

Stories from the brainreels podcast transcript

January, 2014

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Introduction

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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Cynthia Lopez's history working in film

CHERYL: Cynthia, thank you so much for coming and being on my show today.

CYNTHIA: It's great to be here, Cheryl.

CHERYL: You've made a lot of different kinds of films.

CYNTHIA: Yes.

CHERYL: And documentary is one of your big interests.

CYNTHIA: It's probably my main film interest.

CHERYL: Tell me how you got interested and involved in documentary film.

CYNTHIA: I'd made a couple narrative films. My first two films were feature-length narratives, which I won't mention the names of, and I hope no one ever sees, who didn't already see them. And I felt like I'd failed at film. Or I wasn't ready to quit. But I'm like, I need some help. So I didn't go to school. But I did start volunteering with these two filmmakers, Richard Wilhelm and Sue Arbuthnot on their film "Imagining Home: Stories of Columbia Villa." And I just said, "Can I do something for you?" And so you know, I transcribed interviews and held the boom mic, and just, I kind of was like a sponge. I don't know if they realize it. But I was a total sponge around everything they did when they were writing a grant-- and I helped a little bit on those--and when they're interacting with their subjects, when they're doing anything. I was like a sponge. At the same time, I was doing a Social Science degree. So the interviewing and the research and kind of ethics as you approach as an insider and outsider, all that stuff, I felt really comfortable with and excited to learn and confident about. But I wanted to be visual with what I was working on. So that's how I got into documentary. And then I really liked it. It felt good to do that kind of work.

CHERYL: So originally, though, you weren't going to do documentary. It's just that that's who you ended up getting as your mentors, were documentary filmmakers?

CYNTHIA: Yeah, actually. I did make some films as a kid. And I had this strange vision that I would be like--I don't know where Cecil B. DeMille got into my brain as a kid cuz I wasn't exposed to the thought that

you could be a filmmaker. I don't know how that got into my head. But I had these visions. And they were like large director of thousands of people, and you know. So I think I started out just working on fiction and stories. And there's a lotta silliness in me, not that all stories are silly that are fictional. But there's a lot of non-documentary desires that I have. But they haven't bubbled up as much as the documenting part.

CHERYL: So I love that you brought up Cecil--Oh, what was it again?

CYNTHIA: Cecil B. DeMille.

CHERYL: Cecil B. DeMille. Do you know what I'm thinking of? We're partners on directing this film. So you must be able to read my mind.

The start of Who Am I To Stop It and where the film's name came from

CHERYL: The title of our documentary, Who Am I To Stop It--

CYNTHIA: Yeah?

CHERYL: --is a reference to Agnes B. DeMille.

CYNTHIA: [gasp!]

CHERYL: Or Agnes, oops, not B. Agnes DeMille.

CYNTHIA: Oh my gosh!

CHERYL: Do you remember how that happened?

CYNTHIA: That was the letter.

CHERYL: Yeah. From Martha Graham.

CYNTHIA: Martha Graham, dancer.

CHERYL: Mmhmm. So Kris Haas is one of the featured artists in the documentary. But essentially, she is the one who sparked the idea in my head that I wanted to make--I wanted someone to make this film. I just figured it would be you since I'm not a filmmaker. Or wasn't when I started.

CYNTHIA: Well, PS: it didn't start as a film. It started out as I wanna interview five people.

CHERYL: Oh.

CYNTHIA: Remember?

CHERYL: No, I don't remember that at all.

CYNTHIA: Oh, Cheryl Green.

CHERYL: Wow.

CYNTHIA: Yeah! You're like, so I'm working on a different film, right, the other. And then, you're like, "Cynthia, I wanna interview five people."

CHERYL: Oh.

CYNTHIA: And then I was like, no, that wouldn't be a film.

CHERYL: Yeah.

CYNTHIA: And then we developed it from there.

CHERYL: Oh, OK. I'm gonna take your word for it.

CYNTHIA: Oh.

CHERYL: I don't remember that. But that doesn't really mean anything cuz.

CYNTHIA: OK. I was just thinking about the inception of our film this week, like this is how it went. And I was enjoying thinking about it.

CHERYL: Yeah. Kris was sorta the main impetus for getting the film going. And she read this letter to us from Martha Graham.

CYNTHIA: I think so.

CHERYL: Yeah, to Agnes DeMille.

KRIS: [audio recording plays] "Why it's important to not be judgmental for artists towards their own work, because it'll stop your creativity. It just stifles it. And that actually reminds me of, I don't know if you remember me mentioning a quote from Cecile B. DeMille, or actually, I printed it out. Do you want me to read it? "Quote by Agnes DeMille to Martha Graham: There is a vitality and life-force, a quickening that is translated through you into action. And because there is only one of you in all time, the expression is unique. And if you block it, it will never exist through any other medium and be lost. The world will not have it. It is not your business to determine how good it is nor how valuable it is nor how it compares with other expressions. It is your business to keep it yours, clearly and directly, to keep the channel open. You do not even have to believe in yourself or your work. You have to keep open and aware directly to the urges that motivate you. Keep the channel open. No artist is pleased. There is no satisfaction whatever at any time. There is only a queer, divine dissatisfaction, a blessed unrest that keeps us marching and makes us more alive than the others." You know? And I just, I put this, oh March 9th, 2008 in my blog. I just carried that with me the whole time because I mean, you start being judgmental, and that really stops you."

CHERYL: I don't remember what you did, but after Kris read it--We were in her studio. And I ran out to the living room, and I wrote in my notebook "who are you to stop your creativity?" And I was just, I couldn't get that phrase outta my mind for a couple of weeks. And then I decided maybe that could be the name of the film. And then, at the next interview with Kris, I told it to y'all. So the story is, that I approached you saying I wanted to interview people [giggle].

CYNTHIA: Yeah.

How did you get interested in making an observational brain injury documentary?

CHERYL: What got you interested in wanting to work on a brain injury documentary?

CYNTHIA: Well, I wish it were like oh my gawd, brain injury! It's my main thing. But it's really you, Cheryl. You're my main thing [giggle]. No, but because we worked on the other two films, "Cooking with Brain Injury" and "Friending with Brain Injury," that was a positive experience, I think, for both of us. And you wanted to do something more in the documentary genre. But it started out as five interviews. And I felt like I had the bandwidth and like sure, whatever. Interviews sound great, you know? See what happens. But then, my recollection is that you were talking about it like a film. And then I started thinking about it like well, we need to make it have a story. It needs to be a film. What's the story? And so that always kinda sucks me in. And then I got to know the subjects, and learning more from you about the experience of having a brain injury. So now, you know, there's lots of steps to coming in. But the first step was I like Cheryl, we've had fun making these films, yeah, I'm game. Let's keep going.

CHERYL: So, "Who Am I To Stop It," affectionately known as WAITSI (those are the initials), this is going to be an observational documentary, or at least to some degree observational.

CYNTHIA: Mmhmm.

CHERYL: "Marwencol" has got a ton of observation in it. But a lot of the brain injury documentaries and disability documentaries are very much about interviews and getting lots of different people's storytelling and having the person tell their own story to the camera. But you had the idea to go in a more observational direction, which I love. Do you wanna talk about your interest in the observational style?

CYNTHIA: Yeah. Sure. I have not seen all films about disabled people. You've probably seen a lot more than I have. But I do feel like that subject area suffers from too much explaining and not enough experiencing of it. So, especially, yes, having a person tell their story, the contained story of their tragic injury or diagnosis, and so that's sort of a distancing thing, really. So is an expert talking about what it really means or the biology of it or any of that. So is a family member telling their angle of the story. Like, there's a lotta lotta telling. And there's showing too. But I just feel like what if we disciplined ourselves to really try to show the lived experience of these three subjects. Each of them has a very different life: they practice different art, they're different ages, they have different living circumstances. And I think that's interesting. And I just thought it would be good to do that. Now that we're starting to edit some of that stuff, man it's really hard. I wish we were just--I don't wish. But I was like, if we just had interviews and b-roll, this would be a piece of cake to put together! You know, I mean you kind of have it built in. But I'm glad it's not. I'm tired of that stuff anyway, tired of that type of film right now. So I'm happy. It's just more challenging to shoot. And it's more challenging to edit. Maybe because I have less practice. I've never made an observational film before. Have you?

CHERYL: My documentary on Lavaun, for that filmmaking class, certainly had some. I mean, it was still very talking and explaining.

CYNTHIA: Yeah.

CHERYL: That was my first documentary to ever make, and.

CYNTHIA: I mean, we want to be flies on the wall. That's really what it would be in its purest form. And it's hard because we've got three people. And we wanna hear from them. We can't be with them constantly. And we don't wanna do the greatest hits of their life. We wanna get some daily life stuff. And I don't know. It's challenging.

CHERYL: Yeah.

CYNTHIA: Conceptually, we both really liked it. And now in the doing of it, it is more time-consuming and harder than I realized it would be. I'm glad. I'm still happy. I still stand by it but.

CHERYL: Good. I think if anything, audiences might say, "Hey! How come we didn't get to hear their crash story? There were no interviews." But, if we made this a totally interview-based documentary, they still wouldn't hear the crash story. People won't know that.

CYNTHIA: Well, right. I love to watch interviews, conduct interviews, less, I less love being interviewed. But look I'm doing it, but. So I don't have any problem with that. But I just think in this case it's important to not do that. However, it doesn't mean the subjects aren't talking. They're telling jokes, they're talking about themselves, they're interacting with other people. It's quite entertaining. And there's lots of verbal interplay. So we just don't have a formal interview yet. Or we may not.

CHERYL: And I like that.

CYNTHIA: Yeah.

CHERYL: I like that difference because while you get a ton of information from an interview, obviously, and that's why you have it, it's contrived. It doesn't look like daily life. And so you don't really know, well, what would that person be doing otherwise, if they weren't sitting in front of these lights being interviewed?

CYNTHIA: Right.

CHERYL: And so, while you might get to know a lot of information about a person, you could also say that interviews might be distancing. And so in this, you're gonna see people walking about their home and going here and going there and doing things. And I think you're gonna get the same information.

CYNTHIA: Well, also, I would question if your film was full of interviews, why are you doing a film? Unless that person is really important to watch and see talking, I don't know. What's filmic about that?

CHERYL: Well, it's a good question. But the two big ones, "Brain Injury Dialogues" and "Every 21 Seconds" are almost total interview.

CYNTHIA: I know. I saw them.

CHERYL: Yeah. And but it gets so much, they get so much valuable information out that's not out there otherwise.

CYNTHIA: That's true. They do.

Who Am I To Stop It is a non-inspirational documentary

CHERYL: So you have been encouraging me recently to start describing "Who Am I To Stop It" as a non-inspirational documentary, which I love. I love that you've started doing that! Another thing you know about me--and I don't know about my listeners, but certainly my blog readers have seen my satirical PSA called "Your Daily Dosage of Inspiration," which is really a scathing indictment of the term "inspirational" around people with disabilities. So when you came and said, "We've got to start calling in non-inspirational," I was so excited! But I don't know if I ever asked you exactly what motivated that for you. So I'd love to hear that.

CYNTHIA: I love feeling inspired. And I can be inspired by anything. I'm looking at Lavaun's calendar, actually, the January image, Lavaun, if you're listening. And I think it's beautiful. I'm inspired. I'm like, I don't know how she did that. Oh, I think she cut out paper. But I just feel excited cuz I make collages. So I'm pro inspiration, just to get that out there. However, I do find it really depleting and uninteresting for me to approach a story with a lens of inspiration, like I'm gonna make this inspiring, or I'm gonna look for the inspiring, or I'm gonna--That doesn't work. I want to find a truth inside of our story, or truths, you know, more than one. But if we talk about a box of rocks, you know, the end of it that's all it is, but it's inspiring to someone, that's great. I just think it has to be what it is. I know that's different because it's unique to us; we're the people making it. But I can't rally if we approach it as if it were going to be inspiring. Cuz you don't. It is what it is, you know?

CHERYL: Yeah, yeah.

CYNTHIA: If somebody walks out of our film and says they're inspired by it, that's fine.

CHERYL: Sure! Well, and I get inspired by the people in it.

CYNTHIA: Yeah, me too.

CHERYL: And it's that real inspiration too, where I go to Kris's house, and I see a new painting. And I think, oh my gosh, that painting's so beautiful. I feel energized. I wanna go home and make something too. I don't paint. So I might get so energized by looking at her paintings that I write a blog post cuz I'm wordy.

CYNTHIA: Right.

CHERYL: That's real inspiration.

CYNTHIA: Right, and I think the reason, not only are we carrying this lens around where we just wanna see things how we see them and put them together how it feels best, we're actually saying it's non-inspirational because this topic area--probably any film that relates to disability, people with a disability of any kind--is gonna have that stamped on it, either sad or inspiring or some word that doesn't necessarily apply. And so my whole thing about let's call it non-inspiring is watch the film, learn about these people and their lived experience, and then you can be inspired or not. But it's not like an inspiring story. Just, we're not doing that.

CHERYL: Yeah, and I--

CYNTHIA: That's why we're calling it non-inspirational.

CHERYL: Right.

CYNTHIA: That's my impression of why we're calling it that.

CHERYL: That's brilliant. I'm so glad that you brought up the idea that disability-related stories are stamped with inspiring.

CYNTHIA: And I think we agree: there's nothing wrong with being inspired by any story. But before you know the story or meet the people, you can't, why do you wanna do that?

CHERYL: Right, right.

CYNTHIA: I don't know. I don't like it.

CHERYL: I don't like it either. And it really does keep people with disabilities separate from non-disabled people because you can say, "Oh, you're so inspiring..." and the dot, dot, dot is "because I could never do what you did! I don't know what I would do. I would rather die than be blind." Just read that in a New York Times article yesterday.

CYNTHIA: We read the same article online. So you really said that.

CHERYL: Yeah. And I think that's a terrible thing to write and just put out there even though I understand that may truly be true for that person. But I don't know that she realizes the damage she does and does more distancing of "Ew yeah, oh gosh, I guess I'd rather be dead than blind, too. What would I do?" Well, you know what? We're not super human. We're not super crips. What do you do if you are in a bike wreck and you get a brain injury? I don't know. You just do whatever you do. And if you are born blind, or you lose your sight, you just do what you do. And when people say things like, "Oh, you're so inspiring that you do anything!" You know, and I mean we really make fun of it in my little PSA because Caitlin brushes her hair and answers the phone. Oh, how inspiring. But that's actually her daily reality. People compliment her for leaving the house. Some of my friends who use wheelchairs are accosted in public, "Where's your assistant? What are you doing out on your own?" It's so awful. Or people think it's a compliment. They'll say, "I'm so excited to see you out on your own." Well, you don't even know me! What? And it's so, it's oh my gawd, it is so dehumanizing to hear the title of the film or hear the person's diagnosis and automatically say, "I'm so inspired." Inspired to do what? What did you actually do? I never hear of anyone changing their perspective on anything when they say, "Oh, that disabled person is so inspiring." Well, if you were inspired, what did you do next? What did you change? What did you explore? Nothing. I just hear, "That's inspiring!" Just yesterday, I got an email, "Your films were so inspiring!" Inspiring? What did they inspire in you to do?

CYNTHIA: Those films aren't inspiring. Like the "Cooking" and "Friending"?

CHERYL: Yeah.

CYNTHIA: They're really funny, and they're good. But they're not inspiring [laughs].

CHERYL: They are, I am called inspiring for making them.

CYNTHIA: But you know what I mean, like?

CHERYL: Yeah!

CYNTHIA: And they can be inspiring too. But they're not--

CHERYL: They're not even designed to.

CYNTHIA: That's not what you say. I don't know. Of course. They can say whatever they want. It just seems weird.

CHERYL: It is weird.

Disabled people are always expected to share their personal story publicly

CHERYL: And the other thing that I get, that I hear around disability, is people talk about, "Are you gonna share your story?" I hear it all the time. When I presented at that national speech therapy convention? I was talking to a PhD level speech therapist there. We were socializing. She goes, "So, your presentation's tomorrow. Are you sharing your story?" And I find it so insulting. You really think this national-level convention--and it cost me \$400 to show up that day, just to show up. Not even for the airfare and the hotel. Do you think they would schedule someone to share "my story"? No! How about my presentation was heavily research-based. We had like five slides of references. But the default assumption was that I was there to share my story. And what I was really there to do was to share current evidence-based research. And I found it so insulting that the default was that I was just there to talk about "I had a brain injury. Now I'm all better."

CYNTHIA: Well, that's not what we're doing in our film. We're not showing their stories in that way. Unless, if somebody wants to talk about their injury, fine. But it's not about their canned story or the story they always have to tell.

CHERYL: Right, yeah. That's another thing that I love about this film is that every other brain injury documentary I've ever seen shares the story of how the person got injured. In "[Marwencol](#)," it's sort of a sub-plot. And most of it--

CYNTHIA: I love how it's revealed in "Marwencol."

CHERYL: It's so good.

CYNTHIA: And it has a lot of meaning and relevance.

CHERYL: It does. They show it as a part and--

CYNTHIA: They don't lead with it. And it's not about it.

CHERYL: That's right!

CYNTHIA: And that's important.

CHERYL: It's about him today. And you do need to know a little bit of his context, especially because of the reveal that happens. I mean it's very, very important, especially because it was a hate crime. And we need to talk about hate crimes more often and acknowledge that they happen. The other films I've seen center around the story. And when I hear people talking about the importance of "the story," people wanna hear each other's story because they want motivation and inspiration and hope. OK. Well, I want social justice. Caitlin and I were just talking about this on the show earlier this week about we've got to move beyond the personal, individual narrative and the canned story and talk about the community. But I am really excited by the film that we're making because people are going to be expecting to hear was it

a car wreck? Was it a bike wreck? Was it violence? What was it? Were the people in a coma? And I get asked all the time.

CYNTHIA: I get asked all the time. I mean, when I say I'm making this film.

CHERYL: What do you tell people?

CYNTHIA: I usually tell them like a brief like "car accident."

CHERYL: Yeah, yeah. I tell people, "Everyone in the film had a traumatic brain injury."

CYNTHIA: Mmhmm.

CHERYL: And then they'll ask: "Was everyone in a coma?" And I might say, "No." Or I might say, "It's not something we talk about in this movie." And so they still think we'll talk about it here face to face. No, I won't. People have a right to privacy. And I think this constant demanding to hear people's really vulnerable, painful crash stories can be intrusive. Not for everybody! Of course. But it can be intrusive.

What's it like for you working with people with brain injuries?

CHERYL: It's pretty obvious, just from your demeanor when we're filming that people with brain injuries are--You may not have initially thought you wanted to make a documentary about people with brain injuries on your own. But clearly, we're your favorite group of people to work with, right?

CYNTHIA: Yeah, clearly.

CHERYL: Yeah.

CYNTHIA: Absolutely.

CHERYL: What is it like? I mean, you've worked with lots of different groups of people. You've worked in different countries. I don't know. Is there something particular about working with people with brain injuries that stands out?

CYNTHIA: Definitely lighting, the concerns people needing to control the light in their environment for their own health. And that's different for each person, I've learned. So at first I thought, I had a really blunt concept of what that meant like, oh, we have to have low light everywhere. And for shooting a film, that impacts it. But that's not the case. Still, it's a big deal. Being aware of resting and timing, rest breaks for everybody. I like that, actually, a) because I've struggled with fatigue of my own. So I totally understand it. And b) because the film world is so push, push, push, you know, really long days, keep going. And there's a reason behind that. And it's financial a lot and other things, scheduling. But it's really nice to be on a set where people are taking care of themselves or asking, hopefully, as much as possible asking for what they need. When it's time to stop, we stop. That's that. We honor people's health. So I love that. I love each of our subjects. But I can't say like, oh you know, because of the brain injury, brain injured parts of them. What makes them who they are, I think, is just who they are. So for me, it's sort of like the logistical challenges or interesting things logistically that we do that are different than usual sets, film sets, I guess.

CHERYL: Yeah, yeah. That's really interesting to hear. You know, when I contacted Eric Macey to fill in as camera operator because our regular Director of Photography was out of town. And he said, "Well, my regular rate for a 10-hour day is such and such."

CYNTHIA: You're like, "Ha, ha, ha! 10 hours!"

CHERYL: 10? Can you quote me 30 minutes? I mean, we're never even gonna go there. I mean, I just, I can't. Sometimes I take my nap at 9:00 or 10:00 in the morning. I'm just done after being awake for a couple of hours.

CYNTHIA: Mmhmm.

CHERYL: And definitely, not all of our subjects struggle with being exhausted. But some of them do. And you know, there's plenty of footage that Paulius has got of I'm not in the shot, but you can hear people talking to me. I'm lying on the couch in our subject's house. And the subject is bringing me water because I don't feel good, and I'm nauseated and tired. It's a little bit weird.

CYNTHIA: Yeah. Or there's shoots where they're like, you can hear, "Where's Cheryl? She's resting."

CHERYL: [laughs]

CYNTHIA: You know, and I'm there. You were there at first. And then you didn't come back.

CHERYL: Right, right.

CYNTHIA: "Where's Cheryl?"

CHERYL: I think, I mean there's flexibility with a documentary that you don't have with a scripted film. Obviously, I would be fired on the first day of work if I were working in a studio.

CYNTHIA: You're the boss of this film!

CHERYL: Yes [giggle]. But if we were working in a studio, and I were working on a film, and I went to take a couple of naps?

CYNTHIA: I don't, it probably wouldn't be honored.

CHERYL: Yeah, it wouldn't be honored.

CYNTHIA: Yeah.

CHERYL: And that's what's really nice about this, is that we've got the crew and the subjects both needing to honor our own self-care. Not all of the crew. Paulius is young. He'll get there. He'll get tired.

CYNTHIA: He'll honor his tiredness one day.

CHERYL: I loved your answer.

CYNTHIA: OK.

CHERYL: I wasn't expecting that at all.

CYNTHIA: Oh.

CHERYL: I loved it. I was expecting something about how we're funny, or we have a weird sense of humor or--

CYNTHIA: That's true. But I don't attach it to the brain injury part.

CHERYL: Right. I sometimes still don't pay attention to the filmmaking logistics. Like hey, let's close all the blinds and make sure all the lights are off and film Kris doing her thing. Well, you can't. You can't film that.

CYNTHIA: Right, right.

CHERYL: So it is hard for me, at times, to always keep in mind the logistics of actually making the film, as opposed to just being there to witness something that they're doing.

CYNTHIA: Yeah, but also, this part that I forgot to mention is the scheduling part. And I think that is a little bit influenced by brain injury, which is like reminding: "Be sure to call us if something's coming up in these topic areas that we want to tell the story of. Please call us." And everyone forgets. But I think there's more and extra forgetting. And there's checking with maybe relatives or friends or whatever to help for us to just find out when and how to get to our subjects. It's a little more challenging.

CHERYL: Yeah, that's a good point. And definitely, there are times when weeks and weeks go by. And I send reminders: "Be sure to tell me when such and such actually is gonna happen because we'd love to film it." And then a while later, I'll hear, "OK, that thing happened. It was great." And I think oh. And some people might think, oh, they just don't have enough buy-in. If they had enough buy-in, then they would always remember to tell you. But it's not, it's really not that.

CYNTHIA: Oh my gawd, it's not. I think they have full buy-in.

CHERYL: They do. And they appreciate being heard and listened to. And they appreciate being appreciated.

CYNTHIA: But and also, by full, I mean the people around them. Yes, their network has bought in to it, too, to their participation.

CHERYL: Yeah.

CYNTHIA: So they're into it. And they have support around them that says, "Yeah, it's cool." So.

CHERYL: Yep, yep. But there's just forgetfulness and disorganization that--

CYNTHIA: Right.

CHERYL: And it's very challenging too because of how many times I will call you, "Hey Cynthia. Kris is doing something later today. Do you think we should try to film it?"

CYNTHIA: I'm like, "OH!"

CHERYL: And it's just, it's totally too late to hire the crew to go film it. And one time, I managed to go out there. But I didn't bring a tripod. So I set my camera on a light stand, which wobbled the whole time.

How much help is too much?

CYNTHIA: And I'm never sure, just like that thing I sent you about file names, I'm never sure like, is this dumb? I would appreciate being reminded because I forget things too. But I don't know how much is too

much to say or not enough. And I think you've made it clear like just say. If you think something's up, just let you know. Or don't be afraid to remind you of things.

CHERYL: Right.

CYNTHIA: And I still hesitate to remind you of things because you have your sovereignty. We each have our own, so.

CHERYL: Yeah, yeah. I love your use of the word "sovereignty." I never hear that. I love that.

CYNTHIA: Oh.

CHERYL: So that's a really good point because there is a really harmful concept that independence is absolutely the highest thing that you can achieve in this culture, no matter what. And so for some people, doing things completely independently means you have a really hard time, or get there but the price that you pay is too high, and you get sick or hurt or something. And it's really harmful to people with disabilities, this talk of independence because we end up not seeking the help and support that we need.

CYNTHIA: Mmhmm.

CHERYL: Oh, I don't wanna complain. I don't wanna ask for help. I don't wanna seem weak.

CYNTHIA: I think we're trained to feel like it's patronizing or wrong or insulting to offer someone help or to suggest things. I think that's hard.

CHERYL: Yeah.

CYNTHIA: That's part of the culture, and it's hard to make the shift. You know, it needs to shift. But it's, I'm speaking from experience that it's hard to do that.

CHERYL: Yeah. I have a lot of trouble remembering my life before I got really connected to the disability community. So it's hard for me to remember what that's like.

CYNTHIA: Mmhmm.

CHERYL: This is what I need. Just do this.

CYNTHIA: Right.

CHERYL: And I've gotten so used to it that now that I am someone who asks for help and support a lot, what am I trying to say? Help? No! [laughs]

CYNTHIA: That you, are you saying that you forgot that some people aren't used to that?

CHERYL: Yes! Yes. I forget that it is, I mean of course it's patronizing if I'm--Like my friend Rick who's blind. So Rick told this story recently of Rick's blind, he has a cane, and people will come up to him at intersections and ask if he needs help getting across the street. They mean well. How the hell do they think he got to that intersection? I mean, he wasn't dropped off by his nurse or his mommy.

CYNTHIA: Right.

CHERYL: He somehow got from somewhere to that intersection. And the assumption that now he needs your help, that is patronizing. They do mean well, of course. But one thing that happens is a lot of people will grab his arm and try to support him across the street.

CYNTHIA: Right.

CHERYL: But he doesn't need that. And it's also really condescending and really scary to have a stranger come up and grab your arm.

CYNTHIA: Yes. I mean, that's true. There's those types of situations.

CHERYL: Disabled people don't need you to be their champion and activist and to make sacrifices: See! I can! I think when you have confidence in knowing your strengths and your limitations, then it's OK. Cuz I can say to you, I don't feel dumb. I know that I have a lot of trouble reading numbers [giggle].

CYNTHIA: Mmhmm.

CHERYL: And I've messed up scheduling things. And I mess up naming the files. But I'm confident that it's not because I'm dumb. And so I'm never embarrassed that I keep messing it up. Now, I feel bad that I keep messing it up. Actually, I am embarrassed that I keep messing it up. But I don't think that I'm incompetent because of it. Because I know that it's a product of the brain injury.

CYNTHIA: And you probably, well even if, you probably don't think I think you're incompetent when I write you.

CHERYL: Oh, no.

CYNTHIA: But it's still odd to write an email message like that.

CHERYL: Huh.

CYNTHIA: Not hugely odd, just a little bit, because I feel like if I get this wrong, our socio-linguistic interaction, I'll seem like a douche bag.

CHERYL: Yeah.

CYNTHIA: You know, if this comes out if oh, you weren't feeling confused. It's just a typo. I don't think you were literally feeling confused, but, you know--

CHERYL: No, I was confused.

CYNTHIA: OK, but anyway, do you know what I mean? So that's all.

CHERYL: Yeah, cuz if you step in with too much--

CYNTHIA: I mean, we know each other well enough that it's fine. But just you know.

CHERYL: It's a really good point, though, is that it's hard to know what somebody needs and what's the best way to give it to them.

CYNTHIA: And even though I do know you very well, now, like that's still.

CHERYL: Yeah, it's still hard. Yeah.

CYNTHIA: Yeah.

CHERYL: Oh, that's really interesting. I'll try to learn how to read numbers better. I have been trying.

What are you favorite documentary film types?

CHERYL: What are some of your favorite documentaries?

CYNTHIA: I'm really bad at kind of blurting out things that I like, lists of things.

CHERYL: It's totally fine.

CYNTHIA: Crazy dreamer category, those are my favorite types of films. Anything in that arena I'll usually--if it's well made, if it's not just blah--I'll love it.

CHERYL: I try to watch documentaries about topics and issues.

CYNTHIA: Yeah.

CHERYL: And--

CYNTHIA: I'm like yeah, blah.

CHERYL: Those are so much harder for me. I do better with a person I can connect to, or that I'm being asked--

CYNTHIA: Character-driven, darling.

CHERYL: That's what it is, yes. Character-driven.

CYNTHIA: Yeah. I get tired of hearing that because I'm like everything doesn't have to be character-driven. But it's true. You do connect with people.

CHERYL: Yeah, yeah. Now I mean if it's on a subject matter that you just care so much about, then yeah. You can watch something on a topic and see the different experts come in and describe it. But my attention span is shorter for those.

CYNTHIA: Yeah.

CHERYL: Now animal documentaries, I never, I don't even blink while watching nature and animal documentaries.

CYNTHIA: Oh, I just watched "Blackfish." I blinked a lot. I blinked back tears.

CHERYL: Yeah, yeah. Here's another documentary-type question. There's the idea that when you're making a documentary, you wanna have--and correct me if I describe this wrong--you wanna have universals in it, something that everybody can relate to, or some quality that's universal? And that's hard for me because I would like us to see what makes us distinct as well and not fuss too much about constantly trying to hit the universals. But.

CYNTHIA: I think fussing over either of those things is a waste of time.

CHERYL: Not a fusser.

CYNTHIA: I fuss about some things. But I think uniqueness of somebody, that will become apparent, will emerge. And I think universalness will probably emerge. I don't know. When I think about that, I think about people saying like, "Well, everyone relates to the hero's journey, that classic story." And I do think that when you think about a classic sort of journey, linear story like that, it does help to organize your film, your narrative around that sometimes, for sure. That is worth thinking about ahead of time and constantly.

"People with disabilities" versus "disabled people" and our use of language

CHERYL: Right. So you come from outside the disability community, essentially.

CYNTHIA: Yes.

CHERYL: And there's certain words around disability that I might use that are different from maybe other people you know or other people in the disability community.

CYNTHIA: Mmhmm.

CHERYL: Yeah, and so I like to use the term "disabled," usually, as opposed to "person with a disability."

CYNTHIA: Oh.

CHERYL: Yeah.

CYNTHIA: I feel differently, but I'm from the outside.

CHERYL: Yeah. Most all of my friends and the people I communicate with these days are disabled, to some degree or another with various impairments. And so I forget what it's like outside the disability community. So I don't know. What do you think?

CYNTHIA: I feel like it is more honoring of personhood to say "person with X" or "person who is X," whatever.

CHERYL: Yeah.

CYNTHIA: So whether it's "with a disability" or "person who is homeless or who is experiencing homelessness."

CHERYL: Yeah.

CYNTHIA: It's a mouthful. But I do feel like it's important to put the person in there.

CHERYL: Yeah.

CYNTHIA: And saying "disabled," just use it?

CHERYL: Oh, like, "I'm a disabled filmmaker."

CYNTHIA: "Disabled filmmaker." Well, that's still. I'm just saying like "the disabled." That sounds wrong to me.

CHERYL: "The disabled" sounds terrible.

CYNTHIA: So, disabled filmmaker, uh.

CHERYL: Versus a filmmaker with a disability. Or let's just use person.

CYNTHIA: 50/50, yeah.

CHERYL: I'm a disabled person versus I'm a person with a disability.

CYNTHIA: I guess, yeah, those feel equal to me.

CHERYL: They do?

CYNTHIA: As long as we have person in there.

CHERYL: Oh, OK.

CYNTHIA: I think the problem is that if you just say--

CHERYL: I hear "the disabled, the blind, the wheelchair-bound."

CYNTHIA: Right, "the homeless."

CHERYL: Uh-huh.

CYNTHIA: Then you miss, then that starts to be all that that person is instead of a person. And one part of them is this, and another part could be something else. That's all.

CHERYL: I like that. Most people aren't 50/50 on "person with a disability" versus "disabled person." Most people take a hard line on one or the other.

CYNTHIA: I feel 50/50 personally.

CHERYL: I'm glad. I usually use "disabled person," but I will, if I suspect that's gonna offend or gross out or confuse or disturb people, I have no problem saying "person with a disability." But there's a lot of really nice arguments for "disabled person." Well, first of all, "person with a disability." I mean, the person-first language is really big in the medical community. So clinicians talking about us. But it's also really big--and this is--

CYNTHIA: Hmm. So that's baggage already.

CHERYL: That's baggage, yeah. What I find to be positive is that it also comes out of sort of the civil rights movements.

CYNTHIA: Mmhmm.

CHERYL: OK, so all of us have been institutionalized. And we can't vote, we can't be educated, we have no dignity. But I'm a person with a disability. I'm not this diagnosis.

CYNTHIA: Right.

CHERYL: And so it has a really, really important history that I value a lot, this idea of calling someone a person with a disability.

CYNTHIA: Yeah.

CHERYL: But now we have, well now we're past the social model of disability. We have the medical model of disability, the social model. Now we're in the embodiment model.

CYNTHIA: Oh!

CHERYL: Yeah, I like that name. But in the social model of disability and beyond, you would say, "Yes, I have an impairment. I'm a person with a brain injury. I'm a person with, I've got a memory problem."

CYNTHIA: Mmhmm.

CHERYL: But that's not really a disability. That's just who I am. Where the disability comes in is I go out into society, and I'm confronted constantly with barriers and obstacles and attitudes that exclude me. And so society disables me.

CYNTHIA: OK.

CHERYL: So I am disabled in the same way that you might say--

CYNTHIA: You're oppressed.

CHERYL: Exactly.

CYNTHIA: How is the embodiment model different?

CHERYL: What I like about the embodiment model is that in the social model you really, everything is about the disabling society, whether it's the structure, the built environment, or attitudes, institutionalized oppression. But you're really not supposed to say, "Gawd, having a brain injury sucks, you know? It really sucks that I can't walk." You're really not supposed to say that. You're really not supposed to put any of the responsibility for your troubles on yourself. It's all social. And the embodiment model talks about yes, you know what? It is fair to say I'm having a really hard day because my memory sucks. I really hate this moment. I really hate having a brain injury. I really don't like this. This is hard. But I'm not the problem. If there's a problem here with me getting into this building, it is not my fault. It's there's no ramp. Or there's blinking lights. I can't go in. It's gonna make me sick.

CYNTHIA: Mmhmm.

CHERYL: So it's a little bit more of a middle ground. And the other thing is that the social model doesn't take into account the way we internalize oppression and stigma that we get from around us. And the embodiment model is much more into you know, if you're feeling down on yourself and you're feeling like you're not gonna achieve because of your disability, maybe you internalized that garbage from an ableist society. So we like the embodiment model.

CYNTHIA: Yeah.

CHERYL: Yeah, yeah.

CYNTHIA: Nice.

CHERYL: But it is interesting when I talk to non-disabled people who, one person I said, "Sure, I call myself brain-injured cuz I am brain-injured." And this one person who doesn't have a brain injury was like, [gasp] "Why would you call yourself that?!"

CYNTHIA: As opposed to person with a brain injury?

CHERYL: Right. Why would you not use person-first language. Well, frankly cuz sometimes I'm 50/50 on it too. Whatever. Brain-injured person's easier to say than person with a brain injury.

CYNTHIA: Well, in "Cooking with Brain Injury" you introduce yourselves like, "We're brain-injured."

CHERYL: "We're brain-injured! How about that?" Yeah.

CYNTHIA: And that's echoed in my mind because when I, I don't know, a few times that maybe I've written an email or something and said, "A brain-injured artist" talking about you and then had to puzzle through it. Like, is that or do I go "Cheryl is?"

CHERYL: Right. Oh. I think that's great.

CYNTHIA: Yeah.

CHERYL: I mean, I'm sorry it's uncomfortable. But it's great.

CYNTHIA: Well, it's not uncomfortable, actually.

CHERYL: Oh, good. OK.

CYNTHIA: It's just like a puzzle.

CHERYL: It is a puzzle.

CYNTHIA: As long as I'm not, I guess, hurting someone's feelings or otherwise making them feel negatively.

CHERYL: Yeah. You know, when I don't know someone's take, I always go for person-first language.

CYNTHIA: Yeah, I guess that's just what the thing is now, yeah.

CHERYL: Yeah. And when I do it, I'm intending to be respectful. OK. So I just learned this one the other day that I love, which would be instead of saying "disabled" versus "able-bodied" or "disabled" versus "non-disabled," here's my new favorite: "dis-enabled" versus "enabled."

CYNTHIA: Right.

CHERYL: That is my favorite.

CYNTHIA: That's really interesting. Yeah.

CHERYL: Yeah. Because it talks about privilege, institutionalized privilege.

CYNTHIA: Right.

CHERYL: If you don't use a wheelchair, all other things being equal, you're gonna get more.

CYNTHIA: You're enabled.

CHERYL: You're enabled. You're just gonna get more positive reactions. You're gonna get more opportunities. You can go to more places. And I'm talking about somebody with no mobility impairments. I'm not talking about somebody who uses crutches or a cane.

CYNTHIA: Mmhmm, mmhmm.

CHERYL: But all other things being equal, if it is known that you have impairments, you just start sliding down the hierarchy.

CYNTHIA: Mmhmm.

CHERYL: And so to honor that, to honor that that's what's going on, I love "dis-enabled" versus "enabled." Yeah. Sweet.

CYNTHIA: Yeah, I think that's good.

Cynthia's creative retreat in the woods in 2014

CHERYL: Part of your sort of mentoring me into this documentary film world, part of that process has involved you stepping away sometimes, which means, of course, I call you and say, "There's a film shoot in two hours. Should I schedule it?" But there were a lot of things that you sort of held my hand through at the beginning cuz I had no idea. It's not disability-related. I just am new to the field. And then you started, very strategically pulling away from different things. And now, you're actually gonna go on sabbatical and leave town, which is very nerve-wracking for me, but also really exciting. I would love to hear a little bit about this sabbatical.

CYNTHIA: Well, it seems like it's more of a retreat now. But I'm going to live on a relative's property in the Coast Range, kinda between Eugene and the Coast. So it's very rural. It's kind of woodsy. And my primary focus is creative work. So I'll be editing WAITSI and working on another show also, "Mini-van Psychic," which is like a web series, and exploring, kind of developing some new ideas I've had that've been running around, and just kind of getting out of Portland. I've been here for 20 years. And I haven't left for that long during any of that time. So I'll be gone for about five months, if it goes well. I'll have Skype. We've figured how you can get the footage to me. I'll look at it, I'll give notes, you'll give notes. I think it's gonna be fine.

CHERYL: You're not scared? [giggles]

CYNTHIA: I'm not scared about the film.

CHERYL: OK.

CYNTHIA: I'm kinda scared about like moving away to a really different place. But it's not even that different. It's just Oregon. So that is sabbatical. And I think it'll be good. I think it's always good to feed the creative part of you. And that part of me has taken some hits this year. So I need to feed it.

CHERYL: Last year.

CYNTHIA: Last year. Ooh, that's right! It's 2014. So it started out as a plan with a different sort of purpose. And I was calling it "sabbatical." And it had a different feeling. Now, I'm calling it a retreat. I'm excited to kind of like fill up my well.

CHERYL: Yeah. And who are you to stop it?

CYNTHIA: Exactly! Boom!

CHERYL: [chuckles] Cynthia, I'm so grateful that you came to talk to me. Usually, we have these very somewhat orderly meetings with our agenda items that you write and tick off.

CYNTHIA: [giggles] Sorry!

CHERYL: It's all right. No, I'm insulting myself for not ever writing agenda items.

CYNTHIA: You have written agenda items.

CHERYL: I have?

CYNTHIA: Yeah.

CHERYL: Well, see, lookee there.

CYNTHIA: Yeah.

CHERYL: Thank you for your help on that.

CYNTHIA: I'm reminding you.

CHERYL: I didn't remember that.

CYNTHIA: Yes.

CHERYL: [laughs] Well, it was also nice to ask you some questions about some things I think we might sort of take for granted.

CYNTHIA: Right.

CHERYL: For instance, we both agree "non-inspirational." Great. Let's go. But it was nice to actually--

CYNTHIA: Like why.

CHERYL: Yeah.

CYNTHIA: Yeah, we hadn't talked about it.

CHERYL: Yeah, so thank you.

CYNTHIA: Truth. Yeah, thank you.

CAT: [chirps]

[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, <http://WhoAmItoStopIt.com>.

[music]