I needed to stop looking for excuses for Isaac's bad behavior. It was suggested it was our parenting skills that were the problem. .

After all the treatment Isaac had received, we were still without a diagnosis that accurately described Isaac's behaviors, and thus were unable to improve his situation. Then we heard Southeast Human Services had someone working

with people on the autism spectrum. We made an appointment with Dr. Stanton and Isaac was diagnosed with Asperger syndrome. We removed Isaac from the Dakota Boys and Girls Ranch. Isaac was almost 17 years old by now. On the way home from the appointment with Dr. Stanton, Isaac made the comment that he was glad they finally found out why he was acting the way he was and that he wasn't crazy. Within months of a correct diagnosis, Isaac began to show improvement and we could see the different ways in which he learned and needed to cope with situations to prevent meltdowns. Referring to Dr. Stanton, Isaac commented one day after his appointment, "She gets me, the counselor at DBGR just didn't get me".

With a correct diagnosis, we now needed to make changes to his Individual Education Plan (IEP), which had been in place since elementary school. Isaac struggled in school and unfortunately, school was a very negative place where he didn't feel respected, didn't have friends, was bullied and had a hard time sitting all day concentrating and dealing with distractions.

The IEP needed to be adjusted to fit Isaac's unique learning style and challenges, while building on his strengths. Working with many different educators and administrators was a daunting task. Fortunately, there were some teachers who were so helpful and positive in their approach with Isaac and us. Staff who were not familiar with Aspergers were not as agreeable to innovative approaches. For example, we were told that if he could perform a task one day, he should be able to remember it and do it the next day, because he was a smart kid and tested well on his standardized tests. I felt I was being told he was lazy, not applying himself and just being oppositional.

Isaac wanted to quit school late in his junior year. Trying to get through each day at school was taking a toll on him and resulted in extreme anxiety resulting in an ulcer, causing him to become physically sick and miss many days of school. When he got home from school, it took him hours to be able to relax and cope. With Dr. Stanton's insight, we changed his IEP to a four day school week with 3 days of rest, which he used to recharge. This change allowed Isaac to successfully complete his junior year.

Recognizing that this shortened school time was the best way for Isaac to learn and stay in school, we were able to schedule his senior year classes between the hours of 9:30-1:45 each day, although we were met with opposition by some instructors and had to insist that upon a school setting that addressed Isaac's specific needs. In one IEP meeting in his senior year, we were told by one instructor that if we didn't start pushing Isaac to do more things, and if Isaac didn't start applying himself, he would not succeed in the "real world." Isaac was sitting in that particular IEP meeting and heard the comment.

With the appropriate changes made to his IEP, Isaac excelled and was placed on the honor roll. One semester he even achieved a 4.0. I feel a lack of education and an unwillingness to learn about Asperger's is hampering children in their efforts to develop into successful adults. My child should be seen as a person and deserves respect. Neither he nor any other child should ever be looked at as a "problem" to be dealt with each day. The way in which educators and administrators treat a child affects the way that child thinks and feels about himself and has the power to influence a child's success.

Because of the correct diagnosis and implementing strategies to help Isaac, we have a grandson that has graduated from high school, has been able to hold part-time jobs, and has been living in an apartment on his own for the past 5 months and is off all medications. Two grandparents and a mother could not be prouder!

However, I can't stop advocating for educating professionals like doctors, educators, administrators, and businesses in the community to hire these capable people, because someday Pete and I will not be here to help Isaac, and we also have two granddaughters who are 10 and 11 who were also diagnosed a year ago, as being on the autism spectrum.

Thanks for giving me the opportunity to share my story. We would appreciate your help.