

## Thriving in the Unknown

It rocks your world. It really does.

Having a medical background, knowing the milestones a child should be hitting, I knew at one year that things didn't seem quite right. By 18 months, being around people outside of our home practically paralyzed him. By age two, it wasn't much better. We didn't have a diagnosis, but for me it was already real. I was already grieving the reality that my son wasn't going to be the child my husband and I thought he'd be, and I felt like we were wasting valuable time without a diagnosis that could tell us for sure what we were facing.

We finally found ourselves in an appointment at Riley Hospital, and within an hour, the doctor put a stop to the frustration of waiting: "Absolutely. He has autism." When he said it out loud, it was crushing.

All these thoughts go through your head. *He may never speak. He may never be potty-trained. He may never go to school.* And while the helpless feeling of not being able to decisively say "this is autism" was put to rest in that doctor's appointment, it was replaced with helpless feelings of watching our son struggle, of having to rely on trial and error in the pursuit of medication that would make a meaningful difference, of not knowing how you're supposed to plan for something that is so unknown.

A turning point came for us when we enrolled Jackson in Muncie's then-new ABA clinic—an applied behavioral analysis clinic. Most moms get to wait until their kids are five or six before they send them off to a full day of kindergarten or first grade, but my baby was still three years old and I was sending him off to strangers for eight hours a day. And they were challenging him. Really challenging him. To the point where sometimes I'd push back. He was almost four, but he was my baby. My baby. I'd say, "This is too hard for him."

Throw into the mix a financial state that's at its low and a new baby on the way, and you come up with a pretty emotionally exhausted family. It was hard. But for Jackson, it was also working. The methods they were using at the clinic were working, and they continued working.

By age six, he had gone from a little boy who couldn't talk, couldn't make eye contact, and wasn't potty-trained to a student ready to graduate from his ABA program and enter a kindergarten classroom—a mainstream public school classroom, full of neuro-typical children, without the need of an aide. The feeling of joy that brought made it all worth it.

We cherish the joys, while embracing a life that has become a balancing act of accomplishments and struggles. It's an accomplishment for him to thrive in a classroom with peers who can look out for him and help him through unfamiliar situations, but it's a struggle when he gets confused stares and awkward reactions from classmates who don't understand why he's standing so close or why he won't stop talking about video games. It's an accomplishment that he puts his shoes on by himself or gets ready for dinner by

himself, but we might later have to explain why it's important that the left shoe go on the left foot and the right shoe on the right foot, or how exactly to turn the water on, grab the soap, lather it, rinse it off your hands, and turn the water off.

The hardest balancing act comes when I see people watching him and know that they see him as “different.”

One of my greatest fears is that people aren't going to recognize him for who he is on the inside, focusing only on his outward behaviors. I really have to work to balance my immediate feelings of hurt with the knowledge that if it doesn't bother him, it shouldn't bother me. And there's something to be grateful for there. When someone makes fun of him, he may not quite get it, and if he does, he probably won't care enough to hold on to it and be bothered by it for days. It's a blessing, and it allows him to continue to grow.

At age eight, Jackson is getting to the point where he realizes his experience is different than his classmates' and that things are harder for him than others. He realizes the math problems that take him hours might take the kid sitting next to him minutes. That the words other students can spell after a couple tries might take him 20. That's hard for a mom to watch. How do you explain that to a child who's probably worked harder than any other child in his class to get to where he is? How are we going to explain it when his younger brother begins achieving things that he hasn't yet been able to accomplish and might not be able to? That's where we say, “Jackson, it's not fair. It's really not. But this is the hand we're dealt, and we can do the best we can.”

Which is exactly what Jackson is doing. He's exceeded so many expectations that we just keep setting the bar higher.

And now? We celebrate now.

This year is the first year he'll have a birthday party with friends he picked out on his own and invited to come. Back in the “dark days,” as we called them, we wondered things like, “Will he ever have friends who care about him? Will he ever have friends that he cares about?” To have friends who genuinely want to be his friend and who genuinely like him for who he is... it's awesome.

We celebrate his friendships, we celebrate the high-functioning child he's become, and we celebrate the potential that lies in a future unknown but full of possibility. As long as he's finding his place, that's to be celebrated—no matter what.