

Sequence

by **Sarah Belliston**

Ever since my son Jack could walk, he'd head to my bookcases and pull the books from the shelves into a pile. Sitting there like a hen hatching chicks, he'd pick a thick volume and set it on his outstretched legs. He'd turn it sideways so the weight of the book rested on his feet and the cover opened into his lap. Then his dexterous middle fingers would run along each side of the book, catching just one page, and flip it down. One by one. Over and over. When the book was finished, he'd turn it around and repeat the process. My family joked that he was reading; I joked that he loved books as much as I did.

At eighteen months old, a team of doctors diagnosed Jack with autism spectrum disorder.

A hybrid is something born from two different species, or a composite built from two different things. Hybrid cars are supposed to be good for the environment. We would not have the purposeful inventions of the liger, the tangelo, or the blood lime without hybridity. (Lions and tigers do not live in the same areas so the crossbreed of the liger has only been documented in captivity.) Because of their genetics, these hybrid animals are often, though not always, infertile.

At conception, the DNA of each parent is put into a blender and cut into pieces, so the child gets a unique mix of the parents' chromosomes. When those chromosomes merge to make sequenced pairs, they can only match with the same structure. Different species have different structures, but related species like zebra and horse or citrus fruits have enough in common to make a hybrid. In plants especially, the seeds sometimes carry the genes for multiple colors or varieties. Depending on how the plant is pollenated, a recessive color could become more common despite being he recessive trait. When the seed grows up to have the same desired trait as the parent plant,

gardeners call this being “true to the parent.” Many genetic probabilities work the same in plants as in humans. These probabilities can sometimes be determined by a Punnett square.

For example, my husband, Scott, has a genetic blood disorder called hemochromatosis. Two of his five siblings also have the condition, which is relatively mild as long as you know you have it. Those with the disorder absorb too much iron, which can cause liver failure if left unmanaged for too long. Another relative had hemochromatosis and developed cirrhosis of the liver late in life, never once having drunk alcohol. My husband has to get his iron levels tested every few months. When his iron becomes too elevated, he donates a pint of blood, which makes the body produce new blood, which in turn uses up the high iron levels and returns his system to normalcy.

Before we married I took a blood test and found out I carry the recessive gene for hemochromatosis. One study estimates that ten percent of Caucasian people are a carrier, and one in 200-500 develop the disorder. Our Punnett square looks something like this:

	Sarah h	Sarah H
Scott h	Hh	hH
Scott h	Hh	hH

Each of our future children would have a fifty percent chance of having hemochromatosis and a one hundred percent chance of being a carrier.

My mother asked me if I was okay with these odds. I said yes. I married my husband. His genes mixed with mine and the sequence of our combined DNA made a hybrid, what we thought was a good hybrid with smiles and laughs and ten fingers and toes.

I considered the known problems, but I didn't think of the unknown. When autism appeared, I wondered what our Punnett square would have looked like. And what my decision would have been.

Some autistics have symptoms from birth, while others go through a type of regression, usually before the age of five. This regression involves a breakdown of neural pathways in the brain that can affect communication and sensory perception. Some regressions happen overnight; parents wake to find an autistic child in their neurotypical child's bed. This kind of regression produces the common metaphor of autism as a kidnapper that has stolen the child.

Other autistics, like my son, regress slowly, so slowly I couldn't tell you exactly when it started. All I remember is that after his first birthday I noticed more and more signs. By his fifteenth-month well-child visit I had to admit he hadn't met any of his communication milestones. At the hearing screen a month later, I watched him lick the hinges on the door as the specialist said, "Have you considered autism?"

Science doesn't know why people develop autism. A Punnett square is impossible. There may be a genetic component, but if so, scientists have identified over 200 possible genes that could mutate in multiple ways and result in a spectrum disorder. My most recent talk with a geneticist said they can identify a genetic cause in less than ten percent of cases. The identification success rate gets even lower when the autistic does not have intellectual delays. I think of Jack and how he did first grade math at four years old. Testing him wouldn't give me any more answers. My husband's sister was diagnosed with Asperger's after we were married. Her son, who is a few years older than Jack, is also autistic. It was in the sequence all along.

There is no cure for autism. Instead there is what I like to think of as "symptom management," which usually consists of behavior modification therapy. This therapy focuses on substituting wanted behaviors for the isolating repetitive actions autism is known for, like replaying the same five second portion of a video 200 times or flipping pages in a book for hours.

Jack started behavior modification soon after diagnosis. When he was almost three, we decided to stop. Behavior modification works amazingly for many, but it didn't work for Jack. The therapy had made his behaviors worse and caused a larger regression. Before using behavior modification, he mainly ignored my attempts to interact with him. After the intervention he would lie down and will himself to sleep in order to escape unwanted stimulus, i.e., me.

Six months later after we stopped behavior modification, Jack was more interactive with me but we weren't making any progress on his communication. I travelled across the country for a weeklong training on a different kind of therapy based on relationships and social communication instead of deterring behavior.

The program is called Son-Rise and has a reputation in the autism community for the claim it can cure autism. I was more interested in the therapy because it focused on attempting to understand the purposes behind the autistic's actions. The program also has the central idea that the reward for social interaction should be the joy of the other person, not a treat or motivator (as in behavior modification). So, instead of a cue to look someone in the eye, the parent/facilitator acts in a way that makes them interesting to the autistic and then rewards any glance with an overexcited response. In essence, they teach the autistic how interaction with another human being can be fun.

By the end of the week, there were many things about the program I knew would not work for my family or my child. To complete the program with fidelity, you need a dedicated playroom where the autistic stays for eight hours a day while different volunteers rotate through, ensuring that every moment is maximized for therapy and the environment is controlled to decrease the likelihood of surprises for the autistic. I could do the gluten-free and casein-free diet they suggested because Jack only ate a few items anyway. But when they told me to take away screens, I balked. Since then, I have come to see the wisdom in their words. Some autistics, and some neurotypical children, have delicate nervous systems that cannot handle the input from a personal, interactive screen. They become isolated, irritable, and have frequent meltdowns. However, Jack is not one of those kids, at least not yet.

So when I came home, I adapted the new therapy to our family and my son. We used our whole house as his playroom and tried to be observant and ready to interact with him all the time, instead of just for set hours. I saw an immediate increase in Jack's eye contact and verbal communication. When I slowed down and focused on his reactions, he gave me more of them. When I flipped pages next to him, he stopped flipping and came over to take my book, which would turn into a game of passing books from one pile to another. Our "game" was a baby step to interaction, but leaps ahead of where we were before. Our future suddenly looked brighter, and the trip we'd planned to visit my brother across the country looked brighter too.

At the Son-Rise training, one female facilitator told a story of helping a child to say their first word. When she tried to celebrate with the parent afterward, the parent denied hearing their child speak. The session had been videotaped, and the trainer said she had to play back the tape three or four times before the parent could hear what their child had said. When I heard this story, I wondered how it was possible for a parent to ignore auditory evidence, but on that trip to visit my brother, I found out exactly how it could happen.

Sometimes Jack connects with people right away. When we got to my brother's apartment, Jack connected with his then twelve-year-old cousin, Tyson. A good big brother to three younger siblings, Tyson happily sat with Jack in front of the television. They watched the credits of a show scroll by, and Jack supplied a steady stream of what I thought was gibberish. Tyson said, "I think he's reading the names. I can almost understand what he's saying." I brushed off the idea immediately. I had heard this gibberish plenty of times when Jack stood in front of our television at home or flipped pages in his books.

Later that night I sat on the floor next to Jack as his three-year-old hands and eyes concentrated on an iPad. He had gotten into an ebook app and was flipping the digital pages as fast as he could. A steady stream of gibberish accompanied the motion. I thought about what Tyson had said. I scooted closer. Jack's gaze was fixed to one spot on the screen, the top left corner of each page. Staring with him, I listened again

and it was as if a translator had been slipped into my ear. All of his gibberish suddenly made sense. I heard “the,” “and,” “this,” and “can.”

Jack was speaking.

Jack was reading.

His sequence was wrong. He read the first word of each page instead of left to right and top to bottom. He read heavy volumes instead of picture books. But there was no denying it anymore. I wondered how long he’d been reading, how long I had been unable to hear.

I felt for those other parents, the ones who didn’t understand their child’s first word. Maybe their child was like Jack who, I realized, often dropped consonant sounds, so “pig” was a short *i* sound and “horse” was “ohss.” Maybe the parents were like me and couldn’t believe their child spoke because the action was tied to something unimaginable, like a child who could read before he could speak, or like understanding that autism doesn’t break someone’s brain, it only makes them process information in a different sequence.

In critical disability studies, there is an “affirmation model” of disability. The idea is that society and culture have trained people to view and portray disease and disorder as negative and pejorative. This model analyzes literature that highlights the good events or actions that wouldn’t otherwise happen if disability didn’t exist. *Words in the Dust* is a novel that tells the fictional story of an Afghan girl with a cleft palate. The deformity allows her to pursue an education, whereas fixing her cleft palate would result in marriage and little opportunity for learning. In John Elder Robison’s memoir, he writes how his undiagnosed Asperger’s allowed him to understand machinery in a way that led him to create pyrotechnics for KISS after he dropped out of high school. Naoki Higashida, a nonverbal autistic, writes in his book that taking away his autism would fundamentally change who he is as a person.

After reading these stories, I wonder if autism will turn out to be a positive or a negative for Jack. I’m not sure what about Jack is his autism and what isn’t. I don’t know if his ability to match his voice to any melody or sound would still exist without autism, or if his laugh would still bubble up from his center and spill over into everyone within

hearing distance. Would his unusually blue eyes still twinkle? Would his gaze still make people stop and pay attention if it was more frequent?

In truth, I don't know if my husband's gene pool caused my son's condition, gifting him the particular sequence that resulted in his autism. There are more members of Scott's family with autistic qualities, but it could be something in my genes that is hidden in me but manifested in Jack's hybrid sequence. A theory called the female protection effect thinks that genetic mutations must be more severe to cause autism in women, which means that I could have passed on faulty autism genes to my son without having any symptoms myself. Another study found that copy number variations (where sections of DNA are repeated and the number of repeats varies between people in the population) are more commonly passed on from the mother's egg than the father's sperm. At least for one specific area called the 16p11.2 region, found in about one percent of people with autism. However, the study points out that simply having a mutation in this area does not mean the individual will always develop autism.

At this point in the research, it feels to me like it's just as likely that everyone has a gene that could result in autism. Autism affects almost every family I know. Some more than others. One in fifty-nine children are diagnosed on the spectrum in the United States. The statistic just changed in 2018. The rise is attributed to the growing number of mild forms of autism getting an official diagnosis. An article I recently read talked about the detrimental part of having a genetic profile. Two individuals with the same sequential defect can have very different outcomes. Genetics do not determine prognosis, and yet if parents know of a serious mutation, they may think their child is not capable of progress.

After diagnosis, the thing I most wanted was for someone to tell me that my son was capable of learning, that spending hours and years trying to teach him would result in success. I didn't want to put him or myself through the hardship of therapy without a guarantee. If he lacked ability, maybe the kind thing would be to leave him happily sitting on the floor alone with his books.

Maybe he was happy there by himself, but I also know that he was happy when a few months ago he wrapped his little arm around my neck and gave me a kiss for the first time.

Even so, I am going forward with more genetic testing. If there is an answer in the sequence, I still want to know.

I used to think that autism appeared one day and changed my son. When I began this essay I wanted it to be about how my son was a hybrid of himself and autism. But really, autism was part of him all along. I am the one who has become the hybrid.

I spent my life before Jack unconnected with autism. Now, it is my life: in my life, my house, my writing, my brain, and my heart. I begin each day thinking of autism. I've become the autism lady, always ready to regale people with my laundry list of facts and opinions. Now those opinions include the possibility that perhaps my son has benefited in some way because of his hybridity, his sequence.

Moments are more important to me now than milestones. I judge my success as a parent, and Jack's success as a child, not on achieving the goals we set, but on attempting them. I have hope and am more willing to entertain the impossible. If I had never thought my son was capable of reading, I would not have been listening, and I never would have heard his words.



Sarah Belliston lives in Utah with her family while she attends BYU for her MFA in Creative Writing. She loves a good book, a good movie, and a good musical but hasn't figured out how to do all three at once.