London Review of Books

Call a kid a zebra

Daniel Smith

In a Different Key: The Story of Autism by John Donvan and Caren Zucker
Allen Lane, 670 pp, £25.00, January, ISBN 978 1 84614 566 7

NeuroTribes: The Legacy of Autism and How to Think Smarter about People Who Think Differently by Steve Silberman

As psychiatric concepts go, autism has proved uncommonly susceptible to interpretation, appropriation and expansion. And few people have done as much to influence the world’s understanding of autism as Lorna Wing, who died in 2014. For decades a member of the Institute of Psychiatry at King’s College London, Wing was a pioneering clinician, epidemiologist and researcher. Her only daughter, Susie, was autistic, and in 1962 Wing co-founded the world’s first autism advocacy organisation. In 1965 she helped open the world’s first school for autistic children (John Lennon was a major donor). She wrote the first, and still definitive, guide for parents of autistic children. But she is best remembered for the term she coined in 1981, in the journal Psychological Science: Asperger’s syndrome. As she acknowledged much later, in an essay called ‘Reflections on Opening Pandora’s Box’, the consequences far exceeded anything she’d imagined.

Asperger’s syndrome is a high-functioning variant of autism, in which the traits of the condition coexist with normal-to-high verbal skills and intelligence. Wing chose the name in homage to Hans Asperger, an Austrian paediatrician whose work in the 1930s and 1940s with a group of socially awkward, oddly precocious, rule-obsessed children – his ‘little professors’, Asperger called them – remained obscure until she and her colleagues recovered it. Until then there was almost no notion that a high-functioning variant of autism existed. Most experts considered autism to be rare, homogeneous and totally debilitating: a form of psychosis that afflicted young children, sealing them off permanently from normal, loving relations with others and the world. Autism was seen as outside the realm of regular human functioning. When Oliver Sacks read Temple Grandin’s 1986 memoir, Emergence: Labelled Autistic, he thought Grandin’s co-author, Margaret Scariano, must have written it. “The
autistic mind, it was supposed at that time, was incapable of self-understanding and understanding others and therefore of authentic introspection and retrospection,’ Sacks wrote. ‘How could an autistic person write an autobiography? It seemed a contradiction in terms.’ As late as 2001, the epidemiologist Walter Spitzer could still describe autism as ‘a terminal illness ... a dead soul in a live body’.

Wing was convinced that this monolithic notion of autism was both incorrect and, given how many people it blocked from receiving social and educational services, destructive. It wasn’t that the profound, ‘classic’ type of autism didn’t exist: her own daughter was severely disabled by her condition; she spent most of her life in a residential home, and died at the age of 49 in 2005, after her compulsion to drink excessive amounts of fluids diluted her blood and stopped her heart. But autism like Susie’s, Wing had determined, represented only a sliver of what by the late 1970s she had begun to call the ‘autism continuum’, and would later call, to far greater effect, the ‘autism spectrum’.

Wing argued that a ‘triad of impairments’ – in social interaction, social communication and social imagination – characterised all manifestations of autism. But the framework was almost infinitely flexible. Within it, a universe of autistic traits – from screaming to mutism, from an obsession with the parts of objects to switching lights on and off, from excessive formality to banging one’s head against a wall – appeared in a multitude of combinations and levels of intensity, ‘right up to the borderline of normality’. She introduced Asperger’s in order to demonstrate that autism was far more elastic than people had thought. Her goal wasn’t to enshrine yet another discrete category of disorder; so far as autism was concerned, she didn’t much believe in discrete categories: it was to promote a more inclusive, heterogeneous, humane understanding of the condition in general.

To flourish, psychiatric diagnoses need both to conform to reality and to be useful. Asperger’s quickly showed itself to be useful. The concept ‘filled a need’, as John Donvan and Caren Zucker write in In a Different Key. Donvan and Zucker are journalists at the American television network ABC; both have autistic family members. Asperger’s, they write, ‘fitted people’ whom clinicians were seeing in practices, and patients and their families found Asperger’s less frightening to talk about than autism. Where the label matched, there was little reason for a clinician not to use it.

The more clinicians used the label, the more pressure the diagnostic authorities were under to recognise it. That the clinicians and the authorities were often the same people lent momentum to the process. The first international conference on Asperger’s didn’t take place until 1988, but by then, under Wing’s guidance, the American Psychiatric Association had already changed the definition of autism in its Diagnostic and Statistical Manual, softening and expanding the checklist items and introducing a sub-threshold diagnosis, whose name,
'Pervasive Developmental Disorder – Not Otherwise Specified', sounded like psychiatric self-parody. In 1990, Wing prevailed on the World Health Organisation to include Asperger’s in its International Classification of Diseases. The APA had little choice but to follow suit. The psychiatrists in charge of the fourth edition of the *DSM*, which was published in 1994, considered proposals for 94 new diagnoses. Two made the cut. The first was Bipolar II Disorder. The second was Asperger’s.

It was at this point that Pandora’s box truly burst open. Steve Silberman, the author of *NeuroTribes*, describes *DSM-IV* as the diagnostic equivalent of Michael Jackson’s *Thriller*: an unprecedented international hit. The manual and its many tie-ins – including study guides, casebooks, videotapes and software – earned $100 million for the American Psychiatric Association. This once obscure 42-year-old psychiatric manual inserted itself, as Silberman writes, into nearly every facet of American life: ‘classrooms, courtrooms, community clinics, research labs, congressional hearings, pharma stockholders’ meetings, social service agencies and guidance counsellors’ offices’. For autism in particular, this meant that the ‘clinical infrastructure’ of the condition was transformed ‘from a channel for optional reporting of isolated cases to a network for active surveillance of the general population’. The first autism prevalence study, published by the psychologist Victor Lotter in 1964, suggested (with scrupulous social-scientific disclaimers) that the condition affected 4.5 out of every 10,000 children. In 1999 a widely disseminated report by California’s Department of Developmental Services raised that number to 60 out of every 10,000 children. In 2004, the US Centers for Disease Control and Prevention published an alert for paediatricians which claimed that autism affected one out of every 166 American children. By 2007 it had raised that number to 1 in 110. By then, of course, the figures were so high that a few dozen kids more or less hardly mattered; everyone was already in a panic.

Both of these books spend a great deal of time on the recent autism ‘epidemic’. In all likelihood, neither would have been written – or at least not published by a mainstream house – had autism not entered the public consciousness in such a spectacular and alarming way. This isn’t to say that the history of autism doesn’t hold fascinations independent of recent events. Both Silberman and Donvan and Zucker have a lot of fun describing the lives of autistic people before autism was a concept, like the 18th-century ‘natural fool’ Hugh Blair of Borgue, a Scottish laird who filled his bedroom with twigs and feathers and liked to dine with cats, whose paws he licked clean. Silberman includes a chapter about Henry Cavendish, a pathologically shy scientific polymath whose many breakthroughs include the 1766 discovery of hydrogen; ‘The way to talk to Cavendish is never to look at him,’ the astronomer Francis Wollaston was to say of him.

Both books also rightly flay the writings of Bruno Bettelheim, the mid-century psychoanalytic huckster (he called himself ‘doctor’ but had neither a medical degree nor any training in
clinical psychology) who got famous by popularising the idea that autism was caused by emotionally frigid parents, mothers in particular. The ‘refrigerator mother’ theory, as it was often known, led to the institutionalisation of thousands of autistic children. Bettelheim’s work was not only destructive, it was preposterous. In *The Empty Fortress* (1967), his bestselling book about autism, he tells the story of a young girl called Marcia, who was obsessed with the weather and for a long time could talk of nothing else. ‘People with autism can become entirely fixated by, and trapped inside, a single obsessive interest that takes over their lives,’ Donvan and Zucker write. ‘But weather had a special significance for Marcia, [Bettelheim] explained, which could only be understood when the word itself was broken into the three smaller words it contains: “We/eat/her.” Bettelheim explained that the girl’s obsession with the wind, temperature and precipitation grew out of a deep fear that her mother “intended to devour her’.’ There was a lot of this sort of nonsense in the book.

Still, what makes autism an important subject now is the question of how extensive a role the condition plays in contemporary life, and how extensive a role it ought to play. This question has to be addressed in two ways, one statistical, the other cultural and political. On the statistical front, one can make an emphatic statement: there is no autism epidemic. There never has been one. In recent years, scientists have identified a number of risk factors contributing to a rise in autism in certain populations, such as children born very prematurely. Yet overall, the increase in autism that started in the 1980s and steepened in the 1990s and 2000s has nothing to do with an increase in the actual number of autistic people. Instead, as nearly every reputable social scientist who has looked at the numbers has concluded, it has mostly to do with the use of a ‘broader autism phenotype’ – that is, with the deliberate effort to catch more people in the diagnostic net. How wide our definition of autism should be is still being debated. Some have argued that the spike in autism shows merely that we’ve got much better at identifying the condition. Donvan and Zucker describe this theory, which they neither endorse nor reject, as ‘epidemiology catching up with reality’. But the numbers certainly created the impression that autism was a bigger problem than it had been before, and it inspired more anxiety in parents than any condition since polio.

Another factor contributing to the idea of an autism epidemic was that by the late 20th century more people knew about the condition than ever before. The first English-language studies of autism were published in the 1940s by the Austrian-born child psychiatrist Leo Kanner, who gave the condition its name. His work proved influential while remaining relatively obscure. As late as the 1980s, the condition was sparsely researched. The parents of autistic children in the US and UK were increasingly well organised, but they had only modest success in stoking public awareness. This all changed in 1988, the year *Rain Man* was released. In the film, Tom Cruise plays a callow grifter who kidnaps his autistic older brother – Dustin Hoffman in full Stanislavskian splendour – and takes him on a soul-enlarging road
trip to Las Vegas. ‘In the year before the film came out,’ Silberman writes, ‘fewer than a hundred stories on autism had been published in major newspapers in the United States. The following year, that number quadrupled. It would never decline again.’

Autism had been depicted on screen before. In 1969, in his final feature film, Change of Habit, Elvis Presley played a doctor who cures an abandoned autistic girl by hugging her and saying: ‘I love you, Amanda. I love you. I love you.’ Rain Man gave the impression that autism endows people with savant-like gifts, something that’s true only in a small minority of cases. But Hoffman’s performance got a great deal right about the experiences and behaviours that typically come with autism: the need for sameness and routine, the sensitivity to loud noises, the awkward gait, the discomfort with physical intimacy, the literal-mindedness, the tendency to parrot back and repurpose phrases (‘echolalia’ is the technical term), the repetition of actions such as rocking and hand-flapping (‘stimming’). Before 1988, Donvan and Zucker write, autism was ‘a psychological novelty item’. After 1988, it was everywhere, and portrayed in reasonably accurate form. Rain Man both made autism widely recognisable and made the use of the condition in books and films an emblem of one’s interest in and compassion for the disabled. Even the Baby-Sitters Club, the American Young Adult series, got in on the action with an instalment called Kristy and the Secret of Susan. (The secret was that Susan was autistic.)

Appearing on The Oprah Winfrey Show shortly after Rain Man opened, Ruth Sullivan, the doyenne of American parent advocates, said that the movie had ‘advanced the field of autism by 25 years’. The new public fascination with autism, coupled with the rise in diagnoses, gave activist groups a long-awaited chance to secure funding for their cause and help from social services. Their goals were admirable, but they went after them recklessly. Beginning in the 1990s, Donvan and Zucker write, advocacy groups exploited the notion that there was an autism epidemic, as they saw that their appeals for funding would be more effective if tied to a ‘terrifying national crisis’. They relentlessly emphasised two statistics: ‘what the autism rate used to be and what it is right now’.

What made these efforts reckless was that the activists were better placed than anyone to know how contingent and misleading the numbers were. It had been these groups, for example, that in the early 1990s successfully lobbied Congress, under the terms of the Individuals with Disabilities Education Act, to require states to count the number of autistic children enrolled in special education programmes. The children had previously been included in different categories, such as ‘learning disabled’ or ‘other health impairments’, so the autism number now essentially shot up from zero. The activists knew this, just as they knew that there’s an enormous difference between counting the number of children receiving services for autism and counting the number of children who legitimately have the condition (‘like counting vegetarians on an airplane by adding up orders for meat-free meals’, Donvan
and Zucker write). The activists also knew that as schools grew more responsive to the needs of autistic children, more parents would be actively shopping for the diagnosis. And more doctors were complying. Both books quote Judy Rapoport, the former head of child psychiatry at the US National Institute of Mental Health, who said: ‘I’ll call a kid a zebra if it will get him the educational services I think he needs.’ But none of this tamped down the activists’ rhetoric. In 2003 Illinois reported that 5800 students were receiving services under the new autism category – an increase from five in 1993, the first year officials were required to keep track. ‘Autism Increases DRAMATICALLY,’ one group announced, and went on to calculate that the rate had gone up 101500 per cent in a decade.

The danger inherent in this kind of drumbeating is that if you tell people they’re threatened by an epidemic, they’re going to wonder what caused it. And in the absence of a clear answer, distrust and fear rush in. Which brings us to the second great villain, after Bettelheim, in the history of autism: the English gastroenterologist and ur-anti-vaccination advocate Andrew Wakefield. The General Medical Council struck him off the medical register in 2010 and his work has been discredited, but it took too many years for that to happen, and in the meantime he and his followers have caused an extraordinary amount of damage.

*

Wakefield first came on the scene in 1998, at a press conference in which he announced the results of a new study he was soon to publish in the Lancet. Given the host of scientific errors and ethical and financial improprieties for which Wakefield was later found responsible, it isn’t worth going into the details of his paper. All that mattered, then and afterwards, was the link Wakefield claimed to have found between the live measles vaccine, typically given in combination with the vaccines for mumps and rubella, and the presentation of autistic behaviours in young children. Even Wakefield admitted that this purported link, based on a mere 12 subjects, was correlative rather than causal; it fell far short of scientific proof. But he had a messianic streak and a weakness for publicity. Whenever given the chance – and he was given far too many chances – he expressed grave concerns about the safety of the MMR vaccine. It was, he liked to say, ‘a moral issue for me’.

What followed was a self-perpetuating and unusually long and garish trip through the hype cycle. Within months of Wakefield’s announcement, vaccination rates in the UK began to drop. The ample and alarmist coverage of the story in the media further decreased vaccination rates, which led to more and more extreme coverage until rates in some parts of London fell to 60 per cent – far below the level needed to prevent an epidemic. In an attempt to quell the hysteria, Tony Blair made soothing noises, but ended up making things worse when, in absurd deference to ‘family privacy’, he refused to say whether his own infant son, Leo, had received the vaccine. It would have been a farce if it hadn’t played as tragedy. By
2008, measles and mumps, diseases that vaccination had all but eradicated, were again endemic in the UK. In the meantime, Wakefield had taken his message to America, where a parallel anti-vax movement was gaining force: there, parents insisted that their children’s autism had been caused by thiomersal, an antibacterial and antifungal powder used as a vaccine preservative. Thiomersal, which contains trace amounts of mercury, has been used safely since the 1930s. No association has ever been found between the substance and autism; as a safeguard against infection, thiomersal has undoubtedly saved countless lives. Nevertheless, ignorance and paranoia carried the day. The Mercury Moms promoted unproven and often dubious alternative therapies such as chelation, a treatment developed during the First World War to remove toxic elements from the body after gas attacks. In 2005 Robert Kennedy Jr, an environmental lawyer, published an article entitled ‘Deadly Immunity’, which posited a vast conspiracy between government officials and pharmaceutical companies to cover up the link between mercury and autism. The article was found to be riddled with mistakes and elisions. Salon, one of the publications in which it appeared, later published a full retraction and pulled the article from its site. In time, the weight of scientific evidence undermined the credibility of the mercury hypothesis. In Denmark, thiomersal hadn’t been used in vaccines since 1992, yet autism diagnoses continued to increase. But the general suspicion of vaccines has been hard to kill. In 2007, the American model and television presenter Jenny McCarthy used her celebrity to reinvigorate the campaign. McCarthy told Oprah Winfrey that she had gained the expertise required to dispense advice about public health from ‘the University of Google’. The United States had declared measles eradicated in 2000. In 2014, there were 23 outbreaks of the disease. A recent study in the Journal of the American Medical Association concluded that the predominant cause of these outbreaks was ‘vaccine refusal’.

The epidemic and vaccine panics are often referred to as the Autism Wars. A better metaphor would be a custody dispute. The autism advocacy organisations, which proliferated from the 1990s, were riven by conflict. On one side were the anti-vaxxers. On the other were the ‘sceptics’. Neither stinted on vitriol. They accused each other of conspiracy, cruelty and evil. Lost in the noise were the people over whose fates they were supposedly fighting. The parents battled it out because, it was assumed, their children couldn’t do so for themselves.

This, at any rate, is the way autistic people came increasingly to judge the affair: as a paternalistic rejection of their right to self-determination. It isn’t hard to understand why they were offended. The premise of the Autism Wars was that autism was something to be eliminated. Two of the most prominent parent organisations founded in the 1990s were called Defeat Autism Now! and Cure Autism Now. This was the language of eradication, and it played well with politicians and funding agencies. In the first decade of the 21st century, Silberman reports, US federal grants for autism research grew by an average of $51 million
each year. But by far the largest portion of the money went to investigate causes and risk factors, particularly genetic risk factors. Very little went to quality-of-life improvements. If you had Asperger’s, you could be forgiven for thinking that the whole enterprise was geared to reject the very basis of your existence.

The first person to give voice to this thought was a young man called Jim Sinclair. When Temple Grandin emerged as a public figure in 1989, she presented herself as having ‘recovered’ from autism (she’s since abandoned that way of thinking). When Sinclair appeared four years later at a meeting of the Autism Society of Canada, he repudiated the very notion of recovery. Insulted by activists who treated him like Kafka’s ape – it was remarkable that he could imitate humanness so well! – and by parents who focused on their own grief at having an autistic child, Sinclair delivered a scathing manifesto entitled ‘Don’t Mourn for Us’. Autism, he declared, wasn’t ‘something a person has, or a “shell” that a person is trapped inside’:

There’s no normal child hidden behind the autism. Autism is a way of being. It is pervasive; it colours every experience, every sensation, perception, thought, emotion and encounter, every aspect of existence. It is not possible to separate the autism from the person – and if it were possible, the person you’d have left would not be the same person you started with.

‘Autism is a way of being’: the sentiment had its roots in the Deaf (the uppercase ‘D’ denoting pride) rights movement, which insists on Deafness as a distinct and valuable cultural identity, rather than a disorder of perception. Sinclair and his allies wore badges that read ‘I Survived Behaviour Modification’ and ‘I’m Not Just WEIRD, I’m AUTISTIC.’ They organised a gathering for autistic people, Autreat, at which attendees wore colour-coded badges signalling the extent to which they were open to social contact. A red badge meant: ‘Nobody should try to interact with me.’ Green meant: ‘I want to interact but am having trouble initiating, so please initiate an interaction with me.’

As a result of the prominence given to the Autism Wars, it took a long time for the autism-rights message to move from the fringes to the centre. But it has done so, in no small part because of Silberman himself. In 2001 he published a widely read article in Wired called ‘The Geek Syndrome’. It explored the possibility that autism-related disorders were flourishing in Silicon Valley due to ‘assortative mating’: men and women with autistic traits were forming relationships and having children with increasing frequency. The article’s tone was largely celebratory. ‘The Valley is a self-selecting community where passionately bright people migrate from all over the world to make smart machines work smarter,’ Silberman wrote. And: ‘Clumsy and easily overwhelmed in the physical world, autistic minds soar in the virtual
realms of mathematics, symbols and code.’ That there’s a connection between autism and technical proficiency wasn’t a new idea. As Silberman acknowledged, Hans Asperger himself had gone further: ‘It seems that for success in science and art, a dash of autism is essential,’ he wrote. But Silberman’s piece made clear how welcoming the world was becoming for the autistic. The rise of digital technologies meant that autism was not just a ‘way of being’; it was a way of being an active, productive, innovative member of society. And maybe a rich and famous one, too. It has become a Silicon Valley parlour game to speculate about which CEOs have an undiagnosed autism disorder. Mark Zuckerberg, with his obsessiveness and flat, Vulcan-like affect, usually tops the list. Last year, the billionaire venture capitalist Peter Thiel told an audience that in the current economy people ‘who do not suffer from Asperger’s are at some massive disadvantage’ because they’re more likely to fall prey to caution, complacency and the conventional wisdom of the crowd.

*

It isn’t just economic opportunity that the digital world has opened up to the autistic. For people with autistic disorders, sensory distortions and a difficulty in reading facial cues and body language can turn the simplest interaction into a source of crippling confusion and anxiety. Long before Lorna Wing named Asperger’s syndrome, Silberman argues, those who fitted the profile found ways round these problems. NeuroTribes devotes a surprising amount of space to the mid-century culture of amateur radio operators. Building, tinkering with and communicating by way of ham radios satisfied the enthusiast’s technological appetite, obviated face-to-face contact and ‘enabled shy introverts to study the protocols of personal engagement from a comfortable distance’. Computers have enabled the same things, but on an incomparably bigger scale. ‘The impact of the internet on autistics may one day be compared in magnitude to the spread of sign language among the deaf,’ the journalist Harvey Blume wrote in 1997. It was a bold prediction, but perhaps not bold enough. Digital technologies have indeed given autistic people the chance to participate in the wider culture – to organise, lobby, advocate for themselves, and even to ‘pass’ – but they have also nudged the culture in an autistic direction. Worldwide, more than eight trillion (and rising) text messages are sent each year. The popularity of SMS is a consequence largely of speed and convenience. But it’s also a consequence of the technology’s success in smoothing the edges of social interaction. To borrow a line from Frank Zappa: a smartphone has no eyebrows. It provides a space in which to interpret and strategise before responding.

Autistic people were quick to recognise the benefits of the digital revolution. Not long after he spoke in Toronto, Sinclair established an online group, Autism Network International, to discuss the ideas contained in his manifesto. The tone on ANI was often irreverent. Members used the invented clinical label ‘neurotypical’ to refer to non-autistic people. (In 1998, an autistic woman called Laura Tisoncik created a satirical website credited to the Institute for
the Study of the Neurologically Typical. ‘Neurotypical syndrome,’ the site’s FAQ explained, ‘is a neurobiological disorder characterised by preoccupation with social concerns, delusions of superiority, and obsession with conformity ... There is no known cure.’ Listservs, websites and online forums proliferated. In his 1997 article, Blume noted that users felt reassured by these online spaces. ‘Long live the internet,’ one participant wrote, where ‘people can see the real me, not just how I interact superficially with other people.’ He also noted how fertile a metaphor computers provided for the autistic. The concept of circuitry, which drew on cybernetics and brain science, suggested an almost infinite malleability, and therefore an almost infinite inclusiveness. Judy Singer, an Australian sociologist, came up with the term ‘neurodiversity’, which was soon adopted as the watchword of the burgeoning autism-rights movement. ‘It just sang to me,’ one activist told the author Andrew Solomon. ‘I thought, what a beautiful word, that encompasses the reality that God has many different ways to build a brain.’

*In a Different Key* and *NeuroTribes* are similar books. The former is better organised and better written, but both offer thorough accounts – at times exhaustingly thorough – of the history, science, culture and politics of autism. Both offer lively capsule biographies of autistic people, clinicians and activists, and both do an admirable job of digesting and presenting a topic of extraordinary complexity. If there’s a major difference between them, it’s in their angle of approach. The subtitles give it away. Donvan and Zucker (‘The Story of Autism’) aim for comprehensiveness and order; they want to tell the whole tale and tell it cleanly. While no less comprehensive, Silberman (‘The Legacy of Autism and How to Think Smarter about People who Think Differently’) is far more partisan. *NeuroTribes* ends with a plea for a world better suited to ‘the needs and special abilities of all kinds of minds’. The last chapter ends with the line: ‘There is much work to be done.’

In a recent essay for *Vox*, Ari Ne’eman, founder of the Autistic Self-Advocacy Network and a leading neurodiversity activist, praises Silberman for his devotion to the cause. As a gay man, Ne’eman writes, Silberman ‘understands the unique frustrations so many autistic persons feel watching a core aspect of our lives presented to the public as a burden and public health risk’. Donvan and Zucker, on the other hand, ‘are clearly coming from a parent point of view’. Whenever the pain and stress of raising an autistic child is discussed, Ne’eman claims, they exhibit a ‘reflexive sympathy’. Whenever the ideals and aspirations of the neurodiversity movement are discussed, they exhibit hostility and fear.

This criticism strikes me as overblown. Donvan and Zucker do show great compassion for the parents of autistic children, but not necessarily at the expense of compassion for autistic people themselves. Whatever the case, Ne’eman’s position underscores a tension inherent in our current thinking about autism. The source of this tension is that it’s become impossible to say what, exactly, ‘autism’ even means anymore. *NeuroTribes* has two dedications, one to
Silberman’s husband and one, at the end of the American edition, to the memory of Lorna Wing, without whose diagnostic innovations, both books claim, the neurodiversity movement probably wouldn’t exist. Wing and her allies spent decades liberalising the definition of autism. When they began, ‘autistic’ meant ‘profoundly autistic’. It now means everything from ‘profoundly autistic’ to ‘autistic but able to write a 4000-word critical essay for Vox’. Wing’s legacy is a more humane and welcoming world for people born with autistic traits; she was an undeniable force for good. But the larger the crowd, the greater the contrasts within that crowd. An autistic person who’ll never be able to dress herself and an autistic person who’s able to have a career and family are at least as different as they are alike.

This tension is unlikely to be resolved any time soon. On the contrary, it has in a sense recently been made official. In 2013, the APA decided to strike from the fifth edition of the DSM all previous diagnoses based on autistic symptoms. These included Autistic Disorder, the diagnosis most often given to those who ‘function at a retarded level’, and Asperger’s, the diagnosis given to Ne’eman, Sinclair and other ‘high-functioning’ autistics. The DSM-V collapsed everything into one all-encompassing diagnosis called Autism Spectrum Disorder. This means, in effect, that all manifestations of autism, from those approaching the ‘borderline of normality’ to those approaching total disability, are now formally part of the same enormous family. Wing’s organising ideal is now diagnostic law.

Once created, however, psychiatric labels are hard to recall. For some ‘Aspies’ the psychiatric profession’s abandonment of the term felt like an assault on an indispensable and hard-won identity. ‘Imagine that you’ve been a Christian all your life and then some “specialists” come along and rewrite the Bible so you’re not a Christian any longer,’ the journalist Mathieu Vaillancourt wrote last year in the Spectator. ‘The psychiatric bible tells me I’m autistic but in my heart I will always have Asperger’s.’ Wing gave Asperger’s to the world; the world continues to have its say. Not long ago, a friend used a term I’d never heard to describe a co-worker. Her co-worker was a little brusque and unsociable and she thought he might have just a bit of an autistic impairment. The term she used was ‘Splashperger’s’.

Vol. 38 No. 10 · 19 May 2016 » Daniel Smith » Call a kid a zebra
pages 11-15 | 5472 words

Letters
Vol. 38 No. 12 · 16 June 2016

‘Why is autism being diagnosed so commonly these days?’ is the question which, as a paediatrician practising in the field of child development, I’m most often asked. Daniel Smith mentions two reasons: the broadening of the diagnostic criteria and the increased public awareness of the condition (LRB, 19 May). Another possibility is social
change. Autism spectrum disorder is associated with difficulties in the areas of social skills and language skills. These two abilities share a critical period of development in the first few years of life. In the past these years were spent with our families and peer groups, and we learned language from a living person – a sibling or a stay-at-home parent. We learned social skills such as turn-taking and sharing from them as well.

In a generation there has been a dramatic change. Instead of interacting with a responsive human being, children from an early age ‘interact’ with a screen. A recent study has shown that on average, children under the age of two spend two hours a day in on-screen activities. This probably has little effect on the ‘neurotypical’ but may have a profound effect on children on the autism spectrum, providing part of the answer to the apparent increase in incidence of the condition.

Nils Hanson
Meryla, New South Wales

Vol. 38 No. 13 · 30 June 2016

It is a symptom of something or other that two books on autism should have been reviewed by Daniel Smith in the LRB, and one of them recently in the TLS, too, but not in Nature (LRB, 19 May). I was, I think, the first English paediatrician to make the diagnosis, after reading Leo Kanner’s description of the condition. I have since learned that the clinician has to distinguish diseases sui generis from what Harold Himsworth called syndromes (the common endpoint of often quite different conditions), and from what are best seen as the tail ends of a ‘normal distribution curve’ of characteristics. One can discern within what is now labelled ‘autism’ a distribution curve in which ‘cases’ vary from so-called Asperger’s syndrome, characterised by insensitivity to the normal nuances of social intercourse, to persons unable or unwilling to engage socially at all.

The extent to which autism is the result of genetic factors or environmental stimuli or lack thereof, or an interaction between the two, is difficult if not impossible to determine, as is the extent to which adaptation on the part of parents, teachers and their psychiatric advisers to a susceptible infant may enable a child to make the best of his (most cases are male) talents.

John A. Davis
Cambridge