

Stories from the brainreels transcript

January 23, 2015

[music]

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.

[music]

Hello!

Well, hello podcast listen-iverse, today it's just me, no guest. I just wanted to take a little time to fill you in on how things are shaping up for 2015 and what you can expect this year from over here at Stories from the brainreels and Who Am I To Stop It. The first piece of news is that "Who Am I To Stop It," our feature-length documentary on artists with brain injury, we have completed the first rough cut, which is the first kind of rough draft version of the film. Our editor, Emily von Gilbert completed that a few weeks ago. And Cynthia Lopez and I have had the opportunity to review it and give her notes back. And she's hard at work now on the second rough cut of that. We're super excited. It's turning out really beautiful, thanks to the fantastic footage from our Director of Photography, Paulius Kontijevs and our sound recordists Shawn Willis, Esteban Ortiz, and Cassie Cohn. We were really lucky to have all of them. Unfortunately, I think we might even be using some footage that I took. And I say unfortunately because I'm really not a master camera operator. But sometimes, in these independent productions, you gotta fill in and just sort of meet the challenges as they arise. The stories are really taking shape, and we're super proud.

Accessibility in "Who Am I To Stop It"

What's happening at the moment, while Emily is editing, is that Cynthia and I are doing outreach and marketing and trying to get the word out about the film as well as find maybe potential sponsors who can help us fund the accessibility pieces for this movie. It's not super common, still, to provide accessibility like Closed Captions and especially not Audio Description. I think there's still a mistaken belief that blind people or non-visual learners or people with vision impairments don't go to the movies or don't want to go to the movies. But that's just not true as a whole. You really can't tell who likes movies and who doesn't like movies. And so what we are doing is we are building in accessibility from the beginning. Rather than completing the film and then figuring out uh-oh, do these captions cover somebody's face, or oh, these scenes change too fast. We can't audio describe that. We're not going that route. We had Paulius keep in mind, when he was filming, that there would be captions at the bottom of the screen. So he always knew to try to avoid having people's mouths talking at the very bottom of the screen, to the best of his ability. Of course, you never know where someone's gonna

move to and what they're going to be doing at any given moment in a documentary. But he kept that in mind. And while Emily's editing, she's keeping pacing in mind so that things don't move too quickly. There's breaks between scenes. Not that the screen will go black, but that there might be some silence or some slowing of the pace that gives time for the Audio Description to occur. Now, when you watch this on DVD, you'll be able to choose whether to play the Audio Description or not play it. So it's not like it's there all the time, and it will be distracting people who don't want or need to use it. But it's there as an option. And we're accounting for it in the editing process. We're accounting for it before the product is finished because I feel that building in accessibility is just as crucial as beautiful footage and beautiful audio. It's not an afterthought. And it's not optional. So we're hoping that these two pieces-Closed Captions, with the black background behind them so they're very readable-and Audio description, we're hoping that that really can broaden the audience for who is going to be able to access and enjoy this film. And also to just show the world that it's, yes it takes money and it takes time, but it's not hard to build accessibility in if it's part of your philosophy. Which is something I'm reading about in a book called "Digital Outcasts." It's a really good book. And it really talks a lot about the philosophies of why, in our capitalist society, it is so difficult to get people to make things accessible or make them with Universal Design in mind, but that there are real ways to do it. And if we wanna build things accessibly, the people we should be going to consult are the people with access needs. Going directly to the source: what is the problem you have, and how can we make this website fit or make it accessible? Ask the people who have the access needs because they're the experts in it.

Brain Injury Connections Northwest, Ginnifer Mastarone, accessible websites

Which leads me to another, but very related, piece of news. It'll sound like a sidetrack for a moment. But it's not. Some of you might be familiar with BIRRDsong, Brain-injury Information Referral and Resource Development, and then the song. Well, you can't have BIRRD without song. So BIRRDsong is a non-profit that started in 2004. It was founded by some peers with brain injury and their very close family members. It was always a survivor- or peer-driven organization. And just last night, the new Board unveiled a new name and sort of new branding, new mission, new vision. It's now called Brain Injury Connections Northwest. It's no longer really peer-led. Most of the people on the Board are not survivors of brain injury or their close family members. But I still have faith that this organization is going to continue to do very fine work in the community. I hear the responses of people who participate in the organization and what a meaningful, valuable home Brain Injury Connections Northwest really is for people. And it's very focused on action. So it's not so much about writing policy or making legislative suggestions. It is providing direct access and service to the community. One of the most wonderful things that Brain Injury Connections Northwest does is they hold-as far as we know-the only Spanish-speaking support group in the state. And that is something to be extremely proud of. Disability movements in general tend to be very white-dominated. The brain injury community-when I participate online and in person, it's still very white-dominated. And so it's a wonderful thing that Brain Injury Connections Northwest, or when it was called BIRRDsong, they made this commitment to serving more than just the white, English-speaking community. So last night, there was a big event to celebrate 10 years and to unveil the new name and the new branding. And part of the presentation was delivered in Spanish and in English, which was really exciting. And here's the connection to "Digital Outcasts." There's a PhD student in Communications named Ginnifer Mastarone. You're gonna hear her on this

podcast in a few months. She's doing a research project about accessible websites for brain injury information. And she has some of her students working with the team, building the new Brain Injury Connections Northwest website so that it will be accessible and very much useable for people with brain injuries.

Typically, in the world of accessibility, when we talk about accessible websites and accessible documents, we're talking about making things accessible for people who use screen reader technology or maybe who have a vision impairment, and they need high-contrast, low-distraction on the page. But rarely is neurodivergence and neurodiversity and cognitive or intellectual impairment, rarely are those included in conversations about accessible technology outside of those specific movements or communities, such as the Autistic community, the brain injury community, etc. What's really exciting is that Ginnifer, although she doesn't have a brain injury herself (her mother-in-law has impairments from brain injury), Ginnifer deeply understands Universal Design and deeply understands cognitive accessibility. So high contrast is one part of that. But flashing advertisement, confusing links and breadcrumbs that are ten links long, organizing things in a way that maybe your average person doesn't mind, but a person with a brain injury gets lost and lost and lost over and over, she's got those things in mind. And so I think this new website-I haven't looked it up because I don't know their URL-I think this new website is gonna be really a powerhouse and a model for the community in terms of making things accessible. Because why would you have brain injury information online if people with brain injury can't access the information because the website's confusing or roundabout or filled with flashing advertisements and what have you? Now, granted, 50% of people with disabilities don't have reliable internet access. So you can make things as accessible as you want. But if people don't have the resources to access, they're still not going to access. But that is not an excuse to skip accessibility. So I'm super excited that Ginnifer is working on this.

And part of her working on this was to do a research project where a bunch of got together with her one at a time and walked through different tasks on a website to see what was hard and what was easy, what was intuitive, what was a barrier for different kinds of users with different brain injury impairments. As far as she's found, no one has done that yet. And I've been harping about it on my blog for a really long time. I'm excited that someone else has taken up the torch and is doing an outstanding job of that. So she'll be on this podcast in a few months to talk about Universal Design and accessibility in technology, looking really at cognitive impairments and brain injury. But also, we'll probably be talking about race and class because that is also part of what makes a group of people digital outcasts, is not only that websites are inaccessible to certain people with certain disabilities but also in terms of class. If you can't access the internet reliably or don't have a computer or can't pay the fee or don't have ID and so you can't get a library card to use the computer for an hour at a time, you know, all of these things play into what makes a digital outcast. I'm looking forward to having Ginnifer on a few months from now. Seriously, I can't remember exactly when she's coming on. But I believe it will be in the Spring.

My work in media accessibility

And I also wanted to talk about the ways in which I'm branching out my work. So there's "Who Am I To Stop It," the feature-length documentary focused on isolation, art, and transformation after brain injury. There's that. And that will be coming out in a few months from now as well. Which I just realized my

screw up my podcasting schedule. The release of a feature-length documentary is probably gonna take up a little bit of my time. I'm glad I'm thinking of that now. It's always good to plan ahead. I don't think I would've thought of it if I weren't sitting here, talking to someone else. So thank you, podcast listeners, for being there for me. But as "Who Am I To Stop It" wrapped up, and several of my shorter films projects wrapped up, I realized that I have a lot of passion for things around access, and not access just for access' sake, but for the sake of justice. Because we can't have social justice when people are excluded from conversations about their own lives. For instance, digital outcasts who simply cannot even access materials online, here in the middle of the Information Age, because the information is not presented in an accessible way or an accessible format. I'm finding that this is really turning into a big passion of mine. I always have made Closed Captions for my films. And some of my films have Audio Description. But what I've started doing lately, quite a lot this year, is transcribing and creating Closed Captions for artists and activists and filmmakers and people working in higher education when they're doing trainings. So I wanted to put that out there too, that one of the things I'm really focusing on this year is doing more access for others. And so if you go to my website, storyminders.com, I have a tab called "Access." And if you scroll down to the bottom, there is a link that takes you to the disability access services that I provide and a fee sheet. And I'm really excited to be doing this more for other people, and that is transcribing podcasts so that you have a written version who people aren't accessing the audio version, transcribing video-and I'm hoping this year to learn how to make interactive video transcripts. Those are supposed to be very good for your SEO. And I'm doing a lot of Closed Captioning for other people. And I've also started really working on making accessible pdfs. Now, pdfs look so beautiful and look so clean, and you think oh, surely anybody can access this. But there are a lot of steps to take to make a pdf accessible to someone who is using screen reader technology. And screen reader technology will, a computerized voice will read what's on a computer screen or will output it to Braille. You have to do a lot of things on the backend so that screen reader technology can access the pdf, or Microsoft Word document, whatever it is. So it's very common to have articles and all sorts of things uploaded all over the internet in pdf or document format or images. But if they're not made accessible, then you're creating digital outcasts, and you're leaving people out of your information. And I like to think well, if your information is so good that you want people to know about it, wouldn't you want all people to know about it?

I wrote an open letter to TEDx months back when the late Stella Young did [a presentation for TEDx in Sydney](#). And she is a very famous, very prolific disability activist. And her presentation wasn't captioned. So I wrote an open letter. You know, the TED logo is "Ideas worth spreading." But you really, you don't wanna spread them to everyone? And I don't think it's that. People don't say, "I refuse to be accessible because I don't want people with disabilities to have my information!" The truth is, the disability communities are not considered audiences, they're not considered a market segment, they're not considered experts, and they're just simply not considered in general, in the mainstream. I've had many people tell me that my films don't give audiences what they want. But when they tell me what those things are that audiences want, those are reflective of non-disabled, typically middle class white people. And that is not necessarily my audience, or it's not my only audience. I would like anybody to watch my films. But I want people to understand that there are other, completely valid audiences and groups of people with lived experiences that are not being reflected and not being catered to in mainstream

culture. And so that's why making things more accessible is so important to me. Because I wanna get it out there more and more that by not even considering different disability communities in your work, you are excluding them. So every film that I've put up that doesn't have Audio Description, I am excluding blind and low-vision communities from watching my films. And I am aware of that. And I'm working to remedy that. Captions are a lot easier to do. And I've done a lot more captions than I have Audio Descriptions. I'm aware of that shortcoming in my work. And I'm working on it. I think what's important is for people to be able to, with pride, acknowledge that they've missed something and acknowledge that they've missed thinking about an entire group of people. And then, the next step is to then think about them and include them.

So that's what I'm doing now. I'm still working on transcribing past episodes of this podcast. In the meantime, I'm also, one by one, taking the transcripts that are there off the website, reconfiguring them so that they're actually fully accessible to people using screen readers, and putting them back on. That is taking a lot of time. I'm very slow at it. But it is happening. And it is going to continue to happen. And for anyone out there who's got video that you want captioned, audio or video that you want transcribed, pdfs or any kind of materials that you want made in an accessible format so that you know you're being inclusive, I can be of support. So like I said, on my website I do have a sheet with my rates on it. But I'm very open to negotiation, especially in terms of supporting the disability community.

Thank you!

And lastly, I just wanna thank everybody for listening. There was a lot of transition as I first did this podcast as a streaming radio show on BlogTalkRadio. And the audio quality was really, really terrible and made more terrible with uploading pre-recorded audio. And I transitioned to more of a podcast format on [iTunes](#) and on [Stitcher](#). And the audio, hopefully, is really improving with that. And I hope to continue to improve the audio quality and the accessibility of these as well as bring you a more diverse range of guests and topics. The podcast is also becoming available on Soundcloud: soundcloud.com/storyminders if you prefer to access it that way. There are audio recordings of all the blog posts on that same Soundcloud account because I know some people who are not strong readers but who don't use screen reading technology. They have trouble accessing my blog posts. So I audio record them and post them on Soundcloud. They're also available on the blog at WhoAmIToStopIt.com/blog.

So hopefully, if you're enjoying these episodes, you will subscribe on iTunes or Stitcher or follow me on Soundcloud so you can keep up with all the new recordings and episodes that are put up there. You can always reach me at info@storyminders.com. The website is WhoAmIToStopIt.com, named after the movie, "Who Am I To Stop It." And I do hope that you'll be in touch. Let me know what you think of the podcast and the blog. Definitely let me know if I'm not accessible enough, and you need me to make alterations to the podcast or the blog itself or the website that will support more access. Please let me know of those things. I have no pride around it. If there's more that I can be doing to be more inclusive, I really want to do it. If there are topics or guests who you recommend for this podcast, do let me know. It's not so much a place where I have folks on to tell the story of how they got their brain injury, although that has happened in the past. Sometimes that information, while it's interesting, can be very upsetting and triggering. So that's less of what you'll find here. It's more social critique and commentary and political and activist discussions.

So with that, I will wrap up this mini-cast. Coming up in February, you'll hear Jared Franz and Keith Scholz talking with me about transit justice. They're with [OPAL Environmental Justice Oregon](#). After that, I will have Zach Richter, Joshua St. Pierre, and Erin Schick, from the [Did I Stutter Project](#). We'll have Ginnifer Mastarone talking about cognitive accessibility and technology. And that's just a small taste of some of the upcoming guests we'll have over the rest of the winter and into the spring on the Stories from the brainreels podcast. Thanks so much for listening again. Check me out on iTunes, Stitcher, and Soundcloud. And be in touch any time.