

STEVE SILBERMAN

FOREWORD BY
OLIVER
SACKS

NEUROTRIBES

THE LEGACY OF

AUTISM

AND HOW TO THINK SMARTER

ABOUT PEOPLE WHO

THINK DIFFERENTLY

NeuroTribes



THE LEGACY OF AUTISM AND
HOW TO THINK SMARTER ABOUT PEOPLE
WHO THINK DIFFERENTLY

Steve Silberman



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Photograph of Dr Hans Asperger is courtesy of Dr Maria Asperger Felder

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Foreword

BY OLIVER SACKS

I first met Steve Silberman in 2001. He was a young journalist then, assigned to do a profile of me before the publication of my memoir *Uncle Tungsten*. He quickly gained my confidence, and I was to spend many hours talking with him, going with him to London, where I grew up, and introducing him to many of my friends and colleagues. Steve always dug deeper, asked more penetrating questions. He thought about things and made connections.

Around that time, he developed an interest in the growing “epidemic” of autism and Asperger’s syndrome. He had been intrigued when I wrote about Temple Grandin and the savant artist Stephen Wiltshire in *An Anthropologist on Mars*, and now he set out to talk to researchers, physicians and therapists, parents of autistic children, and—most importantly—autistic people themselves. I know of no one else who has spent so much time simply listening, trying to understand what it is like to be autistic. Steve’s journalistic instincts and skills led him to do a tremendous amount of research, illuminating as no one has before the history of Leo Kanner and Hans Asperger and their clinics, as well as those who followed. He has portrayed the remarkable shifting of attitudes toward autism and Asperger’s over the past few decades.

NeuroTribes is a sweeping and penetrating history of all this, presented with a rare sympathy and sensitivity. It is fascinating reading; it will change how you think of autism, and it belongs alongside the works of Temple Grandin and Clara Claiborne Park, on the bookshelf of anyone interested in autism and the workings of the human brain.

Introduction: Beyond the Geek Syndrome

There is more than one way to do it.

—LARRY WALL

On a bright May morning in 2000, I was standing on the deck of a ship churning toward Alaska’s Inside Passage with more than a hundred computer programmers. The glittering towers of Vancouver receded behind us as we slipped under the Lions Gate Bridge heading out to the Salish Sea. The occasion was the first “Geek Cruise”—an entrepreneur’s bid to replace technology conferences in lifeless convention centers with oceangoing trips to exotic destinations. I booked passage on the ship, a Holland America liner called the *Volendam*, to cover the maiden voyage for *Wired* magazine.

Of the many legendary coders on board, the uncontested geek star was Larry Wall, creator of Perl, one of the first and most widely used open-source programming languages in the world. Thousands of websites we rely on daily—including Amazon, Craigslist, and the Internet Movie Database—would never have gotten off the ground without Perl, the beloved “Swiss Army chainsaw” of harried systems administrators everywhere.

To an unusual and colorful extent, the language is an expression of the

mind of its author, a boyishly handsome former linguist with a Yosemite Sam mustache. Sections of the code open with epigrams from Larry's favorite literary trilogy, *The Lord of the Rings*, such as "a fair jaw-cracker dwarf-language must be." All sorts of goofy backronyms have been invented to explain the name (including "Pathologically Eclectic Rubbish Lister"), but Larry says that he derived it from the parable of the "pearl of great price" in the Gospel of Matthew. He told me that he wanted the code to be like Jesus in its own humble way: "Free, life-changing, and available to everyone." One often-used command is called *bless*.

But the secret of Perl's versatility is that it's also an expression of the minds of Larry's far-flung network of collaborators: the global community of Perl "hackers." The code is designed to encourage programmers to develop their own style and everyone is invited to help improve it; the official motto of this community is "There is more than one way to do it."

In this way, the culture of Perl has become a thriving digital meritocracy in which ideas are judged on their usefulness and originality rather than on personal charisma or clout. These values of flexibility, democracy, and openness have enabled the code to become ubiquitous—the "duct tape that holds the Internet together," as Perl hackers say. As the *Volendam* steered into open water, I watched with admiration as my fellow passengers pulled Ethernet cables, routers, and other networking paraphernalia out of their bags to upgrade the ship's communication systems. Instead of dozing in chaise longues by the pool, my nerdy shipmates were eager to figure out how things work and help make them work better. By midweek, they persuaded the captain to give them a tour of the engine room.

Each evening as our ship climbed toward the Arctic Circle, Larry made a dramatic entrance to the ship's dining hall on the arm of his wife, Gloria, sporting a ruffled shirt and neon tuxedo. He wore a different color tuxedo each night, in a retina-scorching array of lime, orange, sky blue, and mustard made possible by a going-out-of-business sale in his hometown. Belying the stereotype of hard-core coders as dull and awkward conversationalists, Larry and my other companions at the Wizards' Table displayed a striking gift for puns, wordplay, and teasing banter. One night, the topic

of conversation was theoretical physics; the next, it was the gliding tones of Cantonese opera, followed by thoughts on why so many coders and mathematicians are also chess players and musicians. The tireless curiosity of these middle-aged wizards gave them an endearingly youthful quality, as if they'd found ways of turning teenage quests for arcane knowledge into rewarding careers. On weekends, they coded recreationally, spinning off side projects that lay the foundations of new technologies and startups.

After a few days on the ship, I came to feel that my fellow passengers were not just a group of IT experts who happened to use the same tools. They were more like a tribe of digital natives with their own history, rituals, ethics, forms of play, and oral lore. While the central focus of their lives was the work they did in solitude, they clearly enjoyed being with others who are on the same frequency. They were a convivial society of loners.

Their medieval predecessors might have spent their days copying manuscripts, keeping musical instruments in tune, weaving, or trying to transmute base metals into gold. Their equivalents in the mid-twentieth century aimed telescopes at the stars, built radios from mail-order kits, or blew up beakers in the garage. In the past forty years, some members of this tribe have migrated from the margins of society to the mainstream and currently work at companies with names like Facebook, Apple, and Google. Along the way, they have refashioned pop culture in their own image; now it's cool to be obsessed with dinosaurs, periodic tables, and *Doctor Who*—at any age. The kids formerly ridiculed as nerds and brainiacs have grown up to become the architects of our future.

WHEN THE *VOLENDAM* ARRIVED in Glacier Bay, at the midpoint of our journey, we drifted through a natural cathedral of ice with the engines switched off. The thunder of glaciers calving a few hundred yards away ricocheted across the deck. At three a.m., the sun barely dipped toward the horizon before rising again.

Just before the ship arrived back in Vancouver, I asked Larry if I could do a follow-up interview at his home in Silicon Valley. "That's fine," he

said, “but I should tell you, my wife and I have an autistic daughter.” I took note of his remark but didn’t think much about it. Everything I knew about autism I had learned from *Rain Man*, the 1988 film in which Dustin Hoffman played a savant named Raymond Babbitt who could memorize phone books and count toothpicks at a glance. He was certainly a memorable character, but the chances of meeting such a person in real life seemed slim. As far as I knew, autism was a rare and exotic neurological disorder, and savants like Raymond were even rarer than that.

Larry was genial and forthcoming during our interview as he explained how Perl was born as a top secret project at the National Security Agency. His boss asked him to design a software tool for configuring two sets of computers remotely, one on the East Coast and one on the West. But Larry—who once wrote that the three great virtues of programmers are their laziness, impatience, and hubris—was loath to spend a month coding a widget that could be used for only a single task. Instead, he crafted Perl and slipped a tape containing the source code into his pocket before walking out the door.

As I chatted with Larry about his illustrious invention, a bulb lit up on the wall behind us. He had replaced the chime on his clothes dryer with an unobtrusive bulb because the little *ding!* at the end of each cycle disconcerted him. Such tinkering seemed par for the course for a man whose code made it possible for a Perl hacker named Bruce Winter to automate all the devices in his house and have his e-mail read to him over the phone—in 1998. It didn’t occur to me until much later that Larry’s keen sensitivity to sound might provide a link between his daughter’s condition and the tribe of industrious hermits who invented the modern digital world.

A few months later, I started working on a profile of one of the most highly regarded female technologists in Silicon Valley, an entrepreneur named Judy Estrin. As a graduate student at Stanford in the 1970s, she helped Vint Cerf develop the TCP/IP protocols that form the backbone of the Internet. Judy went on to a successful career, launching startups in the male-dominated tech industry. To fill out Judy’s personal story, I reached out to her brother-in-law Marnin Kligfeld, and asked him if I could inter-

view him at home. “Sure,” he said, “but just so you know, we have an autistic daughter.”

That certainly seemed like an odd coincidence—*two* technically accomplished families in the Valley whose children had a rare neurological disorder? The next day, I was telling a friend at a neighborhood café about this curious synchronicity. Suddenly, a trim, dark-haired young woman at the next table blurted out, “I’m a special-education teacher. Do you realize what’s going on? There is an epidemic of autism in Silicon Valley. *Something terrible is happening to our children.*”

Her words were chilling. Could they be true?

I STARTED READING every news story about autism I could find and downloading journal articles by the score. It soon became clear that the mysterious rise in diagnoses was not restricted to Silicon Valley. The same thing was happening all over the world.

To put the rising numbers in context, I familiarized myself with the basic time line of autism history, learning the story of how this baffling condition was first discovered in 1943 by a child psychiatrist named Leo Kanner, who noticed that eleven of his young patients seemed to inhabit private worlds, ignoring the people around them. They could amuse themselves for hours with little rituals like spinning pot lids on the floor, but they were panicked by the smallest changes in their environments, such as a chair or favorite toy being moved from its usual place without their knowledge. Some of these children were unable to speak, while others only repeated things they heard said around them or spoke of themselves detachedly in the third person. Claiming that their condition differed “markedly and uniquely” from anything previously reported in the clinical literature, Kanner named their condition *autism*—from the Greek word for self, *autos*—because they seemed happiest in isolation.

Then a year later, in an apparent synchronicity, a Viennese clinician named Hans Asperger discovered four young patients of his own who seemed strangely out of touch with other people, including their own

parents. Unlike Kanner's young patients in Baltimore, these children spoke in elaborate flowery sentences while displaying precocious abilities in science and math. Asperger affectionately dubbed them his "little professors." He also called their condition autism, though it's still a matter of dispute if what he saw in his clinic was the same syndrome that Kanner described.

For decades, estimates of the prevalence of autism had remained stable at just four or five children in ten thousand. But that number had started to snowball in the 1980s and 1990s, raising the frightening possibility that a generation of children was in the grips of an epidemic of unknown origin. After telling my editor about the frightening thing that the teacher in the café said about what was happening in Silicon Valley—the heart of *Wired's* tech-savvy readership—I got permission to pursue this intriguing lead.

My research was facilitated by the fact that our apartment in San Francisco is located just down the hill from the University of California, which boasts one of the best medical libraries in the country. I became a regular browser in the stacks, poring through articles on epidemiology, pediatrics, psychology, genetics, toxicology, and other relevant subjects. Meanwhile, my shelves at home filled up with books like Clara Claiborne Park's *The Siege*, Oliver Sacks's *An Anthropologist on Mars*, and Temple Grandin's *Thinking in Pictures*. Each offered a view of the diverse world of autism from a unique vantage point.

The Siege, published in 1967, was the first book-length account of raising an autistic child by a loving and devoted parent. In a dark age when psychiatrists falsely blamed "refrigerator mothers" for causing their children's autism by providing them with inadequate nurturing, Park offered a candid portrait of life with her young daughter Jessy (called Elly in the book), who would sit by herself for hours, sifting sand through her fingers. With the meticulous eye of an explorer mapping uncharted territory, Park chronicled each small thing that Jessy learned to do in her first years, usually with great effort—only to apparently unlearn it shortly thereafter.

Lying in bed in the leisurely mornings the summer she was two, I listened to her pronounce her name. “El-ly,” she said. “El-ly”—laughing, chuckling, over and over again. The sounds, even the consonants, were exquisitely clear. I’m glad I got the chance to hear her. For a month or so she said it. Then she ceased completely. It was two years at least until she spoke her name again.

Sacks’s books examined autism from the point of view of a compassionate clinician, embodying the tradition of astute observers like Jean-Martin Charcot, the founder of modern neurology, and Alexander Luria, who wrote case histories of his patients so full of insight into the human condition that they read like novels. In nuanced portraits of autistic people like artist Stephen Wiltshire and industrial designer Temple Grandin, Sacks cast light on the challenges that they face in their day-to-day lives while paying tribute to the ways they bring the strengths of their atypical minds to their work. “No two people with autism are the same: its precise form or expression is different in every case,” he wrote. “Moreover, there may be a most intricate (and potentially creative) interaction between the autistic traits and the other qualities of the individual. So, while a single glance may suffice for clinical diagnosis, if we hope to understand the autistic individual, nothing less than a total biography will do.”

Thinking in Pictures was such a biography written from the inside. Grandin, who didn’t learn to speak until she was four, was initially misdiagnosed with brain damage—a common occurrence in the days when autism was still widely unknown even among medical professionals. Encouraged by her mother, Eustacia Cutler, and a supportive high school science teacher named Bill Carlock, Grandin developed her instinctive kinship with animals into a set of practical skills that enabled her to succeed in the demanding job of designing facilities for the livestock industry. Instead of the usual inspirational fable about an extraordinary person “triumphing” over a tragic medical condition, *Thinking in Pictures* was the story of how Grandin had come to regard her autism as both a disability and a gift—as “different, not less.”

Then my real reporting began. I interviewed an eleven-year-old boy named Nick who told me that he was building an imaginary universe on his computer. Chubby, rosy-cheeked, and precociously articulate, he informed me that he had already mapped out his first planet: an anvil-shaped world called Denthaim that was home to gnomes, gods, and a three-gendered race called the *kiman*. As he told me about the civilization he was creating on his desktop, he gazed up at the ceiling, humming fragments of a melody over and over. The music of his speech was pitched high, alternately poetic and pedantic, as if the soul of an Oxford don had been awkwardly reincarnated in the body of a boy. “I’m thinking of making magic a form of quantum physics, but I haven’t decided yet, actually,” he said. I liked him immediately.

But Nick’s mother broke down in tears as she told me that he didn’t have a single friend his own age. She recalled one terrible day when his classmates bribed him to wear a ridiculous outfit to school. Because autistic people struggle to make sense of social signals in real time, Nick didn’t realize that his schoolmates were setting him up for humiliation. I wondered what would become of this bright, imaginative, trusting boy as he got older and his peers became obsessed with social status and dating.

Other parents shared the ingenious strategies they developed to help their children learn to cope with a world full of unavoidable changes and surprises. A family event like a first trip on an airplane required months of careful planning and preparation. Marnin told me about the steps that he and his wife, Margo, an internist in the Bay Area, took to help their daughter Leah feel comfortable on her first visit to a new dentist. “We took pictures of the dentist’s office and the staff, and drove her past the office several times,” he said. “Our dentist scheduled us for the end of the day, when there were no other patients, and set goals with us. The goal of the first session was to have my daughter sit in the chair. The second session was so she could rehearse the steps involved in treatment without actually doing them. The dentist gave all of his equipment special names for her. Throughout this process, we used a large mirror so she could see exactly what was being done, and to ensure that there were no surprises.”

Like many parents, Marnin and Margo had become amateur autism researchers themselves, devoting hours of their precious alone time each week to poring through the latest studies and evaluating therapies that might be of help to Leah. I learned that it was not unusual for parents whose finances were already strained by the cost of behavioral interventions to have to walk away from careers they loved to effectively become case managers for their children, fielding teams of behavioral therapists while going into battle with school boards, regional centers, and insurance companies to ensure that their children got the education and services they deserve.

One of the hardest things about having a child with autism, parents told me, was struggling to maintain hope in the face of dire predictions from doctors, school administrators, and other professionals who were supposed to be on their side. When Leah was diagnosed, an autism specialist told Marnin, “There is very little difference between your daughter and an animal. We have no idea what she will be able to do in the future.” (At twenty-five, Leah is a bright, engaging, and affectionate young woman who remembers the names of every teacher and fellow student in her classes—going all the way back to preschool—and sings along with her favorite songs in perfect pitch.) In some ways, things hadn’t changed much since the era when Clara Claiborne Park and Eustacia Cutler were told to put their daughters in institutions and move on with their lives.

TO GET TO THE BOTTOM of what was happening in Silicon Valley, I asked Ron Huff of the California Department of Developmental Services to isolate the data from the agency’s regional centers in Santa Clara County from the data in other areas of the state. He confirmed that there was a disproportionately high demand for autism services in the cradle of the technology industry.

By the time I wrote my article, the notion that high-tech hot spots like Silicon Valley and Route 128 outside Boston were havens for brilliant, socially awkward programmers and engineers was becoming a cliché in popular culture. It was a familiar joke in the industry that many hard-core

coders in IT strongholds like Intel, Adobe, and Silicon Graphics—coming to work early, leaving late, sucking down Big Gulps in their cubicles—were residing somewhere in Asperger’s domain. Kathryn Stewart, director of the Orion Academy, a high school for autistic kids in Moraga, California, said that she called Asperger’s syndrome “the engineers’ disorder.” In his popular novel *Microserfs*, Douglas Coupland quipped, “I think all tech people are slightly autistic.”

One possible explanation for a surge of autism in tech-centric communities like the Valley, UCLA neurogeneticist Dan Geschwind suggested to me, was that the culture of these places had opened up social possibilities for men and women on the spectrum that had never before existed in history. A speech-language pathologist named Michelle Garcia Winner told me that many parents in her practice became aware of their own autistic traits only in the wake of their child’s diagnosis. Temple Grandin observed in *Thinking in Pictures*, “Marriages work out best when two people with autism marry or when a person marries a handicapped or eccentric spouse . . . They are attracted because their intellects work on a similar wavelength.”

Attraction between people with similar genetic traits is called assortative mating. In 1997, cognitive psychologist Simon Baron-Cohen found that the fathers and grandfathers of children with autism were more likely to be engineers. Could assortative mating between men and women carrying the genes for autism be responsible for the rising number of diagnoses in the Valley?

My story exploring that hypothesis, “The Geek Syndrome,” was published in the December issue of *Wired* in 2001. The world was still reeling from the horror of the attacks on the World Trade Center and the Pentagon on September 11, but e-mail started pouring into my inbox even before the magazine officially hit the newsstands. I heard from parents who said that the article helped them feel less isolated from other parents facing the same challenges with their own children; from clinicians who saw the same dynamic at work in their own high-tech communities; and from readers who

had been struggling in social situations for most of their lives without knowing why. This flood of responses was both inspiring and humbling.

I have a twelve-year-old son. He takes accelerated math and science courses. His hobby is memorizing facts and figures about civil and military aircraft dating back to WWI. He's always had a fascination with clocks and watches. As you may have guessed, he has Asperger's syndrome. I've always asked myself, "Why is my son the way he is?" No one has been able to give me a possible answer until I read your article. You see, my husband is an engineer. After reading your article, it felt like the pieces were falling into place . . .

|||||

Your article sheds light on my original computer mentor. He could play four games of chess simultaneously and best all four opponents. He always knows what the total cost of the grocery shopping will be, including sales tax, before he enters the checkout line. But his son has trouble making eye contact . . .

|||||

When I was five years old, I was taking my electronic toys apart to see how they worked. (I also attempted to put them back together, with mixed results.) I have always been a voracious reader. I was reading college-level physics books bought at garage sales in the second grade. I used to annoy my father to no end wanting to build scale models of nuclear reactors, submarines, trains, anything you could think of. I have only had very small groups of close friends. I always considered that odd but never knew how to go about correcting it. Quite frankly, I find most people quite annoying and illogical—probably another common Asperger trait. :)



It is so important that the general public and the hiring companies understand this group of people. Many will fall through the cracks due to their “odd” behaviors. Many have so much to contribute if given the chance.

Thankfully I received only a few e-mails like this one:

Like many people, I’m starting to get fed up with the multiplication of psychological disorders such as attention deficit disorder and Asperger’s syndrome. In the old days, if you didn’t pay attention in class, you got whacked, and that usually did the trick for many youngsters.

I also got a call from a supervisor at Microsoft who told me, “All of my top debuggers have Asperger syndrome. They can hold hundreds of lines of code in their head as a visual image. They look for the flaws in the pattern, and that’s where the bugs are.”

At a conference a few months after my article came out, the grandmother of a young girl asked me to sign a copy of my article that had been photocopied so many times that I could barely make out the text.

Years passed, and I still got e-mail about “The Geek Syndrome” nearly every week. As time went on, though, I became convinced that by focusing on the dynamics of autism in one highly specialized community, I had missed a larger and more important story.

“THE ULTIMATE HACK FOR a team of Silicon Valley programmers,” I wrote in 2001, “may turn out to be cracking the genetic code that makes them so good at what they do.” The first decade of the new century was a time of hope for many families, as parents told me they felt optimistic that science was on the verge of finally unraveling the mystery of their chil-

dren's condition. At the same time, nearly every public discussion of autism was dominated by a rancorous debate about vaccines, based on the controversial findings of a gastroenterologist in England named Andrew Wakefield who claimed to have uncovered a potential link between the measles, mumps, and rubella vaccine (commonly known as the MMR) and a form of regression that he dubbed "autistic enterocolitis."

Parents seeking advice about raising their newly diagnosed children wandered into a minefield of conflicting information about the safety of routine childhood inoculations and the potential role of heavy metals like mercury (contained in trace amounts in vaccine preservatives like thimerosal) in contributing to their children's developmental delays. As fears of a vast conspiracy between Big Pharma and corrupt government officials to cover up the effects of a global wave of vaccine injury circulated on the newly emerging Internet, vaccination uptake rates worldwide began to fall, raising the specter of a resurgence of plagues like pertussis that formerly killed tens of thousands of children a year. The official explanation for the soaring prevalence estimates was that the diagnostic criteria for autism had been gradually broadened over the years. But if that was the case, why were the criteria so inappropriately narrow in the first place? How could a formerly rare and obscure syndrome that was allegedly rooted in genetics suddenly seem to be everywhere at once?

Driven by the public outcry about the rising numbers, autism research—long neglected by funding agencies like the National Institutes of Health (NIH) precisely because the condition was believed to be so rare—was on the threshold of a golden age. Between 2000 and 2011, NIH grants in the field climbed each year by an average of \$51 million, including a \$1 billion boost in 2006 from the Combating Autism Act. Private funding groups like the Simons Foundation also pitched in, pushing the total investment in autism research to its highest levels in history. In 2011, Autism Speaks, the largest autism fund-raising organization in the world, announced a \$50 million team effort with the Beijing Genomics Institute to map the whole genomes of ten thousand individuals from families with two or more autistic children. The organization's vice president of scientific affairs, Andy

Shih, promised that the project would generate “a transformative level of information.”

By the end of the decade, it was clear that the scientists had done just what they had been paid to do. Molecular biologists had identified more than a thousand candidate genes and hundreds of *de novo* mutations associated with autism. They had also come to a greater understanding of epigenetics, the science of factors that mediate interactions between genes and the environment. The list of suspected environmental triggers for autism seemed to grow longer every day, encompassing dozens of chemicals in common use, prompting *Forbes* science writer Emily Willingham, the mother of an autistic son, to write a blog post with the headline, “This Just In . . . Being Alive Linked to Autism.” Yet for families like Willingham’s, the long-promised transformative moment that would improve the quality of their children’s lives somehow never arrived.

The authors of a major study published in *Nature* admitted that even the most common genetic factors brought to light in their research were found in less than 1 percent of the children in their sample. “Most individuals with autism are probably genetically quite unique,” said Stephen Scherer of the Hospital for Sick Children in Toronto. UCLA neurogeneticist Stanley Nelson added, “If you had 100 kids with autism, you could have 100 different genetic causes.” A wry saying popular in the autistic community, “If you meet one person with autism, you’ve met one person with autism,” turns out to be true even for molecular biologists.

In 2010, I spoke to one of the fathers I’d interviewed nine years earlier. He told me that he was no longer worrying about what had caused his daughter’s autism. Instead, he was concerned about her future. She was about to “age out” of the modest level of services that the state of California provided to the family. Despite years of behavioral therapy, her skills had not developed to the point where he and his wife felt confident that she would ever be able to live on her own. “The question that keeps me up at night,” he said, “is what will happen to our beloved daughter when we die?”

With the Centers for Disease Control (CDC) currently estimating that one in sixty-eight school-aged children in America are on the autism

spectrum, millions of families will be facing sleepless nights in the coming decades. Many autistic adults are not exercising the strengths of their atypical minds at companies like Apple and Google—instead, a disproportionate number are unemployed and struggling to get by on disability payments. Two decades after the passage of the Individuals with Disabilities Education Act (IDEA), parents still routinely find themselves having to sue their local school boards to obtain an appropriate classroom placement for their son or daughter. Furthermore, very little of the money raised by advocacy organizations like Autism Speaks addresses the day-to-day needs of autistic people and their families. By focusing primarily on funding searches for potential causes and risk factors, these organizations reinforce the idea that autism is a historical anomaly—a distinctive problem of modern times that could be solved by a discovery that seems perpetually just around the corner.

As the mainstream world had a long argument about vaccines, newly diagnosed adults were engaged in a very different conversation about the difficulties of navigating and surviving in a world not built for them. By sharing the stories of their lives, they discovered that many of the challenges they face daily are not “symptoms” of their autism, but hardships imposed by a society that refuses to make basic accommodations for people with cognitive disabilities as it does for people with physical disabilities such as blindness and deafness.

A seemingly simple question began to formulate in my mind: After seventy years of research on autism, why do we still seem to know so little about it?

TO FIND THE ANSWER to that question for this book, I decided to start my reporting at the very beginning, even before Kanner’s and Asperger’s allegedly independent discoveries of autism in the 1940s. By taking nothing for granted, I learned that the standard time line of autism history—its creation myth, so to speak—is fundamentally flawed in ways that render autistic people in previous generations harder to see. Until these inaccuracies in the time line are corrected, they will continue to hamper our ability

to make wise choices about the kinds of research and societal accommodations that would be most beneficial to autistic people and their families.

One of the most promising developments since the publication of “The Geek Syndrome” has been the emergence of the concept of *neurodiversity*: the notion that conditions like autism, dyslexia, and attention-deficit/hyperactivity disorder (ADHD) should be regarded as naturally occurring cognitive variations with distinctive strengths that have contributed to the evolution of technology and culture rather than mere checklists of deficits and dysfunctions. Though the spectrum model of autism and the concept of neurodiversity are widely believed to be products of our postmodern world, they turn out to be very old ideas, proposed by Hans Asperger in his first public lecture on autism in 1938.

The idea of neurodiversity has inspired the creation of a rapidly growing civil rights movement based on the simple idea that the most astute interpreters of autistic behavior are autistic people themselves rather than their parents or doctors. In 2007, a woman named Amanda (now Amelia) Baggs posted an extraordinary video to YouTube called “In My Language” that has already been viewed more than a million times after being picked up by major media outlets like CNN and the *New York Times*. At first, the camera follows Baggs—who finds using spoken language difficult but can type 120 words a minute—as she presses her face into a book, rubs her fingers across her keyboard, flaps her hands, hums to herself, and bobs a Slinky up and down. A clinician would likely say that she is exhibiting self-stimulating behavior, one of the classic signs of autism. But in the second part of the video, “A Translation,” Baggs makes clear that she is not sharing these intimate glimpses of her life as a plea for pity. Her intent is more subversive: celebrating the joy of her existence on her own terms. “My language is not about designing words or even visual symbols for people to interpret,” she explains. “It is about being in a constant conversation with every aspect of my environment, reacting physically to all parts of my surroundings. Far from being purposeless, the way that I move is an ongoing response to what is around me.” Her words are articulated by a text-to-speech program, as if a machine itself is speaking, yet few clips on YouTube offer a glimpse into a mind so profoundly humane.

Another impetus for writing this book was attending Autreat, an annual retreat organized by autistic people for autistic people, in a social environment carefully constructed to eliminate sources of sensory overload and anxiety while maximizing opportunities for people on the spectrum to simply relax, enjoy being themselves, and make connections with one another. My conversations at Autreat—some mediated by keyboards or other devices for augmenting communication—taught me more about the day-to-day realities of being autistic than reading a hundred case histories would. They also offered me the chance to be in the neurological minority for the first time in my life, which illuminated some of the challenges that autistic people face in a society not built for them, while disabusing me of pernicious stereotypes such as the idea that autistic people lack humor and creative imagination. After just four days in autismland, the mainstream world seemed like a constant sensory assault.

The notion that the cure for the most disabling aspects of autism will never be found in a pill, but in supportive communities, is one that parents have been coming to on their own for generations. In her last book, *Exiting Nirvana*, Clara Claiborne Park described how her neighbors helped her daughter build a life of happiness and fulfillment in Williamstown, Massachusetts, where Jessy still lives now, years after her mother's death. At fifty-five, she continues to work in the mailroom at Williams College while painting luminous, meticulously precise images of the world as she sees it, as she has done since her high school art teacher encouraged her to take up a brush forty years ago.

“That society has opened up a place for Jessy is what, more than anything else, has made it possible for her to live in, and even contribute to, the community she was born in,” Park wrote in 2001. “I can write these words with a faith in a future I’ll never see.”

Steve Silberman
San Francisco
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Praise for *NeuroTribes*

‘*NeuroTribes* is a sweeping and penetrating history, presented with a rare sympathy and sensitivity. It is fascinating reading; it will change how you think of autism, and it belongs, alongside the works of Temple Grandin and Clara Claiborne Park, on the bookshelf of anyone interested in autism and the workings of the human brain.’ —From the foreword by **Oliver Sacks**, author of *An Anthropologist on Mars* and *Awakenings*

‘In this genuine page-turner, Steve Silberman reveals the untold history of autism. Highly recommended for anyone with an interest in autism or Asperger’s, or simply a fascination in what makes us tick.’ —**Benison O’Reilly**, co-author of *The Australian Autism Handbook*

‘The monks who inscribed beautiful manuscripts during the Middle Ages, Cavendish an 18th century scientist who explained electricity, and many of the geeks in Silicon Valley are all on the autism spectrum. Silberman reviews the history of autism treatments from horrible blaming of parents to the modern positive neurodiversity movement. Essential reading for anyone interested in psychology.’ —**Temple Grandin**, author of *Thinking in Pictures* and *The Autistic Brain*

‘This gripping and heroic tale is a brilliant addition to the history of autism.’ —**Uta Frith**, Emeritus Professor of Cognitive Development at University College London

‘A celebration of diversity . . . a truly wonderful vision of autism and humanity.’ —**Nicole Rogerson**, CEO Autism Awareness Australia

‘A fascinating and thoroughly informative account of the history of autism: a must read for parents, and students and practitioners across education, medicine, psychology and therapies.’ —**Sylvia Rodger** AM, Professor, Health and Rehabilitation Sciences, University of Queensland

‘*NeuroTribes* is remarkable. Silberman has done something unique: he’s taken the dense and detailed history of autism and turned the story into a genuine page-turner.’ —**John Elder Robison**, Neurodiversity Scholar in Residence at The College of William & Mary and author of *Look Me in the Eye*