

Stories from the brainreels Interview Transcript

September 6, 2013

Introduction

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CHERYL: Welcome to Stories from the brainreels. I'm your host, Cheryl Green, from StoryMinders up in sunny Portland, Oregon. This is a monthly podcast about brain injury and disability with a focus on art, culture, and disability pride. Contact me at info@storyminders.com with questions or topics and guests you want to hear on an upcoming show.

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CHERYL: Today, I'm excited to play a prerecorded interview I did with local Portland celebrity Caitlin Wood. And she is another person who does not have a brain injury. I'm pretty excited to have a mix of people on this show who can talk about lots of different perspectives. We do talk about brain injury, mostly about disability culture in general. So sit back and enjoy.

[electronic music]

The Interview

CHERYL: Caitlin, I really wanna tell you that I love your blog, which is called WheresLulu.com. And this blog looks at pop culture, art, news, activism, and advocacy. And it's all through the lens of disability, which is very exciting. And you have some really wonderful goals with the blog. One of them is "to normalize disability." And another one is "to shine a light on disability culture," because most people don't even know that disability culture even exists. If you could start by just describing what disability culture actually is.

CAITLIN: Sure. Thank you for having me, first. I'm really excited. It's actually kind of a hard question, I think because there is so much to it. There is artists, there's activists, there's a way of relating to other disabled people. It involves identity. You know, there's so much richness to it. But basically, I would say it's a culture of disabled people, a community, who embrace their disability, who are looking to change perceptions about disability, who are in activism, and who relate to each other as disabled people and see their disability identity as something positive and valuable.

CHERYL: I talk to people about disability culture a lot. And I often wanna ask: So what are the hallmark foods of disability culture [laugh]? I'm not sure if there are. What do you think? Are there foods that represent disability culture?

CAITLIN: You know, it's funny you say that. I remember watching a movie, and of course I can't remember the title. It might've been the [Vital Signs Crip Culture Talks Back](#), which I haven't seen in years. But it's a great movie, Vital Signs. And I think it might've been in that movie where they actually talk about. And someone is saying, well, you know, in every culture you have food. So what is the food

of disability culture? And someone said, well, it'd be fast food because you don't have to get out of your car. You can just drive through [giggles]. Which I agree and disagree with. Obviously, a lot of people with disabilities don't have physical disabilities and all that. Yeah, food. That's a good question. What is the food of disability culture?

CHERYL: You know, I really did mean it as a joke. But that's so interesting that somebody really was looking at that. I know that, at least on one of the Ouch! podcasts or talk shows, they asked people to call in and talk about the foods that are most problematic around their disabilities. So maybe that might be: drinks that are too thin or drinks that are too thick. Or food that you have to grip a fork or cut with a knife. So maybe disability culture actually is against having food at all [both laugh].

CAITLIN: We don't like it.

CHERYL: We eschew it. We don't need that. We don't need food. But maybe we define our food by those foods that are accessible and then foods that are inaccessible.

CAITLIN: Mmhmm.

CHERYL: And they'll be different for different people, for different reasons.

Embracing disability identity and culture versus the medical model

CHERYL: In your description of disability culture, you talked about embracing disability and looking at disability in a positive way. And I can say from within my community, the community of people with brain injuries, a lot of people I know prefer to not see themselves as disabled or prefer to not say they're disabled. And of course, that's fine. I mean, each person should describe themselves however they want to describe themselves. It's certainly not up to you and me to go up to people and say, "Nope. You're disabled!"

CAITLIN: Right!

CHERYL: That would be inappropriate.

CAITLIN: Inappropriate.

CHERYL: But, I wonder about it. I wonder about a hesitation to think of disability in a good light. And I wonder just what your perspective is. Do you think that sometimes people with brain injuries say they're not disabled because of stigma against disability?

CAITLIN: Absolutely. And it's not just people with brain injuries. It's a lot of people with disabilities. And I think that it kind of boils down to the lens through which you're viewing disabilities. So if you're looking at disability from the medical model, which says disability is the same thing as your impairment in that it's something that needs to be cured or rehabilitated, and it's negative, then why would you wanna claim that? Why would you wanna say you're disabled? If you're looking at disability through say a social model perspective, where you're saying it's not my impairment that disables me. It's society that disables me. It's the lack of accommodations that disables me, then I think if you're looking at it from

that way, you can see things a lot differently. And I think viewing disability from that perspective's a lot more empowering. It also allows you to connect with other disabled people because you're able to share your experiences even if your impairment is different. So I understand that.

And I think just that our society says that to be disabled is negative. So it makes sense to me why so many people would internalize that message, just because it's so pervasive, and it's everywhere. And you don't see positive disability messages in the media. It's still pretty radical to talk about disability pride and to talk about loving your disability identity. So I can see, I can understand the hesitation. But I also am much more interested in surrounding myself with people who share my perspectives on embracing that disability identity and viewing it as something positive and valuable and something interesting.

Do non-disabled people see the social model of disability as victimizing or as being about oppression?

CHERYL: You talked about the social model being that I have an impairment. But what creates a disability is that this place is inaccessible or people's attitudes are inaccessible, and I'm not welcome. We've actually, in a lotta ways, moved on to the next level. Which, I don't know the name of the next level: the post-social model level, which I'm very interested in. But when non-disabled people hear about the social model the way you just described it, do they see us, then, as saying we're victims?

CAITLIN: Oh! That is a good question. Victims of society? Or victims of--

CHERYL: Yeah. Of anything. Just a victim stance. So if I were to say--I always use stairs as an example even though stairs don't present a barrier to me personally, most of the time. If I were to say, "Well, I could go to this event, but it was scheduled and held in a very inaccessible place. And I don't feel welcomed there. And I'm not going to be able to participate there because of all the barriers and the inaccessibility. So I'm going to stay home." Would somebody respond and say, "Well, you just sound like a victim. You're just complaining that you don't like the space. And why do you want everybody to just make everything so much better for you. You're so entitled."

CAITLIN: Huh. Well, I would hate to have to talk with that person who thinks that way [both laugh]. They might need a little self-reflection. You know, disabled people, it's oppression that you're facing. So I guess some people would look at that as being victimized. But I think that's taking the wrong approach. I think that's not really seeing the bigger picture of what's happening. I mean, why would you not want to create spaces that are inclusive for everyone and that are integrated for everyone? Why would you intentionally wanna hold an event that excludes people? That just doesn't make sense to me. And that's an oppressive mentality.

CHERYL: Excellent rhetorical questions. And not rhetorical either, though. Honestly. Disability and access are such an afterthought.

CAITLIN: Mmhmm.

CHERYL: It's not necessarily that people say, "Hey! Let's be sure to have this place that has really loud, thumping music and pulsing strobe lights and stairs because then Caitlin and Cheryl can't come." But when you don't even take the time to think through who are the people I want at this event, how can they be involved, can they get here, and can they enter the space with dignity and participate in the space?

CAITLIN: Exactly.

CHERYL: It's not just about getting in there. And then I put my headphones and my sunglasses on and sit in the corner cuz it's too loud and too bright, that wouldn't be participating. That would be like mainstreaming [laughs].

CAITLIN: Right. And we've talked about this before, but in discussing access, I think it is really important, too, to remember all the different elements of access, that access is not just physical access. Physical access is the bare minimum. Can you get into a building? Great. But what happens if you're going into a building, and no one wants you there in the first place? So I think we were talking about access with disability. We need to make sure to have that conversation and go beyond just the bare minimum of what's required of OK, we need to be able to get in the building, obviously. That's number one. But two, we need to be able to occupy space that is welcoming to us and understands our value.

CHERYL: Well said. Absolutely.

[electronic music]

Normalizing disability and going beyond access

CHERYL: That brings me to one of the other goals of your blog, which is to normalize disability. And so, is that what you're talking about when you talk about going beyond the bare minimum of access?

CAITLIN: Yeah. And I think that when we're talking about normalizing disability, disability is normal. Like duh. It's a normal part of existence. Many, many people are disabled. It's like one in five Americans, I think. It's like 15% of the world's population. It's not like we're talking about two people. We're talking about millions of people here.

And with America too, something that I'm pretty interested in is the fact that in the next ten-twenty years, we're gonna have many more disabled people just with the population aging. And so I'm hopeful that that is also going to spark change and attitudinal change about access and disability. But in terms of normalizing disability, that definitely is a huge goal for the blog just in me trying to highlight stories and people who are disabled and try to promote different aspects about disability and disability culture that aren't really seen elsewhere. There's so much talent and diversity and artistic endeavors that are happening that just go completely ignored by mainstream media. And disabled people are doing a lot of really incredible work.

So when we started the blog, that was definitely a big goal, was just to show people that you know, here's space where people are doing really fantastic work, all these amazing projects that are going overlooked for whatever reason, we're not being reflected in the media. And we really wanted to

highlight that and just show that it is normal. It is fantastic. The art and activism is often incredible. But it's also just a normal part of the disability existence. You've done your movies in showing what it's like to have a traumatic brain injury and doing it with humor and showing this artistic side and showing your talents. And yeah, I guess just that was definitely a big part of the blog, is just we wanted to show that disabled people are capable of doing a tremendous amount of art and great projects and that it shouldn't be considered unusual that we're capable of doing these things.

CHERYL: Right. Part of what you do on the blog to normalize disability and to normalize the activities and contributions of disabled people is that you don't have those inspiration memes up. You never put a link to someone's artwork and then say, "This person has overcome their disability to create the most amazing stuff. They don't let chronic pain stop them! They don't let the loss of a limb get them down!" And that kind of talk, that's like that's making something about disability extraordinary in some way. And you don't do that.

CAITLIN: Right.

CHERYL: You just say, "Here's a person doing a thing. It's wonderful. Check it out."

CAITLIN: Mhmm.

Disabled people as inspirational is actually condescending and offensive

CHERYL: That helps normalize it because goodness knows, that inspiration line is pretty condescending and offensive and disgusting, actually.

CAITLIN: Yes. It is. And it is maybe one of my most hated expressions of all time. I find it so unbelievably offensive when people use disabled people for their own inspiration because it really reflects the difference in standards of what they're expecting. So if you think that I'm incapable of doing anything, then of course brushing my hair is amazing to you, inspiring to you. It shouldn't be. But whenever I get that or read that, I just find it so repulsive. And I see a lot of disabled people who have internalized those messages and think that that's acceptable, calling yourself an inspirational speaker and all of this stuff. I just think that that's very detrimental to disability rights and to the kind of work that we're actually trying to accomplish. I don't think it does us any favors. And I hate it. You will not find inspirational stuff on Where's Lulu. I think too, one thing I would like to say too, is that I think it's fine--I'm personally inspired by certain disabled people but not because of them completing basic tasks. If you're doing some kind of amazing film or creating music or something that I enjoy, of course I'm gonna be inspired by that, but not because you got out of bed that day. I mean, that could be a big thing for some people. But I think you know what I'm saying, just that we need to really pay attention to how we're essentially judging what disabled people are capable of doing.

CHERYL: Right. The notion of inspiration and being inspiring because of your disability is actually a big part of the brain injury community. And I know that my listener--Just kidding, my listeners [both laugh]--I know that a lot of my listeners are in the brain injury community. And so this may sound like a really kind of awkward conversation to be having. But not everyone with a brain injury was close to death at some point. There are so many different levels of brain injury. They can be very mild. Or they can be

very severe. Some people actually do die and are brought back to life through medical intervention. And I think that because a lot of people in the brain injury community actually have tasted death and have come back, and people do things like truly have to learn, as adults, have to learn how to talk and walk and eat and all these basic things, that when people are sort of up and moving around and doing things, everyone around them says, "Oh my gawd, you are so inspiring! This is the biggest inspiration ever! Look how much you're accomplishing."

CAITLIN: Mmhmm.

CHERYL: But I don't think people reflect on it very much because while a lot of people with brain injury take that as a compliment, it's still saying the same thing that you said, which is, "My standards for you were extremely low."

CAITLIN: Mmhmm.

CHERYL: "I am so amazed that you lived." And the other thing is that--Oops. I forgot what I was saying. This happens all the time in the radio interviews. If I do too long of a sentence, I forget what I'm saying. A lot of the times, it comes from people's beliefs, "I could never accomplish anything if I lived through what you lived through. And because I think your brain injury and your disability's so terrible and so tragic, I feel really good about myself." Even though, within the brain injury community, the inspiration line is often seen as very positive, I still feel like it does hurt a movement toward access and acceptance because it's harder to be accepted if you're walking around waving this flag that you're the most inspirational person in the world. I feel the same way you do. True inspiration, where I interact with you, and that motivates me and energizes me and gives me a new idea for me to pursue, that's inspiration. There's nothing wrong with that. But when people just go, "Wow! You work harder than I ever thought you could or harder than I ever would!" and then they just move on and nothing changed? That's not actually inspiring.

CAITLIN: Mmhmm. I think it's just kind of brings up pity too. That mentality's just so common.

CHERYL: Yep. You know, it just gets so tricky when there's something like, "Well, actually, that particular mundane task was impossible for a time. And now it's become possible again." That's great. But I don't see why that's inspiring. Maybe it's just great and exciting. "Good for you."

CAITLIN: Exactly.

CHERYL: "You regained that skill." But I'm pretty skeptical most of the time when I hear the word "inspiring."

CAITLIN: Yeah, me too.

CHERYL: It's a shame that it also means to breathe in because that's something that I often forget to do. But it is a good thing.

"Your Daily Dosage of Inspiration"

CAITLIN: So we did a project, actually, referencing the whole problematic inspirational trope, didn't we?

CHERYL: We did. I remember it fondly even though the video footage that I took was not very good because I used a tablet. That was a really fun one. It's called "[Your Daily Dosage of Inspiration](#)." I gave it that title because I wanted it to sound medical and off-putting.

CAITLIN: Yeah [laughs].

CHERYL: That's where the title came from, "Your Daily Dosage of Inspiration." Do you wanna talk at all about where the idea came from or why it was important for you to make this criticism of inspiration?

CAITLIN: Sure! And I've gotten so much positive feedback about that film. People love it. And I think people really connect with that, disabled people really connect with that because I think a lot of us get really sick of being labeled inspirational for doing really basic things. And I can't remember exactly how we came up with the idea. I think we were probably just talking and decided that it would be fun to make a short video on that. So, essentially, the video is me writing in my diary about my extremely busy day where I brush my hair. And then I wrote in my journal. I think I might've even left the house. I had a phone call.

CHERYL: Nope, you didn't leave the house till the very end, actually.

CAITLIN: Oh, that's true. So that was the dénouement [both laugh]. So yeah, basically, it's just trying to highlight how ridiculous it is that we, as disabled people, will do very nothing important everyday tasks that really are not life-changing. Brushing your hair is not gonna go change the world. But other people will look to that. And because they consider you to be so defective and incapable of doing anything, that they're somehow gleaning this inspiration off of you completing these tasks. So we were really making fun of that oppressive mentality. And I think we did it in a really funny, humorous way that was not in your face. I haven't gotten any negative feedback about it whatsoever. I've only heard really positive things about it cuz I think it was really funny. And it was short and kinda to the point. And I think it was so kind of over the top that people really connected with it and could laugh.

CHERYL: We were talking about the idea with Andrew. And I wrote some notes down. And I came back the next weekend and shared my notes with you. And both of you just stared at me with this blank expression, not hateful or malicious, but just sort of like "Mmmm...nope. That doesn't--"

CAITLIN: [laughs]

CHERYL: Which is totally fine.

CAITLIN: I don't remember that. But I trust you.

CHERYL: Oh yeah, yeah. I mean I have absolutely no pride. Completely fine that the notes that I wrote down didn't work. Because what happened was, the two of you--pardon the expression--got very inspired and said, "I know how we should do it! Let's do it this way instead!" And it just, yeah, it was

improvised. You just improvised all these things. You took a few notes down. And then you just went to town. It was just beautiful. Hopefully everyone realizes this is satire. And I think satire is a great way to point out to people that some of the things they say are very discriminatory, even when they don't really mean to be discriminatory.

CAITLIN: Exactly. Right.

CHERYL: They don't know they're stereotyping.

CAITLIN: And they think they're paying you a compliment. And I think that's what's so frustrating is people have good intentions. And they think they're doing something really nice, when in actuality, it's very hurtful and dismissive. Because you know, I have people tell me that I am amazing for pushing an elevator door button and putting on my glasses, which is absurd. They know nothing about me. They don't know that I've had significant accomplishments that I am proud of and that I do consider amazing. But they don't know that. And I just think, well gosh, what would you think if you knew that I'd done this? You think it's amazing that I can put on glasses? I mean, to me that blows my mind sometimes, just the lack of common sense and understanding that disabled people are just as capable of doing things that non-disabled people are. It blows my mind.

CHERYL: Mmhmm, mmhmm. The whole video itself is captioned. And the captions stay on there all the time so that all viewers can see the captions. At the time that I edited the film and put the captions in, I didn't have the software for making Closed Captions that can be turned on and off. So that's sort of my excuse for having them on all the time. But the other thing is that a lot of people have complained to me that my captions on my films get in the way. And I can see why they would distract you. If you're reading them, then you're not looking at the actors' faces. And maybe that could be distracting. But honestly, I sort of feel like well, um, it's a little bit of an inconvenience for you to have the words up there when you don't need the words. But that's not any inconvenience compared to the idea that if you're hard-of-hearing, and you have no captions, you can't access the film at all.

CAITLIN: Right.

CHERYL: And so it's another reason that I wanted to go ahead and have the captions be the kind that you can never turn off because it's OK to be a little inconvenienced by captions. It's a very small price to pay.

CAITLIN: And I like it too just as a reminder that things should be captioned. I like that. I like that they're there and that people are taking notice that there are captions because things should be captioned.

CHERYL: Absolutely, yeah. I mean, ramps and elevators are an absolutely, completely critical part of physical access. So are captions, actually. People have caught on to ramps and elevators much more so than things like captions.

[electronic music]

Criptiques anthology on Kickstarter

CHERYL: So with all that, you and I are sort of sharing our perspectives, our own opinions about these different things. And I wanna move to talk about this incredible book, this [anthology that you are putting together called "Criptiques,"](#) where lots of other people--including us!--are going to be sharing their stories in their own words.

CAITLIN: [giggles]

CHERYL: So I would love if you would talk about why you started it, maybe talk about some of the authors.

CAITLIN: Yeah. So I agree with you. I think "Criptiques" is gonna be an incredible book. I am really, really, really excited about it. This is maybe one of the most exciting projects I think I've worked on. What it is, is it's an anthology of essays by all disabled writers. There are very few anthologies out there right now that are for and by disabled people. It just does not really exist right now. And I saw a huge, glaring omission there. And I really wanted to pursue a project that highlighted disabled people's experiences and disabled people talking about their own experiences in their own words. Not having people talk for them cuz that's a huge problem within the disability community, is oftentimes we don't get to speak for ourselves. People wanna take control away and talk for us.

So I saw a real need for this book to highlight the really talented and cool people that I know, people coming from really interesting backgrounds. There's burlesque performers in there, there's standup comedians, there's filmmakers, there's writers, there's activists, there's artists: People coming from really fascinating backgrounds and work. So I wanted to put that and compile it in one place to show that disability is not a monolith. There's a huge range of experiences and perspectives in there. And so I wanted to put that in there. [And right now we have a Kickstarter going for "Criptiques."](#) So we're trying to raise money. And I'm almost positive it's gonna get funded. And it should hopefully be coming out in the Spring of 2014. But I think it's gonna be really incredible. So you and I are in there, which should be enough for people to wanna get.

CHERYL: Mmhmm!

CAITLIN: And then artist Reva Lehrer, who's pretty renowned, out of Chicago, she's gonna be in there. She's incredible. Elsa Henry, who does the Feminist Sonar website is in there. And she writes about being a blind burlesque performer. Leslie Freeman is in there, who is an incredible writer out of New York. Nina G. Comedian, who is the world's stuttering female comedian is in there. So we have just a tremendous amount of talent in the book. And I think it's gonna be a really groundbreaking and stereotype-shattering and engaging read for people who are disabled and non-disabled. And we have a Facebook page. People can go to [Facebook.com/Criptiques](#). It's like "critiques" but with a "p."

CHERYL: And the Kickstarter address--Kickstarter and those kinds of things always have such bizarre addresses with all the numbers in them.

CAITLIN: Yeah.

CHERYL: Yeah, if you go to Kickstarter.com and put in the search bar c-r-i-p-t-i-q-u-e-s, you will come across Criptiques. And we are pre-recording this show. At the time of recording, you've brought in basically 45% of your goal in like a week, which is really incredible.

CAITLIN: Yeah.

CHERYL: So believe me, this thing is gonna get funded. At the time that this is airing, it'll be about six days before it closes. So I anticipate that by the time people are hearing this, you will have already surpassed your goal. That's fine. She can take more money beyond her goal.

CAITLIN: Yes, definitely.

CHERYL: So please contribute even if you see that she's reached it. Now, the title "Criptiques," it plays on the word "critique" and the word "crip." I have to come back to the brain injury community because this show is supposed to be about brain injury. It's been really important to me to start branching out to talking to all sorts of different people with different experiences around disability and different relationships to disability on this show. But it still always has a lot to do with brain injury. And so for folks in my brain injury community, most people are not familiar with the term "crip" in the way that you and I are using it. So I wonder if you could give a little bit of background to folks with brain injury why you refer to disabled people as "crips."

CAITLIN: Sure. So "crip" is a reclamation of the word "cripple." I'm not sure when exactly it came into play. I think it was, I wanna say maybe the '80s. But that's my guess of it springing from the disability rights movement with people reclaiming this word that had been used against them in a negative context, and using it as a way of empowering themselves. So I use the word crip, and I self-identity as a crip because I think of it in terms of not just identity but my community and how I view disability and my culture. So I feel very much a part of crip culture, trying to dismantle traditional notions of disability and get rid of disability stereotypes. So crip is just a way of identifying yourself. It's interesting that you're talking about this too because I have had a comment from someone with a brain injury on the Where's Lulu Facebook page who said that they didn't identify with that word because they felt like it left people with TBIs out. And for me, I don't look at it in any way related to impairment. I think they thought more of like someone with strictly maybe mobility issues. But I certainly don't see it that way at all, and I hadn't really encountered that before. To me, it's very much about identity and culture and community, not in any way related to impairment.

CHERYL: Mmhm. And I've heard that too before, too. "Hey, those of us with invisible disabilities, we're being left out." A lotta time we're not actually being left out as much as we say we are. Now, when discussions are always about stairs and wheelchairs, then that might be a discussion where most of us get left out.

CAITLIN: Sure.

Identifying as cripple or disabled or gimp

CHERYL: But in terms of cripple, I use that word. I love that word. I tried to use the word "gimp" once to describe myself as having like a gimp brain. But I was told that that wasn't appropriate because that really refers to physical disability.

CAITLIN: Oh!

CHERYL: But I was told that by a non-disabled person who actually is a medical provider. So I thought, well now wait. Aren't you being a little bit of a thought police here [giggle]? Wait a minute! How did you get to decide what kind of silly terminology I use to describe myself? You know, for a while, I think I liked the word gimp better than cripple only because I was more familiar with it. Back in Austin, when I was there, it was just more about gimp than cripple.

CAITLIN: Yeah.

CHERYL: I didn't really hear about cripple until I got to Portland. So now I like cripple. But I thought that was interesting to be told, "No, no, no, you shouldn't use that" by someone who has no disability.

CAITLIN: Exactly. You know, I feel like people should call themselves whatever they wanna call themselves. I have disabled friends who hate the word "disabled," and they identify as "handicapped." And to me, I hear the word handicapped, and I just cringe. I have a very visceral reaction. It's so old-school to me. I would never identify myself as handicapped, but if that's how you wanna identify, fine. That's your choice. Call yourself whatever you wanna be called. I see cripple as a really empowering word. And gimp to me just sounds funny. I think I would use it in a humorous way. But I probably wouldn't identify as gimp. I think it might be a little more palatable than cripple to people.

CHERYL: Mmhmm.

CAITLIN: It's goofy.

CHERYL: Yeah, it is goofy sounding. And to say, "I have a gimp brain" sounds pretty silly. I think one thing we have to recognize is sometimes we're using different words, but we really do mean the same thing. But sometimes we use the same word, and we mean something terribly, terribly different. And it's good to just find out what someone means before you start judging the term they use to identify themselves.

CAITLIN: Right.

CHERYL: I'm not saying you need to do that. But the collective we should be sure to do that before we start people, "You shouldn't call yourself that. You're not allowed to use that term." Cuz we really don't know what's behind it. And it's important to know what's behind it. OK, well thank you for explaining how you use the word cripple really as sort of an empowering word instead of an insult like "You, you're crippled."

CAITLIN: Yeah. No, if somebody came up to me and said, "Hey, cripple!" I would probably be a little upset. But to me, crip is something also that really only people in my community and culture even know about.

CHERYL: Well, now more people are gonna know about it because of Criptiques.

CAITLIN: I hope so, yeah. People, I think, have never heard that. And so they see it, and they kinda don't know what to do with themselves sometimes.

CHERYL: Mmhmm. Well, I think that what's really neat about the mix of people you have in the book is that there's a lot of information about that's OK that you feel uncomfortable around us, but just hear me out and hear my perspective on it. And maybe folks will feel less uncomfortable. Maybe it will be more normal and normalized, and we can talk about it without getting defensive or concerned. Oh, wonderful. I just love the work that you do, Caitlin. Just wanted to just throw that in there.

CAITLIN: Oh, thank you.

[electronic music break]

Disability and diversity trainings

CHERYL: So in addition to the blog and the different things you do around art and culture, you also are an educator and a trainer. I would love to hear you talk really about whatever part around that you want to, but especially I'd like to hear, in your words, why it's so important that your trainings that you do go beyond "disability awareness."

CAITLIN: Mmhmm. Yeah, so that's another phrase that I'm just not super in love with, "disability awareness." Cuz I feel like awareness is such a passive term. And it's kind of like tolerance, where to me tolerance just doesn't sound that great. Why would you just wanna be tolerated? You wanna go beyond that. At least I do. I don't wanna just be tolerated. I wanna be welcomed and embraced. I don't want people to just be aware of me. [laugh] I want them to take action, you know? So to me, disability awareness is just kind of the terminology that gets thrown around because I think people just don't have another way to phrase it.

But for me, when I do trainings, I definitely try and put out that idea that we can do better than that. We can go beyond just awareness of something so that we can take action and do things that improve the lives of disabled people and that empower them. My passion is definitely disability culture and disability rights. I think that is less, people don't seem as interested in hearing about that. I think that's still a new terrain for a lot of people. I think a lot of organizations still want to hear--or think what they need to hear--is stuff about etiquette, how to treat people with disabilities, and just very basic kind of old-school approached to disability. So I like to try and push the envelope with that and talk about disability justice and disability rights and changing the framework of how we view disability, that it shouldn't be this charitable, I'm gonna open the door for you or just really basic kind of etiquette that doesn't really take us any further or challenge the way we view disability and how we've been taught to view disability.

CHERYL: Yeah. And I actually had the privilege of getting to attend one of your trainings without having to pay. That was very exciting.

CAITLIN: [laugh]

CHERYL: Well, that wasn't the privilege. It wasn't that I went for free that was the privilege was that I wasn't really one of the participants in the training. But I got to come and watch because I was so curious about how you run your trainings. And it's sort of in a way like a diversity training but saying that disability is a form of diversity, and it's a positive form of diversity. But rather than settle with just knowing some statistic, how many people have this disability, how many people use a wheelchair, how many this, that you really talk about here are the ways we experience an inaccessible world. And here's what you can do about it. And that not only helps improve the lives of disabled people, but it gives everyone tools. And in fact, it seems like a lot of people already have the tools. They just don't even realize it. So it's not like information is so completely foreign that people can't take it in. It's really all there. People have a lot of the tools that they've learned from other civil rights movements. And it's not that your needs are special [giggle].

CAITLIN: Right.

CHERYL: "Special needs" is also another terrible term. But you may have specific needs, and you may have things around accommodations that you, I, any of us, even people without disabilities need accommodations in life. You're just spelling out, in these trainings, you're spelling out how those accommodations can really seamlessly be put into society so that we have more equity, and we're all participating, not just at the level of being aware of each other's existence but really participating.

CAITLIN: Yeah.

CHERYL: So yeah, it was good. I would've paid! But nobody charged me at the door, so [laugh].

CAITLIN: Well, it was great to have you there. Yeah, I think another thing with what I'm trying to do is really emphasize that disabled people are a minority group and framing it in that way, that it isn't an individual issue. It's not one person experiencing an impairment. It's a community of people with various impairments who are disabled by society. And that that's how we need to view disability. We need to change the framework here.

CHERYL: And so for folks out there listening who want to hire you to come to their group or their college class or their agency, I know they can find you at www.Caitlin-Wood.com. Do you wanna give an email address or phone number?

CAITLIN: Caitlin, which is C-a-i-t-l-i-n. I know there's a million ways to spell it. But it's caitlin@caitlin-wood.com.

CHERYL: Yes, so that's how folks can get in touch with you to hire you to come into their group or class or agency and do these kinds of really innovative trainings.

[electronic music break]

"Accessible Intercourse" and non-disabled allies on Where's Lulu?

CHERYL: This is going back to the blog. It's a piece of the blog. You have a video chat series called "[Accessible Intercourse](#)" that you've been doing for several years with your co-host, Toshio. On the Where's Lulu site you write that, "Where's Lulu takes the irreverent and under-appreciated view that disability can be fun and funny. We like to highlight this. Haters can suck it," [both laugh]. I love the sense of humor! I actually have no question whatsoever about that quotation. I just love it and wanted to read it out.

CAITLIN: You know, I think Toshio might've come up with that one. So I should give credit where credit is due, although I honestly can't remember. But that sounds like something he would say.

CHERYL: Thank you, Toshio. That was wonderful! But I do have a question, and I think that you already do know. It's something that I've wanted to ask for a really long time. But I always felt too silly to ask before. So now that we're on the air where absolutely anyone can hear this question, I'm just wondering, in the title of the chat series "Accessible Intercourse," does that refer to sex or to intercourse as dialogue?

CAITLIN: It is a play on that because we thought it was really funny. It does refer to the dialogue because it's all about, we answer people's questions, we talk about pretty much anything and everything. We do like to talk about sexuality a lot just cuz it's a fun topic. So it was a play on that. And I thought that also just the phrase "accessible intercourse" was really funny. So yeah, you can take it any way you want to, Cheryl.

CHERYL: [giggle] Excellent. I will, I will. It's different every time. The first time I came across the videos, I thought oh my goodness maybe I should--do I need to watch this? I mean, is this gonna be like a tip show about accessible intercourse? And I may not need these tips cuz I don't have a physical disability, but I'll see what this is. This is way way before I met you. I watched it, and I thought, well, where are the tips on accessible intercourse? Then, what's really funny is I did come across an episode that did have that. And it took a long time for me to remember that "intercourse" was sort of an old-fashioned word for dialogue and discussion.

CAITLIN: Right.

CHERYL: And I started to realize wait a minute. Maybe this is a little bit of a joke [both laugh]! And so I did always want to check. But one thing that I do love about it is that you and Toshio don't shy away from any topic. You don't just say things gratuitously to be disgusting or to make a spectacle. But you talk about topics that people actually really wanna know about, but they don't know how to ask those questions. And so it's really nice that that show is there. And the title is just so funny.

CAITLIN: Thank you. We've been doing it for a few years. It's definitely fun. It's a little harder now because Toshio's down in San Francisco, and I'm in Portland. So we can't film as often as we used to be able to. But I definitely enjoy it. And it's true we--it's interesting to see also, cuz they're all on YouTube,

so you can watch all the "Accessible Intercourse" videos on YouTube. And it's interesting to see which ones people are very much interested in. It generally has to do with sexuality.

CHERYL: And that's good. What's good is that in general one thing that people with lots of different types of disabilities and share is that people think we don't have relationships or love or sex or that we could get married or not get married but have a long-term partner or lots of different partners. All sorts of things that people can do in different kinds of relationships without disabilities, all those same things are going on with people who have impairments. But that's not really recognized very much. I think that's why people are watching those episodes, cuz they think, "Oh, really? You have something to say on that topic?"

I wanna ask you a little bit about Toshio. I'd like you to speak for him because he's not here. Toshio is not disabled. He is an ally of yours. He's a very good friend of yours. He's an ally, and he's an ally to the whole disability community. And I think it's really great that you do this show that really focuses on experiences around disability, but you didn't feel like you had to have another disabled person as a host. It's not that people are either disabled or not disabled, there's only two positions. It's so much more complex and fluid than that. So in addition to working so closely with someone like Toshio, you also do lots of different projects with people with all sorts of different impairments. I would love for you to talk a little bit--unless you already have, and I forgot, then just tell me. But I'd love for you to talk a little bit about why it's important to you to be collaborating with people who, say, don't have an impairment or have impairments very different from yours.

CAITLIN: Mmhmm. Sure. I can't really imagine having done a project like Where's Lulu? with anyone else other than Toshio, especially at that time. It's been around, I think, since about 2007. And Toshio's been my best friend since college. He is someone that I definitely consider a true ally. He really believes in equity for disabled people and understands the oppression involved there. And so when we created Where's Lulu? and were doing the videos, I think it is interesting to have that perspective of the ally. And I think it works for a number of reasons. And at that time too, I don't think I was quite as involved with disabled people in my community, just I didn't know as many people.

And so it made sense to have him there. But I think it works really well. I think he provides a different perspective. And also, for better or for worse, I think non-disabled people watching it probably view him kind of as a translator, which I'm not crazy about that idea. But I think it's, unfortunately, true. That I think when I'm talking about my experiences as a disabled person, a lotta times they're gonna listen to me as much as they will him. So that was a consideration. Sometimes it feels like, as a disabled person, people just don't wanna hear it. They don't wanna hear about the oppression you face. They kind of wanna tie it down into a medical thing, when that's not the issue at all. So Toshio plays a big part, I think, in that, for better or for worse. But also just I think he is a good role model for what non-disabled allies can be. People can look at him and understand what they can do, how an ally, a really good ally functions. Cuz he's such a good person to look to for that because he truly does care about equity for disabled people.

CHERYL: You know, another neat thing that Toshio brings is he brings different perspectives, different minority perspectives as well, even though the topic is pretty much disability.

CAITLIN: Yeah!

CHERYL: You know, it's not like well, if you're not disabled, you'll never get it!

CAITLIN: Right.

CHERYL: Like I said before, it's more complex than that. And he has different perspectives because he is queer and Asian, he understands and brings to the table different kinds of experiences around minority identity and around oppression. And I think that's really valuable, again, to say, not that people can only "get" each other and can only relate if they have the exact same experiences. But that we can say, "Hey, we have some common types of experiences. We have some common ways that people to respond to us in the world and stereotypes that people have about us. And people don't want to get to know us as well because they see us as different." I think it's just really valuable. And he's not there as a token. He's not the token Asian queer guy. He's really there as your friend and as your co-host.

CAITLIN: Yeah, exactly.

CHERYL: To me, it's really lovely to see that mix of different things and different identities that the two of you together bring to it. So I have a different kind of question here. I have a question about using humor. And in the time I've spent with you, and in the projects I've looked at that you do, sense of humor really plays a big role. And I want you to talk about why so many of the things you do have such a strong sense of humor. Because access and social justice are supposed to be a serious business, right?

CAITLIN: [giggle]

The importance of using humor

CHERYL: Why is it that you use so much humor in your work?

CAITLIN: I mean it's just part of my personality. I feel like when I'm writing, I just use my own voice. So that comes through. But I think humor is also a really great way to get things done and to disarm people so that they're not really defensive. When I was in, gosh, I think high school, I saw Second City, the performers. The improv group came through my town. And this was like the Deep South in early 2000s, and it's a comedy group. And through their comedy, they got everyone to rip up their Blockbuster cards, which I thought was so awesome at the time. Because they were basically doing this sort of anti-capitalist, anti-corporation protest. But they did it in a way that was really funny and in a way that people got caught up in it. And they probably didn't even realize what they were doing. But I remember being really blown away by that at the time, like oh, it doesn't have to be serious. You can get things done without being really dry and depressing. So I think there's a huge value to using humor in getting your point across. Also people just don't wanna be depressed. They don't wanna read something really depressing or super serious all the time. So we definitely do try to put in humor in our work with Where's Lulu. And also because there's this misconception, too, that disability always has to be viewed as something like a tragedy or something really sad or to be pitied when the majority of the disabled

people I know completely reject that, and it makes no sense for them. So that's also, I think, a way of subverting this traditional paradigm of disability that says you have to be serious and sad.

CHERYL: Yes, yes. That's wonderful. Oh, I'm so glad you saw Second City!

CAITLIN: Oh, it was really good.

CHERYL: Talk about inspiring [laugh]!

CAITLIN: I know, yeah. That was inspiring.

CHERYL: Yeah. And one thing I wanna say or wanna comment on what you said, at the beginning of that answer, you said you used humor because you're just using your own voice. That's just part of your personality. And that struck me because a lot of people would say, "Oh, you're using a sense of humor as a coping mechanism or some kind of dissent." I hear that kind of thing. And in fact, recently there was a picture of me that was posted on Facebook where I have my I heart disability shirt on, and I'm telling a really unhappy story. But I'm smiling. I just have this huge grin on my face. And people on Facebook were commenting on that: "Wow! Look at that smile! What were you talking about?" And I wrote back: "I was talking about disability discrimination! I don't know why I'm smiling so big!" And someone, I have no idea who, someone commented in saying that it's a coping mechanism. You smile so much.

CAITLIN: Mmm.

CHERYL: I don't know how they know this cuz I don't know who the person was who wrote that back. They wrote through a group rather than a personal page. So there's just absolutely no identity there. So I don't know if this person even knows me. But I thought, coping? Isn't that interesting? Well what exactly was it that was so terrible that I'm coping with? I'm having a good time. Now, in full disclosure, I think maybe you might've picked up on this, Caitlin, that I smile A LOT all the time, especially when I'm talking. I smile, smile. Sometimes my eyes hurt cuz I've been squinting them all day cuz I can't stop smiling.

CAITLIN: Yeah!

CHERYL: I've always been a smiley person. But it's so much worse now. I just can't stop. I mean, if you told me someone close to you just passed away, I usually giggle. And that's sort of part of the brain injury. That's not necessarily a positive or socially acceptable thing. And a lotta times the smiling and giggling is really quite out of my control. And so I was completely shocked to see that I was smiling in that picture because I knew what story I was telling. It was sort of an awful story. But you know, the humor that we use in our art and in our writing and storytelling doesn't have to be explained away as something related to disability. It could just be our personalities. But it does, like you said, it does disarm people, make them less defensive. You can get more dialogue. And it makes things more interesting, absolutely.

CAITLIN: Yeah, and I think explaining it away as a coping mechanism is just dismissive and kind of missing the point. And also again, it's just perpetuating the same old-same old of well, everything has to relate

back to your disability. Everything you ever do has to relate back because you have an impairment, which is just not true.

CHERYL: Well sure, you have other parts of you like your, well first of all, you're a person. There's that part.

CAITLIN: [giggle]

CHERYL: But you have other parts of your identity. You're a woman, you're from the South, you've done all the things that you've done that are a part of you. You have a family history, you have a cultural history. We have so much more than a label. But I think people don't realize that, and that's why they're always asking: "What's your diagnosis? What's wrong with you? How did it happen? Were you born that way?"

CAITLIN: Mmhmm.

CHERYL: Because people don't even seem to realize it's one component. It may be for some people it's a huge component. For others, it's tiny.

CAITLIN: Right.

CHERYL: But it's one piece. It's one identity. So I don't know why I'm lecturing you! [both laugh]

[electronic music]

Cheryl's film work

CAITLIN: You wanna talk about any of your movies or the work we've done together?

CHERYL: Oh! Perfect! Yes! OK, so first of all, I have to thank you again. I know that I've thanked you, and it's probably only over email. So now I'm one step closer to thanking you face to face since we're on the phone. I'm doing a feature-length documentary called "[Who Am I To Stop It.](#)" And a long time ago--I don't know when, but a long time ago--I did an online fundraiser to raise money to start the initial filming and recording. This was before I'd ever met you, and I'm not sure how you came across my fundraising page. But you starting promoting it on Where's Lulu?, which was so exciting to me because I knew a little bit about you and really respected the work that you did and thought oh wow, if Caitlin thinks this is good, this is awesome.

CAITLIN: Yay [giggle]!

CHERYL: And that was sort of when you and I first started talking. But the thing that I just so have to thank you about, again, is that the mass majority of people who came to my fundraising page clicked on your articles on Where's Lulu? to get to me. And that is so impressive to me. Now, most of the people who donated are speech therapists for some strange reason. Actually, it's not strange. I know a lot of speech therapists in my personal life. But the majority of different people who were coming to check the work out, were coming through your site. And I didn't realize that until just maybe a month ago or

something when I was looking up my old analytics online. And that just means the world to me! And so thank you!

CAITLIN: Oh, good.

CHERYL: I don't remember what you wrote. I remember reading it at the time and being really flattered. But it just it's super exciting that kind of community building that happened without me even knowing it.

CAITLIN: Yeah, and that is one reason why I really like doing the Where's Lulu? site, but I need to update it like yesterday. But that was definitely one of the goals of the site was to foster community. I feel like there's still a lot of fracturing within the disabled community. And I think there's power in numbers, and the more we can support each other and highlight each other's projects, the better we all end up being. So I am so glad that you got the clicks that you deserved to get.

CHERYL: Thank you. And I did reach my fundraising goal, very much the same way you are going to for Criptiques, which is currently fundraising on Kickstarter.

CAITLIN: And it looks like it just got a new donation as of two seconds ago. My phone just rang.

CHERYL: Really? Oh!

CAITLIN: Yeah!

CHERYL: That's so exciting.

CAITLIN: I know.

CHERYL: It's fantastic. I'm so excited you just got a donation!

Wrap up

CHERYL: Thank you so much, Caitlin. It was really a pleasure to talk to you.

CAITLIN: Oh yeah! Thank you for having me.

CHERYL: Usually we just email. So it's nice to hear your voice.

CAITLIN: Yeah!

CHERYL: I really wanna thank you for taking the time to be on this radio show. I know you've got a lot of stuff. You're about to conduct a big interview with the author Susan Nussbaum. So thank you for taking the time and for introducing a lot of new concepts and new ideas and ways of thinking to my listening audience. I appreciate that very much.

CAITLIN: Cool. Thank you so much for having me.

[music]

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 on my disability arts blog, WhoAmIToStopIt.com.

[music]