Disability Visibility Podcast

Episode 16: Documentary & Disabled Filmmakers

Guests: Jen Brea and Jim LeBrecht

Host: Alice Wong

Transcript by Cheryl Green

For more information: https://disabilityvisibilityproject.com/podcast/

Introduction

[radio static, voices singing with hip-hop beat]

LATEEF: This is the Disability Visibility Podcast with your host, Alice Wong.

ALICE: Welcome the Disability Visibility Podcast, conversations on disability politics, culture, and media. I'm your host, Alice Wong. Before we get started, take a listen to this.

[beep, then mellow orchestral music]

WOMAN: From as early as I can remember, I wanted to swallow the world whole. [a small crowd cheers and claps] Anything was possible. [ominous music] I just thought I would have more time. [distorted heart beat] I don't know what I did to myself. I don't think I can get up off the couch. I feel like my brain is perspiring.

Sometimes I wouldn't be able to speak. [painfully slow-motion voice pushes out "wow".]

MAN: If you say too little, and if you say too much, they think you're a mental patient.

WOMAN: The doctor would tell me, "You're just dehydrated. Everyone gets stressed."

ALICE: You just heard a short audio clip from the documentary Unrest. Today's episode is all about disabled filmmakers and documentaries. There are quite a few documentaries that feature disabled people but very rarely are they directed, produced, edited, or written by them—that is something that needs to change. I'm in conversation with Jen Brea, the director and producer of *Unrest* and Jim LeBrecht, Co-Director and Co-Producer of Crip Camp. We talk about the politics of representation, the power of disability narratives, the importance of documenting our cultures and communities, and how the filmmaking community can be more inclusive.

Are you ready? [electronic beeping] Away we go!

ELECTRONIC VOICE: 5, 4, 3, 2, 1!

ALICE: So, Jen and Jim, thank you so much for being on my podcast today. I'd like to ask you both to just introduce yourself and just tell me what led you to filmmaking. Jen, do you wanna go first?

JEN: Yeah, sure. So, thanks so much for having us on. I'm so excited. So, I'm a documentary filmmaker, and I am a new filmmaker as well as a new person with a disability. And both of those things kind of came into my life at the same time, and I, in some ways, can't separate one from the other.

So, I got sick about six years ago now, after having a really high fever and got worse and worse over the course of about a year. But every time I would try to seek help from the medical system, was essentially told either I wasn't sick at all, or eventually, that I was just stressed until I finally became bed-ridden. And it was really in coming to realize that I wasn't going to get help from the medical system and going online and finding this whole community of people who were also homebound and bed-ridden and had been living for decades with my disease—Myalgic Encephalomyelitis, or ME—that I started filming myself and making this documentary called *Unrest*.

ALICE: Wonderful. Thank you, and welcome to the community.

JEN: Thank you! It's so good to be here. And Jim is the sound designer on the film, so that's how we met.

ALICE: Yeah, it's all six degrees of separation, right?

JIM: Yeah. Well, I became aware of Jen's film on Facebook and just kinda reached out to her and said, "Hey, sounds like a great film. I do documentary sound for a living." So, I wound up working on the film. We wound up having just a incredible time. We mixed in Los Angeles, and we had a lot of time in the mix room, which you often do, and besides talking about that wind is too soft, or I don't like that sound, or let's bring the music into the room a little bit more, [chuckles] we got to talk a bit about illness and disability and how one identifies themselves. And we just had these wonderful, meaty conversations. And I think, out of that, really kind of forged a lovely friendship, and we're kinda compadres to a lot of extent.

[bouncy organ music]

JIM: Since the time of working on *Unrest*, I've started working on a documentary called *Crip Camp*. *Crip Camp* is the story about a summer camp that I went to in the Catskill Mountains, back in the very early 1970s. It was called Camp Jened, and I was a camper there from 1970 through '72. And then in '73, I worked in the kitchen. And there was a story there about these people who had gone to the camp in New York and this migration out to Berkeley in the '70s, largely because the support services and the Center for Independent Living were here, and there was just a lot of us were starting to migrate out here.

I mentioned this story to Nicole Newman, who's a wonderful documentary filmmaker, and she was taken by the story, did a little research on her own, and said, "Let's make the film together." And we're in the middle of production now. So, that's how I've kinda gotten into filmmaking. I mean, I've worked on well over 200 documentaries as a sound mixer and sound designer, but now, finally I'm kind of, I'm working on everything now and not just the audio post.

[bouncy organ music]

Choosing documentary for storytelling

ALICE: And there's so many ways to tell a story, whether it's based on autobiographical or based on real events, but I'd like to ask you both why documentaries compared to feature films or other ways of telling stories?

JEN: Well, I think for me, I think the story always comes first, and it's sort of what is the story that I wanna tell, and how do I wanna move people, and what are the worlds or the themes or the issues or the characters or the people that I wanna explore? And then, I think from that comes the medium, right? Sort of, you think of the story; you find a story that you think is it best as a documentary, or is it best as a fiction film, or is it best as a VR project, or is it best as an essay? And every story, I think, has a medium that it wants to express itself in. And I think non-fiction film I love in particular because it is such a challenge, and it's a constant process of discovery. So, rather than sort of scripting and planning everything in advance, you're very much following real life as it unfolds. And then again, when you're in the edit, trying to figure out how to structure everything and kind of what is the essence to pull out that tells a truth that's truer than true?

[jaunty accordion music]

JIM: This being my first documentary that I'm making myself—well, making with Nicole and Sara—but the first time I'm involved with making a documentary. It's really interesting how the stories start revealing themselves. It's really kind of like you're going on a hike somewhere, but there's these forks in the road or these things that are calling out to you, saying, "You should look at this." And so, keeping your eyes and ears and mind open for where there may be more meat to the story in places where you didn't expect it is pretty essential. And I'm already seeing it with our film in that there's just enough I still need to kinda uncover about the lives of certain people. But I think that's the great thing about documentary films is that a) like Jennifer said, you're really dealing with real life, and secondly that there is a sense of discovery that really makes things interesting.

But I think that in narrative film—be it television or in the movies—that well— We've seen a lot of some good films about disability in narrative film and a whole bunch of films that kind of feel like they're the same old negative stereotypes, you know *Me Before You*, and the beautiful, handsome guy who becomes a quadriplegic deciding he's better off getting himself euthanized. Or *Million Dollar Baby*: Please kill me now that I'm a quad. And people are not seeing anything in the middle in regards to what our lives are like and that it's not like the worst thing that can happen. So, I'm really kinda starting to see more and more in the media around television shows like *Speechless* that have a real, an actor with cerebral palsy playing the part of JJ. And I think all of these things go a long way for demystifying what it means to know somebody with a disability or to have somebody with a disability or to date somebody or employ somebody with a disability. And so, I think both non-fiction and fiction media is really one of the major keys in really improving the lives of everyone, [chuckling] not just people with disabilities.

[jaunty accordion music]

Editing decisions for how much to reveal in *Unrest*

ALICE: I saw *Unrest* and just, I have to tell you, Jen, I really, really truly enjoyed it. One of the things that's really, I think, seductive about documentaries is that I feel like I know you even though I'm sure I don't really, really know you. But I feel like, as audience members, you give us this kind of insight, this kind of really, you open up yourself. But then you know, also I try to be mindful that directors and writers, the way that they choose what they edit and how they show what they reveal in the films is also definitely considered. So, what is your thought again, in terms of just the decisions you made in terms of editing and how much you wanted to reveal about yourself without giving all of yourself away? Did you ever have those kind of debates or challenges?

JEN: I didn't really, actually, until [chuckling] sort of after the fact. I had a friend who is a writer who told me very early on—I mean, actually before I got sick and before I started making the film—produce what you have it in you to write and to tell without judgment, at least at the first phase of trying to explore the kind of depth and shape of a story. And so, I remember thinking about that as I was filming and realizing that my job was to capture the truth of what I was living and what I saw the people around me in my community living, and to try to make it as true, as real, as present, and as realistic and raw as possible, as authentic as possible. And that I could then, when we're in the edit, then decide is something too intimate, or is this what I really wanna show or say? But to sort of not make those judgments while I was capturing the footage.

I think the hard part came when we actually started to show it and do late rough-cut screenings to larger audiences. In those screenings, I felt incredibly vulnerable and incredibly exposed, and it was really hard. But I had the instinct that I made the right choices. And realizing that my exposing, sharing those very personal moments of pain actually helped for the audiences, especially people who are personally affected, to transform their own pain by being able to sort of see themselves on a screen for the first time. To see their lives and their experiences mirrored in the culture, which they almost never get to see. I mean, there's so few accurate and authentic representations of disability in our culture. And I think the same thing is also true for chronic illness where so many of the narratives are about either you die, and it's tragic, or you are miraculously healed, and it's happily ever after. Like, what is the narrative arc of a story that doesn't end where life just keeps on going, right? And where the only resolution to find is to not in healing your body but in shifting your perspective, in going on an emotional journey. And so, I think I wanted to really show that.

Autobiographical documentary as a lifesaver

ALICE: Yeah. I mean, I think as I watched your film, I felt like you documented really just a lot of the dark and low moments. And I thought this film was really—I don't know; you tell me if I'm making a perception—but it seemed like this project itself was a lifesaver for you. Not just being involved in a larger online community, but also documenting your story and just getting your story out there.

JEN: Yeah, yeah. Yeah, no, I think that definitely is the case. I mean, there's a part of the, a place in the film, where I say you know, "Sickness doesn't terrify me, and death doesn't terrify me. What terrifies me is that you can disappear because someone's telling the wrong story about you." And I think that was very much how I felt at the beginning of the process, that I was being, in a sense, I was being erased in a real kind of metaphysical way by a system and a kind of public story that was wrong and wasn't my experience but that was also endangering my life and endangering other people's lives.

[beep, tense classical music and voices play from the *Unrest* trailer]

JEN: Then I went online and found thousands of other people just like me.

PERSON 1: Yeah, I'm completely bedridden.

PERSON 2: It's just like I'm just watching my life disappear.

PERSON 3: I have ME/CFS. That's chronic fatigue syndrome.

PERSON 4: Historically, you can see illnesses very similar to this called many different things.

RICKY GERVAIS: I saw someone collecting the other day for ME. That's the one where, "Don't feel like going to work today." [audience laughs]

JEN: [sobbing]

OMAR: It's gonna pass.

JEN: [nervous chuckles] OK.

MAN ON VIDEO: Chronic fatigue syndrome!

MAN 2 ON VIDEO: Yeah, I'm tired too!

MAN ON VIDEO: [laughs]

[beep]

JEN: The film was very much an act of reclaiming my own right, my own right and power over my narrative. And I remember very consciously thinking, I wanna build a microphone that's bigger than the one that's shouting me down in this moment. And I have to do that. I must do that. 'Cause if I don't do that, I'm not going to survive. And so, I think it was about power, and it was about taking back power. And I also think it was about a kind of emotional healing where— Like, I've always been someone who's felt things very deeply. I was always a crier. [chuckles] And when I got sick, just because of the sort of extreme low capacity and neurological issues, I just couldn't feel emotions very strongly. It was not, it was something that would crash me and make me feel very, very ill. And so, I had to kind of put a lot of that grief I felt for myself in a box and kind of compartmentalize my feelings about it for the first time in my life. And so, interviewing other people with my disease and hearing their stories and both being that listener and then also constructing their stories in the edit, it gave me a way to deal with my own grief for my life, but with a bit of distance.

I think when you first become disabled, if you were born able-bodied, I think there's a way in which all you're trying to do is think about how do I get back to my old life? And you're fighting really hard. Maybe that's the denial part of the grieving process. I'm not sure. But how do you let go and then start to sort of see what's good and what is possible and what is even different and better about where you are now? And talking to all of these people who had been in that same position but were 5, 10, 20 years on, I learned so much. So, I think it was in that way, telling my own story, telling other people's stories, and also learning from people that really helped me to make that transition to a person with a disability and to kind of regain, to rebuild my identity and to survive the experience. So, yeah, I think on all of those levels, the film definitely saved my life.

[peaceful acoustic guitar]

ALICE: And I think what was great is that your film was not just about you, but it was really about the larger community. Because I think a lot of people assume that people who are "homebound" or "bedridden" have nothing to offer. And through the film, you see a lot of your friends and people in the community with incredibly rich lives and incredibly active lives from their bed. I think that is something that we don't see enough of, and I think that's why having documentaries and also having disabled filmmakers is so important. And I love that both of you are disabled filmmakers and that your projects are in different stages.

Present status of *Crip Camp* and film activism for increasing diversity

ALICE: Jen, your film is out there in the world. It's completed. And Jim, you're still kind of in the middle. Tell me a little bit more about, I guess, the present status and what you see for the future.

JIM: Well, boy, I could go on about four different tangents immediately. I think that one of the things that drives me is that there's a story here about my community, my culture that I think is really important for the world to hear and see. So, it's rather motivating too, and sometimes a little bit scary in that I really wanna do this right, you know? And no film can cover every single facet of a story, but I just really, I feel really compelled to represent the people for who kind of came into this camp and the experience that we had and how that shaped our lives as activists or people just very, very motivated to have a better life. I feel very motivated to show the un-indoctrinated, really kind of what life with a disability is about.

So, kind of where I am now with this process is we're a little bit more than halfway through shooting. We did film Judy Heumann, who so many people in the disabled community know. Judy was a camper at Camp Jened in the '60s, wound up being a counselor in the early '70s, and she, for me personally, was the reason I got into any kind of disability civil rights work. And I got really excited. I mean, I think when you grow up with a disability, or once you acquire a disability, you see injustice. You see people making assumptions about your capabilities or what your worth is that are completely wrong.

ALICE: And for your project, what are some of the current challenges you face in terms of getting it completed?

JIM: Well, I think you'll find funding for any film project or any project like this is really one of the kind of key hurdles that one has to overcome. I'm staying, we're all staying optimistic. We hope to do about three or four more days of shooting and would love to take a trip down to the South. And so, I'm optimistic because I think we have a universal story.

JEN: I just think that's so important, Jim, what you're saying because if we're having conversations about how do we create a culture that reflects the people in it, and how do we use storytelling as a way to sort of shift perspective and shift the power dynamics, over all, I think people who are fighting for—within the film community but also just more broadly—for women, for people of color, for gay and transgender people, they don't think about us. And I say that because I'm so often invited to participate in fellowships or on panels about diversity for my other identities but never for this one. And so, I always turn every women in film panel into a women, people of color, people with disabilities panel, you know, from stage! But it's never anything anyone thinks about. And I think part of what the work that I hope to do and that I think Jim, it really sounds like you're already doing, is to try to really have those conversations to say hey, some of the experiences that you've had are actually not that different from some of the experiences that we've had. And the ways that you're trying to make the world more equal and inclusive are not that different. And that we have to include this story as a part of all of those stories, in part because that will make all of us more free. It's not just about our community. And so, I'm very excited about that coming across in *Crip Camp* and in our conversations as we go forward.

ALICE: I really appreciate what you two are doing within the filmmaking community because I think, again, pushing that idea that disability's part of the overall, broader diversity conversation.

JIM: You know, Sarah my wife, when I say, "Why aren't people— But they're talking about diversity, and where's the panel on disability? Where's the inclusiveness on disability?" And I start thinking out loud, and I'm saying to her, you know, "I just don't think people wanna deal with this. I think they're scared of dealing with it." And Sarah says, "You'd be lucky if that's what's going on. You're not even on their radar." And we see this time and time again. This past summer, I see these wonderful photographs on Facebook of people at this workshop by this organization or that, and it's like in rustic cabins in the Northeast. And it's like, you know, I...I got a film coming up. You guys have gotta start thinking about this. When I hear "rustic," I see stairs and gravel paths and gee, we're gonna do canoeing as a community-building exercise. And I'm thinking well, maybe we could put some pontoons on my wheelchair, but you gotta think about me now. Because I'm coming next year. You gotta get on this.

[plucky synthesizer music]

ALICE: And also, I think it's part of the ableism around us that a lot of people just presume that filmmaking as a activity is difficult and inaccessible. So, of course, people with disabilities can't be filmmakers. And there are a lot of people now with disabilities who are making their own films, whether it's on YouTube, on social media, or in actual documentary films like you two. So, how do you, I guess, encourage more people who are disabled who are interested in filmmaking but somewhat hesitant or intimidated? What would be your advice?

JEN: I think so many times, what prevents anyone—whether it's a person with a disability or you know, a woman or a man or really anybody—from becoming something that they might want to be is that they can't even imagine it for themselves. It doesn't even occur to them to dare to dream the dream. And I think sometimes the dreams that are hardest to dream are the ones that we don't already see out there for us as models and as examples. And I think that a part of why you don't see more people with disabilities making films is because people with disabilities aren't making films. And so, they are making films, but they're not visible, right? And I think that's what I worry about the most.

And so, if a part of the logic of, "Well, we don't host panels about this because nobody cares because there aren't people making films," it's sort of this chicken and egg vicious cycle thing. And so, I would say that be conscious that you are gonna have to forge your own path both within the community of filmmakers as well as for yourself, whatever your specific disability is or constraints are. But that I think we live in a time now where the world is much more receptive, and the technology that exists allows you to make films in ways that maybe you could never make them before. I was bedridden through almost all of production and directed using Skype and remote feeds and every technological hack I could find. And you'll be able to reach audiences in a way that you wouldn't have been able to have before. So, I think I would offer that hope but to understand also that it's not easy.

And I think part of how we get there is by forming community and forming fellowship. And as I've gone and traveled with *Unrest*, I've met filmmakers and also actors and other creatives with other disabilities who come out and see the film, and in some ways, I don't know, who'd almost given up on storytelling because they didn't know quite what to do or how to do it. And so, I think there is a need for more fellowship so that artists with disabilities and filmmakers in particular can connect with each other and share stories and share strategies. So, I mean, Jim and I do that for each other, but it needs to be you know, it should and needs to be a much more organized and, I think, bigger group of people having these conversations.

[plucky synthesizer music]

Wrap-up

[hip hop]

This podcast is a production of the Disability Visibility Project, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes including text transcripts are available at DisabilityVisibilityProject.com/Podcast.

You can also find links to the documentaries by Jen and Jim on our website.

The audio producer for this episode is Geraldine Ah-Sue. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

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Thanks for listening and see ya on the Internets! Byeee!!

♪ Blast off
Stop drop dance off ♪