

Stories from the brainreels transcript

July 5, 2017

Introduction

[theme music]

CHERYL GREEN: This episode is transcribed into a screen-reader accessible pdf. You can find the transcript linked on the show page.

This is Part 2 in a series that I'm doing about voice. Part 1 was on a feminist response to how we criticize people—mostly cis women—for using [uses creaky voice] a creaky voice or vocal fry, which no, is not a voice disorder or a disability. And we do explain why it's not a disorder or disability in the episode with linguist and speech-language pathology professor Jeff Conn. You can find that on KBOO's Bread and Roses from April 7, 2017. Even though creaky voice isn't a disability on its own, people find ways to insult that speaking style and describe it as inferior to basically the voice style I'm using now. As Jeff perfectly puts it, protests against creaky voice are usually some vague ableist, racist, classist note that boils down to "voice wrong." Add this one to the list of many ways we gatekeep each other by falling into the trap of viewing some kinds of communication as naturally superior to others. Check it out.

This episode's story started for me a few years ago when I was talking to a friend with multiple disabilities, including an accent in his speech from having a severe traumatic brain injury as a child. He wanted to be a performer, but he assured me no one with a voice like that could ever be acceptable in music. I introduced him to Krip-Hop Nation, and specifically Leroy Moore's voice, and my friend was pretty floored. Will you be accepted in mainstream, big-money music industry? Probably not yet. Can you make a fantastic album, sell it, and gain adoring fans? You bet. Here's Leroy on the air from May, 2005.

LEROY MOORE: What you about to hear is not corporate media or a reality show. No! What's up everybody? My name is Leroy Moore. This is Pushing Limits on KPFA 94.1 FM, Berkeley.

CHERYL: As I moved from podcasting into producing for community radio, I observed more and more conversations with people about who should and should not be allowed on the air. It often came down to how beautiful someone's voice is. Beauty, pleasantness, goodness, these are subjective. Yet when it comes to gatekeeping who gets to present in the media, these qualities seem to be treated like they're objective truths that will, or at least should, ring true for everyone.

What makes a good radio voice?

I asked some of my friends a series of questions. The first was what they thought makes a good radio voice.

PERSON 1: To me, a good radio voice is about timing, probably more than tone. I really like to listen to someone who has a sense that they're someone who's fun to listen to.

PERSON 2: A good radio voice is someone that's easy to understand and is articulate, doesn't talk too fast or go too slow or too softly.

PERSON 3: Sounds interested, connected, feels a bit intimate, as if it's talking to me.

PERSON 4: I think a good radio voice is one that is easy to understand for me and clear.

PERSON 5: A good voice is one that is true to the person. If you ever watch a lot of TED Talks or listen to NPR a lot, you'll notice a lot of the presenters tend to have the same kind of cadence when they speak, or they go for the specific kind of radio voice. It's a very artificial kind of a sound, and I'm not sure that that works necessarily well for everyone.

CHERYL: This is not scientific research! In fact, all these voice memos came to me via a request on my personal Facebook. And that means that, though you maybe can't tell, most of the people who responded are disabled. Why's that matter? Although I'm super interested in what any podcast and radio consumers think, actually disabled people are rarely asked their opinions about media representation, even if the representation is about disability. So I prioritized disabled people's responses here because I can.

Here's me reading a tiny excerpt from Alice Wong's article, "[Diversifying Radio With Disabled Voices](#)" on Transom:

"Like all cultural institutions, **radio enforces normalcy**. This normalcy is centered on the ability to hear and speak 'well.' With the exception of a few radio shows by disabled people (e.g., [Pushing Limits](#) on KPFA, *Disability Matters* on [VoiceAmerica](#)) and podcasts, you don't hear a lot of people that sound different due to disability on public radio aside from [Diane Rehm](#)."

PERSON 4: I remember Diane Rehm had a Diane Rehm Show.

PERSON 6: I do know of two people who I've heard on the radio: Diane Rehm with NPR and then Robert Kennedy, Jr.

CHERYL: And here's Alice Wong.

ALICE: Meow, meow, meow, meow, meow!

CHERYL: Brrrrrr-ow [laughs]!

ALICE: I can't do that sound.

CHERYL: [laughs]

ALICE: You're very talented.

CHERYL: OK, sorry [chuckles]. That probably didn't seem related to talking about Diane Rehm. Alice and I have corresponded online for a couple years, but this interview was the first time to actually talk to each other. Clearly, we have an intense interest in common, and she wanted to make sure that got acknowledged right away before we got to the other topic I called her about, which is "good" radio voices.

[Alice Wong on diversifying voices in radio to include disability](#)

ALICE WONG: My name is Alice Wong. I'm the founder of the [Disability Visibility Project](#). It's a community partnership with StoryCorps, which is a national oral history storytelling project. And we collect the stories of people with disabilities. The DVP is also an online community that creates, shares, and amplifies disability stories and culture.

CHERYL: To me, Alice's voice, her very presence on the airwaves, is the model of what radio can be.

After the meowing and introduction, I asked her if she feels that radio excludes people who have disabilities that affect their voices.

ALICE: Radio is still very insulated. Especially in public media, this idea of storytelling and structure and sound. Maybe it's intentional, but if it's not intentional, then they do exclude all kinds of voices.

CHERYL: So that's a great point to bring up. Is it intentional or not? Either way, it's exclusionary.

ALICE: Yeah, there's this weird sense of radio: It should be easy for listeners. But my thought is let's have listeners challenged, right? I mean, I think that's kind of the way to push the medium forward. It's very classist and ableist in terms of language, lack of access.

I wrote a manifesto about this.

I really wanted to publish in a mainstream publication that people in radio read. And I was really motivated by [another manifesto by Al Letson](#), you know, diversity of people of color in radio. And I thought there should be a similar one about disabled people. So his manifesto inspired my manifesto.

In a way, my idea is, in terms of why we need more voices is that we don't think about diversity of radio in terms of the kinds of sounds we hear in terms of voices. You and I and other media makers really need to get our fingers into the larger pond and splash around, splash around.

I think disabled voices are not really excluded from podcasting, especially if they're doing the podcasting themselves. So I think that's a great thing about podcasting is do-it-yourself. I think that there is nobody stopping you, and it's relatively easy for most people to do it. Again, being mindful of privilege, and the digital divide does still exist. But I do think radio, I think they just...I think disabled voices are excluded. You and I

cannot name five people that have distinctly disabled voices, however we wanna define that.

I think, just like any other person, disabled people have hearing privilege and voice privilege, right? I mean, for people with speech disabilities, I would be really curious what their thoughts are on radio.

PERSON 7: What I would think would make a good voice for a radio talk show host, it would be somebody who actually cares about the subject that they are talking about and will focus on the same subject. Don't go off on a tangent of some other kind of subject.

PERSON 8: Deep and sonorous strikes my inner ear. Also resonant voices are also very high for credibility as well. But voice goes much deeper to the character of the voice and the intonation.

CHERYL: So you said you've been a guest on several podcasts. Have you ever been on a podcast or a radio show run by another disabled person?

ALICE: Oh yes, once. There was a radio station in New York City that was created by disabled people.

CHERYL: Was it the Largest Minority?

ALICE: Yes, yes, yes! So that was great.

CHERYL: Yeah, yeah. Does it feel different to be interviewed by them?

ALICE: You know what was interesting? They asked me whether I was wearing my mask during the interview, and I took it off, actually. Because I think they wanted a clearer recording. It's interesting.

CHERYL: Do you ever hear voices that sound at all like yours, aside from yours, on the radio?

ALICE: Well, definitely not on public media. I mean, other than maybe Diane Rehm with her show, even though she's retired now. I remember her voice is very distinctive, and she used to get, I think, complaints about her voice because of a neurological condition.

CHERYL: Remember how I mentioned the creaky voice or vocal fry episode from April? Go there, or really anywhere any search engine will take you, to find no end of people complaining that voice celebrities, podcasters, and radio hosts should definitely not be ruining the airwaves by broadcasting the utter offensiveness that is creak and defiling the spoken word with their vocal cord vibrations.

But anyway, here's a clip that Diane Rehm posted on YouTube through The Diane Rehm show where she gives the name of the neurological condition Alice mentioned and also a treatment that she gets for it. If you're squeamish about or triggered by those

kinds of descriptions, fear not: I cut out the description of the condition and the medical procedure she gets.

DIANE REHM: I have Adductor Spasmodic Dysphonia. The last time I had the injection in September, I had waited for a full nine months, and my voice sounded terrible. So this time, I'm going after four and a half months, which is gonna be just fine. It's already beginning to go, and I can feel it beginning to go. It gets breaks in the words. That's how I know it's starting to go.

Shortly after the injection when it finally comes back, the voice is very smooth and doesn't have those cracks in it. But right now, I'm beginning to feel that strain.

CHERYL: Diane Rehm is not the only one who gets attacked for having that particular voice. Spasmodic Dysphonia is so misunderstood that a lot of people with it don't get diagnosed for a really long time. While they're in the process, everyone around them, including doctors sometimes, is telling them to just relax, just calm down, just take some allergy medications, just do some vocal warm ups, just just just: It's all code for, "Fix your voice because it sounds wrong." Women, your voice must be smooth and pleasing, or you should be fired. This is the daily reality of people whose bodies, minds, or voices aren't compliant with these completely arbitrary expectations that people have decided are actually rules.

ALICE: I think there's an episode of Radio Lab where they featured some disabled people, or This American Life. But in terms of consistent, regular voices on radio? I don't think I've heard people like myself. And that to me is a difference. Rather than things like seeing you just on a "very special episode," right? I wanna hear hosts. I wanna hear regulars. That's a risk, right, by radio stations, in terms of listeners. But I guess that's why independent media is so important.

CHERYL: It's interesting that you call it a risk because I think yeah, financially it's a risk. But is it? Is it that people don't wanna work too hard, or is it that people are ableist?

ALICE: It's probably a combination.

PERSON 9: Part of it's probably just all the same reasons that people with disabilities have a hard time getting hired places. Or I guess they think that that's not something people wanna hear. Which is depressing.

PERSON 10: I have heard people on a podcast with a disability, but it was a disability-specific podcast.

PERSON 11: I think there's a cultural bias in favor of people who don't sound like they have a disability when they speak, and that bias leads people to not seek out hosts who have disabilities when they speak. I imagine some people have been disempowered from pursuing a career in voice acting because of a disability when they speak.

Being disabled challenges society's norms

ALICE: I think that we all want information to flow easily. We live in an era where there's expectations that everything comes easily to us. This is where, on a larger theme, is that people with disabilities have been resisting in society, right? 'Cause we are outside of the norm. So we're constantly jabbing and pushing the edges. And I think that's where, in terms of media, we are kind of challenging the norms, just by existing with our own lives.

CHERYL: Yes! At the UCLA Disability Studies conference, Karen Nakamura did a keynote. And they just kept saying the word "non-compliant" over and over. And everyone was cheering. It's one thing to be called "non-compliant" in terms of you didn't do your rehab. But just instead of it being this disciplining thing that's coming from non-disabled people to be like, "I'm owning it. My body, my mind, my voice, what I say is non-compliant." What do you think about that? What do you think about just kind of reveling in non-compliance?

ALICE: Mmhmm. It's taken me a while. I mean, when I first started wearing this mask for long-term and in public, you know, I was embarrassed. There are people who don't understand me, and I have to repeat myself again and again. And there's a little internalized ableism working here. And it's taken me a while to retrain this part of myself.

I used to take pride in my voice, before I wore this mask, and my voice privilege. And now I just love this other dimension to my disability as a part of this long evolution of where I am, and it's been really cool. It's very illuminating in terms of how I feel about myself and my interactions with other people. So it's taught me a lot.

I do think that "good" is such a loaded term. And I think that's the power and the magic of disabled people to really just change or make people elastic. When we talk about "good," what do we really mean? I think that, to me, is exciting.

CHERYL: Yeah.

ALICE: That's what I love about disability culture or what you and I call "crip culture." We're constantly kinda just redefining, pulling at the edges.

CHERYL: Well, and you're asked to be. This example you gave about switching to wearing the mask in public. You're the one who had to do the work to get used to the mask and to get over a sense of shame and, "Oh, goodness. I'm the one in the mask. I'm the one in the mask." And if you can come to this place where you're like, "I'm the one in the mask"--

ALICE: Yeah, yeah!

CHERYL: --then we can expect that other people can too. I hear you talk about it in these positive terms of this evolution and growing your curiosity around it. And that that's what disabled people do.

ALICE: Mmhmm.

CHERYL: And we're out here doing it, but media, mainstream media and even independent media is still not willing to go there for the most part.

ALICE: Exactly.

CHERYL: And then they blame us. "Well, but you don't have a good radio voice. But here you are, doing all this work to find the wonderfulness in your voice, and they're not joining you for the ride.

ALICE: So I do take every opportunity when I do get these interview requests by non-disabled people, journalists, all that stuff. It's all like the 101 stuff. And sometimes, I see it as an investment. I say I'm planting a seed. These are all seeds of disability culture all over the place. Even though I feel like I'm repeating myself. You and I, we're ready to move beyond. But I constantly have to remind myself this is still really new to so many people. Burn out is a real issue.

Sometimes I do wonder, "Why should I educate people all the time?" Especially when it feels like folks like you, me, Leroy have been at this for so long. I really feel that there's so many amazing people in our community that deserve much more recognition, and we're not getting it. So these are tensions I feel all the time.

CHERYL: When I do something with another disabled person, or I'm sharing something from another disabled person, it just doesn't get any traction.

ALICE: Yeah, that's the hustle in terms of getting our stuff out there. And then balancing that with our own integrity and our own kind of standards. What are we willing to do for coverage? I try not to put myself out too much. At the same time, it's like sometimes I definitely toot my own horn. Because if we don't toot our own horn, nobody's gonna do it for us. And we're still at that place in our community in terms of disabled media makers. I think we're still at that place where the hustle and the struggle is real. And we have to fight these bigger groups like The Mighty that somehow speaks for us.

CHERYL: Ugh, The Mighty.

ALICE: Yeah. Things like that where most non-disabled people think that's the source. It gets so much dissemination. That and Disability Scoop. But it's all like aggregated stuff, and it doesn't really highlight work by disabled people.

CHERYL: Yeah, and it passively reinforces the idea that your voice isn't needed. We've got it. We don't need you.

ALICE: Mmhmm. Yeah. So you know, I guess also do we have to follow that model in terms of creating our own media model? I wonder are there other ways to do this? Do we have to follow this capitalist model?

CHERYL: Oh [laughs].

ALICE: Right? And sometimes it feels like maybe we're taking the wrong path. So with the DVP stuff, I refuse to monetize for now. But I do have the Facebook group. It's very much informally, by sharing media in a little digital hub where I try to highlight folks that I care about. Again, that's a group, a Facebook group, one of thousands. And you know, it's not self-sustaining.

CHERYL: Capitalism is a big problem in how we got to this place where we expect ease of information flow, and everything has to be fast and smooth. And not only does your work have to be done fast and smooth, but your voice has to, and your video has to. And everything just has to be efficient and perfect.

I find that so many people just accept it, like "Yeah, that's good. That's not good." And then the second you put something that is so clearly celebrating disability out there, the response is, "That's nice! I mean, nobody's perfect." And so you do get out there, but there's this caveat around you that it's nice, and that was good enough.

ALICE: I think we're still under this thundercloud of inspiration porn, and we gotta dodge it. I think that's where when we post stuff, and it falls outside of the realm of inspiration porn, people just aren't used to it, these narratives. This is the work. This is the work.

[ambient music break]

[Making Contact radio show](#)

CHERYL: You produced and were featured in this radio documentary piece on Making Contact.

ALICE: Yeah, that was really fun. It was something I did just to push myself and to learn new skills. They had a storytelling fellowship, and each fellow created their own radio story. I very much wanted to use this opportunity to feature disabled people. To me, the draw was really being able to give the pitch in the Bay Area disability community in terms of people who use personal assistants and getting really first-person perspectives and narrative, really being intersectional, a lot of people of color, and include disabled people. And that, to me, was kind of my goal as a documentarian of sorts. That was a one-time thing, and I wrote the Transom blog about my experiences doing that fellowship.

CHERYL: Was anybody weird with you about your voice?

ALICE: Not really. Yeah, not really. I think that's what I really appreciated. I was nervous though, because my interpreter was non-disabled, and she was paired with me. And I wasn't sure. And then even the recording process when we were in the field, I needed assistance, and she was great about it. So but the thing that I was really curious and nervous about it, and I wanted to learn more about it was really the nuts and bolts, you know, the actual physicality of creating radio. And I really feel like there were a lot of physical barriers. But I think it was great to be able to record.

You know, I really hoped that as people listened to it, that somehow it might lead to other opportunities to create more radio stories, but I've not heard from anybody, not

even my local radio. And it feels like, oh, I guess maybe I had too much high hopes. But I really thought it was a really great example of what I could do.

CHERYL: When you say high hopes, are you referring to that your hopes were too high for your work, or your hopes were too high that you thought non-disabled people would be like, "We embrace this!"

ALICE: The latter. The latter in terms of even getting a response. You know, supposedly in the Bay Area, there's so many public media people. And I did wish that piece in Transom was one way to really be in their space and hopefully spark something. But it never really materialized. But I'm happy it's out there, and it's a thing that I'll always have, that I can always share. But like you said, it just never got much traction, which despite being in a "mainstream," somewhat prestigious place. But yeah.

CHERYL: Mm.

ALICE: Keep on moving.

CHERYL: Going back to Making Contact for a minute, the first storytelling fellow they had was Lateef McLeod who uses a speech generating device. He types in a message, and his iPad speaks it out. You can hear Lateef and his friend, April Bryant, using speech generating devices in a [Making Contact episode from October, 2014 called "Voice Recognition."](#)

Remember those comments at the beginning about opinions of what makes a good radio voice? I'll admit, my friends are a cool, non-compliant bunch. Several of them focused on the attitude, vibe, or style of the radio voice, not the voice itself. I was surprised, but then I wasn't. Of course when you ask crips what makes a good voice to listen to, they're going to say, "Do I like that person? Yes? I like their voice."

After everyone sent me their first response, I sent them this question: Do you think someone with a disability that affects their voice could have a good radio voice?

PERSON 8: I have a disability affecting my voice. Yes, it's been more difficult. I believe that people with vocal cord dysfunction as a disability or other disability affecting speech could be a good radio person. You need to have training. Absolutely. And I certainly hope that's true for me.

PERSON 4: If they wanna be a radio host, then they should be a radio host. So yeah. I certainly think they can.

PERSON 12: I think that people with disabilities that affect their voice should be on the radio. I think that we have an idea of what is a default "good" voice, and that is an able-bodied one that's pleasant and articulate. And if we only have certain voices on the radio, we're basically not allowing the voice of disabled people to be heard. And that is an othering that I don't think that we should do. So I say absolutely!

CHERYL: And of course, a very interesting twist came in.

PERSON 2: I think to have folks that uh on the radio that their voice is impaired is very difficult. Um such as-- I have a brain injury. So my thought process is already skewed and gets confused easily. And if I have to listen to someone who is stumbling and stammering uh [chuckling] like I do with aphasia, um it's very difficult for me to stay on track. I I I hate denying somebody what they want to do, but it's it's something that I just can't do. I don't like my answer, but that's my answer.

Accessibility and being granted access to content

CHERYL: This is something that comes up constantly in disability community—and it should—that one person's access might pose a barrier for someone else's. But this last person's comment is precisely why I transcribe every episode I do. The transcripts are for anyone, but my main audience is D/deaf and Hard-of-Hearing folks and anyone with a language or cognitive impairment that makes it too difficult to follow just by listening.

How often do media makers reflect on who is granted access to their content and who is excluded from it?

ALICE: When I started the Disability Visibility Project, because it's an oral history project, I did get a few emails saying, "Why did you choose this medium?" Yes, this is an audist form, but I'm gonna do everything I can to make it as accessible as possible. I think that's a challenge of radio and podcasting.

CHERYL: It is. You get your oral history recordings transcribed. And so then they are accessible to anyone who's got the internet connection or can get someone to print it out, but anybody who can easily access the written word. Most podcasts and radio shows I encounter don't transcribe.

ALICE: Yeah, that's the thing. With me and other disabled podcasters out there, we should really set the tone.

I've been a guest on various podcasts. Afterwards, they're like, "Oh, I never thought about" x, y, z in terms of whatever I say.

CHERYL: Mmhmm.

ALICE: And then I say, "Hey, I'm so glad that you had me on here. But something to think about is that you start transcribing your podcasts because I won't share your podcast to my community unless I see a transcript."

CHERYL: I do the same thing.

ALICE: Yes?

CHERYL: Yeah, I write to filmmakers on Vimeo. "Hey, I really liked your video. I'll share it if you caption it."

ALICE: Yeah.

CHERYL: And every once in a while, someone goes, "Wow! What a cool idea!" And they'll caption the one that I liked or maybe two.

ALICE: Right.

CHERYL: If we can't even get people to commit to basic things like access, it's no surprise we can't get people to commit to things like having people with voices that reflect disability or like a Deaf accent or anything like that, to cherish those in audio or visual mediums.

ALICE: And to have them on regularly. You know, not just as guests, but the actual reporters and editors behind and in front of the microphone.

I think a lot of disabled podcasters have hearing privilege. Some people have reached out to me, saying, "Hey, will you share my podcast on the DVP Facebook group?" I'm like, "Is it transcribed?" And if it isn't, I'm done. They give the same response that a lot of non-disabled people would give, like, "Oh, I don't have the resources. We're only a two-person crew." I understand that, but you know, I try to hold myself accountable to what I share. It's hard.

CHERYL: It is hard, yeah. And it is real that it can be expensive, but I think if you can't afford to make your stuff accessible, then the price that you pay is that your content won't be shared in these certain areas. So I never call somebody and tell them to quit podcasting, but I tell them, "No, I won't share your episode."

The Disability Visibility Project, I know one of the many reasons it exists is to get narratives from disability community and disability culture out there to enrich all of society. If disabled voices are passively left out or intentionally excluded, what are we missing? What are we denied when that happens?

[Disabled voices are the medium and the message](#)

ALICE: I think we're denied the rich variation, in not only our bodies, but the way we see, the way we express ourselves. That is a huge loss in terms of just valuing our point of view. You know, there's that famous quote, "The medium is the message." And I feel like disabled voices are mediums themselves in addition to our messages. It's critical that both get out there and we don't just separate them.

CHERYL: Yeah, or clean them up so to speak.

ALICE: Exactly. Or not to make it palatable.

CHERYL: No, no. Because you can expand your definition of what's palatable rather than just be rigid and say, "No, I just don't like that. That's wrong, and therefore, everything they say is not worth listening to."

ALICE: Yeah. People with the power to edit, there's so many internal biases. We're unreflexive, and it's just taken for granted.

CHERYL: It's sort of related to what we talked about earlier: Do you go for being the token, or do you stick with not being let in at all?

ALICE: Exactly. That's why having disabled people, as actual creators, feels so important.

CHERYL: [pause] Yeah.

ALICE: Culture change is really hard. Culture change is sometimes at a glacial pace, especially in our society that is still deeply entrenched in ableism, you know. I think we still have a long way to go, but I think we're at a point now where there's a huge critical mass of disabled people doing great work who can be visible in a way that it's never been before thanks to social media, in terms of identity and pride. So to me, you know, I do look forward to the future. I think we're gonna get there.

PERSON 6: We are not tolerant of anything that deviates from the norm, and I think that that is particularly true for girls and women. I think it's particularly true for minorities, people of color, and certainly people with disabilities are marginalized and kept out of the mainstream. It's unfortunate that people have to work that hard and have so few opportunities in order to be seen. We have got to start normalizing humanity.

PERSON 13: I think people that have disabilities should be doing radio broadcasting, definitely. I think it would be different. And people wanna hear different kinda people's voices, I guess, 'cause everyone doesn't want the same thing. People with disabilities have cool stuff to say as well, and might even be cooler.

PERSON 14: It makes me feel good all over to hear them. Yeah....

ALICE: We're gonna get there. We will absolutely get there.

Wrap-up

CHERYL: I highly, highly, highly recommend you check out the Disability Visibility Project oral history recordings through StoryCorps. You will hear a huge range of voices, identities, representations, and really some sheer wonderfulness from disability culture and community, especially amplifying the voices of disabled people of color. Alice conducts some of the interviews, so you can hear her much more as well. Since the recordings are done in StoryCorps booths, they sound better than what I was able to capture with Alice over Skype, and every posted audio clip has a text transcript.

You heard music from tatreall, Starover Blue, and alright lover, in that order.

CHERYL: Thanks for joining me for another episode of Stories from the brainreels. Find more handy info on brain injury and disability art and culture and transcripts of all the podcast episodes WhoAmIToStopIt.com.

[music]