EVERYTHING ABOUT AUTISM SPECTRUM DISORDERS (ASD)—the cause or causes, the best treatments, the prevalence, even whether some forms should be considered “autism” at all—seems to generate controversy these days. But beneath the Sturm und Drang of the public struggles waged by highly vocal and antagonistic advocacy groups is the experience of individual families thrown into turmoil when a child receives such a diagnosis.

Alexandra Solomon’s breathtakingly candid article in this issue reveals the harrowing ordeal and enormous costs—practical, financial, and emotional—that arise when a family discovers it must face the challenge of a child’s ASD. As she points out, “parents of neurotypical kids can do a relatively mediocre job, and their kids will turn out just fine. Parents of ASD kids have to do an A+ job nearly every day in order to help their kids bypass and work around their condition.” There are undoubtedly triumphs and rewards in this struggle, as Solomon’s story so powerfully demonstrates, but, as Richard Howlin shows elsewhere in this issue, the struggle doesn’t end when people with ASD reach adulthood.

Most of us were born with an innate capacity to “tune in” emotionally to other people, to “get into” each other’s heads, to see ourselves in the context of relationship with others. Although people with ASD apparently lack this fundamental capacity, part of the fascination with the disorder is discovering how much of the ability to “dance relationally” can be acquired, even in the absence of some instinctive neural wiring. In addition to being a tribute to the love, commitment, and gritty hard work of the families and clinicians who try to help people with ASD, this issue is an exploration of the defining characteristics of what it means to be human.

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WE HEARD SOME GREAT NEWS RECENTLY: the Networker has won the 2009 Utne Independent Press Award for Health and Wellness coverage. This is the fourth time we’ve won a prestigious Independent Press Award in our 27-year history. In addition, we’ve won just about every other major magazine industry honor. We’ve been nominated five times for the National Magazine Award (the industry’s Oscar) and won once. We’ve been cited for three Folio Magazine Editorial Excellence Awards and been named one of the 50 Best Magazines in America for the last three years by the Chicago Tribune. With none of the resources or clout of journalistic Big Guys like the New Yorker and The Atlantic, this is a remarkable track record for a tiny nonprofit like us and its band of gifted contributors and loyal subscribers. It inspires us to stand back and reflect on the improbability of what we do every two months.

We typically begin planning each issue with a flickering flame of a question: “What impact is the tanking economy having on the national psyche—and therapists’ practices?” or “What insights can psychotherapists bring to the immigration debate?” or “How is our love affair with electronic communication transforming our experience of everyday relationships?” The posing of these questions generates a lot of discussion in our offices, followed by a search for people in our field who have something compelling to say about these issues. The articles that come out of that process typically are written, not by professional journalists, but by therapists who are willing to put themselves through the notorious Networker meat-grinder (five or six drafts are routine) in order to communicate their ideas with as much clarity and emotional impact as possible.

Ultimately the success of this magazine is the result of the genuine passion of people who’ve devoted their lives to what they do and to the people they try to serve. We sincerely believe that nobody cares more about this profession than our contributors and subscribers, all of whom help bear witness to the astounding drama that we therapists are privileged to participate in every day.

Richard Simon
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AUTISM SPECTRUM DISORDERS

20 CARRYING THE HOPE By Alexandra Solomon
When a child is diagnosed with an autism spectrum disorder, everything in a family changes. Good-enough parenting must give way to the demands of überparenting—always mindful, always well-paced, always at the child’s learning edge.

ARE VACCINES TO BLAME?—26
The controversy over whether the ever-expanding number of recommended vaccines is putting children at risk for autism.

30 SCHOOL DAZE By Diane Yapko
Constant uncertainty about who’s a friend and who’s a foe, the mundane chaos of the classroom, rules that always seem to be changing—an ordinary day at school is a baffling experience for kids with Asperger’s syndrome.

34 THE MISSING PIECE By Richard Howlin
To go through life with Asperger’s as an adult is like walking onto a stage and being the only actor who doesn’t know the lines or plot. But as the condition becomes better understood, therapists are developing ways to provide stage directions that can make a difference.

MEET ME HALFWAY—39
By Nathan Weissler
The worry and wonder of living with AS.

OTHER FEATURES

42 GRAND ILLUSION By Mary Sykes Wylie
In the last few decades, getting ahead, always a leitmotif in American society, gave way to a collective hallucination of striking it filthy rich. As we awaken with anxiety and dread from this version of the American Dream, it’s time to reexamine our mindset about money.

50 THE SECOND AVENUE DELI SCHOOL OF ECONOMICS
By Esther Rothman
You think the toboggan ride of your 401(k) has been rough? A survivor of the Great Depression muses on what that era taught her about managing the unmanageable.
“Mom, you have to come and look at my poop!” Brian yells, running back into the office where Fran, his therapist, and I are patiently awaiting his return. His blue eyes are shining, he grins from ear to ear. He gestures to me (“Come here!”) and then runs and grabs my hand. When I arrive at the potty, I glance at the specimen and then at Brian. His eyes are glued to me, anticipating my reaction. I smile, he laughs and spreads his arms wide, “It’s the longest snake ever!” Such a moment might not strike everyone as so wonderful, but to me it’s utterly amazing—on so many levels. When he was 26 months old, Brian—now 6½—was diagnosed with PDD-NOS (pervasive developmental disorder, not otherwise

by
ALEXANDRA SOLOMON

Carrying the Hope
specified), an autism spectrum disorder (ASD) falling somewhere between autism and Asperger’s Syndrome. Although, even then, he was considered “high-functioning,” he was dealing with some significant problems for such a little guy. He had painfully sensitive ears (auditory hypersensitivity), no interest in other kids, aggressive behavior toward himself and others, scripted language, limited play skills, chronic diaper rashes, and continual gastrointestinal problems, vacillating between constipation and diarrhea.

Now, at 6 ¼, thanks to intensive early intervention that was truly biopsychosocial in nature, he’s making great strides. Not only have his physical and medical problems improved dramatically, but he’s competent enough at relationship skills to want to show me something he made, to figure out how to get me to come see it, to wait for my reaction, to celebrate with me, and summarize the whole event with a declarative statement.

When Brian asked me to come and look at his poop, he wasn’t trying to get me to do something for him or to make something happen. He wanted me to share an experience with him purely to share it. He used gesture, engaging in nonverbal communication both receptively and expressively, which even six months earlier he simply couldn’t do. This level of social referencing (defined as the ability to read, recognize, interpret, and respond to others’ facial expressions and tones of voice), coordination, and experience-sharing is extraordinarily difficult for a child with an ASD. Odd as it may sound to those unfamiliar with this disorder in kids, what Brian did is a very, very big deal.

To this day, Brian remains gluten and casein free. He’s also egg-free, soy-free, citrus-free, and free of all artificial colors, flavors, and preservatives.

Mommy Instinct

Brian’s first year of life was unremarkable—marvelous to his mom and dad, of course, yet unremarkable. He met all of his early milestones on the late side of normal and was social and sweet. At his 15-month well-child visit to the pediatrician, he received a clean bill of health and (I now believe) a fateful combination of two vaccinations: the measles, mumps, and rubella (MMR) shot and a flu vaccine. After the vaccinations, he spent the next three months sick more often than he was well. He battled bout after bout of diarrhea and became extremely sensitive to sound. He seemed tense a lot of the time and preferred repetitive solo play, pulling the books off his shelf and “reading” through them over and over in the same way. He also started to pull hair—my hair and that of the moms and kids at music class. He didn’t seem angry when he did it, just tense.

However, by 18 months, he could count to 100, knew all of his letters, and was beginning to do phonics (“Brian, what letter does ‘lavender’ start with?”). Nonetheless, at his 18-month visit, I asked his doctor how I would know if he had autism. She said, “Does he point?” I said, “Yes.” She said, “He doesn’t have autism.” I was relieved.

As I look back on this interaction, I realize how much the doctor really missed the mark with her cursory screening attempt. Brian did point (“Where’s the cow?” I’d ask, and he’d obligingly point at the cow in the picture), but he wasn’t demonstrating joint attention in an age-appropriate way. Joint attention, a readily mastered milestone for a neurotypical child, means that the child looks at something—say, a balloon that’s captured his interest—then at mom to make sure she sees it, and then back at the balloon. An attempt to join his attention with another’s is lacking in a child
with ASD, and it’s an important diagnostic indicator.

At Brian’s 24-month visit, I expressed clear concern. He hated being around other children, he was self-injurious when frustrated (biting himself and sticking his fingers down his throat), his hearing was painfully sensitive, and he was crazy-good at math (at that point he could identify any three-digit number, and he was beginning to add). I didn’t consciously know what to call this, but the combination frightened me. The doctor simply told me that he was a math genius and that I needed to become a better disciplinarian. “Everyone has quirks,” she said breezily.

**There’s a Name for It**

After another week of comparing my son to similarly situated children and feeling with every comparison that something just wasn’t right, I called my pediatrician again. She told me that she’d actually been thinking about Brian, too, and that we ought to seek an occupational therapy evaluation to rule out a sensory integration disorder. I’d never heard of this disorder, and it didn’t appear anywhere in my DSM-IV, but we went ahead with the evaluation at a local clinic.

The occupational therapist decided that Brian suffered from “auditory hypersensitivity, low muscle tone, motor planning delays, and vestibular and proprioceptive hyposensitivity [low responsiveness].” The vestibular system, located in the inner ear, controls head and body movement, balance, and posture, and influences other sensory systems. The proprioceptive system refers information from the joints, muscles, tendons, and ligaments, telling you where your body is located in space. According to the occupational therapist, Brian attempted to make up for his underresponsive vestibular system by seeking out swinging, jumping, and sliding, but would become overwhelmed by the stimulation and then get upset. He attempted to compensate for his underresponsive proprioceptive system by seeking intense experiences of physical contact—squeezing or being squeezed, jumping, crashing, and pushing (usually other kids!). In short, there were multiple ways in which his sensory system was skewed, resulting in anxiety and behavior problems. The recommendation was for occupational therapy for two hours a week at the clinic. We were sad and a bit confused, but we started the therapy as instructed.

Still seeking more information, I reached out to a colleague, a psychologist who specializes in working with children, and she recommended that we seek a full neuropsychological evaluation to check on “all of Brian’s lines of development.” So we headed to a neuropsychiatrist at a well-known clinic, specializing in neurobehavioral problems. On the way home from the first session, which included some assessment of Brian and some interviewing of me, I began to panic as I replayed her questions in my mind: Does Brian have language anomalies, like reversing his pronouns? Does Brian use gestures like nodding and shaking his head? Does Brian spontaneously direct your attention in order to show interest? I knew that I was answering nearly all of her questions “the wrong way,” indicating a less-on-track rather than more-on-track child. I got home and opened my DSM to the chapter I feared the most, the chapter on Pervasive Disorders of Childhood. I called my husband sobbing, “This neuropsychologist thinks it’s autism. Holy shit, she thinks it’s autism!”

Indeed, six days after the birth of our second child, Courtney, we were told that Brian met the criteria for a “provisional diagnosis of PDD-NOS.” Reality sunk in only slowly over days and weeks. I hear this frequently from parents of children like Brian. The mind and the soul can’t take in all of the meanings, feelings, and unknowns at once—it’s too disorienting.

**Reality Bites**

Those early postdiagnosis months are an existential mess for all parents, and they tormented me. As we started to tell family and friends, no reaction was the right reaction. I remember my mom’s cheerful voice telling me, “He’s fine! He’s more than fine. The only problem Brian has is that he’s too smart for his own good!” But we’d just been told that he wasn’t fine, and her reaction hurt me— it felt like an invalidation of the struggles we were up against. By contrast, I remember my stepmother’s heavy voice telling me, “My heart is breaking for you. I’m just so sorry for you.” Her reaction hurt me, too. Her heart shouldn’t be broken, I thought—this wasn’t a death sentence. We’ll get him what he needs to catch up, I told myself stoutly, and he’ll be “indistinguishable from his peers” by kindergarten (the oft-repeated goal of early intervention).

True, Brian was still the same boy he’d been before the diagnosis, and I resisted looking at him differently. Yet, he also wasn’t the same boy. He was now a boy who couldn’t and shouldn’t be expected to do what other children do. I could feel the ways in which the diagnosis, the label, was becoming a lens through which I experienced him. Autism was beginning to infiltrate everything.

We’d always laughed about how Brian’s transitional objects were never stuffed animals or baby blankets. Related to his deep and abiding love of numbers, his favorite form of comfort always came in the form of an “8”—an 8 of clubs from a deck of cards was the best, but sometimes a magnetic refrigerator 8 or even a hair elastic twisted in half could do the trick. Indulging the love of 8s was now tantamount to reinforcing the autism, but not allowing him to seek comfort with an 8 felt cruel. I was stuck. The 8 of clubs now seemed symptomatic of the autism because one of the DSM criteria relates to “restricted interests,” for example being “highly attached to some inanimate object.”

I had become my own worst fear: the mother of a child with special needs. I remember, long before I became a mother, seeing the mothers of disabled children and pitying them—how shameful for me to admit! And it was autism I feared the most. The little I learned in graduate school about it terrified me. How could I survive having a child who wasn’t responsive, who couldn’t give love? Of course, my stereotype of autism was skewed. I’ve never met a mother who described her child with autism as unable to give love. But long before I faced autism, I feared it deeply.

Thankfully, there’s just too much to do, postdiagnosis, to wallow for long in grief and anxiety. The neuropsychologist told us that there’s a limited window of opportunity for effective early intervention, and that to minimize the
The RDI approach is basically überparenting—
always mindful,
always well-paced, always at
the child’s learning edge,
and always dynamic.

As families create a treatment plan for their child, they face a maze of financial, practical, and philosophical decisions. In my experience, an hour of Applied Behavioral Analysis (ABA) therapy—the most researched treatment approach for autism, but not the one we finally committed ourselves to—costs between $55 for a paraprofessional to $135 for a master’s-level speech therapist. The costs of having a child on the autism spectrum can be staggering, even if you don’t go with the 40-hour-per-week ABA approach. At one point, we were paying almost $60,000 out of pocket per year to pay for therapy, special diets, supplements, and school costs. Health insurance covers a small fraction of these expenses.

Quarterbacking the Treatment Team

Todd and I recently played a fun game, over a bottle of wine: “Name that therapist.” We laughed, in that half-funny-half-morose way, as we named every “expert” we’d consulted over the last four years. I won’t even tell you how many we counted, but I will say it was well over 30!

First let’s talk about healing his body. It hadn’t taken us long to start to explore the vaccine-autism connection (see sidebar, page 26). Within four months of his diagnosis, the potential connection scared us enough that we were sitting face to face with one of the world’s foremost Defeat Autism Now! (DAN!) physicians, Dr. Anju Usman, who used clinical observation and lab work to determine that Brian’s immune system and gut (80 percent of our immune systems lives in our guts) were pretty badly damaged by the 20-plus vaccines he’d received in the first two years of his life. He had overgrowths of yeast and bacte-
ria, little of the “good” bacteria, hyper-immune responses to several viruses, heavy-metal buildup, a “leaky gut,” and rampant food allergies.

We implemented a long list of daily supplements and began the Gluten-Free-Casein-Free (GFCF) diet. I affectionately refer to this time in our journey as the closest I ever got to a psychotic breakdown! Making sense of what it means to have a child with special needs is difficult enough. Thinking about “what might have been” if we hadn’t allowed him to be vaccinated increased the emotional load. Then taking on “biomedical treatment” added another complex plot twist to a narrative already almost too demanding and convoluted for my mind to encompass.

Families who believe their child’s ASD is the result of “faulty genes” may curse their bad luck. But families who believe their child’s ASD is the result of an underlying genetic vulnerability that was ignited by early, intense insults to the immune system through vaccines and other pollutants must then face the choices they made on behalf of their child. I’ve carried anger at myself for not having questioned more, and I carry a lot of anger at pediatricians and others in the medical establishment who ought to be more careful about our rapidly growing, poorly researched, one-size-fits-all vaccination protocol.

So I began this GFCF diet kicking and screaming. I agreed to try it for three months. I circled June 1st on my calendar, and I lived for that day. Figuring out what to feed an already picky 2½-year-old was no fun! Four sippy cups of milk a day? Replace with diluted, organic vegetable juice. Toaster-ready pancakes? Replace with rice and amaranth pancakes made from scratch, with allergen-free chocolate chips and ground flax added for good measure. Macaroni and cheese? Replace with nothing—there’s just no good way to make GFCF macaroni and cheese! I’ve never been the Martha Stewart type, but I was buying cookbooks and trying new recipes every day.

June 1st came and we’d not only survived, but—despite his continual complaining about the diet (particularly about losing his beloved macaroni and cheese)—Brian had definitely improved. In those three months, he’d gained some much-needed pounds and inches, having stagnated on the growth charts in the months before. He’d made nice language gains, he’d increased his eye contact, his poop was normalizing, and his ears were bothering him less. All this was great. There was only one piece of bad news, which my husband broke to me over another bottle of wine: “Al, you know we have to keep doing this diet.” “I know,” I sighed. To this day, Brian remains gluten and casein free. He’s also egg-free, soy-free, citrus-free, and free of all artificial colors, flavors, and preservatives.

Healing Brian’s gut has made him less autistic, and removing offending foods certainly played a huge part. Dr. Usman also used antibiotics to reduce some nasty bacteria in his gut. When those bacteria were under control, Brian stopped hitting, scratching, and pulling hair. Amazing! While some doctors need to reduce a child’s heavy-metal burden with the drug chelation, our doctor has been able to take a less invasive approach and support Brian’s detoxification with supplements. Interestingly, recent research has shown that children with Asperger’s disorder have less metal toxicity than children with full-blown autism.

We’ve learned to manage Brian’s physical health much the way parents would who had a child with diabetes. We think of him as having a chronic medical condition. When the medical condition is well managed, it recedes into the background. When we see old behaviors return, we look at what might be getting out of balance in his body and make plans to correct it.

**Remediating the Core Deficits**

In addition to repairing Brian’s “hard drive”—his brain structure and biochemistry—we’re working on his “software”—his development, behavior, cognition, and psychology—through various forms of therapy. There are three distinct ASD treatment approaches: Applied Behavior Analysis (ABA), Floortime (DIR), and Relationship Development Intervention (RDI) (go to [www.psychotherapynetworker.org](http://www.psychotherapynetworker.org) for more information). Our research and personal experience led us to feel most connected to RDI.

RDI therapy was developed in the late 1990s by Steven Gutstein, a clinical psychologist with a background in family therapy. He observed that autism spectrum disorders “belonged” much more to the world of developmental disabilities than to the world of developmental psychology or family therapy. By breaking down typical developmental targets into infinitely smaller milestones and examining those closely, Gutstein created a way of thinking about ASDs that goes far beyond the DSM’s description of symptoms. For example, children with ASDs frequently demonstrate average or above-average levels of static (rote) intelligence, but show deficits related to dynamic (interactive) intelligence. Gutstein identified five “core deficits,” both unique to autism and descriptive of all children on the spectrum: in declarative communication, referencing, regulating, episodic memory, and flexible thinking.

To address these core deficits in dynamic intelligence, Gutstein created a clinical treatment program that trains parents to teach dynamic-intelligence skills and motivation to their child. Rather than using concrete rewards and reinforcers, RDI teaches the joy of connecting and helps people on the autism spectrum learn how to express friendship and empathy and to genuinely love sharing their world and experiences with others. Although RDI is relatively new to the scene, early research is promising. Within 18 months of starting treatment, more than 70 percent of children in an initial study improved their diagnosis, based on the Autism Diagnostic Observation Schedule (ADOS). The majority of children moved from a special education to a regular classroom, and didn’t need an aide.

Although parents are the guides and children the apprentices in this work, usually families meet with an RDI certified consultant once every two weeks. Using a structured, four-session assessment protocol, the RDI consultant determines the child’s current developmental stage, which is usually Stage 1. For each stage, there are more than 20 objectives the child must achieve before he or she can progress to the next stage. Families
tackle one developmental objective at a time, and each one is at the edge of the child’s learning capacities. In addition to working directly on the current developmental objective, families commit to adopting overarching lifestyle practices, such as waiting until the child is oriented to the parent before beginning to speak to him or her and utilizing an 80-to-20 ratio of declarative to imperative language (go to www.psychotherapynetworker.org for more information).

RDI work takes the form of parent-led activities, usually in the home. Parents record their work, using video and notes, so that consultants and parents can track the progress toward mastery. For example, in Stage 2, a major objective is having meaningful dialogues with your child using only gestures to communicate. When we were working on this objective, one of our games was “traffic cop.” Brian and I would put whistles in our mouths to keep us from talking, and then we’d take turns letting each other know when to come closer, go further away, move slowly, move quickly, etc. I made sure we did this work in a quiet space where distractions were minimal and tried to make it clear to him when I could tell exactly what he was “saying” just by watching his body. It was remarkable to watch Brian gain confidence in this alternative communication modality and to see him generalize it to other settings.

We’ve been doing RDI therapy with Brian for almost four years now, and we’ve seen significant remediation in each of the areas of core deficits. RDI therapy is the hardest and most rewarding work that Todd and I have ever done. It’s basically overparenting—always mindful, always well-paced, always at the child’s learning edge, and always dynamic—and it’s this parenting (or as close to it as merely mortal parents can do) that children with ASDs need. But to attempt to do this kind of parenting is a continual challenge, on every level. Let me take you into my messy RDI world.

I’m sitting at the monthly RDI parent-support meeting feeling like a disaffected preteen, arms crossed, rolling my eyes at my friend, Samantha, who’s sitting across from me. This isn’t my usual M.O. I adore our RDI consultant, believe fully in the program, and consider myself a fairly mature adult, so what’s my deal?

The topic of this particular meeting is “appreciating messiness.” The consulting staff is working with this group of moms and a few dads to figure out how we can incorporate more messiness into our lives in the service of helping our ASD kids appreciate the messiness (literal and figurative) of relationship and of the world. In fact, we’re brokered up into small groups and sent into therapy offices to make a “stew” with oil flour, liquid soap, toothpaste, oatmeal and salt.

Later in the meeting, we’re given handouts with suggestions of messy activities that we can try at home, like filling balloons with shaving cream and water, having a snowball fight with crumpled paper, painting a mural, and eating breakfast for dinner. The suggestion that still sends Samantha and me into fits of laughter months later is to create a sand pile instead of a sand box. The details of the idea are: have a truckload of sand deliver...
ered to your backyard, play all sorts of messy games on the mountain all summer long, and order new truckloads every few years. This is the idea on creating mess that makes me really mad.

The nature of my anger is complicated. I absolutely agree that ASD kids need lots of opportunities, more than typically developing ones, to experience messiness in the safety of their own homes with their primary caregivers before they can be expected to handle competently the messiness of the world. And I absolutely agree that ASD children’s difficulties with messiness operate on many levels. Putting their hands into a bowl of toothpaste and flour can be overwhelming to ASD children’s already skewed senses. Such messes upset their black and white notions of where toothpaste belongs and doesn’t belong. And making messes like that requires joint attention and the sharing of the experience if the mess-making is to be meaningful and fun. I absolutely agree that making a messy stew with my ASD child is a great idea.

But then I start to examine the RDI consultants’ message, which sounds to me as if I, an ASD parent, need to be encouraged to loosen up and get messy. That seems fine on the surface, but, at the emotional level, the message seems to imply that my kid has an ASD because I can’t loosen up. And maybe they think that my kid’s ASD will get better if I can just loosen up. This all sounds suspiciously like blame, and makes me feel defensive as hell. My rational self trusts that the RDI consultants respect me as a mother and don’t blame me for my child’s ASD, but my irrational self is having a field day!

I start thinking about friends of mine who are far more neurotic than I—friends who don’t allow finger painting indoors, friends who rub Purell on their kids hands at every turn, friends who’d never tolerate the shaving-cream treasure hunts and mud pies that we enjoy at our house. These friends aren’t sitting on the floor with other grown-ups making oatmeal stew. These friends, in fact, are raising kids who are the poster children of typical development.

Fast-forward a few months. I attend one of Gutstein’s two-day RDI workshops. By way of empathizing with ASD parents, he says something like, “Parents of neurotypical kids can do a relatively mediocre job, and their kids will turn out just fine because the force of typical development is very powerful. Parents of ASD kids have to do an A+ job nearly every day in order to help their kids bypass and work around their condition. That’s exhausting.” This is an “aha” moment for me, offering some clarity about my anger. The biggest difficulty, for me in parenting an ASD child isn’t the financial strain or the chronic worry. It’s having to bring my “A game” into play every moment with Brian every day.

In my heart, I believe that I’m British psychiatrist D. W. Winnicott’s “good enough” mother. In my heart, I believe that I was and continue to be empathetically attuned to Brian pretty well. That wasn’t enough to prevent Brian’s ASD, and it’s probably not enough to remediate it. Parenting him requires vigilance and creativity far beyond parenting.

overwhelmingly against the link, according to the New York Times.

Yet there still appears to be science on both sides of the issue, and parents of affected kids are fighting on both sides. The number of children diagnosed with autism has skyrocketed since the 1980s, when the autism rate was 1 in 10,000. Today autism affects 1 in 150 children (66 per 10,000). Some argue that the increase is due to better diagnosis and changes in diagnostic criteria, as we now think about autism as a spectrum disorder (http://www.cdc.gov/ncbddd/autism/faq_prevalence.htm). Additionally, there are now reporting requirements for the schools, which had never had to report autism cases before 1991. According to the “no-epidemic” people, many now diagnosed with autism wouldn’t have received that diagnosis before 1994 (including, possibly, Brian). According to the “yes-epidemic” people, the vast majority of cases of ASDs aren’t the Brians of the world, but the more severely affected children who’d always have been diagnosed with autism. The “yes-epidemic” people say there are now many more of those children. The whole issue of counting and determining who has autism and who doesn’t is astonishingly complex, given the facts that there are no medical tests for the ailment, and diagnosis is based entirely on behavior.

A further complication is that some researchers, activists, and parents state that while Thimerosal certainly has seemed to be a likely suspect, it isn’t the only suspect. The number of vaccines given to children in the first few years of life has grown rapidly in the last 20 years. In 1988, babies received 10 vaccinations. Today, they receive 36. This is an increase of 260 percent.

Beyond Thimerosal, other vaccine ingredients (aluminum, formaldehyde, and monkey kidney cells, to name a few) appear troubling. In addition, the cumulative effects of the entire vaccine schedule recommended by the American Academy of Pediatrics has never been studied. Doctors who believe that vaccines and the current vaccine schedule are safe state that the amount of the troubling ingredients is small: and that safety testing is adequate. But many critics are increasingly convinced of the link between vaccination and autism, and argue that much of the opposition to this idea stems from a reluctance to recognize the possibility that modern medicine may be playing a role in damaging a generation of children.

Some even take this argument further and believe that exposure to a wide range of chemicals is implicated in the increase in the incidence of autism. There are an estimated 85,000 household chemicals on the market, of which a mere 20 to 50 have been safety-tested for effects on neurodevelopment. We have no idea of what they’re doing to any of us, much less to children who may have preexisting vulnerabilities.

Increasingly, researchers are investigating autism as a complex multisystemic, environmentally affected condition—not just a hardwired brain state, but “an ongoing biological process.”

—ALEXANDRA SOLOMON
Courtney, who meets and often exceeds my level of engagement with her. She came into this world ready to dance relationally, but Brian must practice each microstep of that dance over and over to become competent at it.

He deserves parents who have the energy and the persistence for all of that practice, and I frequently lie awake at night replaying the day’s missed opportunities and rushed interactions. Did I offer him 80 percent declarative language? Did I wait to speak to him until he was oriented to me? Did I properly reduce external demands on him, so he could experience productive uncertainty? Did I share with him my self-narrative, so he could continue to master the complexities of intersubjectivity? Never well enough it seems.

**Why Him? Why Me? Why Us?**

Autism not only transformed me as a mother, it transformed my marriage. I think about standing with Todd under the chuppah 10 years ago as bright-eyed and optimistic 25-year-olds, ready to tackle any challenge that came our way. Certainly his law degree, my doctorate in psychology, and our endless conversations about our relationship would protect us from the expected and unexpected challenges of marriage, right? Even the 50 percent divorce rate didn’t scare us—I’m a marriage and family therapist! We knew our strengths and our “growth areas” like the backs of our hands.

Parenting brought some unexpected challenges. Who knew I could use such foul language at 3 a.m. when requesting help from Todd to change Brian’s diaper? But I think we both agreed that we handled the transition to parenting fairly well overall. It was the transition to special-needs parenting that rock us to the core.

Under the chronic stress of raising a child with special needs, everyday annoyances begin to feel unbearable. Emotions are too raw, and fear is palpable, to be able to handle a forgotten errand or an unrecorded check. Those “growth areas” turn into painful triggers.

Recently, his teacher said on the phone that Todd was doing so well. He was looking forward to the opportunity to participate in the “growth areas” of the classroom. Those were坏 areas turn into painful triggers. Todd was excited about the opportunity to participate in the classroom.

I remember one night when Todd walked into the family room where I was watching a news program must have been a story about the pharmaceutical industry because I launched into a rant about how corrupt and greed have hurt our children. Todd looked at me and said, “I find your rage really unattractive.”

He’d readily admits that he’s always been driven to write, affect, my expressiveness, his passion. But around Brian ASD, my passion about the dangers created by the drug companies hits him too close to home, because we’ve developed different narratives about why Brian is the way that he is. My narrative looks back at my choices and gets political. Todd’s narrative doesn’t look back. He takes what is, in this moment, and tries to cope. I’ve long admired and needed Todd’s levelheadedness and unfailingly ability to just “accept what is” bewilders me. Our different storylines have been difficult for us to reconcile. I suppose I’d say that we try to “witness” each other’s stories, but I think, mostly, we try to focus on our points of similarity and connection.

Our relationship was built upon a deep appreciation of each other’s sensibilities of humor, and autism has been...
added to our repertoire. We share a lot of mordant humor on the subject. Some of the things we say to each other, jokes that we find healing and hilarious, can never be repeated. Okay, fine, I can share one example. While recent holidays have been happy and overwhelmingly positive for our family, in the early years, we'd been known to dictate to each other the text of a fake "Holiday Letter" to friends and family. For instance:

"This year we were thrilled to drop $60,000 on a variety of complicated therapies, only to be told 'it's a long road ahead, but you guys are doing so much good.' Our Christmas miracles included nearly complete social isolation and 382 viewings of 'The Wiggles Safari.' Another gift was Brian's new habit of pulling his sister's hair every time she cries (as you know, newborns rarely do that)! Finally, it wouldn't be the holidays unless you could cozy up to your spouse. Check that, we haven't been intimate in a while. Best wishes for a less miserable New Year!!! Todd and Alexandra."

Is this appropriate? Definitely not. Is this ability to make light of your pain in a manner that connects you with your partner healing? You're damn right it is!

We also connect with each other around a sense of isolation and "differentness." Coming home from a birthday party at which your child was the only one who ran screaming from the room during "Happy Birthday" stings less when you can share that honor with your partner. Further, we frequently feel alone together in our worry about Courtney's journey. We feel pride and sadness when we see her helping her big brother put his shoes on. We know about the problems of special-needs siblings, and we want her to feel neither invisible nor like a third parent. We also know that our hard work to heal Brian is, in part, an effort to protect her from having to bear responsibility for him in the future—a terrifying possibility that we rarely voice.

The bottom line is that, like any kind of adversity a marriage can face, our journey with Brian has given us opportunities for intimacy that we wouldn't otherwise have had. When I watch an RDI video that Todd and our son have made together, I swell with pride at how much Todd "gets" Brian. When I offer an autism workshop or mentor a parent of a newly diagnosed child, I know that Todd feels proud that I've found some adaptive ways of coping with my pain and anger.

Carrying the Hope

I remember sitting in my own therapist's office after Brian was diagnosed, and trying to figure out what I was supposed to "do" about this ASD. I remember her saying that my most important job as Brian's mother was to "carry the hope." These words come back to me frequently as we face decisions about biomedical options or school placement or how to set expectations of him. I carry the hope that we, as a society, can turn the tide and curtail this epidemic. The vaccine-autism connection is strong, and more and more people are questioning the safety and efficacy of the current vaccination schedule. As for my Brian, I carry the hope that he'll someday read this article and be mortified that I wrote about his poop! I carry the hope that I'll dance with him at his wedding and hold his newborn in my arms.

Last week, I had the chance to hang out at recess with Brian and his kindergarten buddies. Brian and three other children were engaged in a game that seemed to be called, "Rescue me, I'm dead." When Ethan yelled to Brian from the top of the jungle gym that he needed rescue due to the fact that he was, in fact, dead, I watched my boy, my sweet, blue-eyed boy, climb competently and confidently up the ladder. "I'll save you Ethan," he called out, "I just have to get across this hot lava." A far cry, indeed, from the boy who used to read license plates in the driveway while the neighborhood kids played. I carry a lot of hope for Brian.

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Publication and Website References


Further Reading


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