

Two Truths and a Lie

by Sharman Ober-Reynolds

The arc of scientific discovery is long and bends slowly toward progress. Before “science,” the best physicians in England examined King George III’s poop and urine and blistered his back with heated cups. They tried strait jackets, arsenic-containing drugs, and soaking his feet in water and vinegar. Some of his doctors thought his illness resulted from wearing wet socks, eating peas, or “flying gout,” which flew to his brain from his painful feet. The King was psychotic, maybe from Porphyria; more likely, he had bipolar disorder and later dementia, and the battle for his mind was crude, frightening, and finally ridiculous.

We look back to the previous generations and wonder how they survived bleeding, animal dung ointments, or cannibal cures. Of course, many didn't. And our children and grandchildren will look back at us, shaking their heads at the horror of our ways. Things do change, but the increments are sometimes too small for us to notice. The strength of the scientific process is that people who have different ideas do experiments, transcend prior beliefs, and build a foundation of facts. And voila, we've progressed from poop examination to brain surgery. And, if science is allowed to follow this proven path, imagine what physicians practicing 250 years in the future will think about brain surgery.

The problem is there are lots of people who no longer believe in science.

My family learned this thirty-three years ago when our son was diagnosed with autism. Our love for him is as natural as breathing or dreaming, although we no longer dream of a time when he won't have autism. And that's okay. On most days, his happiness level hovers around an eight out of ten, and, of course, I'm happy he's happy. He is solidly built, with an open expression, and when he laughs, which is often, you can't help but laugh along with him. His dark humor makes him good company. He is perceptive. When he was five, he was immediately aware that his grandmother, whom he visited twice a

year, had painted her kitchen a different shade of white. He is a thinker. At six, he had his own theory about autism: his two younger blue-eyed brothers didn't have it, so his brown eyes must have been responsible. He is a hard worker and makes sure travel plans, minor illnesses, and major snowstorms don't interfere with his job as a courtesy clerk at a neighborhood grocery store.

The autism spectrum is expansive. Dr. Stephen Shore, an autism advocate who is on the spectrum, once said, "When you meet someone with autism, you've met one person with autism." Some on the autism spectrum, because of an accident of birth, a complicated interplay between genes and the environment, never utter a word, never learn to smile, never lift their eyes to another's face or lock with another's gaze. And, while our son sometimes talks when he shouldn't—how he really feels about birthday gifts, unpopular relatives, and a movie while still in the middle of the movie—for some with autism, communication with words or gestures is not possible or desired. Sometimes, our lives are not what we deserve but what is given, and we become what we are made to be.

When he was diagnosed, our world was rearranged. I changed jobs, hoping to bend science a little faster in autism research. Over the years, progress has been slow, one foot in front of another and then another, plodding and cautious. Yes, there have been advances, but also wild detours, like when Google Maps, because of faulty information, takes you to a dead end or, worse, off a cliff.

In the 1940s, children with autism were lobotomized for "living in fantasy worlds." Clearly, not all brain surgery represents progress. If our son had been born in the 1960s, when autism was thought to be a kind of schizophrenia, I would have been charged with bad mothering. The theory of "refrigerator mothers," as these women were labeled, emerged from a sort of pseudoscience confirmed by the general misogynist basis of the Freudian psychoanalytic idea in which the mother, alone, was viewed as the source of harm. These fraudulent claims injured mothers terribly and surely entered their souls. Mothers who'd given as much as any mother could give in their heartbreaking and endless maternal tasks were crushed and shamed for years. You do not tell a woman who is

already distressed by her child's challenges and suffering that it is her fault. But that is just what psychiatrists did well into the 1970s.

While environmental, genetic, and biological causes of autism have been proposed, a complete understanding of its origin is fragmentary. In that void, disinformation has rushed in like toxic waste. So, without a good deal of skepticism, when we go online, instead of accessing *the* truth, we access *their* truth. Or the information superhighway takes us faster and farther in the direction we are already headed, confirming our preconceived notions and bad ideas. Emerson recognized that humans are "fickle creatures and easily misled," anticipating, perhaps, confirmation bias, motivated reasoning, and social media algorithms. He provided a warning, "Most men (and women) have bound their eyes with one or another handkerchief and attached themselves to...communities of opinion."

For parents, an autism diagnosis feels like being run over by a truck. And then, it feels like being run over again when the truck, driven by deluded professionals and hucksters, backs up over you. In 1992, when our son was diagnosed, the medical community had moved on from Freudian pseudoscience. In its place, a strident, populist, antiscientific movement against vaccinations emerged. So-called "autism experts" online, some with credentials, some with a grudge, and some hoping to make a few bucks lectured me, confused me, bossed me about, and told me to yank out my mercury dental fillings, especially if I expected to have more children. Since our son clearly had autism before his two-year measles, mumps, and rubella (MMR) vaccination, we wondered how the mercury-based preservative in thimerosal caused his autism. There was a response to that, too, "Vaccines made his autism worse." If you believe mercury causes autism, chelation is the next step. The next step after that was death for some children, when self-deceived practitioners "excised" heavy metal from their vulnerable bodies, like ridding them of evil spirits.

You may say, "Who would believe such a crazy thing?" It takes some effort. In Wonderland, Alice said, "There's no use trying. One can't believe impossible things."

"I daresay you haven't had much practice," said the Queen. "When I was your age, I always did it for half an hour a day. Why, sometimes, I've believed as many as six impossible things before breakfast."

In Autism-land, we were encouraged to do the same, ignoring volumes of evidence in favor of flashes that meet the eye and hunches that seize the gut. A magic potion was promoted. Unlike the shimmering blue one Alice drank, tasting of “cherry tart, custard, pineapple, roast turkey, toffee, and hot buttered toast,” this brew tasted like vitamins and was about \$800 a month. We were told to try Facilitated Communication, a kind of Ouija Board that made it possible for non-verbal children to spell out their innermost thoughts, compose poetry, and sometimes accuse innocent parents, caregivers, and teachers of sexual abuse, always with the help of a “facilitator” blind to their own unconscious demons. Some autism experts swore by restricted diets. But if a child with autism eats only six white foods and the prescribed diet eliminates three of those foods, one of which is dairy, without medical supervision, some kids end up with fragile bones and fractures.

For \$2000, our son could listen to filtered and modulated music. Auditory Integration Therapy (AIT) claimed to provide “very positive results for dyslexia and autism” and cure depression. Somehow, this made me very depressed. And angry. Kids with sound sensitivities so extreme that even glimpsing a Hoover sends them running into another room screaming often found the prescribed pitches painful. If weird music failed to “fix” our son, we could move on to hyperbaric oxygen chambers, which promised to correct the “low oxygen levels and inflammation” in his brain. The number of sessions needed would vary depending on our ability to pay for them. A research colleague told me, “The only way a hyperbaric oxygen chamber will help your son is if he gets applied behavior treatment while in the chamber.”

Because the media rewards outrage and outlandishness, unfounded and weird claims are given equal billing with careful research. And, once an unproven idea is spoken and cultivated, it takes on a life of its own. When fraudulent claims echo through the chambers of social media, they become contagious. In addition to pseudoscience, astonishing recoveries online prompted desperate parents to inject their children with blood cells and pour raw camel milk into their gluten-free cereal. And, on days when our son was not happy, and I wondered if he ever would be, I would surely have given him a snake oil-infused raw camel milkshake if I could only believe. But I couldn't.

The easiest dollar a scammer ever makes is selling miraculous remedies to distraught parents. Sometimes, I tried reasoning with families burning through their

savings or taking out a second mortgage to pay for yet another newfangled way to rescue their child from autism. Sure, there was no evidence, but the testimonials were terrific. I'd look at them with an expression of solidarity and concern and say, "You know, if there were a cure for autism, Blue Cross would definitely cover it." They would rearrange their bottoms in their seats and glance at me apologetically, helpless that they couldn't do even more for their perfect children. And really, you can't make people listen.

It's still possible to access all these kooky treatments, but their popularity is waning. An avalanche of recent research has undermined bogus claims. It cost a fortune and took years, but it had to be done. Erroneous assumptions can persist for a long time, as King George's physicians proved. After 7000 years, you'd think someone would have concluded that bleeding debilitated patients, some at death's door, was a bad idea. However, King George's doctors clung to this theory dating back to Hippocrates, which proposed that imbalances in one of the four key humors—blood, yellow bile, black bile, and phlegm—in the human body were responsible for physical and mental illnesses. But bad ideas are not humorous.

Now that parents are no longer advised to lobotomize their children as there were in the 1940s, have overcome the lingering shame of "refrigerator motherhood" expounded in the 1960s, and are emerging from the dangerous quackery of 1990s and beyond, there is a growing recognition that pharmaceutical companies have complicated motivations as well. A required course, *Fraud, Waste, and Abuse*, at the university where I'm employed asked the following question, "If a pharmaceutical company offers to compensate you for prescribing their products, you should: A. Accept, as this is a standard way to earn extra money. B. Decline. Federal healthcare programs cannot reward business referrals for reimbursement. C. Report the offer to Compliance Services, Office of General Counsel, or Risk Management. D. Both B and C." The biggest lie we tell ourselves is that we aren't influenced by "big money," which we merely see as "effective advertising."

I didn't work for Big Pharma for twenty years, but with them, coordinating clinical trials at a non-profit autism research center. Bringing a drug to the market requires a Herculean effort and a king's ransom. In 2022, the average cost of developing a new drug was \$2.3 billion over ten to fifteen years. The agency I worked for was a clinical site for

one of the sixteen different secretin trials. This pancreatic hormone, which sounds like it could be classified as one of the body's liquid humors, gained notoriety in 1998 when a mother championed its effectiveness on two national television shows. Anecdotal reports claimed that secretin led to improvements in the behavior of autistic children because problems with the stomach and digestion interfered with their ability to learn. If digestive issues were managed, autistic children were "freed up" to focus on developing skills. But we didn't need sixteen clinical trials to disprove this theory, and the word secretin makes me think of a body fluid best not discussed in public.

Pharmaceutical companies will sometimes persist in conducting clinical trials with the same investigational medication despite all odds. There is a reason for this. When companies seek FDA approval to market a new drug, they submit all clinical trials they have sponsored to the agency. If two of those trials demonstrate that the drug is more effective than a placebo, which already has a seventy percent chance of showing improvement, the drug is generally approved. Companies may sponsor as many trials as they like. All they need are two positive ones. Drug companies make sure that positive drug trials are published in medical journals and that healthcare providers know about them. In contrast, negative drug trials usually languish unseen within the FDA, which regards them as proprietary and, therefore, confidential. Not surprisingly, this practice significantly biases the medical literature, medical education, and treatment decisions.

People with autism do live better "through chemistry," as the Dupont advertising slogan claims. While there are no drugs that treat the social and communication challenges, medications successfully treat many co-occurring conditions. My son takes a "drug cocktail" of two medications to treat generalized anxiety so he doesn't "endlessly worry about everything," which is what a cocktail is supposed to do. When he was an adolescent and taking public transportation across town, medication for his ADHD helped him remember to get off at the correct bus stop.

The scientific community has now determined that applied behavior analysis, or ABA, is the mainstay for autism treatment. ABA has passed tests on its usefulness, quality, and effectiveness and has been endorsed by the US Surgeon General and the American Psychological Association. Based on the science of learning and behavior, this strategy works on husbands, in-laws, co-workers, and dogs, as well as people with

autism. Positive reinforcement is one of the main strategies used in ABA. Very simply, when a behavior is followed by something that is valued, a person is more likely to repeat that behavior. For example, my dog and husband have trained one another. Our collie-poodle sits patiently in front of my husband at every meal. For a doggy grin, he rewards her with a stretchy, sunshiny bite of his cheese sandwich. If she stares at him long enough with her penny-colored begging eyes, he slips her a piece of savory-sweet chicken satay dipped in a velvety peanut sauce. No, we can't make people listen, but whether we intend to or not, we prompt, discourage, incentivize, guide, embarrass, comfort, indoctrinate, evoke, instruct, and shape one another's behavior every day.

When our son needed more experience chatting comfortably and appropriately with his middle-school friends, his speech therapist arranged for him to eat lunch with a group of kind adolescent boys, which, believe it or not, is not an oxymoron. These boys, like most teenagers, lived on the boundary between hubris and the abyss, and this lunch-bunch social club provided a bit of healthy structure to their lives, too. We discovered that even fourteen-year-olds can bask in the ecstatic glow of altruism. We praised and thanked the therapist, and she received kudos from the school administration. My reward? Our son no longer ate alone.

Our homework was to watch *The Simpsons* and talk about recent episodes at the dinner table so our son would learn conversational starters at school. That, in itself, was rewarding. I was also recruited by the speech therapist to provide more tangible perks to the lunch group. Once a week, I would go to a slightly malodorous classroom at the middle school at noon and meet with my son and his chatting buddies. Backpacks would drop, and chairs would scrape on the linoleum floor while I set out litters of soda and greasy pepperoni pizza. While the kids ate slice after slice of the Super Supreme, I would suggest a couple of games. Two Truths and a Lie was a favorite. In this game, each student tried to trick everyone with three statements about themselves. Two of them must be true, and the third statement is a complete lie. After the reveals, sometimes the kids groaned, sometimes soda shot out of their noses, and sometimes, they would fall over laughing. We practiced this game at home, too, because deception, the ability to understand and manipulate false beliefs, is difficult for people with autism.

Really, understanding that people lie is an essential lesson for everyone. We caress the touch screens on our electronic devices and, with a few swipes, access one truth and two lies, sometimes three truths and one big lie, and sometimes, just alternative facts. Rigorous skepticism, an ear primed to hear false notes, and the unflappable skill of cache-emptying on our electronic devices are evolutionary imperatives. When it comes to caring for our children, who has the energy, money, or a single moment to waste on bad ideas?



Sharman Ober-Reynolds was born in Los Angeles and completed a master's in fine arts at Arizona State University. She is the primary author of *The FRIEND Program for Creating Supportive Peer Networks for Students with Social Challenges, including Autism*. For over thirty years, she worked in health care as a family nurse practitioner, primarily in autism research. In 2023, she was the first-place recipient of the Olive Woolley Bert Awards. Sharman now lives and writes in an old house in Salt Lake City with her family and Cadoodle, Lizzie.