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BOOKS

SEEING THE SPECTRUM

By Steven Shapin

January 17, 2016



The world is unpredictable and disorderly. Sometimes your train is late; sometimes it rains when it's not supposed to; the drugstore doesn't have the brand of dental floss you like. Boundaries are violated and rules are ignored. The green spinach on your plate touches the white chicken, and someone has bought your boxer shorts from J. C. Penney instead of from Kmart. People are hard to figure out. Sometimes they promise and don't deliver; it's not clear whether the expression on a face is a smile or a sneer, or, if it is a smile, what it's about. People say things that they don't mean literally: they tell jokes and they use ironic expressions. Other people's minds are a foreign country in which we're guests, tourists, or strangers, unsure where we are and what's expected of us.

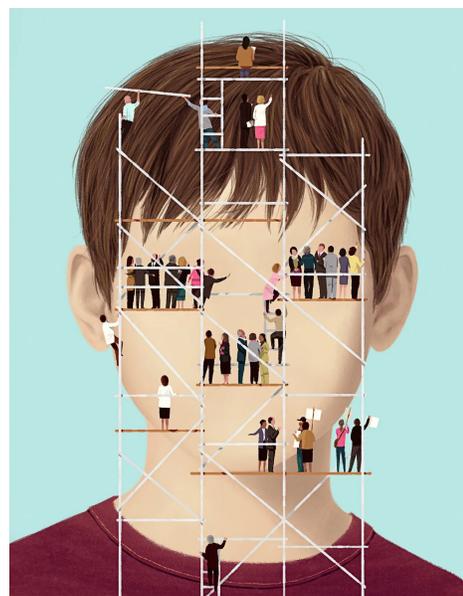


Illustration by Leo Espinosa

Some people accept all this as the way things are in an imperfect world, and they get on with life as best they can. Others find these unpredictabilities intolerable. To cope, they construct physical and mental neighborhoods where things are more regular and better arranged. Repetition reassures, whether it's to do with your environment, your speech, or your bodily movements. People want these sorts of order with different degrees of necessity, secure them with different kinds of success, and, when they don't succeed, react to failure with different degrees of despair and

disengagement.

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The world has always been unpredictable and disorderly, and some people have always found its ways unbearable. But there hasn't always been autism—or its related categories, Asperger's syndrome and (the current official term) autism-spectrum disorder. Autism was discovered, and given its identity as a discrete pathological condition, by two physicians working independently of each other during the Second World War. One was Leo Kanner, an Austrian émigré at Johns Hopkins; the other was Hans Asperger, who was working in Nazi-occupied Vienna and whose findings were little known in the Anglophone world until the early nineteen-eighties.

The discovery of autism carried with it the insistence that it had always been there. Retrospective diagnosis is now something of a subspecialty for both psychologists and historians, and the catalogue of famous figures who have been placed on the spectrum now includes Newton, Mozart, Beethoven, Jane Austen, Kant, Jefferson, Darwin, Lewis Carroll, Emily Dickinson, and Wittgenstein. But the past was presumably populated with countless uncelebrated people who might have received a diagnosis. Some of these uncommunicative social isolates were likely misdiagnosed at various times as suffering from other psychiatric disorders—"imbecility," "mental retardation," schizophrenia. (Kanner gestured toward that history, borrowing the word "autism," derived from the Greek for "self," from a sort of social isolation then attributed to schizophrenia.) Sometimes they were treated with hideous cruelty, and sometimes with surprising indulgence. Others lived their lives outside historical systems of medical diagnosis and management, and were probably just considered "eccentric"—one of the accepted ways of being normally abnormal.

As a result of Kanner's and Asperger's findings, many people were transferred from one psychiatric category to another. In the early part of the twentieth century, children who would now be diagnosed as autistic were often dumped in mental institutions. Parents were routinely counselled to forget about their afflicted children—whose symptoms typically became clear at around two years of age—and to move on with their lives. Kanner's new category came as welcome news for parents who could not bring themselves to institutionalize their children, and who were certain that there was an intelligent, feeling person locked inside what's sometimes called "the mask of autism."

The history of how autism was discovered, how the term entered the vocabulary of psychological expertise and also of everyday speech, and how its identity has evolved has been told many times. Chloe Silverman's 2012 book, "Understanding Autism," is the most sensitive account by an academic historian, and Steve Silberman's best-selling work "NeuroTribes" (2015) is a deep history of autism, which ends up as a discussion of how we ought to think about it today. Now comes "In a Different Key: The Story of Autism," by John Donvan and Caren Zucker (Crown). The authors are journalists, and, like many writers on the subject, they have a personal interest in autism. Donvan has a severely autistic brother-in-law. Zucker's son has autism, and so does a grandson of Robert MacNeil, a former anchor of "PBS NewsHour," for which Zucker produced a series of programs on the condition. Appropriately, a major focus of the book is on autism in the family and the changing historical role of parents of autistic children. "In a Different Key" is a story about autism as it has passed through largely American institutions, shaped not only by psychiatrists and psychologists but by parents, schools, politicians, and lawyers. It shows how, in turn, the condition acquired a powerful capacity both to change those institutions and to challenge our notions of what is pathological and what is normal.

The establishment of autism as a distinct pathological condition has certainly improved the lot of countless patients and their family members, but, as Donvan and Zucker relate, the road has been far from smooth. Not long after Kanner's discovery, autism came to be seen as a developmental disorder caused by bad parenting—especially by mothers who withheld affection from their children and created kids who were incapable of affect. The villain here was another Austrian émigré, Bruno Bettelheim, who, on the strength of a doctorate in art history and supersized intellectual chutzpah, had wangled Ford Foundation funding for his research and a prominent position as a child psychologist at the University of Chicago. In an article titled "Joey, a Mechanical Boy," published in *Scientific American*, in 1959, Bettelheim put forth the idea that autism was a rational response of children who, dealing with a deficit of maternal emotion, reengineered themselves as machines. Bettelheim reckoned that a cure would come through an expertly designed systematic introduction of emotion into emotion-starved kids.

Kanner, too, veered toward blaming mothers. Though he initially judged autism to be "inborn," he is now held responsible for coining the term "refrigerator mothers" to describe Bettelheim's autism-causers. Kanner eventually recanted and returned to his original view: "Herewith I acquit you as parents," he told an audience of mothers and fathers of autistic children in 1969. By then, indications of a neurological component were accumulating: there were many families in which some children were afflicted and others were not, and there was no evidence that parents of autistic kids were colder than anyone else. Later studies showed that identical twins were more likely to share autism than were fraternal twins, which suggested a genetic basis. The search for the causes of autism has for some time increasingly belonged to the neurologists and the geneticists.

As harmful as early misconceptions were, they did promote a growing awareness of the condition. In the first few decades after Kanner's original work, few people had heard of autism or had much of an idea what it was. But, if you were watching "The Dick Cavett Show" in 1971, you might have seen Bettelheim call autism "the most severe psychotic disturbance of childhood known to man." For parents of autistic kids, awareness is desperately important. It's a searing experience to have a child who doesn't talk, who doesn't want to be touched, who self-harms, who demands a regularity and an order that parents can't supply, whose eyes are not windows to their souls but black mirrors. Public recognition is vital, both for its own sake and as a means to mobilize resources for care, support, and a possible cure. How this wide awareness was achieved is an important element of Donvan and Zucker's book. Dustin Hoffman's meticulously prepared performance in "Rain Man" (1988) almost certainly marked the cultural tipping point. After that, some people knew more and better than others, but most were aware that there was a condition called autism and had some idea of how an autistic person might behave. Since then, popular conceptions have been refined further—by the late Oliver Sacks, in his book "An Anthropologist on Mars" (1995); by Temple Grandin, the remarkable autistic animal-science professor, in "Thinking in Pictures" (1995); and by Mark Haddon, whose novel "The Curious Incident of the Dog in the Night-Time" (2003) vividly evoked how an autistic child might experience the world.

All this boosted the awareness campaigns, but it is the energy and the political savvy of parents that is central to "In a Different Key." One of the book's heroes is Ruth Sullivan. When her son was given a diagnosis of autism, in 1963, she found little in the way of recognition, support, or therapy. Moving from one state to another—she was a faculty wife—Sullivan became one of the founders of the National Society for Autistic Children, which pressed schools and state legislatures to recognize the condition and to provide resources for it. She became adept at enlisting politically powerful friends in the cause. Just a few years after she moved to West Virginia, in 1969, and began to organize there, the state became the first to mandate that public schools offer special education for autistic children.

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Parents like Sullivan, refusing to put their kids in mental institutions or to blame their own parenting for the condition, gradually formed themselves into a bewildering constellation of activist groups, with different agendas and different conceptions of what autism was. They all insisted that “something must be done,” but they diverged when it came to what that something was and how it should be carried out.

One of the first autism therapies was Applied Behavior Analysis (A.B.A.), a radical program of behavior modification which the Norwegian-American psychologist Ivar Lovaas began developing in the nineteen-sixties. After an early unsavory use of “aversives”—punishments, including the use of electric cattle prods, to discourage undesired behaviors—Lovaas and his colleagues settled on an intensive regime of bit-by-bit positive reinforcement of desirable behaviors. By 1987, Lovaas claimed to be able to restore forty-seven per cent of his patients to total normalcy—this at a time when many experts thought that a cure was impossible. Some therapists and activist groups were skeptical; others embraced A.B.A. with evangelical fervor. Regardless, the main sticking point was that A.B.A. was both intensive—requiring as many as sixty hours a week of expert attention for two to three years—and expensive. In the eighties, Donovan and Zucker report, the tab for a full, home-based, individualized A.B.A. program could be as much as fifty thousand dollars a year, and parents were taking out second mortgages to pay for it.

This is where parental lobbying of legislatures yielded real dividends. In 1990, the Individuals with Disabilities Education Act specifically mentioned autism among the conditions that all public schools were required to accommodate. If schools refused or dragged their feet, parents could sue. Schools pushed back. The bill would draw resources away from other deserving recipients, and many people suspected that A.B.A. was, as Donovan and Zucker put it, “just another fad treatment.” But some of the parents were litigious—some were lawyers—and the schools started losing dozens of what became known as “Lovaas cases.” You could say that the law was deciding what was medically effective, or you could say that the parent activists were deciding. Best to say that the law acted in response to the parents’ view of what worked.





Between the law, the activist groups, and the more optimistic therapists, the matter had been settled: the life of autistic children could be significantly improved, and cures were possible. But wherever there are doctors there are quacks. Hype and even fraud are unavoidable parts of the autism story. Practitioners of a therapy called facilitated communication (F.C.), which became popular in the nineteen-nineties, claimed that the apparent linguistic incompetence of autistic kids could be overcome, and the communicative “child within” could be released, by means of a “facilitator” who gently supported the child’s hand as it moved over a keyboard and picked out letters. “We need to realize that not being able to speak is not the same as having nothing to say,” an enthusiast argued, though skeptics warned that F.C. was “no more real than a Ouija board.” Soon, shocking allegations of sexual abuse started to emerge. Guided by a facilitator, an autistic girl in Maine spelled out that her father “FUCKS ME AND HHE FUCKS ME AND HE MAKES ME HOLD HIS PENNISS.” Both the girl and her brother (who was also suspected of abusing her) were taken into state care and placed with foster families. The parents, believing in F.C. but faced with an accusation of child rape, could now defend themselves only by calling their own daughter a liar. All the charges were dropped.

Eventually, F.C. was discredited. In a simple yet elegant experiment, designed by the speech pathologist Howard Shane, a facilitator and an autistic child were simultaneously shown pictures, with a divider between them to prevent each from seeing the picture shown to the other. The facilitator could still support the child’s hand as she picked out the word indicating what she saw. Sometimes they were shown the same picture, sometimes different ones. It was only when the facilitator and the child saw the same image that the child was able to spell out the right answer. To the extent that F.C. revealed anyone’s intentions, it was the intention—perhaps unconscious—of the facilitator, not of the autistic child.

A more recent imposture, which is still having harmful effects, is the vaccine scare that began in 1998. That year, a British gastroenterologist named Andrew Wakefield was the lead author of a paper, published in the prestigious medical journal *The Lancet*, that claimed to establish a causal link between the M.M.R. vaccine—which has been given since the early nineteen-seventies to young children to protect them from measles, mumps, and rubella—and the mental deficits of autism and the digestive disorders that often accompany it. Wakefield advanced the view that there had been an increase in the incidence of autism following the introduction of the M.M.R. vaccine, and that a mercury compound used as a preservative in the vaccine was the likely culprit. Parents eagerly embraced a scientific idea that finally identified a specific physical etiology for autism. In the U.S., an activist group of “mercury moms” was so effective that one of them got herself appointed to the federal autism policymaking body. The fact that the scientific and medical

establishments were united in reassuring the public about M.M.R. didn't matter—activists just took it as proof of a conspiracy. Yet Wakefield really was a fraudster: he had an undeclared interest in an alternative vaccine, and he had manipulated the data. *The Lancet* retracted the paper; its editor said that it was “utterly false.” The British General Medical Council called Wakefield “dishonest,” and he was removed from the medical register. The greatest damage was done to the children whose parents fearfully refused to have them vaccinated. Immunization rates dropped and measles cases, some of them fatal, proliferated.

Toward the end of the last century, an increase in the incidence of autism—by one estimate, one out of every eighty-eight children in the U.S. is affected—prompted talk of an autism “epidemic.” But, as is often the case, it is hard to tell if we are looking at an increase in incidence or in diagnosis. The first serious attempt to assess the prevalence of autism took place in Britain, in the nineteen-sixties. Researchers soon ran up against radically different definitions, produced by different authorities. In order to find out what percentage of the population was afflicted, you had to decide what autism actually was. Experts disagreed—not just about what to call the condition but also about its diagnostic criteria. A British child psychiatrist wrote, “It is by no means clear that all these authors are talking about the same condition.”

In the mid-sixties, a psychologist working at London's Maudsley Hospital cobbled together a checklist of twenty-two diagnostic signs. He sent questionnaires to schools and hospitals in the London area, and then directly observed the children who he decided had met enough of the criteria to merit further investigation. He found that there was a range, with some children showing high levels of impairment and others less. He divided the sample by drawing what he admitted was an “arbitrary” line through the array, and produced the first estimate of a “prevalence rate”: 4.5 per ten thousand of the “age-appropriate” people in London, or roughly one in twenty-two hundred. The finding proved both influential and controversial, but ultimately more important was the very difficulty of establishing a rate at all. The British psychiatrist Lorna Wing (also the parent of an autistic child) fixed on the “near-misses”—those children who met some diagnostic criteria but not enough to be designated autistic. Through the nineteen-eighties, Wing was drawn to a notion of autism not as a fixed entity but as a “continuum,” with some kids “right up to the borderline of normality,” and she eventually settled on the term “spectrum” to describe the array. This was the context in which Asperger's wartime paper, “Autistic Psychopathy in Childhood,” finally attracted serious attention in the English-speaking world. Wing's husband, who happened to speak German, translated it for her, and she published an account of what she called Asperger's syndrome.

Unlike Kanner's population, Asperger's children had good linguistic abilities and some had remarkable cognitive skills in areas such as mathematics. For Wing, Asperger's was not a separate disorder; it occupied a point on the autism spectrum. Her ambition was not purely theoretical: as an activist, her intention was to enlarge the population of children receiving a diagnosis of autism, and thereby to secure support for the greatest possible number of people. (Some years ago, a child psychiatrist at the N.I.H. was quoted as saying, "I'll call a kid a zebra if that will get him the services I think he needs.")

The expansion of diagnostic criteria inevitably made definitions of what autism was even more diffuse. The best place to track this is the *DSM*, the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*, which, since 1952, has provided official definitions of all psychiatric conditions. Autism didn't appear in the *DSM* until 1980, and with each edition its definition and the criteria for diagnosis have changed. It first appeared as "Infantile Autism"; it was subsequently redesignated "Autistic Disorder"; and now it comes under the heading "Autism Spectrum Disorder" (A.S.D.). Asperger's was added as a distinct condition within the spectrum in 1994, but has now disappeared, having been merged into A.S.D. The *DSM* not only defines the condition; it makes it institutionally consequential. Beginning in the nineteen-eighties, school districts used the *DSM* standards to determine whether children were eligible for services.

There is now general agreement that autism is a condition rooted in neurological and chemical processes and that there is a strong genetic component. However, the search for specific causes continues and it's unlikely that any single candidate will ever account for every case on the currently accepted spectrum. Nor is there a cure. If you are "on the spectrum," you may never feel that you are like other people, but with therapy you may learn to seem so, and that can count for much. Plenty of autistic adults live independently, but many cannot. Indeed, the capacity for independent living is an important factor in whether an individual is held to be "high functioning" or "low functioning"—a distinction that exists in the vernacular but is no longer part of the official psychiatric literature.

There are obvious ways in which the history of autism can be seen as progressive: the quality of life for many people receiving a spectrum diagnosis has undoubtedly improved. Yet this same history has come under attack from proponents of so-called medicalization theory. This set of views, loosely linked to the work of Michel Foucault, criticizes the modern tendency to recategorize human behaviors as medical pathologies demanding expert diagnosis and care. For some writers and activists, medicalization is just a power grab, and its arch-villains are a greedy pharmaceutical industry and an arrogant psychiatric profession, which together have pushed pills for states of mind about which nothing can be done, or should be done, and which rightly belong to the realm of individual moral responsibility. The disease categories developed by modern

psychiatry and psychology—such things as social anxiety disorder and mixed anxiety-depressive disorder—have been among the most popular targets for the critics of medicalization, as is autism.

And so, more than seventy years after the work of Kanner and Asperger, vigorous dissent has emerged over whether autism is a medical phenomenon at all, whether what was discovered was a disease, a disability, or another mode of normalcy. The most forceful dissent comes from many of those who have themselves received an A.S.D. diagnosis and who have become eligible for the recognition and the support that flow from being on the spectrum. Some activist groups reject the very idea of therapeutic treatment, claiming that there is nothing pathological to be treated. They say that, in the same way that we've learned to celebrate racial, ethnic, and sexual diversity, we should be celebrating "neurodiversity." The journalist Harvey Blume, writing in *The Atlantic*, has even claimed, "Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general." Donvan and Zucker take a generally disengaged position on this matter, blandly approving the acknowledgment of "the dignity of individuals who are different by virtue of fitting the label in some way."

The neurodiversity activists have learned a trick or two from history, even if they'd like to see much of it undone or rebranded as a history of medical hubris. One is to attach spectrum tendencies to increasingly valued "normal" social roles, and they've seen the utility, as well as the fun, of contesting ownership of the word "normal" and coming up with a sharply sardonic account of the disease symptoms of "neurotypicals" (NTs)—"preoccupation with social concerns, delusions of superiority, and obsession with conformity." Neurodiversity activists confront parents of severely autistic children in exchanges that are as full of pain as they are rich in irony. Activists insist that there should be no more talk of pathology and no more programs for treatment and cure; the parents are outraged that activists who place themselves on the high-functioning end of the spectrum have no real understanding of the serious disabilities afflicting children at the other end, and are undermining the gains in treatment and recognition achieved over so many years.

Meanwhile, "autism," "Asperger's," and "the spectrum" no longer belong solely to the psychiatric profession, and have drifted into lay usage. If we all have spectrum tendencies and Aspie moments, then the labels no longer have much use as medical categories. The spectrum has been stretched to the breaking point, and autism now sits astride a social fault line between what's considered normal and what's pathological, what's an eccentricity and what's in need of expert therapy. These matters belong to our moral life, and we can't reasonably expect them to be settled by medical science or clinical evidence or even the law. ♦

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