

Seán Collins ([00:04](#)):

Animal behaviorist. Temple Grandin understands the first rule of TED Talks: Know your audience.

Temple Grandin (audio clip) ([00:11](#)):

Autism is a very big continuum that goes from very severe. The child remains nonverbal all the way up to brilliant scientists and engineers. And I actually feel at home here because there's a lot of autism genetics here. (laughter)

Seán Collins ([00:29](#)):

Dr. Grandin earned a special place in the history of autism. She was one of the first people to publicly disclose their autism, and that helped break down social barriers of shame and stigma and misunderstanding that had literally shrouded the lives of autistic people for generations. In the Forward to Grandin's 1986 book, *Thinking in Pictures*, the neurologist Oliver Sacks wrote that Grandin's openness about her autism provided in his words, a bridge between our world and hers, allowing us to glimpse into a quite other sort of mind on today's program, a conversation about the history of autism and about our understanding of those quite other sorts of minds, and the changing landscape for autistic people in our society. This is the Hear Me Now podcast, coming to you from the Providence Institute for Human Caring. I'm Sean Collins. Thanks for listening

([01:39](#)):

With this podcast episode, we're inaugurating a project to collect oral histories of autism from autistic people and people who work alongside them or care for them or love them. If you're interested in being a part of that storytelling effort, you'll find a link on our website. Hear me Now, [podcast.org](http://podcast.org). Click on the link label, tell us your story. We're going to begin by tapping the storytelling skills of a veteran science and tech reporter Steve Silberman. In 2015, Silberman's book, *NeuroTribes* was published and soon took a place on the New York Times bestseller list. And in Britain, it was awarded the Samuel Johnson Prize for best nonfiction writing in English. The work was groundbreaking, exploring both the legacy of autism, but also the future of neurodiversity. It brought clarity where there had often been confusion and it began to answer questions that have led to even more fascinating questions. I'm pleased to welcome Steve Silberman to the Hear Me Now podcast. Steve, it's a pleasure to meet you. Welcome.

Steve Silberman ([02:54](#)):

Hey, buddy. I'm very honored to be here. Thanks so much for asking.

Seán Collins ([02:57](#)):

It's a pleasure. Autism is a topic you've been tracking now for years, and I'm curious, given everything that you've learned about it after what I'm sure are many hundreds of conversations with researchers and autistic people and family members, how do you describe it? What is autism?

Steve Silberman ([03:20](#)):

I'm gonna give you a very personal, uh, you know, rather than a sort of clinical answer. When I started writing about autism, uh, back in 2001, uh, I was a science reporter for Wired Magazine, and I approached autism as a diagnosis, a syndrome, you know, a conditions that was associated with a checklist of deficits and impairments that defined that condition. But as I got to know autistic people better, as I spoke to researchers, as I started to really get to know autism more from the inside, by hearing the perspectives of autistic people mm-hmm. <affirmative>, I started to think of autism more as

a way of being human. A natural variation, like in a sense, you know, a biologist might notice a, a new kind of flower out there, you know, growing. And so I stopped thinking of autism as, uh, associated with a, you know, a medical condition or a list of impairments and started thinking of it more as a way of being human, and one that was not in particular supported by people who did not have autism, which included, uh, you know, many of the clinicians of the 20th century. So I started writing about a diagnosis and ended up writing about a community that was on its way towards autonomy and fighting for its civil rights.

Seán Collins ([04:48](#)):

Hence the name of your book, NeuroTribes.

Steve Silberman ([04:51](#)):

Yep. I was tired of, you know, basically so many words associated with autism have the negative judgment built in, you know, kind of baked into the word autism spectrum disorder. Well, who am I to say what the order of the universe is supposed to be? So I stopped thinking of it as kind of an automatic, like less than, and started thinking of it as just a different way of being human. Steve,

Seán Collins ([05:18](#)):

Do you remember when that notion came to you? Was it a sort of aha moment, or did you slowly come to a realization that your thinking had changed?

Steve Silberman ([05:29](#)):

That's a very interesting question, and the answer is that there were several aha moments as well as sort of a slow ripening of my understanding. Uh, probably the very first moment that I started to doubt, you know, the inherited idea of what autism is as a, you know, a mysterious baffling mystery or enigma or puzzle or et cetera, was when I was writing, uh, the, the first thing I ever wrote about autism, which was an article called The Geek Syndrome in Wired in 2001.

Seán Collins ([06:04](#)):

(laughs) Such a perfect title for a Wired story.

Steve Silberman ([06:06](#)):

Right, right. Well, you know, there's a very germane bit of inside information about that title, which is that the editor in chief of Wired at the time, Chris Anderson, uh, told me that he wanted to change my title to the Geek Disease. Um, and I, I, you know, I kind of went to the mat against that, and I finally, it's funny, I, I had to prove it to him by showing him that the word disease did not appear in the Autism Society of America website once, you know. But all I can say is, you know, I I point back to the Geek Syndrome, uh, without too much shame because I actually got some things right. But, oh boy, if it had been called the Geek Disease, I would've wanted to bury that headline, you know, in my past forever. But, so one of the moments that, you know, the aha moments that changed my mind was when I was researching the Geek Syndrome.

[\(07:03\)](#):

Um, you know, I was reading medical textbooks and interviews with clinicians and, uh, talking to researchers up at the University of California in San Francisco just uphill from where I live. And so I had, you know, what autistic self-advocates call the medical model, like firmly in my mind. But then one day I

was kind of like just, you know, surfing around on the web, and I saw this website called the Institute for the Study of the Neurologically Typical, it had been created by an autistic woman named Laura Taik. And it was a hilarious pitch, perfect satire of like an American Psychiatric Association listing for, you know, this terrible disorder for which there is no cure, and which is distinguished by a deficit of attention to detail, uh, you know, incredible vulnerability to peer pressure and, uh, desire to speak in small talk. So it was hilarious.

[\(08:05\)](#):

It had flipped the lens of the medical model around and looked at non autism or neuro typicality, or, you know, the major, the neuro majority, uh, under the lens of the medical model. And I thought, boy, that's interesting. Yeah, I've never seen anything like, you know, I've never seen anything quite like that except I had seen something quite like it because I am gay. And when, uh, it was in high school, of course, uh, homosexuality was listed in the Diagnostic and Statistical manual of mental disorders as a, as a medical condition. Yeah. And you could be arrested, you could be put in a mental asylum, et cetera. And what changed? That was a bunch of, you know, uh, gay psychiatrists coming out and also a bunch of, of street queens doing street actions, and they would satirize the medical model. And so it kind of reminded me of that it was a group of people who, you know, I started to, or that was like the first, um, glimpse that I had of what we now call, you know, kind of the neurodiversity movement or neurodiversity culture.

[\(09:16\)](#):

That's fascinating. Yeah. And one of the things that was fascinating about it, by the way, was that it was part of this sort of standard description of autism. Autistic people don't get humor, they do not get sarcasm, you know, and then here was this hilarious, you know, satirical website. And then the second huge aha moment was an autistic self-advocate named Ari Neman, who launched, uh, an organization called the Autistic Self-Advocacy Network, when he was a teenager in high school, had told me basically to go to a retreat for autistic people called a treat. It was run by autistic people for autistic people. And I actually had to sort of get a waiver from the organizer of the conference to be there as a non-autistic person. And, uh, you know, I remember I was, uh, looking for the bus that was leaving for Aery from the Buffalo, New York Greyhound station.

[\(10:18\)](#):

And so I'm like looking for a group of autistic people, um, and I'm thinking like, okay, what should I be looking for? Will they be like rocking back and forth? Will they be sitting apart? You know, will, will they look sad? You know? And so I'm looking around the Buffalo Greyhound station, which is not, shall we say, you know, the most uplifting setting in the world. But I saw this one group of people who were laughing, hugging, having fun, jumping up and down. They were the autistic people, <laugh>. And so we went to a and I spent, uh, almost a week there, fully immersed in what I called in my book Autistic Space. And I noticed a bunch of stuff, which was that for one thing, autistic people not only did get humor and, and, uh, sarcasm and everything, they were hilarious. Um, case in point, Ari had been appointed to the National Council on Disability by President Obama, which caused a bunch of right wingers to raise a ruckus and say, having an autistic person on the National Council on Disability is like having a blind surgeon, uh, and, you know, all this awful stuff.

[\(11:32\)](#):

But finally they dropped their objections, and Ari was seated on the council, and the next day he came to Au So he was like the homecoming hero. And he walks into the room, and a young woman at the back of the room says, we love you, Ari, if we were capable of feeling such an emotion, <laugh>. So when I came back from a and sat down in this chair, or a chair much like it in the same position, um, I, you know, I started typing, you know, kind of my first chapters, and I'm like, okay, so what is the checklist of

deficits and dysfunctions that I should type here to so that my readers know what autism is? And I literally, you know, stopped myself and said, Steve, stop it. This is not how they are. You are just with these people. They, they have much richer inner lives than that. So that was one of the big aha moments that changed my mind.

Seán Collins ([12:27](#)):

That's wonderful. The history of the condition is really fascinating. Goes all the way back to pre-war Vienna and the work of a Austrian pediatrician whose name will be pretty familiar to listeners, I

Steve Silberman ([12:43](#)):

Think, Hans Asperger. Yes, it does. Um, in fact, it goes back farther than that in that, uh, there were descriptions of people who were clearly autistic in the 19th century. And then in the early 20th century, a uh, physician in, uh, the former Soviet Union sva, uh, described a bunch of teenagers in wonderfully humanistic and compassionate detail who clearly had what would later be called Asperger syndrome. But yes, um, you know, sort of the, one of the things that my book did was that while I was writing it, I figured out that the timeline of autism's discovery, which was, you know, reiterated everywhere from thousands of textbooks to Wikipedia, was that autism was quote unquote discovered by this guy Leo Kanner in the early 1940s. And then in some amazing coincidence, um, it was independently discovered by this guy, Hans Asperger, uh, in Vienna a year later that all turned out to be wrong, <laugh>.

([13:49](#)):

In fact, um, I discovered that autism and indeed the autism spectrum, even as we now call it, was discovered by Hans Asperger and his Jewish colleagues, George Frankel and an Weiss at the University of Vienna in the mid 1930s. And many of their insights were incredibly prescient. For instance, at a time when science was just learning about the role of genes in certain hereditary conditions, Asperger speculated that autism was caused by the interaction of multiple genes. There was no autism gene. And yet, when I wrote the Geek Syndrome in 2001, all these parents were, you know, the kinda Silicon Valley rich parents were hoping to find the autism gene. So, you know, <laugh> Asperger and his colleagues had already figured out that that was wrong, uh, in the 1930s. And they also had a very, I would say, compassionate and humanistic view of how to treat autistic people up to a crucial point, which I'll talk about in a moment.

([14:58](#)):

Uh, for example, Asperger talked about a kid who became obsessed with geometry when he was like two or three, and would, uh, draw triangles and circles in the sand. And instead of telling him, you know, will you stop doing that? That's annoying. You know, pay attention to your other subjects or your friends, or whatever. She encouraged that, uh, interest, and he ended up badgering his teachers to give him advanced tutoring in math because they thought that he was too intellectually disabled to understand it. So he got that tutoring because he demanded it, uh, and then ended up going to university where in, uh, I believe his first or second year of university, he detected an error in one of Isaac Newton's proofs. And he ended up becoming an assistant professor of astronomy while remaining, uh, as, uh, Asperger put it, very autistic. Um, he, you know, he wouldn't recognize people he had met the week before while passing them in the street, et cetera.

([16:04](#)):

And so many of the aspects of the model of autism that Asperger and his Jewish colleagues Frankl and Weis came up with were very prescient. But the problem is that in 1938, the, uh, you know, Nazi forces marched over the mountains and occupied Vienna, the On slo, you know, with tremendous violence

against Jews. Frankl & Weiss had already gotten out because the things were looking bad, uh, for the Jews. And the university was being turned into a, uh, you know, sort of a sweat shop of eugenic Nazi ideas. Meanwhile, in Berlin, eugenics laws were passed that specifically targeted children with hereditary disabilities. And I noticed that, uh, two of the largest categories of children who were exterminated by the Nazis in a sort of practice run for the Holocaust were kids with epilepsy and kids with schizophrenia. And because the autism diagnosis had not yet been formulated, most of the kids who were autistic were probably diagnosed with either epilepsy or schizophrenia or both.

(17:22):

So, uh, that, uh, horrible extermination effort was called action t4. And so after Frankl & Weiss left, Asperger decided to stay on at the university. And there's been a lot of controversy in recent years about what his role was once the Nazis started exterminating children. My thought is that he knew it was happening, I believe, but I do not condemn him as stridently as, uh, some of the people, uh, are doing out there, because I think he was in a very, very difficult position, and I think he was trying to save the kids that he could. Did

Seán Collins (18:03):

He stay at the university through the duration of the

Steve Silberman (18:05):

War? Yes, he did. He stayed through everything, and, and he wrote his paper, which, uh, you know, has in it this kind of special plea for the value of the lives of autistic people. Um, and, you know, in the context of normal psychiatry, that plea is somewhat, um, unusual. Like you notice it, like, why is he speaking up like this? And yeah, well, he was speaking up like that because he was being asked to exterminate, um, these kids. Yes, he stayed. What happened to Frank and Vice turned out to be the biggest historical scoop of my book, which is that when Kanner wrote his paper at Johns Hopkins in, in, uh, Baltimore in the early 1940s, it was assumed that he had no connection with Asper whatsoever. While that was completely wrong, in fact, Kanner and his wife had done something really heroic, and they had rescued a bunch of Jewish clinicians who were under threat by the Holocaust, including Frankl & Weiss.

(19:15):

So when Kanner saw his first autistic patient, a guy named Donald t, um, he did not know what to make of him. And he wrote, I saw the card on which he wrote Schizophrenia. So he sent him to George Franco, who knew exactly what to make of him, because Franco Vice and Asperger had seen hundreds of autistic people by then at all ages, and at all, sort of, you know, levels of, of disability from, um, you know, that assistant professor of astronomy that I spoke of earlier, to kids who couldn't talk, and kids who were, uh, needed 24 7 support. So they called that range the autistic continuum, uh, within their own communications in the office. So that was clearly the precursor to the autism spectrum. But Kanner defined autism much more narrowly, and he ended up, instead of talking about the role of genes, unfortunately, he ended up sort of jumping on a bandwagon of mother hating, he attributed autism to refrigerator, mothers and fathers. Right. Um, that idea was popularized, uh, hugely, uh, much later by a guy named Bruno Bettelheim, who was a complete fraud,

Seán Collins (20:34):

Meaning people who were

Steve Silberman ([20:35](#)):

Cold. Yes. Cold, ambitious, super yuppies, basically. And you know, what Kanner was probably picking up on was autistic traits in the, the parents. But it turned out, you know, that Asperger and his colleagues had already figured out what was going on there, which was that yes, the parents had autistic traits because it was hereditary genetic, uh, but that all that opened up avenues of understanding and communication between the parents and the kids. Whereas Kanner just blamed the parents for causing autism. And furthermore, and that had a very dramatic effect on his, um, advice to parents, which was he told parents to put their kid in an institution and move on with their lives, both to protect the kid from the, allegedly, you know, damaging influence of the parents, and to protect the parents and other siblings from the effects of the kids'. Autism, Kanner's theory ended up turning autism into a source of silence and shame. Mm-hmm. <affirmative> for families for the rest of the 20th century.

Seán Collins ([21:44](#)):

So you have a group of children who have been diagnosed with something, but they probably wouldn't have used the term autism who are now institutionalized. Is, is that right?

Steve Silberman ([21:58](#)):

Well, that's kind of right. They, they were often diagnosed with, um, what was called childhood schizophrenia. And that came from, uh, you know, sort of a bunch of, uh, confusion that I write about on NeuroTribes, uh, that's hard to sum up in a, in a sentence. But, um, basically there was this conflict between psychiatrists who thought, uh, that autistic kids grew up to become schizophrenic adults. That's what Leo Kanner thought. And he was completely wrong. Kanner went to his grave considering autism, a form of childhood psychosis. Um, and that's wrong. Autism has nothing to do with psychosis. I mean, sometimes they overlap, but they're not the same thing. So basically, in the fifties and sixties, there was a, a quote unquote epidemic of childhood schizophrenia in mental institutions in the United States, including, by the way, um, Langley Porter Institute, which is just like a short walk up the hill from where I live in San Francisco.

([23:01](#)):

And when I got a hold of case descriptions of, uh, cases of childhood schizophrenia from Langley Porter, it was autism. It was autism, it was autism. It just wasn't called that, it was called childhood schizophrenia. Wow. So where did that epidemic of childhood schizophrenia go? Well, now we understand the childhood schizophrenia, while it does exist, is very, very rare. Whereas autism is very, very common. And so, uh, that was one of the places that I found, you know, as I was writing neuro drives, I kind of played a little game with myself of find the hidden populations of autistic people right. In the 20th century. And behind that diagnosis was one of those places.

Seán Collins ([23:46](#)):

So, so put a pin in that fact that there, there was an epidemic of childhood, uh, schizophrenia and fast forward to the nineties, where a belief that routine childhood vaccinations cause autism. And that idea sort of took over like wildfire, um, in the popular press and discussions about autism. I mean, everyone was talking about it. I remember that the argument was, you know, there didn't used to be so much autism. Where were these kids before all these vaccines came to play? And what you're saying is they were in institutions, they were labeled as schizophrenics.

Steve Silberman ([24:28](#)):

Right. And that's something that I want to make clear, which is that even though, um, I've done a lot of work that supports the idea that vaccines have nothing to do with autism, and, and oh, by the way, Andrew Wakefield the gastroenterologist who, uh, really, uh, launched that theory was a complete hoax and fraud and utterly corrupt, and had a, um, competing patent for the formulation of the MMR vaccine that he hoped would, you know, make him rich once he, uh, put the stink around the MMR vaccine by claiming it caused autism. And in fact, I, I have him on record saying I knew nothing about autism before I wrote my, you know, famous paper. Yeah, that's for sure. Um, but, uh, and he, you know, he did all kinds of things, but what I wanna say is that I completely understand why parents were attracted to that theory. Oh,

Seán Collins ([25:25](#)):

Ab, absolutely.

Steve Silberman ([25:26](#)):

The problem was that there was this inexplicable until I wrote my book, inexplicable, you know, sort of ski jump curve, like climate change of, uh, estimates of autism prevalence and autism diagnoses that started in the, in the early nineties. So it's like, what's going on there? And if you looked at any website for any parent's autism organization, you would see that, you know, that alarming, you know, steep curve of rising diagnoses. And, you know, they would often say, like, in 1950, autism was, uh, determined to be, you know, one in 60,000. In 1960, it was one, you know, so they would have this, you know, kind of suspenseful horror movie buildup to now it's one in 88, you know, and you're supposed to be scared. Well, it turns out that was very intentional, uh, that the diagnosis became much more common because in the late eighties, a British cognitive, uh, psychologist named Lorna Wing was asked by a, uh, you know, representative of the public health, um, to estimate the number of autistic kids in a multicultural suburb of London called Camberwell.

([26:43](#)):

And, um, she and a colleague named Judith Gould went into Camberwell and started looking for autistic kids everywhere. And boy did they ever find them. And the prevailing, um, model of autism in the only model, really, because Asperger's writing were, was, had been completely forgotten, in part because he wrote in German and German papers were not very popular after the Holocaust, let's put it that way. Um, uh, although Kanner almost certainly read that paper because he read that journal. Um, but he ne he did not, uh, even mentioned Asperger's name until very late in his career. Oh, really? Yeah. Wow. And very dismissively. He said something like, you know, oh, what, you know, what Asper described, that's a completely different condition. So Kanner's monolithic, narrow, and basically, you know, white people, upper middle class white people. And so, you know, one, one thing that distinguished upper middle class white people was that they had access to Leo Kanner's office.

([27:52](#)):

Right. To get a diagnosis, you know? Right. So, so anyway, so they wa they walked into Camberwell and saw all these kids who had what they called bits and pieces of Kanner's syndrome. So they might help their mom do the dishes and then go to their room to listen to their favorite record 25 times over afterwards. But they clearly love their parents. And instead of not being interested in people at all, they clearly wanted to have friends. They just didn't know how to do reciprocal social interactions gracefully. And so, uh, wing and Gould started to think, Kanner's model of autism is bogus. It's too narrow, we should get rid of it. But they quickly figured out, after writing a paper or two, suggesting that they

quickly figured out that there was so much sort of vested interest in the autism, uh, diagnosis in the field, that instead of trying to replace Kanner's model, they should supplement it.

[\(28:53\)](#):

So they formulated the diagnosis called Asperger syndrome. Note that Asperger and frontal and vice never came up with a term or even, you know, a, a, a model mm-hmm. <affirmative>, uh, of autism called Asperger's Syndrome. What they came up with was the autistic continuum, or what we now call the spectrum. But one reason why, uh, wing wanted to call it Asperger's syndrome was because Conroy and Bettelheim had stigmatized autism so much that parents didn't wanna believe the diagnosis, because if you gave the kid a diagnosis of autism, there was so much cultural baggage around it that it was like suggesting to the parents that they were inadequate or hostile or damaging or toxic parents. Right. So they got rid of the word autism, you know, came up with this fascinating new <laugh> diagnosis called Asperger syndrome, got that into the dsm, and then all these people who would've been left out of the diagnosis before were able to get support and help the diagnosis starts soaring as indeed, you know, wing and Gould intended. And then Andrew Wakefield this dus, uh, comes along and says, oh, it's because of vaccines. He just didn't know anything. But because it was a good story, you know, I know that you're interested in, in the role of narrative in medicine, Sean, and, um, it was a very good story. It just turned out to be completely false.

Seán Collins [\(30:25\)](#):

Right. And it certainly provided parents who were in a, a situation where they were being blamed and that their parenting was being talked about as a sort of toxic precursor to their child's condition. It gave them an out, a sort of psychological out to find something else that was responsible.

Steve Silberman [\(30:47\)](#):

Yeah, exactly. And it was a very, you know, sort of plausible, uh, explanation. Like, you know, I mean, I've spent a lot of time, um, you know, disputing anti-vaxxers because I've done a tremendous amount of, um, damage to the world, and I must say more damage since NeuroTribes was published because of the, uh, anti-vaccine and anti masking, um, rhetoric around Covid, very much encouraged by the G O P. But, um, you know, basically it was a plausible story because everyone knows big pharma, it can be really corrupt. Big pharma had totally, you know, concealed deaths like with the drug, the heart drug, Vioxx, like they had totally, like, you know, actually killed, you know, people, and then tried to cover it up. And also, you know, a lot of the parents were, um, you know, say they were my age, so we remember Watergate, we remember, you know, the mass corruption of, uh, you know, Nixon and all that.

[\(31:53\)](#):

So it was like, all of a sudden there's this unexplained rise in autism diagnoses. And I mean, that was really what inspired me to write NeuroTribes was that Geek Syndrome comes out, uh, in 2001, hardly anybody's even heard of autism, really. It's just starting to, to get around. Um, and, uh, you know, and then 10 years follows, I'm still writing for Wired, but about other stuff. Um, I thought that my article, the Geek Syndrome, would be completely ignored because I filed it right before nine 11, and so it was supposed to be on the cover of the magazine. And then nine 11 happened. And I thought, oh, well, okay, that article will never see the light of day, really, you know? Um, but instead what happened was, I got email about the Geek Syndrome for 10 years, but it was not like, you know, I gave my kid a vaccine and now he's autistic.

[\(32:50\)](#):



It was more like, I am autistic and was told I was a genius, my whole, uh, you know, school career, but I've never been able to have a job because I can't get through a face to face interview, or now I understand why my uncle used to talk about such and such Battle of World War II all the time, you know, in other words, there were autistic people everywhere, but they were wrestling with much more basic, um, problems of access to human services, like housing, employment, healthcare. This was before the Affordable Care Act. Um, and so I thought, why is everyone talking about vaccines? Like, it's not that, I mean, I kind of knew why they were doing it, but it was also, I knew it was wrong, particularly after a bunch of studies came out that tested, uh, hypothesis. And so, why, you know, I, I was asking myself, why is everyone obsessed with the wrong questions about autism? And I realized that what I would have to do is tell a story that was as compelling as the vaccine story. But unlike the vaccine story, it was a true story <laugh>, and it really did explain that, you know, that spike in diagnoses,

Seán Collins ([34:05](#)):

I'm talking to Steve Silberman, author of NeuroTribes, the Legacy of Autism and the Future of Neurodiversity. When did you see a turn? Um, and I mean, a turn towards thinking about how autistic people can function in society serve happily and productively. When, when did it go from being a very grim diagnosis to a livable condition that can be accommodated?

Steve Silberman ([34:36](#)):

Well, that happened over time and is mostly, um, attributable to the efforts of autistic self-advocates. And, um, two of them that come to mind. Um, I mean, obviously my book helped, but it was, but it was going in that direction already. Um, and I, you know, in a sense, I got to, um, surf this wave of awareness, uh, in a way that probably only comes to a writer once in life. Um, but, uh, it was pretty amazing because when I started writing NeuroTribes, um, I thought that I was, I mean, to be honest, I thought I was quote unquote committing career suicide. Like that was the phrase that would ring in my mind at three in the morning, um, because I knew that I was writing a book that was unlike any other autism book that had ever been written. But I thought maybe that was a bad sign, you know?

([35:28](#)):

And so I was like, I didn't even send any chapters to my incredibly patient editor for like five years, because it was, I had been told she was a tough case, and, you know, that if she didn't like the chapters, that she might scotch the deal, you know, that turned out to be wrong, you know? And plus my editor loved the book. But, um, boy, I wish I had known that while I was writing it. But, you know, basically what what changed things was, uh, the autistic self-advocacy movement, and also the popularity of the first autistic adult to come out in a sort of a mass way Temple Grandin. Um, temple Grandin is an industrial designer. She designs, uh, facilities for livestock. Um, one of the ways that she does that, she very much empathizes with animals, as many autistic people do. And so she sees the facilities from the animals' perspective, uh, and that helps her design facilities that are less frightening, uh, for livestock.

([36:32](#)):

But anyway, so, uh, Oliver Sacks, she wrote a book called Emergence Oliver s Sacks wrote a profile of Temple in the New Yorker, called an Anthropologist on Mars, which then became the title essay of one of his great bestsellers. And Oliver Sax was not only, you know, my friend, but he was also an, an incredibly compassionate and precisely observant clinician. And an anthropologist on Mars was far and away the most humane, um, portrait of an artistic person that had ever been written to that point in history. And it's, it's profound that when, uh, temple Grandin wrote her autobiography emergence, um, she wrote it with a, a ghost writer or a partner collaborator. Um, and so when Oliver first heard about

that book, he assumed that the ghost writer must have done, you know, the heavy lifting of turning it into a story, because autistic people were allegedly not interested in narratives.

[\(37:44\)](#):

Um, but then once Oliver started to read Temple's papers in the, you know, livestock industry magazines or whatever, um, he saw that she had a very inimitable voice and that she was writing as herself. And what's so interesting about emergence is that the first additions of it, uh, carried an introduction by a guy named Bernie Rimland, who helped launch the autism parents movement in America. And he, I talked about him a lot in my book, and he was a very mixed figure because he, um, did wonderful things for the parents, uh, of autistic people. But, um, he also was early on to anti-vax long before Wakefield, actually. He probably thought, in fact, Wakefield might have gotten the idea from, uh, Bernie rim's writing. But, um, so basically, uh, what happened was Bernie Rimland said that this was, Temple's autobiography was a book by a recovered autistic person.

[\(38:51\)](#):

She used to autistic. She no longer was, well, now we know, you know, I mean, temple Grandin has written many, many, many books since then. She's certainly not anything but a proud autistic person. And so, temple, uh, appearing in the New Yorker, and then in the, in the, uh, anthology by all of her sacks of his essays. And, uh, there was a guy named Jim Sinclair, who, um, is a very brave person, was sort of the Martin Luther King of neurodiversity in a way. Um, and he wrote an essay called Don't Mourn for Us, which was, um, the astonishing, um, you know, kind of must read if you're interested in neurodiversity. It's a short essay about, um, people treating their autistic children as if they were dead, basically, or as if they were tremendously disappointing. Um, and, you know, Jim spoke up for, you know, he himself and his brothers and sisters, um, and said, actually, we are, you know, we are us. We're just us. We're, we're, you know, independent, um, lovable people. You just may not be able to love us <laugh>, you know, the way that you're used to, but you can learn, you know, so, uh, don't mourn for us. And the Temple Grandin, um, uh, you know, experience of her, her wonderful, you know, personality in the media, um, I think really, uh, was the first big push in that direction. Yeah.

Seán Collins [\(40:31\)](#):

The subtitle of your book, NeuroTribes Includes the Line, the Future of Neurodiversity. What did you mean by that?

Steve Silberman [\(40:40\)](#):

Well, neurodiversity is a term that was, uh, come up with by a woman named Judy Singer, who was a graduate student in Australia, uh, and a journalist named Harvey Bloom, who used to write for the New York Times. Um, they were in a, uh, an online discussion group called Independent Living on the Autism Spectrum, um, that was run by a programmer in Europe named Martin Decker. Uh, I write in the book How Online Communities, um, provided a safe space, uh, for artistic people to communicate, or particularly autistic academics. Um, and so some of the earliest, you know, medicines as they, as we used to say, right, were autistic. Um, so because they were autistic people in academia who had access to the, to the, you know, the primitive internet, Usenet, the news groups, all these things that have been completely forgotten. The well, the well, yes, absolutely.

[\(41:43\)](#):

Um, and so there was this, you know, uh, online mailing list called Independent Living on the Autism Spectrum. Uh, there were many women on the mailing list. They would talk about, um, you know, uh, how do neurotypicals use eye contact? Like, I don't understand this, and, you know, so they decided

collectively that eye contact was obligatory at the beginning of a conversation with a neurotypical, but, you know, then became more optional. So it was like hilariously, you know, knowing. But one of the things that Judy noticed was that every single word for autism impairment deficit disorder, syndrome, condition, they were all medical terms. And Judy had been mentored by a, uh, a psychiatrist, I believe, or psychologist, maybe a union psychologist actually, who grew up with polio, so was a wheelchair user. And, uh, that person impressed upon Judy, what's known as the social model of disability, which is instead of saying like a disability, like autism is a flaw, uh, in the person which should be corrected, uh, it looks at disability in a social context as, um, a mismatch between the person's needs for support and, and, uh, uh, you know, just living daily living, uh, a mismatch between the person's needs and their environment.

[\(43:20\)](#):

So disability is not a flaw located in the person. It's a flaw located in the relationship of the person to society, thus the social model of disability. And so, Judy started to think of autism in terms of the social model of disability, even though considering autism, a disability wasn't even, um, uh, the prevailing belief at the time, the prevailing belief at the time was autism was this baffling mystery, you know, and possibly a plague of some sort, you know? And so she started to think we need new words, um, so that we can talk about who we are and what we are without automatically stigmatizing ourselves. And so she and Harvey Bloom came up with the word neurodiversity, um, you know, noting, uh, the existence of words like biodiversity in a rainforest, biodiversity meaning a wide variety of life forms that can adapt to different conditions, um, uh, increases the resilience of that biological community.

[\(44:28\)](#):

And so their notion was that that neurodiversity would increase resilience in human communities as we face new challenges like climate change. And I see, you know, people like Greta Thunberg as a neuro divergent response to changing, you know, unpredictably changing conditions in the environment. She's been, she's an, you know, autistic teenager, one of the most outspoken youth leaders in the, uh, anti-climate change movement. And she's, you know, totally frank and totally honest, and calls out the hypocrisy of, you know, these people who go to these conferences or oil company executives or whatever, as complete hypocrites. And she does that in a way that is very autistic, actually. Um, one thing that I have noticed over the years is that, uh, a passionate interest in social justice is so closely associated with autism that it could be diagnostic even. Um, many of my autistic friends are, are very keen on social justice and profoundly disturbed, um, by hypocrisy and lying. Now, that's not to say everyone, you know, I know autistic liars, you know, I know autistic MAGA fans, you know, but, um, I, uh, uh, you know, so I'm not saying that autistic people are all saints, but there is this very keen interest in social justice. And so it was sort of natural that once the community could see itself, um, both in the rising number of diagnoses and also see each other in social media, that they would form a movement to demand their equal rights.

Seán Collins [\(46:16\)](#):

Yeah. Well, you know, the empowerment that we've seen among autistic people having the agency to direct their lives in their, their futures, it's, it's just such a far cry from the future and visioned in a sort of diagnostic health that was prevalent when you and I were kids. I mean, if we knew anything about autism, we knew that it was a sort of inescapable, um, there was hopelessness attached to it. And it's so different now the way we think about autism.

Steve Silberman [\(46:50\)](#):

That's true. And, you know, I can point to a very, very interesting historical inflection point that hardly anyone notices. Um, everybody knows that Rain Man was, uh, you know, one of, well, the first time that most people ever saw an autistic adult on screen. And in fact, one thing that's been forgotten about Rayman was how revolutionary that was. It. Now, it sort of looked back on even by young autistic self-advocates as this kind of embarrassing, you know, uh, Sava stereotype. Oh, he is counting toothpicks, you know, it's like, like the autistic equivalent of the boys in the band for, you know, for gay people. Um, but, um, it was actually a very revolutionary and groundbreaking film. But here's what's so interesting about it, um, that hardly anyone knows. Uh, I, I do have a chapter about it in the book. Um, the real life autistic characters that Dustin Hoffman based, his character of Raymond Bait, they were not in institutions.

[\(48:00\)](#):

They were living their lives. Their parents were, you might say, early adopters of the neurodiversity paradigm. They were parents who refused to put their kids in institutions. And in fact, one of those parents was Bernie Rimland. And in fact, one of the models for Raymond Bait was Mark Rimland, who, uh, I met and spent the day with, and is one of the most, you know, that he was, when he was young, he was so difficult that, uh, that, you know, Bernie launched a parents' movement to cure kids like him. Well, anyway, he's now a middle age. He's an artist, and he's just a delightful person. Uh, his parents are no longer alive, but he has a very comfortable niche for himself, uh, in this town where the Remands lived. Um, so the real characters that Rainman was, was based on the character of Raymond Babbit.

[\(48:56\)](#):

Um, they were not in institutions. And yet, if you remember, at the end of Rainman, Dustin Hoffman has to go back into the asylum because, uh, a, um, an autism, an autism expert who was otherwise a very good guy named Darrell Chor, told the screenwriter, no, no, no, you know, in the end, he can't just move to Las Vegas with his brother Tom Cruise <laugh> to, you know, to, to dominate the, you know, the poker table, whatever, you know, he's gotta go back into the asylum because that's what happens to autistic people. And so Ray was already onto something early, but then, you know, it got sort of slapped back by an expert who said, oh, we can't have autistic people just running around in the street. They'd never make it <laugh>.

Seán Collins [\(49:49\)](#):

Oh, man, I have a, I have a friend who's an M.D./Ph.D, neurologist and psychiatrist, and, um, a lot of his research involves functional MRIs and mapping the brain. And he's made the point to me more than once that, you know, so much of the literature, so much of the research, and not just in psychiatry or neurology, but surgery, for instance, talks about the typical brain and, you know, diagrams the typical brain, and he'll look at you and say, no one has a typical brain. Yes. There is no such thing. Yes. As a typical brain.

Steve Silberman [\(50:34\)](#):

Absolutely.

Seán Collins [\(50:35\)](#):

And the notion of neurodiversity, uh, we might as well just call it being human, right? Everyone's brain's a little bit different.

Steve Silberman [\(50:43\)](#):

Right. Well, you know what's funny is there's a very dramatic demonstration of that in, uh, autism research history, which is that, um, basically there have been, you know, a million studies, uh, what causes autism, too much white matter in the brain, and then they, you know, the, you see the diagrams, oh, look at the, it's white matter, you know, and then like, the next study is like, what causes autism too, little white matter in the brain. And then, you know, you look, it's like, well, actually all you're doing is you're describing the brains of one group of autistic people, and the next group of autistic people whose brains you might measure might be completely different because everybody has a different brain.

Seán Collins ([51:25](#)):

Steve, I see that there's another book from you on the Horizon, A Taste of Salt. Can you tell me anything about that?

Steve Silberman ([51:32](#)):

Yeah, the Taste of Salt. Um, it's a book about cystic fibrosis. Uh, one of my very best friends has cystic fibrosis, um, and, uh, the, the seed of the new book, which by the way, will not be coming out for a couple of years. I'm very much working on it now. Um, but the seed of the new book was started when I had this friend who I made online. We met, uh, because we're both fans of the Grateful Deads,

Seán Collins ([52:00](#)):

That's Steve Silberman, co-author of The Skeleton Key. I might add

Steve Silberman ([52:04](#)):

<laugh>, right? The skeleton Key, A dictionary for Deadheads. Uh, very few people know that I wrote both books, but in any case, so I'm coming out as a dead head.

Seán Collins ([52:13](#)):

Here. I'm standing squarely in the middle of the Venn diagram at the moment.

Steve Silberman ([52:16](#)):

Right, exactly. And being gay, it's like ridiculous. But so, uh, so, you know, basically what happened was I was talking to this guy Phil, for years about the Grateful Dead Online, and he seemed like a really incredibly sweet guy. Um, and so eventually we got to know each other enough that we could sort of confess, you know, the things to each other that we were holding back, uh, with a worry that, you know, the other person wouldn't wanna be friends with us or something. So I came out to him as gay and, and told him I was very happily married. And, you know, of course he was completely cool that because he is not a monster, you know, he is a good guy. Um, but then he told me, well, you know, I should tell you something. I had this condition called cystic fibrosis.

([53:00](#)):

And I was like, oh, what is that? You know, I hadn't heard much of that, and I hadn't heard much about cystic fibrosis, even though I was a science and medical writer. It turns out that the story of cystic fibrosis is one of the most astonishing successes in medical history, but very few people know about it because cystic fibrosis was mistakenly considered very rare. Which if you'll notice as an an echo of NeuroTribes and in NeuroTribes, a community became aware of itself, um, because of changes in the diagnosis and because of the advent of the online world, um, in, in, uh, the taste of Salt, a community becomes aware of itself because they were able to survive their childhood. Whereas when, uh, my

friend Phil was born, which is not that long ago, he is much younger than me. Um, they were, people at CF were told, you're gonna die when you're a teenager, or you're gonna die when you're 30.

(53:59):

And so basically there's a whole generation of people out there who were told that they were gonna die pretty soon. So retirement, forget it, you know, having a family of your own, forget it, having a career, eh, go work at Starbucks. You know? So, um, basically this is an entire community that is in the existential position of not thinking that they would be alive at this point. Wow. And because of various medical successes and not just a new drug called Tri Kafta, which is a wonderful, amazing, and life transforming thing, but also because of a bunch of other research I write about, they exist and they're not dead. And so they have to think about what are they gonna do with the rest of their lives. And so I thought that was an interesting, uh, existential, uh, question that I could pursue while, um, finding out more about, you know, what has kept my friend alive long enough to be my friend in the first place.

Seán Collins (54:57):

I can't wait to read it. And I, I hope you'll come and talk with us about it when the book comes out.

Steve Silberman (55:02):

Thank you. I look forward to it.

Seán Collins (55:04):

Steve Silberman is the author of NeuroTribes: the Legacy of Autism and the Future of Neurodiversity. You'll find links to his website and TED talk, and much more on our website. [www.HearMeNowPodcast.org](http://www.HearMeNowPodcast.org). Steve, thanks so much for taking the time to chat today. Enjoyed it.

Steve Silberman (55:22):

Thanks so much. It was delightful, Sean. I appreciate it.

Seán Collins (55:33):

The Hear Me Now podcast is a production of the Providence Institute for Human Caring. Do us a solid and subscribe. You'll find the Hear Me Now podcast on Apple Podcast, Google Podcast, Spotify, and just about anywhere else you get your audio on demand. The program is produced by Scott Acord and Melody Fawcett. We have research help from medical librarians, Amanda Schwartz, Seemah Bahkta, Sarah Viscuso, Katherine Gibbs, Carrie Grinstead, and Heather Martin. We couldn't do it without them. Our theme music was written by Roger Neill. The executive producer is Michael Drummond. Join us in two weeks when we ask whether surgery is still a boys' club, and look at ways that women have been changing the profession. Best wishes to listeners in the US who are celebrating Thanksgiving. I'm Sean Collins, for all of us here, we're thankful to Steve Silberman for joining us today, and thankful for you listening. Be well.