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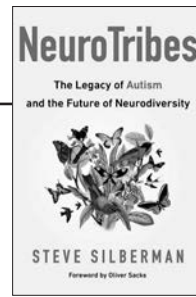


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NEW RELEASE BOOK REVIEW

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Steve Silberman, *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*. New York: Penguin, 2015. 544 pp.

In his engaging history of the autism diagnosis and the emergence of people with autism into disability rights consciousness, Steve Silberman describes Autreat, a conference and retreat for people on the autism spectrum. At Autreat, the social and cultural norms were not determined by “neurotypicals,” people without an autism diagnosis, but by autistics. For the 18 years it ran, Autreat sought to enact the value of neurodiversity, a term coined by Judy Singer in 1999 to describe an emerging conviction that neurological syndromes like autism are not forms of pathology so much as variant, and valuable, forms of cognitive difference that require acceptance and accommodation, not treatment. Silberman’s description of Autreat and the rise of self-advocacy is the culminating chapter of his book, and for Silberman it marks the beginning of an era when we can collectively begin to “think more intelligently about people who think differently” (471).

Steve Silberman has written an entertaining, compassionate history of autism. It is a history that offers a particular, and ethically inflected, interpretation of the various research programs and controversies that have characterized the history of the diagnosis. Silberman begins in the present, a moment when many diagnosed with autism have achieved a growing community consciousness and political visibility. Meanwhile, there is growing public awareness that autism is, in most cases, a lifelong condition rather than a disorder of childhood. Silberman’s story is about how this present came about, and what kept these changes from happening earlier. The narrative points to contemporary educational programs that teach to the strengths rather than the deficits of students with autism, and growing public and professional recognition that accommodating and accepting

autistic people is as important an intellectual challenge as research into underlying genetic and neurological causes.

Silberman's chapters roughly alternate between two different journalistic projects, capsule biographies that highlight the contributions of autistic people, and a revisionist history of the autism diagnosis. Hence, Chapters 1 and 2 deal with contemporary and historical figures. Chapters 3, 4, and 5 describe the early history of the autism diagnosis, including well-known researchers like Hans Asperger, Leo Kanner, and Bruno Bettelheim; Chapter 6 finds the roots of autistic culture in ham radio culture and science fiction fandom; Chapters 7 and 8 outline the evolution and expansion of the diagnosis and the birth of autism parent advocacy; Chapter 9 considers the outsized impact of the movie "Rain Man" on public awareness; Chapter 10, the causes of the increase in diagnoses over the past few decades; and Chapters 11 and 12 recount the emergence of self-advocacy and the movement for accepting neurodiversity.

Both projects underscore Silberman's focus on the underlying unity of the autism spectrum and the contributions of autistic people to science, engineering, and technology. He begins on a 2000 Alaskan cruise for Linux programmers, many of whom, Silberman notes, have autistic traits that facilitate rather than hinder their work (3). He follows that in Chapter 1 with a delightful brief biography of Henry Cavendish, the eccentric 19th century natural philosopher and discoverer of hydrogen. Cavendish strenuously avoided human contact, wore versions of the same green suit throughout his life, and pursued his solitary research projects with single-minded devotion: his "mind was like a mirror held up to nature, unclouded by bias, rationalization, lust, jealousy, competition, pettiness, rancor, ego, and faith" (29-30). *NeuroTribes* offers a series of such profiles, from Cavendish to Hugo Gernsback, a proponent of science fiction fandom and popular ham radio culture at the turn of the 20th century, to John McCarthy, a 1950s hacker and author of the programming language Lisp, to a contemporary 11-year-old named Leo Rosa and his family.

Silberman's other project, interwoven with the first, is a retelling of autism's history. Leo Kanner has traditionally been central to histories of autism; his remarkable 1943 diagnostic case series, with its richly detailed depictions of children with autism, surpassed Kanner's limited efforts at explanation or causative theory. Silberman, in contrast to most histories, starts with Hans Asperger. Asperger's work in a Viennese child psychiatric clinic in the 1930s was overshadowed by Kanner's for most of the 20th

century, until British psychiatrist Lorna Wing made diagnosticians and the public aware of its relevance.

In Silberman's telling, the relative obscurity of Asperger's contributions for much of the history of autism is not a historical accident caused by the disruption of World War II, the possibility of Asperger's Nazi Party membership, and ignorance of Asperger's work on the part of English-speaking colleagues—and Silberman's discussion of Asperger's clinic and research is better than anything published elsewhere. In fact, Kanner, working in the US, did not “simultaneously” discover autism but rather benefited from the diagnostic acumen and case finding ability of two former colleagues of Asperger, Victor Frankl and his wife Anni Weiss, whose escape to the US Kanner had facilitated (165-170). Other historians, myself included, have overlooked this connection. In his eagerness to receive credit for the discovery, Kanner may have intentionally failed to acknowledge the similarity of the children Asperger had identified to the cohort in his own studies.

This matters, Silberman argues, because Kanner emphasized the homogeneity of autism, the similarity of presentation in his cases, and their combination of significant social impairment but typical apparent intelligence. As Silberman notes, Kanner wanted to create the impression of identifying a new kind of person that had always existed but never before been noticed (181-183). Asperger, in contrast, emphasized the variability of those children he diagnosed with what he called autistic psychopathy, their potential for meaningful social contributions, the uniqueness of their intellectual skills, and the wide range of their levels of impairment. Kanner wrote that autism was an “inborn” trait, but implied that cold parents might have had a hand in generating the disorder. Asperger (1991:41) anticipated genetic theories by noting the presence of autistic traits in family members, like a mother and son who walked down the road, seemingly each unaware of the presence of the other.

Because Kanner asserted autism's identity as a distinct, specific, and homogeneous disease entity, rather than a spectrum of behavioral and communicative traits, and left the door open for psychogenic causation, psychologists like Bruno Bettelheim were able to build popular and professional support for parent-blaming explanations of autism's cause through the 1950s and 1960s. Activist parents like Bernard Rimland, a founder of the National Society for Autistic Children (now the Autism Society) and the Autism Research Institute, had to devote their energies to exonerating themselves. Rimland did this by helping to establish the significant genetic

contributions to autism in his 1964 *Infantile Autism*. Because parents had been needlessly stigmatized and their children subjected to unnecessary psychoanalysis instead of educational supports, those same parents naturally embraced treatments and interventions based on medical and neurological theories of autism. There was little space in families' experience of autism in the US for a positive or supportive approach to the diagnosis. Imagining autism as a type of neurological variation demanding support more than treatments required significant shifts in professional and public understanding. These included Lorna Wing's reintroduction of Asperger Syndrome, the DSM III-R and DSM IV's expansion of the diagnostic category, and the growth of an effective self-advocacy movement.

If Asperger Syndrome, rather than Kanner's infantile autism, had defined autistic experience in the 20th century and beyond, Silberman suggests, people with autism and their families in the US and elsewhere would have been saved a great deal of unnecessary grief. Educational specialists would have learned earlier to focus on strengths rather than deficits, recognizing that the unique abilities shared by many on the autism spectrum—pattern recognition, visual cognition, systematic thinking; concentration—are an integral part of autistic intelligence. Unnecessary time and resources would not have been devoted to medical treatments of questionable efficacy. It would not have taken so long to realize that autistic adults as well as children require supports, services, and accommodations, and that focusing exclusively on early intervention at the expense of these programs meant neglecting a significant part of the population. Because Asperger was clear that autism represented a whole range of cognitive abilities and behavioral challenges, we would have less trouble visualizing the commonalities between people who require significant supports in most areas of daily living and those whose primary challenges are social.

All of this makes for a gripping and plausible narrative: Kanner, in his desire for recognition, both appropriated and marginalized the work of his more humane and far-sighted colleague, at a dear cost to the millions of children and adults given an autism diagnosis in the years since, as well as their families. However, in terms of both comprehending the sources of past injustices and forestalling future ones, this approach has some limitations. Historians of science and medicine are fond, maybe overly so, of pointing to social and professional contexts as causes for different research trends and interpretations of illness. This can make it difficult to attribute responsibility for truly harmful practices and violations of human

dignity—of which the history of psychiatry has an abundance, from institutionalization to psychosurgery. But in this case, context matters. Kanner's detailed case studies, his insistence that autism represented a distinctive psychiatric disease entity, and the pains that he took to distinguish infantile autism from competing diagnoses like childhood schizophrenia are all, as Silberman correctly notes, symptomatic of psychiatric practice at a time when psychiatrists in the US were eager to establish their credibility as medical professionals working within a standard disease model. Kanner was a protégé of Adolph Meyer, whose clinical emphasis, case studies, and focus on discrete psychiatric “reactions” to particular stressors, helped set the tone for American psychiatry (Pressman 1997).

Likewise, Bruno Bettelheim's ugly language about the mothers of children with autism was profoundly hurtful. However, it was also emblematic of psychoanalytic approaches to emotional disorders in children at a time when psychoanalytic theory was ascendant in American psychiatry and popular culture. Bettelheim was far from the only professional to locate the traumatic causes of childhood disorders in early experiences. He argued—understandably at a time when many were told to institutionalize their autistic children—that psychoanalysis offered more hope than theories that located the causes of autism in neurobiology. He worked that behavioral therapies taught children tasks that emphasized compliance over genuine learning (see Bettelheim 1967:412; though this is a critique that others have leveled at Applied Behavior Analysis and similar approaches). Bettelheim's belief that a therapeutic environment entirely oriented toward responding to a child's needs could positively influence personality development may not have done much for the children with autism in his care, but it was more humanistic and responsive to their lead than other approaches popular at the time.

The other theme of *NeuroTribes*, the contributions and innovations of people with autism and the social environments that have fostered their gifts, is both the most fun to read and the most difficult to approach in a review. These portraits—some of people with formal autism diagnoses, some without—make the point that people with autism have unique strengths that ought to be cultivated by caring families, friends, and colleagues. These strengths, far from being “splinter skills,” accidental islands of exceptional ability in the context of profound disability, are part of the neurological profile that characterizes autism. Discouraging behaviors that mark people with autism as different, like special interests or sensory

fascinations, may come at the cost of their creativity and calm. Silberman, writing on John McCarthy, the Stanford Computer Science professor, speculates that he would have qualified for an Asperger Syndrome diagnosis. “But McCarthy would have had no need to seek out a diagnosis, because he was able to carve out a niche in an emerging field that was perfectly suited to his strengths while being tolerant—indeed, appreciative—of his many eccentricities” (251).

Silberman depends on some retrospective diagnoses—of Henry Cavendish, Nikola Tesla, Paul Dirac, Hugo Gernsback, John McCarthy. It’s an effective and familiar strategy for demonstrating that the traits that we associate with autism have long been present, and not necessarily marked as pathological, in the general population. One problem though with describing someone without a diagnosis as having autism, and reading their biography through that interpretive lens, is that formal diagnoses shape the experience of autism or any other psychiatric or neurological disorder. A diagnosis is a portal to the therapies and educational interventions a person encounters during their formative years. It determines how their simplest acts are interpreted by friends, family, and experts. Silberman sees how the advent of the Asperger Syndrome diagnosis, and then the parents’ listservs and organization meetings that allowed adults with a diagnosis to find their “tribe,” involved a kind of “making up people,” as described by Ian Hacking (see Eyal et al. 2010:226-233, Hacking 1999). Adult autistics learned to recognize each other, and following that recognition they were able to invent new forms of autistic community. But professional recognition of the diagnosis was a precondition for that experience, so what we as social scientists can learn from retrospective diagnoses has definite limits. Noting that different kinds of minds are indispensable to scientific and technological progress doesn’t require that the owners of those minds be called autistic—and recognizing the singularity of those minds can still teach us important lessons about making a world more hospitable to different types of people.

Silberman dwells on how revisions to the DSM both standardized the diagnosis and formalized Kanner’s criteria as its limits, with the effect of excluding those with milder visible symptoms. Lorna Wing’s introduction of Asperger Syndrome, and its inclusion in DSM-IV, meant that those “higher functioning” individuals who would come together to create autistic awareness were now being diagnosed, but it had the unintended effect of vastly expanding those meeting the criteria for an autism diagnosis, creating the

impression of an epidemic of autism spectrum disorders beginning in the 1990s. Silberman argues that this perceived increase in incidence was largely an increase in diagnoses, an issue on which most epidemiologists concur. Silberman might have included a point that forms the center of Eyal et al.'s (2010) argument: that another key component of this increase in autism diagnoses was the delayed effect of deinstitutionalization, the mass closure of psychiatric institutions. This slow process, which began in the 1950s but continued for decades, meant that many people who would have been previously classified as "mentally retarded" or intellectually disabled were instead described as autistic. Silberman correctly notes that another of Wing's major contributions, in collaboration with her colleague Judith Gould, was to assess children with lower measurable IQs for autism, despite Kanner's insistence and the conventional wisdom that autism only occurred in children with typical or high measurable intelligence.

In Silberman's reading then, autism is a coherent, though heterogeneous, natural entity. This is in line with the claim made by many self-advocates, who have embraced the definition of autism as a brain-based disorder as part of their identity (Fein 2011, Ortega 2009). There are many advantages to seeing autism this way, because it allows advocates to draw attention to the important fact that someone who seems very disabled in one setting or at one time may have great capabilities in another, and that verbal adults with autism who share perceptual or cognitive differences with non-verbal children or adults with autism have much to teach policymakers and researchers about the condition. However, it obscures the socially constructed nature of this category; that autism is not only variable symptomatically among individuals and across the lifespan, but also varies biologically, despite attempts on the part of researchers to wrest coherence from the diagnosis (Verhoeff 2012, Fitzgerald 2014). This fact is important for assessing the legitimacy of spokespeople for autism, whether parents or self-advocates: the idea of autism as a natural entity is historically located, and consequential ethically.

The self-advocates who founded Autism Network International drew substantially on the intellectual work and social advocacy of the disability rights movement, which helped establish that people with disabilities are a social category deserving of civil rights and protections (Shapiro 1994 provides an excellent if now dated history). However, the range of challenges—and strengths—represented by the autism spectrum and other cognitive differences may require more creative forms of accommodation. Eyal

et al. (2010:36) developed David Holmes's (1990) concept of a "prosthetic environment" to describe how changes to surroundings can functionally alter people's capacities. Someone who has significant apparent impairments in an environment ill-suited to them can flourish in an environment matched to their strengths, and can, indeed, acquire even more abilities. But it's also important to recognize that the level of social supports needed by many go beyond acceptance and accommodation. Companies like Specialisterne, which hires and supports adults with autism in the tech industry, and which Silberman highlights as promising evidence of efforts to better include autistic employees in the workplace in his concluding chapter, "Designs for a Neurodiverse World," have a screening process that excludes numerous applicants (Cook 2012). And the data on adults with autism are not encouraging: following high school, many are adrift, not in school or employed, often isolated (Roux et al. 2015; also see Bumiller 2013). Comparisons between people with autism diagnoses and successful computer programmers only go so far, and the real point of divergence is in economic opportunities.

It's also worth noting that environments have real and physiologically important consequences—that's why Eyal's use of the concept of a prosthetic environment, one that a person does not only inhabit but which has corporeal and psychological effects on a person, is so useful. The line between accommodation and treatment, between acceptance and intervention, probably isn't as bright as Silberman suggests. Parents, as Silberman recognizes, though hardly infallible, have been sharp observers of their children's development and perceptive about their idiosyncracies. They have embraced biomedical treatments not necessarily because they can't handle or are ashamed of their child's autism (though that is undoubtedly the case for some), but because they wanted to do what they could to help. Though Bernard Rimland may have always wished for his son to become "normal" (477), many parents are able to reconcile the values of neurodiversity with supportive practices that ameliorate some aspects of autism (Kapp et al. 2012). They recognize that just because a given intervention does nothing for other children, or nothing significant for the population of children with autism as currently defined in clinical trials, does not mean that a given intervention can't work for their child. In doing so, they also take on an ethical question that Clara Park, author of the classic 1967 memoir *The Siege* (reissued in 2001), grappled with, and one that Silberman spends less time on. Debating whether treatments as a whole

are legitimate may keep those interested in autism from asking what kinds of treatment can legitimately be imposed on a child in order to potentially broaden their range of opportunities and choices later in life (Park 2001:10).

Research communities remain devoted to understanding the genetic contributions to autism. They have also affirmed the likely contribution of environmental factors to that genetic risk, though it's difficult to ascertain what those factors are (e.g., Newschaffer et al. 2007). This research is likely to eventually yield both public health recommendations aimed at lowering autism incidence and pharmaceutical treatments for some people with autism diagnoses. It's important to remember that even widely available and standard treatments like Applied Behavior Analysis, begun early, have the power to significantly shift the abilities of children with autism. Determining what the ethics of both research and intervention are, and what it means to treat people with autism in a manner that respects their agency and the legitimacy of their desires, is a challenge that researchers in the social sciences will need to address, and in some cases, are already addressing, sometimes in collaboration with people on the autism spectrum (e.g., Hart 2014, Lappé 2014, Singh forthcoming, Pellicano and Stears 2011).

The focus of *NeuroTribes*, though, is how shifting public and scientific perspectives on autism can fundamentally change what it means to be autistic; how ideas inform treatment programs, organizational structures, and educational practices in ways that can be beneficial or devastatingly harmful to people with autism. In this sense, weighing in on medical frameworks for autism or the nature of autistic intelligence, and changing the minds of families and professionals who care about autism is not merely an intellectual project but an urgent political act. In 2007, the organizers of Autreat, the meeting organized for and by autistic adults, invited a handful of volunteers, myself included, to serve on an "Ask a Neurotypical" panel. It inverted a type of panel frequently convened at parent conferences. Sessions featuring adults with autism allowed parents, eager for insights into their children's behavior, to ask those adults about their daily experiences and challenges. The sessions reflected a genuine desire on the part of parents to understand their children and envision their futures, but the effect was to segregate adults with autism, rendering their participation that of subjects in a "self-narrating zoo exhibit" (438), in Jim Sinclair's evocative words, rather than genuine participants and collaborators.

The Ask a Neurotypical panel at Autreat served both a political and a practical purpose. In practical terms, the attendees posed a number of

questions and we answered as well as we could. In political terms, we participants understood quickly and viscerally the absurdity of questioning members of a social category about the behavior of other members of that group: who was I to say how neurotypical people manage at big parties? I dislike them, too. In another sense, though, and one that Sinclair and the other organizers were surely aware of, the panel wasn't a true reversal. The panelists could walk off the stage and into a social world built to accommodate us. We could laugh about the foibles of neurotypical people and speculate on bizarre neurotypical behavior, because highlighting our own strangeness didn't run the risk of subjecting us to further stigma and exclusion. My recognizing that hurt. That third effect was the best one, and I hope the other participants learned as much from it as I did. Silberman's book aims to recreate something like that experience for a wider audience. He is largely successful, though sometimes at the cost of writing a more accurate historical and sociological account of autism research and advocacy.

Although other authors have covered some of the same ground as Silberman (on history, see Eyal et al. 2010, Nadesan 2005, Feinstein 2010, Grinker 2008, Silverman 2011; and on culture and representation, see Murray 2008 and Jack 2014, as well as key pieces such as Ortega 2009 and Orsini 2009), none has done so in such an accessible and appealing manner. This book can and should reach a wide audience. In that sense, Silberman does not simply chronicle the cultural and intellectual shifts that are changing the way autism and other cognitive differences are understood—he participates in them. ■

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