


TEMPLE
GRANDIN
AND RICHARD PANEK



THE
AUTISTIC
BRAIN

EXPLORING THE STRENGTH OF
A DIFFERENT KIND OF MIND

'An extraordinary source of inspiration' *TIME*

Contents

Cover

About the Book

About the Authors

Also by Temple Grandin and Richard Panek

Title Page

Prologue

The Autistic Brain

1. The Meanings of Autism

2. Lighting Up the Autistic Brain

3. Sequencing the Autistic Brain

4. Hiding and Seeking

Rethinking the Autistic Brain

5. Looking Past the Labels

6. Knowing Your Own Strengths

7. Rethinking in Pictures

8. From the Margins to the Mainstream

Appendix: The AQ Test

Notes

Index

Acknowledgments

Copyright

About the Book

Temple Grandin is one of the most accomplished adults with autism in the world. Her parents were told she should be institutionalised but, today, she is a university professor and bestselling author, rightly celebrated for transforming attitudes towards autism.

In this groundbreaking book, Grandin reports from the forefront of autism science, including remarkable discoveries about the brain and the latest genetic research. In her view we need to treat autism symptom by symptom, rather than with an umbrella diagnosis.

Most exciting of all, Grandin argues that raising autistic children needs to be less about focussing on weaknesses, and more about fostering their unique contributions. Autism can be turned into a gift, not a disability.

About the Authors

Temple Grandin is a professor of animal science at Colorado State University and the author of several bestselling books, which have sold over one million copies. These include *The Way I See It* and *Animals in Translation*. The award-winning film based on her life starred Claire Danes.

Richard Panek is the prize-winning author of *The 4 Percent Universe* and the recipient of a Guggenheim fellowship in science writing. His books have been translated into 16 languages.

Also by Temple Grandin

Animals Make Us Human: creating the best life for animals (with Catherine Johnson)

Animals in Translation: using the mysteries of autism to decode animal behavior (with Catherine Johnson)

Emergence: labeled autistic (with Margaret M. Scariano)

Thinking in Pictures: and other reports from my life with autism

Genetics and the Behavior of Domestic Animals (editor)

Livestock Handling and Transport (editor)

Developing Talents (with Kate Duffy)

Humane Livestock Handling (with Mark Deesing)

The Way I See It: a personal look at autism and asperger's

Improving Animal Welfare: a practical approach

Different... Not Less: inspiring stories of achievement and successful employment from adults with autism, asperger's, and ADHD (editor)

Also by Temple Grandin and Sean Barron

Unwritten Rules of Social Relationships

Also by Richard Panek

The 4 Percent Universe: dark matter, dark energy, and the race to discover the rest of reality

*The Invisible Century: Einstein, Freud, and the search for
hidden universes*

*Seeing and Believing: how the telescope opened our eyes
and minds to the heavens*

Waterloo Diamonds

TEMPLE
GRANDIN
AND RICHARD PANEK

THE
AUTISTIC
BRAIN

EXPLORING THE STRENGTH OF
A DIFFERENT KIND OF MIND



RIDER

LONDON • SYDNEY • AUCKLAND • JOHANNESBURG

Prologue

IN THIS BOOK I will be your guide on a tour of the autistic brain. I am in the unique position to speak about both my experiences with autism and the insights I have gained from undergoing numerous brain scans over the decades, always with the latest technology. In the late 1980s, shortly after MRI became available, I jumped at the opportunity to travel on my first “journey to the center of my brain.” MRI machines were rarities in those days, and seeing the detailed anatomy of my brain was awesome. Since then, every time a new scanning method becomes available, I am the first in line to try it out. My many brain scans have provided possible explanations for my childhood speech delay, panic attacks, and facial-recognition difficulties.

Autism and other developmental disorders still have to be diagnosed with a clumsy system of behavioral profiling provided in a book called the *DSM*, which is short for *Diagnostic and Statistical Manual of Mental Disorders*. Unlike a diagnosis for strep throat, the diagnostic criteria for autism have changed with each new edition of the *DSM*. I warn parents, teachers, and therapists to avoid getting locked into the labels. They are not precise. I beg you: Do not allow a child or an adult to become defined by a *DSM* label.

The genetics of autism is an exceedingly complex quagmire. Many small variations in the genetic code that control brain development are involved. A genetic variation that is found in one autistic child will be absent in another autistic child. I will review the latest in genetics.

Researchers have done hundreds of studies on autistics' problems with social communication and facial recognition, but they have neglected sensory issues. Sensory oversensitivity is totally debilitating for some people and mild in others. Sensory problems may make it impossible for some individuals on the autism spectrum to participate in normal family activities, much less get jobs. This is why my top priorities for autism research are accurate diagnoses and improved treatments for sensory problems.

Autism, depression, and other disorders are on a continuum ranging from normal to abnormal. Too much of a trait causes severe disability, but a little bit can provide an advantage. If all genetic brain disorders were eliminated, people might be happier, but there would be a terrible price.

When I wrote *Thinking in Pictures*, in 1995, I mistakenly thought that everybody on the autism spectrum was a photorealistic visual thinker like me. When I started interviewing other people about how they recalled information, I realized I was wrong. I theorized that there were three types of specialized thinking, and I was ecstatic when I found several research studies that verified my thesis. Understanding what kind of thinker you are can help you respect your limitations and, just as important, take advantage of your strengths.

The landscape I was born into sixty-five years ago was a very different place from where we are now. We've gone from institutionalizing children with severe autism to trying to provide them with the most fulfilling lives possible — and, as you will read in [chapter 8](#), finding meaningful work for those who are able. This book will show you every step of my journey.

Part I

THE AUTISTIC BRAIN

1 The Meanings of Autism

I WAS FORTUNATE to have been born in 1947. If I had been born ten years later, my life as a person with autism would have been a lot different. In 1947, the diagnosis of autism was only four years old. Almost nobody knew what it meant. When Mother noticed in me the symptoms that we would now label autistic — destructive behavior, inability to speak, a sensitivity to physical contact, a fixation on spinning objects, and so on — she did what made sense to her. She took me to a neurologist.

Bronson Crothers had served as the director of the neurology service at Boston Children's Hospital since its founding, in 1920. The first thing Dr. Crothers did in my case was administer an electroencephalogram, or EEG, to make sure I didn't have petit mal epilepsy. Then he tested my hearing to make sure I wasn't deaf. "Well, she certainly is an odd little girl," he told Mother. Then when I began to verbalize a little, Dr. Crothers modified his evaluation: "She's an odd little girl, but she'll learn how to talk." The diagnosis: brain damage.

He referred us to a speech therapist who ran a small school in the basement of her house. I suppose you could say the other kids there were brain damaged too; they suffered from Down syndrome and other disorders. Even though I was not deaf, I had difficulty hearing consonants, such as the *c* in *cup*. When grownups talked fast, I heard only the vowel sounds, so I thought they had their own special language. But by speaking slowly, the speech therapist helped me to hear the hard consonant sounds, and when I said *cup* with a *c*, she praised me — which is just what a behavioral therapist would do today.

At the same time, Mother hired a nanny who played constant turn-taking games with my sister and me. The nanny's approach was also similar to the one that behavioral therapists use today. She made sure that every game the three of us played was a turn-taking game. During meals, I was taught table manners, and I was not allowed to twirl my fork around over my head. The only time I could revert back to autism was for one hour after lunch. The rest of the day, I had to live in a nonrocking, nontwirling world.

Mother did heroic work. In fact, she discovered on her own the standard treatment that therapists use today. Therapists might disagree about the benefits of a particular aspect of this therapy versus a particular aspect of that therapy. But the core principle of every program — including the one that was used with me, Miss Reynolds's Basement Speech-Therapy School Plus Nanny — is to engage with the kid one-on-one for hours every day, twenty to forty hours per week.

The work Mother did, however, was based on the initial diagnosis of brain damage. Just a decade later, a doctor would probably have reached a completely different diagnosis. After examining me, the doctor would have told Mother, "It's a psychological problem — it's all in her mind." And then sent me to an institution.

While I've written extensively about autism, I've never really written about how the diagnosis itself is reached. Unlike meningitis or lung cancer or strep throat, autism can't be diagnosed in the laboratory — though researchers are trying to develop methods to do so, as we'll see later in this book. Instead, as with many psychiatric syndromes, such as depression and obsessive-compulsive disorder, autism is identified by observing and evaluating behaviors. Those observations and evaluations are subjective, and the behaviors vary from person to person. The diagnosis can be

confusing, and it can be vague. It has changed over the years, and it continues to change.

The diagnosis of autism dates back to 1943, when Leo Kanner, a physician at Johns Hopkins University and a pioneer in child psychiatry, proposed it in a paper. A few years earlier, he had received a letter from a worried father named Oliver Triplett Jr., a lawyer in Forest, Mississippi.¹ Over the course of thirty-three pages, Triplett described in detail the first five years of his son Donald's life. Donald, he wrote, didn't show signs of wanting to be with his mother, Mary. He could be "perfectly oblivious" to everyone else around him too. He had frequent tantrums, often didn't respond to his name, found spinning objects endlessly fascinating. Yet for all his developmental problems, Donald also exhibited unusual talents. He had memorized the Twenty-Third Psalm ("The Lord is my shepherd ...") by the age of two. He could recite twenty-five questions and answers from the Presbyterian catechism verbatim. He loved saying the letters of the alphabet backward. He had perfect pitch.

Mary and Oliver brought their son from Mississippi to Baltimore to meet Kanner. Over the next few years, Kanner began to identify in other children traits similar to Donald's. Was there a pattern? he wondered. Were these children all suffering from the same syndrome? In 1943, Kanner published a paper, "Autistic Disturbances of Affective Contact," in the journal *Nervous Child*. The paper presented the case histories of eleven children who, Kanner felt, shared a set of symptoms — ones that we would today recognize as consistent with autism: the need for solitude; the need for sameness. To be alone in a world that never varied.

From the start, medical professionals didn't know what to do with autism. Was the source of these behaviors biological, or was it psychological? Were these behaviors

what these children had brought into the world? Or were they what the world had instilled in them? Was autism a product of nature or nurture?

Kanner himself leaned toward the biological explanation of autism, at least at first. In that 1943 paper, he noted that autistic behaviors seemed to be present at an early age.² In the final paragraph, he wrote, “We must, then, assume that these children have come into the world with innate inability to form the usual, biologically provided affective contact with people, just as other children come into the world with innate physical or intellectual handicaps [*sic*].”

One aspect of his observations, however, puzzled him. “It is not easy to evaluate the fact that all of our patients have come of highly intelligent parents. This much is certain, that there is a great deal of obsessiveness in the family background” — no doubt thinking of Oliver Triplett’s thirty-three-page letter. “The very detailed diaries and reports and the frequent remembrance, after several years, that the children had learned to recite twenty-five questions and answers of the Presbyterian Catechism, to sing thirty-seven nursery songs, or to discriminate between eighteen symphonies, furnish a telling illustration of parental obsessiveness.

“One other fact stands out prominently,” Kanner continued. “In the whole group, there are very few really warmhearted fathers and mothers. For the most part, the parents, grandparents, and collaterals are persons strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genuine interest in people.”

These observations of Kanner’s are not as damning about parents as they might sound. At this early point in his study of autism, Kanner wasn’t necessarily suggesting cause and effect. He wasn’t arguing that when the parents behaved *this way*, they caused their children to behave *that way*. Instead, he was noting similarities between the parents and

his patients. The parents and their child, after all, belonged to the same gene pool. The behaviors of both generations could be due to the same biological hiccup.

In a 1949 follow-up paper, however, Kanner shifted his attention from the biological to the psychological. The paper was ten and a half pages long; Kanner spent five and a half of those pages on the behavior of the parents. Eleven years later, in an interview in *Time*, he said that autistic children often were the offspring of parents “just happening to defrost enough to produce a child.”³ And since Kanner was the first and foremost expert on the subject of autism, his attitude shaped how the medical profession thought about the subject for at least a quarter of a century.

Late in life, Kanner maintained that he “was misquoted often as having said that ‘it is all the parents’ fault.’” He also complained that critics overlooked his original preference for a biological explanation. And he himself was no fan of Sigmund Freud; in a book he published in 1941, he wrote, “If you want to go on worshipping the Great God Unconscious and His cocksure interpreters, there is nothing to keep you from it.”

But Kanner was also a product of his time, and his most productive years coincided with the rise of psychoanalytic thought in the United States. When Kanner looked at the effects of autism, he might have originally told himself that they were possibly biological in nature, but he nonetheless wound up seeking a psychological cause. And when he speculated on what villains might have inflicted the psychic injury, he rounded up psychoanalysis’s usual suspects: the parents (especially Mom).

Kanner’s reasoning was probably complicated by the fact that the behavior of kids who are the product of poor parenting can look like the behavior of kids with autism. Autistic kids can seem rude when they’re actually just

oblivious to social cues. They might throw tantrums. They won't sit still, won't share their toys, won't stop interrupting adult conversations. If you've never studied the behaviors of children with autism, you could easily conclude that these kids' parents are the problem, not the kids themselves.

But where Kanner went horribly wrong was in his assumption that because poor parenting can lead to bad behavior, all bad behavior must therefore be the result of poor parenting. He assumed that a three-year-old's ability to name all the U.S. presidents and vice presidents couldn't *not* be caused by outside intervention. He assumed that a child's psychically isolated or physically destructive behavior couldn't *not* be caused by parents who were emotionally distant.

In fact, Kanner had cause and effect backward. The child wasn't behaving in a psychically isolated or physically destructive manner because the parents were emotionally distant. Instead, the parents were emotionally distant because the child was behaving in a psychically isolated or physically destructive manner. My mother is a case in point. She has written that when I wouldn't return her hugs, she thought, *If Temple doesn't want me, I'll keep my distance.*⁴ The problem, though, wasn't that I didn't want her. It was that the sensory overload of a hug shorted out my nervous system. (Of course, nobody back then understood about sensory oversensitivity. I'll talk about this topic in [chapter 4](#).)

Kanner's backward logic found its greatest champion in Bruno Bettelheim, the influential director of the University of Chicago's Orthogenic School for disturbed children. In 1967 he published *The Empty Fortress: Infantile Autism and the Birth of the Self*, a book that popularized Kanner's notion of the refrigerator mother. Like Kanner, Bettelheim thought that autism was probably biological in nature. And

like Kanner, his thinking on autism was nonetheless grounded in psychoanalytic principles. Bettelheim argued that an autistic child was not biologically *predetermined* to manifest the symptoms. Instead, the child was biologically *predisposed* toward those symptoms. The autism was latent — until poor parenting came along and breathed life into it.^{fn1}

If Mother hadn't taken me to a neurologist, she might eventually have been vulnerable to the refrigerator-mother guilt trip. She was only nineteen when I was born, and I was her first child. Like many young first-time mothers who find themselves confronting a child's "bad" behavior, Mother initially assumed she must be doing something wrong. Dr. Crothers, however, relieved that anxiety. When I was in second or third grade, Mother did get the full Kanner treatment from a doctor who informed her that the cause of my behavior was a psychic injury and that until I could identify it, I was doomed to inhabit my own little world of isolation.

But the problem wasn't a psychic injury, and Mother knew it. The psychoanalytic approach to a disorder was to find the cause of a behavior and try to remove it. Mother assumed she couldn't do anything about the cause of my behavior, so her approach was to concentrate on dealing with the behavior itself. In this respect, Mother was ahead of her time. It would take child psychiatry decades to catch up with her.

People often ask me, "When did you really know you were autistic?" As if there were one defining moment in my life, a before-and-after revelation. But the conception of autism in the early 1950s didn't work that way. Like me, child psychiatry back then was still young. The words *autism* and *autistic* barely appeared in the American Psychiatric Association's initial attempt to standardize psychiatric diagnoses, in the first edition of the *Diagnostic and*

Statistical Manual of Mental Disorders (DSM), published in 1952, when I was five. The few times those words did appear, they were used to describe symptoms of a separate diagnosis, schizophrenia. For instance, under the heading Schizophrenic Reaction, Childhood Type, there was a reference to “psychotic reactions in children, manifesting primarily autism” — without further explanation of what autism itself was.

Mother remembers one of the early doctors in my life making a passing reference to “autistic tendencies.” But I myself didn’t actually hear the word *autistic* applied to me until I was about twelve or thirteen; I remember thinking, *Oh, it’s me that’s different*. Even then, though, I still wouldn’t have been able to tell you exactly what autistic behaviors were. I still wouldn’t have been able to tell you why I had such trouble making friends.

As late in life as my early thirties, when I was pursuing my doctorate at the University of Illinois at Urbana-Champaign, I could still overlook the role that autism played in my life. One of the requirements was a statistics course, and I was hopeless. I asked if I could take the course with a tutor instead of in a classroom, and I was told that in order to get permission to do that, I would have to undergo a “psychoeducational assessment.” On December 17 and 22, 1982, I met with a psychologist and took several standard tests.⁵ Today, when I dig that report out of a file and reread it, the scores practically scream out at me, *The person who took these tests is autistic*.

I performed at the second-grade level on a subtest that required me to identify a word that was spoken at the rate of one syllable per second. I also scored at the second-grade level on a subtest that required me to understand sentences where arbitrary symbols replaced regular nouns — for instance, a flag symbol meant “horse.”

Well, yeah, I thought, of course I did poorly on these tests. They required me to keep a series of recently learned concepts in my head. A flag means “horse,” a triangle means “boat,” a square means “church.” Wait — what does a flag mean again? Or the syllable three seconds ago was *mod*, the syllable two seconds ago was *er*, the syllable one second ago was *a*, and now the new syllable is *tion*. Hold on — what was that first syllable again? My success depended on my short-term memory, and (as is the case with many autistic people, I would later learn) my short-term memory is bad. So what else was new?

At the other extreme, I scored well at antonyms and synonyms because I could associate the test words with pictures in my mind. If the examining psychologist said “Stop” to me, I saw a stop sign. If he said “Go,” I saw a green light. But not just any stop sign, and not just any green light. I saw a specific stop sign and a specific green light from my past. I saw a whole bunch of them. I even recalled a stop-and-go light from a Mexican customs station, a red light that turned green if the officers decided not to search your bags — and I’d seen that light more than ten years earlier.

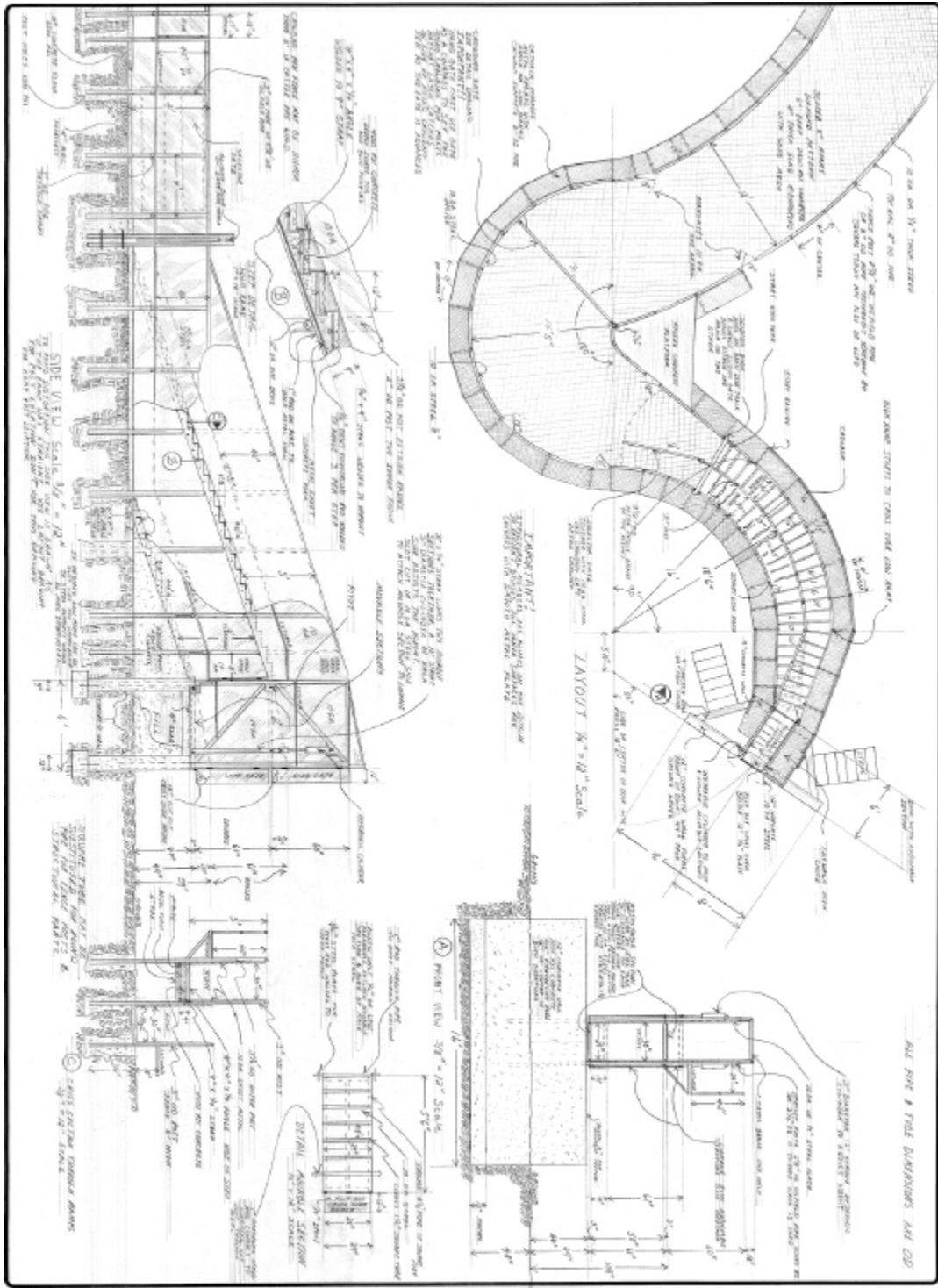
Again: So what? As far as I could tell, everybody thought in pictures. I just happened to be better at it than most people, something I already knew. By this point in my life, I had been making architectural drawings for several years. I’d already had the experience of completing a drawing and looking at it and thinking, *I can’t believe I did this!* What I hadn’t thought was *I can do this kind of drawing because I have walked around the yard, committed every detail of it to memory, stored the images in my brain like a computer, then retrieved the appropriate images at will. I can do this kind of drawing because I’m a person with autism.* Just as I didn’t think, *I scored in the sixth percentile in reasoning and in the ninety-fifth percentile in verbal ability because I’m a person with autism.* And the reason I didn’t think

these thoughts was that “person with autism” was a category that was only then beginning to come into existence.

Of course, the word *autism* had been part of the psychiatric lexicon since 1943, so the idea of people having autism had been around at least as long. But the definition was loose, to say the least. Unless someone pointed out an oddity in my behavior, I simply didn't go around thinking of what I was doing in terms of my being a person with autism. And I doubt that I was the exception in this regard.

The second edition of the *Diagnostic and Statistical Manual of Mental Disorders* was published in 1968, and, unlike its 1952 predecessor, it contained not one mention of autism. As best as I can tell, the word *autistic* did appear twice, but again, as in the *DSM-I*, it was there only to describe symptoms of schizophrenia and not in connection with a diagnosis of its own. “Autistic, atypical, and withdrawn behavior,” read one reference; “autistic thinking,” read another.

In the 1970s, however, the profession of psychiatry went through a complete reversal in its way of thinking. Instead of looking for causes in the old psychoanalytic way, psychiatrists began focusing on effects. Instead of regarding the precise diagnosis as a matter of secondary concern, the profession began trying to classify symptoms in a rigid and orderly and uniform fashion. The time had come, psychiatrists decided, for psychiatry to become a science.



1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

AUSTRALIAN DOUBLE DECK LOADING RAMP
 GRANDIN LIVESTOCK HANDLING SYSTEMS
 SUITE 3, 1701 SILVER ST.
 VERBANA, ILL. 61081 USA 815/389-4425

11	12	13	14	15	16	17	18	19	20
----	----	----	----	----	----	----	----	----	----

Being able to “download” images from my visits to cattle-handling facilities in order to create this blueprint for a double-deck loading ramp didn’t seem

This reversal happened for a few reasons.⁶ In 1973 David Rosenhan, a Stanford psychiatrist, published a paper recounting how he and several colleagues had posed as schizophrenics and fooled psychiatrists so thoroughly that the psychiatrists actually institutionalized them, keeping them in mental hospitals against their will. How scientifically credible can a medical specialization be if its practitioners can so easily make incorrect diagnoses — misdiagnoses, moreover, with potentially tragic consequences?

Another reason for the reversal was sociological. In 1972, the gay rights movement protested the *DSM's* classification of homosexuality as a mental illness — as something that needed to be cured. They won that battle, raising the question of just how trustworthy *any* diagnosis in the *DSM* was.

But probably the greatest factor in changing the focus of psychiatry from causes to effects, from a search for a psychic injury to the cataloging of symptoms, was the rise of medication. Psychiatrists found that they didn't need to seek out causes for symptoms to treat patients. They could ease a patient's suffering just by treating the effects.

In order to treat the effects, however, they had to know what medications matched what ailments, which meant that they had to know what the ailments were, which meant that they were going to have to identify the ailments in a specific and consistent manner.

One result of this more rigorous approach was that the APA task force finally asked the obvious question: What is this autistic behavior that is a symptom of schizophrenia? In order to answer the question, the task force had to isolate autistic behavior from the other symptoms suggesting schizophrenia (delusions, hallucinations, and so on). But in order to describe autistic behavior, they had to

describe autistic *behaviors* — in other words, have a checklist of symptoms. And a checklist of symptoms that didn't overlap with the other symptoms of schizophrenia suggested the possibility of a separate diagnosis: infantile autism, or Kanner's syndrome.

The *DSM-III*, published in 1980, listed infantile autism in a larger category called pervasive developmental disorders (PDD). To receive a diagnosis of infantile autism, a patient had to meet six criteria. One of the them was an absence of symptoms suggesting schizophrenia. The others were:

- Onset before 30 months
- Pervasive lack of responsiveness to other people
- Gross deficits in language development
- If speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, pronominal reversal
- Bizarre responses to various aspects of the environment, e.g., resistance to change, peculiar interests in or attachments to animate or inanimate objects

But that description was hardly precise. In fact, it became something of a moving target, changing with each new edition of the *DSM* as the APA attempted to nail down precisely what autism was — a common enough trajectory in psychiatric diagnoses that depend on observations of behavior. In 1987, the revision to the *DSM-III*, the *DSM-III-R*, not only changed the name of the diagnosis (from infantile autism to autistic disorder) but expanded the number of diagnostic criteria from six to sixteen, divided them into three categories, and specified that a subject needed to exhibit at least eight symptoms total, with at least two coming from category A, one from category B, and one from category C. This Chinese-menu sensibility led to higher rates of diagnosis. A 1996 study compared the

DSM-III and *DSM-III-R* criteria as they applied to a sample of 194 preschoolers “with salient social impairment.”⁷ According to the *DSM-III*, 51 percent of the children were autistic. According to the *DSM-III-R*, 91 percent of *the same children* were autistic.

The 1987 edition of the *DSM* also expanded an earlier diagnosis in the PDD category, atypical pervasive developmental disorder, into a catchall diagnosis that covered cases in which the symptoms of autism were milder or in which most but not all symptoms were present: pervasive developmental disorder not otherwise specified (PDD-NOS). The *DSM-IV*, which was published in 1994, further complicated the definition of autism by adding a new diagnosis altogether: Asperger syndrome.

In 1981, the British psychiatrist and physician Lorna Wing had introduced to English-language audiences the work Austrian pediatrician Hans Asperger had done in 1943 and 1944.⁸ Even as Kanner was trying to define autism, Asperger was identifying a class of children who shared several distinct behaviors: “a lack of empathy, little ability to form friendships, one-sided conversations, intense absorption in a special interest, and clumsy movements.” He also noted that these children could talk endlessly about their favorite subjects; he dubbed them “little professors.” Asperger called the syndrome “autistic psychopathy,” but Wing felt that because of the unfortunate associations that had attached to the word *psychopathy* over the years, “the neutral term Asperger syndrome is to be preferred.”

This addition to the *DSM* is important in two ways. The obvious one is that it gave Asperger’s formal recognition by the psychiatric authorities. But when taken together with the PDD-NOS and its autistic-symptoms-but-not-quite-autism diagnostic criteria, Asperger’s was also meaningful in how it changed the way we think about autism in general.

The inclusion of autism in the *DSM-III* in 1980 was significant for formalizing autism as a diagnosis, while the creation of PDD-NOS in the *DSM-III-R* in 1987 and the inclusion of Asperger's in the *DSM-IV* in 1994 were significant for reframing autism as a spectrum. Asperger syndrome wasn't technically a form of autism, according to the *DSM-IV*; it was one of five disorders listed as a PDD, alongside autism disorder, PDD-NOS, Rett syndrome, and childhood disintegrative disorder. But it quickly gained a reputation as "high-functioning autism," and by the time the revision of the *DSM-IV* appeared in 2000, diagnosticians were using *pervasive developmental disorder* and *autism spectrum disorder* (or ASD) interchangeably. At one end of the spectrum, you might find the severely disabled. At the other end, you might encounter an Einstein or a Steve Jobs.

That range, though, is part of the problem. It was almost certainly no coincidence that just as the idea of an autism spectrum was entering the mainstream of both popular and medical thinking, so was the concept of an autism "epidemic." If the medical community is given a new diagnosis to assign to a range of familiar behaviors, then of course the incidence of that diagnosis is going to go up.

Did it? If so, wouldn't we see a drop in some other diagnoses — the diagnoses that these new cases of autism or Asperger's would have previously received?

Yes — and in fact, we do see evidence of that drop. In the United Kingdom, some of the symptoms of autism would have previously been identified as symptoms of speech/language disorders, and those diagnoses in the 1990s did go down in roughly the same proportion that autism diagnoses went up. In the United States, those same symptoms would have received a diagnosis such as mental retardation, and, again, the number of those diagnoses went down as autism diagnoses went up. A Columbia University study of 7,003 children in California diagnosed

with autism between 1992 and 2005 found that 631, or approximately one in eleven, had had their diagnoses changed from mental retardation to autism.⁹ When the researchers factored in those subjects who hadn't previously been diagnosed with anything, they found that the proportion of children who would have been diagnosed with mental retardation using older diagnostic criteria but who were now diagnosed with autism was *one in four*.

A later Columbia University analysis of the same sample population found that children living near autistic children had a greater chance of receiving the diagnosis themselves, possibly because their parents were more familiar with the symptoms.¹⁰ Is the kid talking on schedule? Does the child stiffen up and not want to be held? Can she play patty-cake right? Does he make eye contact? Not only were children who would once have been diagnosed with mental retardation now more likely to receive a diagnosis of autism, but more children were likely to receive a diagnosis of autism, period — enough to account for 16 percent of the increase in prevalence among that sample population.

I can see the effects of a heightened awareness of autism and Asperger's just by looking at the audiences who come to my talks. When I started giving lectures on autism in the 1980s, most of the audience members with autism were on the severe, nonverbal end of the spectrum. And those people do still show up. But far more common now are kids who are extremely shy and have sweaty hands, and I think, *Okay, they're sort of like me — on the spectrum but at the high-functioning end*. Would their parents have thought to have them tested for autism in the 1980s? Probably not. And then there are the geeky, nerdy kids I call Steve Jobs Juniors. I think back on kids I went to school with who were just like these kids but who didn't get a label. Now they would.

I recently spoke at a school for autistic students, to a hundred little kids sitting on the floor in a gymnasium. They weren't fidgeting much, so they were probably on the high-functioning end of the autism spectrum. But you never know. They looked to me just like the kids I had seen several months earlier at the Minnesota State Science Fair. Did the kids at the autism school get the diagnosis just so they could go to a school where they'd be left alone to do what they did best — science, history, whatever their fixations might be? Then again, did some of the kids at the science fair fit the diagnosis for autism or Asperger's?

The number of diagnoses of autism spectrum disorder almost certainly went up dramatically for another reason¹¹, one that hasn't gotten as much attention as it should: a typographical error. Shocking but true. In the *DSM-IV*, the description of pervasive developmental disorder not otherwise specified that was supposed to appear in print was "a severe and pervasive impairment in social interaction *and* in verbal or nonverbal communication skills" (emphasis added). What actually appeared, however, was "a severe and pervasive impairment of reciprocal social interaction *or* verbal and nonverbal communication skills" (emphasis added). Instead of needing to meet *both* criteria to merit the diagnosis of PDD-NOS, a patient needed to meet *either*.

We can't know how many doctors made an incorrect diagnosis of PDD-NOS based on this error. The language was corrected in 2000, in the *DSM-IV-TR*. Even so, we can't know how many doctors continued to make the incorrect diagnosis, if only because by then the incorrect diagnosis had become the standard diagnosis.

Put all these factors together — the loosened standards, the addition of Asperger's and PDD-NOS and ASD, the heightened awareness, the typographical error — and I would be surprised if there *hadn't* been an "epidemic."