

Autism as Seen from the Inside

By Ishaan HOLLOWAY (transcribed by Madison MARTIN)

Ishaan is a 14-year-old boy with autism spectrum disorder (ASD). I first met Ishaan through my pediatric neurology clinics in 2016 and have had the pleasure of working with him and his family ever since. By all conventional measures used in medicine, Ishaan would be categorized towards the more severe end of the autism spectrum; however, over the years I have had the opportunity to observe, assess, and work with Ishaan, and have learned firsthand that, like many children with ASD, there is much more to Ishaan than standardized cognitive and diagnostic tests can capture and describe. It is clear we (the medical community, families, caregivers, all of us) need better tools and strategies to communicate with and better understand the minds and abilities of children with neurodevelopmental conditions like ASD, especially in children who have limited verbal language.

As a medical professional, I believe it is essential to provide treatments and interventions supported by scientific theory and evidence. And where that evidence does not yet exist, we must seek it out. From finding research laboratories to sequence and study novel mutations to using communication assistance devices such as letterboards, Ishaan's family has worked tirelessly to improve Ishaan's life and our understanding of his autism. The use of letter boards in individuals with ASD remains controversial as some techniques, such as the rapid prompting method, involve therapists prompting patients as they spell out words, making it impossible to verify whether or not the words are coming from the patients themselves. Ishaan uses his letter board independently, without any physical assistance, painstakingly spelling every word and punctuating every sentence. Although there is still much to learn about Ishaan's use of the letterboard, Ishaan's essay represents a significant step forward in his ability to communicate with others and an important step towards unlocking the mysteries of the autistic mind.

—Dr. Kimberly Ann Smyth MD, MMed, FRCPC,
Ishaan's Neurologist



Autism is a complex neurological disorder created from genetic and environmental influences. Autism impacts children starting as young as two years old and is more likely (1/68) to affect boys. Autism impacts many aspects of these children's lives including education, family dynamics, and the significance of stims.

I was in a private school for many years. It was both good and bad. Some of the good was that I got to make friends, but there wasn't much positive beyond that. Then I began homeschooling when I was starting grade seven. I am so happy my parents made a choice to change. It has made a huge difference in my quality of life. It has been so rewarding to work with teachers who can support me the way I need. I wish to see an improvement in the education of children with autism in my lifetime.

Family is a very important aspect of my life. It's what gives me hope. My family has sacrificed a lot for me. My mom especially has given her life to help me. She has dedicated countless hours to research and therapy implementation. She is the most astounding woman I have ever met. My dad is also a rock star. Even with a huge job and lots of travel, he still manages to be involved. He never lets me forget how loved I am. I have also been blessed with a phenomenal sister. I cannot imagine how she has managed to be so strong all these years. I love my family dearly and am so grateful for the life I have been given.

Lastly, I want to stress the purpose of stims. Stim means self-stimulating behavior and is a trademark of autism. Although, stimming is not unique to just those with autism. In fact, everyone stims. That being said, stimming in autism looks very different. It is typically characterized by things like arm flapping and random vocalizations. Stims can lead to obsessions, which are very debilitating. Stims may impact

one's personal image. Many passersby might not even know I have autism if I didn't give it away with my stims. Luckily, I have learned control over my stims, so I adjust better when I am in public. Stims have had both a positive and negative impact, but they are a part of who I am.

Autism is clearly an important pillar in my life. On a wide range from the failing education system, to a mind controlled by obsessions and stims, to a family made strong by diversity. My hope is that this essay will inspire, motivate, and educate people on my life and others like me. This is an insider's view on autism.

Ishaan Holloway is a 14-year-old boy with autism. He is semi-verbal but composes poetry and short stories using letterboard and keyboard. He enjoys swimming, skiing, and therapeutic horseback riding. He lives with his parents and sister in Calgary, Alberta, Canada.

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