

The Accessible Stall: Episode 004: Identity and Microphones

TRANSCRIPT

Emily: Hi, I'm Emily Ladau

Kyle: And I'm Kyle Khachadurian

Emily: And you're listening to another episode of The Accessible Stall.

Kyle: What are we going to talk about today Emily?

Emily: Well first of all, we're going to talk about our new microphones

Kyle: Yes, they sound very sweet.

Emily: Well so we hope because in the interest of total honesty, this is a temp number 5000 to try to make it sound good.

Kyle: It's actually number three, but who's counting?

Emily: Apparently you are and I'm not.

Kyle: Mhm.

Emily: But anyway, now that we've gotten that out of the way, we are excited to get into her fourth episode and we are going to talk about disability and identity. So why are we talking about that Kyle?

Kyle: We're talking about it because it's very vague and everyone in the community sort of has a different idea of what it means so for example, this is one area where Emily and I really don't agree at all and we're going to tell you why.

Emily: So it's interesting because I think we agree on most things actually when it comes to disability but this is one where we've never been able to come to some kind of consensus because I feel so strongly in one direction and you in the other. I think that disability it's something that I considered part of my identity it's something that I count just as much as I would count being Jewish or being female and it's something that I consider a large aspect of what makes me who I am, and I would say that you largely differ from that.

Kyle: yes. I acknowledge my disability and I acknowledge its existence and it is a part of me but it means as much to me as me being a male or me being brown eyes or something, it doesn't really have any intrinsic value and it doesn't play into the person that I am, although I'll give it credit for the person I became but that's it. It's just there, so to speak.

Emily: I'm not sure that I get that because if you're saying that it has something to do with the person that you became, then becoming means that you know are what you became.

Kyle: well I mean that in sort of things like employment and social awareness common like all the work I've ever done has been disability focused and I don't know if that would be true if I didn't have it, but at the same time I don't know how much that actually matters so even though it helped me become this guy I don't wear it on my sleeve, I just don't. Although, I respect people who do.

Emily: I am the type of person where is it on my sleeve. But it took me awhile to get to that point because for a really long time I did everything I possibly could to separate myself from my disability and I always tried to come across as being one of the able-bodied or non-disabled crowd if you will, and I hate to say this but I would use disability when it was convenient for me but otherwise the biggest compliment you could pay me was to say "oh I totally forgot you were in a wheelchair", I used to love when people said that to me and now it makes me so sad because I consider my disability so inextricably linked to who I am that if you're forgetting that have a disability then you are kind of forgetting what makes me me in a lot of ways.

Kyle: I think a lot of that has to do with using a wheelchair though don't you think? Because somebody who forgets I'm disabled it's like yeah it's a compliment because to them I pass, to them I did it, I made it.

Emily: yeah there's no way I could ever pass, and passing meaning appearing that I don't have a disability because I wear my disability attached to my butt every day, like it or not. and so I guess having that highly visible piece of equipment has led me in the direction of just embracing it. I mean, I have a tattoo of a peacock feather on my wrist and part of the reason that I got it it's because I've always felt like a peacock stands out with all the feathers that they have and I'm not calling myself a peacock over here, but I feel like maybe my chair in a way serves as my feathers, because it's really noticeable and so I've just turn that into something I take pride in.

Kyle: I understand that but at the same time, I'm a person who is much more proud of the things that I've done than things that I am mostly because I've had no control over things that I am, but have total control over things that I do.

Emily: sure but the things that you are and then a bleeding in some way or another to the things that you do. I mean, think about your experiences when you were younger, I went to a mainstream school and I know that you went to a school for people with disabilities.

Kyle: Yeah

Emily: so, you don't think that that place where you got your education for how many years out of your life so far had something to do with who you became?

Kyle: Yeah well, when I said that it gave me more knowledge about disability and it gave me more knowledge about the "world", it certainly did that, going to school where I did, but that's all

it did. I don't think I got a stellar education or subpar one in a school that was just for people with disabilities.

Emily: oh yeah, I'm not talking about the quality of the education. but just being surrounded by other people with various disabilities day in and day out, that was never the case for me, so in a way it's almost interesting to me that you're the one who considers disability as just a fact of your existence and not as an identifier, whereas for me I'm very conscious of it being and identify it even though I wasn't surrounded by it.

Kyle: I think being surrounded by it is part of the reason why it's just not an identifier, because it was so normal that it almost didn't matter. As much as I hate to say that. But it's true. It just was. Everyone was disabled, and if everyone's disabled no one is, in a weird way. there's nothing to stand out, everyone just is.

Emily: yeah, I hadn't thought about it that way, but you're right. I think there's logic to both sides of it. I know I went to summer camp as did you less than I did but we went to a summer camp for kids with disabilities and there I was so conscious of my disability, I also felt very comfortable in myself for those few weeks, but at the same time being surrounded by disability really made it stick out to me that I am disabled. But I don't think that was what really caused a shift in my mindset for embracing disability, I think it was once I stop seeing disability as something that I needed to suppress for most of my school year and for most of my life, and I started realizing that it was just another aspect of what makes me Emily then I began to identify as disabled as and identity just as much as I am so many other things.

Kyle: that makes sense I suppose. I guess it's because I was so inundated with it for my whole life that by the time I got to college I was just like "get it away from me" [Emily laughs]. No, I'm serious! I'm not ashamed of it but how much is too much? And I think that being surrounded buy it certainly didn't help in that regard.

Emily: well the how much is too much question sort of points to another aspect of disability in that sometimes or all the time I would say, or pretty close to it, you're expected to being an advocate or an activist as a direct part of being a disabled person.

Kyle: Yes.

Emily: And for me, again here's a large place where we differ, I proudly call myself an activist, you again...

Kyle: Don't. At all.

Emily: I was going to say run screaming in the other direction but don't works too. [Emily laughs]

Kyle: I do, I run screaming in the other direction.

Emily: and so how come that's the case? Because I mean we're sitting here doing this podcast and this in and of itself is a form of activism, not a preachy one but it still is so I'm curious why you stray away from that.

Kyle: well because I sat here with you for about 30 minutes one day and discussed picking your battles and I found that the general Battle of activism wasn't really for me, but also unlike you and I happen to think that as long as it doesn't inconvenience me it is my job to educate you-- the you at large--and that's a very unpopular opinion in the activism community but I think that that's the exact opposite opinion of what they should have to be honest.

Emily: so you're saying that because you've noticed my hesitance to be a teachable moment on wheels that... what are you saying? I want you to explain this to me actually. because, why is it that you don't want to be called an activist but at the same time you are willing to be an educator?

Kyle: because I think activist is a title that you can call yourself, I'm not gonna take that away from anybody, but that's sort of a title that you earn, and I would say that YOU did but anyone can educate and I think that the best way to advocate is to educate and I would much rather be called one than the other because there's no baggage with an educator first of all, but secondly it doesn't have the pressure and responsibility of having to always be "on" all the time so that's what I'm saying.

Emily: yeah, that's really a good point because I do as we talked about earlier where my identities very much on my sleeve so in a lot of ways because I am disabled, because I am an activist, and I actively Define myself as those things I do feel this constant need to have an "on" switch and to always be on top of my game and if I don't jump on every single disability issue that I somehow feel like it's a betrayal of my identity.

Kyle: Yeah, but... I shouldn't have probably waited until 12 minutes into the episode to say this but I'm very weird about labels, I don't dislike them, but before I call myself anything I try to make sure that the person I'm describing myself to knows what I mean when I say certain words because a lot of them are very loaded and I think after this is one of them, because you sort of get this mental image in your mind of somebody and I don't want to be a part of that. I respect people who do, I'm not making fun of anybody and I'm not taking anything away from anyone but in order for me to use certain words to identify myself I like to make it very clear what they are first, and when I do that I find often that you don't really need the words anymore which is why I try to stay away from it all.

Emily: I can understand that it's really unfortunate that activism gets such a negative rap but there's a term that internet trolls love which is social justice warrior and I've definitely seen my name linked to that term...

Kyle: I wouldn't call you that.

Emily: right but some people would if they take my work and they don't know the context that I usually write him, so I wrote about a commercial, the Guinness beer commercial where there were people playing wheelchair basketball...

Kyle: I liked that commercial!

Emily: yeah see I did not like that commercial and you did like that commercial and I one day was kind of clicking around checking how people landed on my blog and I ended up finding a conversation about that blog that I wrote and people were calling me a social justice warrior and saying all these negative things about me and in that moment I was frustrated by being an activist and calling myself an activist because it seems like the people who I really need to reach are the ones who don't take you seriously but I've learned not to let that be a deterrent to my identity.

Kyle: Well, it shouldn't, but... I feel like if you really want to reach the people who need it most, you kind of have to-- I mean, you said a quote in the first episode which I can't remember because I'm trying to think about it.

Emily: Oh! It was "advocating is getting you to see my point of view on your own terms"

Kyle: Yeah, something like that. And I think that's what you have to do, and I think that's what you do now. I don't remember how good you were back then but you certainly-- you did it, and that's good but I don't know... trolls will be trolls, right?

Emily: Exactly, sometimes you just gotta let it roll off your shoulders and speaking of activism I think one of the biggest things that I am an activist or an advocate for is language as it comes to disability

Kyle: Oh here we go...

Emily: Yeah, I know but I really wanted to bring it up in this episode because language is a major subject especially for us because I was an English major and Kyle with a double major one of those being linguistics and so the two of us are really really attentive to language and the meaning of words and so when I advocate a lot of it has to do with person first language and identity first language and I'm willing to bet that most people have heard of person first it rather than identity first because it is the way of the academic and professional and medical world right now. Person first language is saying "person with a disability" and there's absolutely nothing wrong with it but there's a huge camp of people-- and I do believe it's huge at this point-- people who have come to embrace disability as an identity and they use identity first language which is saying "disabled person", so this is something that I talk about a lot and I think that it does make people feel a little bit unsure about how to identify me or how to refer to me because they worried that I'm going to call them out for using the wrong language.

Kyle: yeah, I also prefer identity first which is ironic, but I prefer it because it's correct English, it is, we put our adjectives before our nouns.

Emily: Right, it's a descriptor, and that's really what I try to tell people. I considered disability and identifier as in it is part of my identity, but if you don't want to go that far it's a descriptor it not derogatory word, it just is.

Kyle: yeah, I wouldn't call a derogatory word ever.

Emily: but I think there is something that is a derogatory word that we should also talk about.

Kyle: Which one? Is it the R-word or the C-word or the other C-word?

Emily: Ha ha, it's "cripple", we should talk about cripple.

Kyle: Right, that's one of the C-words. now, I don't like that word at all.

Emily: why?

Kyle: Because I'm not a cripple and I was asleep for the meeting where everyone with a disability decided that that was the word we're all going to use. I forgot to send in my absentee ballot, I didn't put a stamp on it, I missed the boat, how many more euphemisms can I come up with? [Emily laughs]

Emily: oh, you're making me want to jump topics now because I also want to talk about euphemisms and disability so remind me to get back to that, remind me that I said that because I really still want to talk about cripple. So, cripple is a word that has come to be reclaimed by members of the disability community. Certainly not all but a fair amount. And it's also used in various movements and campaigns and initiatives so you can "crip" something, as in it's a verb

Kyle: Oh that's the worst...

Emily: why do you think that though?

Kyle: I just don't like it. I just don't. You ever not like something? It just rubs you the wrong way?

Emily: Sure! I understand that but I also think that it's effective and that it grabs attention.

Kyle: it does do that. But here's why I don't like "crip the X". I almost always like what the "X" is like "crip the vote", I'm all behind that. getting presidential candidates to care about issues related to disability is great, but when you make crip a verb, it's off-putting to the people who need to hear it most, and it's embraced by the people who need to hear at least and I think that's why I don't like it although it does have that element of shock value, and I appreciate it for that and it's the same thing with crippled I suppose, but I just don't like that word because like I said I'm not one, and I just don't think a group should be able to own a word on principle, I get that a lot of people think that but I don't. And I'm not afraid of words, I don't censor myself but I also don't--what am I looking for?--I don't succumb to the fact that because I'm disabled I have to use that word to identify myself with.

Emily: oh yeah, I don't think anybody HAS to do anything, I mean I was adamantly against the use of the word crippled for a while but just being who I am and being involved with what I'm involved in in terms of work and community activity and things like that, cripple has sort of slipped its way into my vocabulary and it's to the point now where even my mom and dad use it, so they'll say "oh we got the cripple spot! we got the cripple spot!", you know?

Kyle: well I'll do that, that's a joke.

Emily: yeah of course it's a joke, but that's usually how I use it and I think that's okay and really I think that using whatever words you want to refer to yourself is ok as long as you don't impose that another people. That's the big issue.

Kyle: Yeah, I would say so too.

Emily: Because, especially with language choice going back to person first vs. identity first, same person with a disability verses disabled person, I've always felt that people who are big proponents of do it with the absolute best of intentions because they want to ensure that you are acknowledging a person as a person and not just seeing the disability, but at the same time I think that implies that you are less of a person or you're not a whole person so you have to remove the disability and sort of hold it at arm's length, and again I know it comes from a place of respect, but I have always felt like it's just another aspect of who I am rather than something to be ashamed of and that's why I'm so adamant about using "disabled person" and calling myself disabled.

Kyle: yeah, it just sounds better to me.

Emily: See, you have a much more simplistic reason for using it than I do.

Kyle: yeah, but whatever works right? We are on the same page.

Emily: Yeah and, oh! I remember! I want to talk about euphemisms can we please?

Kyle: Yes.

Emily: I think you know what I'm going to say but what's your take on euphemisms?

Kyle: I don't like them. Because, I think they sugarcoat things to the point where those things that they sugarcoat become unidentifiable and it loses any and all meaning. So for example, I know your favorite is "special needs", but I would say that people with glasses have special needs because they can't see so they get specially needed tools to put in front of their eyes, it means nothing. And it's just a word that people use--or or a term that people use to make themselves feel better.

Emily: see I feel a little twitchy talking about the sort of thing because I just really am bothered by the use of terms like "differently abled" or "physically challenged" or "special needs" because I just don't feel that it really gets to the heart of the issue.

Kyle: Which is?

Emily: that you have a disability! that you don't have the ability of the majority

Kyle: Most of the world?

Emily: Yeah! and I suppose that people could argue that disability is not really a great word because it's creating a sort of binary between abled to and not abled.

Kyle: So? that's exactly what it's doing. and that's exactly what it's for. you're either abled or you're not, it is a binary! Binaries aren't always bad!

Emily: No I'm not saying it's a bad thing necessarily, but who's to say what ability really is?

Kyle: C'mon that's... I know what you're saying but if you take an able-bodied person-- well if you take a non-disabled person, which is your typical human being and you remove something, that's what a disability is, and that's okay there's nothing wrong with that, but it's a binary, you're either disabled or not, you can't be kind of disabled--I'M kind of disabled!

Emily: yeah but I think that's cause to you as much difficulty as it has in terms of being positive thing because I know we've talked about a lot way before we started this podcast how you've been told you're not disabled enough.

Kyle: Right. by people with disabilities. People without them don't-- they take my word for it, so it's on us.

Emily: is that alienating to you?

Kyle: yeah but I mean what can I do about it? I mean it's within the community, you can't fork the disability community, I mean sure you can but what's left after that?

Emily: Well I do wish that people in the disability community would be more aware of the fact that there really is no such thing as a disability hierarchy.

Kyle: no but, there's a hive-mind that our community has that if you don't agree with it a lot or don't succumb to it every once in awhile that you're wrong and I'm wrong a lot according to the silent majority-- or the loud minority rather.

Emily: yeah, because the thing is that this hive-mind that you're talking about is really the disability bubble that we are in on social media and in our day-to-day lives just because these are the people that we surrounded ourselves with, so we hear opinions from a particular group of people day in and day out and those are the ones that I think you tend to feel like you should share. and I'll admit there's a couple of things that I have not always agreed with, but then I get a little nervous about saying that because then I don't want to lose my disability card for my activism card if I'm allowed to pull a Donald Trump for a second.

Kyle: no but that's my point I don't think you should be afraid and risk anything for having an opinion and the fact that you do says a lot more about the community than you.

Emily: yes. Also though, I don't want this to sound like it's an attack on anyone, this is more just us keeping it real about how complex and tangled the web of identity and community can truly be.

Kyle: yeah, we're not here to attack people that'd be silly.

Emily: yeah, we're not about that. But there's so much to think about and I know this is going to be a little bit of an abrupt jump but I also wanted to make sure that we talked about when person first IS supposed to be what you use and when "identity first" is not really identity first, so examples being when you use an object to identify someone so like calling me a "wheelchair person"

Kyle: But... [Kyle laughs]

Emily: Go ahead and say it!

Kyle: okay, if you're in a room and you're the only one, you're a wheelchair person. I mean, you're not [Emily laughs], but have you ever tried to describe somebody without using their skin color? that's what wheelchair is to you, you just have to, and that's okay, I mean you shouldn't do it, you should say "oh, she was a person in a wheelchair", but if you're one out of a hundred that's how people are going to remember you even before your name. and that says a lot about society but it's also not something to ignore.

Emily: yeah and also wheelchairs have such a negative connotation to people it makes me so angry, I mean your described so often as "confined to a wheelchair" or "bound to a wheelchair" or disability, also a negative, "suffers from a disability"

Kyle: That's a good point... you can go on.

Emily: Oh I thought you were gonna... drop some Kyle wisdom

Kyle: I was I'm gonna let you finish.

Emily: Imma let you finish... [Emily laughs] yeah, I just wish there was at least some consciousness of what not to say, I think there's certain things that you really just should not say, some things are very much personal preference when it comes to Identity but some things are just not cool. don't call me wheelchair person, don't call me wheelchair-bound, I mean I'm not, my wheelchair is my freedom, it's a part of how I get around and that is a part of me, I do consider it part of myself, because it's essentially a stand-in for my legs but it's not something that I'm literally tied up to.

Kyle: the people who argue against that would say that they're bound to it in the sense that-- in the same way that you're saying it's your freedom-- they would say that without it they can't

move therefore they are attached to it, therefore they're bound to it, it's like the other side of the same coin... you're saying the same thing. I don't have a preference, I mean the de facto is wheelchair user so that's what I say but I won't get on anyone's case for it.

Emily: I think that "wheelchair user" vs "wheelchair bound", even though this is just an argument about semantics over here, when you're bound to something it sounds like you're trapped but when you are the wheelchair user, the power is back in your control.

Kyle: I get it. And regarding "suffers from", it's funny I hate that one so much, because I actually hated, it's just a treasure trove of misinformation

Emily: What do you mean?

Kyle: so "sufferers" has a definition and one of them means "to be affected by", and so literally everyone with a disability suffers from it because without it we wouldn't have one, but that's a word that almost always comes with negative connotations, kinda like the word awful. it's synonymous with awesome but you'd only ever use one to describe something bad and so while it's not wrong to say, be mindful that by using it you're putting negative imagery in the heads of your listeners and that's not good.

Emily: yeah that's what it all comes down to is the image that a word puts into your head so I think that's why a lot of people are hesitant to use disabled or disability as an identifier or to consider it part of their identity because we're just--

Kyle: Well they change too.

Emily: What do you mean?

Kyle: I mean, words--they change, they change meaning.

Emily: oh yeah, language evolves all the time, for sure. and also we have this Collective image in our head that disability is this terrible tragic thing when really in the vast majority of cases it's not and so I understand when you're attacked every day by a society that says hey disability really sucks and your life sucks and everything is terrible, then sure, you're not going to want to call yourself disabled but if we just see it for what it is as a descriptive terminology, and also as something that has a culture behind it-- a rich and wide culture in which there are tons of people that came before me who did incredible advocacy work that I look up to then we stop seeing it as a negative and we start seeing it as something that just is.

Kyle: yeah, I don't see it as a negative, I just-- it's there. I don't distance myself from it as an identifier because I'm ashamed of it-- that's something that I actually never really went through-- I feel like I'm late. it's going to hit me later in life, I just don't like it because I don't see a point, I mean I get why people do it, but it's just not for me, I don't gain anything from describing myself as a disabled person--except for occasionally better seats at concerts--than I do any other word.

Emily: yeah, not going to lie sometimes being disabled isn't so bad, and we can definitely-- or we should definitely talk about disability parks and another episode.

Kyle: Yeah, we should, they're pretty great. [Emily laughs] it's not really a fair trade but when you think about it, but if you don't think about it too much it's pretty good.

Emily: yeah sometimes they're just silly, the "perks" that you get but perks or not, I mean I'm very proud to call myself disabled, it's something that I've grown into even though it's been with me my whole life it's finally something that I say without feeling this little twinge of shame or being embarrassed.

Kyle: I think part of the reason why I never called The Pride but I guess because I never had the shame, I'm serious. I imagine if I had that that I'd be more willing to shout it from the rooftops, but for me it was always such a non-issue growing up, or such an invisible one anyway that I never looked at myself and said "man, I don't like me because of my CP", that never happened.

Emily: Do you think that has to do with the fact that your disability is not very visible?

Kyle: Yeah, I do, because on it's worst day, my CP kinda just... is annoying. I mean it hurts a lot, but there's medicine for that, on it's worst day all it is is a trickster, but I realize that most people with CP and probably disabilities can't say that. So... there ya go.

Emily: and also it's not very noticeable in most of your movement either.

Kyle: Yeah that's true.

Emily: So, I don't know if that has something to do with why you are so... almost indifferent...

Kyle: I am totally indifferent, that's exactly what I am. [Emily laughs] I'm completely indifferent.

Emily: and yet you're not though, I'm going to push back on that one because here you are doing this podcast.

Kyle: I'm sorry, I'm indifferent to it as an identifier Kama that's what I'm indifferent to, but in terms of using it to be a better person, in terms of using it to help people and educate people then sure. If that's your definition of an advocate which by the way is it, but if your definition is to where the wheelchair symbol on your shirt and to shout it from the rooftops I'm not about that life man, it's not for me.

Emily: so you're not getting a tattoo of an accessible symbol on your shoulder anytime soon?

Kyle: well, I mean if this becomes the top 10 listen to podcasts of all time, but no I'd rather be caught dead.

Emily: oh, hold on know you heard it here first, so I think I'm going to challenge you.

Kyle: Oh here we go.

Emily: Yup. if this project becomes popular, I don't exactly know what the measure of that would be.

Kyle: Top 10 of all time.

Emily: All time? Okay that's a lot to contend with.

Kyle: Yeah.

Emily: We have to contend with Serial and all the good NPR ones, okay but when we eventually Reach This pipe dream, you are going to get a giant accessible icon tattooed on your shoulder.

Kyle: but even in that case though Emily, it wouldn't be for disability would be for this. That's the difference between everything.

Emily: Yeah but people would see it and...

Kyle: People would see it and get angry with me because I'm not in a wheelchair is what people would do.

Emily: Probably. Or, they would see it and say "oh wow he has a lot of disability pride!"

Kyle: Yeah, which is like the worst thing I would ever want anyone to think about me. [Emily laughs] It's true! My god!

Emily: no, it's in there somewhere. It's there.

Kyle: it manifests itself through the podcast, that's it.

Emily: no they were definitely precursors that led up to this podcast.

Kyle: arguments with you

Emily: Right. Arguing with me is fun. If that's where your disability pride comes from, then good! I've done my job.

Kyle: Yeah, there you go, you've earned your activist stripes, you did it, good for you, you can go home now. [Emily laughs]

Emily: what color are my stripes?

Kyle: White and blue.

Emily: Oh, yes.

Emily: Anyway, so clearly Kyle and I were getting a little silly just now but as we like to do, we just kinda want to wrap it up and leave you with the takeaways from this episode that we hope you'll carry with you after you've listened to it, so if you could sum up identity in one word, what would it be?

Kyle: Yours. And yours alone.

Emily: alright, hey! that was three words

Kyle: well I said yours, but it took you awhile so I just sort of clarified.

Emily: oh I didn't know if you were going to throw anything else out there

Kyle: Nope.

Emily: I'm going to say identity is complex and personal because you got three words so I get three words.

Kyle: that about covers it.

Emily: And I think that's a wrap on episode number 4 of The Accessible Stall! Thank you so much for listening! I'm Emily.

Kyle: I'm Kyle!

Emily: And we will catch you next time, bye!

Kyle: Bye!