There’s a videotape I have a problem with.

It’s of a toddler running through fallen leaves with a Nerf sword. The time code is October 1993. The boy runs like kids do at that age, about two and a half, with a reckless, head-long wobble that will soon be gone. We know this because, by late in the image-drenched twentieth century, we know how things are supposed to look, and can read all manner of inference into the moving landscape, most of it spot-on. He’s a wide-eyed, curly-haired boy, clad in green cords and a brightly colored winter jacket; tree types and topography suggest the northeastern United States; the leafy yard is behind a smallish home, though the swing set is elaborate—grand and spanking new, a sign of young parents trying too hard. The kid is being chased by a boyish, dark-haired man who’s laughing and holding a small stick as he knee-slides into the leaves, prompting the boy to turn, smiling and ready to fight. As they cross swords, the man says, “He’s not a boy, he’s a flying devil!” in a passable imitation of Captain Hook from Disney’s Peter Pan.

That the man and boy are reciting dialogue from an animated movie made in 1953 bespeaks the ubiquity of the VCR, the then-latest step in the electronic capture of sound and image begun a century before by Thomas Edison with his first recording. Rather
than traipsing to the movie theater, one could then watch movies countless times in a free feed. So they did. Disney began releasing classics, like *Dumbo*, *The Jungle Book*, and *Peter Pan* on video-cassettes; movies baby boomer parents once loved that they could buy and share, afresh, with their kids. It was a commercial bonanza that helps explain this artifact: a video of two people reciting from a video.

Now take these specifics to the universal. This appears, after all, to be a father and son playing the roughhouse games that tend to nimbly carry volumes of hidden emotions: the boy, with each step, grows into the hero of his fertile imagination; meanwhile, the dad, knowing, in some deep recess, that the boy will grow to someday replace him, considers the many creative ways to perish. All played out, effortlessly, as the boy offers his best, most elegant thrust and the man falls—as dead as the crunching leaves—before pulling the giggling child on top of him.

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I’m the father in this nice if unremarkable little video. That’s my son. I’ve watched it a hundred times, as has my wife, until we couldn’t bear it anymore. It’s a last sighting of him, captured mercilessly and forever on the magnetic tape.

A month later, the boy vanished.

• • •

Her name was Cornelia Kennedy—from a large Irish-Catholic clan in Connecticut—before we were married. She now uses Suskind. I’m her husband, Ron, a Jewish guy from Delaware. The older of our two sons, Walt—named after my father, who died when I was a kid—is now five. Our younger son, the boy with the foam sword, is Owen. The starter home with the leafy backyard is in Dedham, Massachusetts. I’ve spent three years in the *Wall Street Journal*’s Boston bureau. We’re bound for Washington, DC, where I’m to be a national affairs reporter for the paper. The video is shot the day before the moving van arrives, and we’re all still firmly ensconced in the land of normal. I never thought much about that word, how it’s one of those definitions by default, shaped not so much by what it is as what it’s not—a circle defined by everything outside of it.

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Cornelia sees it first a few weeks after we get to Washington. She’s with him all day, every day.

Something’s terribly wrong.

Owen is unglued. He cries, runs about, stops, cries some more. When he pauses to catch his breath, he just seems to stare into space.

That is, when he isn’t staring at Cornelia with searching eyes. She cups his wet, red face in her hands and asks what’s wrong. It appears he can’t tell her. Owen has never been quite as chatty as his talkative older brother, but chatty enough—the usual going-on-three vocabulary of a few hundred words, there, at the ready, to make his needs known or express love, or even tell a little joke or story.

We have moved to a rented house in Georgetown and everything transpires within a flurry of ambient activity: boxes to unpack, a new school for Walt, and a new job in a large, noisy news bureau for his father. So the loss of speech isn’t noticed until Owen is down to a few words. A month after the moving vans depart in November, Owen has but one word: juice.

Sometimes, though, he won’t drink what’s in the cup—a sippy cup. He graduated to a “big boy’s cup” nearly a year ago. But in Georgetown he’s spilling, as though he’s lost his bearings. He has.
He's whirling and weaving. So Cornelia holds him, as much as she can, sitting in the gliding chair, as her mind races across the months. Did something happen, something she missed?

It's like reviewing clues to a kidnapping. There was that one time, on a trip to Southampton last August, when he cried inconsolably for much of a day, though he'd never been much of a crier—not ever. Then there was the day the moving van was being loaded in late October, when a close friend had taken the kids for the day and, dropping them off, told us Owen had slept the whole time. He still took naps, but half the day? Unpacking a box, Cornelia finds a video from that very day, moving day. The sun was setting and Walter led a tour of our half-empty house. He was gleeful. A big trip to Washington. His goldfish, Artie and Tyler, named after his two best buddies, were already in a sealed bowl, ready for the journey: “My fish are coming with us, too!” And then a glimpse of Owen, briefly on camera, saying softly, sleepily, “This is my crib and all my things.”

She finds another video in that same box—the *Peter Pan* sword fight. That night, she and I watch. It makes no sense. *Look at the way he moves, the ease of his speech.* We rewind, watch it again. And again, looking for clues.

Come mid-December, Cornelia finds herself lying with Owen in his lower bunk, Walt fast asleep up top. A small lit tank hums on the bookcase, where Artie and Tyler swim silently through bubbles. It's three A.M. Owen is rolling side to side, mumbling nonsense. Cornelia holds him as tightly as she can, to calm him down. In the dark night of desperation she now prays, whispering through tears to her baby, hoping God can hear: “Please help us. Whatever is going on I’m going to love you so much that I’ll love it out of you. I’ll keep holding you until all this is over.”

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The holidays are approaching—there are gifts to buy and Washington is alive with events, the season of giving.

It should be a time of great expectations. On the surface, it seems to be all coming together, our life plan, years in the making. Cornelia and I had become friends after college, running a political campaign. She read my law school application, sitting on my desk, and told me it didn't sound much like I wanted to go to law school—which I didn’t—but that it was well crafted and I should consider being a writer. She already was one, a youthful prodigy, and I immediately liked the idea. Before my father died of cancer at forty-six, he wrote a letter to my older brother and me imploring us to do “something worthwhile” with our lives. Journalism seemed to fit, opposing authority, searching for bits of truth, building a readership. Our candidate lost, but we became a couple, with her landing a job in New York as a reporter at *People* magazine and me off to Columbia University Graduate School of Journalism, followed by two years as a news clerk at *The New York Times*, while she moved up as a New York magazine editor; a year and a half reporting at the *St. Petersburg* (Florida) *Times*, where we married; then the editorship of a small business magazine in Boston and, in 1990, a slot at the *St. Petersburg* *Times*' New England bureau, a stone’s throw from Boston's Old South Meeting House. I'd been crafting stories since I could barely talk—at the behest of my fiercely prideful Brooklyn-bred mother—and even turned them into stand-up routines during the difficult years after my father's death. But I was learning, year by year, to write them, long form, for the paper's signature front page. I was transferred to Washington to do that full-time—a dream job.

So in the evenings we try to focus on all the positives—new friends, deals on used furniture for our rented three-story Federal-style row house, neighborhoods where we might someday buy a home—before Cornelia reluctantly mentions a story from her day,
some troubling thing Owen's done. “Everything will be all right,” I say before trying out some plausible explanation: Owen is experiencing some sort of distress, maybe gastric, maybe, even, some hearing loss—and we'll get to the bottom of it.

“No kid loses what they’ve already attained. You don't grow backwards.”

The pediatrician asks to see our son for a moment, by himself. He tells us to sit in the waiting room. We're extraneous. He wants to see how Owen interacts with a stranger, without us there. Because kids are trusting little people, they tend to look at strangers. They're curious. They suck in information like small vacuum cleaners. They make eye contact and express themselves. At least, that's what they're supposed to do.

After a few minutes, the doctor calls us into his office. These things aren't happening. We say, yes, we know, that's why we're here. Cornelia briefly describes what she's been seeing, the nature of our worries, how our lives have been upended.

He listens. “If something is causing this much of a disruption in the life of the family,” he says, “then it is definitely a problem.” When pediatricians aren't sure what they're seeing, especially with small children, they default to “mother concern.”

He says he wants to take a blood sample for two genetic tests. One is for fragile X syndrome (a neurological condition, we find out later, with a detectable genetic marker and devastating outcomes). The other test is for Tay-Sachs. I know what that one is: a disease that causes mental and physical decline in babies and usually kills them by the age of four. It's especially prevalent in Jews of Eastern European descent. That'd be me. This is something you learn about in Hebrew school, along with the Holocaust. And then he refers us to a center—a place in Rockville, Maryland—that might be more helpful.

By February, we're sitting in a very different kind of waiting room, inside the Reginald S. Lourie Center for Infants and Young Children. It's attached to a playroom, visible through a one-way mirror. Inside are large, multicolored blocks, swings, and mats for children to play with. . . while they are being observed.

We're shown to an office where a tall, severe-looking dark-haired woman waits. She greets Owen, whose hand Cornelia is holding with the firmest possible resolve. In her office where she talks to us are more items to play with. Owen ignores them. Minutes pass. Then she has him walk down that long hall, from me to Cornelia. Letting him go, I want to say, “Walk nice and straight, like back in Dedham, just this once.” He doesn't. He's moving his arms, veering, catching himself, a zigzag, like someone running with their eyes closed. Cornelia scoops him up. Then we return to the woman's office. “It appears he has a pervasive developmental disorder, affecting most of the traditional areas of development,” she says, and, “It's clear in his gait, among other things.” She continues to talk in a removed, antiseptic way, barely looking at Owen, sitting on the floor, fussing with his fingers. We're not really present at this point. Cornelia and I both are somewhere else, floating off, looking down at the young couple frozen in their chairs, nodding every few seconds, next to a child who's intently studying his hands. Which is why I'm not sure precisely what point the doctor was making when she said the word “autism.”

Denial is a powerful force. Years later, a close friend's father, an old psychiatrist, said something wise to me: “Respect denial. It's there for a reason: a way we cope with what we cannot face.” At thirty-four, I didn't respect it; didn't even recognize it.

Driving home, Cornelia and I sit silently, while Owen thrashes behind us in his car seat. There is no way that woman is right. We
know about autism what most people do in this time period. We saw *Rain Man*, like everyone else in America. Our son is not Raymond Babbitt, that guy Dustin Hoffman played. No way in hell.

A month later, we find a new doctor: a young developmental pediatrician in a booming Bethesda practice who looks uncannily like Cornelia's longtime high school friend—a guy I befriended in college, who first introduced us. This feels much better.

Dr. Alan Rosenblatt takes Owen on his lap and says, ever so softly, “Hey there, buddy.” This time, Owen looks back. They do a few exercises—touching fingers, watching, together, as the doctor moved his hands—and then they get down on the rug. Owen seems comfortable. They build little houses using blocks, Rosenblatt starting one, seeing if Owen adds to it.

He doesn’t. There isn’t much interaction. Owen gets up and begins to wander. Rosenblatt calls his name. And then Owen crawls under a chair and glances back at the doctor with a “come and get me” look—a brief expression, there and then gone—beckoning a chase. Rosenblatt jots something on his clipboard.

Back in his chair, he says, “I’m afraid that Owen has what we’re nowadays calling pervasive developmental disorder, or PDD, with the addition of NOS, for ‘not otherwise specified.’” That means Owen has some “autistic-like behaviors” but also others—like that “let’s play” look—that don’t fit the current definitions of classic autism.

He goes through a regimen for Owen that he feels we should start immediately. Intensive speech and language therapy, occupational therapy, play therapy, and the immediate hunt for an appropriate school for the coming fall, for which he has some suggestions. “Early intervention,” he says, “is crucial.” He adds, “Families who have religion or some faith community in their lives tend to do a bit better,” which chills us both—that catastrophe awaits—but is something Cornelia, raised Catholic, will soon draw strength from.

That Owen was not labeled “autistic” is a relief, as is Rosenblatt’s characterization of Owen’s problems as a “delay.” We’ll learn more later about the connotative cover these terms offer us. The important effect: it keeps us from running out of the office and driving home feeling like we’ve both just had our arms and legs cut off.

We make small talk with Rosenblatt walking toward the parking lot that day in April and get a bonus in building our defenses. We mention our wonderful pediatrician in Boston, a Harvard doctor named Bob Michaels. Rosenblatt does a double take. From Pittsburgh? Yes, we say excitedly—raised in Pittsburgh. “Do I know Bob Michaels? His father was my pediatrician. A great one. He was a major reason I became a pediatrician!”

As soon as we get home, we call Dr. Michaels at Harvard to tell him of this extraordinary coincidence and—not incidentally—elucidate what we’ve been seeing with Owen since leaving Massachusetts. He puts us on hold and gets Owen’s charts. He scans them but hardly needs to. “I just examined him in the summer. He was completely fine. I don’t see how this could be.”

Neither do we. Yes, something went haywire, but something that is confusing even to the doctors. He is “atypical”—Rosenblatt’s word—and his problems are assorted delays. They can be corrected. We sleep that night in a wash of relief. We will save this boy, rebuild him—rebirth him!—every waking hour of every day. *Fools.*

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The next morning, Cornelia takes Owen by the hand and walks Walt the seven blocks to Hyde Elementary, down the street from our house in Georgetown. Walt is thriving there. Other than a slight disciplinary issue—for playing the harmonica to announce his presence at a morning meeting on the first day—he’s enjoying school; making friends; playing, learning, growing. That day, after drop-offs, Cornelia, Owen in tow, meets with a small group of parents.
Hyde isn’t quite measuring up to some of the elementary schools in other Northwest DC neighborhoods, but it’s aspiring to—an effort discussed in that morning’s coffee klatch about the upcoming Hyde Spring Fair. It can, and should, raise plenty of money for the school, and Cornelia—as the fair’s co-chair—has been busy lining up sponsors, donated goods, and the like.

All of which makes the day—a Saturday in early May, two weeks hence—a big one for a new family in a new community. The large fenced-in playground alongside the school is starting to fill up by late morning as the ride managers hustle to get the moon bounce pumped. It feels like what we hoped to find in DC—what anyone would want, really—the company of happy warriors, building a little bordered world of fun and food, where equal, matching armies of parents and children gather and cheer for a good cause.

We’ve taken great care, of course, in planning the day for Owen so he can attend with us. There’s only one gate to the playground, managed by parent volunteers who know him and are on guard against him slipping out; and that isn’t even an issue, considering that either Cornelia or I will be with him every minute. And we are, over hours, as the frenzy of running a fair like this ebbs and flows: more ice; does anyone know where the power switch is; are we out of hot dogs!

It’s hard to pinpoint the exact moment. Generally, Father Error is to blame. Mothers probably have hard-wired neurological equipment, dating back to roughly the Big Bang, for instantly knowing the coordinates of offspring. It’s well along into the afternoon when I let go of his hand to shove the remainder of a hot dog—Owen’s lunch was the other half—into my mouth and then grab a Coke can I’d rested on the ground. When I turn, the patch of swing-set gravel a foot to my left, where he just stood, is empty.

Fathers have equipment in these situations, too. But the circuits fire differently. First rule: don’t panic. Scan the perimeter, steady and swift: 90 degrees, 180, 270, 360.

Then panic. I start to run, first a slow trot, toward the gate and ask one of the dads at the gate: “Did you see him—did Owen slip by?” It’s astonishing how much attention a running man can draw. I turn to see a small crowd of parents already behind me . . . led by Cornelia.

I don’t have to say he’s gone; that, she can see, so I jump to pertinent facts. “I was with him at the swing set thirty seconds ago. He didn’t get out of the gate!”

It helps that the fair is winding down—there are fewer people to block our lines of sight. After five minutes, he’s still nowhere to be found. Cornelia and I, running and panting, are tamping down the same, shared memory: a year before at a school fair in Wellesley, near our home in Massachusetts, he was briefly lost. We filed it away: two-year-olds get lost. It happens. Actually, it doesn’t happen all that often. They tend to have at least a remnant of separation anxiety—a match of the mother’s radar—and a dawning awareness that no parent is nearby. That’s the moment they realize they’re lost and start crying. Whether or not Owen once had that equipment, it is now shut off . . . and this isn’t verdant Wellesley. It’s a patch of fenced concrete in Georgetown, with cars weaving down cobblestoned O Street and, half a block away, speeding down Wisconsin Avenue—one of Washington’s main thoroughfares.

At ten minutes, panic spreads. Parents start fanning out into the streets. Cornelia and I run into the school—off limits for the fair, but a door, through which some of the power cords run, is open. It’s a turn-of-the-century brick box, huge and empty, with crumbling cornices and two hallways we run down—I, down one hall; she, the other. There’s honking outside—sounds like a wreck on Wisconsin. My heart stops beating—Please, God, let that not be him. Cornelia is now moving like a spirit—silent and swift, breathless—her feet skimming the ground. Not really in her body. She’s in his head, looking around and then out through his eyes, the two of them meeting
in there, talking softly: “Where would you go, honey . . . where would you want to go?” Most classrooms are locked. A door is ajar.

And there, next to a wide window, partially open onto the playground where everyone had been shouting “Owen, Owen!” he’s standing, quietly, next to a sand table. Outside, parents move in fearful unison while Owen intently watches grains of sand run through his fingers.

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Seats in the jammed ballroom just north of Washington are already scarce by eight a.m. on a very hot June morning. The air inside the Crowne Plaza Hotel in Rockville, Maryland, is electric, all clipped conversations and eager looks, this way and that.

Cornelia spots a lone seat at a crowded table as Dr. O. Ivar Lovaas—gray-haired and energetic at sixty-seven, with a wide smile, blue eyes, and only the slight trace of a Norwegian accent—takes the stage to raucous applause.

He’s come east from his offices at UCLA and his growing California operation, to encourage the faithful, but also to win converts. He’ll do that by putting on a show. Soon the stage is alive with a kind of psychodrama—therapists working with the Lovaas Model of Applied Behavioral Analysis, or ABA, on autistic children, and Ivar, himself, presiding.

His technique is, at its core, bracing, whereby an ABA-trained therapist sits across from a small child and, with rewards and verbal “aversives”—stern language and sometimes shouts—forces changes in the child’s behavior. It’s pure behavior modification. Lovaas is a disciple of B. F. Skinner and his use of rewards and penalties to condition responses: in this case, how to reduce interfering behaviors, how to build the child’s attention span, how to use succinct instructions, how to use effective consequences for behavior, how to sequence the teaching materials to shape more complex behaviors, and so forth. It looks to the untrained eye like animal training.

To build eye contact, for instance, the ABA therapist will put the reward (M&M’s being a favorite) on the bridge of the child’s nose to make them look up toward the therapist’s face. If, after succinct instruction—“Look at me”—eye contact is made, the M&M is popped into the little mouth. Crisp instructions, like “Quiet hands” (autistic kids often flap their hands) or “Mouth quiet” (no self-talking), are backed up with some grabbing and manipulating, moving the child’s hands into their proper place. Lovaas’s selection criteria for an early quartet of autistic kids he worked on in the 1970s included the request that they have a healthy appetite so the withholding of food would have maximal effect.

A master of one-liners, Lovass implores the audience to get children into one of his intensive, forty-hour-a-week programs before they turn four for optimal outcomes.

“Once they reach four, it becomes more difficult—so please don’t wait,” he says before offering inspirational stories of how lives have been turned around through the use of his method.

Lovaas presented startling results in a 1987 research paper regarding nineteen children. His finding—that nine of the severely affected autistic children were “cured” by his technique and went on to successful lives in mainstream settings—has not yet been replicated by early 1994.

But there was no shortage of those willing to try.

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We’ve furiously run up a learning curve since meeting with Rosenblatt. There’s a lot more to know than Rain Man, of course, a history going back to the late 1930s, when Leo Kanner, a child psychologist at Johns Hopkins, first tested eleven kids and wrote up his findings:
of a particular boy “drawing into a shell and living within himself” and being “oblivious to everything around him.” The kids generally had difficulty with expressive language, treated objects with a care typically reserved for people, threw tantrums when routines were changed, but often had strong yet narrow memory capabilities and, Kanner wrote, “could not be regarded as feebleminded in any ordinary sense.”

Around that time, half a world away, Hans Asperger, an Austrian researcher, was doing original research on four boys whose behavior and capabilities showed “a lack of empathy, little ability to form friendships, one-sided conversations, intense absorption in a special interest, and clumsy movements.” Asperger, who never met Kanner, dubbed these children “little professors,” hyper-verbal at a young age, deeply focused on their particular affinities, but still “autistic” in that they lived lonely, socially isolated lives—much, in fact, like Asperger himself.

In the decades to follow, there were battles over causation, including Kanner and later the celebrated Bruno Bettelheim attributing it, falsely, to so-called “refrigerator mothers”—a theory that finally collapsed when genetic testing in the early 1980s showed a high prevalence of autism in twins and siblings who had been separated at birth.

But the numbers kept growing. By the early 1990s, children with a wide array of profiles, from those who spun, self-stimulated, and never spoke to the hyper-verbal and hyper-focused, were finding a diagnostic home somewhere along the shoreline originally mapped by Kanner—defining what eventually would be called “classic autism”—and Asperger, whose “Asperger’s syndrome” wasn’t even discovered until his lost papers were translated by German child researcher Uta Frith in 1991. Somewhere in the middle was PDD and PDD-NOS, for kids who didn’t fit neatly into either category.

In the latest *Diagnostic and Statistical Manual of Mental Disorders*, or *DSM*, published in early 1994, all of them are listed, and a few doctors, including our Dr. Rosenblatt, are already calling it a *spectrum* of related disorders. Why the numbers seem to be growing is a mystery, as are effective treatments. The two that seem most promising are Lovaas’s behaviorism and a technique developed by a George Washington University professor named Stanley Greenspan called “Floortime,” a system of basically following the kids—driven by their intense self-directed urges—wherever they go, and in whatever they utter, and try, with various methods, to draw them out. Very different therapies—almost polar opposites—that share a one-on-one model of intense engagement and a goal of bringing these kids into the world.

Because Owen is “atypical” in some of his features and, at that point, ABA is more the destination of “classic autism,” presenting at birth or soon thereafter, Rosenblatt suggests we go with Floortime. Owen has already been to a few sessions with one of Greenspan’s longtime adherents, a middle-aged woman who doesn’t seem to have much of a knack for getting on the floor. Mostly, she gets Cornelia on the floor and coaches her about how to follow Owen around to pick up motions she could imitate, sounds she might repeat, or looks—at whatever object might be in his path—that she can mirror. Exhausting, but no discernible progress. Cornelia figures she should at least see what Lovaas had to offer, which is what brings her to the hotel this morning. At the lunch break, she chats with a dozen or so other attendees sitting at her round table, loaded with piles of ABA materials, and realizes they are almost all teachers and therapists from Montgomery County, looking to get certified as ABA trainers. This session is a first step. Once certified, they’ll be ripe for hire as, in essence, a member of a family with a burdened child. The protocol is to spend forty hours a week in someone’s house, to stay on top of the child all day, and then train the parents to carry forward conditioning on evenings and weekends. The key is to totally shape the
environment. It is expensive, but desperate families are willing to try anything.

Cornelia listens, quietly, to the excited chatter, not saying much. After a moment, she realizes she’s a rarity in this ballroom: a parent.

She lets on . . . and their faces flush with sympathy. Tell us about your child, how old? Three. Does he have any speech? No, not really.

One asks if the ABA training is difficult to watch. She nods and forces herself to smile. If she’s looking to hire someone, a therapist mentions, she’d be happy to travel each morning to DC. Cornelia doesn’t let on that we’re drifting toward the opposing camp.

It isn’t until late afternoon after picking up Walt from school, putting Owen in his car seat, and racing north from DC to Rockville, Maryland, that I meet up with Cornelia. She’s already waiting outside the hotel and slips silently into our Volvo station wagon—our only car—looking shell-shocked. “It was like spending a whole day, eight hours straight, with the Ice Queen,” which is what we now called that first autism doctor. She describes the day and then offers her summation: “We don’t have to do this monkey training, because Owen isn’t like those kids.”

I nod. We both nod. It’s just a matter of reaching him, of figuring out what caused this storm to envelop him, so we can clear away the clouds and let the light back in. It also costs about forty thousand dollars a year for Lovaas. I figure that’s a lot of cash, well over half of my after-tax income, that we just saved.

To celebrate, we decide on dinner out on the Rockville Pike—a repeating Hanna-Barbera landscape of every franchise created by the wit of man. We end up at the Silver Diner, one of a chain of restaurants crafted with admirable precision to look like genuine, home-grown neighborhood diners—a favorite of our kids and their beleaguered parents: a perfect place to vanish, where they serve ice cream sundaes all day.

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A Georgetown video store has a life-size cardboard standup of Walt’s new favorite movie, The Sandlot, 20th Century Fox’s recent hit about a group of neighborhood kids who forge friendships as a ragtag baseball team. As September 1994 arrives, our months of pleas and cajoling pay off: the manager, ready to swap it out for another movie studio giveaway, hands it to us. So, for his sixth birthday party at a park near our house, Walt’s buddies crowd around their cardboard Sandlot doppelgangers—Bertram Grover Weeks, Mike “Squints” Palledorous, Benny “the Jet” Rodriguez—with Walt front and center, making for a thin line between the imaginary and the real. We snap pictures—lots of them.

A year before, this fairly conventional scene would’ve barely elicited a shrug. So, he’s got lots of friends, is at ease in the world—of course, and why not . . . to be expected. That’s the way it was back in Dedham. We didn’t make a fuss over what was expected. Now it fills us with a sense of the exceptional.

And a wash of relief that Walt, smiling away, doesn’t seem to notice that the rest of us are barely keeping our heads above water.

A few days after the birthday party, we put Owen in the car for the forty-five-minute drive to Rockville, Maryland, and the Ivymount School, which, with two hundred students, from kindergarten through high school, is the largest and best school for kids with disabilities in the area. When the school was started in a church basement in 1961, there was no place for children with serious disabilities like Down syndrome or those with most developmental disabilities to go. Before Eunice Kennedy Shriver started Special Olympics in 1968, and public awareness began to grow, most were either kept at home or institutionalized.

It is a long way from there to this large Eisenhower-era school building, once a public elementary school, with its painted cinder blocks, blond wood, a library, gymnasium, and student artwork taped to the walls of long hallways. There are two children waiting in
Owen’s classroom—a Down syndrome boy named Eric and another boy, Julian, very much like Owen, with a PDD-NOS diagnosis and no speech. Owen makes three. The teacher, Lucy Cohen, explains that the school recently had more kids, but in the past year many decamped to receive Lovaas-style ABA training at home. It will just be the trio, with Lucy, a speech therapist, and an aide. We’re asked to sit on floor mats against the wall to observe. And we do, as Lucy attempts to get the children to do simple tasks. Owen and Julian spin, murmur to themselves, and look about as Eric draws a figure on a page, per the teachers’ instruction.

Sitting on a mat, my back to the wall, I find myself thinking, in a kind of rueful amazement, how many wild-eyed expectations you carry around about your kids, especially when they’re young. Presidents? Nobel Prize winners? Global celebrities? Super Bowl quarterbacks and prima ballerinas? It could happen. Or, more soberly, millionaire philanthropists or, at the very least, graduates of the finest colleges, Harvard or Yale, then graduate school stars, most-recognized professionals in their field. More likely, certainly than the Nobels . . . and, thereby, certainly likely. Their enrollment in school—where they meet other children and start slotting into lines, receive test scores, make teams or get cut—starts the process of wrestling those unspoken fantasies toward abiding reality. And even then, those fanciful notions are surprisingly resilient. After all, as long as that kid’s on the field of play, in the tournament’s main draw, it could happen.

How many of these breathless expectations—also called dreams—constitute the traditional allotment? Best way to figure that is to extract them, one by one, and smash them in the corner. The pile is quite high. And that’s what we do, minute by minute, sitting on the floor mats, backs pressed against the cinder blocks. Owen spins and murmurs next to the sweet blond boy. We haven’t seen other kids like Owen before. Here is one who could be his twin. But Eric? Someone my age, growing up, knew those Down syndrome kids—spotted, peering from the window of the “short bus.” No, they weren’t in the game. Damaged goods. Ripe to be mercilessly ridiculed. Why? They wouldn’t even know they were the butt of the joke. It was a free kick. That was the reality of it—just as ugly as it gets.

And that’s where Owen has landed. Of course, we know nothing at this point—we’ve just landed on this planet—like the way Down syndrome folks often have highly evolved sensory equipment. There’s something about the way one area of challenge, a blockage, often creates compensatory skills somewhere else. No different than blind people with powerful hearing, but, in this instance, in subtler areas of emotion or expressed sensitivity.

Suddenly, Eric is standing in front of me, his eyes at the same level as mine. He looks at me, his brow furrowed, then at Cornelia. He can see we are sitting there frozen in misery. He reaches his small arms around my neck, hugs me, and says, “I love you.” I’m not sure if he hugs Cornelia or not—all I know is I’m in a daze, my world upended. Then he walks back to finish his drawing.

Cornelia needs someone to talk to.

She can’t get me on the phone. None of her friends really know what the hell’s going on. Little bits, maybe—yes, trouble with Owen—but not the real deal. All that, she figures, should remain private, at least until we figure out what we’re dealing with.

She dials the number to her childhood home in Fairfield, Connecticut, and, as the phone is ringing, she realizes she’s not exactly sure what she’s going to say. Her folks don’t really know what’s been happening, either. It’s November 1994. We’ve been in DC a year. But being far away from family and old friends means there aren’t regular visitors to the house.
She’s about to hang up when her mother’s voice comes on. “Hello?”
“It’s me, Mom.”
“Oh, Lily, how’s your day been?”
That’s her old nickname, Lily. And how’s her day been?
A disaster. She drove Owen to school, picked him up at midday, and drove him to intense speech and language therapy and then occupational therapy. None of it seems to be doing much good. He’s still acutely agitated, unable to make his needs known, crying from time to time, and just a few minutes ago, he threw a wooden step stool down a long flight of stairs at her. He was frustrated—he didn’t seem to want to hurt her—but she’s shaking.
And none of this she tells her mother. She tries to make small talk and not cry. But her mind starts to race, looking for a way out of this solitude. We still don’t ever use the “A word” in the house, and Owen’s many therapists don’t either. But she’s thinking about one of her mom’s first cousins, who had a son named Tommy, whom Cornelia saw a lot when she was a child. He had no speech and was sometimes hard to control, though more out of agitation than anger. He ended up living up in a state home. Cornelia’s mother, a woman of headlong and unfettered compassion, was close to her cousin and had regularly visited him there.
Now, hesitantly, Cornelia asks her mother an out-of-the-blue question wrapped in “oh, by the way” casualness, about Tommy’s diagnosis. “They said he was retarded,” her mother says. “But I always wondered if he wasn’t autistic.” Cornelia takes a deep breath and pushes forward, telling her mom about some of the things that have been going on of late, right up to the worst of it: that day’s throwing of the wooden stool. “I feel like I’m with Johnny!” she blurs out, a fireball rising from her gut.
The phone line seems to go dead. It hasn’t. From the silence, her mother says, “Did I tell you I bought a new quilt for my bed today?”

At this moment, Owen is upstairs in the one place where he always seems calm, at ease, even content: in our bedroom watching his Disney videos.
In the first year in Washington, that’s mostly what Owen has done on his own and what the boys have done together. What they can do. They watch on a television bracketed to the wall in a high corner of our smallish bedroom. They’d pile up pillows on our bed and sit close, Walt often with his arm around Owen’s shoulders.
It’s hard to know all the things going through the mind of a six-year-old about how his little brother, now nearly four, has changed. But we can’t help wondering if this is a big brother’s way of holding the world in place, holding on to what he knows.
After all, Walt’s been sitting in front of a screen watching Disney movies for a healthy share of his own short life. That’s the way it is with most kids around his age. A year after Walt was born in 1988, Disney, following a few decades in the doldrums, roared back to the fore of popular culture with The Little Mermaid. Families flocked to theaters and even more bought the video—it was the top-grossing video of the year. The same happened with Beauty and the Beast in 1991, only more so—that one was the first animated film nominated for a Best Picture Oscar. Then there was Aladdin in 1992, which was that year’s highest-grossing movie. People our age were building up video libraries for their kids. Not just the recent hits—which critics dubbed Disney’s “new golden age”—but videos from the original golden age starting in 1937 with Snow White and the Seven Dwarfs, Dumbo, Fantasia, Pinocchio, and Bambi.
We watched them all, sang the songs, danced to them.
All this to the mild disdain of some of our graduate-degreed, baby boomer friends. They had a world-wise, right-minded riff: that Disney was a voracious, commercialized, myth-co-opting
brainwasher, using primal tales to shape young minds into noxious conclusions about everything from dead mothers (forget about step-mothers) to what happens to thrill-seeking boys (Pinocchio’s Pleasure Island, as donkeys forever) to how a princess ought to look (utterly unattainable!), all before the tykes knew what hit them.

Many of them, though, didn’t have kids. Cornelia and I weren’t huge fans of Disney, but the comfort and convenience of these videos was overpowering. The movies were an instant babysitter, a group activity, something parents and kids could do together, and always within reach. When Owen arrived, Walt learned to use the remote on self-serve.

And soon enough, his little brother slotted right in. It was the house he was born into. And we were just about average on the video front with a few special restrictions. The year before we left Dedham, we limited viewing time and, at one point, even stored away the TV. We were surprised Walt wasn’t more upset. After a few weeks we realized why: he was watching the Disney movies at houses of other kids. They all had them.

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All that, though, was before the move and the change. Now, seeing the two boys on the bed, pillows piled high, Peter Pan or Aladdin flashing on the screen—we want to freeze time.

Of course, by six, Walt is being drawn away. New friends. New everything. He taught Owen how to use the remote control last summer and began to slip out. Not that his little brother has that many hours free. We “program” Owen as much as we can. Cornelia has him moving, carpooling to this therapy session or that, taking him to the market, the park, on errands. By the time they get home, she’s exhausted and letting him watch some movies doesn’t seem like a terrible crime. So, often he’s up in our bedroom with the remote control. Movie after movie he watches. Certain parts he rewinds and rewatches. Lots of rewinding. But he seems content, focused.

We ask our developmental specialists, doctors, and therapists about it. They shrug. Is he relaxed? Yes. Does it seem joyful? Definitely. Keep it limited, they say. But if it does all that for him, there’s no reason to stop it.

So we join him upstairs, all of us, on a cold and rainy Saturday afternoon in late November. Owen is already on the bed, oblivious to our arrival, murmuring gibberish . . . “juicervose, juicervose.” It is something we’ve been hearing for the past few weeks. Cornelia thought maybe he wanted more juice; but, no, he refused the sippy cup. The Little Mermaid is playing as we settle in, propping up pillows. We’ve all seen it now a dozen times—more for Walt—but it’s one of the best parts: where Ursula the sea witch, an acerbic diva, sings her song of villainy, “Poor Unfortunate Souls,” to the selfish mermaid, Ariel, setting up the plot in which she’ll turn her into a human—allowing her to seek out the handsome prince—in exchange for her voice:

Poor unfortunate souls
In pain, in need
This one longing to be thinner.
That one wants to get the girl.
And do I help them?
Yes, indeed! [. . .]
Now it’s happened once or twice
Someone couldn’t pay the price
And I’m afraid I had to rake ’em ’cross the coals.
Yes, I’ve had the odd complaint
But on the whole I’ve been a saint
To those poor unfortunate souls . . .
Have we got a deal?
That’s what I hear every day, I tell Cornelia, from corporate public relations departments. She laughs and says, “Right, we’ve had the odd complaint, but on the whole I’ve been a saint.”

On the screen, the song’s over. Owen lifts the remote. Hits REWIND. “Come on, Owen, just let it play!” Walt moans. But he doesn’t go back to the start of the song, just twenty seconds or so, to its last stanza, with Ursula shouting:

Go ahead—make your choice!
I’m a very busy woman
And I haven’t got all day
It won’t cost much
Just your voice!

He does it again. STOP. REWIND. PLAY. And one more time.
On the fourth pass, Cornelia whispers, “It’s not juice.”
I barely hear her. “What?”
“It’s not juice. It’s just . . . just your voice!”
I grab Owen by the shoulders. “Just your voice! Is that what you’re saying!”
He looks right at me—first real eye contact in a year.
“Juicervose! Juicervose! Juicervose!”
Walt starts to shout, “Owen’s talking again!”
A mermaid lost her voice in a moment of transformation. So did this silent boy.

“Juicervose! Juicervose! Juicervose!” Owen keeps saying it, watching us shout and cheer. And then we’re up, all of us, bouncing on the bed; Owen, too, singing it, over and over—“Juicervose!”—as Cornelia, tears beginning to softly fall, whispers, “Thank God . . . he’s in there.”

Three weeks after the “Juicervose” dance, we’re at Walt Disney World.

We’d already scheduled a trip to Florida, with cheap flights booked months ahead, to visit my brother, Len, and his family—two boys, same age as ours—in Hollywood, Florida, where my mother also now lived.

The joke in the family is that Len never read the deathbed letter from my father about seeking the “worthwhile” life, which is why he is now raking it in as a financial manager. The easy lore is that I am more like our aesthetic, head-in-the-clouds father, an insurance executive who dreamed of teaching or writing; my brother, more like my ferociously pragmatic mother. It is, at best, half true.

As we became parents, we could see that—just like our kids—we were mixtures of both of our parents’ traits, along with plenty of untraceable origins. What didn’t change through the years—back then to right now—is that, at day’s end, there’re just the two of us, two brothers, having to figure it all out. Late that night, after everyone has gone off to sleep, he asks me how things are going. We talk most days—a quick call—but sitting quietly under a palm tree by his pool and beneath a canopy of stars, we can cut deeper.

“Best of times, worst of times,” I say, explaining that things couldn’t be going much better at work, or, with Cornelia—never more amazing than when she’s challenged—or Walt, lunging forward, reaching for six-year-old glories. But we’re not really sure what the future will hold for Owen.

“I see he’s not speaking yet,” Len opens.
Nope.
“Could it be a while?”
Yup.
“All these therapies, five or ten of them a week—at one hundred twenty dollars an hour. They covered by insurance?”
Nope.
Then we just sit there as a gentle breeze rustles the palm. I know
he is doing some calculations. That’s what he does for his clients, every day: life math. He’s quite good at it—definitely got that from our mom.

After a minute of silence, I figure I’ll sketch the size of the equation.

“Worst case, we’ll have to support him for the next fifty years and thirty years after we’re dead.”

He’s already there.

“That worst case or likely case?”

“Somewhere in between, but we’re hopeful.”

Hmmmm. He’s not one to discount hopeful. And he knows its uses, like the time in high school I convinced him to run for senior class president and he won.

“Hope’s not nothing,” he says, quietly, to his reflexively optimistic little brother. “Just tough to run the numbers on it, that’s all.”

And we both nod, get up, hug, and go off to sleep.

Two days later, we borrow one of their cars to drive the three hours to Orlando.

For the big day, Walt wears his Georgetown sweatshirt. He has a favorite babysitter who goes there, just down the street in the town where he now lives. Great basketball tradition—he knows all about that and can cite statistics. As a typical kid, at seven, his identity is becoming rooted to a place, his place, which he carries with him wherever he travels. This is the kind of awareness—of where one sits, or fits, in a widening world—that starts growing in most kids from around the time they’re three.

It is hard to know whether any of these traditional steps are being crossed by Owen. His thoughts and feelings remain a mystery. We told his various therapists about what happened watching The Little Mermaid. Cornelia and I could think of little else. It felt, in our video-inspired imaginations, like Rain Man had been replaced by The Miracle Worker, and that we had lived that iconic scene where Annie Sullivan breaks through to the young Helen Keller by signing w-a-t-e-r into the deaf and blind girl’s one hand as water from a pump gushes across the other. We had to be Annie Sullivans, too, and felt we’d had a breakthrough on that rainy afternoon watching Ariel lose her voice. Owen reached out, if only for a moment, from his shut-in world. We spoke to our child.

The speech therapist tamped down our enthusiasm. Dr. Rosenblatt, too. He explained “echolalia” is a common feature in kids like Owen. It’s something babies sometimes do between six and nine months, repeating consonants and vowels as they learn to turn a baby’s babble into words. It’s also something seen in the people with developmental disabilities who can’t speak. Just like what the term suggests, they echo, usually the last word or two of a sentence: “You’re a very smart and pretty girl,” a mother might say to her daughter. “Pretty girl,” the child will respond, an echo. Do those kids know what the words mean, we pressed Dr. Rosenblatt. “Usually not,” he said. “They may want to make a connection, which is hopeful,” he added.

“They just repeat the last sound,” I croaked. He nodded. Why, I persisted, in a last stab, would he be rewinding that one part, for weeks, maybe longer, and choose that phrase—from so many in an eighty-three-minute movie—as the one he uttered? Dr. Rosenblatt shrugged. No way of knowing.

So, left groping in darkness, somewhere between Helen Keller and a pet store parrot, we now enter the gates of the Magic Kingdom.

It is remarkably unchanged from when Cornelia and I visited ten
years ago, before we had kids, or from when I visited in 1971. It is we who have changed . . . now, as parents, seeing it all through our children’s eyes, seeing what they see and feel. Walt grabs Owen’s hand, and off they go, the two of us right behind them, down Main Street, U.S.A. There are attractions in Fantasyland—Mad Hatter’s Tea Party, Snow White’s Scary Adventures, Mr. Toad’s Wild Ride—that echo movies they both love. Walt dives in full bore, laughing, joking, sitting with Owen on Peter Pan’s Flight in the two-passenger flying schooner, the one just ahead of us, as it swirls and dips over landscapes and figures from Never Land—the “Lost Boys” frolicking in their lair, Wendy walking the plank, Peter Pan crossing swords with Captain Hook. They look like any other pair of brothers and—in the trick of this light—they are. We run to Disney-MGM Studios, in search of the Teenage Mutant Ninja Turtles. That day’s park schedule says they’re having an autograph session. The boys wait—the line is long—and get pictures with Donatello and Raphael, the characters they dressed up as for their last Halloween in Massachusetts. It’s as if nothing has changed, as if the last year and a half was a bad dream. And each time we feel that we catch ourselves. After the “juicervose” euphoria—and the cold water poured on us by doctors—we try to make sure we aren’t just seeing what we want to see. But by mid-afternoon it’s clear that Owen isn’t self-talking in the streams of gibberish, or flapping his hands as he usually does. Some, but not much. He seems calm and focused—following the group, making eye contact—and oddly settled, a slight smile, eyes alight, just as he is while watching the movies on our bed. By day’s end, we’re feeling a bit of the same—settled, in a kind of walking repose that we’ve not felt since the days in Dedham. Owen seems at home here, as though his identity—or however much of it has formed—is somehow tied to this place. On the way out of the Magic Kingdom, when Walt spots the Sword in the Stone near the carousel, we can’t help indulging fantasy. It is a fortuitous moment: A Disney actor dressed as Merlin appears near the sword periodically during the day. As the boys approach the sword, he’s there, reciting dialogue—“Let the boy try”—and then, approaching the anvil, someone flips a hidden switch that loosens the sword. Walt pulls it out as Merlin cries, “You, my boy, are our king!” Then both of them turn to Owen. “You can do it, Owie,” Walt whispers. “I know you can.” Owen looks evenly at his brother and Merlin, then steps to the anvil and lifts it true. Did he understand what Walt was saying? Did he just imitate what he’d seen his brother do? What the hell difference did it make! Today, in sunlight, he’s the hero of his imagination.