Finding Your Niche

The Diagnostic and Statistical Manual (DSM) is the bible of the mental health world and contains every psychiatric case and diagnosis ever presented. The fourth edition utilizes a spectrum to describe autism, commonly called autism spectrum disorders (ASDs). Under the ASD umbrella are three sub-categories: Asperger’s Syndrome, autism, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). This means individuals with Asperger’s Syndrome are on the “high-functioning” end of the spectrum where as individuals with more classic cases of autism or PDD-NOS are near the middle and/or lower end of the spectrum. There are two pillars to diagnosing an autism spectrum disorder: obsessive or repetitive thought patterns/behaviors and problems with communication and social interaction severe enough to disrupt or prevent interpersonal relationships. I have experience with individuals on both ends of the spectrum. Let’s start on the lower end of the spectrum with one of the more severe cases of autism I have seen. The scene is in a home in a regularly ordered, mundane suburb in Ann Arbor, Michigan.

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I am sitting on the floor across from a severely autistic thirteen year old girl trying to explain the concept of larger and smaller numbers.

“Amita\*, come on, focus. I know you can do this. Which number is larger? 16 or 8?” I tap my pencil repeatedly on the worksheet full of integers, number lines, and greater and less than signs. Amita (\*name has been changed) drops her pencil, stares back at me, and starts stimming with her hands, the way she does when she is frustrated. She flexes her hands so they looked like the beaks of a bird and starts intertwining and tangling her fingers in and out of one another, over and over. Stimming is a hallmark characteristic of autism spectrum disorders and can manifest itself in many different ways from spinning in circles to twitching to lashing out. In most cases, stimming is the result of sensory overload and is a way for the individual to take a time-out from the present situation to re-calibrate their sensory systems.

Amita’s homework was four pages of different ways of comparing numbers. It all boiled down to knowing which number was larger and which was smaller. It didn’t take me too long to realize that the concept of bigger and smaller numbers was completely lost on Amita. What was more lost on me was any way of explaining this concept to her. I counted out cards; sixteen for her, eight for me. Who had more? I drew pictures. If Amita gets sixteen bananas and Katie gets eight bananas, who gets more bananas? I drew out a number line. We counted out loud together from one to sixteen. Which number came first? That’s the smaller number. I tried using the concept of place value. Never expected that one to work; place value is tricky. No luck on any front.

I could tell Amita was getting more frustrated and my own frustrated attempts at explaining number values ten different ways in as many minutes did not help. We wrap up the homework and go downstairs to play ping pong from 5:20-5:25pm the way we do every Monday, Wednesday, and Friday. Amita is good at ping pong, much better than me. At 5:25, we go upstairs and spend the last five minutes completing her daily journal. Answer the following questions in complete sentences: what did you eat today? What are you wearing today? What was the weather like today? How are you feeling today-happy, sad, angry, bored, confused? At 5:30pm, I say good bye to Amita’s mom, Amita shows me out, I tell Amita I’ll see her next time, she does not respond.

I began tutoring Amita at the beginning of the year and we have slowly developed a relationship of sorts. I took the place of Amita’s previous tutor who was studying abroad. The first day I began tutoring, Amita cried. I felt horrible and tried to explain who I was, but all I was to her was a huge break in her routine. Things slowly improved as we re-established a routine with me in it. Amita’s autism is severe enough to prevent her from initiating speech, so much of our time together is a one-sided dialogue, at least as far as the English language goes. Amita also speaks Hindi, but her parents told me they often catch her doing a sort of Spanglish act with Hindi and English, or entirely making up her own words. Amita often makes noises; for example, it’s easy to tell when she is excited, bored, or distracted, she just does not concretely convey those emotions with words anyone else can understand. Amita’s level of comprehension is far behind where it should be academically for a seventh grader. Any questions that ask “why” or “how” cause her to freeze up. Small deviations from an algorithm ruin the entire concept for her.

Slowly, I come around to understanding the world from her point of view. Story problems in math are hard and ambiguous. The English language is abstract, high-context, and full of figurative language. People rarely say what they mean. Perhaps the hardest thing for me to *learn* was that just because Amita could not talk to me did not mean she did not understand me. Perhaps the hardest thing for me to *accept* was that Amita did not need my pity; she needed an ally, someone to guide her through the more amorphous aspects of life. I wish that I could give Amita an algorithm for how to approach every math problem, every social situation, and every question. I cannot do this for her any more than her own parents can. Some things can be worked out, such as if someone asks you, “Hi, how are you?” Your response should be “I am fine. How are you?” Amita does this diligently when I ask her this as we walk back from the bus stop. She responds in a monotonous, distant voice that clearly conveys she has memorized her lines in this scene of the play.

Now let us slide the scale down to the “high” end of the autism spectrum where Asperger’s Syndrome lives. This is the side of the scale I grew up with (only to my later knowledge). My younger brother, Matthew, has Asperger’s. The conundrum with high-functioning autism is that people like my brother are cognizant of the fact that they are different and when they do not know the right cues or lines for a certain social scene. This means they try to learn the lines and they try to fit in, like all of us are trying to do, really. It is hard to watch someone continuously knocking from the outside and never quite getting far enough in to be included. The story of my brother begins on Door Street in Toledo, Ohio when Matthew and I were toddlers.

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He had the kind of curly reddish-brown hair that would stop old ladies in their tracks.

“Aren’t you just the cutest thing?”

“Oh how I just *love* curly hair! And that color!”

This would undoubtedly be followed by an uncomfortable rubbing of arthritic hands and protruding veins against the head of my younger, rosy cheeked brother. Matthew disliked this interaction nearly as much as he hated the smell of their overwhelming department store perfume. The odor burned his nostrils and his ears would become as red as his cheeks. When this happened, my mom, Debbie, would politely thank the old ladies and pull Matthew away.

When Matthew was a baby, lots of things made his ears turn red: the cat, cotton in the air in the summer time, certain foods, even his mother’s breast milk. As a baby, Matthew had severe eczema that covered his face and torso. Debbie thought the red, itchy patches of skin were the reason he resisted being held by anyone. Maybe even the reason Matthew fought going to bed with all his might. My mom and dad often recall many a fond memory of trying to get Matthew to go to sleep at night. Nothing worked: he did not want to be held, he did not want to be fed, he did not like the light or the dark, he did not like laying on his back or his stomach, and he did not want his pacifier.

When Matthew was about a year old, my parents took him to get tested for deafness when he stopped responding to his name and showed no recognition of any family members. The cashier in the checkout lane of the grocery store was as “mom” to Matthew as Debbie was. The results came back negative. Still, Debbie could not help but wonder why her daughter, the dog, and the cat all spooked at the sound of the vacuum cleaner, while Matthew continued to sit on the floor undeterred, failing to even look in the direction the noise was coming from.

One night, when we lived on Door Street in Toledo, Ohio and I was too young to remember, my mom and dad tiptoed quietly to bed, exhausted after finally getting Matthew and me to sleep. Time to sleep was hard to come by with my brother and I just a year apart and Matthew’s sleep cycles on the order of minutes. In the brief window before the brain goes offline and sleep becomes your state of being, Dave and Debbie were jarred into panic-stricken consciousness.

“Daddy! Daddy! Help me! Help me!” My dad lunged for the door and across the hall of our one-level house into our room, flipping the light on to survey the room for an intruder or foul play. My brother and I were in our beds, unharmed, tucked in up to our necks. Matthew was in fact the cause of the uproar and he laughed at the sight of his disheveled dad and repeated the line. Though my dad was completely bewildered, my mom was not so easily fooled.

“It’s from the movie they watched earlier. *The Great Mouse Detective*? It’s the exact line from the damn movie.” My mom offered by way of explanation, rather than consolation to my dad. Matthew had an uncanny ability to repeat movie lines verbatim. This was at odds with the fact that he had stopped talking and babbling recently, not even uttering *mama* or *papa.* My dad recounts how he had hoped that Matthew was not only actually saying “Daddy” tonight, but meaning it for him.

Truthfully, my mom did not suspect Matthew was anything but a typically developing baby until my aunt Trish came over to the house to work on a project for her college classes where she was training to be an early intervention specialist. Trish went through the tests she had just learned in class with Matthew, but found that at 12 months old, he had failed to reach several developmental milestones. The word “autism” was thrown out for the first time and my mom immediately began to research. Finding more overlap with the symptoms of autism and Matthew’s behavior than she was comfortable with, she took Matthew into his pediatrician who suggested autism as well. Reluctant to be the one to dole out the Rain Man diagnosis, he encouraged a second opinion. When my mom told my dad what Dr. Rogalski had said, my dad balked at the idea of labeling a toddler who could not even talk. He wanted to wait six months and see what happened.

Six months later, my mom took Matthew, now 18 months old and more mute and distant, to see a child neurologist. He confirmed the autism diagnosis and then bluntly suggested she look into finding a permanent home for Matthew as he would be too much of a burden on her and never be “right.” He sent her on her way without so much as a referral or a pamphlet. With the official diagnosis, my mom turned into the stereotypical “warrior mom” that is often associated with women in my mom’s situation. She was very proactive becoming a self-made expert and ultimately quitting her job to devote more time to Matthew and his therapies. She was offered little support by the medical community or even my dad who never bought into the “label.” The cost for all of Matthew’s therapies was out of pocket because there was no insurance coverage offered in the nineties. My parents emptied their retirement and savings accounts and on a teacher’s and counselor’s salaries, it has never recovered. As with all cases of autism, there exists a small window of time when the child is rapidly developing through a so-called critical window where the brain is highly plastic and capable of forming new neuronal connections and pruning others. My mom ensured we hit that critical window with my brother and it is the reason he is able to participate in society the way he is today.

By the time Matthew was three years old, he had gone to appointments other kids would never need to go to in their lifetime. Six times per week, Matthew saw any one or combination of the following: a speech pathologist, an occupational therapist, a psychologist, a neurologist, an early intervention specialist, a dietician, a pediatrician, and a perceptual motor development specialist. Most of my early childhood memories involve some kind of therapist: we are at their office or they are in our home. When we would go visit Occupational Therapist Maureen, I remember playing an arcade game in the back about some kind of large ocean fish. I remember the oddly shaped swings we had set up in the middle of the basement that Matthew got to use when Occupational Therapist Jane came to our house. I remember going to Matthew’s first allergy test where they put something like 40 small purple circles all over his back with different potential allergens in them. There were needles for every single little circle. We left the doctor’s office with a printout of allergies no less than three pages long. I remember the unconventional string of diets we would undertake as a family. I ate my first bowl of tofu ice cream long before it was a fad and when diet was just a four letter word to me. Despite the quirks in my upbringing-more obvious to the third party observer than me- everything was so normal to me growing up that I never thought it could be different.

Luckily for my family and Matthew, all of this worked. My brother is incredibly high-functioning today. He got a 34 on his ACT, he is in college, and he has an internship in DC this summer. He has roommates and is talking with a girl. He does his own laundry and heats stuff up in the microwave for food. Still, “high-functioning” is read with the connotation that it is relative to the “low-functioning” individuals on the other end of the spectrum, like Amita. Does “high-functioning” then always imply he is somehow short of fully, normal functioning? Or maybe even that he is functioning at a level above and beyond the average person’s level of “functioning?” Regardless, the dichotomy speaks a lot more to the connotation of the language than any necessarily practical application. In regards to my brother, one could argue both ways. In terms of academic intelligence, Matthew is above and beyond “high-functioning” relative to just about anyone. Growing up, Matthew never played with traditional “boy toys:” no trucks, Legos, dinosaurs, or baseballs. His first real love was Egypt. We had a board game called Wadget that should have been far too advanced for someone his age in which we played as archaeologists trying to procure treasure from ancient pyramids. It was too hard for me and too boring at a year older than Matthew. He knew all of the gods of ancient Egypt: Set, Anubis, Nefertiti and the like. He loved the movie *Prince of Egypt,* went to see a play about Egypt in sixth grade for his birthday, and a year later to the Toledo Art Museum to see the Egypt exhibit. When I was in middle school, I was more interested in convincing my parents to let me go to concerts by myself than viewing the sarcophagus of King Tutankhamun.

So it would cycle every year or two for Matthew. He became intensely focused on a subject, immersing himself in every aspect of it eventually becoming a quasi-expert. Whatever it was at the time dominated his conversations with his family, classmates, and random strangers. Matthew has since moved on to become obsessed with politics, a topic my parents and I are only slightly more relieved about. The remnants of Matthew’s Egypt phase still clutter his room today from random posters hung haphazardly on the wall to various books on hieroglyphic patterns. My brother’s ability to hone in on a single subject and become an unofficial expert on it overnight has always evaded me, but it is one of the primary characteristics I associate with my brother and the hallmark obsessive thought patterns described in a typical autism diagnosis.

To illustrate the extent to which my brother is obsessed with politics, we have to go to Amer’s café on State Street in Ann Arbor, MI. I was eating frozen yogurt with a friend when I noticed a man come in with two body guards, an American flag pin on his lapel, and a black SUV with blacked out windows illegally parked outside. I determined he was some kind of political figure, but could not call to mind which one. I called my brother, like a Who Wants to be a Millionaire lifeline and offered only these descriptors: thin, white male with black hair and a big nose. *Eric Cantor*, Matthew replied. I Googled it and he was absolutely, unbelievably correct.

On the flip side, in terms of emotional intelligence, Matthew is certainly not “high-functioning” and this inherently disadvantages him and others like him on multiple levels in our society. Firstly, we live in a society that is fairly high-context in that meaning of words and phrases are inferred out of all the contextual clues that make up a given social interaction. For example, think about how you know if someone is lying to you. You look at where their gaze is directed, their body language, if their eyes shift, if they blush, if they avoid or misdirect you. Even more specifically, think about everyday phrases like “Take a seat.” Individuals with autism, especially high-functioning tend to interpret the world very literally. The literal interpretation of “take a seat” would be to have a seat in your possession somehow. Granted most of us would sit down to claim our possession, but “sit down” would work better. Better yet, think about the emphasis on political correctness in today’s society. I struggle with what’s PC and what’s not, imagine how hard that would be with a social disorder and trying to make friends or get hired for a job.

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According to an article in *Scientific American*, emotional intelligence (EQ) comprises social intelligence, the ability to control and manage your own emotions, and the ability to discern or read others emotions. The article cites evidence that EQ is the single greatest predictor of future success in terms of length of marriage, income, job promotions, and reported happiness. Let me reiterate that: the single greatest predictor of success is not the socioeconomic status you are born into or the level of education you obtain; it is an innate skill easily recognizable in those who have it, but painfully obvious in those who do not. The *New York Times* ran an article recently about a Dutch father of an autistic son who took this matter into his own hands. The man realized his son had an uncanny ability to memorize maps at a single glance. On family vacations, he was their GPS after looking at maps of unknown cities only once before. Amazed and inspired by his son’s talent, the dad founded an agency that looks specifically to hire high-functioning autistic individuals with these kinds of savant like capabilities that could be useful to companies. He then contacts companies and contracts his employees out to them so these individuals ultimately get full-time jobs and some level of self-sufficiency. He stresses that it is not charity and only the well-qualified are chosen to work at his agency. Part of the agreement with the companies is that they have to understand the kind of employee they are hiring; they are not like everyone else and they will require special leniencies and accommodations. In the end however, it is a win-win because the contracted autistic employees are doing the jobs that the average guy cannot or will not do. For example, one man has completed the exact same list of over 800 commands to find bugs in new cell phones for over twenty years. He has never complained, he has never asked to be promoted, and he has only missed roughly three bugs in the phones over his entire career. He never loses focus. You and I have attention spans of roughly eleven minutes, give or take, and I will be the first to say that job sounds like hell. But this system works in certain arenas, like tech companies. Companies need people to do these boring, monotonous, tedious, time and focus intensive jobs and many high-functioning autistic individuals are capable of providing that kind of workplace stamina.

This acceptance and concerted effort to incorporate high functioning autistic people into society is a relatively recent effort. Maybe our society is progressing, or maybe it is necessitated by the population. Let’s assume first that maybe in the year 2013, our views of including people and helping out those who cannot help themselves are borne out of a collectively progressive public place and we have learned from years of pain and mistreatment. There is an old adage that says you can measure the progress of a society by how well it treats its animals. I contest that by saying that a society’s progression should be marked by how well it treats its mentally ill. Both of my parents worked during the era of big state hospitals and the subsequent deinstitutionalization. It was not a flattering portrait of society. Patient treatment was Draconian at best and the mentally ill were treated as subhuman. People could drop off family members they thought were unruly or “retarted” and go on their way without any further obligation. On the grounds of every state hospital was a cemetery because not only were there a lot of deaths, but many people passed into the afterlife unclaimed by the living. Patients were sedated, untreated, under-stimulated, abused, and experimented on. Many of their cells had chains on the walls. Basically, movies such as *One Flew Over the Cuckoo’s Nest and Shutter Island* are not horribly far off from reality. Deinstitutionalization, which began in 1955 and ended in the 1990s, dissolved the big state hospitals, but offered no other alternative for patients which caused the mentally ill to flood the streets without direction or prospects of where to go. People fear what is not understood and mental health and the brain are a vast frontier of misunderstood and simply uncharted science and psychology.

Autism is no exception to a rough history of diagnosing and treating mental health issues. After World War II, the well-accepted theory was that autistic children were normal children who developed the autistic social disorder as a result of distant mothers who did not hold or coddle their babies enough. This “refrigerator moms” theory was the brainchild of one Leo Connor and has since been heartily disproven, but the connotation lingers enough to still make an ASD diagnosis feel very personal. The next fad cause of autism was the highly publicized and controversial vaccine scandal. A British surgeon and medical researcher by the name of Andrew Wakefield released a completely falsified report creating a link between vaccines and incidences of autism. The link was convenient fodder that caught fire with moms who were tired of being blamed by society for their autistic children and could now blame the medical community. Because symptoms of autism emerge around the same time children are vaccinated, it was a hard school of thought to shake. Millions, if not billions, of dollars were spent debunking Wakefield’s fake research and proving there are *no* correlations and definitely no causative links between vaccines and autism. However, Wakefield scared enough people away from vaccines that we are starting to see a reemergence of previously eradicated, old-world diseases like mumps and pertussis because families are afraid of having their children vaccinated.

So the argument for us learning from our mistakes leaves a lot to be desired. So why now for this high-profile, NYT article on putting people with ASD into the work place? The answer is simple: there are more children diagnosed with ASD every day and it is increasing at a rate worth paying attention to. In fact, the CDC called it an “urgent public health crisis.”

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It is a common stereotype regarding ASDs that the individual will have some sort of savant like mind-power. Sometimes, this is the case. My cousin, who is currently training to be a special education teacher, told me about a boy in her classroom who could recite the daytime lineup of television shows on all the major networks beginning in the early 2000s. My brother is some kind of living encyclopedia of semi-useless facts. Temple Grandin, one of the most famous and outspoken people with Asperger’s alive today, has an ingeniously mechanical mind and has dedicated her life’s work to developing a humane process for leading cows to the slaughter house. Throughout history, there has been speculation that people such as Albert Einstein, Emily Dickinson, Charles Darwin, and Andy Warhol may have been residents on the autism spectrum. Does this mean every individual with autism is like Rain Man? Of course not, but it does bring up an interesting concept that is starting to gain momentum: *neurodiversity.*

I first heard this term from the book *House Rules* by Jodi Picoult about a boy with Asperger’s who gets implicated in a murder case (a must-read if you want a glimpse into the Asperger’s perspective). In the book, neurodiversity is thrown out to describe the difference in people with ASDs and so-called neurotypicals, or everyone else without an ASD. More realistically and more recently, I attended a conference at the University of Michigan called “Neurodiversity: Autism Speaks Back.” There was a panel of experts from various institutes of higher education and the president of an organization that was of, for, and by autistic individuals. Morton Gernsbacher, a brain researcher from the University of Wisconsin-Madison and parent of an autistic son, offered this view on neurodiversity. To paraphrase: historically, when we started looking into brain morphology, a lot of differences were labeled as disorders, beginning with left-handedness. The literature on the research on left-handed people is horrifying. Think about all the accommodations a well-functioning left handed individual needs: desks, scissors, and placement of a computer mouse. We have very little room for diversity in our society. One person can never represent all autistic individuals because its manifestations are diverse. We need to move away from the fantasy that we need to focus our attention on finding the autistic equivalency of Braille, the magic bullet that will allow the ultimate end-game of integration into society. The data is in and it backs the conclusion that acceptance and parent perception of their child’s “disability” is directly correlated to that parent’s level of stress and happiness. The actual severity of the child’s disability is entirely independent of stress and happiness levels.

Sounds like pretty good stuff, right? We just need to be more accepting and regardless of the degree of actual disability, caregiver and individual with ASD can both enjoy a higher quality of life? There are a couple of examples in society where neurodiversity is working.

The example that readily comes to mind that most people have probably at least heard of is the popular CBS network sitcom, the Big Bang Theory. The protagonist on that show is one Sheldon Cooper, a theoretical physicist who works at a university. Sheldon’s extremely literal interpretation of the world provides many moments of comic relief to the audience and is a great source of frustration to his friends and roommates. As a fan and frequent viewer of the show, I though Sheldon was autistic right away. He has a high IQ and a low EQ, he has numerous sensory issues that prohibit people from touching him, and his signature literal interpretations of everything are the basis for the show. Sometimes, this gets him in a lot of trouble such as when he ended up with a sexual harassment lawsuit. Sheldon informed his female grad assistant that women are slaves to their ovaries and thus cannot control their sexual urges. He goes on to somehow compare women’s hormones and eggs to an egg salad sandwich left out in the sun too long. The point of all of this is that everyone ultimately forgives Sheldon’s sometimes extraterrestrial behavior because he is in a niche that supports, stimulates, and fosters the way his mind works and the way he engages with the world. He found a niche in society where it was mostly acceptable to forgo being well-versed in social niceties and etiquette because he was surrounded by similar people and his intellectual capacity for theoretical physics is incredibly desirable in academia. In other words, he could be himself. He found a place where his neurodiversity was not only tolerated and accepted, but celebrated.

A more specific and real life example is that of Temple Grandin. Temple is famous for being an outspoken advocate of accepting ASDs as normal brain diversity and developing the gold standard model for humanely taking cattle to the slaughter house. Temple had to work extremely hard and face nearly insurmountable adversity to contribute to society in a way that optimized and valued her skills. Temple’s journey is beautifully chronicled in a self-titled movie where she is played by Claire Danes. Watching Temple try to integrate and assimilate into the world at her incredibly high functioning level was sometimes comical, sometimes heartbreaking. The take away message from the Temple Grandin move is a positive one: different, not less. However, the trials of navigating a complex social world are not lost on this film. One scene in particular beautifully depicts the terrible truth that Temple knows she is different and there is really nothing anyone can do for her. Guests are at a party at her mother’s house to celebrate Temple getting her master’s degree. Temple gets overwhelmed from all of the sensory information and flees to her room; her mom follows. Temple bursts out, “I hate parties. There are too many people and no one listens to me and they keep giving each other looks and I don’t know what they mean.”

“People just don’t want to know all those details about cattle.” Temple’s mother responds. “I don’t want you to avoid people.”

“They make me feel bad.”

“Temple. Look at me. Do you know when people tell each other things with their eyes? This is me telling you that I love you and I respect you. “

“I will never learn how to do that.” Temple concedes in a rare, vulnerable moment of heightened self-awareness.

“I know.” When her mother admits this, there is such a feeling of helplessness that contrasts the amazing accomplishments they are celebrating for Temple of being the first to get an advanced degree because she still, and will forever be, incapable of reading human emotion to any appreciable extent.

In light of the amazing, real-world accomplishments Temple has brought to society with an autistic mind, let’s re-examine the concept of neurodiversity. I believe that in theory and maybe in practice, it has a lot of potential, but then again so does every kind of diversity and look where we stand with that today. Affirmative action is an issue that deeply divides the country and something almost everyone has an opinion on. I do not need to take you on a journey of American history with regards to racial diversity, religious diversity, or any kind of diversity which calls out a difference amongst people. People can barely tolerate diversity they can see like skin color or sexual orientation, let alone diversity they cannot see from the least well-understood organ in the human body. It is asking a lot of people, perhaps more than we are capable of as a society.

Here are the facts. We have to do something because the composition of our population is forcing us to. Maybe because there is no associated mortality with autism or maybe because families tend to deal with ASD very privately like mine did, the astronomical rise in autism diagnoses in the past several years has progressed without much fanfare. The 2008 CDC report on the issue declared a 78% increase in ASD prevalence from 2002-2008 with 1 in every 88 children now receiving an autism diagnosis. The exact reasons for this increase are still under investigation, but emerging theories vary from conceivable and probable to the extreme and outlandish.

One the probable end of the spectrum, a popular school of thought is that we are simply getting better at diagnosing and recognizing the symptoms of ASD at a younger age. The DSM-V (released just weeks ago) is more inclusionary in its definition by collapsing the previously established subgroups of ASD (autism disorder, Asperger’s, and PDD-NOS) and eliminating the “spectrum,” a move not only a little more PC, but also based heavily on research. The DSM-V also sought to make diagnosis easier and more definitive by lifting the previous age restriction of three years and providing more streamlined criteria including restrictive or repetitive behaviors and combining problems with communication and social interactions into one as they are inextricably symbiotic. A similarly related theory posits that better access to healthcare under the new Obama healthcare legislation is responsible for the increase in ASD cases. As more and more families are able to be seen by doctors, the more the diagnosis can be made meaning ASD is not actually on the rise, we are just now learning about what was already there. Much of the data in the 2008 CDC Report supports the issue of access theory. The largest increases in ASD diagnoses have been among ethnic minorities including black and Hispanic populations with increases between 90 and 110%, respectively.

The panel of experts from the neurodiversity conference at the University of Michigan took great issue with the CDC numbers saying that their method of collecting data-phone surveys-was reprehensible and should not be interpreted as legitimate data. They agreed that the CDC was only trying to paint autism in a negative light and create a public health scare. Whatever their intentions, it garnered a response from even my own economically depressed, human services budget gutted state of Michigan. Our dear Governor Rick Snyder released the New Michigan Autism Spectrum Disorders State Plan which “…represents another major step to addressing the many needs of the 16,000 students with ASD in our public school system and the 50,000 individuals and their families living with ASD in our state.” The report from the state directly cites the CDC Report as the impetus for the overhaul. Oh, and Lieutenant Governor Brian Calley has an autistic daughter. I am being cynical about the politics side of the policy change because at the end of the day, it was a means to a positive end. Dr. Susan Risi, a clinical psychologist from Eastern Michigan University who is the director of a clinic in Ypsilanti, MI and has been working in the field of autism for over twenty five years is on-board with the new state plan. She thinks it will bring positive and much-needed attention and resources to a field that clearly needs it. Although she was hesitant to speculate on the validity of the CDC numbers, she described the rise in autism diagnoses in the last 25-30 years of her career as “staggering.”

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The realistic camps of thought are the improvements in diagnostic criteria and increased access to healthcare leading to the 1 in 88 children with autism diagnoses we are seeing now. The more outlandish creative camps offer completely different options, like we are seeing evolution happen right before our eyes. Some people believe that individuals with autism are a more evolved form of the current human neurotypicals that are capable of laser-like focus, increased productivity, and novel ways of thinking all without having to get mired down in the quagmire of human emotion that can cost us all of the aforementioned things. Neurotypicals are going to be the old human; humans with more autism like tendencies will be the new breed. This theory seems only to have clout because of one particular report that was run on National Public Radio. This report found that there were hot-pockets of increased density of autism diagnoses around areas like MIT and Silicon Valley, or these technology home bases. The theory behind this was that individuals who are exceptional in the STEM areas have higher levels of testosterone and that they all tend to marry each other because they end up working in university areas or places like Silicon Valley. The exposure to increased levels of testosterone in vitro was then pre-disposing their children to autism. It must be noted that while sensational and very curious, these are all just correlations and should only be interpreted as so. We will only entertain this a tad further: technology is the future and it is not going away. Amita, the girl I tutor whom we met at the beginning, is the daughter of two computer science engineers.

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Let’s check in with the hard scientific research: what does it say? Most autism research money is funneled into figuring out a cause. Unfortunately for a lot of donors and expectant, anxious parents, nothing has turned up. After the scandals of vaccines and refrigerator moms, researchers took a hard look at the genetic contribution to autism. The moral of that story so far is that genes are very complex and there is definitely not one gene to link autism to the way you can with some other traditional, somatic diseases like sickle-cell anemia. The best genetic breakthrough was in Fragile X Syndrome, a complex interaction of genes that appears to sometimes cause social and cognitive disorders associated with autism, especially in boys. The other problem with autism research is that autism is often accompanied by other co-morbidities such as ADD, ADHD, anxiety disorders, etc. making the brain difficult to study as far as isolating differences. Known differences in the brains of autistic people include larger overall brain volume, some differences in the corpus callosum and cerebellum. Since the genetic component has not really panned out, it begs the question: what about the environment? We ingest chemicals from the air, our food, plastics, containers, and our water every single day. It is not unrealistic to suspect that this may be affecting our offspring.

Possibly because we went there once and we were very wrong. Perhaps because the moral implications of finding environmental components could be very personal to a mom or dad who was unknowingly turning their child into Rain Man. Dr. Dale Ulrich, an autism and Down Syndrome researcher at the University of Michigan gives the most weight to the idea that autistic individuals are genetically pre-disposed and environmentally stimulated. I do not mean to be facetious here either because investigating the environmental component also nails down this sort of disease/disorder component of ASDs as something to be corrected or fixed and that is a scary prospect when you are dealing with social disorders. Nobody is going to die from being autistic and no one would think to call them sick or ill. It would be morally questionable to have an autism pill. Social disorders inherently define a person and become their personality whether it should or not. As my mom put it, “People have muscular dystrophy or they have the flu, but you *are* autistic. It so fundamentally affects who you are.” And then there is that research mentioned earlier from Dr. Gernsbacher at the Neurodiversity Conference that higher quality of life and lower stress levels of parents was a direct function of how much they perceived their child to have a disorder or be dysfunctional. It is a very tense line to walk and leaves a lot more questions than answers for all parties involved.

The fact remains that there are more children being diagnosed with autism every single day. The bottom line is that we need to get away from the causes component of autism, whether we are looking at causes of ASDs or causes in increased diagnoses. It is all a moot point until we figure out who is going to adjust and who should have to so society can offer individuals with autism a more constructive option than group homes or jobs working far below their potential. Better treatment options currently seek a way to get autistic kids functional enough to assimilate into society. The current best practices from the National Standards Report on autism show that there have not been leaps and bounds in social disorder research in the last 50 years the way there has been in nearly every other sector of medical research. That is because simple approaches, like attentive responsiveness and mirroring really work with autistic children. It just takes a lot of time and resources. Yet, the current best option today for lower functioning autistic individuals besides their parents or relatives homes are group homes or aggregates of people living together with the same condition. It sounds a lot like small state mental hospitals to me and a giant step back to the 1970s.

In my own personal situation, I was lucky enough to have parents who allowed me to play and know and argue and challenge my brother as a person, not tiptoe around or judge him because he was a diagnosis. Still, neurodiversity is the most difficult concept of diversity I have ever been confronted with to date and I have had a lifetime to get used to it. As I prepare to graduate college and enter the “real world,” it is with the knowledge of an increased responsibility to my brother who is just a year behind me and to support him in navigating a complex social world of job interviews, office culture, and relationships. The reality is that the world is coming to our doorstep in more ways than just cultural and ethnic diversity. Autism is on the rise and like any kind of diversity that is different from the norm, it requires a certain level of understanding and acceptance not always easy to come by or readily available.

After all, aren’t we all just trying to fit in somewhere?