

The Accessible Stall Podcast

Episode 69: Inspeak

E: Hi, I'm Emily Ladau

K: And I'm Kyle Khachadurian

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

K: What are we talking about today Emily?

E: Inspeak! Although I feel like, now that I'm saying Inspeak, that in and of itself is some kind of jargon that I just don't like.

K: Well you're gonna have to explain to this non knowledgeable person what Inspeak is, as if I didn't plan this before with you before we pressed the button.

E: So I think the best way to explain it... And you can kind of jump in here. Is words and phrases and ideas I would say that different communities use to describe certain things that don't make sense or translate well to people outside that community.

K: Right...yeah. It's almost like how can somebody outside of that community sort of come in...even though, that's what we want in many cases, if the language choices that we use is off-putting, or at least overwhelming to the people that don't already know.

E: Yeah. I think that in the case of the Disability Community, we can unintentionally be alienating when we are trying to explain and shed light of concepts that actually have a big impact on us. Because the terminology that we use just doesn't make sense to people who aren't familiar with the day to day of Disability or even really he ins and outs of experiences.

K: I mean, we're two Professionally Disabled People™ and I don't mean to speak for you but I know that I sort of almost forget that not everyone knows. Meanwhile, even like my parents who obviously know me, when I talk to them about stuff like this like, they know as much as they need to take care of me, or have raised me. But if I talk about "Inspiration Porn" to them, they'd be like "What the heck are you talking about?" And I could explain it to them and they'd still be like, "What are talking about?" You know, and they're not dumb... And you would think that they're like the perfect people to understand what that is because I'm their kid, but they don't. And that's sort of what we're talking about, how to communicate that.

E: See, my parents get inspiration porn, but only because I spend most of my time yelling angrily at the TV when that final story on the 6:30 news comes on and it's an Inspiration Porn

story. And so they sort of adjusted to me yelling about it. But in all seriousness, I think inspiration porn is a really good example to start with because I encountered this time and again when I'm trying to give a presentation to people and I'm trying to introduce the concept of inspiration porn and I'm trying to explain why it's not a good thing but I can't even get people to get past the word "Porn." So how can I accomplish my mission of trying to explain that you gotta stop sharing inspirational stories that objectify people with disabilities when people see the word "Porn" and freak out instead of seeing the word "Porn" and understanding that it's a way of saying "Objectification."

K: I mean, I suppose you could say objectification, or I suppose you could say that phrase you just said. But I mean, isn't that the point of coining terms is to condense complex ideas into simpler phrases. But I mean, how far down does that go? And I mean, I agree with you I think Inspiration Porn is exactly the phrase that it should be...And I think that people who get offended at that word, depending on why, or they're too far gone. But I also think that word is there for a very explicit reason and although the choice to call it that was an explicit one, it isn't anyone's fault that when you hear that word, you automatically think of something that isn't what you're talking about. In this case, pornography.

E: Yeah, but I think one that I wanna touch on that you said is that it really kind of hits you in the face. Right?

K: Yeah, yeah...

E: It's a very strategic word choice, and I think there's a reason for that, but on the flipside I feel like it backfires a lot of the time because nobody wants to see themselves as the inspiration pornographer. You know what I'm saying?

K: It's hard for me... and I imagine you as well, to feel that because we're on the business end of inspiration porn which obviously also sucks like we've talked enough about that. I imagine it's sort of like... it might feel a little bit like being called sexist? Your immediate reaction is to be like, "I'm not sexist!" But it's not you specifically, it's things that you have done that are construed as sexist now. And it's like you never wanna be labeled as the person's who's responsible for that and especially when you don't know what the term is or if you get hooked on the word "Porn" it's never gonna get to you no matter how hard we try.

E: Or if you call it Disability Porn, which is my personal favorite because a lot of people are like, "Oh yeah, I never share Disability Porn." And it's like, "You know, I should hope you don't share that on Facebook!"

K: "Do you want a cookie?" By the way, don't Google that!

E: Please don't!

K: That's a whole different thing!

E: But what you said about sexism also makes me think about ableism which is actually a perfect example of a word that still alienates people

K: ... Yeah I should've used that word instead

E:... Because last time I checked...And I want to do a little experiment here. When I type "ableism" or "ableist" into Microsoft Word, I still get that little red squiggly line.

K: It's not a word, you gotta add it to your dictionary!

E: Let's see... (*Typing in the word*) I must've added it to my dictionary.

K: Here, let me do it on my phone. Oh actually, funnily enough, it is in the Apple dictionary

E: You know what, maybe that's why because I'm doing it on a Mac computer...

K: Oh. But I've definitely seen it before. I've seen it hundreds of times.

E: Yeah but it used to happen to me all the time when I was writing papers for college and I was like, "Ableism is just as real as racism and sexism!" But to be quite honest I don't think ableism has any sort of recognition or raises any sort of alarm bells in the way that racism and sexism does. I just don't get it.

K: If any of you listening...If your knee-jerk reaction is "Of course it is!" consider your favorite social justice whatever probably doesn't have that listed. I mean, how many Causes have there been that have listed every single... I mean, *every single* other "-ism" there is except for that. I mean the Women's March is notorious for that.

E:...Women's March! Yup! We're on the same page.

K: Yup! I mean, and they learn, they learn, you know? Bless em' But that happens *all* the time. I mean, everywhere! And it's like, then the question becomes, if the people who are supposed to be susceptible to these things, aren't seeing it. I mean, how on earth can we talk to Joe Schmo who is just a normal person with a normal life that has never thought of any kind of institutional anything because he has some form of privilege, but also, he's too busy! You know? Like how do you even do that?

E: And also, and this is a little bit of a tangent...A writer, who I've worked with many times and admire very much, S.E. Smith, uses *Disableism* instead of Ableism which quite honestly I think is a little bit more accurate to *Disablism* rather than Ableism

K: I agree with that!

E: And while that's not really the point of the episode here, I think it's worth mentioning because I also think that when we say ableism, people don't even have the right frame of mind when they're hearing a term like that for the first time. Because it automatically centers the idea of able.

K: I would agree. In fact, I'm gonna start doing that now if I ever am finding myself in a situation where I would have to explain that to somebody. But I would also say that obviously, ableism is the far more popular term. So when you do see it, you're probably gonna see it stylized like that.

E: Yeah

K: But I agree with you, that is way more accurate.

E: Yeah but again, another term that I think alienates people rather than brings them in to what we're trying to accomplish here.

K: Where do you go? I mean like, okay I am some guy, right? And I bump into you on the streets of Manhattan, and I say "Oh, Sorry Miss!" Actually no, sorry.. you bump into me, it's your fault! And I say, "Oh, Sorry Miss!" And, you know for some reason you're feeling particularly teach-y today and you say, "That was my fault, I wasn't watching where I was going." And I say, "Oh, come on! Do you need a license to drive that thing?!" And now you're angry. There are so many people like that. And i know that a lot of them are obviously going to not care and be lost causes but I have too much optimism in this world to think that most or even a majority of them at all would be that way, even if there was just an efficient way to communicate these ideas to them.

E: I want little business cards. I think about this a lot and it's not an original idea, I've seen it on the internet before but just business cards with assorted phrases on them that are problematic and just a QR code that you can scan to read more about why this particular phrase is problematic. But the problem is honestly, that but the time I got one of those out, the interaction would be over and the person would walk away...But a girl can dream, right?

K: Yeah, certainly.

E: Also, apparently Disablism stems from British English where they do things a little bit more sensibly.

K: Oh yeah, there you go!

E: At least according to Wikipedia

K: Wikipedia's never been wrong! Except for all the times that it has

(Emily chuckles)

E: I mean, it makes sense because they also say, "Disabled People"

K: Oh, do they?

E: They do.

K: Oh, neat

E: Yeah, no they are several steps ahead of us in life

K: That's good!

E: But anyway, so back to alienating terms. Another one that is on my mind constantly is "Spoons" and "Spoon Theory"

K: By a show of hands, or whatever limbs that you currently have to indicate yes...how many people know what that is? I can't see all of you but I imagine that all of you just raised your hand and/or limbs or whatever that you have.

E: What if you are a quadruple amputee?

K: Then you raise your nose at us, ma'am!

E: What if you don't have a nose?

K: Then if you if you are innovative enough to find a way to listen to a podcast then you have a way surely to answer a question posed to you by someone on those podcasts!

E: We're very adaptable people, the disabled community

K: It's true, no. Disabled people are like born MacGyvers guys

E: So anyway, I was just joking honestly, but when I first heard of The Spoon Theory it kind of filled a gaping hole for me in terms of understanding how I experience the world and how I can explain to other people how I experience the world. But the thing is, first of all, I never really used the spoon theory to explain my experience to anyone. Instead, I think it's become a thing that disabled people, or "Spoonies" use to validate their own experiences to themselves. And I don't think it makes much sense to dive too deep into what The Spoon Theory is, but essentially

it's like you start the day with a certain number of spoons and you have to determine how you're going to spend your spoons and each activity is worth a certain number of spoons and the onus is on the disabled person or the chronically ill person to figure out how to spend their spoons and conserve as much energy as possible. So spoons is a standard for energy. And I recommended Googling The Spoon Theory and learning all about it and its originator, Christine Miserandino on, *But You Don't Look Sick*. It's very helpful, but it's become Inspeak. It's become a symbol among the community.

K: But, that...The essay itself, not the terminology used within, is a completely amazing, great way to do exactly what we're trying to do. That essay is a perfect, perfect way to at least describe her condition to an able-bodied friend. I don't identify with much of what The Spoon Theory says. I think it works better with people who are slightly differently disabled with me. But, because it's become so ubiquitous in the community, like it clearly touched a nerve. And I think part of that is because it can clearly be used a bridge between us and The Ables™

E: I think the problem is again, that we go around wearing Spoon Jewelry and Spoon Shirts and calling ourselves "Spoonies," and comparing how many spoons we have, and sending messages to each other like, "Sending you an extra spoon!" or something like that. But it didn't really serve the purpose to bring other people into our experience unless we then actually use a spoon or use our energy to be like, "Let me actually explain to you what this means!"

K: Well, that's my point like I don't do that! I don't do any of that. You know, I don't care if you do but I'm just saying that I'm in this and I still don't do that. Like I've seen people say that, I see it all the time. I think it's weird. Not bad, just something I don't do. But my sister, right? Who was no clue about any of that...I can tell you right now, if she read that stuff she would be like, "What is wrong with these people? What? Spoons?" And that's what she would say. And I'd have to be like, "Look... there's this essay..." And then I'd have to do that whole thing. And then she'd be like, "Oh, okay but spoons?" And she's not an ignorant person so like, what do you do?

E: Yeah, it's definitely confusing for people. But on the flipside, I think the other fun thing that people like to do is co-opt terms too.

K: Oh, absolutely!

E: Like now everyone and their mother uses the words "Spoonie" and "Spoons" And I know that kind of negates what you just said but It's kind of like you either know what it is, or you don't. And then sometimes the people who know what it is but don't necessarily have a "valid reason" to talk about energy units in terms of spoons, then they begin to use it.

K: It's true though.

E: And it's like, "Are you disabled? Are you chronically ill?"

K: I think...But you actually raise a really good point because I think that "Spoonie," has...I don't want to say like evolved from its original point because we still do use in exactly the way it was intended but I can tell you I have definitely seen people without disabilities, presumably without disabilities, use the ideas behind The Spoon Theory in their own lives. Which, normally in any other context would probably make us mad. But this is just demonstrating the point that we're trying to get at is like, it cuts both ways. It's either, you're clueless, or you just make it your own thing to the point where it's meaningless.

E: Well I think that people do get mad

K: Oh yeah, yeah, yeah I know! I'm just saying not us right now!

E: Oh! I'm not mad. But also I guess it makes me wonder...are you really taking the time to understand what it is that you're saying? And you know should we be up in arms? I should say on the flipside: Should we be up in arms about people co-opting a term like "Spoonie" when it's exactly the kind of term that we want to use to get people to understand what we're going through. So I guess what I'm saying is like, "We build a bridge and then we wanna like chop off the end of it?"

K: Yeah, it's like you can't have it both ways, It's like, "Look, here's something that will make you understand us." "Oh cool! I like it!" "No, no no! You're not allowed to like it, all you have to do is understand it. We like it! You don't get to like it."

E: Or you can like it but you can't have it!

K: Yeah, exactly.

E: Which to be fair, I guess (*unintelligible*)

K: Well, that perspective is a little more valid, depending on well....I don't know. Your intersection of life. But even so, it's like where's that line? I think The Spoon Theory is on it. Because honestly, on the flipside, like a much more extreme example of an inspeak term like if an able-bodied person called me a "Crip" or called themselves a "Crip" I would sooner assume that they were talking about the gang than being disabled. Because nowhere in my mind would it occur to me that someone who's clearly not disabled is describing themselves as such.

E: As usual it takes us several minutes to get to the

K: Meat and Potatoes?

E: The main point of the episode, but yeah that's it! "Crip" is an excellent example because I say, "Crip" and "Cripple" all the time but I will punch you in the face... I won't actually

K: Like in her mind...

E: Yeah. Like if you don't know me, or you know nothing about me, or you just call me a cripple as an insult? *Forget* it! But meanwhile, I'm perfectly happy going around calling myself a cripple, referring to parking spots that are accessible as "Cripple Spots" saying I'm too crippled to do anything, saying I'm hanging out with my Crip friends. Totally fine doing that but don't you dare do that if you're not in any way affiliated with Disability or a part of my life.

K: Yeah... We really shoulda said that twenty minutes ago.. But I mean, it's like, yeah... Yeah what can you do? Because when you say it, Not you but you as in "Joe Schmo Able-Bodied Person" when you say it I know that you could be meaning it exactly like I am but I know that you're probably not. You know? That's really what it is. If I knew in your heart of hearts that you meant it exactly the way that Emily, you mean it when you refer to yourself? By all means! But because I can't read your mind and because all the evidence points to the contrary...Ehhh you know... I'm not in the business of telling people what to say and what not to say but it's just, it's not good for ya. Just don't do it.

E: I think this touches on our recent episode how we were talking about how "Doctors are Dickheads" kinda feels alienating versus like how, "Crip the Vote" has some shock value,

K: Yeah

E: But it can also I guess kind of be alienating. And so I guess "Crip" and "Cripple" are also words that also are part of that very fine line or on that very fine line of like, "Are we pulling people in or are we pushing them away? Are they completely lost, or do they get it?" If they get it, do they think that they get it enough that they suddenly have license to start saying it themselves.

K: And it's funny because that's one of those things where you just sorta know it when ya see it. Like there's no way to... I can't write down the criteria or explain the criteria by which I am beyond reasonable doubt sure that someone "gets it." And yet, if someone I have no idea uses all the terminology in the right way or even as simple as has a wheelchair in their Twittle, um Twitter handle. Like, really.

E: Their Twitter handle?

K: Or their Twittle handle. I mean, social networks are out of control in the year 2018. Jesus, I sound like my 70 year old grandpa.

(Emily laughs)

K: "Get off the Facebook!" It's like, I don't know, just one of those things where you know it when you see it. But like, also to your point and I'm sincerely asking this! This is not sarcasm,

this is not like a thought experiment, but do we ever extend olive branches to people who would usually be in our little group, disabled or not. Disabled or a really good ally, whatever. But feel intimidated due to all the Inspeak and jargon and practical college course worth of knowledge you need to know before you could talk about it.

E: How do you extend an olive branch for something like that? I mean if you're talking-- I guess, my question in response to your question because that's very helpful, respond to your question with a question is... are you talking about an olive branch in the sense of like giving them kind of a free pass and like reaching out and trying to bring them in? Or are you talking about an olive branch in the sense of like avoiding these inspeak terms all together and using language that brings them in. I just think...i see "Olive Branch" in two ways, do you know what I mean?

K: Um...Yeah and I meant it both ways. It's entirely context dependent on what happened before you decided to extend that olive branch. If a good friend of mine uses a Disability term wrong, and I don't mean like in an offensive way, I mean like just wrong or like close but not quite I am more than happy to be like, "Hey man, blah blah blah." And if they're decent they'll be like, "Oh, okay!" And if they're not decent they'll be like, "Ehhh...alright, whatever!" But as far as using plain language, I'm a big fan of it although I'm also, I don't really have a problem with using jargon amongst people who you know know it. But otherwise yeah, I would avoid it, personally. And I do! I do for the most part. I don't call myself a "Spoonie" I don't call myself a "Crip" it's not because I don't believe those terms are valid, I think that if someone else who's not me or you or in this world hears me say that, that they're gonna think the completely wrong thing and it's gonna be my fault.

E: See, I have called myself both a "Spoonie" and a "Crip" however, I can't help but feel like I get enough eyebrow raises when I call myself Disabled instead of a "Person with a Disability" that like "Spoonie" and "Crip" and the like are in a whole other level. And i'm still here trying to get people not to clutch their pearls when I say "Disabled." You know what I mean? I think that's where we're at with people outside the bubble at this point.

K: Well that's kinda far away from where we need to be though, isn't it?

E: Yeah, honestly it's to the point where I think about before every presentation that I give or talk that I give if I want to do a quick note prefacing my talk in which I explain that I'm going to switch back and forth between "Disabled Person" and "Person with a Disability" and that neither is wrong, it's a personal preference and it feels natural for me to switch back and forth. Like I still feel like I need to defend and explain basic language choices. So I don't think that a lot of people, and maybe I'm not giving people enough credit, but I just don't think that people are ready to be brought along on the "Spoonie/Inspiration Porn/Crip/Ableism Ride." quite yet.

K: I agree with you. But I feel like if you're doing a talk like that, that it's sort of important to do that. I don't think you're defending yourself--I mean, I'm not gonna tell you what you're doing. But I would rather look at it like, "Look, I don;t know who's in this audience so they might not

know that they're interchangeable" you know. For me it wouldn't be a defense mechanism. For me it would just be a way of letting someone who might not know, know that they're both okay. Because I mean what if you're someone that does wanna learn and has no idea about Disability but you find your way into whatever conference you're at and you're like read to soak up all this knowledge and you hear this Disability world renowned activist get on stage and like, use terminology that sounds similar but isn't the same and it's like, "Oh, okay now I know it's the same, now I know it's okay."

E: Yeah. And that's what I try to do, I think it's a two way street in terms of how we welcome people into the movement and in order to do that we need to kind of meet people where they're at sometimes. But that can be a bit challenging to do when you start to talk about more highly specialized terms, for lack of a better way to put it... I mean for that matter, I even still think that, and I'm sure we've had this conversation before probably on some previous episode. Terms like "intersectional" are still...

K: Oh, oh, oh yeah! There's a really good *Onion* article or something like that... One of those websites that's like a man who finally read through five hundred thousand pages of Queer Feminist Theory finally understands why he's problematic. The whole point is like, you need that! It's not gonna say you shouldn't need that, but yes I am, you shouldn't need that because how on Earth can you expect *anyone* to understand why what they're doing is wrong if you can't explain to them in a cohesive why what they're doing is wrong. And it's the same for this!

E: Yeah, and when we only have academic jargon or inspeak to inform how we're explaining things in the first place, how are we supposed to expect people to even bother coming along for the ride?

K: Oh and by the way I said, "What you're doing is wrong" It's not just when what you're doing is wrong, it's also when you're doing stuff right. It's like, it's just more commonly for negative stuff but really you're absolutely right. It's like... If you need to learn how to learn what we're talking about, it's gonna be an immediate turn off for so many people! So many people who otherwise, and I'm sure that there's bad people in any sort of sample group but for the vast majority of people they're just gonna be turned off by the sheer depth of the stuff.

E: Yeah, and I know that I mentioned when you were mentioning about olive branches before about whether or not you meant giving people a free pass. And I think that coming back to that, I do not mean that just because you may not understand something that you get a free pass to be an ableist, sexist, racist, asshole. But I do think that when someone is trying and they screw up, it's not that they should get a free pass, but that we should be willing to wiggle a little bit more. And I know that that is labor on our part...

K: No, no...

E: It is, it is!

K: Everything, *everything* is labor on our part then though. Everything is! I understand what you're saying. I didn't mean to cut you off. You're right, sure! But where does that stop?

E: I know!

K: Because, the alternative, the alternative if you don't want to do that then you don't have to do that, then you can spend your labor sure okay, but then they do get a free pass! It's one or the other.

E: I guess cause you're kind of giving them one by default. But I mean really then you know people are like "Go do your own homework. Where do I start?"

K: Well I don't agree with that either. I'm not talking about if you hear someone say something terrible I'm not saying just be like, "Nah!" I'm not doing that, I'm not saying that. I just meant that if something is off color or maybe misses the mark, use your common sense, use your good judgement you know? If you're explaining it to them is gonna make you more of a jerk than what they said? Don't say anything! At least in public.

E: Unless you wanna pick that fight!

K: Yeah, unless you're willing to do that. But then, you know that goes all the way back to good ol' episode one about picking your battles.

E: Wow, it all comes full circle. This has been the last episode of *The Accessible Stall* thank you and good night! No, I'm just kidding! (*giggles*)

K: No but you're right, you're right... You're always right. I don't know why I keep doing that, you're right by default.

E: It's good to hear. No, I'm not always right but this is a complicated issue and there was a lot to unpack here.

K: It's funny, you always say that during like episodes that are not complicated (*laughs*) And, well relatively not complicated and like now this one, we could talk about this for hours and hours!

E: We should honestly make a tee shirt with a little Accessible icon and he should be holding a suitcase and it should say, "There's a lot to unpack here!" (*laughs*)

K: You know, we've been meaning to reopen our store...that we had open for like seven whole days!

E: Please tell us if you would buy one if you've listened this far.

K: Yeah because let me tell you something, we'd buy one!

E: All the money would go back to transcripts which reminds me that we have a little bit of business to take care of, and why don't we just switch up the order of things? Before we do Final Takeaways...

K: Why don't we remind people how they can support our show! Well, first of all! Because it's Giving Tuesday tomorrow when we're recording this although it's gonna be way done by the time you hear it, if you wanna support the show and you do cause you're feeling giving-like go to Patreon.com/AccessibleStall. Just one dollar a month guarantees that all future episodes of *The Accessible Stall* will be made accessible! Basically we get to feed our transcriber! And if you do not have the funds or you just don't want to that's okay too, we would really appreciate a "Like" on Facebook or a follow on Twitter. Maybe if you don't want to do that either maybe you could rate us on iTunes or write us a review. You can do that right on the app that you're listening to us on, you have no excuse for that one! And we love you.

E: Couldn't have said it better myself. So, that interlude is over with...Final Takeaways! Go!

K: It's hard to be olivey!

E: Pshh... What? *(both laugh)* I mean, I get you.

K: Yeah isn't that weird *(laughs)* It is difficult in a way that almost doesn't feel difficult as it's happening. But upon reflection is difficult to gauge when and how and where you use plain language versus inspeak. I mean it's really not black and white. It's not as easy to say, "Oh, you use inspeak with who knows inspeak and those people are usually disabled too and in the community." It's like "Yeah, but maybe they're not." And you can't just use plain language because certain pieces of jargon have very, very useful terminology that any good person who wants to learn should eventually know. And so my final takeaway is that if you ever find yourself in the same pickle that we found ourselves in for the past thirty-five minutes, use your better judgement. It's probably right.

E: I don't really like pickles. Uh but...

K: Pickles are delicious. You are wrong.

(Long Pause)

E: You just told me I'm always right!

K: I said "By default!" This is a non default situation.

E: It's fine, we'll argue about pickles later. Um..tell us your opinions on pickles please!

K: I swear to God, when we get out of this bathroom stall!

E: (Laughs) Can you imagine if somebody thinks we've been in a bathroom stall every time we've recorded an episode?

K: We haven't. Sorry to disappoint you.

E: Wah wah wah... Um anyway, my final takeaway is that if we want people to get what we're talking about, to understand our experiences, we gotta budge a little to let them in. Yeah, that's how I feel about that. And I know that not everybody agrees with that, and this is coming from me who is the "Queen of Whining About Teachable Moments," but honestly you know if you're gonna make something a teachable moment or if you're gonna teach somebody something, sometimes you gotta meet the person where they're at. Not all the time, and we should always expect the best of people but unfortunately we can't so sometimes we need to do what we can to make what we're talking about accessible to everyone.

K: And uh, if none of you want to do any of that you can always just throw a person a link to this podcast episode.

E: Wow, I see what you did there.

K: That was it. This has been another episode of The Accessible Stall. I'm Kyle, she's Emily and might we say you look great today!

E: Thanks so much for listening!

K: See ya next time

E: Bye!