

saving **BEN**

A Father's Story of Autism

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DAN E. BURNS

Number 3 in the Mayborn Literary Nonfiction Series

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Interior design by Joseph Parenteau.

To all my children

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PREFACE

This is not the book I had hoped to write. Soon after Ben was diagnosed in 1990, I began keeping a diary. By 1995 I had accumulated more than five hundred pages of observations, fears, and hopes, all shaped by the vision that someday he would emerge from autism and re-enter the world practically indistinguishable from someone who had never been afflicted. Indeed, hundreds if not thousands of preschool children are recovering from autism (see www.autism.com), and I still hold onto the hope that someday, Ben will be among them. But by 2008, when he turned twenty-one, “someday” had crossed the river to a more perfect time and place where every tear will be wiped away. Until then I have an imperfect story of an ongoing struggle, one that has left me with much to celebrate, and much to grieve.

This book is in a sense an answer to my grief. When I sat down in December of 2007 and wrote the first sentence, I could not have said how the book would end, or even why I was writing it. I only knew that the time had come. I dreaded writing the scenes that exposed aspects of myself I would have preferred to keep hidden, but it became clear to me as I relived those times that Ben’s story was inseparable from his mother’s story and from my own. Autistic children discover the fault lines in a marriage, and their fates hinge on challenges to the family, how we rise or fall: how we resolve our guilt, our anger, our shame; how we reach out to a future that seems at times dark as the Styx. Perhaps I could help other parents strug-

gling with autism and with the medical profession, the school system, their marriages, and themselves. I had only to tell the truth.

In the end, I found that I had written a recovery story after all. What is recovered is a family more resilient, forgiving, and loving. Like the characters in *The Wizard of Oz*, we have made a journey through a perilous land, and we have discovered in ourselves the gifts that prepare us to seek the future beyond the fear, the darkness. After the earthquake, wind, and fire, a still, small voice of peace.

The journey is not mine alone. It is yours, brave, brokenhearted father and mother; it is yours, teacher, doctor, preacher, caregiver, administrator, scientist, politician, you who see in the tragedy and triumph of a child a challenge and a hope. We do not know why some children recover and others do not. We have much to learn about autism etiologies and effective treatments. At the end of the road is not a gleaming emerald city, but a promise: We will persevere. We will tell our stories. We shall continue our journey. Together, we will overcome.

ACKNOWLEDGMENTS

I am indebted to the many professionals and family members who walked beside me on this healing journey: To Dr. Bernard Rimland, who established *Defeat Autism Now!* and pioneered the behavioral and the biomedical treatments that are helping so many children. His personal response to my queries nudged me in the right direction. To Dr. Constantine Kotsanis, who helped pioneer the new biomedical protocols. He gave Ben's mom and me valuable professional advice when most conventionally trained doctors offered no treatment and no hope. To Sharon Hawkins, Ben's aide and "mom-at-school," who took him into her heart and home during the darkest days. To the Reverend Shelley A. Hamilton, for her prayers these many years. To Mom, who was always there when Ben and I needed her, who still speaks in the spirit of love whispering through these pages. To Ben's mom, Susan, who with courage and persistence overcame her crippling psychological disorder to help revive Ben's biomedical program. To Ben, my courageous, wonderful son.

I am also indebted to the writers, critics, and editors who helped me construct a coherent, well-paced narrative: To Sandra Williams, Ph.D., whose quick and cogent feedback helped shape every scene, whose encouragement and admonishments kept me writing through long months when the task seemed endless. To Mark Noble and the gang at The Writer's Garret peer workshop, Stone Soup, who provided useful technical feedback and cheered me on. To my senior editor, Ronald Chrisman, whose steady hand guided the manuscript

through many drafts. To George Getschow, writer-in-residence of the Mayborn Conference, whose reading, editing, and invigorating questions prompted a cover-to-cover rewrite, and to the farsighted folks at the Mayborn Graduate School of Journalism, whose award made this book possible.

Thank you.

PART 1

THE STORM

WISHED UPON A STAR

July 1990. Carrollton, Texas

The Carrollton Public Library didn't smell like an office; it smelled of cedar pencil shavings and Windex, an elementary school classroom. The tables were populated by schoolchildren writing their book reports. I was dressed for success: suit, tie, and briefcase. I didn't belong here. Likely a pedophile, the librarian no doubt thought, playing hooky from work.

I should be in an office building downtown, handing speech drafts to a secretary, or on an American Airlines flight to New York to interview the CEO of IBM, or giving a presentation in the Dell boardroom.

The librarian, black-frosted Miss Colfin, hair done up in a Pentecostal bun, pretended to ignore me but I felt she was watching out of the corner of her eye. Would she think I was going to stash books in my briefcase and sneak out? Would she think it was full of drugs?

Trying to look professional, I found the card catalogue and pulled out the musty "AU" drawer.

"No, Blunderbuss," a voice in my head said, addressing me.

One of my inner characters was afraid that Miss Colfin might put two and two together and deduce that I was searching for books on autism. "The pedophile must have an autistic son," she would surmise.

And that would make Ben autistic.

Turning my back on Miss Colfin to shield the file drawer from her view, I thumbed through the cards. There was only one book on autism, and the title was not reassuring: *The Ultimate Stranger*.

I pulled the book from the shelves, found a secluded table, and flipped through the pages.

"Endlessly biting his own hand, screaming like a wounded animal when you approach, endlessly slapping his own face, finger-painting his body with his own feces ... this is the autistic child," wrote Carl H. Delacato, the author.

If had been in the bathroom I'd have thrown up. I saw myself straddling the space between the washbasins, looking in the mirror. "This is not me," I would have thought, hands trembling. "Not me furtively scouring the back shelves of a public library at two-thirty in the afternoon, not me with baby puke on my suit, red-eyed, wrinkled, and unkempt. I've wandered off the set of the movie they are making about my life and stumbled into somebody else's film."

This is not me any more than the children described in this accursed book are like my three-year-old son.

Sometime in the dim and distant past, distracted by grief, I'd turned my old gray Buick left in front of speeding motorcycle. The bike hit the passenger door, flipping the rider over the top of the car. This is not happening, I thought. And for a moment I believed it.

Whew. That was a close one. For a minute there I almost thought—ha ha—Ben was autistic. Silly Dad. He's as normal as you or me, just slow, like Grandma and Grandpa said.

Boom. And the body hit the ground.

I stashed the book in my briefcase and fled.



Three years earlier ...

"Scissors." *Snip.*

"Big head," said the doctor. And out came Benjamin, my third child, beloved son. Sue went into false labor on the Fourth of July, 1987, and from the hospital window we could see bursts of fireworks branding the sky, followed by the tardy pa-pa-pa-pop that sounded like champagne corks toasting Ben's arrival. Though his birth was delayed until the middle of August, he was to be my fireworks baby, inheritor of everything his siblings had missed. At a party to celebrate Midsummer's Eve I explained to a former professor, a nun who specialized in Emily Dickinson, that Ben's brother and sister had grown up with hand-me-down clothes and Salvation Army bikes. But with my new job as the speechwriter for the CEO of a major oil company and an empty nest, "We can afford to give Benjamin whatever he wants."

The nun was unimpressed. She took a sip of her wine. "Don't," she said, "spoil him."

But I was looking forward to spoiling him. Ten years of penury in Stillwater, Oklahoma, living hand to mouth on graduate school stipends and my wife's salary, had given me an itch for a life without fear of overdrafts, a life lulled by the sturdy and certain flap-flap-flap of the cash machine. In the 1980s, oil-rich Dallas, J. R. Ewing's boomtown, was the ultimate cash machine. Sue and I were dressed for success, an image from *Ozzie and Harriet*. "That necklace Harriet wore?" said Sue. "I want one like it. Those are Republican pearls."

Surely no child has ever been more eagerly anticipated than Benjamin. "Don't you want a sweet little baby?" said Sue, in bed, the night he was conceived, her hand seeking an answer. "A sweet, itty-bitty baby?" I said no, but looking out the window that clear cold January evening at a twinkling star, I wished upon it, and we rolled the dice. Yes, I wanted another baby. I wanted another chance to be a great dad.



1962. *Stillwater, Oklahoma*

The first time Susan moved from the fringes of my consciousness to somewhere near the center, she was in my way. She sat one desk ahead of me in high school geometry, junior year.

Two minutes until the 12:50 bell. I could feel the lunch line lengthening. Mr. Mihura, the teacher, was droning on and on about point Q at the intersection of a ray that bisects parallel blah, blah, one minute until the bell. Susan raised her hand and Mihura was driving into overtime for sure.

"Mr. Mihura?"

"Shut up," I hissed.

Susan turned around and stared at me. She was the only girl I knew who wore sunglasses indoors.

"Lunch," I stage-whispered, pointing to the clock.

"Tough titty."

The bell rang and Susan was up and out of her desk, blocking the aisle, jamming books and papers into satchels that hung off her body like overstuffed butt cheeks, half the students already out the door. "Class dismissed," said Mihura. Susan lurched into the aisle in front of me, swinging her ass, a moving obstacle blocking the fast lane. I was hungry for lunch, impatient, and to my seventeen-year-old eyes she looked like a granny driver in a '53 Ford pickup, going twenty miles an hour in a high-speed zone, me stuck in traffic behind her. I imagined her driving a beat-up truck farting black exhaust, blocking my way as I tried to pass to the right or the left, her book satchels bouncing off her hips like piles of sandbags rocking and rolling off the tailgate.

That was the year I told Dad that I was gay. "No, you're not," he argued. "You just need to meet the right girl." In search of Miss Right, I gave a party for my friends but only a few came. After the last goodnights were said, Susan stood beside me.

"Let's laugh," she urged. "Let's laugh for one minute."

I held my watch up and we *aha-ha-ha'd* as loud as we could, kept it going. But I couldn't tell from looking at Susan's face whether she

was laughing or crying. There in the deserted living room, lights low, music playing, she looked up and put her mouth to mine. "Thy breath was shed / Upon my soul between the kisses and the wine," wrote Ernest Dowson. Now I understood. I was smitten.

Next day Susan and I skipped study hall and snuck to the brook. Waving her wand, she summoned up the creek snakes. Heads poked out of the water like little Loch Ness monsters. "I want to paint you naked," she told me. That night, after *David and Lisa*, a movie about star-crossed teenage lovers, I pulled up in her driveway. I was kissing her goodnight when her tongue took me by surprise. I accidentally stepped on the accelerator and smashed Mom's T-Bird through the garage door.

Reined in by the adults in her family, devalued—"You never *were* worth the trouble," said her mother—Susan saw herself as Cinderella sitting among the clinkers. Her self-portraits showed hard, bony figures with swollen, outsized hands and knuckles, drooping faces, waiting. Her favorite tune was Miles Davis's haunting trumpet solo, "Someday My Prince Will Come."

Enchanted, I fancied myself her prince. The Age of Aquarius was dawning, and Susan was an Aquarian, bound to the wellsprings of art, music, literature. In my adolescent mind, awash in hyperbole and hormones, all compasses pointed toward her. Tides moved with her moods. Subterranean rivers flowed through her veins. Blossoms opened and closed as she passed, and moon vines bred in her footsteps, flowers with fresh white faces lifted, like hers, toward the sky.

My boyfriend was Joel, a year older, my guide to all that was dark and dangerous, serpent in my Garden of Eden. Tennessee Williams once had picked sixteen-year-old Joel out of a line of boys and men hustling sex in Fayetteville, Arkansas. Williams said Joel looked literary, and Joel took the compliment to heart. His ambition was to become a bestselling author, like Jack Kerouac. There in the Moonlight Lounge by the drive-in theater, he assumed his *Rebel Without a Cause* pose, sleeves rolled up like an arm wrestler, and drummed his left-hand fingers on the table to a beat only he could

hear: drummed and moved his head and shoulders side to side like a cobra. Joel believed that anyone of either gender who looked into his unblinking eyes would fall in love with him.

"Stillwater. Armpit of the world," he said. He licked his lips and blew onto his shoulder, a wet fart.

So it went: Joel by night, Susan by day.

Every weekday I would pick Susan up at 7:15 a.m., drive her to school, leave my Model A with the "Goldwater for President" sticker in the parking lot. After school we'd meet at the car and I would drive her to the Campus Drugstore and buy her an ice cream.

One Friday afternoon I found Susan wandering around the parking lot. The Model A wasn't where we'd left it that morning.

"Where did you go?" she asked.

"Joel and I went to DeLavon's for lunch."

Her green eyes flashed. Like a Rottweiler that turns on a kid, no warning, she fast-slapped me. "Princess was always such a good dog," says the bewildered owner, "a good dog."

In the end, I married the Rottweiler.



July 1967. Iowa City, Iowa

Clearly, I had found the right girl. Sue believed in fairy-tale endings, and when it came right down to it, so did I. But marriage didn't make me straight. Shortly after Susan and I settled into our new home in Iowa City, a former army barracks converted to married student housing, a maintenance worker arrived to paint the window trim green. Looking out the bedroom window, I watched him from the bed where Sue and I had recently finished celebrating our marital privileges. He was young, cute, and shirtless. My mind said no but my dick didn't get the message.

"Oh shit," I thought. "I'm still gay."

Here I was with a child on the way, married to a dependent wife whom I had promised to love, honor, and obey. Yet I couldn't keep my eyes off that shirtless painter.

I remembered Dad's advice when I confessed my inclinations to him: "Put a lid on it, put it in a safe, take it down to the basement, dig a deep hole, and pour concrete on it."

That's what I did. For the next twenty-five years, I became the person I thought Mom and Dad wanted me to be: the successful, upwardly mobile Dr. Jekyll. My heterosexual persona became a suit of armor, a shell that defended me from the outside world. But there was another person hiding deep inside. And if the lid came off every so often and Mr. Hyde came out for a romp, who was to know, and what harm was done?

QUIRKY BEN

August 1987. Carrollton, Texas

"Do you think the hospital would take him back?" I asked Sue in mock exasperation.

"We could leave him on the steps," she kidded. We both laughed and welcomed the comic relief. After two days of Ben at home we were exhausted. He screamed. Before feeding, after feeding, while his diaper was changed, bedtime to witching hour, Ben screeched like a madman howling through a megaphone. Twenty minutes of sleep, more screeching, another short nap if we were lucky, then back to the megaphone. Our other two kids hadn't been like this.

But Ben wasn't like our other kids; no, not from hour zero. First, his head was gigantic, above the 98th percentile, off the charts, sticking out of his mom's birth canal then out of the papoose wrapper like a preposterous Tootsie Roll Pop. I held my newborn son while the doctor sewed up Sue. *Big head, I thought, good. With all that space for brains, he'll be a genius.* But as the medics wheeled him down the hall, he screeched woefully, painfully.

"Stop," I yelled. They stopped the cart. "Something hurts," I insisted, rushing up to Ben. Could it be a wayward safety pin?

"No," the medics assured me, the first of many lies doctors would tell us about our son. "He's OK."

OK? Then why is he screaming?

"We don't know," they might as well have said, "it's not our job."

Then whose job is it? Surely not ... mine?

At home, Ben didn't take the teat. He lost weight, failed to thrive. He lay at the bottom of the baby bag, a kangaroo pouch, emaciated, a concentration camp victim.

At the pediatrician's urging we switched from breast milk to baby formula, Enfamil, loads of which he burped up or projectile-vomited. "I know how much you love our son," Sue explained. "I wanted to breast-feed him because I thought it would make you love me more." We walked around the kitchen and nursery with towels on our shoulders, ready for the next Enfamil moment. But the formula that stayed down seemed to nourish him. Ben gained weight, though his head was growing faster than his body. And he screamed and screamed. "It's colic," the doctor assured us. "He'll outgrow it."

Our older children were busy with their own lives. Hannah was a senior in high school, working at Target, miffed by this usurper who took her place as the youngest child in the family, worried that people would think Ben was her baby. Pete was living in his own apartment, coming home weekends to practice with his garage band, which drowned Ben's cries. We learned to cope.

Ben loved to be held and rocked, but for the worst of his gut storms the rocking chair wasn't enough. I bounced him up and down on the bed: the bigger the bounce, the better. I put him in the baby carriage and raced him over the roughest parts of the sidewalk. I drove him around in the back seat, seeking bumpier roads. I set him on top of the washing machine and juiced it up to the spin cycle. I took him horseback riding, swung him in his baby bag, tossed him high, high, higher. Ben would squeal his joy, then burp, leaking Enfamil. The burp signaled a few minutes of peace.

On the sunny side, Ben loved music and kinetic nursery rhymes. He'd squeal with delight at action-packed thrillers—Jack *jump* over the candlestick, Wee Willy Winkie *runs* through the town, Scotland's burning: Fire, fire, fire. He'd jam his palms together, clapping, and demand encore after encore. He craved to be knee-bounced on the rhyming words: "One, two, buckle my *shoe*. Three, four, close the *door*." His favorite games were hide and seek and "Here comes the big hairy monster: *Arrrrgh*." Tickle tickle tickle *squeal*. Followed by the blessed Enfamil burp.

Ben preferred looking at things and people upside down. He'd hang backwards over a cushion or pillow, his arched back a U-turn, his head an inverted smiley face, and he'd lock his radar-detector gaze onto my eyes. "Look," said my brother, Cris, sitting across the room with Mom and Dad. "They're bonding." And indeed we were. Gazing into Ben's eyes, I felt a connection so deep that I had to give voice to it. "I will always love you," I said. "I will never, never abandon you." It was a vow I would keep in times better and worse.



November 1987. Dallas, Texas

By the time Ben was three months old, Sue was receiving urgent phone calls from her boss urging her to cut her leave of absence short and return to work. Or else.

"Dan," Sue asked me, "Can you take care of Benjamin *and* the business?"

I thought about it. Well, I was already working at home, marketing my speechwriting software, *Thoughtline*. My start-up business produced cash flow, but Sue's job with the Dallas Park and Recreation Department paid for the medical insurance that funded our high-maintenance baby. Raising a baby and a business together would be difficult, but I was a Burns, following in the footsteps of my entrepreneurial father, whose business card read "Difficult tasks performed immediately. The impossible may take a little longer." Hadn't I organized a commune of Canadian hippies into a docu-

mentary film production company? Hadn't I landed one great job after another, taught myself software engineering, created an innovative speechwriting product, and launched my own company?

"You bet," I answered.

"Great," said Sue. And she was gone.

I'd had a preschool playhouse and had learned to cook waffles and beat eggs, but my domestic training was cut short when I was arrested—yanked out by the collar—for playing in the girls' sandbox at school. It had more sand. Except for vegetables wrapped in tinfoil and tossed in the campfire, a culinary skill I'd learned as a Boy Scout, food was something set in front of me by a mother, grandmother, or school cafeteria lunch lady. As I grew older I understood that there were various theories of nutrition troubling the land, and my position was that diets were like religion: matters of personal belief, numerous and contradictory; they could not be proved or disproved and had no practical application for me. My weight stayed forty pounds below the boiling point of water and was just about as invariable.

My entrepreneurial training, however, was outstanding. In fifth grade my best friend, Scrib, and I invested in a squeegee and set up a regular window-washing route along Main Street. We fancied ourselves the Wright Brothers. We designed fantastic flying machines and built a motorized go-cart, attracting the attention—and cash commissions—of neighborhood children who wanted a go-cart like ours.

On the one hand I was well prepared to grow a home-based software business. On the other, I was only marginally prepared to assume primary care for a high-maintenance child like Ben.

"What happens," Dad used to ask, "when an irresistible force meets an immovable object?" The question was supposed to be a stumper, but in the real world when continents collide—the one immovable, the other irresistible—a mountain range arises. The mountain range was the altered landscape of my life, challenging as Everest.

Not every day was equally challenging. On good days, four-month-old Ben was an easy baby. He'd sit strapped in his seat on the shipping desk and study his mobile while I staffed the communications desk a few feet away. I'd be lost in my work for an hour or so, then I'd notice that Ben was still mesmerized by the mobile. Shouldn't I be stimulating him? Odd, I thought, but my motto was Do Not Disturb a Quiet Baby.

For a change of venue I'd take Ben downstairs and set him in his baby swing in front of the television. His favorite shows were *Wheel of Fortune*—he loved the spinning and clapping—and *The Weather Channel*, which in those days consisted of a radar scan line sweeping around Texas at the approximate speed of a minute hand, the most boring broadcast on TV. Ben loved it. "It's slow," said Sue, "like him."

For a rainy day diversion, Sue tied a mailing tube to the rocking chair. Ben would drop a walnut down the tube and listen, watching while it rolled to the other end. Fascinated, he'd pick up the walnut and do it again until we distracted him. I pictured him as a patient scientist performing an experiment over and over until he got every last bit of information. Couldn't he roll something else down the tube, a marble, a wooden bead? No, had to be a walnut. Such intense concentration. He'd be a research scientist, or an engineer. Such persistence. Such dedication. Such single-mindedness. Surely these were the qualities of an Edison.

Like Edison, Ben had ear infections and colic. On difficult days he cried inconsolably. Mom, who handled a good chunk of the babysitting, told me the story of her phone call to Dr. Neal, my pediatrician. "Danny won't stop crying. What can I do?" she asked.

"Go to the drugstore and pick up a prescription of phenobarbital, a bottle of whiskey, and a shot glass," the good doctor answered.

"You want me to give my baby whiskey?"

"Give him the phenobarbital. Then pour yourself a shot of whiskey."

I could sympathize with Mom. There are few things worse than being unable to help a child in pain. On the bright side, though,

colic is caused by a buildup of gas pressure in leaky intestines like overpressurized steam in an ancient rusty boiler—safety valves hissing, alarms ringing, needles in the red zone—the baby never explodes, though sometimes the parent may. Eventually the crisis subsides, though never, as any survivor will tell you, soon enough.



The ear infections began crowding one on top of another about age one. Sue and I set Ben on the bed, his forehead hot as the orange bedspread, fever spiking.

“This is scaring me, Dan.”

“Let’s go.”

It was the first of many late-night trips to the Kaiser HMO emergency room, all following the same script: the sudden shrieks of pain late at night or in the wee hours of the morning, the frightened drive through darkness, the long wait in the comfortless fluorescent room whose bare walls echoed Ben’s screams, the prescription for pink bubblegum-flavored Amoxicillin that Ben would spit out all over his clothes and us. We mixed it with applesauce or squirted it down his gullet with a turkey baster. He threw up so much of it we often had to order a refill: a ten-day prescription lasted only about a week. We hoped that we got enough of it down him to do some good.

Ben would improve for a couple of weeks until he was knocked down with another ear infection, which would be treated exactly as if it were the first. Ben’s doctors—or “service providers,” as the Kaiser Permanente HMO preferred to call them—simply followed the medical algorithm, the repair manual. When I pointed out that Ben’s ear infections were recurrent, six in four months, I thought the medical service provider would say, “Yes, you are right. What is driving these infections? Let’s get to the bottom of it.” That didn’t happen. So we added another bottle of gooey Amoxicillin to the collection in the fridge. Perhaps some other doctor could have helped, but with limited finances we felt that we were stuck, for insurance purposes, in the Kaiser-Permanente system.

A dozen years later I sit in my study, going through Ben's medical records from 1987 through 1991. I turn the tattered pages of these fading carbon copies, these pink and yellow forms. It takes the better part an afternoon to read through them. Some nearly illegible, but it doesn't matter, because they nearly all say the same thing: "Acute distress ... child crying *hard* ... pulling at right ear ... thrush on tongue and throat ... yellow mucus ... inflammation ... passing gas ... diarrhea ... severe diaper rash ... screaming and kicking ... vomiting." Further, the treatment was always the same, more antibiotics: Amoxicillin, Ceclor, Septra.

I count 173 records of visits to the Kaiser emergency room, Ben's Kaiser pediatrician Dr. Eakman, a referred specialist, or to a lab, between Ben's first birthday, when the ear infections started in earnest, and Ben's fourth birthday, when he received his four-year vaccinations and began the last leg of his descent.

One hundred and seventy-three medical events in three years.

The last time I saw poor, hapless Dr. Eakman, he excused himself from the medical examination room and was gone for so long that I went looking for him. I found him in an office, sitting at a desk, reading a thick red book—the *Physicians' Desk Reference*. I hadn't thought of it until then, but likely Dr. Eakman was as frustrated in his own way as Sue and I were. The answers we needed were not in the book. A few weeks later Eakman resigned from clinical practice to go back to school so he could pursue a career in medical research. I wished him the best. I might have quit too if I'd known where to submit my resignation.



As Ben approached his developmental milestones we were with him every step of the way, helping. We taught him how to hold a bottle, how to roll over, how to pull up his blanket, crawl, sit up, stand up, walk. It wasn't that Ben couldn't move his limbs; it was that he seemed surprised that they were attached to his body: he didn't know what to do with them. So we showed him by moving

them for him. We were the puppeteers and he was the puppet. To teach him to crawl we pushed him across the rug while we puppeteered his arms and legs. To teach him to walk, we coaxed year-old Ben to fall forward into my arms while his mom bike-pedaled his legs to keep them under him.

Ben learned to scramble up anything. He would climb out of any crib, escape from any playpen. Turn around and we were likely to find him on the table or the kitchen cabinet. He'd have mounted the refrigerator if he could have found a foothold.

To our eyes, all of this odd behavior was endearingly quirky. How else to explain our indulgence of his obsessions? He'd collect long, straight, pointed objects—sticks or soda straws, coat hangers, long stems of grass—which he squirreled away in odd nooks. He'd run about the house bouncing from wall to wall and waving these objects a few feet in front of his face yelling *E-e-e-e-e* like a daredevil, a kamikaze pilot, Evel Knievel performing his Grand Canyon jump. How charming. How precocious.

Running and screeching constituted his routine during the day. But at night? Ben didn't distinguish between sunrise and sunset. Every night was a lock-in party, a contest to see who could stay awake the longest. Ben always won. While his stuporous parents tried to sleep, Ben walked around the house on the balls of his feet, toes curled under, waving his wire coat hanger, sucking his bottle, mustering Mom and Dad to demand a refill, another hit of Enfamil. Next morning we'd find him passed out on the floor beside his crib, diapers yellow, heavy, and stinking of ammonia, or curled up in the fireplace pit, or on the couch, or in his sister's clothes closet, or in the nook under the stairs.

He chewed his wet diapers. He flipped light switches on and off. He raided the coin jar and filled his mouth with pennies and nickels. He ate with his fingers and wiped his hands on the walls. Then there was the grape raid ritual. Ben would sneak a purple grape from the fruit bowl and beeline to the nearest exit, a shoplifter fleeing the cops, legs spinning like the Looney Tunes roadrunner as he stuffed

the pilfered grape into his mouth. Halfway to the door he'd stop short and stare at his empty hand as if in disbelief, Marcel Marceau miming comic surprise: *Where's the grape?* Then he'd turn around, spy the fruit—*Aha!*—and trot resolutely back to filch another purple prize. "His feet work faster than his brain," quipped Uncle Tever.

Ben also was becoming more sensitive to sounds.

"Attention, Kmart shoppers," barked the voice from the overhead speaker. "Blue Light Special on aisle five."

Ben covered his ears, screamed and scrambled for the exit as if pursued by the four trampling horsemen of the Apocalypse. His face—Munch's *The Scream* looked comic by comparison—testified to his terror. His pediatrician ordered a brain stem audio test. All of Ben's auditory equipment was working normally. What was I worried about?

Well, for one thing, some days Ben was as slow as a gravel truck climbing a mountain.

"Throw it, throw it," I called to Ben from the bottom of the staircase. He was on the landing at the middle holding a heavy orange rubber ball pitted like a moon rock. It had been a carefully chosen first birthday present, something we could play with together. From his perch on the stairs he'd give a toss and bouncy, bouncy, bouncy, *boom*. Down it would roll. He'd squeal with delight as I tossed it again and again, playing fetch with tireless Rover. But our playtimes, it seemed, were becoming few and shorter. Sue and I assumed that once Ben had learned a behavior, learned how to hold a pencil, draw a line, say a word, untie and remove his shoe, that he'd learned it for all time and would move on. But we were wrong. Yesterday he could take off his shoe; today he can't, or won't. It is raining, the guests will arrive in twenty minutes, I am out of coffee and must take Ben to the store with me. But he has forgotten how to put on his shiny yellow rain boots. I put them on for him just this one time. I discover that this one time becomes every time.

Today I'd had enough. My eighteen-month-old son was going to play ball with me, and that was that. I plopped him down on the stairs and tossed him the orange moon rock. He ignored me and stared into space. "Catch it, catch it." His hand twitched, a half-hearted move, shudder of a sleeping dog's paw. I moved Ben a few steps down, crossed his legs to make a basket, and set the ball in it. "Throw." He gave the tiniest possible push with the back of his hand. Kerplunk, thud, one step down, ball going nowhere. I retrieved it. "Ben, heads up." It landed beside him. "Throw." He gave me an odd look as if to say, "You want it back already?"

One step forward, two steps back. The forward step is greeted with enthusiasm, cheers, relief. *Now he's getting it, he's on the right track. Attaboy!* The steps back aren't always marked. Didn't he used to say "Daddy" when I came home? Didn't he used to bounce around in his walker like a Hells Angel? Yikes, where is his walker? I look around. It's gone.

So it went with the rocking horse, the Slinky, the windup record player: Ben seemed less and less willing to exert even a minimum effort to play with his toys. With energetic prompting—yea, Ben! Let's go, Ben!—he would string a few beads or put a domino through the slot in the plastic top of the coffee can. But he took no joy in it. Unprodded, he'd just sit there. Well, I had a business to build. I decided it best to leave Ben to his own devices, which were fewer and fewer.

He's growing up, we told ourselves. He's outgrown his exuberant phase; he's more mature, more serious. His interests have changed. Or, he's not feeling well today. He has a cold, an ear infection. He's tired. He's recuperating. Give him a day or two. We had such busy, interesting lives to lead while our son slipped away.

Language, too, was vanishing. Sue and I would prompt him, pointing to objects, naming them, and wait for him to pick up new word. Finally he'd pronounce one, "doggie," as if he'd been preparing to birth it for days and now was delivered of it, perfectly formed. "Yea, Ben! You said 'doggie.' Good for you, Ben." We congratulated

each other, relieved. "See, he can talk. He said a new word." Ben looked at us as if he wondered what all the fuss was about and toddled off. So much for *doggie*—that's the last time we heard it. A day or two later out would come another fresh word, "choo-choo," first and last off the assembly line, never to be heard again. Was he going to go through the whole dictionary this way?

One evening I realized that I could keep Ben within my field of vision, fix my eyes on him, but I couldn't *attend* to him for more than a few seconds. *Odd*, I thought. *My kid is invisible*. I tested my theory by paying full attention to Ben and nothing else for a full minute. I held my watch in my right hand and focused my eyes on Ben. He was sitting beside the green woven picnic basket filled with colored golf-ball-size wooden beads: red, yellow, blue. I'd taught him to string those beads, starting with colored pipe cleaners and working up to a thick red and white candy striped shoelace. I'd cheer him on to each bead, each victory. "Yea, Ben!" He'd squeal with pride. But tonight he was not stringing beads. Fifteen seconds into my experiment I realized that my mind had drifted. I was remembering what he used to do. *What is he doing now?*

Nothing. He sat in front of me, staring off into space, his hands dangling from his wrists like tired dog tongues. My attention radar wiped him out, overwrote him as if he were a blot in the blind spot on a piece of paper held eighteen inches in front of the eyes. I tried the experiment again. With determination, I fixed my attention on him for perhaps twenty seconds, then he "disappeared." My son was vanishing before my eyes.



I was under unremitting stress. Balancing baby and business was getting harder and harder. Even on good days, Ben was fussier, more refractory, his eating messier, his colic more persistent, his tantrums more frequent.

Today, I'm at a breaking point. I'm downstairs in the family room at three o'clock in the afternoon, my worst time. My computer

is on the floor beside twenty-two-month old Ben, who is watching *The Weather Channel* and keeping an eye on me. Ben is the Motion Police, and I am his prisoner. I am allowed to move my hands a few feet or turn my body within certain parameters, known only to Ben, as long as my butt stays planted. If I stand up, stir, or give any hint that I am about to leave the room, he will start screaming. But I have to pee. Is there a coffee can handy?

Tension had been building all week. On Monday afternoon I'd finished my coffee and walked out the back door, coffee cup in hand. It was part of a set my grandmother had given Sue and me for a wedding present: gray, shallow, with a flat bottom and blue rim around the top and bottom. Deliberately, as if I were delivering the final blow to a nail, I smashed it to bits against the stone terrace. Then I swept up the pieces and hid them in the wastebasket.

Tuesday I wrote "Help" forwards and backwards with lipstick on the mirrors in the bathrooms, downstairs over the bar, and on the white top of the grand piano.

"What's that all about?" asked Sue.

"Nothing," I said.

On Wednesday, I kicked a hole in the drywall in the hall beside my study. It felt good.

"Dan, what happened to the wall?"

"I kicked a hole in it."

"You're going to fix it, aren't you?"

On Thursday, I sequestered screaming Ben in the bathroom so as not to frighten him. I picked up the hatchet that Sue had been using for a hammer and buried it in the wall like a tomahawk. Frightened—*how could I have done that?*—I fixed the hole with putty and plaster so Sue wouldn't see.

On Friday, I needed to pee. But I'm prisoner of the Motion Police. I plot my trip to the bathroom like a quarterback planning an end run. If I'm lucky, I might be able to get to the toilet and back before Ben rages out of control.

The phone rings, out of reach. Big sale? How can I take the sales call, use the bathroom, and evade another ear-piercing tantrum?

I can't. I cannot do this. I cannot raise this child and build a business.

I muse over this revelation, turn it around in my mind. Surely it cannot be true. *I can do anything I set my mind to, always have. But I cannot do this.*

The telephone continues to ring. Ben is still crying. I go into the bathroom and close the door because I don't want to alarm him. I scream, "I can't do it, I can't do both." I can't. Yet I must.

"I can't," I scream again.

I smash my fist into the bathroom door, breaking through the first layer of fiberboard into the hollow space.

"Christ Almighty."

I kick the wall, the way I had done upstairs, where my foot had made a hole through the Sheetrock. This time I strike a stud. The pain breaks the curse. I limp out of the bathroom. Ben is looking at me as if I have lost my mind, Jack Nicholson over the edge.

I load Ben into the old gray Buick and drive to the north end of Grapevine Lake. I park on a cliff facing the stark winter sunset and watch the water, my toe throbbing, my mind blanked by the pain.

I could just drive in.

DIAGNOSIS

"He's so advanced for a two-year-old!" gushed the teacher.

"Really?" Great. Sue and I had finally found someone who agreed with us.

"In what way?"

"His fine motor skills," the teacher said. "The way he cranks that jack-in-the-box." Ben was still cranking the tinny tune. *Round and round the mulberry bush*. Out popped Jack. Ben squealed.

"He did that all day," she offered.

"Yes, he loves music," I said, shifting the subject.

"I should say he does!" she said. "He could be a composer."

"How about a writer?"

"Or an artist!" Sue chimed in, handing Ben a crayon. "Look: thumb, middle finger, index finger. That's a tripod grip!"

"Hey, Ben. Great first day!" I cheered. "Let's go." *While the going is good*.

"Oh, Mrs. Burns. And Mr. Burns." I should have seen this coming.

"How do you get him to take a nap?"

"We don't," I started to say, stopping myself. *Naps*, I thought. A *big deal at day care, required for tenure*.

"Just burp him and rock him," Sue bluffed. "He'll be fine."

"We tried that but he cried."

And he kept the other kids awake, I thought.

Sue was having no more of this discussion. She hurried us toward the door.

"I'll bring some Gas-X tomorrow. Dan, let's go."

The next day, Ben was in a corner by himself, rocking in his rowboat, staring in the mirror.

"He fusses when we try to make him sit with the other children," the teacher said, glancing at Ben. "When he's crabby like that he crawls to the corner and we just leave him alone."

I didn't blame her. Do Not Disturb a Quiet Baby.

"Did he take a nap?" I asked.

"I've been meaning to talk to you about that, Mr. Burns. No, he did not. Do you have a number where you or your wife can be reached during the day?"

On Friday, at naptime, the teacher phoned me. Ben was screeching like an ambulance siren and the other kids were going off like car alarms.

"He's a lovely little boy," the teacher said. "I'm afraid we can't keep Ben."

I shouldn't have been surprised. I couldn't keep him either.

Sue and I tried Freewill Baptist Academy. The Baptists surrendered by the end of the week. White flag. But Sue and I had no such option. We'd have put Ben in a basket and floated him down the Nile if we thought we could get away with it.

"Dan!" Sue was waving a brochure at me. "I've found a great school for Ben!"

Just what we needed, because he'd been expelled from TLC Child Development Center, where children "experience success on a daily basis," for successfully practicing his Houdini escape act.

"A great new school. Tell me about it."

"It's the Kathy Burke Pre-K Academy for Gifted Learners."

"Yes?"

"It's a drama school. The kids dress up."

I looked at the brochure. Was this a good idea? Gifted. Well, that's Ben: so sensitive and moody, so music-loving, plays his Old King Cole tape over and over, so artistic, decorating the walls with his advanced tripod grip. On the other hand, he didn't play with other children. Wasn't that what drama was all about, play?

Never mind, counseled Sue. According to the brochure, this was an "avant-garde" school where teachers "truly engage the children at their optimum level," where Ben would at last be "appreciated for her or his unique talents and abilities."

Admission by interview and referral only.

Of course, they would never take him.

"Listen, Dan," countered Sue. "It's for underachievers. They take difficult kids."

"What about the naps?"

"Dan, Ben is better. He can take his vibrating mat to school."

"And the referral?"

"Got it." Sue worked for the Park and Recreation Department, City of Dallas. Through her social and professional network she had pulled some strings. We had an interview.

Sue and I prepped him for the meeting. We jimmed the playground gate and snuck into the schoolyard so Ben could get used to the environment, go down the slide, play on the climbing toys. We peeked in the windows, Ben on my shoulders. The school really did seem colorful, new, well equipped.

"This is your new school, Ben. You like your new school?"

If crying was any indication, he did not.

Somehow we bluffed our way through the interview, spinning hope. "Separation anxiety. So sensitive. He'll get over it."

Weekly reports from the school suggested otherwise.

Ben doesn't relate well to the other children," began the first one. "He wants to be held and rocked."

"Well, hold him and rock him," Sue said through gritted teeth.

One of the teachers, Madelyn, took a special interest in Ben, stood up for him in parent-teacher conferences, pleaded for pa-

tience and more time, and gave him the one-on-one attention he needed to get through the day.

The big test for Ben was the Halloween party: lights low, apples in a washtub, spider webs dangling, spooky music, kids dressed for trick or treat. Orange and black masking framed the stage. Imagine Ben's terror. He tried to keep everything the same. He thought the sun should stand still and stop making the shadow of the kitchen table race across the floor.

He made a break for the car, screaming. But we dragged him back into his front-row seat. Waiting to greet him downstage was his good teacher, Madelyn, dressed like a witch. She held out her arms to him, expecting a hug, but Ben shrieked and drew away. Madelyn's face fell. All was lost. It was curtains for Ben.

Next day Sue received a call at work, a summons. One of the staff had observed the encounter with Madelyn and had written it up. *Documentation*, I thought, *not a good sign*. The principal handed Sue a note, more documentation, and told her that Ben wasn't responding age-appropriately. She recommended that we have him tested.

It's a trap, I thought. Kathy Burke was building a case to expel him. The note came with an ultimatum: test him or take him home. The school district had already been notified of Ben's case. It was all arranged.

A few days later I received the news from Sue by phone.

"How did it go?" I asked.

"Ben just cried so they asked me a bunch of questions."

"And?"

"Not good."

That evening I saw the report. It observed that Ben was two years, three months old. In graphic detail it showed that his language, social, and motor skills ranged from nine to eighteen months, with most skills grouped at about a year.

He was testing half his age.

We'd have found a reason to discredit the test—he's right-brained; they test for weaknesses. But the look on Madelyn's face had already told me more than I wanted to know.



"Mr. Burns, there's a package for you."

"Oh." I set Ben down under the Eagle Postal Center counter near the jar brimming with cellophane-wrapped red-and-white penny candy. He was waiting for his treat. I removed the cellophane for him.

"Developmentally delayed," the teacher said.

"Developmentally delayed?"

"Significantly."

"Oh."

I see.

The mask was off, the wrapper removed, exposing a child I hardly knew, a snail without a shell. He wasn't cute; he was infantile. He wasn't playing postman; he was trying to escape. He wasn't bright; he was dim as a coal-oil lantern. He wasn't unconventional, charming, or Bohemian. He was feral.

"Mr. Burns?"

He wasn't advanced; he was ...

"Mr. Burns, how is your son?"

"Oh, he's ... he's ..."

Retarded.

Like Donnie, the first-grade dunce who couldn't read the word "breakfast" without saying "breakfast fast." Like Kenny, who came to school with snot on his clothes. I'd heard of families hiding away their mentally challenged members in attics or basements and wondered why. Now I understood.

Shame. Humiliation.

Yesterday Ben was delightful. Today he needed to be rolled back under a log, sheltered from veiled stares, unspoken judgments.

I wanted to get him out, to hide him away from the gaze of strangers.

I'm sorry, Ben. Sorry for the future you may never know you missed. Friendless. Wifeless. Childless. Homeless. I'm just ... so ...

Sorry.



It was not his fault, so it must be ours. In the marathon of life, devil take the hindmost, Ben was running at half speed.

Our fault. Through poor genes or a mismanaged, irresponsible pregnancy, we had brought into the world a retarded child.

The good news was that his test scores qualified Ben for enrollment in the Early Childhood Intervention program (ECI) through the Carrollton Independent School District. He could attend the ECI classes at McCoy Elementary, where his sister had gone to school, just a few blocks from where we lived. Ben would be under the care of special education teachers with children like himself, and there would be no more expulsions, because Ben belonged there.

So did we.

Yesterday Sue and I were dressed for success, gussied up, suited and tied, strung with Republican pearls and bound for glory. Today we were in blue jeans and tennies at a parent-teacher meeting at the correctional facility where Ben would serve time.

We were humiliated, incredulous, angry.

To compound our shame, the school offered to send a specialist to our home to show us how to take care of our child.

No, they didn't offer; they insisted. A specialist would visit our disintegrating home. A very young, single, childless specialist, a spy for the school district, would see what a shambles our lives had become.

Kristi Fair, Ben's teacher at McCoy, must have understood our chagrin. She told a story that she shared with every new parent.

"You are on a journey," she began. "You think you bought a ticket to France, but somehow there was a mix-up and your plane lands in Holland. You are shocked, disappointed, angry. You pound your fist. 'I paid for Paris!'"

Yes, that was exactly how I felt.

"But it is a one-way ticket and there are no refunds."

I'm not listening to any more of this story.

"So what do you do?" she continued. "Over time you find that Holland has its own charms: Amsterdam, Rembrandt House. You are glad you found this out-of-the-way destination for its unusual rewards."

Bullshit. I wanted him fixed as soon as possible. That's why we were here, wasn't it?

The in-home specialist gave us good advice. She said, "Make him talk. Don't give him what he wants unless he says the word for it." She showed us how to teach Ben activities hand over hand: "push the train," "turn on the tape player." He was a tactile learner.

How long it would take Ben to catch up? We would just have to step on the accelerator.



Most children learn from their peers, especially siblings. By age three, Ben's brother and sister were grown and out of the house—Hannah at Oklahoma State University, Pete married and starting his own family—so Sue and I volunteered to teach three-year-old Sunday school. We could encourage Ben to interact with normal kids his age and learn faster.

It is one thing to fill out a checklist that reveals that your child is lagging in language, interaction, small motor skills, imagination. It is quite another thing to see him side-by-side with normal children. These kids—Kendall, Tanner, Jason, Ashley, Stephanie—were *way* ahead of Ben, little artists and playwrights and architects and musicians soaking up knowledge and learning new skills right before our eyes.

Show Jason how to strum a toy guitar and he thinks he's Elvis Presley. Give Ashley, Kendall, and Stephanie a box of robes and hats, and before you can say "Samson and Delilah" they're improvising dramas. As for the discussions, Tanner said the darndest things.

"If you had been in the Garden of Eden with Adam and Eve, would you have listened to God?" I asked. "Would you have obeyed the rules?"

"No," said Tanner.

"Why?"

Great discussion. Ben wasn't paying attention. When placed in the discussion circle, he crawled away to the corner. When forced to stay, he cried. Now I understood why Ben might want to just hide away in his own world. Who hasn't dreamed of showing up unprepared for the final exam in a course never attended? Every Sunday must have been like that for Ben. In the interactive three-year-old classroom, our son was a non-starter.

Back at home, Sue and I redoubled our efforts to get Ben on the ready-for-kindergarten track. Sue worked with him to identify letters of the alphabet, to match, to point. Hour after hour, day after day, but with no training in behavior modification, no appropriate expectations, no notion of how what she was doing could fit into a larger scheme. She often felt, as did I, that we were on a path leading nowhere. Failure after failure, ear infection after ear infection. We all but gave up.

Sue came home from work exhausted. Made dinner. Vegged out in front of the TV. So did I. We could barely stir ourselves to go to bed.

My nightmare: No matter how hard I ran, carrying Ben, we would never catch up.



"We're losing Ben," said his grandmother Dorothy, Sue's mother. It was Thanksgiving 1990. He was a little over three years old.

The realization comes in little shocks, sheet lightning, a thunderstorm still far away on the horizon.

Better keep busy. Grasp at a memory, a fact, a theory that helps you believe for a little longer that what is happening before your eyes is not real.

"I remember when he smiled when Sue and I kissed, how he cooed and cuddled; he's so socially aware."

"His teacher said he was advanced, handled the music box like a kindergarten kid."

"Remember how he worked and worked with the key until he made it fit? And how he laughed when I said, 'Jack jump over the candlestick. Jack Burns!' He has such a highly developed sense of humor. That's the real Ben. He's just going through a stage."

Kristi sent back glowing reports: "I took Ben by the hand & led him to the sandbox. He sat right in the middle of all the children and tolerated all of the noise SO WELL! He had potty accident at 9:30. I bathed him and changed his clothes."

But Ben's attention span was dwindling. He was losing his language. His temper tantrums were increasing. We could not quiet or comfort him. He could no longer feed himself.

Or read his books. Where he used to turn each page carefully—*The Owl and the Pussycat*, *Where the Wild Things Are*, *Goodnight Moon*—now he rifles through them, forward, backward, turns the book upside down, tears out pages.

I explain to the doctors—Ben's Kaiser pediatrician and the specialists he referred us to—and they don't hear me. They offer nothing, not even the cold comfort of the truth. They don't say, "He's regressing; sometimes these children lose their hearing and sight and stop talking; we don't know why. You might as well get used to it because he's headed for an institution and there is nothing that can be done."

No. The lab tests are normal. Neurosonogram, CAT scan, normal. Brain stem hearing test, normal. But this is not Amsterdam. This is someplace I have glimpsed only nightmares, a dungeon in The Hague.



Most of what I knew about autism was a myth. In the late 1980s I had written and published a scholarly analysis of the rock opera

Tommy, which tells the story of an autistic boy imprisoned in a mirror. Tommy is deaf, dumb, and blind. But he is sensitive to “vibrations,” a gift that enables him to become a pinball wizard, then a rock star. With the help of a Dumbledore-like mentor he breaks out of the mirror and is cured.

Sounds like a fairy tale? It is.

Tommy is based on Bruno Bettelheim’s psychogenic theory of autism: A child suffers a psychological trauma, withdraws into a shell, and remains there until the spell is broken by a psychotherapist, a modern Dumbledore. The self-imprisoned child is released.

Nonsense.

Bettelheim’s theory was tragically flawed. It gave birth to the myth of the “refrigerator mother,” too cold and uncaring to raise a functional child. But it made great theater. It also seemed to partially describe Ben: functionally deaf, dumb, blind, in a shell, fascinated with mirrors, and sensitive to vibrations: music, touch, rocking.

Could Ben possibly be autistic?

No, no, surely not.

The very word, “autism,” alien-looking and -sounding, struck fear into the pit of my stomach. In the real world, psychotherapy had proved to be 100 percent ineffective against autism. The spell could not be broken. Autistic kids were modern-day lepers, cursed, beyond help, institutionalized for life when they became adults, locked up and forgotten.

I didn’t mention the “A” word to anyone. Saying it aloud might subtly alter the quantum structure of the universe and make the worst-case scenario come true.

But the doctors weren’t helping, and Ben was getting worse. Someone had to act, research, step into the unknown, descend into the dungeon, rescue Ben.

First we needed to know if Ben was, in fact, autistic. I obtained a checklist from the Autism Research Institute, and Sue and I went down it together.

Looks through people?

"No," said Sue, "but he walks into rooms backwards."

Uses adult's hand to point?

"Yes," Sue answered. "He grabs my wrist and shoves it toward whatever he wants."

Deliberately hits his own head?

"Yes."

Covers ears?

"Stuffs paper wads in them."

Collects odd items? Wire clothes hangers, stems, and knives.

Bizarre pose or posture? Hangs upside down. *Chews nonfood items, especially metal?*

The list went on.

The problem was that on many points we could answer either yes or no. Sometimes Ben walked on his toes, and sometimes he did not. He avoided interaction with others, but he loved to be held and rocked. Which box to check?

Still ... Running with those coat hangers and screeching. Not making eye contact. Severe tantrums. Sound sensitivity. We'd checked enough *yes* boxes to raise Sue's concern and mine.

As I considered the evidence, however, there were two strong arguments against autism. First, only one kid in thousands was autistic. That meant there was less than one chance in a thousand that Ben was autistic, right? I would bet on those odds any day. Second, if he were autistic, wouldn't the doctors know? In three and a half years, no doctor had even breathed the word "autism."

Wouldn't any competent pediatrician have explored that possibility?

Maybe not. A doctor looks in my son's ears and writes a prescription for Amoxicillin. Another doctor inserts ear tubes and refers us to other doctors, who send us through the labyrinth of the hospital, heart pounding, blood pressure careening, Ben screaming, to take tests.

But no doctor puts the pieces together. No doctor sees the whole child.

And the half dozen doctors we'd consulted to date could not answer even the most basic questions. Why does my son cry so much? Why does he cover his ears with his hands? Why does he tear up books when he used to love books? Why does he whisper when he talks, and why did he stop whispering?



I shared my concerns about autism with Ben's Kaiser pediatrician, who referred us to Dr. Nancy Hitzfelder. She was one of the few pediatric neurologists in Dallas who saw autistic children. It was December 7, 1990, my birthday. Ben was three years and four months old.

If we had a diagnosis, I felt, we could fix Ben.

"Autism, a tough case!" I imagined Dr. Hitzfelder saying. "We've got to reverse the downward spiral."

"How?"

"We'll take a three-pronged approach," she'd say, scribbling on her prescription pad. "Genetic, neurological, metabolic."

"Great."

She'd rip the sheet off her pad. "Here," she'd say, handing it to me. "Call Children's Hospital and schedule a glutathione infusion. I'll alert my colleagues and arrange a complete workup." She'd pick up the phone. "We'll get to the bottom of this!"

"What about speech therapy?" I'd ask.

She would finish punching numbers into the phone and look up at me. "Ben may not need it," she'd say cheerfully. "Many of these children start talking after the first push."

That is not what happened.

Dr. Hitzfelder picked up a blue beach ball and set it in front of Ben.

"Kick the ball," she commanded.

Ben did nothing.

"Kick!" she repeated.

Ben seemed not to hear.

Dr. Hitzfelder turned to me. "When did you first notice that Ben was developmentally delayed?"

"Developmentally delayed" was too clinical a term for the nightmare that had brought us here. For the first year and a half, I explained, Ben was eccentric but more like a normal child, though fussier, messier, and more exuberant than his older brother and sister. By eighteen months, pencil in hand, he had covered the walls of his room with fancy lines and intricate loops. He was going to be an artist for sure, or maybe a writer. But at about twenty months his tripod grip had twisted into a fist, and his loops had shriveled into scrawls. Then he stopped scrawling.

And talking.

Now, on his better days, Ben would spend hours waving a pencil in front of his face or looking in the mirror and making motorcycle noises.

"Does he resist change?" the doctor asked. She was making notes.

"Yes, he doesn't even like me to move."

I explained that Ben was the Motion Police, and I was his prisoner.

"I see," said Dr. Hitzfelder. She made another note. "Is he getting any assistance through the school system?"

"Yes, some."

Kristi was grasping at straws. "He stopped masturbating and got out from under the easel when I told him to," her last note said. "He didn't verbalize any words for us but he did make eye contact for a second when I said his name."

We were losing Ben.

Dr. Hitzfelder stopped writing.

"Well?" I asked.

The doctor hesitated, weighing her words. "Ben does demonstrate a number of clinical features of autism," she said carefully.

"Does that mean he's autistic?"

"Too early to say." She was warming to her subject. "It is difficult to separate autism from mental retardation, especially for a severely impaired child like Ben. In either case, it is doubtful that he will ever achieve normal developmental potential."

"What is the treatment?"

"There is no medical treatment for autism or mental retardation."

"No treatment?" I repeated. "That's it?"

Dr. Hitzfelder sighed wearily. "Some parents are experimenting with diets and other non-medical interventions," she said. "I'll give you contact information for the Dallas Autism Society should you decide to follow that route."

How could diet and "non-medical interventions" cure a brain disorder? I wanted teams of doctors, ambulance sirens, surgery, drugs.

One more question. "What about speech therapy?"

Dr. Hitzfelder leaned forward, as if to speak confidentially. "I have seen many parents like you spend a small fortune on speech therapy for children like Ben." She leaned closer.

"My advice to you is to take him home, love him, and let the school system look after him for as long as possible. Save your money for his institutionalization when he turns twenty-one."