

INTRODUCTION

The maps of Asperger Syndrome have been drawn and redrawn over fifty years, but the borders remain maddeningly vague.

The disorder, sometimes called a form of “high-functioning autism,” was first pointed out by, then named after the Viennese pediatrician Hans Asperger in 1944. The phrase “high-functioning” is meant to distinguish Asperger’s from classical autism—the latter condition is typically characterized by much more obvious deficits in speech, intelligence, and development. Asperger’s sufferers, in contrast, appear largely normal. Or almost normal. They can function intellectually at a high level and can, more or less, blend into the general population. Nonetheless, whether Asperger’s is or is not on a continuum with autism (the issue is not resolved), it most assuredly can be what the distinguished researcher and writer Uta Frith has called “a devastating handicap.” In the United States, the syndrome was only made “official” with its entry into the fourth edition of the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) in 1994.

What, then, is a reasonable definition? Perhaps the most workable one I’ve encountered is from researchers and writers at the Yale Child Study Center:

Paucity of empathy; naive, inappropriate, one-sided social interaction, little ability to form friendships and consequent social isolation; pedantic and monotonic speech; poor nonverbal communication; intense absorption in circumscribed topics such as the weather, facts about TV stations, railway timetables or maps, which are learned by rote fashion and reflect poor understanding, conveying the impression of eccentricity; and clumsy and ill-coordinated movements and odd posture.

The most workable, but still unsatisfying. Through these clumsy and ill-coordinated clouds of psychiatric prose, one glimpses a unique condition. Asperger people are not idiot savants like Rain Man or head-banging mental patients rocking in their chairs and screaming;

they do not conform in any way to the clichés roused in us by the word “autistic.” Instead, the cognitive disability appears to be purely, or almost purely, social. Essentially, for reasons that are completely unknown, Asperger people cannot read the human face or its emotions. They cannot learn social rules, nuances, or metaphors. Often brilliant intellectually, they cannot read the simplest social cue or hint: instead, rigid obsessions, often numerical, dominate their inner life. And they live with the affliction for the whole of their lives.



It’s a curious fact that a great many people in the U.S. who have Asperger Syndrome are self-diagnosed. As the number of people designated as being on the autistic spectrum rises, I have the feeling that thousands of people like myself are re-examining their childhoods with a certain anxiety, but not without a certain relish as well. Every tic they have ever had is now suspect, a sign of something systemic and previously concealed. A century of widespread psychology and psychologizing has made this apprehensive mind-set respectable. Eccentricity itself is less and less accepted as an innocent aberration, a potentially *fruitful* quirk of character, for the question of normality imposes itself constantly. *Did* you play the lute when you were a boy, or not? *Did* you line up your toys in rows or spin on your heels imitating a propeller for hours on end? In a culture defined by obsessive navel-gazing, we have taken to using our navels as medical crystal balls. What disorder do we have? What form of autism do we think we have, however slight and superficial? And, most importantly, which section or subsection of the *Diagnostic Manual* do we fit into?

Characteristically, people often now describe themselves as having “Aspergerish traits” without actually going so far as to call themselves autistic. Having Aspergerish traits is today one of the most fashionable self-diagnoses in America, while autism is still a dread word. For Asperger people have a reputation for cleverness, subtlety, and even for genius. Einstein is now frequently claimed as an Asperger’s genius, as are the pianist Glenn Gould and the composer Béla Bartók. In 1996, *Time* magazine even ran a piece entitled “Diagnosing Bill Gates,” in which the nabob of Microsoft was roundly defined as a classic Asperger’s type. If the richest man in the world has Asperger’s, why not

you? Asperger Syndrome is indeed, as autism researcher Uta Frith puts it, “the first plausible variant to crystallize out of the autism spectrum”—and perhaps only the first of many. But where should we place the emphasis—on “variant” or “autism”? Clearly, Asperger’s stands apart from autism in general, and it is no wonder the parents of so many brilliant middle-class Asperger boys grow abusive at the very mention of the word “autistic.” For them, Asperger’s is an asset, not what the Greeks called a fate.



For years, psychologists argued over whether the mental derailments observable in autistic children occurred because of disturbed parenting and a hostile environment, or because of in-built neurological disorders. The great psychoanalyst Bruno Bettelheim was the most noted proponent of the former idea and is accordingly reviled by parental activist groups and especially Asperger’s support cells all over America. Indeed, even so much as mention the word “Bettelheim” at conferences and seminars devoted to Asperger’s and you will immediately hear a murmur of scandalized disapproval.

In latter decades, the biological model has come to triumph in the domains of professional expertise, especially after the publication of Bernard Rimland’s work on autism in the 1960s. In fact, not only Asperger Syndrome but virtually every developmental disorder is now seen as biological and genetic in origin. As Arthur Kleinman of the Harvard Medical School has written, “Biology has cachet with psychiatrists.”

The vast and thorny ensuing debate cannot really be explored here, but it’s apposite to remember that nothing is as simple as it looks. Richard DeGrandpre, author of *Ritalin Nation*, makes this comment about Attention Deficit Disorder, another affliction that is increasingly explained in terms of biology:

More than anything, ADD represents a growing prejudice in our culture—led in large part by the powerful influence of psychiatry professionals and pharmaceutical companies—which is that personality and behavioral traits are inborn and biological.

The debate between the two camps seesaws endlessly back and forth, without any decisive outcome. People like DeGrandpre argue that ADD, for example, is largely a culturally constructed disorder, not the biological deficit so many drug-wielding psychiatrists like to claim. In other words, the speed-intoxicated culture itself induces attention-deficits (what DeGrandpre calls “pseudo- ADD”) then fails to understand its own handiwork. How else can one explain the fact that levels of ADD are 20 times higher in the drug-prescribing U.S. than in Western Europe? It comes as some surprise, moreover, to discover that there is little in the way of hard scientific proof for a biological origin of many developmental disorders. But it matters little. With their gleaming promises that whatever is biological in origin can be manipulated by medicine and technology for the better of all, materialist and determinist models of the human mind are in tune with our age. Most harried doctors might say that whatever works, works. How many suicides, they ask, have been avoided through a judicious use of Prozac? The question is grimly compelling.

A biological conception of mental disorders, though, does not necessarily guarantee sweeping promises of cures—and Hans Asperger himself never suggested that a cure for “his” condition would eventually be found. Notions that there must be a cure, at least somewhere in the future, have crept into the deepest crevices of the American psyche: the premise that the soul is chemical in nature and can consequently be altered by chemical engineers, that the problems of happiness and social adjustment can be solved mechanistically by a brave new pharmacopoeia, and that no one is doomed to disorders or even to unpredictable moods unless it be because of medical malpractice, poverty, or an intolerance to drugs.

Lawrence Diller, in a popular work on current pediatric psychiatry called *Running on Ritalin*, argues that the vague but complex notion of “personality” has been abandoned by American psychiatry in favor of a neuro-chemical vision of the individual, in which different parts of the brain determine behaviors and moods. Psychotropic drugs intervene at these sites in order to remake the troubled person—end of story. It is what Peter Kramer in *Listening to Prozac* famously dubbed “cosmetic psycho-pharmacology.” And although these cosmetic drugs have been criticized frequently in recent years, their lure remains powerful.



Doctors rarely admit how little they know about the workings of drugs like “serotonin uptake inhibitors,” while pointing pragmatically instead to the sometimes-dramatic improvements they seem to produce in, say, chronic depressives. It’s difficult to say where addiction and cure begin and end; and with children the question is even more obscure. But it is most often there, in childhood, where lifelong diagnoses are applied.

Child psychiatrists who rely heavily on prescription-writing often defend themselves by claiming that their treatments save families from uncontrollable forces in the disturbed boy or girl, which they doubtless sometimes do. But the means they employ are hardly those of an exact science, whatever the impressive-sounding vocabularies they employ. And it is precisely the vocabulary of psychiatry that is striking to me. Do we, the ignorant laymen, have any right to feel put off by it? Can we doubt the workings of treatments that seem to drag people from the edge of despair?

A recent exchange of views in the pages of *Salon* magazine between Lawrence Diller and Ross Greene, a psychologist at the Harvard Medical School, became snappish after Diller criticized Greene’s book *The Explosive Child*. The latter recommends the use of psychotropic drugs to control children’s behavior. Greene reacted angrily to Diller’s criticisms, but also drew an explicit link between Asperger’s and what he calls “non-compliant behavior.” Adopting psychiatry’s current language of behavioral management, Greene inveighed:

. . . explosive/noncompliant children lack important skills related to managing frustration and handling demands for flexibility and adaptability. The goal of intervention flowing from this conceptualization is to teach these skills. Not by cajoling, but by having adults engage the child in a process by which important problem solving and conflict resolution skills—thinking of good solutions, anticipating problems before they arise, taking others’ needs into account—are taught.

The child, in other words, is like a poorly performing junior executive. He or she has to learn “management skills,” cooperation with the team, productive negotiating strategies. In the same vein, Greene continues:

Dr. Diller also writes that *The Explosive Child* “overpathologizes” difficult children. Perhaps difficult children are more complicated than Dr. Diller is aware. Our research at Massachusetts General Hospital shows that noncompliant children almost always meet criteria for at least one other psychiatric condition, including attention deficit/hyperactivity disorder (ADHD), depression, bipolar disorder, anxiety disorders, nonverbal learning disability, language processing disorders, Tourette’s disorder and Asperger’s disorder. Our research at Mass. General also documents that the approach described in *The Explosive Child* is highly effective at reducing explosive outbursts, reducing adult-child conflict and, yes, improving a child’s compliance.

Beyond the understandable self-interest of doctors advancing their own treatments, in this case a child-control system, one has to ask here if the egg comes before the chicken. Are children really a seething mass of pathological abnormalities, or have we made them into such? Greene suggests that every child is a candidate “for at least one other psychiatric condition”; but of course they are often candidates for most or even all of them. And the goal of bringing up children presumably should be the instilling of intimacy and respect, not “compliance” and legalized drug addiction. Diller’s appeal for common sense, meanwhile, is aloofly dismissed as “unsophisticated.” But it’s an open question (as Diller himself asks it) what exactly the sophistication of the Harvard Medical School is all about. In short, profound questions in the psychiatric treatment of children remain entirely unresolved.



Some rebel pediatricians have begun to go much further in their defiance of what they see as a kind of psychiatric fundamentalism based on the *Diagnostic Manual*. Dr. Mel Levine is a Professor of Pediatrics at the University of North Carolina at Chapel Hill and the author of the recent book *A Mind at a Time*. As a developmental pediatrician working in schools, Levine has become increasingly dismayed at the way children are shoehorned into dubious categories of so-called Disorders.

“This whole thing,” he said to me, “has become a huge problem in America. And it’s not being subjected to any skeptical debate. We’re pathologizing all human behavior, and in so doing, we’re creating an institutionalized nightmare—a truly mad system in which everyone is ‘sick.’ The *Diagnostic Manual* is an absurd document, though of course

it makes the American Psychiatric Association improbable amounts of money!" I asked him about Asperger's. "I for one am strongly opposed to the whole concept of Asperger Syndrome. It's yet another label around which the psychiatric industry can spin its usual paraphernalia. As for other would-be syndromes, I treat them with a high degree of skepticism. I refuse to even use the term ADHD in my clinic—I think it's monstrous. Children cannot be crushed by these reductionist labels." He laughed bitterly, or so I thought. It could have been merely ruefully. "I've banned all the D's from my practice!"

Levine thinks that American psychiatry embodies a deeply pessimistic, gloomily simplistic view of the world. Unable to conceive of a healthy eccentricity (or a truly complex individuality), it has elaborated a vast coding system instead. Every patient is coded as soon as he or she walks in the door. The codes are quick and convenient, especially for the purposes of filling out insurance forms and getting reimbursed, but they bear little relation to the complexity of people's lives. Why not, Levine asked, code situations rather than patients—could we have a classificatory code for "going through a difficult divorce"? Of course not, it would be too troublesome. Give the depressed divorcee a "disorder" instead and a fix-it drug regimen. Even worse, according to Levine, is when children are diagnosed with disorders that contain the word pervasive. "It's like a death sentence at the age of two. But of course it gives the doctors and professionals total control over the family from then on."

Essentially, it's an interlocking system. A plethora of newly coined labels is sanctified by the *Diagnostic Manual*. And the Manual, in turn, justifies the careers of tribes of specialists (each one an expert in a single label and each one scrupulously loyal to the Manual), which, in turn, makes the job of the mental health care system more streamlined while also legitimizing a vast consumption of drugs. Everyone is happy, so to speak.

"I see this all the time. You put the child on Ritalin because he's 'difficult.' Then as he gets older the drugs wear off and you declare that he has Obsessive Compulsive Disorder. So you give him different drugs. Then those drugs wear off and you say he's bipolar depressive: a new round of drugs. And so on." But depression is a response in the individual to intricate problems that have to be faced; it's not a disease like kidney failure.

"I think," Levine sighed, "that in this country we always simplify everything to the maximum degree. So we simplify the suffering individual. We make him into a material malfunction."

I had already noticed a tendency among people with syndromes to use the verb "to be" in describing their condition. Instead of saying, "I have Attention Deficit Disorder" they'd say, "I am Attention Deficit Disorder." The disorder becomes the man. Imagine, though, someone declaring, "I am renal failure."

"Perhaps," Levine concluded, "we need to get back to a more humanist way of dealing with people. Just describe the patients as they actually are."

I thought to myself that this might be a good way to proceed in my own journey in pursuit of the enigmas of normality and its opposite. For "Asperger people" are essentially as baffling today as they were to Hans Asperger himself. "The path to understanding," Asperger wrote, "necessarily begins with the individual himself . . . it looks for parallels between an inner region and an outer one."

This is a metaphysical quest, not a biochemical one. It admits that a biological inner shape is always meshed with an outer world, a culture. The afflicted individual is not a bundle of neurological problems. He or she is a story, a kind of tale—a narrative made from the epic conflict of two hostile principles. If this is a truism to any sophisticated psychiatrist, it still needs emphasis in a culture long sold on the putative miracles of pharmaceuticals that bear an eerie resemblance to soma, the happiness-inducing drug of Aldous Huxley's *Brave New World*.

American Normal

The Hidden World of Asperger Syndrome

Osborne, L.

2002, XVI, 224 p., Hardcover

ISBN: 978-0-387-95307-6