

# [“Neurodiversity is not an opinion. It’s a living fact”](#): Interview with Steve Silberman

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Transcribed by Julie Ann Lee

(Theme song – soft piano music)

**Anne:** Welcome to Noncompliant. I’m your host, Anne Borden King. Steve Silberman is an award winning science writer whose articles have appeared in *Wired*, *The New York Times*, *The New Yorker*, and many other publications. He’s the author of *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*, which Oliver Sacks called a ‘sweeping and penetrating history, presented with rare sympathy and sensitivity.’ The book became widely praised as a best seller in the United States and the United Kingdom and it won the 2015 Samuel Johnson prize for non-fiction. It was chosen as one of the best books of 2015 by *The New York Times*, *The Economist*, *The Financial Times*, *The Boston Globe*, *The Independent*, and many other publications. His TED talk “The Forgotten History of Autism,” has been viewed more than a million times and translated into 35 languages. Steve lives with his husband Keith in San Francisco.

Steve Silberman, hello, thank you for being here!

**Steve:** Hello! It’s an honour to be here. Thank you for asking me.

**Anne:** Thanks. I wanted to open by quoting from 16-year-old climate change activist, **Greta Thunberg**. I’m going to read it in English because she said it in Swedish, on a talk show on January 19 this year. So, Greta Thunberg says “If I didn’t have Asperger’s and I wasn’t so strange, I would have been stuck in this social game that everyone else seems to be so infatuated with, but it makes me function a little bit differently. I see the world with a different perspective, and I think that if I didn’t have Asperger’s, I wouldn’t have been able to see this from the outside. I see things very much in black and white, and most people say “it doesn’t matter if you do a little of this, nothing is black and white,” but the climate question is actually black and white. In one way it’s one of the most complicated questions that exists and it will take a huge effort to stop it, but the solution is still so simple that a five-year-old can understand. We have to stop emissions. It *is* black and white.”

I’m wondering what you think about that and the way she contextualized it within her own diagnosis as well.

**Steve:** Well, I think that’s a really beautiful statement ...and I’m so inspired by the actions of young autistic people like Greta and also, I’m sure you’re familiar with a kid named **Dara McAnulty** from the UK – @NaturalistDara on Twitter who went on strike from school to protest climate change. I think yesterday he was the only kid in his school who walked out, but he talked about how glad he was to do it because it was such a serious issue. Something that I’ve noticed in talking with autistic people for many years now, that I’ve never actually seen in a textbook about autism, and I think it’s really interesting – is I think autistic people have a very strong ethical sense of the world. And they are very sensitive to unfairness or hypocrisy or lies. There’s a wonderful moment in Hans Asperger’s writing when he talks about an 11-year-old boy in his clinic and he asks the boy if he is religious and the kid

says, 'I don't like to say I'm not religious, I just don't have any proof of God.' And that was an example of what Asperger called *autistic intelligence*, and I know what he means. I feel like autistic people whether they're thinking about how other autistic people are treated, whether they're thinking about Behavioural Therapy or any number of the other terrible things like quack cures and anti-vaccine lies, that have been really oppressing autistic people for decades, they're very sensitive to inequality and hypocrisy. Climate change is probably the biggest threat facing the planet and I know a lot of autistic people are very upset about it and very sensitive to ways that neurotypical society is not responding adequately. So, I think it's beautiful and I think it's very appropriate for Greta to locate her response within the context of her diagnosis.

**Anne:** It really is. I like what you're saying, and there hasn't been research on this idea of ethics and authenticity or just being interested in truth. I think it is over-represented in us [compared to] other groups. And I guess now with what's going on in the world, I'm really concerned about the impact of what we're currently living through with so much false news. What's the emotional impact, right? – on people who value truth or who maybe need the stability of truth around them. Some people need it more than other people. What kind of impact that's having on all of us.

**Steve:** Yeah. And that's a very beautiful way to put it, I think actually. I mean one thing that I don't want to do is, I don't want to cross over into creating a stereotype where, you know, it has been said, 'autistic people can't lie' ...well that's not true, you know. I mean I've certainly had autistic people lie to me or about my book or whatever particularly if they are sort of anti-neurodiversity people. So it's not true that autistic people are *unable* to lie, but even in the cases of the people I was just talking about, in their own way they're sensitive to unethical behaviour and what-not, even if they're doing it themselves.

I think that it's very important to consider as we think about the gifts that autistic people can bring to the larger neurotypical society that a finely tuned sense of ethical authenticity is part of that gift.

**Anne:** Hmm. I'm thinking about your Twitter account while you're saying this, because you have a very popular Twitter account, with autistic and non-autistic followers. 101,000 followers I think it is.

**Steve:** Yeah.

**Anne:** It's picked up obviously a lot since election time 2017 and I think you've played this incredible role as kind of a documenter. You're synthesizing all of the information out there, what's true and what's not true, commentating, kind of validating, a truth teller. Like, even when you're talking about bad news, I kind of feel better when I read it, because it's just speaking *the truth*...talking about what's happening as we're living in this age where the administration is basically trying to tell us 2+2=5.

**Steve:** Yeah, absolutely! And a lot of that is me trying to console myself in a sense. You know I have family members who are Trump supporters, members of my husband's family and that is...it's very, very difficult for me to understand it. Like it literally keeps me up at night that people who have for instance supported my marriage to my husband and who seemed like, you know, ethical Republicans have been dragged into this racist place where they're supporting someone who obviously tells big lies every day. The fact that that happened came really as a shock to me, particularly because I had just written about the descent of fascism onto Austria and Germany in *NeuroTribes* and you know in a sense, even though I didn't know it, it kind of anticipated some of the things that were about to happen in America--although I would have been horrified if someone had told me that that was going to happen. You know, all the

time I was writing *NeuroTribes* Obama was President, and you know thank God we weren't living under Trump yet. It would have been very difficult to even get up the gumption or the spirit to write *NeuroTribes* under Trump, because there's so much being destroyed in front of our eyes every single day. Everything from norms of governance to the actual value of the spoken word. So it's been very-very difficult for me to watch even people close to me, even people who I formerly trusted for decades adopt, support, or silence...you know, strategic silence. I was just having this discussion with my husband actually – one thing that nobody talks about are the Germans who stayed silent as Hitler rose. It's like, we don't say 'not all Germans supported Hitler'. Oh really! – you know, it's like it doesn't really matter, once the Holocaust happened!

**Anne:** Yeah.

**Steve:** ...but we're seeing now that people can be simply silent or you know supporting a party that supports one of history's greatest villains, I believe. And so yeah, it's been a very emotionally challenging time.

**Anne:** I think it has and we're getting the news in a different way now. ...I don't know...I definitely stay up too late on my phone...being curled up and having my phone there and looking at it – I mean, it's, it's a different world because there are also a lot of things in that world that I *do* like and gravitate towards.

**Steve:** Yeah. And you know it is all happening within a context of lots of progress in other areas, and now it's like a big boulder sort of fell off a mountain in the middle of the road and is blocking progress but one of the things I'm very happy about is this world has changed in some very particular and good ways since I started writing *NeuroTribes*--in ways that make me very happy.

For instance, even the word *neurodiversity* was kind of a new and strange thing when I wrote the proposal for *NeuroTribes* and in fact I had at least one major editor in New York who I really actually wanted to write the book for say 'well, you should just talk about neurodiversity but don't talk about all this history, but you have to introduce this concept.' And then in England they didn't even use the word Neurodiversity in the subtitle of my book. It's called – it may be true in Canada as well, I don't know – called *NeuroTribes: The Legacy of Autism and How to Think Smarter about People Who Think Differently*, which, you know is fine but I think it's a little cumbersome, at least compared to *The Legacy of Autism and the Future of Neurodiversity*.

And you know, like some of the things that I've seen are **autistic people demanding more representation**, in media when there's a story being told about them or when there are actors playing autistic people. They are demanding more input into news articles about autism

**Anne:** Mm-hmm.

**Steve:** When I started writing *NeuroTribes* it was very unusual to hear the voices of autistic adults in news articles about autism which made it kind of 'now here's an article about feminism with all men.'

**Anne:** (laughter)

**Steve:** (laughing) and so, I'm very happy to see that it's become on the radar of at least some of the better reporters to talk to autistic people when they do an article about autism, and that's something

that I always try to do myself if I'm called for a quote, which I often am. I often say 'well, have you spoken to autistic adults?'

**Anne:** Right.

**Steve:** Because that's really the most important thing you could do. And you know part of the reason why I'm sensitive to that is because I'm gay and I grew up at a time when homosexuality was in the DSM. It was a mental illness, you know in the 'Bible' of psychiatry. I remember when I was a little kid, I would watch tv talk shows and they would have, you know a gay man there but he'd either be wearing a hood or his face would be blacked out...

**Anne:** Yeah.

**Steve:** ...issues of representation in media are coming to the fore in this day and age, driven by autistic people and I think that's a really positive development. I'm seeing a lot more push back against, quacks offering phony cures, and anti-vaccine people. The sad thing is that at the same time lately the anti-vaccine forces have been rising. Which is really a tragedy now that we have measles epidemics breaking out in several countries at once. You know another great kid--he's not autistic--but did you see the kid, **Ethan Lindenberger**?

**Anne:** Yes, yes.

**Steve:** - Got vaccinated even though his mother is an anti-vaxxer.

**Anne:** I know people that have done that too, yeah.

**Steve:** Yeah. And he's wonderful. I became his friend on Facebook. But what's kind of amazing is the viciousness of the people who went after him. He's 18, you know, and they were trying to prove he was fake (which he isn't) and his [Facebook] wall just filled up with vicious attacks... he was just making a decision...

**Anne:** Right.

**Steve:** ...that he thought was wise for global public health, and I really support him. So, I think we're at a really interesting moment when the forces for good are very strong and the forces for evil are very strong, and so, you know, its not exactly a relaxing time to be alive.

**Anne:** No!

**Steve:** But, a very interesting time.

[14:47]

**Anne:** Definitely, definitely. I want to talk more about the technology we've just been talking about... social media and some of the positive aspects of it, and the stresses that come along with it as well because everyone's in there. You said in an interview with *The Sun* which we'll link to on the blog, you said: "In a sense, through the use of technology that encourages us to text instead of talking to face to face, the world has become slightly more autistic and maybe that's no accident. People with autistic traits are often involved in the *development* of new technologies." I found that so interesting.

**Steve:** That's definitely true. I don't go as far as some people, you know **Temple Grandin** likes to talk about Silicon Valley as if everybody there could get a diagnosis practically. I think that's a little overly hyped. I would say what is definitely true is that Silicon Valley is full of people with autistic traits and autistic kids, and that autistic traits have been associated with the development of new technology even before the development of the diagnosis of Asperger's Syndrome.

One of the things I found in my research for *NeuroTribes*, was that a marriage and family therapist had written a book in the 80s called *Silicon Syndrome* and it was about basically the early communities of people who were developing technology in what was not yet called Silicon Valley but would be someday, and she described men whose interests were narrow but very deep, who had few friends but they tended to be friends who were involved in whatever interested them. If they had problems in their marriage they would, as she put it "seek data like Mr. Spock" and so I actually talked to her and I said, "did it ever occur to you that you were really writing about Asperger's Syndrome before there was such a label?" And, it hadn't occurred to her. She hadn't thought about it, but that struck me as very interesting, that even before the notion that Silicon Valley was full of people who were somewhere on the spectrum that there were people with clearly spectrum traits working there, developing new technologies, and the more that I looked at that, the more that I found that that went back decades.

**Anne:** Right.

**Steve:** People who were cracking code – the Enigma code at Bletchley Park in England and helped the Allies win World War II. That **Alan Turing** was probably autistic as well as gay, and I think that's... Oh, in fact I remember something that's not in *NeuroTribes*; it was the most haunting fish that I almost caught and then lost. I came across a reference somewhere to a guy in the 19th century who seemed to be autistic. He lived alone, he liked it that way. He lived in this little village in Europe. He would not attend the Friday night dances that everyone went to in this little town, but what he did do, was that he had an incredibly sophisticated understanding of all the drains in town, so he fixed everyone's drains and kept them running smoothly. It occurred to me like this guy was like a systems thinker...

**Anne:** Right.

**Steve:** ... before there were systems.

**Anne:** Yeah, yeah!

**Steve:** Before their existence. So I think that's why I say that I think autism is one of the shades of the human spectrum that has contributed to the development of science, art, technology, music. I mean, look at **Glenn Gould**, the videos of him playing Bach. (A) they're so beautiful and (B) he's so autistic.

**Anne:** Right. And certainly math too and... You talk in your book about conceptualizing neurodiversity in terms of human operating systems. you say 'just because a computer isn't running on Windows doesn't mean that it's broken; and that one of the wonderful things about the internet it is sort of platform agnostic.' I'm wondering, if you applied this *platform agnostic approach* to the real world, basically, that would be accessibility and inclusion.

**Steve:** Oh, absolutely. I think it's what people talk about when they talk about 'universal design'

**Anne:** Mm-hmm.

**Steve:** ...you know, universal design for learning for instance in schools. I think what we're doing as a society is that we're evolving from a rather primitive understanding of human normalcy. For much of the 20th century, psychiatrists almost acted like secular priests, kind of helping everyone get to this 'saved' place where they're allegedly normal.

There is no normal human brain, there's just human brains and it is true that some human brains have such significant challenges in dealing with a world that is not designed to support them that they need accommodations, but that's just part of life. I mean, we all need accommodations, like I can't walk up 10 flights of stairs so there are elevators.

**Anne:** Right.

**Steve:** We've gotten so used to accommodations for neurotypicals that they're kind of invisible in the world, really. That's just the way the world is. But, I think as we understand that there're all different kinds of human intelligence, all different kinds of brains and some brains are dyslexic, some brains are autistic, and some brains are ADHD and that's just the way it is, and there're a lot of those people and unless you want to ignore those people (which sentences them to leading unfulfilling and unsupported lives) ...but if you want everyone to be able to (A) reach their own maximum potential, but (B) also make a huge contribution to society, that idea of creating a platform agnostic society where everybody has the access to the communication tools that they need, the creative tools that they need, that really should be one of the first things on our agenda as a human society.

**Anne:** That's right. I mean if you look at the work that's going on through AAC, it's been going on for a long time, the technology gets there before the shift in the consciousness gets there that makes it accessible to more people.

**Steve:** Yeah, absolutely and I think it's interesting that sort of the moment that the computer industry became aware of issues with accessibility was very, very early on when a guy named **Ray Kurzweil**, who invented some of the first music synthesizers and the first Optical Character Recognition scanners, what prompted him to do it was sitting next to, I believe it was a deaf man on an airplane and the guy said to him, yeah I don't really have problems being deaf, I have problems that the world doesn't understand what I need.

**Anne:** Right.

**Steve:** You know? And in fact coming out of that interaction, there was an initiative at Apple. In the early days, Apple was really focussed on accessibility and I have to say that some of the early researchers who gave input into Apple's mission in the early days strike me as undiagnosed autistics. I've spoken with them a lot, but one of the things that they did was to develop a kind of keyboard that made it very, very easy even for someone with really profound communication challenges to communicate, and they were very aware that they were unlocking a massive amounts of potential by making their computing more accessible. Unfortunately, under Steve Jobs, Apple sort of drifted in that mission a bit, but Tim Cook seems to be quite focussed on restoring interest in accessibility to Apple products, so hopefully that's a good thing.

**Anne:** Well, I hope so. We're going to shift it over to talking a little bit about states of consciousness because I think that's something that you're certainly interested in looking at and maybe you've been

able to conceptualize neurodiversity in the way that you have because you've had some deep dives into your own operating system through meditation or other kinds of experiences.

**Steve:** Yeah, you know, I have to say that's such an interesting question. I've never been asked that question. I've done dozens of interviews and I really appreciate it because it really makes me stop and think.

I think that my experience, I'm a life-long meditator more or less. I was taught, or I was urged to learn how to meditate by the poet **Allen Ginsberg** who was a very well known poet and who was one of my teachers, and he very much encouraged all his students to learn how to meditate. So, when I was 19, I learned how to do Zen meditation, just very simple – if you're a Buddhist, it's... just like breath counting. It's like Meditation 101, but I've been doing it now, what 50 years? Something like that, almost. You know, I can't even exactly tell you why I do it, but I know that I feel a lot better when I do, and it just seems to be a very healthy thing to touch the base level of where my mind is at without being distracted by every thought cloud that drifts through the sky.

And one thing I noticed when I was having my first experience in being in autistic space which was at an event called **Autreat** which was designed by autistic people for autistic people, by **Jim Sinclair** who was really one of the founders of the Autism Rights movement, I felt very calm and very grounded. I think that was because for one thing, because it was an autistic space, everyone could do whatever they needed to regulate themselves, so there were people flapping, and I felt that people were not judging each other for kind of superficial things like, you know, I'm a fat person. I'm just fat. I've been fat my whole life, but I didn't feel judged for that. People were not taking each other's measure in that neurotypical way.

There was a very funny moment when I ran into a guy who I had spoken to the night before at breakfast and I was kind of making conversation, and I said, 'Hey Craig, how'd you sleep?' And, he looked at me, 'Why?' And it was like a really good question, I felt like, *yes, why* am I making this chit chat, it's like we don't need to do that, and after a few days of that I felt just very calm and very authentic in some way, and it was actually hard to emerge from autistic space and go back into neurotypical space, kind of like if you spend time in Japan, even in Tokyo, which is of course one of the biggest and busiest cities in the world, like when you come back to America, it's like everybody is so loud and pushy and in your space. And, that's what it was like coming out of Autreat. It's like *God, be quiet!*

**Anne:** (laughter)

**Steve:** And so I feel like there was something about autistic space that helped everyone ground themselves. This was early in the process of researching *NeuroTribes*. [Before that] I had only seen autistic people in kind of stressful situations, like clinics or doctor's offices...

**Anne:** Yeah.

**Steve:** ...with their parents or you know, and so this gave me a chance to see autistic people being themselves and it was even grounding for me as a neurotypical observer.

**Anne:** It's a glimpse into what could be or what sometimes *can* be, I would imagine.

**Steve:** Yeah. Exactly.

**Anne:** I'm in a provincial autistic self-advocacy group, and I'm also in a national group and in an international group of self-advocates. We all work together. We have our meetings using platforms like Slack or Google Hangouts, and they're all text. That's the preferred way to have the meeting because you can really think ...and then I also have a contrast because I work freelance doing writing for various not-for-profits and they're mainly neurotypical-run, and they have a meeting and they want to have a Skype call. I get on the Skype call, and I immediately click that button to take my face off the call, and then everybody says 'I can't see your face' and I'm like I don't want to have a face right now, I'm trying to think, I don't want to look at the screen, because it's easier to think that way, and so there's a certain kind of quietness [in text meetings] – and the more that you're in it, the more you get used to it.

**Steve:** Yeah. You know one of the best things about the digital world is that you can sort of sculpt these communication media to our preferences. I am a last...I'm kind of an old person so I still like talking on the phone. Hardly anyone likes to do that anymore, but there's one autistic friend of mine named Alex who I actually talk to quite a bit who loves Skype and so we do Skype a lot. There are other autistic friends of mine who prefer text, and so we talk in text – you know text on the phone perhaps.

And so I think that this era that was very much brought about by, as I said, people in Silicon Valley with autistic traits like **Craig Newmark** for instance. Craig invented **Craigslist** which was one of the very first really huge websites that transformed several industries, killed off the bartering newspapers where people would offer goods for sale...and it also impacted journalism. But, Craig is definitely somewhere on the spectrum. He's been a long time neighbour of mine. We've talked about this, he's even been attacked for being autistic which is horrible, but he's certainly helped invent the future that we're all living in now.

In the intro to *NeuroTribes* I talk about this guy **Larry Wall** who invented a programming language called Perl that was so useful in the early days of the internet that it kind of went everywhere; like Craigslist and Amazon both used Perl; Microsoft software uses Perl. He has an autistic daughter and he has autistic traits, and he's talked about considering himself perhaps on the spectrum and so I think we really owe a great debt to a virtually unheralded and unrewarded group of people who helped invent our future while their neurological kindred – autistics-- were being put in institutions.

[31:18]

**Anne:** Mm-hmm. The kinds of conversations that are coming coming out through these types of technologies are really interesting as well. Maybe it's possible that you can have *a kind of conversation* that you can't have in another platform. Like, I'm thinking particularly between parents and [autistic people]. If you get into one of these platforms that first of all, you can turn it off if you need to and I think that's important for some people in having these conversations and so it is certainly interesting that it's coming from that, and that really the idea of neurodiversity and the **Neurodiversity Movement** came out of the online world.

**Steve:** Ye, absolutely. **Judy Singer** and **Harvey Bloom** coined the term, also the mailing list, called Independent Living on the Autism Spectrum run by a programmer named **Martine Dekker**, and yes, I think it's fascinating that the concept of neurodiversity came out of online conversations. One point I

really want to make is that Neurodiversity is not like an opinion, theory or platform or something like that. It's a living fact, like biodiversity.

**Anne:** Right.

**Steve:** It's clear that there are different kinds of brains that learn in different ways and often require different methods of learning in order to maximize their potential and that's just true. You don't get to say, 'well, I don't believe in neurodiversity', it's like saying you don't believe in homosexuality or Judaism, you know it's just there it doesn't matter if you believe in it or not. The question is are you going to face the challenges that we need to face as a society to support the diversity that is already existing in the population of human minds.

**Anne:** Right, and it seems really important to add onto that what Judy Singer had to say about neurodiversity which is comparing it with biodiversity, that having a variety contributes to the overall resilience of everyone.

**Steve:** Yeah, absolutely. That's the thing. That's why diversity is so important in the rainforest, because as climate conditions change then the different forms of flora and fauna with various virtues and challenges can then thrive in a way that copes with the changing environment and it's looking like, you know sadly that mankind- or humankind is going to have to face a lot of unexpected and perhaps much more rapid than we thought, and so we need to have different kinds of minds working together to face those challenges.

**Anne:** Right and that kind of connection and dialogue that you're having. When your book came out it really changed things, because everybody was reading it and everybody was really introduced for the first time to the concept of neurodiversity. I see kind of this connection that you have with the autistic community as one of mutual respect and in a sense like fellow travellers.

**Steve:** I definitely could not have written the book without tremendous amounts of input from autistic people. And I sort of looked to the autistic community as sort of conscience of the book so that I would be sure to treat autistic people in my writing with the respect and humanity and the depth that they deserve. ... It's not always comfortable because there are times when what's appropriate is for me to kind of yield the space or share the spotlight or shut up and let autistic people talk. And so I get that. I totally get that.

You know, if I had heard that a big book about homosexuality had been written by a straight guy I'd be like (cynically) *Oh, really?* You know, but I would then listen to what he was saying and see how much of it was informed by the concerns of the gay community. That's what I tried to do and to model in working with the autistic community is just keeping my ears open, trying to know when to shut up, and setting forth as I understand it with my own ethical sense of the world and my own sense of what's scientifically accurate, which I built up being a science writer for many years for *Wired* etc. I've tried to bring all of that to my discussions about *NeuroTribes* and it's basically a beautiful experience. You know there are some haters out there, you know how it is, but it's been basically a beautiful experience.

**Anne:** That's wonderful. I really like how you pivot and you advocate...how you bring things back over to the voices. I'm still thinking about what you said earlier... I hadn't thought about this in years but, like I grew up in the 80s in Madison, Wisconsin so I knew gay people, but my first media image of gay men

was during the early AIDS crisis, and it was a guy with a blanked out face and a garbled voice, talked like [garbled voice], you know you could barely understand what they were saying. And that was gay people in the media.

**Steve:** Right.

**Anne:** Right?

**Steve:** Yeah, exactly. And not only that but they were, you know, allegedly spreading this possibly fatal disease. Like, I live in San Francisco, so when AIDS first came along, they literally called it “Gay Cancer,” like that was the first label I heard when I was here when that happened. And so I am very, very aware of how stigma and stereotypes and mythology and prejudice can sort of build up and completely obscure the identities of a minority group. I’ve been really trying to fight that around autistic people with the publication of *NeuroTribes*.

**Anne:** That’s wonderful. I think it’s happening more and more, especially as AAC grows as well that we’re really hearing a multitude of voices and slowly I think mainstream culture is tuning into it.

**Steve:** Yeah. I think so too.

**Anne:** As we wrap up, I’m just going to get back to the question of truth again and this question of speaking truth to power. In your TED talk, which we’ll link to on our blog, you talk about the seductive power of storytelling and how that propelled really the anti-vaccine myth...that anyone who has argued with an anti-vaxxer knows that for some of these people they’ll ask you for citations and you send them 18 citations and they go ‘I don’t care because I heard this story’.

**Steve:** Yeah.

**Anne:** And so you go in up against this *story*.

**Steve:** Yeah, happened to me just the other day actually on the wall of the kid who got vaccinated against his mother’s wishes. Some guy was sort of going after me for *NeuroTribes*... and for one thing I didn’t want it happening on Ethan’s wall, I thought it was like incredibly rude, but the other thing- no matter what citations I came up with, he would find some way to ignore them. And I finally just blocked him. Like I hate to block people but life is short.

**Anne:** Yeah.

**Steve:** We have to move on, we have to do self-care, we have to protect ourselves. We have to focus our energies on what we can change and what we can make happen and some people are just energy vampires.

**Anne:** Yeah.

**Steve:** Basically it’s really important that we all speak our truths to power because what the world is suffering from in part is a clear lack of what the truth is.

**Anne:** Yeah.

**Steve:** And it's very important that we work together to fight the various forces that are trying to oppress autistic people and People of Colour and women and gay people, and it's a very important time in history.

**Anne:** I think my concern for me as someone who is kind of in 'middle age' now is for the younger people who are going up against all of this – I feel concern for them. I worry about burnout. I worry about whether they're going to have self care because there is so much. Do you have any advice on that?

**Steve:** Yeah. I mean, I was raised... my parents were left-wingers. They were very anti-war during the Việt Nam war, in fact my mother was kind of like AOC in that she was you know this very dynamic young woman who had what were called very radical ideas, like one of the ideas was to withdraw from Việt Nam. Well, that was a good idea, and it turns out not to have been radical so much! It was just good sense, you know. I am so inspired by people like Dara McAnulty and Greta and Ethan speaking their truths to power and yes, they have to learn how to take care of themselves. Yes, they have to learn how to make sure they're not exposed to voices that will eventually overwhelm them but if they can stay in there for the long game of telling the truth the world will end up in a much better place.

**Anne:** Thank you very much. I have one last question for you if you have a moment: what's going on with you for 2019 and 2020?

**Steve:** Well, I'm starting to work on the next book which is not about autism. I can't really say what it is, but it'll be public news in within the month probably. It is another history of science and history of medicine book, but it's a very, very different kind of condition from autism and there's certain interesting parallels in the subject. For one thing, it's a life or death condition, so I'm talking to people who are literally facing death, and it's very, very intense. And one of the reasons why I'm doing it is because I have a kind of audience so that I can hopefully bring along with me at least some of them to pay attention to this condition which doesn't get enough attention. Like I felt the same way about autism seven years ago.

I wanted to deal with real people who are dealing with real stuff, instead of just having my head filled with Trump tweets all day. So, in a way it's intense and you know very, very challenging situations that I'm writing about. The fact that it's real and the fact that people are trying to do their best when they are literally facing death, is very inspiring to me.

**Anne:** Well, Steve Silberman, thank you very much for your time. It was a lovely conversation. So much to think about! Thanks again.

**Steve:** Well, thanks so much. I really appreciate it. I'm really honoured to be here.

(Theme song – soft piano music)

**Anne:** We were speaking with Steve Silberman, an award-winning science writer and author of *NeuroTribes*. He spoke to us from San Francisco.

[42:58]

**Anne:** Afterthought – I had so much to think about after talking with Steve Silberman but the first thing that came back to my mind was that image he talked of. The image in the 1980s of a gay man on

television. The first gay man that many Americans would ever see on television, on the Phil Donohue show, the CBS evening news, 60 minutes. His face covered with a shadow – shame? His face electronically garbled – fear. He was the victim, a dying man condemned by the “gay cancer” – AIDS, a disease that terrorized the gay community in real life and terrorized the imaginations of heterosexual middle Americans. This gay man with the shadow face wasn’t really *real* to most viewers. He couldn’t be. It’s likely that the actual man didn’t show his face because he feared violence – retribution for having AIDS, but was that always the reason we didn’t see their faces? Why was this iconic image of the times? Could it be that this faceless man just represented gaiety inside much of the American consciousness, and as a reflection of their fears and their anxieties just made good television?

Because meanwhile, in Washington and in cities around America gay men were rising up, taking to the streets and demanding action from our government on this crisis. But it took some time for that image of a gay man to make its way to the mainstream in the way that it ever did. AIDS activism had many names, many real faces, many people working for justice and change. But their bodies couldn’t be controlled through the smoke and mirrors of the garbled voiced, shadowed AIDS informant. The people who joined hands around our Pentagon and fell to the ground for their lives, who were hauled away to jail through civil disobedience, who worked non-stop in grassroots health care and sexual health outreach--they all had faces, yet few were ever really seen on our televisions in those early years.

In thinking about this, I can’t help but think of another first media voice, the voice supposedly of autism. The first group to introduce that voice was Autism Speaks and in their imagery autistic children may well have been faceless and certainly were voiceless. Autism Speaks’ “I am autism” video is narrated by a disembodied, gravelly throated man. Nothing like the nameless children shown in the video, who are shown notably all alone.

**Voice from “I am autism” video:** I am autism, I am visible in your children but if I can help it, I am invisible to you until it’s too late.

**Anne:** How far have we come since that video? In Canada, I still see children pushed in front of the cameras without their AAC, voiceless while their parents talk about their needs. I see autistic kids holding signs that their parents shoved into their hands. Signs containing their parents’ words. Here in Canada the face of autism is a parent’s face. The child usually is silent, out of focus – other. Fear, shame and stigma all drive that narrative. It impacts our culture. It impacts our lives. Becoming visible is tricky business. Sometimes it requires a megaphone and a human chain. Sometimes it means going into a social media group and claiming space.

And then, there was last summer. I stood with some friends in the beating sun, counter-leafletting the Autism Speaks fundraising walk at Toronto City Hall, to raise awareness about the Neurodiversity Movement, to become visible. Did anyone see us? We didn’t make the papers. The parents either hurried on, or in a few cases got mad at our little band of nine standing on the edge of the sidewalk with a hand-painted banner. We were ‘ruining a good day’ according to one large, kind of scary father. Did anybody *really* see us? One member of our group, Sara, handcrafted stimmy toys, these were so great. We had them in baskets, and as the kids rolled by in their strollers or being tugged along by their Mom and Dad, we offered them. Toward the end of the day one sister and brother came along in a wagon and they were having a tough time. It was a loud space with a booming PA of speakers and music, random

superhero actors and clowns and, oddly, a gaggle of powder-blue clad cheerleaders. I approached the kids and offered them the stimmy bracelets. They took them, eagerly. He saw us. She saw us. As marginalized groups, we are constantly at the precipice of invisibility. We might be *in* this week and gone the next from the public consciousness and in two weeks become an enemy or become the harbingers of a plague – an *epidemic*. One step forward can sometimes turn into two steps back - another theme I'm thinking of after talking to Steve, but most of all I've come away from this conversation with a sense of hope. Sticky and stubborn as it may be, I'm holding on to it. As Steve said, "it's really important that we all speak our truths to power because what the world is suffering from in part is a clear lack of what the truth *is* and if we can stay in there for the long game of telling the truth, the world will end up a much better place."

Thank you for these wise words, Steve Silberman.

You've been listening to Noncompliant. I'm your host Anne Borden King. Noncompliant was recorded at DB Audio and MCS Recording Studios. Various episodes were engineered by Dave Boir, Nathan Greavette and TJ Liebgott. Thanks to our engineers and thanks for listening.