

ASD: Awe-Some Delight

by Sharman Ober-Reynolds

We watched autism long before we recognized it. When Andrew was a toddler, he'd been spinning objects for half his life, and he was a phenomenon. He favored the colorful, plastic doughnuts that children stack by size on a rocking white column, but he wasn't a stacker. Instead, he crawled forward, spinning rings on the entryway tile of our Tempe house, mesmerized by their sound, vibration, movement, color, and by the air on his face. He'd do this for hours until we stopped him. Andrew worked on his technique and learned to launch the perfect spin with his fingers, appreciating all of its subtle variations. If Andrew couldn't find rings, he spun coins, cups, plates, and the lids of pots from our kitchen cabinet. He once spun a baby doll on its head. Years later, I related my experiences to a mom whose autistic son tried spinning an abandoned car tire in their weedy backyard.

Andrew walked on his hands and feet, his bottom in the air like a soft, padded hinge. Sometimes, he would go forward, sometimes backward, sometimes in a circle, looking back between his legs to see if he'd left a "twiddle toy" behind. He was constantly in motion, his thick hair swinging like a spangled gold curtain above his eyes, dark as embers. I would find him, grab him, and squeeze him tight. Andrew would laugh and sometimes stiffen his body and shake, so we called him Franken-baby. We also called him Thunder-thighs because of his delicious, plump, dimpled legs. Andrew now uses Thunder-thighs and Franken-baby as computer usernames. Who knew he was listening back then?

When Andrew was two years old, a developmental specialist conducted a standard screening during his well-child visit and raised some concerns. Some folks say CIGNA, a mega health maintenance organization in Arizona, stood for "called in and got no answer." This is an underserved wisecrack; they did their job. By the time Andrew was evaluated by a child psychologist a few months later, I had learned all I could about autism. I was

guilty of preferring that he not have it, so I was creative with some of my answers. It didn't matter; the psychologist suspected autism as soon as she saw Andrew in the waiting room, spinning a book on its corner. My friend at the autism center where I later worked would have said, "A blind man on a galloping horse could see he had autism."

Her experience taught the psychologist to recognize autism spectrum disorder (ASD) nearly on sight, but she still needed to ask several screening questions so she could complete her paperwork. Some of the characteristics of autism that Andrew demonstrated as a toddler persisted over time. He just put a different spin on them.

Does your child use words to communicate?

At two, I worked to make sure Andrew used words, prompting him as I pointed to familiar objects. He knew about fifty from these prompts. His first spontaneous word was "light." He loved lights as much as plastic rings, and when his dad held him up in the air, which Andrew also loved, close to a ceiling fixture, he would say "light." He discovered that language was a functional tool. To Andrew, light meant being lifted up in the air. When Andrew was four, he would disappear like Houdini while we shopped at Lowe's, Target, or Walmart. After way too many panicked sprints up and down merchandise aisles, I finally realized that Andrew would always be in the lighting department.

How many different phrases does your child use to communicate?

This was a more challenging question to finesse. At two, Andrew said, "diga, diga, diga, seven, seven, seven, ticka, ticka, ticka," which were not meant to communicate anything. Andrew liked the way these words sounded. He might get partial credit for "bye-bye," but even that was prompted. Before he turned three, Andrew made up and sang new verses for *Wheels on the Bus*, although he couldn't reliably say his name. Andrew's first actual phrase was, "Be nice," which he said whenever he pulled our black cat's tail, a phrase he'd heard from us with regularity.

How often does your child respond when you call his name?

If Andrew were watching plastic rings vibrate on the tile floor, he might respond if we got right in front of him and said, "Andrew," fairly loudly. He could become overly focused as a toddler.

How often does your child engage in unusual hand or finger movements?

This emerged when Andrew was three. He loved watching and listening to the sound of flushing toilets. If we hadn't found him in the lighting department of a department store, we knew Andrew would be in a bathroom somewhere, flushing all the toilets. In pre-school, he flushed the toilets in the boys' bathroom, the girls' bathroom, and the teachers' hidden bathroom. When Andrew was four, I sent him into the men's bathroom at Sky Harbor Airport about forty minutes before our flight to California. When he didn't emerge after ten minutes, I realized there was a good chance we'd miss our flight. I was ready to embarrass myself when, miraculously, a neighbor emerged from the men's bathroom. He persuaded Andrew to leave the flushing toilets behind so we could board our plane.

What does this have to do with hand mannerisms? When we took long car trips, and Andrew couldn't bring the objects he used to self-regulate, he swished his hands together and made a flushing sound. He was the best virtual toilet ever.

How often does your child repeat what you say immediately after hearing it?

For example, "Do you want a cookie or broccoli?" Andrew would always say broccoli, but I assure you, he has never eaten broccoli in his life. Of course, he wanted a cookie, but his auditory processing challenges made it hard for him to unravel the question. Andrew became an expert at immediate echolalia, repeating the last word he heard in any phrase or question.

Andrew has a complicated relationship with food. On his first birthday, he stuck his hand into his birthday cake and gagged. When Andrew narrowed his diet to about five different foods, I included more child-friendly vegetables, such as thinly sliced carrots, in his peanut butter sandwich (without jelly), with limited success. If we had corn for dinner, he would swallow a single kernel, like a "pill," with lots of milk.

How often does your child seem interested in other children?

Andrew struggled to play with other children. He followed other toddlers but was clueless about what to do once he caught up with them.

What gestures does your child use?

How could we miss something as crucial as gestures? Nonverbal body movements, such as waving, nodding, shaking your head, giving high-fives, giving a thumbs up,

pointing, blowing kisses, and even giving parents dirty looks, make up 80-90 percent of a child's communication. No, Andrew wasn't using any gestures.

Responding to these questions in the psychologist's office when he was thirty months old, I felt a wave of panic building far, far from the shore, a wave that would eventually knock the air out of me. I can't claim I was surprised by his diagnosis, but there is always a before and an after moment when you're told your child has an ASD. Before, was wishful thinking. After, my husband and I looked at each other and said, "This is who we are now, parents of a perfect little boy with autism."

The behaviors revealed by the psychologist's questions have persisted in Andrew's life, though they have manifested in different ways. His early phrase "Be nice," could be a mantra for how he lives. Andrew has always been nice. However, not everyone has been nice to Andrew. Over the years, we've braced ourselves for this. When Andrew was in the 9th Grade, a carful of teenagers threw a half-full can of Coke at him while he rode his bike to school. My neighbor, in the car behind them, took down their license plate number and reported them to the principal.

Andrew continues to become fixated on things that interest him. In the 11th grade, needing to unwind on a Friday afternoon, Andrew plopped down next to an ant's nest in a xeriscape strip outside our neighborhood. He plucked a twig from a pink Fairy Duster, pruned it to the right "Y" shape, and spun it between his fingers so he could study it and enjoy the spinning sensation. We'd persuaded him to give up plastic rings after he was diagnosed, having been told that if all a child thinks about and looks at are spinning objects, he won't notice or learn about anything else. But twigs were everywhere; they became his new twiddle toy. He sat there a long time, oblivious to the multiple times he was bitten by irate ants. He stumbled home with hives, a swelling tongue, and dizziness. We headed for urgent care, where he received steroids and antibiotics. The experience in urgent care exposed him to a pulse oximeter, which measures oxygen levels in the blood, for the first time. He has loved this device ever since. Over the years, Andrew has enjoyed a variety of intense interests. Once he latches onto one subject, theme, or object in life, such as pool cleaners, foreign languages, music, or architecture, he pursues it with an inspiring and sometimes annoying fixity.

Andrew would continue to struggle making friends or knowing how to interact with others. In kindergarten, he made friends with another child who also had autism. On the playground, Andrew asked his friend about appliances, and his friend responded with questions about trains. By the time he was in the 4th grade, however, Andrew wandered the perimeter of the playground alone.

That image of Andrew wandering alone was potent as I faced the psychologist's diagnosis. No matter my reluctance to answer her questions, largely she confirmed what I already suspected. With time, I not only accepted his diagnosis, I dedicated much of my professional life to researching and understanding ASD.

When she first diagnosed Andrew, the psychologist told us nobody knew what autism was or what caused it. In 1992, there were no support groups, behavioral specialists, school trainings, or clinical studies. Autism was just a blip on the radar, maybe one in 500 children, not the one in thirty-six that the CDC reported in 2020.

Times have changed. Now, everyone knows, celebrates, is concerned about, and loves a neighbor, cousin, sibling, or grandchild with an autism spectrum disorder. Clever and eccentric autistic characters are everywhere on TV, solving crimes and math proofs, exploring the unpredictable world of romance, or being adorable on *Sesame Street*.

As humans, we strive to understand, and as a child, Andrew had his own ideas about why he had autism. One morning, he followed me into the laundry room where I was sorting colors, and with his absolute directness, said, "I have brown eyes, and Ben and Danny (his brothers) have blue eyes. That's why I have autism." This crazy idea was perhaps understandable for an eight-year-old. Still, it broke my heart in a way that was all out of proportion to the greater sadnesses of life.

Clearly, Andrew had some misconceptions about autism, so I bought a book written to help parents explain autism spectrum disorders to their autistic kids. It's called, *Autism: What Does It Mean to Me?* by Catherine Faherty. The morning of our planned "talk," I felt anxious, and Andrew looked anxious, bouncing his legs on the edge of the sofa. I'd spent as much time as possible getting everything set up. My husband was assigned to keep Ben and Danny occupied. I adjusted curtains, fluffed pillows, and Andrew and I each had a fruit roll-up. The moment finally came when there was nothing else to do but open the

book and get on with the task at hand. By the time I'd finished reading the first section, Andrew's legs had stopped bouncing, and he'd relaxed into the couch. It was as if a trickle of air had escaped from a balloon about to burst. I could tell Andrew was glad to learn more about autism, even though it meant an avalanche of personal challenges for him. I think calling autism by its name helped Andrew transform the vague, scary feelings overwhelming him into something he would spend the rest of his life trying to understand.

Over the next week, we studied each section of the workbook, which included various facets of an autistic person's life: focused interests, sensory experiences, communication, self-advocacy, supportive structures in school, friendships, and emotions. The book concluded with a lovely section on happiness, and isn't that how we hope everything ends up?

At the time I thought, if I combine everything I learn from Andrew's therapists, teachers, autism specialists, and developmental pediatrician with the advice offered in that excellent book, I might be able to find the confidence and compassion to build a good life for my son. Is it possible that anxiety ends at the moment when we no longer have time for it? . I finally had a plan and not enough hours in the day to help my son.

Given sufficient resources and motivation, science will chart the actual boundaries and determinants of autism. Perhaps one day an MRI scan will reveal a unique brain structure or function in those with autism, like a kaleidoscope with a telltale palette and pattern of colors. Or maybe an EEG with atypical brain waves, which zig instead of zag, will provide an essential clue in the diagnosis of autism. An imbalance in specific metabolites or neurotransmitters may predict some forms of autism. Algorithms calculating toddlers' eye movements while they watch videos on a computer screen may help identify those at risk for ASD. Do they look at people's eyes or fans, and light switches? Perhaps identifying one of the various mishaps that can occur when genetic decks with their mutations, deletions, and duplications, are shuffled will point to their cause.

Whatever tools we develop to understand autism, the syndrome will always be defined by behavioral characteristics. The questions I struggled with as a young mother may still be required and can prove to reveal objectively measured indicators of differences will help researchers understand the pathways that lead to them. And since there are many

types of autism, there will be a variety of diagnostic markers. Eventually, we'll understand what's happening behind the scenes, and that could lead to a different story altogether.

We are still in the infancy of understanding ASDs. If Andrew had been born just fifty years earlier, before autism was first described by Leo Kanner in 1943, the cause of his difficulties would have remained unnamed and a mystery. And if he had been born in the 1970s, I would have been labeled a "refrigerator mother" and blamed for causing his autism by being cold and unfeeling. In the last fifty years, researchers have moved on from accusing grumpy, exhausted moms as the villain in causing of autism in their children to determining that a microscopic genetic glitch is the most likely culprit. That kind of paradigm shift is more like an earthquake.

Facts are stubborn things, so I remain perversely optimistic. While the flood of new autism diagnoses creates an intuitive sense of despair, it offers a hopeful picture as well. We're finally paying attention. After all, those who "fit the criteria for autism," also belong in families, schools, workplaces, communities and our collective futures. In our ever-expanding golden age of medicine, as we search for a cure—a highly contested goal for some on the spectrum—we may stumble upon effective treatments to add to the behavioral therapies we currently rely upon. We may even decide to provide what is needed to improve the quality of life for those living with an ASD like Andrew. After all, he is a complex and expansive human being, funny, frank, hardworking, good company, so much more than the assembled questions used to diagnose an autism spectrum disorder.



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