

Behind The Locked Door: Understanding My Life as an Autistic

INTRODUCTION

“What do I do?” I asked my mom as I looked at the play-ground. I was four years old. “Go swing, or go down the slide,” she responded. I did as I had been told, then returned to ask, “Now what?” I liked the swing and I liked the slide, but that enjoyment didn't really push me to want to do it again and initiate myself. The past experience of enjoying it just wasn't driving action. When I played with toys, I limited myself to the “right” way. If a piece was missing from a set, I wouldn't fill in a similar one. I wouldn't use my imagination to fill in gaps, or view the toys as real cars and airplanes. I didn't pretend to be an adult, let alone some more fictional role like a superhero. I hardly understood playing with others or got much out of it—I simply couldn't understand what they were thinking.

When I did invite someone over, it was for a purpose.

They were here to play a specific game, or do a specific activity. The rules were to be followed to the letter: No variations, no improvisations. When we were done, we were done, time for them to leave. This hardly changed as I grew older. Even in high school, if a friend had come to watch a movie or play videogames, I often was ready for them to leave once planned activities were over.

For twenty-two years I went through life experiencing the world and the motions both of myself and those around me in a very different way than others do. Meanwhile, every few years I found myself in a new school with new kids to fail to befriend. I often just buried my nose in a book, and the difficulties were attributed to the frequent changes in our lives, and my difficulty adjusting to them.

I didn't really understand friendship the way others did. I shared activities with people, but it often didn't connect to me that it matters so much which people I was sharing those activities with. If I ran into someone I knew, it wouldn't really occur to me to speak up or call out—they were just another person out in the world if not part of a planned activity. If they spoke to me, there would often be a severe impatience to get back to what I was doing and no real desire to catch up or bond socially.

Despite my challenges, I managed to graduate from high school normally at eighteen with no repeated grades or significant academic failures, though I repeated a year of Spanish and squeaked by in a few other classes. I did excellently on my AP exams and had a nearly perfect SAT score missing just one question. With these I felt prepared, and went off to college. By twenty-two I'd failed twice to graduate from college, had similar luck with employment, suffered from recurring bouts of severe depression and generally found myself unable to come to terms with navigating the world around me. I was unable to manage my own life, and saw little chance of gaining control of it.

By chance, during this time I read an article about the odd behavior of a public figure, and how it might represent a condition known as Asperger's syndrome. I can't remember who it was about, where I read the article, or even precisely how I happened to stumble across it. Yet, as I read the article I found myself relating more and more to the descriptions of this person, and the kind of reasoning that leads an Asperger's individual to behave that way. He didn't have a diagnosis, at least not publicly, and neither did I, but now I thought one might be warranted. I felt I had a starting place, and a little bit of hope.

As soon as I finished the article, I forwarded it to my parents. I didn't want to research too much about Asperger's for fear of attempting to fit myself to the symptoms, and instead left it to those who had been observing from the outside to see if my idea made any sense. After reading the article, they saw something there too, and we found a neuropsychologist with experience in autism to perform testing and potentially provide a diagnosis. After written tests, IQ tests, hearing tests, in-depth questions about past behavior for my parents as well as myself, and more I'm sure I no longer remember, we eventually received a diagnosis of Asperger's syndrome.

Asperger's syndrome is a developmental disorder on the autism spectrum, and as such is defined in part by impairments in social communication. It was at the time treated as a separate diagnosis from autism, and alongside "Pervasive Developmental Disorder—Not Otherwise Specified." The distinctions were often fuzzy, and related to whether certain types of other delays or additional behaviors were present, as well as how high-functioning the patient seemed to be. Recently in the The Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the latest edition of the diagnostic manual, the three separate diagnoses have been organized into one—"Autism Spectrum Disorder (ASD)"—based on our current understanding of the disorder and how it can present.

Discovering that there was a real problem in my way with a name and known properties brought tremendous relief. Though there is no cure for ASD, there are libraries of research on managing and treating aspects of it. From here I could begin to learn the causes and underlying aspects of my weaknesses, define my strengths, and begin to work toward gaining control. The relief alone was life changing, and while not eliminated, the burden of depression became vastly more manageable.

It has now been nearly a decade since my diagnosis, and I am in a much better place. I'm still often overwhelmed and require a lot of alone time, but I know why I need these things, and can often manage when, where, and how I get them so as to minimally impact the life I'm trying to have. I am writing this book in the hope that others who either suffer from something like this themselves, or know someone who does, can begin to understand what life may look like through the eyes of one of our group. I believe that a more general understanding of autism is the first step toward better relationships.

I've been told I have an unusual ability to explain what it's like living with autism. I hope this is true. Everyone lives with fears, and my greatest fear is the day someone else on the spectrum

approaches me and says, "This isn't my experience at all! You're misleading and confusing them, and making it harder for me to get the help I need!" Unfortunately, I know this will happen eventually, because people with autism are exactly that: people. I would never make the claim that every blind person has the same personality, needs, desires, wants, life goals, or even experiences with being blind. I want to make clear that I don't intend to do so in regard to autism either. Every life is a unique experience, and what I'm trying to share here is mine: my trials, failures, challenges; moments of despair, hope, sadness, and yes, occasional victory; and how I experienced them then, now, and possibly going forward. While I can't tell every autistic person's tale accurately, I genuinely believe that by reading mine, with my words, I can show how a life can be different, and perhaps provide ideas about how others may too be different.