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Autism: An Unexpected Journey

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Ten-month-old Simon sat on the floor next to a basket of books, intently gazing at page after page. The books held his attention, even as I called to him, “Simon, there’s a train outside! Do you hear the train? Simon. Simon! Simon, do you hear the train?” He didn’t look up at me. The windows were open on that beautiful May morning as I visited with my friend and her daughter, Isabella, in my home. Even without being prompted, Isabella perked up, engaged her mom with eye contact, and proclaimed a toddler’s version of “Choo-choo!” She was born one day before Simon, and as I watched her interact with her mom that morning, my heart sank.

I had noticed for some time that Simon was lagging in his development, not mastering motor skills like his peers. He wasn’t measuring up to his older brother, who had been ahead of the curve on his milestones. I had secretly congratulated myself that my first-born was award-winning, but this son? He wouldn’t even look up when I called his name. I imagined that it would be okay if he crawled and walked later than normal, and it was fine with me if he wasn’t the fastest kid in the neighborhood. But his spotty communication with his mama started to tie me up in knots.

As he passed his first birthday and eventually started walking, it wasn’t that he didn’t communicate with me, it was that it was only on his terms. He was sweetly affectionate, generous with snuggles and smiles, but there were times when he wasn’t available, and it was then that I needed him. I grasped tightly to the idea that I needed him to see me and connect his heart to mine, but the louder I chanted his beautiful name, “Simon! Simon Benedict!” the more absorbed he seemed to be in his favorite stack of books.

It was another day in May when Simon was nearing his third birthday that my husband and I received the definitive diagnosis which collected his global delays into a single word: Autism. It sure made sense, given his language delays and idiosyncrasies, repetitive behaviors, and unawareness of social customs. Although the diagnosis fit what we were seeing in Simon, it was devastating to have to admit that this was going to be a lifelong struggle which he would not outgrow.

In his early years, we ran ourselves ragged, literally chasing after him every time we were outside or at a social gathering. Our commands to stay close in public were either unheard or filtered out as he ran toward whatever seemed more fun. He was eventually joined by two more brothers, growing our family to a total of four young (wild!) boys. His interest in knocking down a sitting baby or twisting his little brothers' ears brought on stress and frustration, not just for me but also for my husband and the poor little boys who learned to duck and hide whenever he approached them.

The real difficulty in helping Simon to grow and develop was that he didn't understand or respond to us in the same way as his brothers. Not only was he slower to develop speech to communicate his thoughts and feelings, but he didn't receive language in the same way as the rest of us. At times, he was encased in his own world, oblivious to our calling him into communion. With the help of speech therapists, we worked with him on following multiple-step commands, but for him it was hard to follow more than one step without becoming distracted. Now, at age thirteen and with an added diagnosis of ADHD, his mornings involve a lot of hand-over-hand reminders of each step in his routine so that he can be ready for school on time. His difficulty with receptive language has made us try to communicate with him in ways he more easily understands, such as pictures, written schedules, or, often, bribery!

Although Simon has difficulty receiving language in ordinary ways, he nevertheless has a fascination with sound. So intense is this fascination that it's disrupted household harmony more than once. When his brother Joseph, two years his junior, was just learning to sit up, two-year-old Simon regularly helped him back on the floor with a shove. Simon's fascinated expression after this offense made him impossible to discipline. He didn't hear our corrections but, rather, seemed to revel in the shrill sound his brother was making. Over the years, he has often tinkered with sounds on toys to discover cause and effect, filling his sensory system with the auditory stimuli he craves. His early "baby bowling pin" adventures seemed to be the start of his experiments in controlling sounds. At the time, while he examined cause and effect with his brother's crying, seemingly lacking empathy, we desperately searched for a way to end the madness and keep the baby safe.

As a mother who planned from the beginning to homeschool her kids, Simon's challenges moved me to look deeply within myself and acknowledge my need for more support. Instead of being taught at home, he has taken us on many adventures, including therapies, different schools, and respite care. When he was first in preschool, I wanted so badly to know everything that he experienced each day, so I asked what many moms ask when their children come home from school: "What did you do today?" His answer never, ever made sense. It served instead as a springboard for him to sing a song or piece together a nonsense sentence that didn't apply to the situation. He certainly never answered my question directly. One day, when he was three and seemed to be enjoying his preschool routine, he came home and said, "Jayden, come get your stick!" At last, a story from his day! I eagerly pieced together a few facts I knew about preschool: each child had a wide popsicle stick with his or her picture on it; as the children moved to different stations, they brought their sticks; and there was a girl named Jayden in his class. I had it! A teacher had told Jayden to take her stick as she moved stations, and Simon was repeating the exact words for me. It seems a tiny thing, but to me, it was momentous. He was communicating to me in his way, and I was decoding and understanding him.

His preschool report to me that day was an example of echolalia, a unique way that he sometimes uses language. It showcases an intelligence that isn't obvious to people who first meet him. Echolalia is common in people with autism, who repeat a phrase or sentence picked up earlier. Sometimes he will repeat a question that has just been asked as he processes it.

Usually, Simon brings a remembered sentence from a show or book and plugs it into a situation where it fits. Oftentimes at dinner he'll say something that sounds stilted given the family conversation, but we've learned to ask him where the words are from, and he can almost always tell us. One of my favorites is, "Mommy, you're a master chef!" This may not be perfectly applied, but the context is right and the sentiment sweet.

One evening when he was five and I was helping him to get ready for bed, he spoke to me in a somewhat robotic voice, "Don't worry, things'll get better." I was touched at his thoughtfulness as he repeated it over and over. Zipping through the room, his older brother informed me that Mom Asparagus utters something very similar in a VeggieTales cartoon. Though I was slightly disappointed that it wasn't unique, I marveled that Simon had applied the phrase correctly, using it in his own way to share a moment of tenderness. As I later watched the clip of Mom Asparagus sitting on the bed and singing to her son who had had a hard day, I realized that Simon may have been connecting the affectionate exchange between mother and son in the show to our relationship. Even though he didn't use his own words, the discovery of his meaning in the borrowed words was perhaps more touching than any other "I love you."

In the past few years, we have welcomed two daughters into our family. Simon, then, has four younger siblings who have all in turn been good preschool playmates for him, teaching him how to play and talk with other children. His siblings have been the best therapy, accepting him as normal and finding him curiously fun. They also know when to duck and hide from the occasional ear twist or head swipe, which we continue to discourage.

Our journey with our son is not one that we would have chosen had we been given a list of abilities and disabilities in a child. We long to communicate with him, with his soul, and to enjoy meaningful conversation, but the way his brain functions does not allow him to engage with us in this way. He has difficult behaviors that make for some very challenging moments, and I can't count the times I have asked God to heal him and to bring him out of the fog that seems to keep him at arm's length.

But the suffering of this journey is being transformed by grace. At times I feel that it's my Simon, not the Cyrenian, who walks under the heavy burden of the Cross, always struggling against his body and mind to do or say the right thing. And when I approach him in his difficult state, hoping for patience to deal with him, I shoulder the Cross that I, too, have been given. Messy and sometimes disappointing, raising a child with autism is painful work. My cries to God in the early days after his diagnosis to "heal and change Simon, reroute my path, make this easier!" have been transformed under the weight of the Cross next to Simon and Jesus. My prayer has become, "Change my heart. Help me to understand and love this child. And thank You." It seems that, slowly, the patient, long-suffering Lamb of God is teaching me the value of hidden communication and unexpected gifts. My own weakness has been revealed to me in uncomfortable ways along this path, but the revelation is the gift. Without knowing it, Simon is helping to refine his mother in fire. Then again maybe he does know it, and he smiles to himself when I'm not looking.

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