

## Stories from the brainreels transcript

October 10, 2014

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

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### Introduction

CHERYL: Today is a really exciting and unique day. I'm doing a mini-cast. That's exciting and unique because I've never kept one of my podcasts under 30 minutes. Often, they're a full hour. Right now, my co-director and co-producer, Cynthia Lopez, and I are running a [Kickstarter campaign online](#) to raise money to edit and polish our film, "Who Am I To Stop It." What can be challenging about a project like ours is that people are really not used to supporting movies about disabled people that are actually made by disabled people. It's hard to explain, but even though I so hugely value that I bring my own TBI experiences into making the documentary about other people with TBI experiences, I'm not totally sure everyone does see that as inherently valuable. What I wanted to do today is bring on a guest who has direct experience making a disability documentary. Jane Hash is a blogger, podcaster, activist, and real disabled person. Today we talk about some of the overlaps in the ideas behind her film, "[Plain Jane: The Shockumentary](#)" and my film, "Who Am I To Stop It." Enjoy the show, and please support our independent documentary on Kickstarter through October 31st, 2014!

CHERYL: I'm gonna have you on again, on another episode later on where we can spend much more time talking about your work and your freak shows and all the activism that you do. Today, I wanna talk about documentary film.

### Plain Jane: The Shockumentary

JANE: Sure. My name is Jane Hash. It really is my name. My mom was not a pothead. I wanted to make a documentary about how I became who I am. And I had no idea how to do it. So I just kind of made it up as I went along. The first step was one of the most challenging ones, and that was finding a videographer that saw what I saw and didn't want to use me to tell their own story or to make something up. Because my life experiences have been so unique and diverse, I don't feel I need to make anything up to have an impact on people.

CHERYL: I'm sort of focusing on disability today. But I see you, and other people with disabilities, as much more than your disability. But I'm sort of focused in on that concept today. So I'm just gonna erase all the other parts of you just for today, if that's ok?

JANE: OK.

CHERYL: OK, great.

JANE: That's fine.

CHERYL: [giggle] Your documentary, it's not just about disability. Because disability is part of your life, it's part of the documentary. But we see you as a complete person and all these different sides of you.

JANE: A lot of disability-centered documentaries are so clinical and ick. I'm not a patient.

CHERYL: And it's something I hear a lot in my community too where for the rest of our lives, we're called TBI patients. I have a lot of friends also who are not in rehab and are not currently waiting for another brain surgery, and they're called patients in their daily life. In your documentary, you definitely show some footage of you going to the doctor several times. But you don't have a doctor stare at the camera and say, "Jane's condition plays out like this. And there are this number millions of people with this condition." And I find that so many disability documentaries have that clinical part of them.

JANE: No matter how much awareness or activism or any of that hocus-pocus that we do, there is going to be a percentage of people that only recognize our disability. I don't know why, but that's all they will ever see. And I don't think much is expected of us. I mean, just based on legislation alone, if you are born with this degree of physical limitation, and your family is at a certain income level, then you are permanently put in this tiny box where you're not allowed to get a job. You're not allowed to do jack shit, or you will lose the care that keeps you alive. So that tells me that not a whole lot is expected of us. So just, we won't put you in a Gulag, but we'll just put you over there.

CHERYL: That happens in my community too, of people who acquire a disability from a brain injury. It's these different ways that people have of keeping you in poverty, and people don't question it.

CHERYL: Your movie is called "Plain Jane: The Shockumentary." And I love that. Tell me about that name.

JANE: The working title was "Plain Jane." And then, when we started editing, we realized this is not a regular documentary. But we didn't wanna lose the huge following we had acquired

during the making of the movie. So you know, it is a bit shocking to some people. So that's how we came up with keep the "Plain Jane" but let them know that it's not a family movie.

CHERYL: It sounds like it's kind of just practical in nature, but it creates such an amazing contradiction. Now, the things that you show in your film that are shocking, do you think they'd be shocking if a non-disabled person was doing and showing them?

JANE: Maybe the waxing scene.

CHERYL: Yeah. I agree.

JANE: [giggle] I enjoy watching people watch the movie because seeing huge, bad-ass biker guys cringing and covering their face during that scene just amuses the shit outta me.

CHERYL: Again, another contradiction that's so pleasing. But a lot of the other stuff that you do, I don't know. Maybe I've just been around the block. It wasn't grotesquely shocking. But I felt, when I was watching it, like I bet that a lotta people don't think people with disabilities get their nipples pierced or drink alcohol or go to parties and have a lot of friends and have a sex life. And so there's a part of it where it's so everyday and yet so not everyday at the same time.

JANE: I think that's the shocking part for the average person in the audience, that I'm just a person. Like if it was a clinical where you got to see me get a cast off of a broken leg and bruises and the gruesome parts, that would not shock them because that is their expectation. But the fact that the movie does not even come close to what is expected is what's shocking.

CHERYL: Yeah, yeah. Absolutely. And I do hear that in response to what I've filmed so far. People are shocked that we have not recorded any of the people in the movie talking about how they got their brain injuries. And that's what shocks people. Whereas, from where I stand, I feel like ooh, those details are very shocking, very intimate, and vulnerable. It's really up to each person to tell their story. A few people we have in the documentary really love to tell the story of how they got hurt. They have no issues around privacy or objectification around it. But we didn't record it for this documentary for what you said: because people expect it. And so I don't want to just let people be lazy and get their expectations for oh, disability documentary, and then just have their expectations met and just leave. I want people to question what they saw.

JANE: Right. And I think the way you're doing that will hold their attention cuz when they start watching your movie, they're gonna go into it with this mentality, oh, I can't wait to see how they got fucked up. And they wait and they wait for it. But while they're waiting, they see a different perspective.

CHERYL: Yeah! And they meet an actual person. It's gonna be nice.

JANE: Yes.

CHERYL: Yeah.

JANE: What was your favorite part?

CHERYL: What I love the most about it is the unabashed, unapologetic kind of normalness. Hey, this is what I do! Watch. I really love the scene where you're in the car asking for a drink. I LOVE that scene. What's neat about your documentary is that it's very much a hybrid documentary. So you've got some real life, everyday footage, you've got some interviews, you've got re-enactments of stuff, you've got fantasy. I mean, it's such an amazing mash up of styles. But the scene where you are in the back of the car, demanding a drink and then demanding to drive so you can get your drink.

JANE: [laugh]

CHERYL: And then, before you know it, the person in the front seat is actually blending you a drink. And in that moment, you remind people you're an adult of drinking age. You are an adult and a person who has the right to demand, "I'm thirsty. And I want this now." You've got this person at your beck and call, which is hilarious. And just the notion that you would suggest that you would drive. Do I remember correctly, you're in like a child-sized car seat?

JANE: Yes!

CHERYL: Which just adds to the hilariousness of it!

JANE: [laugh]

CHERYL: I'm like wait. She's in a baby seat, asserting the most adult thing. "I demand a drink."

JANE: [laugh]

CHERYL: But you don't question yourself. It's such great acting. You don't question your intention. Well, of course I should be driving and all this. I love that scene. And frankly, I remember when I watched it, that in between scenes, very, very many times I thought, oh that was the best scene. Oh no, that was the best. I think it's a brilliant documentary. And it's so funny. It's so not tragic. It's so not inspirational and overcoming. And lemme tell you one other thing I love about it: when you presented at the prison, you talked about--on your blog--how what you loved is that the people you presented to treated you with dignity and respect. And I love that you assert, "I'm gonna make this movie where you see me getting waxed, you see me getting my nipples pierced, you see me doing all these things and drinking. And I deserve dignity and respect." That to me is such a needed, amazing message. Don't discount me for any reason. I love it.

JANE: Thank you, thank you.

CHERYL: No, thank you for making it. Make more. I hope you make a sequel.

### Using documentary to shatter stereotypes and reject tropes

CHERYL: In your documentary, which I've seen, and in my documentary, which is not done yet, that one of many goals with the films is to get away from the tropes and disability stereotypes. Let's have a little speed contest and see, in 60 seconds, how many of those tropes we can come up with that we're trying to shatter. OK.

[bell rings]

CHERYL: Disabled people as inspiration.

JANE: Barf. It so makes me throw up in my mouth.

CHERYL: Yeah, it does. Disabled people as incompetent and can't make their own decisions.

JANE: Oh, I get a dose of that almost every day.

CHERYL: OK, uh, somebody has a physical disability. Therefore, their brain doesn't work.

JANE: Oh, of course. Duh. That's a no-brainer!

CHERYL: [laugh] Lemme see if I can come up with one more. I just have to speak for you and help you, period.

JANE: I love that one because you know, a perfect example of this is when I'm interviewing PCAs. I'll call them on the phone, do a phone interview. If they pass that version of the competition, then they move on to the face to face interview. And I always wrap up these interviews by asking, "Do you have any questions of me?" Because if they get the job, then there's things they need to know about me. And every now and again, I will get one that says, "Well, how am I supposed to know when to feed you?" [laugh]

CHERYL: It's so interesting that these people you're talking about don't believe that you know when you're hungry and that you can say, "Hey, let's make some lunch."

JANE: And like after what, two hours of communication between the phone and face-to-face? After all of that, they can't decipher that if I'm hungry, I'm going to let them know?

CHERYL: Yeah, by speaking--

JANE: [laugh]

CHERYL: --going into the kitchen, sending a text, whatever. There's a lot of--

JANE: Yeah!

CHERYL: That speaks to that deep-seated, deeply ingrained ableism, that belief that if you need any kind of help or accommodation, you need it across the board, and you couldn't possibly communicate in a conventional way even though you just did for two hours. In my world, what I hear--and I hear it a lot--is things like an acquired brain injury, a severe one, much more severe than I've ever had, I hear people say that it turns people into a child again. And that one's really hard for me to take. And then you hear like degenerative diseases like Alzheimer's, people revert to a childlike state. And I think people don't mean to be insulting. But an adult is an adult. And there's no other situation where an adult becomes a child. There's no situation where an adult becomes a child. And I understand that some people with a severe TBI and a coma, they have to relearn basics like eating, talking. Sometimes people will come home and not recognize their own house and get lost in it. I think you show a lot more respect if you look at that person as an adult with a brain injury who's lost.

JANE: Yes, absolutely.

### **Family members in documentaries**

CHERYL: So one of the things I did in my documentary was, there is no footage of family members giving their opinions about the people in the film. Now, the family members who are in the film, love the person with the brain injury. Like we have some moms and aunts and cousins and stuff. And they actually don't see their loved one this way. None of them describe the person with the brain injury as childlike or inferior. But even though they are so respectful, we still don't interview them talking about the other person because then, we would be giving this statement that people with brain injury don't have agency and can't tell their own stories.

JANE: Right. I did let my mom and my aunt have a few minutes of camera time because regardless of anything that came out of their mouths, I know once people are starting to get to know me, and they forget about the whole disability factor, they're like, "How the fuck did she get so weird?" And seeing just a peak of the diversity of the two main female influences in my life--you know, at least for the first half of my life--I think that may answer a few questions. Because neither of them were acting.

CHERYL: Oh my gosh.

JANE: That is [laugh]. See, I didn't even recognize, during that shoot, how weird it was until I saw the scene through the videographer's eyes, if that makes any sense.

CHERYL: It does. Because then you stop and say, lemme get some distance. What do people who don't know me yet see this as? Yeah, yeah. Have you seen brain injury documentaries before at all?

JANE: I never made it through an entire one. I did do some research on YouTube because I have family members with different degrees of brain injury. And I do a little research when I'm going to have an interaction, just wanna make sure I'm doing the right thing, being helpful in ways that are appreciated and not like, "Oh! Let me do this for you." Because I hate that shit, you know? Just to learn about what they're going through so I can be more sensitive to that.

CHERYL: Yeah. Why not go out and get some information? I'm curious what it is about the ones that you haven't finished--which sounds like all of them--what it is about them that makes you not be able to finish them?

JANE: The clinical non-human aspects. I don't wanna see what your brain looks like. I'm cool with that. I don't wanna see what the inside of your brain looks like, you know? I have seen what my family members looked like hours after they sustained their injuries. Those images will be burned into my brain forever. I'm stocked up. I don't need any more.

CHERYL: Well said.

### **Focus on awareness-raising and "experts"**

CHERYL: In my community, awareness-raising is a really big thing: this is how many happen, this is what the symptoms can be, this is how recovery goes. And I feel like the actual human gets lost in all that awareness-raising.

JANE: Uh-huh.

CHERYL: Yeah, cuz we're still so much more than our brain injuries. Even the person who has severe physical and cognitive and communication impairments is still a person and still has other things about them that didn't get erased by the brain injury. And yet, I think a lot of those films--the kind that you can't get through--they erase the other parts of the person.

JANE: They do.

CHERYL: Some people have told me that they feel so far, my documentary is missing something. And the things that people have told me are missing are stories about how people got their brain injury, like you know, describe the wreck; family members and other people talking about the emotional and mental challenges of the person with the brain injury; and just a general, over-arching sort of sensational, inspiring story. And it intrigues me.

JANE: So basically, they're saying, "Dance, monkey, dance! Entertain me!"

CHERYL: Yes, yeah, yeah. And it is so interesting that people feel so entertained by hearing painful details and hearing what's wrong, what's wrong, what's wrong? And I told somebody, you know, we're not interviewing the family and asking them to describe the person's

challenges, 1) because that's still like getting the expert's opinion, and 2) uh, we're not focusing specifically on people's mental and emotional challenges. We're filming people.

JANE: I love that you brought up the experts because I am the expert on me. You are the expert on you. And anybody else who thinks they are an expert on us is on some delusional ego trip.

CHERYL: I think it comes a lot of the time from if you have a disability or an impairment, and you're interacting with providers, they went out and got specialized training to deal with "someone like you." But I feel like disability and illness are the only times that we face people who tell us that they know us better than we know ourselves.

JANE: Exactly.

JANE: The documentary that you're doing is so unique and so worthy of support because it doesn't perpetuate stereotypes. And we need more of that. So everybody needs to go support your Kickstarter fund so we can get more real-life media about people with disabilities. So go, support it, \$5, \$10, whatever. Don't go to Starbucks today. Save those \$50 that the coffee costs, and support "Who Am I To Stop It."

CHERYL: All right, Jane, thank you so much.

JANE: Thank you. You too!

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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 [www.WhoAmIToStopIt.com](http://www.WhoAmIToStopIt.com).