

Stories from the brainreels podcast

January 3, 2014

Introduction

[music]

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.

[music]

CHERYL: We're kicking off the new year with a lot of new arts buzz. I decided to have some chats with three of the women with disabilities on the Portland art scene who've been most influential in my development as an artist and with my identity as a person with a disability. I wanted them to come on the show to promote their work and reach out to some new audiences.

One big theme that came up with each of them is the idea of community and that people with all types of impairments or disabilities may have a lot more in common than differences. Sure, someone with only a physical impairment in their legs might not have the same difficulties with memory, attention, organization, and communication as someone with a brain injury like me. At the same time, we do have some common experiences around feeling like people find our requests for access to be too much trouble sometimes. Or they talk to our friends and family about us instead of talking to us, even if we're right there in front of them, ready to talk. Or they decided whether they think we're disabled, not disabled enough, or over-identifying with our disability. Happens across the board, regardless of impairment type. And so there's great value in connecting in these cross-disability conversations to work toward more inclusion in general.

The best part, I think with my weird sense of humor, is that during the interviews, I didn't realize how many similar things I was talking about with all three of them. I certainly didn't remember what I'd talked about with each person by the time I went to talk to the next. Yet, there they all are: so many common ideas. Plus, there's just some damn fine art being created that I think everyone should know about. [Caitlin Wood](#) of Where's Lulu? and I will talk about our upcoming [Regional Arts & Culture Council](#) grant-funded project called Criptiques on Film. Kathy Coleman of [Disability Art and Culture Project](#) talks with me about the upcoming Disability Pride Art and Culture Festival and the third Sex, Love, and Disability fundraiser. Finally, [Lavaun Heaster](#) and I talk about her upcoming working group for entrepreneurs with disabilities to network and share ideas and experiences for successfully running your own small business.

Interview with Caitlin Wood

CHERYL: Thank you so much for being on the show again. I had a really great time talking to you a few months ago. And so I'm really glad that you're back.

CAITLIN: Thanks for having me.

Our RACC grant and Criptiques On Film

CHERYL: One of the reasons that I brought you on the show today is to share some really exciting news about how you and I got together and wrote a grant proposal to the Regional Arts & Culture Council. And we got the grant. It's super exciting.

CAITLIN: Yes.

CHERYL: Would you like to describe what the project is that we got the grant for?

CAITLIN: Sure. So you know, I've been working on a project, [Criptiques, which is a book of essays about disability written by disabled authors](#) about disability. You, of course, are one of the authors. The idea behind the Criptiques project was that it would be a book exploring different sides of disability that aren't seen in the mainstream. And our grant that we received, which is so awesome, is sort of an extension of that. And we're going to work on some short films, Criptiques on Film. And we're gonna make at least one and possibly more films on disability. And we've been thinking of some fun ideas and what we wanna do with that, which I'm really excited about.

CHERYL: I am too. I am too. And it's really quite an honor to get to sorta contribute to your Criptiques project from the film perspective because that opens it up to so many more people. A lot of people don't read or can't read or don't wanna read,

CAITLIN: Mmhmm.

CHERYL: or for various reasons are not going to use or access the book. And so here is a different way to get some of the same types of stories and experiences out. But I will say, when I said the word "stories," it raised a red flag for me. This is not your typical disability let me share my personal story with you! Right?

CAITLIN: Right. Right. You and I have had several conversations about that. And I certainly come from a perspective where I feel at this point in time within disability culture, there's a lot of focus on individual narratives, not from everyone. But there is still that emphasis so often of people feeling the need to tell their story, which is great. But at the same time, one of the goals that I had with Criptiques is that we can move further than that. We can actually get past the individual narrative and look at more of a community perspective and look at what other marginalized communities have done, once you get past the initial identity politics. And so that is a really exciting aspect of this for me with the films is that here is this creative endeavor. It's a new medium we can explore. It's fun. We're gonna have a lot of humor in it and show a different side of disability than what is normally out there.

CHERYL: Yeah. Have you read the book "[Loud Hands: Autistic People Speaking?](#)"

CAITLIN: No, I haven't actually read that you. But I wanna borrow it from you. I've heard it's wonderful. But I haven't actually read it yet.

CHERYL: [laughs] When you said you wanted to borrow it from me, I realize that I think I have asked you that question three times. And I never remember that I've asked you until after you say no. And then I always remember. Didn't I email Caitlin telling her I would lend my copy of the book when I'm done? I don't know why I can't remember that you already told me you haven't read it. I have it here in my hands. So I know I haven't lent it to you yet. Something I read in one of the early essays in the book is, I think it might've been one of the essays by Jim Sinclair. But I'm not positive. But there was something

early on where they talked about this brand new, very radical thing, which was that Autistic people wanted to go to conferences about Autism and have Autistic space. Meaning, we're not gonna talk about cures and interventions and treatments. Autistic space, it's a space to be yourself as you are and proud and be part of your community. And they moved from that to having their own conferences that were specifically Autistic people and their allies and families as opposed to the conferences with medical professionals. One of the rules they had in this Autistic space was if you're going to present at the conference, you can't present your personal story unless it goes somewhere for us as a community. Those are my words. That's not exactly how they worded it. But I was really taken by that as a rule in the early conferences because it's very different in the brain injury community. You're very much expected to just tell your story: what happened to you, what went wrong, what's hard now, and what is good now. And then that's it. That's the whole story.

CAITLIN: Yeah, I love that they did that. And I wish there were more of that in other communities as well. Just I think that's really important. I think that we as disabled people need to get past that already. And I think it makes sense when, especially if you acquire an impairment and it's new to you, and you wanna tell your story, it's important, of course. But at the same time, focusing exclusively on the individual really, I think, is detrimental to looking at disability community and disability culture as a whole and seeing the commonalities in that. While our impairments may be different, and some of our experiences may be different, a lot of our experiences are the same. And I think it makes our community stronger when we do look at cultural aspects and community aspects versus here's what happened to me.

CHERYL: Mmhhh. And I wish that people who acquire their disabilities, such as a brain injury, I wish they found out about disability identity sooner because when you're existing in the medical world, you've gotten injured, you've got your diagnosis, you've got your rehab plan, or you're sorta kicked out, and you've got no rehab plan, it's all about I'm an individual, and how am I going to recover. Or how am I gonna go on whatever path I'm going on. And people do tend to turn to other individuals and say, "What happened to you? And how did you deal with it?" And so there's a huge, important place for that in communities of people with acquired disabilities. But I feel like we do get stuck in that sort of medical mindset when we stick with those individual stories and you know, I'm going to educate you to give you hope. Well, that's great. And we need hope so we have motivation. But then, then what? [giggles] What do you do?

CAITLIN: Right.

CHERYL: So that's what I love about what you put together with Criptiques because these are stories of people, some of the people were born with impairments, some developed them at different points in their lives, some people acquired their impairments or disabilities. But the emphasis is on identity and culture.

CAITLIN: And activism and where we need to go. I really think claiming disability identity is huge and it's important. But I also feel like it's sorta just the first step in becoming a part of this community. I feel like claiming that identity, coming out as disabled is really, really important. But at some point, we need to take our analysis a step further instead of just like here's what's happening with me or within my own impairment group. How do we step back and look at the bigger picture of what's going on with our disability culture as a whole?

CHERYL: Yeah. Oh, well said.

CAITLIN: I mean, in addition to that, the films we're gonna be working on, another part of why it's so great is that this gives us an opportunity to have fun and to play around with disability and show that disability, the representation of it doesn't have to be always serious and earnest and sad or tragic. That there's humor in there and silliness and all different ways to illuminate that, that really just is not seen in our culture.

CHERYL: Oh, absolutely! Well, and people think oh gosh, you look like you have a disability. Your life must be really hard and awful. You must not have the time or the energy to laugh. Or you must not have anything fun in your life worth laughing about.

CAITLIN: Right.

CHERYL: And I mean that's such, that's such a misconception. It really is not an accurate representation of the community or really of any particular individual.

CAITLIN: Mmhm. Right. There's complexity there. And it's not completely one-dimensional with disability. Disability is a part of the equation. But it's not everything.

CHERYL: Right. And now, speaking of one-dimensional: we'll be using film. So we'll at least be two-dimensional in that medium [chuckles].

CAITLIN: Oh, I think it's gonna be awesome. And we have some ideas that maybe I won't mention yet cuz I don't wanna give anything away. But I'm hoping, knock on wood, that there might be an opportunity to bring in some disability superstars into our movies.

CHERYL: Oh, yes! Yes! Yeah, we'll definitely bring in disability superstars. We'll definitely bring in, it'll be superstar level material too. Cuz one of the reasons that we proposed this project was, I mean I think all the homemade videos on YouTube, I think it's wonderful that anybody can use a webcam or an iPod or an iPhone or anything and just document and make things and tell stories. I think it's wonderful. But one of the things that happens is that say, there's not a lotta disabled filmmakers. The money's not going to us.

CAITLIN: Right.

CHERYL: And people think that those webcam YouTube videos are really the best we can do cuz we're disabled and we don't have money.

CAITLIN: Right.

CHERYL: And so that's one reason that we wrote this grant was to say no, no, it can still be super high definition and beautiful and artistically created.

CAITLIN: Exactly.

CHERYL: And so we're aiming for that. Now, here's a little teaser. I haven't told you this yet. But I have started editing the short film that we made in October called "DisAbled Anonymous."

CAITLIN: Oh, great!

CHERYL: Yeah, it's a real treat. I've actually been using it as a reward. Like some people might have a beer or have some ice cream when they've worked really hard. My treat for working hard recently is that I get to edit "DisAbled"-

CAITLIN: Is more work.

CHERYL: Is more work, yeah! But it's so much fun. And I was gonna wait until the new year. But I just could wait one more minute. And I'm very excited about that because I think it touches on a lotta the things that we've talked about in this Criptiques On Film, which is it's got humor, it's got complexity. This one is definitely a satire and is pretty scathing. [laughs] So we'll see how that comes out. I don't know how long it'll take me to edit it. Hopefully it can maybe become the body of Criptiques On Film. We'll see.

CAITLIN: Oh yeah! I would love it. I am really excited to see the finished product. It was fun filming that.

CHERYL: Yes, it was. It was a lotta fun. And it's fun to watch it and relive it and think wow, I have three different shades of green eye shadow on my eyelids. How about you?

CAITLIN: [laughs]

Projects coming up in the future?

CHERYL: So! Speaking of eye shadow, are there other projects or blogs or things that you want to tell people to be looking out for here in the new year?

CAITLIN: Well, I have been really terrible about blogging for quite a while now. So one of my goals is to do more writing on the Where's Lulu? blog and maybe have guest bloggers such as yourself, if you're interested.

CHERYL: Oh wow!

CAITLIN: But also, I would love to start a Criptiques podcast-

CHERYL: Oh!

CAITLIN: and interview you on my podcast and switch things around.

CHERYL: All right.

CAITLIN: And really just, I like the idea of Criptiques is not just one thing. You know, it's a book, it's a movie, it's writing, it's encompassing different mediums and exploring disability and showing different sides of disability. And I would love to do a podcast and get to interview people. There are so many great people doing great work. Emily Ladau, [Words I Wheel By](#), her blog I like. I like Elsa Henry's [Feminist Sonar](#) site. Of course, [Lydia Brown](#). There's so many people doing wonderful work. So I would love to interview them and work on that.

CHERYL: Oh, that's exciting. Yeah, wonderful.

CAITLIN: Yeah.

CHERYL: And again, I mean it's just a way to include more people. And it really does increase access when you start using different media like that you're just gonna increase the different ways that people can get to the material. And that's super exciting. I'm so glad to hear that.

CAITLIN: Yeah.

CHERYL: Yay.

CAITLIN: And I'm just mostly excited about our movie though, at this point.

CHERYL: Yay!

Wrap up

CHERYL: It was so wonderful talking to you. I know today was a short conversation because we'll also be airing Lavaun Heaster and Kathy Coleman today. I am so excited to ring in the new year with three disabled women who are just wonderful friends of mine and wonderful mentors for me as a newbie to the disability world. It's just really great. So I'm happy to have three on the show cuz three is the magic number.

CAITLIN: Well, I'm in great company [giggles].

CHERYL: Yay, awesome.

CAITLIN: Well, thank you so much for having me.

CHERYL: Yeah, thank you. And I look forward to the Criptiques podcast starting in the new future.

CAITLIN: Yeah.

CHERYL: So I will let the listeners know when that gets rolling. All right, thank you.

CAITLIN: All right.

Interview with Kathy Coleman

CHERYL: Well, hello Kathy. Thank you so much for joining me.

KATHY: Well, you're welcome. This is gonna be great.

CHERYL: I really appreciate you making the time to come on here and tell folks about the Disability Art and Culture Project.

What the Disability Art and Culture Project does

CHERYL: So I would love it if you'd start out by telling us a little bit about what the [Disability Art and Culture Project](#) is.

KATHY: Well, the Disability Art and Culture Project is a non-profit arts organization. We do a variety of things. One is dance. So we have a dance company called Inclusive Arts Vibe Dance Company. And that's ages middle school, so 12 years old to transition age, so people usually in their early 20s. We teach dance in the schools. And we do a festival every other year. Our dance company performers fairly regularly in the community and also does their own show on the year we don't do the festival. And then

we do other programs. Like we've done reading groups and movie nights and things that are all about disability art and culture!

CHERYL: Who are the audiences who usually come to your events?

KATHY: You know, it's a mix. It's a lot of family and friends, people who know the performers or people who are interested in disability arts and disability culture and what that's about, and in general, anyone who wants to come. Usually, people have a connection to disability in some way, I would say, or is curious in some way.

CHERYL: The work that you do is not just for people with disabilities to enjoy, right? Anybody could come to the events and performances.

KATHY: Oh, absolutely, yeah. It's not just for disabled people or people who identify with having an impairment in any way. It's art, basically. So it's the same that would go to any other art event.

CHERYL: Right, right. And it's not art therapy either.

KATHY: No, it's not about art therapy or recreation. You know, our focus with DACP is to support emerging and established artists. And that's partly why we do the school program and have the youth company so that people have a chance to learn to choreograph and learn dance skills and concepts. There isn't enough out there for arts for people with disabilities to really learn a craft or to participate in arts period unless it's specifically, you know, in a specific disability program or impairment-focused program. That's one of the reasons why we do what we do. Is we wanted to expand what it meant to be an artist if you have a disability. It doesn't have to be connected necessarily to your impairment or necessarily to somehow getting over your disability or learning social skills. But it can be about the art itself and the creativity itself.

CHERYL: Right. The gap that it fills and what it provides in the community in terms of arts training and high quality and professional arts experiences for people who are generally left out of all these creative arts experiences and opportunities to train and perform. I think because people just assume they can't or don't want to.

KATHY: Yeah, yeah. Or they don't see that art can be something that doesn't have to look one way, that art doesn't have to be able-bodied. There can be many ways of having art that's based on different minds and different bodies and be very interesting and fascinating and give a different picture of what creativity and what art is.

CHERYL: Now, I've talked to people with various disabilities who are doing all sorts of training with the goal of moving their bodies exactly the way say a professional ballet dancer moves their body, attempting to make disability dance look exactly like dance of non-disabled people.

KATHY: I approach dance differently. I mean, I think everybody as an artist has the right and can follow their own desire and path with what they wanna do. So for people who wanna do that, that's great. For me, I wanna see with their organic, original movement and creativity is and watch them explore that and grow that so that they're doing something that reflects who they are and how they move instead of looking to look like someone else. That's what's fascinating to me as an audience member.

Kathy's background in the arts and starting DACP

CHERYL: How did you get into arts in general?

KATHY: I grew up around music. My mom taught piano lessons and music in school. I actually did a lotta music as a child, partly cuz everybody in my family did. We learned to play guitar. We all had to take piano lessons. And then I chose as an instrument to play the oboe. And that's what I did all through my junior high and high school and college. So that's kind of where that all came from for me, and I still love it. You know, I always loved to dance like, you know, on the dance floor, shakin' your booty and doing all that kinda stuff. Or-I'm gonna date myself-like in the 80's when we were doing the whole New Wave jumping up and down stuff. I actually do think that why I dance is related to my impairment or how I first entered disability, which is as a cancer survivor or someone who had cancer. Cuz I really wanted to explore my body. And I really wanted to connect with it in a way and learn about it differently. And that's kinda where my wanting to dance came from, except for the fact that I just liked it, and I thought it was fun. So that's when I started taking some dance classes.

And I actually joined a dance company for a while. At the time, I didn't identify as disabled. So that wasn't it at all. But I was interested in that whole piece of examining and looking at it, like really looking. Like we always had mirrors in our classes. But I also was more interested in some of the things we did: we did like poetry and dance. Some of the stuff was a little more improvisational and kind of exploratory. One of the dance teachers I worked with was really not a typical bodied dancer. She was a larger woman and taller. You know, it's really hard to say what is large cuz she wasn't all large. But compared to a lotta dancers, she was. And I was really interested in her ideas about different bodies dancing, and that you didn't all have to look the same way was really powerful to me. And that anybody could-not so much anybody could dance in that philosophy, but that-they were open to anyone trying to dance and learning and taking technique. You didn't have to have ballet when you were three years old. It was more open about what kind of things could be done. And I took some dance classes, actually after I graduated, but college classes in dance and things like that. And I got to work with some different teachers that were really interesting and experimental in the kinds of art and dance that they liked to do. So that's kinda where that background happened.

As a cancer survivor, sometimes you have late effects from your treatment, which is what happened to me. Somehow in that process, I couldn't walk anymore [giggles]. So then, that's when I got into disability arts. You know, in Portland, there was a bunch of us dancing. A lot of us had studied with [Alito Alessi with DanceAbility](#). He does some amazing work worldwide with dance and disability. And we wanted more to happen more in Portland. But there wasn't always a place for us to dance. So that's kind of a big piece of why we started DACP. And there were other things starting at that time too. It was kinda just a brewing time with a bunch of people with disabilities saying, "I wanna do my artwork. And how do I do it, and where do I do it?" At that point, that's when Disability Art and Culture Project started. We really wanted to have a place to perform and to dance and to create our own work.

CHERYL: It sounds like when you were first taking dance classes, you were really exploring your body and exploring how you move and getting to know your body. And the way you do arts now is much more about social justice rather than the individual's narrative. So can you talk a little bit about how you use arts for social justice?

KATHY: Even in our mission with DACP, there's always this piece about how disability and art are all connected to how we make our way through the world, you know, with economic justice and racial justice and social justice and all the things that we experience day to day. And a big piece of what DACP

wants to do is change the perception of how people value and perceive disability in general. And I feel like that art's a really powerful way to do that. Disability doesn't need to be seen as a problem or as something to overcome or as something that is a terrible thing, necessarily. I mean, there may be aspects of impairment that suck, right, that aren't fun to deal with. But overall, it doesn't mean we need to be treated differently as human beings. Cuz we're really just human like anybody else. And that's what I feel like DACP brings through the arts and through the social justice lens for people to be seen just as human, just like anyone else. We do a lot of evaluation. And we get comments from our performances about like, "Gosh, I didn't think people could memorize that much." Or "I never thought of dance that way before." Over the years, it's kind of changed. There's this shift. You see people talking more about the arts than actually about the impairment or the disability. And that's the shift we wanna see. We wanna have people be seen as whoever they are. If they're artists, if they're performers, then we want them to be seen as artists and performers, not just the focus on disability. I'm not talking about that thing where people say, "I don't even see your disability!"

CHERYL: [laughs]

KATHY: I didn't even notice it. Cuz that's kinda ridiculous, you know? If you see me, you're gonna see a chair. You may not see a chair, depending on your impairment. But you know, it just doesn't make any sense.

CHERYL: No, it really doesn't. I get the feeling that it's supposed to come out as now that I've gotten to know you, I see you as potentially my equal. I see you as a human. So I think that's the compliment behind it. But what you're getting at is that's not always a compliment. Let's respect and acknowledge all aspects of a person and consider them potentially your equal and a full human being.

KATHY: Mmhmm.

DACP is cross-disability

CHERYL: I don't mean this to come out as a judgment, but I have noticed a lot of disability arts groups where everyone in the group has an intellectual or developmental disability. Or you have mixed abilities groups where the people who are involved have physical impairments, or they're non-disabled. And I know that DACP has always been dedicated to working with people across disabilities. So for instance, you've involved me a lot, Bill Alton who has both brain injury and mental illness, and lots of other people with a range of impairments and a range of identities. When I'm just thinking about all these other programs, my question for you is why doesn't DACP focus really closely just on one kind of disability?

KATHY: I think there's a couple reasons for that. At a personal level, I don't think I've ever really been impairment-identified, which sounds kinda funny. But from my perspective-and other people might not agree with this, but-I feel like a lotta people who have impairment identification, that happens a lotta times in treatment, in rehab where they first make those connections, or somehow in the medical world. And for me, I never had rehab. So I never made an impairment connection like that. Some people, for instance, they get into an accident, they might live in a rehab facility for six months to a year. So what I hear is that when people do that, there's a real strong impairment connection that is made. And that wasn't my way of becoming disabled. And my work with disability, from the beginning, was really focused in disability studies. All my exposure was cross-disability work.

CHERYL: OK.

KATHY: I was part of the National Disabled Students Union, when it was around. And that was cross-disability. And that's just from a personal level, that's just where I was at. People who perform with disabilities, maybe they have it through school or you know, I have an acquired disability. So my situation's different. So that's part of it. And the other part of it, I really feel strongly about undoing this whole thing of a disability hierarchy, which happens in disabled communities, along with non-disabled communities. And I know there are reasons why it happens, you know. There's reasons around ableism and privilege and survival that we create these hierarchies in our community. Sometimes it's scary if people lump us all together. But I also wanna empower people in the feeling that we're all equal. There's equity. That no disability is better than another kind of disability.

CHERYL: Mmhmm.

KATHY: I like to see communities of people coming together. Community is a big focus of mine. You know, I don't wanna see us separated. So I think we have more in common-again, that's opinion-than we have that's different. I mean, our impairments might be different, but our experiences in the world are often the same. Might be different situations, but we experience a lot of similar things around not belonging, not being accepted, oppression, ableism. I mean, those things we share. And I just think it's powerful when we can come together as a group and not separate from each other.

CHERYL: Mmhmm. When I first had my brain injury, a big part of moving forward with that is connecting to other people specifically who've had a brain injury and asking them, "What do you do about this? How am I supposed to figure this out? Now what do I do?" And that is super valuable. And I got much more heavily involved in disability arts in 2011. And I remember starting to come to you with my questions although you don't have a brain injury. But my questions were less impairment-based and more identity-based and more like, "Hey Kathy, somebody said something to me, and it just hurts to hear that. Am I being a fool?" And you really helped me understand a lot about those common experiences and the way that we internalize negative messages that we hear. And we might pass them on to other disabled people. But yeah, it was really valuable, is still very valuable for me to be in cross-disability settings where we can have those conversations, moving more toward what's the best way for me to advocate for myself and do activism and change attitudes in society. So thank you, Kathy.

KATHY: [giggles] Well, you're welcome! You know, and there's nothing wrong with going to someone and asking about an impairment question. I wanna make that really clear, too. Learning from each other is totally valuable information.

CHERYL: Oh yeah. And I would be nowhere without those opportunities to talk to other people with my same impairment to support each other. Oh yes, yes.

Disability Pride Art and Culture Festival & Sex, Love, and Disability Fundraiser

CHERYL: So right now, you are working really hard with your different planning committees to get the Disability Pride Art and Culture Festival and the Sex, Love, and Disability fundraiser going. So let's talk about those events that are coming up early in 2014.

KATHY: So the Disability Pride Art and Culture Festival, this will be our sixth one, which is pretty exciting. There's a variety of things that happen during the festival. We bring a disabled artist to Portland to work with us. And this year's guest artist is going to Leah Lakshmi Piepzna-Samarasinha, who is a Lambda Literary Award winner for her book of poetry, "Love Cake." So she's a writer, a performance artist, the founder of Mangos with Chilis, she's a Sins Invalid artist, and she brings with her the disability justice piece. Cuz that's a lot of what her work and writing and performance is about. So I'm really excited that

she's coming. So the festival itself, we usually have a guest artist do an intensive. We're not just bringing someone to watch them perform. People have a chance to interact and to build community with other artists. One of the reasons why we started doing the guest artist thing is that we felt like that people didn't realize that disability art is international. Some people don't even know it exists! You know, that there's people all over the world who do disability art. And there's disabled artists all over, and there's festivals, performances, dance companies, and theater groups. It's all over it. It's not something like this unique, little, special thing that happens that some cute disabled person is doing in Portland, you know? And we wanted to show that to people by bringing someone in and giving people opportunities to work with people and network. Cuz sometimes it's really expensive too, to be able to go and study with all these people and work with them, right, if you're going to intensives and trainings and all over the place. So to bring someone here, that makes it more doable for people, too. So she'll be doing an intensive to create a piece for the performance.

So there is two nights of performance. We actually do a call for performers. And again, it can be emerging or established performers cuz again, we want people to have that opportunity to show their work, even if it's something new or something they haven't done a lot of. Cuz you need to have that, as an artist. And then we do some different things. This year, we're gonna have a panel on what is revolutionary art and trying to talk about what does that mean as an artist if you feel like you work, what you do, your program, your art, or your organization is about revolution and what that means. And it means a lot of different things to people. And then Leah's also gonna do a poetry reading. So we like things both that people can participate in, but for those who aren't interested in performing or participating in something, you can come and watch and still get your disability art and culture fill.

CHERYL: I have been to the festival several times. I was in it one time in small piece. I've been on planning committees. And it's a really exciting, diverse group of people. And there's a question that I know comes up each time, which is if you want to participate in the intensive and/or you want to be in the performance, do you have to be disabled or have some kind of impairment to participate?

KATHY: The answer is no. So anybody can participate. And because of who we are and what we do, we want to give opportunities for disabled performers. But we don't wanna be isolated or segregate people from each other. We want people to create and build community all together, for everybody.

CHERYL: And that's how I first met you and got involved with you and the various other people doing DanceAbility back in 2005. I was non-disabled at that point. Everyone was completely welcoming. And in the festival, there is quite a mix of people participating. It's really exciting. So to get ready for that festival, I know you've got the fundraiser coming up. So talk a little bit about the Sex, Love, and Disability fundraiser.

KATHY: The Sex, Love, and Disability fundraiser is a fundraiser we do to celebrate disability and disabled people in all our beautifulness and sexiness and loveliness and oneness. It's a party. Basically, it's a party. It's a night of performance and film. And we have an auction with all sorts of nice, sexy, and lovely gifts that people can bid on, from dinners out to chocolates to self-care, and the whole gamut.

CHERYL: A lot of times fundraisers have a theme. For this disability-oriented event, why do you focus on sex and love in the disability experience?

KATHY: We started focusing on that because there's a sense, somehow, that disabled people aren't sexual, that they're asexual. They're assumed that disabled people don't have relationships, don't fall in love, and things like this. And we do because we're human. We fall in love, we have crushes, we get our

hearts broken, we get in relationships, we break out of relationships, we get married, we have families--sometimes. You know, not everybody makes the same choices. But all those life experiences are things that we experience too. So that's kinda the emphasis on that. It's like yeah! We are about love and sex and relationships and just being human, period, and all that goes with it. There's also the other piece that sometimes people don't view people with disabilities as sexy. You know, I will come clean here that I don't know when I would consider myself able-bodied, if I did. I didn't. I don't think I ever thought of people as disabled as sexy. And I think we're taught that we're not sexy. I think that's an ableist kinda thing that we all grow up with and we're taught, that somehow people with disabilities are not sexy and attractive and gorgeous and awesome. And yet we are, right?

CHERYL: [giggles] Yes! Yes, that's what we learn. There's segregation from an early age in Special Education. And when you look at arts and media, TV, movies, print ads, you don't see disabled bodies sexualized.

KATHY: Mm-mm.

CHERYL: If you see pictures of disabled people, they're advertising something about disability as opposed to advertising sexy lingerie or advertising for dating sites or just being a character in a movie who is sexy. So yeah, we don't see it. We are conditioned to think that disability is the opposite of sexy.

KATHY: Yeah, but it's a lie!

CHERYL: It's a total lie.

KATHY: It is a lie! Absolutely.

CHERYL: OK. There'll be information all over the internet when these things are getting closer. There's some really cool things you have going on right now around the fundraiser for people to get involved. And one is contributing essays or poetry or other writing to the zine. And the other is that people and businesses can now become sponsors of the event. So do you wanna talk about either of those things real quick?

KATHY: We would love to have more sponsors for our event, either individuals or businesses. We have tiers of what you can do to sponsor. And of course, we're gonna give thank yous back, with acknowledging people on our website and tickets to the festival, and all that good stuff, posters, things like that. So if anyone was interested in that, they can contact us through our website, which is <http://DACPHome.org>. Facebook is another place you can contact us, or our Gmail, which is disabilityartculture@gmail.com. The more, the merrier. The zine is pretty exciting. So if you are a writer, and you like to write about sex and love and disability, you are more than welcome to submit something. Again, contact us if you're interested. And check out our Facebook for these announcements too.

CHERYL: You're looking for volunteers, too. If folks in the Portland area wanna volunteer on some of these planning committees, you're still looking for volunteers?

KATHY: Absolutely. And there's different ways to volunteer. Joining the committee would be great, cuz the more the better. But if you just wanna help out, we can use people to get more auction items for us, do outreach, get all your friends to come, all that kind of stuff--to the fundraiser or the festival or both. Yeah, we can always use more help and more community. Portland is gonna be the disability arts hub of the future.

CHERYL: Yeah.

KATHY: That's gonna happen.

CHERYL: People can go to DACPHome.org or look you up on [Facebook at Disability Art and Culture Project](#). So thank you so much for taking the time to talk with me today and tell everybody about your projects.

Wrap up

KATHY: Well, thanks for having me.

Interview with Lavaun Heaster

CHERYL: Lavaun, thank you very much for coming onto my radio show today to talk about your art.

LAVAUN: I am so happy to have this chance to talk with you.

CHERYL: Great. So tell us a little bit about yourself and maybe how you became an artist.

LAVAUN: It's an interesting story. When I was a kid, we were very poor. My mother was a single parent before it was in fashion, and there was no real child support coming in. And so when we needed gifts for Christmas and things like that, my mother would create calendars. And everybody in the family would create art for calendars. So when I went onto dialysis, and I had lost a job that I had for a fairly long term and was on dialysis, I was pretty poor. And I was trying to figure out how do I make a gift for this new boyfriend I had in my life who I knew was making me a gift. And I thought, go back to the calendar. So I went and I created a calendar. And I had some printed up, and I gave them to family and friends cuz people have been amazingly supportive through the process of my kidney disease. And I felt like I wanted to give some gifts to people. But I didn't have very much money. And this made it work so I could figure out how to do that. So that was how it all started.

Becoming an artist and representing parts of culture usually not shown

LAVAUN: About two years ago, I had the opportunity to show work at a [Colored Pencils](#) event where they were trying to get the disability community involved. I was kind of the point person between the Portland Commission on Disability and Connecting Communities Coalition. And then I also got Disability Art and Culture Project involved in that. As a point person, I thought, you know what, I've been doing this art. I've never shown it publicly. But people keep on saying you should be showing your art. I'm gonna just ask if I can. And so they showed my art for the first time. I had a good response. And someone from Regional Arts & Culture Council came up and talked to me, and some different things happened. And I said, OK, I'm gonna keep trying. And different friends have done things, like one friend introduced me to a coffee shop owner who hung my art. Another friend, her friend has a hair salon. And he has done two of my shows so far.

I'm highly influenced by being part of cultures that are not seen. My skin color definitely looks Caucasian, but my mother has brown skin and almond-shaped eyes because she is Navajo, Ute, and Spanish. I look like my father who's Irish. I feel like these things are not shown anymore. These are pictures that you don't see. When I go back to art, I don't see pictures of my family where my mother's brown, and she has two white children. I have friends who are blonde and married to Black men. And there's not a lot of pictures out there for them, for their families with their beautiful children. And so I try and create art that shows that. I create art that shows people using sensing canes and wheelchairs.

Sensing canes tend to be my favorite just because it's a reminder that the blind community can also participate in art. Because when you do tend to show people with disabilities, when you see them, nine out of ten times, they're people using wheelchairs.

CHERYL: Mmhmm.

LAVAUN: They don't make it in, in general. But if they make it onto a commercial or into an art piece, they tend to be using a wheelchair. And so I try and bring the sensing canes to the forefront cuz it's part of my community as a legally blind person. One of the things that I find particularly challenging in being an artist with a disability is that I don't drive. And in your documentary, you had a scene of me on the bus. I insisted on that being in there for a specific reason, which is many artists have big vans or trucks. Some of them only have cars. But a lot of them have some way of transporting their artwork. And I don't. I have to rely on friends and the bus! It's pretty funny. I have a great story about being on the bus and traveling with this huge suitcase, which has all my paper and my scissors and a boom box and stuff like that for doing a workshop.

CHERYL: Uh-huh.

LAVAUN: And I was going towards downtown. But I didn't get off at any of the places near any hotels. And people were kind of, seriously, somebody actually asked me about this [giggling]. I said, "Oh, these are my art supplies! I'm an artist. And I'm going to teach a workshop!" And she thought that was amazing. And I had to explain to her I'm legally blind. Driving is not an option.

CHERYL: Right.

LAVAUN: And she was just fascinated with someone who has to use the bus and doesn't have the option of a car.

CHERYL: When I'm doing my short film projects, everything I'm taking on the bus: lights, light stands, video/audio recording equipment, so much stuff. That's how I get around to do my art as well, is on the bus. Was she fascinated that you are a professional artist with disabilities? Or was she just unfamiliar with the concept of--

LAVAUN: Actually, she didn't--A lot of people are fascinated with the concept of a person who is legally blind and an artist. And they say, "How can that be done?" People with vision loss are very different. You know, some people have peripheral vision, no central vision. Some people have great central vision but no peripheral vision. I have 22 degrees of central vision in one eye. And I have no peripheral vision. And the 22 degrees is slightly blurry. Anytime you have only one eye, you lose depth perception. I probably could figure out how to paint or draw. But I found that cutting paper was what worked for me. And I have been able to really elevate it to a different level that most people haven't figured out how to do with paper. It's just an unusual craft to be done my way.

CHERYL: When I made that documentary about you and was talking to people about it, yes, of course, a lot of people were just like, "I don't understand. She's a visual artist, but she's blind?" And I would clarify, "Well, not completely blind." It's important to listen to the description. But also at the same time, it's like well, what if she was? What if Lavaun had absolutely no vision whatsoever? She could still be a visual artist. It was such as--

LAVAUN: And there are people who are.

CHERYL: That's right. And you had at least one woodcarver who's blind in your holiday gift fair.

LAVAUN: Yes.

CHERYL: But I guess what's really exciting to me is when I talk to you or talk to people about your artwork, I enjoy the opportunity that we all get--myself included--to try to expand our ideas. There are so many more possibilities than what are your own experiences.

LAVAUN: And that's part of my thing of doing the paper cutting. I made it tactile so people who are blind can feel it. And usually then, I describe to them. I actually had a woman who's completely blind buy a piece of art from me. And it was called "Winter Sprite." And I described it to her: there was a woman in the center. And she had a green wreath on her head that had a candle in the center, and it had poinsettias around her. And I said these are poinsettias that are red on the outside and yellow and black on the inside. And she's wearing a white gown. So I was able to describe it. But she was able to feel it. More important to me is keeping the glass off so people who have no vision issues at all can touch it and feel it and begin to go oh, art is available in other ways to be enjoyed. So that they get the idea. And they can make the connection too, that art does not have to fit into the box of how they see it.

CHERYL: Right, mmhmm.

LAVAUN: But art can be available to a variety of people. Cuz there's this thing out there that oh, well you must really love music if you have vision loss! I like music. But I'm not a highly auditory person. So it doesn't really work for me. And this is a way of giving an opportunity to say to people who are fully sighted, "Oh, people who have low or no vision can enjoy art."

CHERYL: Mmhmm, mmhmm. When you make the art accessible to people. I felt your pieces. And you really can. You really can start to paint that picture with the different shapes and the edges, and you have soft, round edges and sharp, pointy ones. And then you can feel the multiple layers in different spots.

The short documentary "Paper Visions"

We have mentioned several times that I made a short documentary about you called "[Paper Visions](#)." And not only the bus scene, but the whole thing, I had a great time making it. I asked you a lot of questions in filming. But there's one thing that I didn't ask you. So I wanna ask you now. I've never been in a documentary. I just wanted to know what it felt like to have a documentary made about you.

LAVAUN: I'm unusual. I love public speaking. I've done a lot of trainings. I've been part of a group speaking to 400 medical professionals. So I'm really comfortable in front of human beings.

CHERYL: Mmhmm.

LAVAUN: The camera, to me, was just another human being. It was like a way of reaching other human beings. So to me, I just see it as a way of--this is really bad, but--preaching my message! Because I think that deep down, I'm an educator at heart. But I don't like traditional education methods. My thing is about creating curiosity in people and really giving a gentle push for whatever people are already beginning to play with in their minds and giving them a gentle like, either engaging in them in a conversation, which makes them curious. So for me, that part of it was great. It is kinda weird to have to try and say things. You don't get it quite right at the moment, and you say it over. It didn't happen very

much with that. But you just never know what's gonna go out of my mouth. And it made me painfully aware of how much I talk. And I really, I talk a lot.

CHERYL: [laughs]

LAVAUN: So it was hard to watch it because I have to admit I've become very uncomfortable with my body after my transplant because the medications have increased my appetite. And my muscle tone is not the same as it used to be and all these things. It was painful for me to watch because I had to see who I am, which I know. But it's hard to put it out there to the public. And I think that's reality for some of us. We know that this is who we are, and this is the body we live in, that sometimes, even though I go out and I interact with the world every day, I don't think about the fact that people are viewing me at that time. So that was kind of hard for me. But I thought that the experience of having someone want to hear what I have to say was amazing for me because I often times feel like I'm saying the wrong thing or that people are saying, "But we don't wanna hear that from you."

CHERYL: Mmhmm.

LAVAUN: And so give me the freedom to be able to say it and nobody monitoring me and saying, "No, that's not the message we wanna give!" was amazing for me.

CHERYL: Oh, I'm so glad to hear that.

Kickback from communities who want to work on only one issue at a time

LAVAUN: But what's funny is that I get a lot of kickback, and I'm gonna just apologize before I say it, but from the disability community. I've gotten kickback when I have been doing racial equity work. You know, I'm doing all this stuff. And I'm not staying focused into one area. I'm bridging and connecting all these things. And often, people want a focus that I don't have. I refuse to have that narrow focus. My experiences are very wide. I grew up in a very multi-experienced community. My mom, you know, was not out when I was a child. But we'd had a conversation about her being interested in women when I was six years old. I didn't really care that much because I didn't get it at that point. I didn't understand social stigma and stuff like that. During my mid-20s, I ended up working with a project that worked with the transgendered community and the intersex community. So I see bigger pictures because I still have my fingers in a lot of different pots. So when everybody's excited about one thing, but I see how it's gonna impact another community, I'll bring that up. And I'll not just take it from what we consider to be the dominant community. But I also get it within the other communities because I do work very differently than a lot of people.

CHERYL: Mmhmm, mmhmm. Well, it's so great that I've got you on the same day that Kathy Coleman and Caitlin Wood are talking because they say the same things every time I meet with them and work with them on different projects. And that is that you can't work for social justice for only one group. People don't belong to only one group. And because when you work on one thing, like you said, it has an impact and an effect on other groups. I'm really glad that the three of you are all on the same day. Because you're all approaching it that same way, that we're not gonna go to a meeting that's about race and only talk about race and then later go to our disability meeting and talk only about disability and then later only gender. It's all intertwined.

LAVAUN: It's just the truth.

Serving other artist-entrepreneurs with disabilities

CHERYL: Yeah! I believe I understand that you enjoy making art more than you do the more business and administrative sides of running a business. But you're doing both. And you're doing well with your art business. And you're getting a lot of experience with entrepreneurship. And now you have a new project that's about to start where you're gonna share this really hard-earned wisdom with other entrepreneurs with disabilities. Would you talk about that project?

LAVAUN: Absolutely. So you mentioned at some point about having an art fair, creative-types fair because we had musicians selling CDs. And we had people selling their soap, a woodcarver, different things. It was not financially successful. But I think it was great having us all in the room together. We loved having the opportunity to interact with already people. And I was already thinking of it, but this kinda cemented that I think that we need to create a little entrepreneurs club for the artistic types. And we'll bring in speakers from the Regional Arts & Culture Council, folks who have done successful Kickstarters. I'd like to bring in, at some point, someone from the Portland Art Museum to talk about how to get your work into the Portland Art Museum. Musicians aren't gonna be interested. But for those of us who are really working on doing the level of work that is museum quality, bringing them in. That would be down the road, way down the road. This group will be meeting, probably at Panera Cares. And I'm trying to figure out what's the best day because there's all the other things that go on. I'm looking at maybe the last Friday of the month, probably from 3:00 to 4:30, and bring people together to learn about how do you develop the business of art, whether it be filmmaking, music, crafts. And then the other thing that we're hoping to have come out of this is a group that actually plans another event like the holiday gifts fair. So I wanna have two things borne out of that: one is just to be kind of an entrepreneurial learning group. And then the second one will be to develop two events. Because a lot of us were talking. We'd like to have two events per year: one in the summer, and one right at the holiday time to be able to sell our arts and our creative goods to the public and not have it be about oh, those poor, we're gonna go support those poor disabled people.

CHERYL: [laughs] Right!

LAVAUN: But to have it be [laughing] be about supporting local small business owners.

CHERYL: Yeah.

LAVAUN: You know, supporting entrepreneurs. We happen to all have disabilities. And we band together to learn together because there's not a good program out there that supports us, you know, learning from each other. So this is gonna be just kind of a learning group, entrepreneur development group.

CHERYL: I love it! That sounds, it sounds fabulous. You know, a lot of art that's made by disabled people is automatically put into boxes such as, oh, well that's a sweet little hobby. Or that's very therapeutic, and that must be wonderful rehabilitation that you're getting from doing that. Those things really sort of flatten us out and flatten out our experience. And there are plenty of people who do art therapy, plenty of people who engage in art for rehab, or they just make art and they enjoy the rehab they can get from it. But there's this other side too, of I'm an artist. I'm an artist. I'm an artist with a disability. I'm an artist. By putting together this group, you're just broadening the number of people who are gonna be able to say, "No, this is art. This is not charity or therapy or pitiful. It's art."

LAVAUN: I'm very excited.

CHERYL: Yeah! When you get the date set, I will definitely have it on my blog, on WhoAmIToStopIt.com. It sounds like it'll also be cross-disability and cross-artistic mediums.

LAVAUN: It will absolutely. It will be absolutely cross-disability and cross-creative discipline.

CHERYL: So people can find you online at <http://Accesibleart.webs.com>. And "accessible" has one "s" in the spelling. Another way to find Lavaun is her profile on the Out of Step Tool, which is OutofStep.com. And you can search for Lavaun's art. She's got a beautiful profile up there.

LAVAUN: And the spelling for Lavaun is L-A-V-A-U-N.

CHERYL: Thank you. And then you're on Facebook: <facebook.com/LCHeasterDesigns>. And Heaster is H-E-A-S-T-E-R.

LAVAUN: People can email me, and I'll put them on my email list. And that's inclusionandaccess--all one word, inclusionandaccess@gmail.com. If you just ask to be stuck on the artist update list, I will go ahead and put you in there. And you'll be kept up to date on any upcoming events.

Wrap up

CHERYL: Is there anything else I didn't ask you about that you would like to share today?

LAVAUN: I think that being an artist, whether you have a disability or not, is a lot of work in Portland because we have so many artists. So it's about figuring out what you have to offer that is unique and really tells a story that people can connect with. It's about really finding a way to tap in to people's experiences and be vulnerable about your own. The other thing is, I really do believe that we do need to work together as artists, the disabled communities, because it's not an easy thing to do. And there's so much to learn. And I know I have made a million mistakes already within a year and a half. I've only been doing this for a year and a half. And I've made a million mistakes. But I've also had some real successes. And so the more we can work together, we can learn from each other. If you don't choose to be an artist, well then, participate as an audience. Come out to art shows. Come out to events in the community and show your support in that way.

CHERYL: I'm all for it. So yeah. I love it!

LAVAUN: Yeah, go see the dancers at Disability Art and Culture Project. Their Inclusive Arts Vibe dancers. Oh, they're fun!

CHERYL: There was one performance they did where I never got to see it because I was backstage helping with costume changes. I was so sad! You could hear the crowd.

LAVAUN: [laughs]

CHERYL: And the dancers would rush back. They're panting. And they looked so happy and excited. I'm like, "Gawd! I can't!" Next time, I'm watching the show. I love their performances. Oh my gawd, yes. Thank you so much for being on the show and talking about this new entrepreneur group. I really look forward to attending those meetings. Great.

LAVAUN: Thank you so much for having me on.

CHERYL: Absolutely! We'll do it again.

[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]