

ASD and Me

by Jessie Lynn McMains

I feel shitty admitting this, but I spent a lot of the first few years of my son, D.'s, life worrying he might be autistic. I knew I wouldn't love him any less if it turned out he was, but I feared it anyway. It's the specter of our era. Everywhere you turn, there's someone shouting about how more and more kids are now diagnosed with autism. They spout bullshit theories, about how it's because of vaccines or milk or plastic. On top of that, there are a bunch of people telling you to watch out for the "signs of autism." These can range from aggression and lack of social skills to being attached to a particular toy or lining blocks up in a row. I'm not exaggerating. I've seen a PSA suggesting that if a child gets upset when they don't have their favorite toy, they may be autistic, and a billboard saying that lining their blocks up in a row may be a sign of autism.

I know that autism isn't caused by vaccines—that theory has been debunked. I know that even if it was true I would still have D. vaccinated because I don't want him to get an infectious disease. I know that having a favorite toy isn't a sign of anything except childhood—when I was my son's age, I had a favorite teddy bear I couldn't sleep without. And I know the reason more and more kids are diagnosed with autism is most likely just that they've gotten better at diagnosing it. In the past they would have called it something else, or not diagnosed it as anything at all. I know all that, but with all the fear-mongering, it was hard not to worry. I'd notice things, like D. having a difficult time interacting with other children, or that he likes to run around the house making sound effects, and I'd think: "Oh god, he's autistic." Then I'd think: "But he's verbal and communicative and affectionate." And it was easy to brush off the other things as something else: "He probably has a hard time interacting with other kids because he's

an only child, and none of my friends have kids so he doesn't spend much time around them. After all, I was an only child, and I preferred hanging out with adults, too. And the running while making sound effects thing? That's just a personality quirk."

And then he was diagnosed with ASD (Autism Spectrum Disorder).

D. had some issues in preschool last year. He had difficulty taking direction, sitting still, and participating in group activities, and a tendency to get frustrated if he couldn't do something perfectly the first time he tried it. At first, I brushed all that off, too. I thought: "He's still young, some of that will fall into place as he grows and matures." I remembered that I had a couple of the same issues when I was in pre-K and elementary school. In Kindergarten, I once got in trouble for deciding that during quiet time, I'd rather stand up on my desk and sing "Twinkle Twinkle Little Star" at the top of my lungs. Many of my school reports said things like: *Jessica is smart, but she doesn't take direction well. Or: Jessica is good at many activities, but only if she decides that's what she wants to work on at that particular time.* And I was—and still am—someone who gets frustrated to the point of tears if I am not immediately perfect at a new thing I'm trying to do. So I tried brushing it all off, but after I went to the parent-teacher conference toward the end of the school year, I could no longer do so. D.'s issues were becoming overwhelming for his teachers. They wanted to help him but didn't know how, and couldn't give him the special attention he needed because they had a whole classroom full of kids they had to attend to. So they suggested we have him evaluated by the school district.

This summer, I was interviewed by a social worker. Then a special education teacher, a speech therapist, and an occupational therapist came to our house. They asked me more questions, and they asked D. questions, and played with and observed him. It was nerve-wracking, as those kinds

of things always are, because I would hear them hmmm-ing under their breath and see them writing things down on their notepads. I wondered what they had noticed, what they were thinking was wrong with my son. I couldn't get that out of my head: "They think there's something wrong with him. His teachers think there's something wrong with him, that's why they wanted him evaluated." Before they left that day, they pulled me aside and asked if I had ever considered he might be on the autism spectrum. They mentioned things: that I'd said he had an issue with the textures of certain clothing. That I'd said he needed me (or his dad, or grandma) to cuddle with him in order for him to fall asleep at night. That he got stuck on particular subjects and wouldn't let them drop (that day he kept talking about a particular Transformer he wanted). That he didn't want to do the activities they asked him to do, or answer all their questions. His running around while making sound effects. The fact that he sometimes walks on his tiptoes (which they called "toe-walking"). I said: "No, I've never really thought he was autistic. After all, he's verbal, and he's affectionate." They told me that it's a spectrum, and there are many different forms it can take. They told me that they thought it was a strong possibility he was on the spectrum.

We met with them a second time a week later—D. had been coming down with a cold and so they couldn't complete their observation in one day. After the second meeting, they diagnosed him with ASD. They told me it was only an educational diagnosis, not a medical one. They said they had to diagnose him with something so he could get help at school. They suggested I seek out a doctor who could give him a medical diagnosis. They also gave me an information packet on "living with your child's autism" which I threw in the recycling bin as soon as I got home. It was put together by Autism Speaks, and I've read enough about what a crap organization they are that I didn't even want to look at it. To be honest, I wished I could set it on fire.

Here's another thing I feel shitty admitting: I did not handle the news of D.'s diagnosis well. I put on a brave face to the world. I said: "Well, this diagnosis will just help me, and the other adults in his life, understand him better." I said: "He's still the same kid he was yesterday." But in private, I had a meltdown.

First, I was furious. I thought: "How dare they label my son autistic? Just because he doesn't always do what he's told?! Neither did I! He's a rebel, just like his mama!" I thought: "And the things they observed on their home visit? He was coming down with a fucking cold! Of course he decided he'd rather talk about the Optimus Prime toy he wanted than play their bullshit games!" I thought: "Of course he still wants someone to cuddle him to sleep! He's four! My mom cuddled me to sleep when I was four, too!"

Then, I got sad, and I cried about it a lot. One evening, I was sobbing alone in my office/studio/study, and I thought: "They were right. There's something wrong with my son. And it's all my fault. I just wish he was normal and could have a normal life."

Oh. There it was—the real reason I'd been so upset. I was blaming myself, and I was wishing for him to have "a normal life." As soon as those thoughts crossed my mind, I was able to see that it's not my fault, it's just who D. is, and that there's nothing wrong with him, he's just not neurotypical. I also realized—why would I want him to be normal or have a normal life? I'm not normal or neurotypical—I live with bipolar disorder, panic disorder, and generalized anxiety disorder. And god, what the fuck is a "normal life" anyway? What does that even mean?

Once I realized all that, I started seeking out alternative sources of information. I began talking to friends and acquaintances who are, themselves, on the spectrum, and/or who have children on the spectrum. I started reading articles and watching videos

made by people on the spectrum. (I'd recommend this comic by Rebecca Burgess.

<https://themighty.com/2016/05/rebecca-burgess-comic-redesigns-the-autism-spectrum/>). And I met with the team that had observed D., to work on an IEP (Individualized Education Plan).

He has since started school again, and they've implemented the IEP. He has therapists and special education teachers come in and work with him several times a week, and his daily teachers have learned how to better work with him. I have learned from what his teachers have told me, and what I have read on my own, and I am getting better at being a parent to him. No

one is forcing him to do anything he's not comfortable with. Rather, we've all learned how to communicate with him in ways he responds well to, and to help him be his best self.

I've realized that he *is* still the same kid he was before the diagnosis. He's still my silly guy who loves Transformers and Legos and rock'n'roll and baking cookies and making art.

I no longer care about him having a normal life. I only want him to have his best life.

And now I think I might be able to help him do that.

Use this page to write down your thoughts on alternative parenting or whatever.

