

## Autism: Through a Parent's Eyes

By Shawnta S. Barnes – April 25, 2017



April is National Autism Awareness Month. The Centers for Disease Control and Prevention defines Autism spectrum disorder (ASD) as, “a developmental disability that can cause significant social, communication and behavioral

challenges.” According to the CDC, “about 1 in 68 children has been identified with ASD.”

How do you navigate the education system and life while raising a child with ASD? Estacia Stokes is a parent of 2nd-grade twin boys who attend Paul I. Miller School #114 in Indianapolis Public Schools. One of her sons has an autism diagnosis. This is her story.

I found out Jordan was autistic when he was about 3 ½ years old. He had a speech delay, but I didn’t think much of it because he was premature. One pediatrician, that I didn’t care for, looked at me and said, “He’s slow. Get him tested!” Outraged, I left her office never to return. Yes, I knew he was different, but he was very smart in his own way. I did take her advice and got him tested. I took him to Riley where he went through eight hours of testing. I was told that he had a speech delay, but he was not “slow” and that his receptive language was way beyond his age. Then, they connected me with the Christian Sarkine Autism Treatment Center where I received the news that he had Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) which is on the autism spectrum.

This diagnosis changed my family in so many ways. When I left the doctor, I was heart broken. I had no clue what autism was. I’m the most medically inclined in my family so I knew that if I didn’t know anything about it, my family didn’t know either. I can remember sending out a group text to my family that said, “Jordan has autism. No, I’m not okay and no, I don’t want to talk about it.” I shut my phone off because I wasn’t ready to deal with the responses and questions that were to follow. My mom drove to my house, hugged me and said we would get through it and we would get him any help he would need to be “normal.” I started to do my research and doing that helped my family and I understand some of his behaviors and adapt to his need to have a set schedule.

He has faced difficulties with people not understanding what he is saying because he hates to have to keep repeating the same thing over and over again. He looks normal, so sometimes in public, we get those, “wouldn’t be my child” stares if he’s having a meltdown.

School is a challenge for him. He struggles in reading, but is brilliant in math. He attends speech therapy weekly in addition to the therapy he receives at school on a

weekly basis. At this point, we haven't gotten over this reading hurdle. He is below grade level on reading, but he says, "It's hard and the letters make too many different sounds. I will stick to math because numbers don't change." He's never been on honor roll which breaks my heart as a mom, but I know his grades in no way measures his intelligence.

I'm kind of on the fence about his school experience. You have either the degree track or non-degree track. These kids have an IEP, but they are still graded the same as a "normal" child; I have a problem with that. His grades would make you think he sat and did nothing, but he actually works very hard trying to keep up with his classmates. I believe students with an IEP should be graded where they are and not graded based on the same standards as the other children. There needs to be a better grading system for children with IEPs. I think if they did this it would boost these kids self-esteem to want to work even harder than they already are. I do love that they offer speech and occupational therapy at school. Jordan has had the same resource teacher, Ms. O'Neal, the last two years and she is nothing short of amazing to him! I hope we can keep her until he transitions to middle school.

My community, as in the African American community, really has no knowledge of this disorder unless they have someone in their family that is dealing with the same thing. It's becoming more common for a child to have autism now so in the "autism community" there is a lot of support. You just have to be willing to accept it!

Jordan is a twin and having one twin with autism is harder than one may think. Jordan's twin, Justin, doesn't understand why we make special accommodations for his brother or why he is trusted to do certain tasks that Jordan isn't. There was a point where Justin was jealous because Jordan was always going to therapy and specialists and he felt like we didn't love him as much. They balance each other out. Justin will help Jordan with reading while Jordan can whiz through Justin's math problems.

If I had to let people know anything, it would be to teach their kids the golden rule. Treat others how they want to be treated and just because another kid isn't "just like them" don't count them out. Include them in your day and let them into your world. It's hard enough for parents who have special needs kids; don't add to the problem!