We Are a Family

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We Are a Family

Abstract
"One mom's perspective on parenting a child with autism. 'When God created him in his mother's womb, God created him to be a beautiful child so loved by God and so loved by so many others.'"

Posting about parenting an autistic child from In All Things - an online hub committed to the claim that the life, death, and resurrection of Jesus Christ has implications for the entire world.

http://inalthings.org/we-are-a-family-parenting-a-child-with-autism/

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Comments
In All Things is a publication of the Andreas Center for Reformed Scholarship and Service at Dordt College.
When he came home at eleven months old, he cried a lot. Hours upon hours he would cry and scream, often clinging to my legs or to my side. He must have felt lost in his new home and his new surroundings, far from his home in Ethiopia.

Hours of crying and screaming turned into weeks and months. Sometimes the rages would get violent as his little body would kick and hit, as his head would hit the floor and saliva would spew out of his mouth. The days were long and the nights longer. It was scary for us as his parents and for him as a struggling one year old.

As his parents, we worked hard on attachment. We had read many adoption books and recalled our attachment training prior to his adoption. We tried to limit his interaction with others and encouraged holding and eye contact. But as he developed more into his two year old body, his meltdowns increased and the severity only worsened. We often didn’t know what would trigger his tantrums—a loud noise, a touch on his back, a supermarket filled with colors, bright lights and strange music. My husband and I described life as “walking on egg shells” unsure when something would snap and the tantrum would ramp up to a 45 to 50 minute violent rage.

I recall sitting at his bedside late in the night praying to God for direction with our sweet hurting child. I begged for clarity on how to parent well. I asked for patience in the depths of the unknowns. I prayed for peace.

We sought the help of professionals much wiser and trained in parenting children with trauma and loss. Through their guidance we were given tools to help us in parenting our beloved son. We made huge improvements with attachment. But, his easily irritated-self continued to control his behavior. His language skills were still delayed as he struggled to get his words out. He would repeat his pet-phrases like “hamburger-pea” or “bumble-bee-hamburger-pea” rhythmically throughout the day. And, his eye contact improved, only as we asked him to “use his eyes” or to look at us as he spoke.

In May of 2013, our son was diagnosed with autism. He was three years old.

In that year, the DSM-5 lumped the Autism Spectrum Disorder into one category, rather than separating the autism disorder, Asperger’s disorder, childhood disintegrative disorder, or the catch-all diagnosis of pervasive developmental disorder into separate diagnoses. After our son’s testing with a developmental pediatric specialists and a team of experts on the ADOS testing criteria, he was placed in the Autism Spectrum Disorder. I can recall asking the doctor the severity of his disorder and her response was "mild in some areas and moderate in others." She was accurate.

Honestly, the diagnosis brought a sense of relief along with a sense of unknown. I felt a sense of relief with affirmation that perhaps some of his struggles weren’t something we were doing wrong as his parents. But, I felt a sense of unknown with the realization that this diagnosis didn’t mean this is something he would eventually “grow out of” and wouldn’t be a struggle for him any longer. This diagnosis would bring a steep learning curve for us as parents. Although in all reality his diagnosis didn’t mean we were suddenly parenting a new child. Already life with our son was our norm. The ways we interacted and lived life were simply now labeled as parenting an autistic child. The diagnosis didn’t change our love for him. The
diagnosis simply brought clarity on why we did the things we did in life with our son.

Here are a few things I have learned in the last 1 ½ years.

**We don’t do Walmart or Target without a tantrum.**
*Sensory Processing Disorder* is part of life for many kids on the Autism Spectrum Disorder. Imagine walking in a store to see hundreds of colors, lights, and sounds come zooming your way without the ability to shut it off or ignore what you see. Not every autistic child struggles with this inability to process the lights at Target, but my son does. Our times at the big box stores usually results in some sort of meltdown in the store or on the car ride home.

Our son likes deep pressure touches but does not like to be brushed lightly. He likes to have his hooded sweatshirt on his head, but his body temperature rises quickly. Some days he is completely comfortable with having no shirt on (or even a coat on outside, for that matter, in the frigid Northwest Iowa winters) but at other times he wants to be squeezed tightly and wrapped up in a blanket.

He recently started sucking on his shirt sleeves, leaving the shirt wet and smelly by the end of the day while chewing holes through the hem of the sleeve. This is how he is likely processing some sort of internal anxiety or stress. Some days are worse than others. He might change to a different stimulation need a few months from now. It seems like his sensory needs are always changing.

**There are a variety of opinions on how to treat autism.** Some families have gone 100% gluten-free, claiming the intake of gluten increases irritability and other symptoms of autism. Other families swear by ABA therapy, a therapy used to increase social skills for those on the spectrum. Occupational therapy works well for some children and not for others. Medication approved by the FDA works well for some children, helping to decrease meltdowns and rigidness. Other parents feel strongly about not medicating their children. There are a variety of choices and a variety of opinions.

Personally, medication has helped our son cope well. Since being “easily irritated” is part of his behavioral needs, the medication has helped take the edge off and helped him find ways to cope. We have found his communication skills have improved and his meltdowns have become less violent. Occupational therapy helped for a season shortly after his diagnosis. And, social interaction at daycare has helped him adjust well to being with his peers in a social setting.

**Autism looks different on everyone.** The Autism Spectrum Disorder is a long spectrum. For some children their place on the spectrum is quite obvious while presenting clear characteristics of the disorder. For others, it is not as clear. I can’t count the number of times we have been told “but he doesn’t look autistic” or “he acts normal to me.” The *Mama-bear* in me wants to quickly pull out his ADOS test results and show them the facts. Or, I want to snidely say, “Spend 24 hours with him and then we’ll discuss.” I’ve learned to simply be okay with what other people think and move on from there. My son is not their child. We are his parents. We know him the best. I am not an expert psychologist or developmental specialist. I am a mom.

**Autism is triggered in different ways.** Some people have strong feelings on what causes autism. Some believe certain vaccines trigger autism. Other experts would say stress in the mother while carrying the
child in vitro causes it. Could it be from certain foods or red dyes? Could it be as a result of trauma as an infant? Is it hereditary?

I’m not so concerned how autism is developed or what caused my son to be on the spectrum. I am more concerned with the skills he is taught today to live life to the best of his ability—to live life glorifying God. When God created him in his mother’s womb, God created him to be a beautiful child so loved by God and so loved by so many others.

**My son is amazing.** I can’t believe how brave my son is and how much he has worked through in the 4½ years of his life. He is funny and loves to laugh. He really loves life, often saying “I LOVE spaghetti” when I tell him what’s for dinner or “I LOVE baths” when I tell him it is bath night. He will clearly tell us what he does not like, too—like chili soup, asparagus, or salad. He does not like kisses and he gives hugs on his terms.

He is observant and notices everything. He remembers signs and pictures well. He LOVES ants and bugs. Walks around the neighborhood with him are never fast. He is always noticing the little things around him. He has taught me to slow down, too. He has helped me to notice the little joys in life. Yet, he also notices those who might not like him or who treat him unfairly. He might not let you know he notices but he does. He is not stupid. I hurt for him and his sensitive-self.

I can look back now, nearly four years since I first held him in my arms, and am amazed by how God works and how God has healed. Not every day is perfect, but not every day is horrible either. I love how God has molded and shaped our family to what it is today. As we sit on the couch together on weekends, arms and legs woven together as we laugh and snuggle together, we’ll often say to one another, “We are a family.” Yes. Yes, indeed we are a family. And, I am so grateful for it.

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