



Sensory support is helping this man with autism spectrum disorder to connect with his therapist.

AUTISM

Seeing the spectrum entire

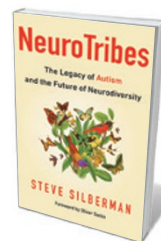
Chris Gunter examines a comprehensive history of the science and culture surrounding autism studies.

Within two generations, the popular and scientific understanding of autism spectrum disorder (ASD) and related conditions have undergone a massive shift in some parts of the world. We have moved from routine institutionalization (or worse) of people with ASD to an appreciation of a spectrum of social communication.

How did this sea change come about? Journalist Steve Silberman has been writing and commenting on autism for years, notably with a 2001 feature in *Wired* magazine on ASD rates in California's Silicon Valley. He has compiled his exhaustive research into *NeuroTribes* to try to answer that question.

Genetic and neurological studies now firmly suggest that 'autism' describes a constellation of behaviours. This is defined in the fifth edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (DSM-5, 2013)*

as "persistent difficulties in the social use of verbal and nonverbal communication" and "restricted, repetitive patterns of behavior, interests, or activities". In 2014, the US Centers for Disease Control and Prevention estimated that 1 in 68 US children had ASD. Co-occurring challenges abound — including anxiety and digestive problems — but only about half of people diagnosed with ASD also have intellectual disability. We now recognize that autistic people can have a hugely varying range of impairments and abilities, which can change throughout life. This recognition



NeuroTribes: The Legacy of Autism and the Future of Neurodiversity
STEVE SILBERMAN
Avery: 2015.

has been hard won. Silberman takes us back to the early twentieth century and clinics in Europe, Russia and the United States that first began using the terms autism or autistic psychopathy (from the Greek word *autos*, meaning 'self') to describe apparent withdrawal into an inner world.

The clinicians most often credited with discovery are Hans Asperger and Leo Kanner. Asperger's clinic in 1930s Vienna embraced the full range of ASD. But Silberman asserts that to protect his charges from euthanasia by the Nazis, Asperger focused his case reports on gifted children ostracized by their peers, later termed high-functioning. Eventually, these cases would be called Asperger's syndrome; in the *DSM-5*, controversially, this diagnosis is folded into ASD.

Kanner wrote a 1943 paper about his patients in Baltimore, Maryland, which is generally considered the first description of autism (*Nerv. Child* 2, 217–250; 1943). He focused on "extreme autistic aloneness" and "an anxiously obsessive desire for the maintenance of sameness". This restricted view would shape the field for five decades.

With child psychologist Bruno Bettelheim, Kanner did further damage in the 1940s and 1950s by popularizing the unfounded idea that loveless "refrigerator" parenting caused autism. The pair suggested that children with autism be institutionalized 'for their own good'. Silberman provides ample biographical detail on many such personalities in early autism research, as well as Bernard Rimland, who founded the US National Society of Autistic Children (now the Autism Society) in 1965 and pioneered the involvement of parents in support networks and the search for treatments and educational strategies.

As he must, Silberman discusses the disastrous impact of the now-retracted 1998 paper in which UK surgeon Andrew Wakefield (since struck off the medical register) alleged a link between ASD and the measles, mumps and rubella vaccine. Silberman demolishes the study's claims, long dismissed as fraudulent and debunked by massive longitudinal studies.

Instead, rising rates of ASD diagnosis in the past four decades (US prevalence was estimated at 1 in 5,000 in 1975) can be tied to — but not wholly explained by — the use of expanded diagnostic criteria from the 1980s. UK clinician Lorna Wing and her colleagues, whose revisions to the *DSM-III* were adopted in 1987, fully expected to see a rise in diagnoses, harkening back to Asperger's 1944 definition of "autistic psychopathy", in which he described his observations as "not at all rare". Wing adopted the term autism spectrum, recalling the words of statesman Winston Churchill: "Nature never draws a line without smudging it."

The rise in diagnoses is also linked to awareness increased by films featuring autistic

characters, such as *Rain Man* (1988), as well as the advent of the Internet and social media, which enabled the formation of support groups and allowed communication in ways that can be easier for people with ASD. As some of the stigma has ebbed, parents have become more willing to seek diagnoses for their children and even themselves.

One of the most powerful talks at the 2015 International Meeting for Autism Research was by John Elder Robison, who has been diagnosed with Asperger's syndrome. He told the room of scientists and clinicians, "The reason diagnostic labels are so important to those of us with autism is that without those labels, we only have the labels we got in the streets, which are hateful." While we debate diagnostic criteria, we must remember that there are people receiving these labels (and not) who deserve respect, understanding and support.

Fittingly, *NeuroTribes* ends with the neurodiversity movement that is now emerging. Groups such as the Autism Self Advocacy Network campaign for spending less on finding 'cures' and more on designing appropriate support and accommodation for people with ASD and their families and caregivers.

Any work on ASD will be seen as a triumph by some and a travesty by others; Silberman has opted not to be shy. Great contributions include interviews with prominent scientists and self-advocates. He intersperses these with his own opinion, for example portraying the *DSM-III* as a way for psychiatrists to link to "Big Pharma". His affection for detail can get in the way, as in a chapter on the development of radio and electronic bulletin boards. Readers should look elsewhere for a primer on what we do and do not understand of the basic biology of ASD; that is not Silberman's intent.

NeuroTribes is no casual read. The parent of a newly diagnosed child looking for information may be put off by the weight of past horrors on show. But for people in the field, or anyone seeking to understand the interplay between medical science and patient communities, it should be an essential resource. My own copy is already dog-eared and underlined throughout. ■

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GENOMICS

Bioethics on stage

Brendan Maher reviews a play inspired by a famous clash between geneticists and a Native American tribe.

In the early 1990s, researchers at Arizona State University (ASU) in Tempe collected blood samples from the Havasupai people, an isolated Native American tribe living in the Grand Canyon. A decade later, tribe members sued the university for misusing the samples, on the grounds that they had not been fully informed of the study's scope. The legal battle culminated in a US\$700,000 payout from ASU; the remaining samples were returned.

That much is true. But much else about the story is disputed. It has surfaced in articles and books as an example of the cultural sensitivities that come up in research. Some argue that it has become a fable of arrogant scientists riding roughshod over people's rights — a tale that has hardened mistrust between researchers and Native American groups.

The latest retelling is the drama *Informed Consent*, playing at the Duke on 42nd Street in New York City. Seasoned playwright Deborah Lauffer sees her work as an exploration of truth and the clash between science and religion. Although the scientist at its centre comes across as a caricature of hubris, the piece effectively presents some ethical, legal and social complexities of modern genomics.

It is highly fictionalized. The real researchers were anthropologist John Martin and geneticist Therese Markow, who in the 1990s were trying to find genetic underpinnings for the Havasupai's high incidence of type 2 diabetes — roughly 55% among women and 38% among men. In the play, Ken (played by Jesse Perez) is a social anthropologist who has worked with an unnamed tribe in the Grand Canyon for 40 years, and

Informed Consent
DEBORAH ZOE LAUFFER
The Duke on 42nd Street, New York City.
Until 13 September.

Jillian (Tina Benko) is an ambitious genetic anthropologist struggling with the knowledge that she carries a

genetic mutation that ensures that she will develop early-onset Alzheimer's disease.

Jillian jumps at Ken's offer to run a study looking for diabetes markers in tribe members' DNA. Soon, she reveals other intentions, such as studying how the tribe came to America — even though this would conflict with their own story about where they came from. Ken emphasizes that this is "strictly" a diabetes study. The fourth wall fading momentarily, Jillian tells the audience that he never said "strictly". Other cast members jump in to support her version, and Ken revises his line — a playful swipe at the indefinite nature of remembered truth.

Jillian convinces tribe members to hand over samples of their blood — which they deem sacred — by suggesting that DNA tests are their only hope of halting the diabetes epidemic. She also deludes herself into thinking that the work will lead to funding to pursue a cure for Alzheimer's. Her ambition is driven by fear, for herself and for her daughter Natalie (DeLanna Studi), who has a 50% chance of inheriting the mutant gene. In a parallel plot line, Jillian and her husband fight over whether to test Natalie.

The play crescendos as a tribal spokesperson (also played by Studi) confronts Jillian at a talk on the tribe's early migrations out of East Asia, saying that she had no right to use the samples to study this. Under threat of a lawsuit, Jillian's university fires her and the remaining samples are ceremonially returned.

In the mid-2000s, when the real case came to wide attention, progress on techniques for studying DNA was outpacing understanding of how the research might affect participants. There was no clear evidence that Markow or Martin had broken any rules, but the case and others prompted reconsideration of informed-consent documents, which are meant to lay out the risks for participants.

Lauffer acknowledges the limits in presenting this story with certainty, especially in an engaging stage play, which *Informed Consent* most definitely is. She notes: "I guess what happened is much less important than what we can learn from the outcomes." ■

Brendan Maher is a features editor at Nature.



DeLanna Studi (left) and Tina Benko in *Informed Consent*.