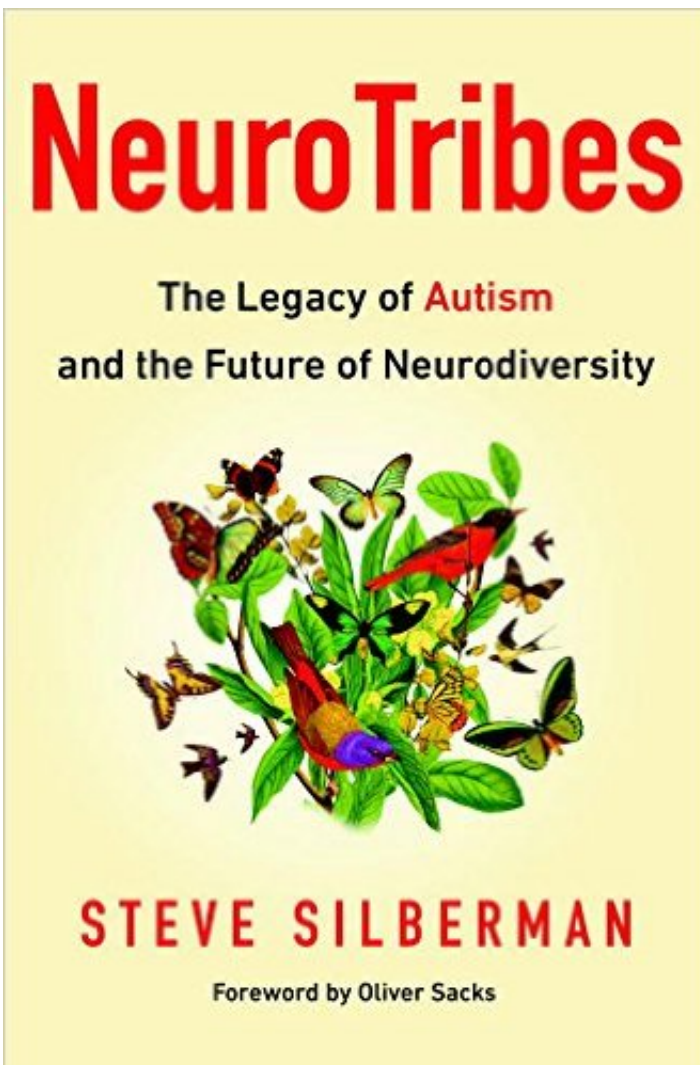


# Researcher discusses neuroscience history and new hope for autistic people

August 25 2015, by Emily Willingham

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*To mark the publication of the book *NeuroTribes* (Aug 25, 2015; Avery/Penguin Random House) by Steve Silberman, whose blog of the same name has been hosted on the PLOS BLOGS Network since 2010, we invited independent science writer Emily Willingham, PhD to review the book and conduct an in-depth interview with the author. Willingham's review and interview follow, with her full bio at the bottom of this post.*

*"Not everything that steps out of the line, and is thus 'abnormal,' must necessarily be 'inferior.'" –Hans Asperger*

The subtitle of Steve Silberman's new book, *NeuroTribes*, is "the legacy of autism and the future of neurodiversity." But Silberman also delineates the legacy of our collective acts of humanity and inhumanity toward those who are different, tracing in exquisite and engaging detail a narrative that is as much about how we treat each other as it is about autism. In his meticulous, haunting, and sometimes hopeful account, he reveals not only the multifaceted features of the neurotribe known as autistic people but also the affiliative inclinations of all humans, the way we gather, clamoring, and build exclusive ways of being around shared beliefs—for better and for worse.

Filling in what was, before this book, a patchwork history of autism, Silberman's story begins in the 18th century and follows the path of autistic people through the decades as they were persecuted, misunderstood, mistreated, killed, brutalized, and institutionalized. The perpetrators in Silberman's telling are scientists, political leaders, and clinicians whose fixation on their interpretation of "normal" led to acts of deep cruelty and inhumanity against autistic people, deeds that span the spectrum from superficial to sadistic.

The narrative arc is roughly chronological, stretching across time and highlighting some of the Big Non-autistic Names in autism's long, strange and often terrible trip: Hans Asperger, Leo Kanner, Bruno

Bettelheim, Bernard Rimland, Ole Ivar Lovaas, Lorna Wing. Although some of these clinicians and researchers contributed critical insights about autism, they all brought their own psychological lenses to their work and interpretations, sometimes helpfully and sometimes to the terrible detriment of the people they thought they were helping.

## **Autism and scientific publishing**

Silberman thoroughly covers the contributions of the various marquee names in [autism research](#), making clear exactly how publications of their work became inflection points for the broader public understanding of autism. An example is Kanner's seminal 1943 paper describing 11 cases of what Kanner called "inborn autistic disturbances of contact."

Like some clinicians and researchers who followed him, Kanner shaped his published research and public talks neatly around his ambition to make his mark in the nascent field of child psychiatry. For Kanner, achieving that goal meant establishing his own narrow interpretation of autism as the archetype of the condition—and obscuring his familiarity with the diagnostic groundwork that Asperger had already laid.

Kanner's success in constraining the definition of autism left many autistic people without support or services for decades. And as Silberman details, Kanner might have been the first autism researcher to channel interpretation to fulfill deep ambition, but he was by no means the last. As the 20th century closed and the 21st century dawned, autism clearly became a path to public attention for academic journals, researchers, and a news media increasingly hungry for readers.

Silberman deals appropriately with the most notorious of these examples, a now-retracted case series published in 1998 in *The Lancet*. The journal, says Silberman, dealt with peer reviewer concerns about the paper by dubbing it an "early report" to emphasize "its speculative

nature" (p. 417). Despite this step, Silberman says, this "early report" became "one of the most influential journal articles in the history of public health ... But it would also become one of the most widely and thoroughly refuted" (p. 420). Discussing this paper in a book covering the history of autism is practically compulsory. But Silberman rightfully treats it as a cautionary tale, showing that when personal and publisher ambitions take precedence over hypothesis-driven science and data, vulnerable populations bear the brunt of the consequences.

## **Studying the 'protocols for personal engagement'**

Midway through his sometimes-harrowing narrative focused largely on the historical context of autism research, Silberman includes what at first look seems like a digressive chapter on science fiction fandom and ham radios. But a step back from the text makes the relevance of this apparent detour clear: That chapter describes the hinge, the tool that autistic people used to open the door to a room of their own, to say 'We Are Here', even if these were words that they could not always speak.

As Silberman writes (p. 245), "The society of hams also enabled shy introverts to study the protocols of personal engagement from a comfortable distance." And ultimately, the ability for autistic people to find and connect with others like them became a lifeline for some. One ham radio aficionado was finally diagnosed as being on the spectrum at age 70 and described connecting with his local Asperger's support group as "like coming ashore after a life of bobbing up and down in a sea that seemed to stretch to infinity in all directions" (p. 247).

The book ends in the present, with the author's portrait of an autism community that is, finally, self-empowered to create a more hopeful place of advocacy, acceptance, and understanding.

After finishing the book, I spoke with Silberman about his research and

writing, his intentions with this careful work of humanity, and his own impressions of the all-too-real characters who have harmed—and sometimes helped—autistic people across the centuries.

Below are some excerpts of our Q&A. [Disclosure: Silberman and I are friends, and he mentions me in the introduction and the acknowledgments of his book.]

**EJW: Your book's opening chapter tells the story of Henry Cavendish, whom you call the "wizard of Clapham Common." Later in the chapter, you weave in the story of Paul Dirac, the 20th-century physicist and the subject of Graham Farmelo's book *The Strangest Man*. What drove your choice of these two historical figures—whose commonalities are obvious—as the opening character sketches in your narrative?**

SS: My problem as I started writing the book was that there were very few accounts of autistic people's lives from the past that were not already overlaid with almost endless layers of clinical clichés.

I've been reading case studies of autism since 2001, and there are these phrases that people all use like 'gaze avoidance' and 'inability to understand satire', and many of these things were just clearly not true or slightly off in crucial ways. So I found that I had to force myself to stop writing in clichés when writing about autistic people.

What was interesting about Henry Cavendish was that he was a guy who was important to history not primarily because of his autism but because of discoveries he made in dozens of fields of science. He was also a guy

whose life was meticulously chronicled by people who knew him, by people who lived immediately after him, and by a couple of historians.

There was meticulous documentation and many descriptions of his personal conduct, which everyone noticed was strikingly odd. But what I loved about the descriptions of his behavior, particularly from the past, was that because the people describing Cavendish didn't know about autism, they were looking at him with completely fresh eyes and making descriptions of what I came to feel confident was autistic behavior, without clichés.

I found that by putting Henry Cavendish and Paul Dirac first, I was able to get dependable accounts of their behavior without its being filtered through 70 years of medicalized clichés about autistic behavior.

For instance, one thing that I thought was fascinating was that Cavendish's contemporaries did notice that he didn't like to look people in the eye, but they also noticed that he didn't want to avoid people. He liked to be around people who shared his intense interests, but he liked to stand off to the side and eavesdrop on what they were saying without being directly engaged. That was an observation Asperger also made [about autistic people].



Asperger performing a psychological test on a child at the University Pediatric Clinic, Vienna, c. 1940

I did not retro-diagnose Cavendish or Dirac, and I tried to avoid doing that because I think it's a mistake that contemporary writers on autism make. In both cases of Henry Cavendish and Paul Dirac, I had sort of higher authorities making the retro-diagnosis.

**EJW: How much of today's current insistence on conformity, normalcy, and cure do you think traces to our cultural heritage of the eugenicist beliefs described in your book, where references to non-typical people, in the context of arguing for their sterilization, institutionalization, or murder, are littered with phrases like "unfit," "social discards,"**

## **"morally impaired," "menace," "hopeless"?**

SS: It's the same impulse behind talking about autistic children as being kidnapped or not leading the lives that they were supposed to lead, both of which phrases have been used by Suzanne Wright, the co-founder of the leading autism organization in the world, Autism Speaks.

It makes me think that it's very important to understand the history of disability to understand the history of autism: We are so used to looking at autism as this isolated medical condition and not looking at it in a social context.

The thing that I tried to do most of all in my book was to situate autism and autism research in its historical context. I'll give you an example: How many times have we read about Asperger's syndrome without being told that Hans Asperger was a clinician who was working in Nazi-occupied Austria?

If you pull the camera back from Asperger's 'little professors', what's going on in the background is bringing Jews to concentration camps and children being exterminated. It's strange to me that people thought that we could understand the history of autism without understanding the social context of every decision that every clinician made, so I situated Asperger in the context of the Third Reich and I situated Kanner in the context of child psychiatry as a new venture in America.

I think that it is crucial to understand the specific decisions that these clinicians and researchers made that had a such a profound effect on autistic people and their families.

**EJW: So many of the people charged with the care and investigation of these children not only**



**dehumanized them but also demonized them. As an example, Lovaas literally treated autistic people like rats, saying that "they are not people in the psychological sense."**

SS: Here's the thing: At the time, parents considered Lovaas a hero because what Lovaas thought he was doing was saving the kids from lifelong institutionalization. The children that Lovaas was working with were primarily the kinds of kids that Kanner would have diagnosed as autistic, and many of them were nonverbal. What we can see now that Lovaas could not see at the time is that much of the behavior of his patients was caused not by autism but by years of institutionalization.

Lovaas routinely saw kids who had bitten through their own fingers and who bashed their heads against furniture. Because the recommended course of "treatment" for autism under Kanner's model was institutionalization, Lovaas thought that the only prayer [these kids had] of not ending up bloody in a psych ward was for him to subject these kids to these clearly brutal treatments. So he thought he was doing something that may have been rough for them but saving them from a much worse fate.

Like Kanner and Asperger, Lovaas's personal psychology played a major role in the treatment of the children in his care. He definitely had a paranoid and hostile attitude towards his early patients.

I talk a lot about [an autistic girl], Beth. He literally beat her with his hands. That was how he decided that punishment—using the word in the very technical way that behaviorists use it—was the most promising approach to 'extinguishing' autistic behavior. He saw Beth as this hostile adversary who was actively plotting against him. It's a weird thing to think that of a child who is basically powerless and in fact in your power.

With that kind of paranoia and hostility toward his patients, the inescapable conclusion is that there was some glitch in Lovaas's personal psychology that enabled him to treat children like that so brutally with behavior that was torture by any standard.

And he [Lovaas] not only treated children like that himself but he persuaded his colleagues, including [B.F.] Skinner, his mentor, that it was OK. The way that he did that was by persuading his colleagues that the children were not really human. He framed his children as tabula rasa upon which Lovaas and his colleagues could inscribe humanity, and that is absolutely horrific. Once you define a person as a non-person, then you'll do anything. The disease of describing another human being as nonhuman is still very much with us and very much unfortunately a part of human psychology.

In the case of Lovaas, that's what he did to the children in his care; in a sense, he thought he had to torture them to prevent them from being tortured. Lovaas himself eventually realized that he had mistreated people who were attempting to communicate with him and that it was actually the children who were the most troubled and most rebellious and most resistant to his control who had the most to say and [were] self-advocating using the only means they had.

It's definitely true that when it comes to how society has treated autistic people, it's neurotypicals who seem to exhibit the most glaring lack of empathy.

**EJW: What do you think of the lack of scientific process and transparency that Kanner's story (and Rimland's, and that of Lovaas) illustrates, combined with what is clearly a passion for power and prestige ... how much did that lend itself to today's negative**

**impressions of autism? What would it be like if Asperger's characterizations and early observation of the spectrum and the high prevalence had established the common wisdom, instead?**

SS: I have no idea what would have happened because the prevailing winds of psychiatry in America for the '40s, '50s, '60s, and '70s were blowing in the direction that there is a normal psyche and that psychiatry is a way to fix psyches that are not normal, and that the way to do that is psychoanalysis. All that would have happened anyway, so if the notion of autism as a spectrum had prevailed over Kanner's notion of autism as a narrow monolithic syndrome, I still think that many of the same tragedies would have unfolded.

Even though it's now almost exclusively associated with autism because of Bruno Bettelheim's book, *The Empty Fortress*, the refrigerator mother archetype was also applied to schizophrenia and many other forms of mental illness. [It] was sexist as well as being factually wrong, so much a projection of anxiety about women in the postwar era taking jobs that had traditionally been occupied by men and women becoming more independent. Once you start picking one thread from the weave, it's hard to figure out how it could have woven itself differently.

**EJW: How much do you think some of the opinions and convictions these researchers had about their "patients" were reflections on or compensation for their own issues?**

SS: One thing that I find fascinating that no one else has asked me yet is the relationship of Kanner and Asperger with autistic traits, in themselves and in close relatives. For instance, it's pretty clear to me—I

suspect that Kanner also thought about this—that Kanner's father was autistic. He wrote a dozen books that only he would read; he never intended anyone else to read them. They were extensively cross-referenced, they were written in Hebrew, and they were books about Jewish law. And his father was socially inept and generally kept to himself, and Kanner sort of charmingly described those books as his father's way of playing solitaire.

Yet Kanner's mother, whom he called Klara the Cossack, was clearly hyper-neurotypical and was very aware of what people thought about her and what people thought about him. Kanner, in his unpublished autobiography, was quite harsh on his mother and his mother's relationship to his father.

I think that Kanner's eventual blaming of autism on mothers, this so-called 'schizophrenogenic mother', loomed largely in Kanner's conception of what triggered autism. And I think that Kanner's own relationship with his mother and father played into that very fateful choice that Kanner made. Equally profound was Asperger's relationship to his own autistic traits. When he was young, he was very solitary. He was ridiculed for being tedious by his classmates.

What saved Asperger from a life of tedious pedantry was joining this Christian youth group, the Wandering Scholars, and they got away from their oppressively Teutonic parents. I think that Asperger clearly related very deeply to the autistic children in his clinic whereas I think that Kanner had a much more conflicted relationship with the children in his clinic.

I don't think Kanner himself had very prominent autistic traits. If anything, he took more after his mother. He was keenly aware of what people thought of him, and he was constantly jockeying for position in his field and doing it exquisitely well to maintain the high regard of his

colleagues, even changing his own memory of what he had said in various papers to fit whatever the prevailing theory in vogue was.

So I think that many of Kanner's mistakes were neurotypical mistakes whereas Asperger was sort of brilliantly autistic in his rejection of the prevailing views among his colleagues, which were Nazi and eugenic. He was able to maintain a deeply humane view of the children in his clinic despite the fact that all of the people around him, including his bosses and former colleagues, were actively involved in exterminating them.

I came across a case that I didn't write about in the book, one of Kanner's early autistic patients. He specifically recommends institutionalization for this boy, and once the boy is admitted to a state hospital, he is re-diagnosed as having childhood schizophrenia. That is one of the major themes in my book. Because when people say autism used to be so rare, what I point out is that in the '50s and '60s, there was an epidemic of what was called childhood schizophrenia in state hospitals and special schools, and if you look at the description of childhood schizophrenia, It. Is. Autism. It's autism, it's autism.

There were thousands of autistic children in state hospitals and residential schools hidden behind other labels: childhood schizophrenia, attachment disorder, symbiotic psychosis.

I felt a profound chill when I came across in the historical record the fact that most of the children exterminated under the secret [Nazi] eugenics program known as Action T4 were diagnosed with either schizophrenia or epilepsy. If you think about it, the two diagnoses that autistic children were most apt to end up with before the concept of autism was invented by Asperger were schizophrenia and epilepsy. So it's obvious that many, many, many of the children exterminated in Action T4 would now be called autistic.

**EJW: Like the narrative around autism itself, the book does not include in-depth historic examples of autistic women (with the exception of brief sketches of girls who had dire fates). Did you come across any historic examples of women who might have met the criteria, and what do you think about the possibility that autistic girls and women might not necessarily fit the mold of having scientific interests (and thus have gone unrecognized) in part because of historic cultural conventions around exposures to such interests?**

SS: In the Kanner chapter, I open with a paragraph from one of Kanner's female autistic patients. I spend a lot of time talking about both Kanner's female patients and what happened to them, and that is in part an attempt to try to balance out the male–female ratio in my historical narrative.

I never came across a trustworthy retro-diagnosis of a female autistic character in history. The problem is that of course Asperger didn't describe any autistic women whatsoever; Kanner did, to his credit. I also followed up what happened to Kanner's original female patients, which is horribly tragic because like so many of Kanner's original patients, they ended up in institutions.

I tried to address that problem because it's a very profound problem and continues to be a problem for autistic women. The inability of women to get a diagnosis is shameful and comes from this decades-long history of autistic women being overlooked. Asperger kind of apologizes for not having an autistic female prototype in his gallery of prototypes. He says

we're not sure if that's because full-fledged autism doesn't happen in women or if we just don't know what to look for, and now we know the latter is true.

It was Uta Frith, one of the great female autism researchers, who mentioned that while a male autistic in the 18th century might have been interested in chemistry, a female autistic might have been interested in weaving: It involved patterns and recurrence and detection of meaningful patterns and is soothing.

One of the real difficulties of writing this book was that one of the most subversive statements made in the 20th century by any scientist was Lorna Wing's statement to me that the spectrum shades into eccentric normality. She pointed out that there is no type of behavior that is uniquely autistic and that is not also possessed by some people who are not autistic.

There's nothing that you can point to and say, "Aha! Only autistic people do this." In fact, people with all kinds of neurology do the same thing that autistic people do. What Kanner and Asperger were so insightful about was that it was a co-occurrence of certain behaviors—this syndrome—that was [autism](#).

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