

Autism

Hidden in Plain Sight

Sarah Casburn



When I was a child, I became intrigued by autism when I saw a movie that depicted a non-verbal child who was intelligent but who had no friends. Something awakened within me and I somehow knew that I wanted to work with children with special needs. I wanted to understand them better. I accomplished this goal by completing a graduate program in Autism and Behavioural Science after finishing my studies in Early Childhood Education. Although educated in autism spectrum disorder, I couldn't have predicted that my own child would teach me more about autism than any graduate course or place of employment.

My youngest daughter has autism spectrum disorder. Her name is Emily. She was diagnosed at the age of four. Ironically, despite my educational background, I missed many of the early signs of autism in my own child.

Emily had many challenges as an infant and a toddler. None of these challenges seemed to directly point to autism, but I always had a feeling that something was "off." After the toddler years had passed, Emily's challenges persisted so we contacted our family doctor with our concerns. I was determined to get to the root cause of her biggest challenges: trouble sleeping, aggressive outbursts, constant stomachaches, picky eating, difficulties engaging in pretend play, obsessing over screen time, being unable to manage herself away from home and extreme separation anxiety, among others. Emily's various challenges meant that we saw many pediatricians. The first pediatrician insisted that our parenting skills needed improvement. The second pediatrician diagnosed Emily with anxiety, attention deficit hyperactivity disorder (ADHD) and oppositional defiant disorder (ODD), and sent us home with no advice except to be patient and loving. The third pediatrician was adamant that she simply had a strong personality and warned that parenting her would be difficult. I was not convinced that any of these recommendations addressed the root cause of her issues. I became determined to advocate for her more than ever before and find the answer. Finally, we consulted a local child psychologist. When he suggested that Emily had high-functioning autism, you could have knocked me over with a feather. How could someone with my education and my experience with autism miss this diagnosis in my own child? I continue to carry a feeling of guilt for not seeing what is now so obvious.

Emily's aggression has been the biggest challenge for our family. Her older sister is the target of most of the incidental occurrences that take place on a daily basis. However, the majority of her aggression is directed at me when it comes to her daily meltdowns. Occasionally, our pets will be attacked, or she will cause damage to our property. It means we have to monitor Emily constantly. It has been especially difficult for Emily's older sister to manage Emily's violent outbursts. As a result, she is now showing signs of trauma related to abuse. This hurts me to my core to see my other daughter in so much pain. To add further complications, I have a diagnosis of complex post-traumatic stress disorder (C-PTSD). Emily's violent outbursts trigger my C-PTSD daily, which can

affect my ability to effectively manage her aggression. While it is very difficult for me to discuss my mental health issues, I feel it is important for others to know that they are not alone.

Raising a child on the spectrum is hard. In fact, it's the hardest thing I've ever done. Every day is hard. Some days, every hour is hard. I wonder how I will ever be able to maintain a healthy relationship with my husband since every second of our day is consumed with caring for Emily. I wonder what the future will hold for our oldest daughter who has taken so much abuse from Emily. I wonder how difficult this journey must be for Emily. My body and my mind are exhausted. I am only consoled by the fact that there are other parents in the same situation as me – doing their best to love and raise a child with autism.

After Emily was officially diagnosed, I went to work relearning everything I could about autism and ways to help her. I rifled through piles of dusty schoolwork, volunteered briefly at a local school for children on the spectrum, watched hours of online treatment videos, searched for up-to-date research studies, and even contacted my previous professor. I wanted her life to be easier, and I wanted our life to be easier. I wanted the aggression to stop overshadowing the kind, larger-than-life girl that we know and love. I'm in awe of how Emily doesn't care what anybody thinks of her. She's bold and outgoing. She loves to sing and dance, performing for anyone who will watch. She feels music in a way that I do not understand but that I admire. She may even be a nurse one day because she is nurturing and goes to any length to care for someone who is sick or injured. She has no fear and gets the most out of life. She is a singing-down-the-street kind of girl. She loves to be fancy and has her own unique sense of fashion. She is very smart. She's creative, energetic and hilarious. She adores her Daddy and wants to be just like her sister. Mark my words, one day she will be famous. I look forward to the day that we will be able to manage her aggression so that everyone can see the amazing child that Emily is.

While Emily might be a challenge, I am thankful every day for the things she has taught me. She has taught me patience and perseverance. She has taught me that no matter how difficult my day might be, I need to be brave and I can't give up. She has taught me to apologize and be humble. She has taught me to appreciate the small things in life because, sometimes, in our home we have to work really hard to accomplish very small things. We don't take anything for granted.

As Emily's mom, I offer this advice – find your autism community. Find parents on social media or in your community that can relate to your story and with whom you can form a bond. Find parents that can offer you advice when needed and who will be eager to listen to your advice when you have learned something. This is a hard place to be in. I might not know how to help you, but I get it. I understand you and you understand me because we live this life together.

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Sarah Casburn lives in Southern Ontario with her husband and two daughters. She has a diploma in Early Childhood Education as well as Autism and Behavioural Science. Sarah worked briefly as an Instructor Therapist for children on the autism spectrum using ABA principles for a local government-funded agency. She left the field to start a family and has homeschooled for eight years. Sarah now promotes Sensory Enrichment Therapy, which has changed her life and brought her family out of an emotional state in which they had spent six long years. Sarah is pursuing the training to become a nutritionist and is also working towards obtaining a counselling certificate. She is also a certified sensory enrichment therapy provider and consults part time with families with special needs.

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