

Rethinking autism's past, present, and future:

A review of Steve Silberman's *Neurotribes*

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Neurotribes: The Legacy of Autism and the Future of Neurodiversity

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“Neurotypical syndrome is a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity. There is no known cure.”

- Institute for the Study of the Neurologically Typical (Silberman, 2015, p. 441)

The legacy of autism is not a happy one. Throughout history, autistic people have been misunderstood and marginalized, isolated and ignored. They have been bullied by peers, abandoned by parents, and murdered by the Nazis. They have been the subject of and subjected to some of the worst treatments (and science) imaginable, involving everything from chelation to electric shocks. And that's just within the last century.

For readers who have only a passing acquaintance with autism, a brief primer may be helpful. Autism is a lifelong, neurological condition whose causes are unknown. There is no biological marker for autism, no blood test, no brain scan; it is diagnosed on the basis of clinical observation. The criteria in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) involve impairments in communication and social interaction, and the presence of restrictive and repetitive patterns of behaviors, interests, or activities (American Psychiatric Association, 2013). These symptoms must be present from early childhood, cause clinically significant impairment, and cannot be better explained by intellectual disability. Recent estimates in the U.S. suggest autism affects about 1 in 68 people (Centers for Disease Control,

2014), though there are tremendous differences in prevalence rates across countries (Norbury & Sparks, 2013).

One of the things that makes autism so fascinating and frustrating is its heterogeneity. Some autistics talk too much, some don't talk at all. Some score off the charts on IQ tests, some are unable to take those tests. Some can't stand bright lights or loud sounds, some thrive on them. There's a saying in the autism community that if you know one person with autism, you know one person with autism. There is no cure for autism. The data on outcomes for adults are paltry, but what little data exist suggest that outcomes are terrible: A study on autistic adults in their 40s (who were diagnosed as children and had average nonverbal IQ scores at that time) found that most did not live independently, were unemployed, and had never had a meaningful relationship (Howlin, Moss, Savage, & Rutter, 2013)

The good news, according to science journalist Steve Silberman's engrossing new book *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*, is that a movement is afoot, one that may fundamentally change for the better how autistic people are treated, studied, and educated. Neurodiversity advocates hold the radical view that autism and other neurological differences are not devastating disorders in need of curing or eliminating. They are instead part of the natural variation of the human condition--variation that can result in unique challenges, to be sure, but also in unique strengths. The reason autism can be so debilitating, the argument goes, has more to do with society's lack of support, accommodation, and understanding than with autistics' atypical neurology. We should be working to create inclusive communities where autistics can flourish with (and perhaps because of) their autism, not trying to turn autistics into non-autistics.

The neurodiversity movement is young (the term was coined in the 1990s), but the ironic thesis of Silberman's book is that "viewing [autism] as a lifelong disability that deserves support, rather than as a disease of children that can be cured . . . [is] the oldest idea in autism research" (p. 81). According to Silberman, the person responsible for that idea and the hero of his story is

Hans Asperger (1906-1980), a pediatrician who directed the special education unit at the University of Vienna's Children's Clinic. In 1944, Asperger published a report describing four young boys who had great difficulty navigating the social world, but who were extraordinarily verbal and talented in subjects like mathematics and poetry. Asperger proposed that their social challenges and their talents both arose from the same *Autistischen Psychopathen* ("autistic psychopathy"): their "ability to turn away from the everyday world" (qtd. In Silberman, 2015, p. 103). His approach to treating autistic individuals (or really anyone with a disability) was to provide them an environment where their strengths could be fostered and their challenges supported--the rallying cry of today's neurodiversity movement.

The man Silberman holds most responsible for keeping Asperger's progressive ideas about autism from entering the mainstream earlier and the villain of *Neurotribes* also happens to be the person most often credited with "discovering" autism:¹ Leo Kanner (1894-1981). Kanner emigrated from Germany to the U.S. in 1924, and became the first child psychiatrist at Johns Hopkins a few years later. In 1943, he published a remarkable report describing 11 children with "a unique 'syndrome,' not heretofore reported," involving an "extreme autistic aloneness that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside" (Kanner, 1943, p. 242). Kanner reported that this "autistic aloneness" manifested itself in two primary ways, which can still be seen in the criteria for autism in the DSM-5: an inability to relate to others (i.e., social impairments), and an insistence on sameness (i.e., restricted/repetitive patterns of behaviors and interests).

Silberman paints a portrait of Kanner as an overly ambitious, self-promoting scientist, who studiously ignored what others had to say about autism. His paper was published a year before Asperger's, but according to Silberman, it strains credulity to think that Kanner did not know that Asperger was working on something similar: One of the clinicians who worked under

¹ Scare quotes are used around "discover" because autism has always been around of course; it had just not been described in the scientific literature previously, though similar cases had been reported earlier as examples of other conditions, including "childhood schizophrenia."

him and contributed observations to his paper had arrived at Johns Hopkins in 1938 after fleeing from the Nazis. His previous post had been working under Asperger in Vienna. Silberman also takes Kanner to task for failing to mention Asperger's work in his later publications, except in a book review where Kanner explained that the autistic psychopathy Asperger described was "at best a 42nd cousin" (qtd. In Silberman, 2015, p. 221) of the autism Kanner had described.

Silberman's argument that Kanner deliberately ignored Asperger's work on autism is intriguing. But to be fair, the overlap between the autism described by Kanner and that described by Asperger is almost certainly more obvious with the benefit of hindsight. As Silberman notes, Kanner initially believed autism to be a homogeneous disorder, and he is likely to have considered the 11 children he described to be more disabled than the four Asperger described (e.g., three of Kanner's subjects were non-speaking and none appeared to have the kind of talent in science or art that Asperger had noted). Because he was looking for individuals who closely resembled those he reported initially, he found relatively few of them. In 1957, 14 years after the publication of his paper, he said he had seen only 150 true cases of autism.

In contrast, Asperger reported in his 1944 paper that he and his colleagues in Vienna had seen more than 200 children with varying degrees of autism, from those who could not communicate in conventional ways to those who could describe complex mathematical operations. But the focus of his paper (and lectures) was exclusively on the "little professors" who could talk. Why? According to Silberman, it was a calculated attempt to save autistic lives, allowing Asperger to present autism in what he thought would be the most favorable light to the Nazis, who were in the midst of their campaign to rid the Reich of disabled people. Perhaps if they saw some autistics as having exploitable talents (those with a facility in mathematics might make good code breakers, for example), they would be more likely to spare individuals with that diagnosis. Of course, as described in an emotionally powerful section of Silberman's book, Asperger's efforts did nothing to stop the Nazis from murdering autistic (and other disabled) children by injection, shock, starvation, exposure, or any of a number of other methods.

Compared to his portrait of Kanner, Silberman's portrait of Asperger is practically that of a saint. But a book about autism would not be complete without controversy, and there has been a great deal of controversy about whether Asperger was actually a Nazi sympathizer--for example, he signed letters with "Heil Hitler" and took a loyalty oath to him (though Silberman writes that he was also harassed by the Gestapo). Most damning to Silberman's case, though, is a fact that does not appear in *Neurotribes*: Asperger may have served on a medical committee that determined which disabled children would live and which would be murdered, and his signature appears on a letter of referral that sent a young girl with encephalitis to one of the killing centers (Donvan & Zucker, 2016). Earlier this year, Silberman (2016) wrote that he will revise the next edition of *Neurotribes* "to reflect this darkest episode in Asperger's career." It will be interesting to see how this changes Silberman's argument; it certainly raises questions about the moral compass of the primary hero of the first edition of his book.

Silberman argues that Kanner's failure to recognize (or acknowledge) that autism was a spectrum meant that many affected children (and adults) who did not fit his very narrow definition lacked access to the services and support they needed. Getting the field to recognize similarities between the kind of children Asperger profiled in 1944 and the kind Kanner profiled in 1943 was an excruciatingly slow process, led by another hero in Silberman's book, the British psychiatrist Lorna Wing (1928-2014). Wing's own daughter had "Kanner's autism," as it was called, but her research and a chance encounter with a reference to Asperger's paper (still available only in German at the time) led her to believe that the criteria for autism should be much broader. Wing's efforts brought orders of magnitude more individuals into autism's tent, from 4-5 cases per 10,000 in the 1960s to 1 in 68 today. The critical mass of self-advocates and their supporters, along with the rise of the internet, led to today's neurodiversity movement.

Silberman claims that in addition to having different conceptions about the scope of autism, Asperger and Kanner also had different conceptions about its cause. Whereas Asperger always believed that autism was innate, Silberman suggests that Kanner waffled. In his original

paper, for example, Kanner wrote that his patients' inability to relate to others was evident "from the beginning of life" (Kanner, 1943, p. 242). In the same paper, he described his patients' emotionally cold and distant parents, and wondered "whether or to what extent this fact has contributed to the condition of the children" (*ibid.*, p. 250), which could be read as wondering about the genetic transmission of autism or about the role of parenting in autism. A few years later, *Time* magazine reported on a lecture Kanner gave, in which he seemed to favor the second interpretation ("Frosted Children," 1948): He said that all of the autistic children he had seen had been "kept [by their parents] in a refrigerator which didn't defrost," and apparently refused to rule out the possibility that this was the cause of autism. According to Silberman, Kanner's public ambivalence about the role of parenting, combined with the psychodynamic zeitgeist in the U.S. at the time, contributed to the now completely discredited "refrigerator mother" theory of autism.

And here we have another controversy. In a 2016 rejoinder apparently directed at Silberman (though he is never mentioned by name), James Harris, a student of Kanner's and his successor as the director of child and adolescent psychiatry at Johns Hopkins, and Joseph Piven, a professor of psychiatry at the University of North Carolina at Chapel Hill, argue that Kanner never believed parents were to blame for autism. Even before the publication of his 1943 paper, Kanner had written a book (*In Defense of Mothers*), encouraging parents not to blame themselves for their children's problems. Furthermore, in an address to the 1969 National Society for Autistic Children, he stated clearly that parents were not to blame for their children's autism: "Herewith I especially acquit you people as parents." (Harris and Piven do not address Kanner's refrigerator quote in *Time*, but perhaps the quote was taken out of context.)

According to Harris and Piven (2016), Kanner described various traits possessed by the parents of his patients not because he thought they had caused their children's autism, but because they were similar to traits possessed by the children themselves--many were intensely detail-oriented and socially awkward, for example. They write that Kanner's descriptions of

similarities between parents and children set the stage for today's research investigating the genetic underpinnings of the disorder (e.g., Geschwind, 2011; Piven, Palmer, Jacobi, Childress, & Amdt, 1997) and the broader autism phenotype, a term used to describe personality and cognitive traits that are similar to those in autism among people who do not have a diagnosis (e.g., Ruzich, Allison, Smith, & Watson, 2015; Sucksmith, Roth, & Hoekstra, 2011).

Harris and Piven (2016) also argue that although Kanner did not believe parenting behavior caused autism, he did believe that the way parents (and others) treated children could affect their development. This is a reasonable belief; a good deal of developmental psychology focuses on how parenting practices can be related to child outcomes. Research has shown, for example, that the number of words children hear as infants is related to the size of their productive vocabulary as preschoolers (e.g., Hart & Risley, 1995); children who are spanked more tend to be more aggressive (e.g., Gershoff, 2013), and warm and sensitive caregiving is related to children's self-regulatory abilities (e.g., Deater-Deckard, 2014). Unfortunately, in the case of autism, the belief that parenting can influence development has been taken to an extreme, with scientists and charlatans alike (sometimes embodied in the same person) claiming that with the right kind and amount of treatment, an autistic child can be made indistinguishable from his or her non-autistic peers.

The foremost proponent of this belief and another villain in Silberman's story is O. Ivar Lovaas (1927-2010), a UCLA psychologist and radical behaviorist. Lovaas developed a method of intervention that came to be known as "applied behavior analysis" (ABA), which was built on the principles of operant conditioning. ABA has a long and sordid history (for a riveting account, see Dawson, 2004), but remains the most commonly used and recommended therapeutic approach to autism. In traditional ABA programs, trained therapists use rewards like food or access to desirable activities to shape successive approximations to a desired behavior, whether it be producing words, stacking blocks, or interacting with peers. In the early ABA protocols, therapists would also deliver slaps, loud sounds, and other "aversive stimuli" to

reduce the frequency of undesirable behaviors. In one of the most disturbing sections of Silberman's book, he describes how Lovaas and his colleagues delivered electric shocks (apparently gleefully) to 5-year-old autistic twins.

Eventually, Lovaas came to believe that children could "recover" from autism if they were provided with 40 hours/week of one-on-one ABA therapy, ideally beginning in preschool. In a badly designed and poorly executed study, Lovaas (1987) claimed that 47% of children who had received ABA therapy (including aversives) for at least two years had average or above average IQs and were enrolled in mainstream first grade classrooms compared to only 2% of those who had not received the intensive treatment. These findings have never been replicated in a randomized, controlled trial (Sallows & Graupner, 2005; Smith, Groen, & Wynn, 2000), and according to a government report, the Lovaas method may have a small influence on performance on IQ scores, but it has no effect on communication/language, social-emotional development, or functional abilities (U.S. Department of Education, 2010). Nevertheless, Lovaas's (1987) claim that autistic children cannot learn from their everyday environments and instead need a "special, intense, and comprehensive learning environment" continues to have a devastating influence on how autistic children are educated.

For example, although not directly addressed by Silberman, in the U.S., nearly 35% of autistic children spend most of their school day in self-contained classrooms where they are segregated from their typically developing peers (in South Carolina, it's over 50%), and over 7% are educated in completely separate institutions (in New Jersey, it's over 30%) (Kurth, 2015). These numbers are astonishing on moral grounds (think *Brown v. Board of Education* and "separate but equal"), but also because the academic and social outcomes of autistic students tend to be much better when they are educated, with appropriate supports, in inclusive classrooms (e.g., Kurth & Mastergeorge, 2010; Lyons, Cappadocia, & Weiss, 2011; McGregor & Vogelsberg, 1998). For example, Kurth and Mastergeorge (2010) compared autistic students in junior high who had been taught since kindergarten either in inclusive or self-contained

classrooms. The two groups were matched on IQ and adaptive behavior scores, but students in the inclusive classrooms outperformed those in the self-contained ones on every academic achievement assessment of reading, writing, and math given, with effect sizes ranging from .58 to .85. What's the explanation? Those in inclusive settings were: 1) exposed to the general education curriculum (those in self-contained classrooms often are not; e.g., Causton-Theoharis, Theoharis, Orsait, & Cosier, 2011); and 2) expected to be able to learn, with support, in the same environment as their peers (contra Lovaas, 1987).

Silberman limits his discussion of the autism intervention industry to ABA, but it has grown by leaps and bounds to include such programs as Pivotal Response Training (Koegel & Koegel, 2006), the Early Start Denver Model (Dawson et al., 2010), Floortime (Greenspan & Wieder, 1999), and a host of others. These programs vary in a number of ways, but one thing they all have in common with Lovaas's approach is an explicit or implicit insistence that the sooner autistic children begin therapy and the more they receive, the more likely they will be to lose their diagnosis--to achieve what one research group obtusely calls an "optimal outcome" (Fein et al., 2013; Orinstein et al., 2014). To be clear, no one knows why a handful of autistic individuals (maybe 9%; Anderson, Liang, & Lord, 2014) eventually lose their diagnosis while others who receive the same intervention do not (Padawer, 2014). The guilt parents once felt for causing their children's autism has been replaced by guilt for not doing enough, soon enough, to "cure" it.

Autism interventions by and large are predicated on the notion that autism is something that should be cured (and ideally prevented from occurring in the first place). Many members of the neurodiversity movement, including Silberman, reject that notion. For example, according to the autistic self-advocate Jim Sinclair (1993/2012), many autistics feel their autism is an essential part of who they are. Sinclair writes that when parents long for a cure, it sends a message to the child that she or he is somehow inadequate, that they wish they had a different (non-autistic) child. If this discourse reminds you of the kind used in the broader disability rights

movement (including in the Deaf community) or the gay rights movement, it is not an accident. Rather than finding ways to support and accommodate disabled and gay people, society and scientists have historically sought to change them, to normalize them. (Indeed, at the same time Lovaas was using principles of operant conditioning in an attempt to turn autistics into non-autistics, he was also involved in a project to use the same techniques to turn feminine boys into masculine ones--an effort that most psychologists today would find abhorrent.)

It should be noted that although some autistic self-advocates have said that they would not choose to cure their autism (including Temple Grandin), others have said they would (for example, Sue Rubin). Regardless of how one feels about curing or eliminating autism, we should all be able to agree that it is important to learn how best to support autistic people in the present. As Silberman persuasively argues in his concluding chapter, "Imagine if society had . . . denied wheelchair users access to public buildings while insisting that someday, with the help of science, everyone will be able to walk" (p. 470). And yet, society's priorities are clearly in the cure camp: In 2012 (the most recent year for which figures are readily available), over \$110 million in U.S. federal research funding was devoted to the biology or causes of autism, \$49 million to treatment and interventions (presumably focused on children), and just \$10 million to service provision and lifespan issues (Government Accountability Office, 2015).

In addition to the social justice argument for accommodation and support rather than elimination and cure, Silberman makes a pragmatic argument: Without the unique perspective of those with autism, a number of scientific and technological advances might not have occurred. Silberman chronicles several of these advances, from Cavendish's discovery of hydrogen to Gernsback's invention of the amateur wireless telegraph to McCarthy's work on artificial intelligence. In fact, he opens *Neurotribes* by explaining that he was introduced to autism through his reporting for *Wired* magazine, writing an extremely popular piece in 2001 called "The Geek Syndrome," for which the teaser was: "Autism--and its milder cousin Asperger's syndrome--is surging among children of Silicon Valley. Are math-and-tech genes to

blame?” The tech world, Silberman suggests, is ideally suited for individuals who can focus intently, detect patterns, and are not constrained by what has come before--skills possessed by many autistics. Plus, it relies less on face-to-face social interaction than other professions.

Silberman's book is quite long, and it is written for a popular audience rather than scientists. But I found myself occasionally wishing that he had used his considerable journalistic talents to describe some of the amazing experimental studies that support his assertions about autistic strengths. For example, there is a sizeable literature demonstrating enhanced perceptual abilities in autism (for a review, see Mottron et al., 2013). Here are a few examples. On average, autistics: have visual acuity that “lies in the region reported for birds of prey” (Ashwin, Ashwin, Rhydderch, Howells, & Baron-Cohen, 2009, p. 17); are faster than non-autistics to locate one figure embedded within a larger one (Joliffe & Baron-Cohen, 1997); have greater perceptual capacity than non-autistics (Remington, Swettenham, & Lavie, 2012); and outperform non-autistics on abstract spatial tests, like choosing which of several drawings represents how a folded piece of paper would look when unfolded (Stevenson & Gernsbacher, 2013).

I also wished that Silberman had pushed back a bit more on the stereotype of autistics as lacking in social motivation, that they are not interested in relating to other people. He does this somewhat when he describes the camaraderie that autistics revel in when they get together (which scientists would do well to study). But often the only evidence offered for an autistic's lack of motivation to connect with non-autistics is that they do not do so in conventional ways (for discussion, see Akhtar, Jaswal, Dinishak, & Stephan, in press). Consider Donald T., the first child described in Kanner's (1943) original report. When he was in high school, some older boys, perhaps in an effort to tease him, asked him to count the number of bricks on a building. Donald gave a number, and the boys left him alone. When he was 77, a pair of journalists tracked him down, and asked about this incident. He readily confessed that he had chosen a number at random, and when asked why, he said, “I just wanted for those boys to think well of

me” (Donvan & Zucker, 2010). That seems to me like evidence of a desire to connect with other people.

I’m a developmental psychologist and the father of a non-speaking autistic child, and I have read more than my fair share of gloom and doom accounts of autism. One can take issue with how Silberman characterizes some of autism’s historical figures, but the perspective he offers is a breath of fresh air. As a companion piece--one that has little to say about the history of autism, but which also represents autism as a different way of being rather than a devastating disorder--I highly recommend psychologist Barry Prizant’s (2015) *Uniquely Human*. It will take time for science and society to recognize that, as Asperger put it, “Not everything that steps out of line and is thus ‘abnormal,’ must necessarily be ‘inferior’” (p. 128). *Neurotribes* and the neurodiversity movement it chronicles give me hope.

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