You First Episode 23: Disability Media Representation

Announcer:

Welcome to You First, the Disability Rights Florida podcast.

Keith Casebonne:

I'm Keith Casebonne, and welcome to this episode of You First. Before I introduce today's subject, I want to remind you to subscribe to the You First podcast. Each month brings a new episode and you should subscribe to catch them all. Search for You First where you get your podcasts and subscribe today. You can also find us at disabilityrightsflorida.org/podcast. Today we're talking about the representation of people with disabilities in the media, movies, TV shows, streaming media, and whatnot. I think the best way to introduce this topic is to read a quote from Lawrence Carter-Long, an activist and performer, from a piece he wrote in 2019 in Film Quarterly.

Keith Casebonne:

"Once upon a time, disability was just a diagnosis. That's all you got, something to be fixed, cured, cut out, or gotten rid of. Through time the definition has evolved to mean much more. Nearly three decades after the passage of the Americans With Disabilities Act, ask anyone with a disability who politically, culturally, or artistically embraces the rebellious act of being disabled what the world means to him or her, and you'll most likely hear back words like community, constituency, and identity. No handkerchief necessary, no heroism required. By any definition, that's progress. But if we are to expand a deeper meaning beyond the flock, these changes must be reflected in the movies we make, the films we watch, how we watch those movies, and perhaps most importantly, who gets to make them."

Keith Casebonne:

To talk with me about this subject today are my guests, Doctors Beth Haller and Jeff Preston. Beth teaches disability studies and media studies at Towson University in Towson, Maryland, is the co-editor of the Routledge Companion to Disability and Media and the author of Representing Disability in an Ableist World: Essays on Mass Media. Jeff teaches disability studies at King's University College at Western University in London, Ontario, and is the author of The Fantasy of Disability: Images of Loss in Popular Culture. Beth and Jeff also coauthored the chapter "Confirming Normalcy: Inspiration Porn and the Construction of the Disabled Subject" in the book Disability and Social Media: Global Perspectives.

Keith Casebonne:

Thanks, Beth and Jeff, for being the guests today. Let's start with, at the time of this recording, a very recent and controversial subject. Music is a new movie by musician Sia that portrays a child with autism who is non-verbal by an actor who is not a person with autism. Several media sources have panned the movie, Salon having a particularly strong reaction, calling it a "baffling and patronizing cringe-fest of ableist minstrelsy." Disability rights organizations have declared the movie dangerous and referred to it as a film that should never have been made nor should be shown. Strong opinions indeed, and I'd like to hear yours.

Beth Haller:

Yeah, I'd like to point out that that article in Salon was written by an autistic writer.

Keith Casebonne:

Yes.

Beth Haller:

So we're getting both criticism from the disability communities and it's been panned royally by lots of just non-disabled movie reviewers. So something is going on here where the Foreign Press Association, which decides the Golden Globes, has a very different understanding of what an authentic movie should be. I'm still wondering why this movie that's been universally panned by both the disability community and the movie review world got a Golden Globe nomination. And I must say that I feel like everything that Sia has been doing is not very sincere. She's putting up a warning, she's apologizing, but she was having outright fights on Twitter with autistic people in the early days when they were complaining, rightfully complaining.

Beth Haller:

And I want to point out too that non-verbal autistic people have created a fabulous film called LISTEN. And it basically just talks about not just Sia's film, but everything that tries to portray them without ever even meeting them or asking them or finding out what their lives are like. So in one sense yes, it's a nightmare, but this is how things happen in the disability media world. We have something really bad blow up and it ends up being kind of good in the end because a lot more people become aware of the topic of authenticity film. And we can go back to Million Dollar Baby and see what a nightmare that was for the disability community, but we didn't have social media back then. So now with social media I feel like we can build allies in the non-disabled community, and her movie is toast because everybody now sees how bad it is.

Jeff Preston:

I think what Dr. Haller is saying is that the real film are the friends you make along the way. I think Sia's film Music hits the trifecta of do-nots when it comes to disability film and media representation. You have a non-disabled person who says, "Hey, I have an idea. What if I use disability as a means to tell a story?" Not to have a story with disability, not to tell a story about disability, but rather to use disability, as Mitchell and Snyder would say, this narrative prosthesis, this convenient little tool to inject to derive a certain response, whether it is emotion, whether it is happiness or sadness, and then, "Let's not have any real disabled people involved in this process."

Jeff Preston:

I know that Sia has stated that there was an autistic person that was hired originally. I find that extremely hard to believe, given the fact that the woman who ends up playing the character is an actor that Sia has worked with, or a dancer that Sia has worked with throughout her entire career. I have a very hard time believing that she was not thought to be the main target for this role from day one. And then finally, Sia then committed the final mortal sin, which is, when people start to call her out on it, she fought back. She doubled down. There was no real attempt to understand what the problems were. And it's like I'm amazed at how big Sia's mouth must be because I think she's managed to shove four or five feet in there throughout this entire time. It's pretty incredible. It's like what not to do when confronted with these issues.

Jeff Preston:

But I think, to Beth's point around the Golden Globe, I think this speaks to the broader issue, which is that awards season seems to think that disability is a really important check box when it comes to awards and films. That if you're representing disability in some way it's somehow edgy, it's somehow vital, important, emotional, that it hits all these levels that we wouldn't put generic top Hollywood films.

It's not the type of thing you're going to see in a Star Wars film, for instance, although maybe you should. I really honestly imagine that the Golden Globes, they probably give this a nom because they didn't even bother watching it. They were just like, "Oh, it's about autism? Yeah, that's going to be a winner. If Rain Man, if all these other films have done it, this one surely is worth consideration."

Jeff Preston:

Which just shows how the industry, I think, fundamentally doesn't understand what people with disabilities have been saying. It's not that we want you to just recognize any representation of disability, but rather we want you to actually honor and cherish the really good work that are telling real, legitimate, honest stories about disability. And those stories are predominantly done by those who have disabilities.

Keith Casebonne:

Well, and Sia's movie is just a recent example of this. As you guys have already mentioned a few of them, Rain Man, Million Dollar Baby, this has gone back quite a while. What are some of the bigger issues in recent years as far as disability representation goes in movies? And why do you think this is even done this way?

Beth Haller:

I would like to talk a little bit about Rain Man, because I think it's a more complex issue because it's so old now. What was it, like 1988? And if you've read Steve Silberman's book NeuroTribes, he has a whole chapter about Rain Man. And I think back then, not like it's ancient history or anything, but still, there weren't the networks, there wasn't even the web, to find disabled actors. So I think that was ... Yes, Marlee Matlin had a hit right before that, but it was just the beginning of acknowledging disabled actors. And so I think on Rain Man they did actually, Dustin Hoffman met with the real person, his name was Kim Peek, I think he was from Colorado, who he was portraying. So there was that at least. And in the Steve Silberman book, in NeuroTribes, he talks about the importance of this media image, because it was a first time people around the world, not just in America, saw a person with autism represented.

Beth Haller:

And so looking back on it with our eyes now, it's horrific to us. But back then it was actually giving voice to somebody and giving a representation. Even though it was a very kind of high-level stereotype and distortion, I don't even know if you'd call it a stereotype because we didn't know what autistic people were really like in the media representations at that point. And so it has this back story that started us on a path that we could have gone down a good path in terms of representation, but unfortunately went down a bad path in terms of representation. And apparently, according to his book, families saw that movie and said, "That is what my child has." And doctors have been notorious for not diagnosing people and not even understanding autism, it's that recent, and even the word autism didn't really exist until the mid-20th century.

Beth Haller:

I have a friend who's in her 80s that has a younger brother who's autistic. They grew up in Omaha, Nebraska, and there was no word for her brother having autism, so her parents didn't know what to do, because he was non-verbal at that point. So they sent him to the deaf school, even though he wasn't deaf, and he learned sign language and then he started communicating verbally. So people were out there not knowing anything about autism for so many decades and there was so much bad information perpetrated by bad doctors too, which Steve Silberman covers in NeuroTribes. So I think that is a particularly unique representation that had a lot of information in general. It was giving people, even if it was just representation of one person, it was still a representation that needed to exist. But like I said, they could have gone down a path where, "Okay, next time we do a story about an autistic person we'll use an actual actor with autism," or have more consultants or whatever.

Beth Haller:

And I always tell my students that my particular problem with the inauthentic representation specifically of autistic people is, to me it sounds horrific. The way that actors who aren't autistic portray autistic characters, it sounds like they're mocking them. Even when you have something like Claire Danes who, Temple Grandin gave the okay for her biopic on HBO, and Claire Danes and Temple Grandin was on set and she had total access to her. When I saw the trailers for that when it was first coming out I was like, "Oh my God, what is Claire Danes doing?" And so even when you have 100% approval by the person, it just comes off to me as mocking. There's no two ways about it. When you have somebody that has not lived in that experience, they don't know what they're doing.

Beth Haller:

It's not just learning how to wheel a wheelchair. It's not a physical movement. It's portraying somebody's brain, and you can't portray somebody's brain when you're not using that brain. There's a show on TV, we'll probably get to TV a little bit, but it's doing so much better job because they have the ability to right their ship really quickly if they're doing something that's screwed up. And so now there's a new show, I think it's called Everything's Going to Be All Right, and has an autistic actor playing an autistic teenager. And as she says, nobody should be playing autistic except for an autistic actor. You have not lived her experience. So that I think is really important. Sorry to hog it, Jeff.

Jeff Preston:

No, no, it's good. I actually want to pick up on the point you were making about Rain Man and how complex these things are. I think Rain Man's actually a great example of so much of what's wrong about the way that we represent disability. And that's namely that, so Rain Man comes out and it's like most people who watched it felt like, A, this is authentic. This is the final word on autism. This is what autism is. This is what it looks like. This is how it is for everybody. And this is how autistic people should be. And from then on you have all of these iterations of essentially the same character of Rain Man. So you get this fixing of the savant syndrome, you have this fixing of the childish humor or the childish in the sense of the humor of a child and how cute that is, and this belief in the need for really patronizing care that the non-disabled brother must care for, but also that the non-disabled brother can learn from the beauty of the simple mind of what she has found to see.

Jeff Preston:

And that might be very accurate of one individual's experience. But the problem with media is that it is very much a world of mirrors, where constantly everyone is just holding up a mirror to past representations and repeated them iteratively. Because if you don't represent autism like Rain Man, you now have audiences that are like, "No, no, that's not how autism is. Rain Man is how autism is." And so you end up getting these myths of disability that get re-inscribed over and over and over again, passed off as truth statements, when actually they are fictitious creative representations of people just trying to tell stories.

Jeff Preston:

And at the end of the day, people generally speaking, and general audiences, don't actually care enough about disability to actually go in and learn about the differences and learn about the complexities and understand that this is just one window, that we're looking into the world of one individual. And so instead they just totalize it. So they say, "Okay, well, all people with autism are like the Rain Man. All wheelchair users are like Ron Kovic in Born On the Fourth of July. All blind people are like Ray Charles, if he even is blind." And so you've got this complete just washing out of the complex realities of disability and the experiences of disability that becomes more true than the actual lived experience. And we start to see that with the Sia response to Music, because the bit response of a many media producers is, "Well, no, it's true, so it has to be right. I've seen this before. I have this one example of this one person who is this way, and therefore, this is completely fine."

Jeff Preston:

When at the same time you then have children going to school who have autism, and then they become essentially devalued if they don't have a savant ability. So it's like, "Oh, you're not able to count cards? Well then not only are you autistic, but now you're the wrong kind of autistic. Oh, you're not an inspirational wheelchair user? Well yeah, you're disabled, but you're the wrong kind of wheelchair user." And that I think is what that... That's the real problem here, that people don't seem to be actually understanding. Within whether it be Hollywood, whether it be in television, or whether it be in online creative communities.

Beth Haller:

And even I think it moves onto even the documentary setting. There was a documentary I used to show my classes called Autism the Musical from about 10 years ago. And all these autistic kids are given great agency in that documentary to talk about their lives, and it's a program teaching them music and theater. And there's a non-verbal kid in the show. And so I remember there was a review of it from a pretty prestigious newspaper here in the States saying, "Well, these weren't real autistic kids. Where's the meltdown, where's the screaming? These are really wise, articulate kids talking about their lives and what they're interested in." And my students when I would show it, they just loved that because they were like, "These kids, why are they... This is not what autistic kids are like." They really were confronted with real autistic kids and really enjoyed it.

Beth Haller:

But here's a mover reviewer that has bought into those stereotypes Jeff is talking about, and then watches a documentary and doesn't think they should have used the kids that weren't autistic enough, I guess, by his stereotype method. I'm just like, "What is going on?" And I mean it also merges into some not very good autistic organizations that don't include autistic people, where they're using tragedy narratives and screaming meltdown narratives to try to get people to donate. Because they're just feeding into this tragedy narrative that isn't there, when you have happy autistic kids that are describing unhappy incidences in their life. But on the whole, they're pretty happy. And so I think it really filters out into the culture really in a horrific way.

Keith Casebonne:

Well you brought up documentaries, and that's a good segue to another question I had. It seemed to be a number of new documentaries out in the last few years about people with disabilities, and I wanted to get your opinion on that in general. Some are better than others for sure, but it seems like a number of them are really just essentially made with the goal of motivating able-bodied people, suggesting that if a person with a disability can accomplish something? Well then surely this able-bodied person can. Essentially I'm defining inspiration porn. But what are y'all's thoughts on that, as far as the new spate of documentaries lately?

Beth Haller:

Well, I haven't really watched the bad ones, but I think there's some really good ones coming out like Crip Camp. I think Crip Camp is a last movie I saw in a theater before the pandemic, because there was a screening of it in New York in February. And I can't recommend it enough, it's so fantastic. And it's potentially being shortlisted for an Oscar nomination, and I think it should get one. Because in addition to really showing the disability rights history in the United States, it's also showing the agency of disabled kids who came together in the future. It's about them at this camp when they were kids, but in the future, they become these really powerful activists who really transform the United States. And I mean there's just no two ways about it, these are people that have transformed the United States. And I feel like the film is also going to be transforming the United States, because it really is giving people a sense that we have a disability rights history.

Beth Haller:

I think Americans know about our civil rights history, but they never really thought about our disability rights history. And I'm showing a clip, not of Crip Camp but of another short film on the ADA anniversary to my students these days. And they're all flipping out with what they didn't know. And what's ironic is, there several States in the U.S. that now require LGBTQ history and disability history and high school curriculum. But I don't think that curriculum is being written and it's not being implemented, so here we have a great moment with something like Crip Camp. I think that's going to get people interested in making changes into curriculum for young people. I think it should start at the preschool level, but that's just me.

Jeff Preston:

Sure [crosstalk 00:22:27].

Beth Haller:

And then another good documentary is one that was made about the Paralympics. I believe it's also a Netflix.

Jeff Preston:

Yeah, Rising Phoenix.

Beth Haller:

Yeah. And I think it really gets at a broader perspective of what the Paralympics are all about, and it gets into some controversy too about people not showing up and there not being enough funding for it to continue with the 2016 Rio Paralympics. So I think it got into political, financial issues as well, it wasn't just some kind of inspiration porn. Which the Paralympics are I always say the one place where you can be inspiring, because you're an elite athlete and that's what sports is all about, right? And you're inspiring other people to be interested in your sport. So anyway, I'll quit hogging it and let Jeff talk.

Jeff Preston:

Yeah. So I'm going to out myself here, and I'm going to refer to a beloved scholar of mine. Who didn't write really about disability, but I think gives us actually a really important concept here, which is of course Louis Althusser. And he talks about the concept of interpellation, and the ways in which our subjectivity is essentially called into being. That we are asked to define ourselves, and in the way that... Althusser's example is a police officer on the street saying, "Hey you, who are you?" And you have to respond, you're like, "Well, I am this person."

Jeff Preston:

So too does all of our discourses of disability call out to us to identify in certain ways, that brings into existence certain types of disabilities subjectivities that are believed to be authentic or appropriate or valuable. And I think when we look into the world of documentary, we have these very well-worn paths of quote unquote, "Incredible disabled people who are, by definition, incredible because of the ways in which they've been able to overcome their limitations, so to speak." So this is the classic, although not exactly the documentary, The Theory of Everything, the biopic about Stephen Hawking. Where fundamentally this movie was... It ends with a fantasy of Stephen Hawking getting up out of his wheelchair and walking to pick up a pen for an attractive woman. Which is so far divorced from what makes Stephen Hawking actually incredible, which is that he's basically was the brightest mind since Einstein in the world of physics, generally speaking.

Jeff Preston:

But the stories that we want to hear about are not about disabled people doing incredible things that are non-disability related. Those are not the things that really clock. Because, often when people who are disabled do incredible things, we then doubt whether or not they're actually disabled. We then say, "Oh, well it's a gimmick." So Stephen Hawking, there's a whole world on the internet that fundamentally disbelieves that Stephen Hawking was a disabled person. We have the exact same thing with Ray Charles, we have the same thing with pretty much any successful-

Beth Haller:

Helen Keller.

Jeff Preston:

Helen Keller. Oh man, if you want to fall down a hole? Jump on YouTube and watch a billion hours of content of people that are just convinced that Helen Keller was a gag, that the disability was just a trick in order to sell this broader narrative. Or, that Helen Keller was completely disabled, and that really she is actually just a mouthpiece, a convenient mouthpiece for Anne Sullivan. And that Helen Keller had no actual functioning brain, and of course she couldn't because she was disabled. Or, she was a very, very intelligent non-disabled person hiding it. But what all of this is to say, is that we have this feedback loop that happens where it says, "If you want to be a successful disabled person, then you need to perform normativity in certain ways. You need to strive to become normal, you need to strive to overcome. And those are the things that we're going to then reward."

Jeff Preston:

And so we end up in this very complicated bind, especially with people like Paralympic athletes. Who after they're done being Paralympians, where they don't make a whole lot of money, where they can make money afterwards is through the production of motivational speeches, inspirational tales. In which they are basically implored to provide the feel-good narratives that the non-disabled have said, "That is how disabled people provide value in our culture, that is where they are valuable." And so rather than saying, "Let's tell the story about Judy Heumann, and the way in which she was this frigging force of nature in the disability rights movement in America, no, let's tell the story about Steven Hawking and how great it would be if he could have walked." That's the story people want to hear instead.

Jeff Preston:

And so I think we're at this interesting impasse right now, where suddenly Hollywood and other media producers online, especially Netflix, Hulu, streaming services have said, "Oh, actually, there's this huge audience of disabled people that want to hear stories about them as opposed to watching movies made for non-disabled people to get these lovely feelings from. These comforting feelings of their normalcy."

Jeff Preston:

And so I think we're now starting to see this schism in disability representation, where you have things that are actually rooted in legitimate disability culture. Whether that be something like Crip Camp, or whether that be like CODA, the film that was just picked up by Apple TV. You have these legitimate disability culture representations that are clearly for a disabled audience, that this is who will enjoy this. While still having this stuff, this other, my opinion, garbage culture. But it's just being brought to the trough for the non-disabled to eat up and feel comforted, either in the way in which somebody overcomes the impairment, or comforted in the ways of which they are not that. Like Rain Man, how many people walked out of that film being like, "Thank God I don't have autism. Things might be bad for me, but at least I'm not that."

Jeff Preston:

These are two fundamental different drives in media that's happening right now, which honestly I'm glad I could be alive for it. This is great, this is the dawn of a new era in a form of media representation. How often do you get to say you were around for that? I was here for the internet and for the dawn of disability culture representation, I feel like I've won the cultural lottery.

Keith Casebonne:

Wow.

Beth Haller:

I think the younger generation though is not approaching these disability culture films from the same garbage way that the older generation has. Because when I talked to my students about this, to them it's like, "Well, why not? They like shows about, or movies about other cultures that aren't their own, and they're just interested." They think they're all about the authenticity. They want to see real people in their real lives, and they can relate to that. Because, they just want... They know everybody, they don't understand the complexity of intersectionality, and that people are more than one thing. I think the younger generation gets that.

Beth Haller:

And, we have a whole generation that now can be out and proud with their invisible disabilities or chronic illnesses. So I think the younger generation... I talked to my students after class for a long, long time, and usually it's the disabled students who want to chat about... And a lot of them have invisible disabilities, but they want to join the community. It's no longer hide that, but they have to deal sometimes with parents who say, "No, don't tell anyone."

Beth Haller:

So I think the younger generation, I have a bunch of hope for their shoulders to move us forward. Because literally, they're wanting the same things that all of us disability media scholars have wanted for a long time. And also, just being more inclusive of the chronic illness community, and people with invisible disabilities. Because actually, wheelchair use is actually quite a small sliver of the disabilities in the world, North America too. So also understanding that people could have multiple disabilities, and that there's something called ambulatory wheelchair use. So I talked to my students a lot about it. There's a wonderful woman on YouTube, Annie Segarra, who talks about ambulatory wheelchair use.

Beth Haller:

And I was watching the new film out, or the new TV series out of Britain called It's a Sin. It's about the AIDS crisis in London, and I was really pleased, because one of the main character's mother is an ambulatory wheelchair user. Sometimes she walks, and sometimes she's in a wheelchair. And I'm like, "I think nobody says anything about it." There's no comment about her getting up and walking sometimes, and using her wheelchair sometimes. And I was like, "This is amazing, this is what we need to have happening." And who knows, maybe the character was planned that way, or maybe the actor said, "This is what I need." But either way, I think we're starting to see more nuance in some of these representations, because I think the younger generation wants that nuance.

Jeff Preston:

I think that the nuance, and I think part of the reason... I think why some of the younger generation are drawn to this is because of the ways in which disability is fundamentally resistive. It resists the olden times. I think that while some, maybe beg unto quote unquote, "Make America great again," I think that there are a lot of young people in America that looked back on the past and say, "That's seems really boring. That seems really vanilla, and I actually don't want to fit in these tiny little archetypal boxes that framed who an American was over the last 70, 80 years. But rather, I want to live outside that. Because I look at the world that we have today and say, 'Maybe the old way of doing things wasn't the right way.' Maybe the state of the world right now is reflective of all the horrible choices that we've made. And so we need new choices, and we need new identities, and we need new ways of being and thinking."

Jeff Preston:

And I think disability has this binary opposition to normalcy, it then becomes this really interesting space where people can let go of that oppressive sense of normalcy and start to dream bigger dreams and different dreams. Because if a person with a disability can be okay despite being different? If disability is not the end of one's life, then anything is possible. Then maybe normalcy was the lie all along, as opposed to the truth of disability as a moment of despair. I think that's the ... And I think that applies everywhere, whether it be in racial justice, whether it be in gender justice, within the LGBTQ community. I think all of these are saying, "There are different people that exist in this world and we're also okay, and it's okay to be us, and it's okay to intersect with us." And I think that actually gives a lot of people hope in the younger community, despite it maybe causing a lot of anxiety for people in the older populations.

Beth Haller:

And I think they're hungry for those narratives too, because they've been through school that is still using the curriculum of the olden times. And so when they hit a disability studies class, they're so excited. They're like, "What? I didn't know this. Wait, I didn't know this." And they get kind of angry because it reminds me of why I was angry when I was in high school, because until I was 16, I never heard of the Japanese internment camps in America. And I'm like, "What did America do to me? Why did they hold this information away from me for these 16 years I was living in this country." And I think they're having a similar experience of, "So you taught me all the stuff that I don't really care about, but you left out all these really cool people that really did interesting things, and really we're living better because of them and not because of people that did things in 1782 or whatever?"

Keith Casebonne:

Right. Yeah. Well, so let's talk about some of the movies and series in recent years that are doing it right, are either portraying people with disabilities by casting actors who have those disabilities, and some of these are made by people with disabilities. What are some of the recent successes that stand out to you?

Beth Haller:

Just this week I was watching a whole set of short films during Slam Dance that were curated from disabled directors, actors, performers on disability issues. And it was 25 different films, and they were excellent. I mean, just for a major film festival to have a whole disability ... It's called Unstoppable. So they also got away with ... From all those words that we don't like. I thought that was a really interesting choice of terminology for the series of short films.

Beth Haller:

And then major studios actually last year, right about this time before the pandemic got us all changing our lives, I was actually giving a presentation to the Lionsgate Film Studio in Santa Monica, California, because they wanted to hear about how they could better represent disability. And they were about to come out with a film called Run that's now on Hulu, they didn't realize they were going to be able to release it the theaters. It stars the first wheelchair using actor since 1948 to be the main character of the film. So that just shows how little we use disabled actors.

Beth Haller:

But it's a really interesting thriller. And actor, Kiera Allen, who plays the disabled daughter in the series ... Or in the movie just really carries the whole film. It's very small cast, because it's a mother daughter thriller. And so there's only a few other characters. And so she is on screen, I would say 99% of the time. And she's a real MacGyver kind of character. I mean, she has all this ability because of her disability, because she's had to think outside the box.

Beth Haller:

And because she has been homeschooled, she knows how to do all these things. And so she's ... There's no pity, or tragedy, or anything involved. It's all her figuring out the world and using every tool she has in it, even to fight against somebody who knows how to try to stop her because of her disability, she still figures out a way to go around that. So that's a really, I think, great thing that's just happened.

Beth Haller:

And also just the commitment. I mean, and when I looked out into the audience of those 50 or so people at Lionsgate Films who came to my talk, they were just kind of like, "Of course, this is what we're going to do." And they also talked about how ... When I talked about CGI being a way to use disabled actors, if you have to have a past storyline, you can just use a body double, it's simple, it doesn't look at all different. And so they're, "Yeah, we're doing that in this new film." Of course they did it the wrong way because I didn't really like what they did at the end with the CGI, but still at least they're going that.

Beth Haller:

And I know another disability advocate has spoken with him Sony pictures too, so I think we're seeing major Hollywood studios understanding that it's not okay anymore to have these crippling up kind of disability mimicry style movies. And I've had meetings with Lionsgate since and talk to them about ... And I now have somebody I know who a disabled filmmaker, who's now one of their consultants. Because I've just told them, "You need to be having somebody with a disability involved from the idea stage. Even before there's a script. You need to have somebody with a disability reading every script, it doesn't matter if there's disability in it or not. Somebody with a disability should be reading every single script." Because they could suggest, "Oh, well, why don't you make the store clerk a disabled character?" I mean, they can just say that. And they're like, "Why not?" Even if it has nothing to do with disability, they would be there understanding how to integrate more disabled actors into just any kind of film.

Beth Haller:

I mean, you see that in TV, where ... I remember the show Murphy Brown. I forget what years it was in, the '90s, I think. Whenever they show the newsroom, there was always a wheelchair user in the background in just the workspace. And there was a show I was watching recently where that was happening as well. Just, of course, we work with people with disabilities, if we don't have one, if somebody has a visible disability ... Or I've talked to them too about how they could integrate an invisible disability.

Beth Haller:

I mean, I think the last series or movie that we had that had a portrayal of an invisible disability, not that anybody had this disability, was Panic Room. I don't know if you remember that film, Kristen Stewart played the kid, and the whole ... A lot of plot line was around her having type one diabetes and making sure she could get her insulin and all that kind of thing, or have the food that she needed.

Beth Haller:

And like I said, that could be easily ... You could hire an actor with an insulin pump and you don't have to even talk about it. You could just like have a shot when they're putting on their shirt or whatever and you see that they have an insulin pump, doesn't even have to be mentioned. Or somebody's like, "Oh yeah, I can't go to that fair because I have a seizure disorder." I mean, it could be one line in a film, but it could do so much to really talk about the issues.

Jeff Preston:

Yeah. And it helps to center it, right? To make it real. I don't think we can go through this podcast without talking about Peter Dinklage and what Peter Dinklage has done for representations of disability. In part kind of by existing, but also by being really good at what he does. A not great movie, but a really interesting example though, was the X-Men movie that Peter Dinklage is in. This was a character that was not originally written as a disabled character, as a little person in this instance. But Peter Dinklage has a name. He is a known actor at this point. And they wanted him on the ... It's great to have him on the poster, essentially, if it's just his name even.

Jeff Preston:

And so they hired him, they'd put them into this role and they didn't rewrite it. They didn't change the character at all. They're just, "Okay, it's just Peter Dinklage playing this role." And what I think is so great about it is that it didn't feel forced. It didn't feel like the studio was checking off a diversity box when they did this. There wasn't the same sort of backlash that we've seen when other characters have been changed, whether it be changing the gender of a character, or changing the race of a character.

Jeff Preston:

And I think part of that success was that Peter Dinklage's character was just injected. Peter Dinklage was just injected into the film to take on this character. And he did a great job of it. He represented the authentic perception of that character and did so without there have to be any ... I was really worried going into that film. I thought for sure there was going to be some light ham handed stuff about him being a little person. Or my worst nightmare was that they were going to kind of retcon and be like, "Oh yeah, no, the character had a science disaster and now they're a little person as a result."

Jeff Preston:

But they would have that need to give an origin to it or whatever. And they didn't, but they walked away from that cliff. And so I think there are like those types of examples where they just sort of seamlessly are starting to integrate, I think are quite good. I was a big fan Of Peanut Butter Falcon, in large part because they allowed the actor to really influence some of the scenes. To be, "Let's bring your knowledge, bring your strengths and abilities to make this thing better."

Jeff Preston:

And that, I have a friend who was recently in a film, and he's a wheelchair user, and I was blown away by what he described on set. When he rolls in the character had a different spinal cord injury than he did, and so he pulled the director aside and he's like, "I don't have that spinal cord injury. I will have to do the wheelchair differently as a result of this."

Jeff Preston:

And the director was, "Well, whatever then, screw it. We'll just change it." So the character now has the spinal cord injury that you have, because that will be more real. And going into shoots, they would ask him things like, "So if you're going to go to the counter to buy something at this coffee shop, what does that look like? What are the steps? What do you have to do? How do you do this naturally so that we can incorporate that into the way in which the scene is structured, the way which it's shot, everything from whether it's pushing the button to have in the door, versus how does the person hand you the things over the counter if the counter's too high? How do you pay for it? Where could we capture the [inaudible 00:45:34]?

Jeff Preston:

And so there was this real interest in bringing him into the productive process, which I don't think is typically how disabled people have been seen in the production of media, typically. But I think more so disabled characters are basically just props. And at the same way you wouldn't ask like the Corvette how it wants to drive down the road. So two are they looking at .. I'm not a wheelchair and they're like, 'Well, you're going to do what I say, because you're the actor and I'm the director.

Jeff Preston:

I think there's starting to be a bit of that change. And it's reflected in films like Peanut Butter Falcon. And there's a great, I believe it's a Hungarian film called Kills on Wheels, which I'm a pretty big fan of. It's quite good. Which also similarly is saying, "We're going to not just tell a little bit of a different story about disability, but we're also going to kind of openly mock and ridicule past representations. We're going to really poke fun at and show the absurdity of the other ways." And I think it's that satirizing that does so much work to undo the Rainmans of the past, but it reveals the way in which it's silly, and it breaks some of that aura that gets wrapped around some of these quote unquote iconic films.

Beth Haller:

And it becomes a collaborative process too, which I think makes it better in so many ways. I happened to interview the writers for Switched at Birth, the teen drama that included quite a number of deaf actors. And I mean the backstory, and this is actually on the Emmy website. They did a panel about how Switched at Birth came to be.

Beth Haller:

The show runner, Lizzy Weiss was actually just pitching a show about two teen girls who were switched at birth. And it was the network who asked her, "Can you make one of the main girls disabled?" And so Lizzy Weiss had taken an ASL for theater class when she was an undergrad and so the first thing that popped into her head was, "We'll make one of the girls deaf." And the network executive was like, 'Great, okay, great. And so after she said that, she said, "That's going to mean we're going to have sign language interpreters on set. I'm only going to hire deaf actors."

Beth Haller:

I mean, once you have this executive on the hooks for what you wanted to do. She made sure all the writers had learned all about deaf history, that all that was an ASL master and a deaf culture expert on set at all times. A bunch of the actors only spoke with sign language. There was literally no ... One of them did not speak verbally at all. So when I was interviewing one of the writers, she said she had a back and forth with one of the deaf actors because of a scene that she had written. And he texted her and said, "No, that would be offensive to have that." It think it was a closeup of a hearing aid or something like that. And he said that would be offensive, that shouldn't be in there.

Beth Haller:

She's like, "Oh, okay, thanks for telling." I mean, the way she was so happy that he had told her, it's not the writers, "You do it my way or get off the set," kind of thing anymore. And that collaboration that she was pleased to have the input, she encouraged as much input as they could give. And so it probably made the actors feel ... And Marlee Matlin, who played the mom of one of the deaf kids.

Beth Haller:

So it was a joy for her because she actually got to be an actor in her native language, which is sign language. And that's a very freeing thing for deaf actors. And I think because it was very popular for the first few years, that also showed a lot of other TV productions. I mean, you know how Hollywood would have speaking to each other with everything they're doing. And if it's successful, everyone jumps on board.

Beth Haller:

So that's why I'm hoping that with a couple of movie studios being much more collaborative and authentic in their process, and TV shows doing the same, that it's just going to get a lot of other ones doing that too. And I think the actors are becoming tougher as well. I mean, back to Peter Dinklage, he said from the get go of his career as a young guy, that he was never going to take those stereotypical dwarf roles. And I think that helped him in the long run, of course he's really good too, so he could get work.

Beth Haller:

But I mean, he struggled. A lot of people have to really struggle for turning down roles. And then there's a classic scene in the movie Elf, which he actually is in, but not as an elf where he's an irate business man. So I mean, I think it's, again, what Jeff was talking about, turning those stereotypes on their head and making them ... And especially the younger generation is going to see that and go, "Yeah, that's what I get." They know that they're making fun of the past ways that things were done. So I think the collaboration, the kind of little inside jokes that people that are about authentic representation will get is really moving us forward in a really good way.

Keith Casebonne:

Well, let's end talking about the internet, a little bit about social media and how it has impacted this movement, as well as maybe a bit about how it seems as if Netflix and Hulu, the streaming platforms, have sort of been some of the push behind. It seems like if it wasn't for them, we might not have some other networks doing and studios doing what they're doing. So share a little bit about social media streaming and how they impact the movement.

Beth Haller:

Yeah. I mean, I think from a technological standpoint, and I'm hoping that post pandemic we're going to move into a much more streaming kind of environment because a lot of what happened to non-disabled people during the pandemic is the way people with disabilities have been living for their whole lives, having to work from home, having to deal with places they can't go into or are closed all the time. If you look at everything being closed, like not having a ramp, people are getting it I think more.

Beth Haller:

Except for the younger generation that wants to going to a movie to be a social experience, I think a lot of people are just happy to watch what they want to watch at home. I think the whole structure of big name stars selling a film and getting what you used to call butts in the seat is not relevant anymore. People want to watch a good story. My students don't even understand when things happen. So they were telling about a movie that they thought the disability representation was awful. And it was What's Eating Gilbert Grape. I'm like, "Well, that's really old." I was thinking, oh, they probably just saw it on Netflix. So people also don't have any sense of time when things are happening.

Beth Haller:

My students tell me about, because I think the younger generation is streaming everything. They don't even see why as old folks would watch a show that you have to wait a week to watch the next episode. I mean, even shows they like, they'll wait till it's available on streaming. And so they're just going to start rejecting. And also, all that data is there on the Hulus and on the Netflix where people are not watching things.

Beth Haller:

Another show we should talk about is Special on Netflix, a short series with Ryan. I say short because it's short episodes of like 10 or 15 minutes, but they don't seem like they're short. He stars and wrote the whole thing, and it's so great because he's really kind of hard on himself because it's a lot of it is about his own internalized ableism, how she is hiding who he is. He's an out gay man, but he's not with his disability. I mean, that kind of nuance is what I think we're talking about.

Beth Haller:

And then with social media, then you get everybody interested, so it becomes not just the disability community saying this is a great show. Everybody says, "Oh, that's a great show." And so people can come to disability content so much easier because everybody just recommends what they like and different genres and what they think is good. And it just becomes about that rather than, "Oh, go watch this. There's this great disability representation. No, go watch it because it's a great series and you can relate to it." So I think that's going to move us forward. And the intersection of social media and our mass media now I think is really, I mean, for all the bad stuff that social media has brought, it has plenty of a bad side. I think for the disability representation world and for disability community in general and activists in general, it's a way to really, back to what Jeff was saying, show that there is a way to move forward that has nothing to do with the old school normalcy crap of the past.

Keith Casebonne:

Sure.

Jeff Preston:

Yeah. I feel that the streaming platforms have a latitude that is not typically offered to, especially not to big budget, those tent-pole movies. You look at any of the big ones, whether it be Marvel, whether it be Star Wars, I've just referenced two Disney productions. Are there any other production houses in the world? I think Disney owns everyone now, more or less. But when you look at the mass media, the mass film, you essentially get this kind of watered down story that is trying to hit as many people as possible. And so it then needs to be able to speak some sort of truth to as many people as possible. And as a result, you then get movies that are very heavy on, say the action or very heavy on the aesthetic, and are very light on details. Because if you put too many details in, you might start losing some of those segments that you really need in order for it to be popular.

Jeff Preston:

But then we get streaming platforms right around the same time as social media is kind of reaching its zenith. And it should be no surprise to us that the social media platforms say, "Well, wait a minute. We actually don't need necessarily the big actor to be the evangelist for this text. We don't necessarily need the big media reviewers to be the evangelist for this text, but rather we can hit a smaller population, a smaller segment that is far more engaged in what we're producing to evangelize for us. And so if we tell a story like Special, you're going to have a bunch of people that are going to watch that and say, 'Whoa, this is me. This is my experience. And I want everyone to see this to understand me.'"

Jeff Preston:

And so if I go on and I tweet, "Oh man, check out this new thing I just saw on Netflix," you've got about 150 people in my social circle that are going to look at that and say, "Yeah, I want to see what Jeff is talking about," and they're going to take a shot at it. They might love it too, and then share it. And then you'll get that viral spread. So it's a complete upending in the ways in which we define success for a cultural product online. And I think as well that I think places like Hulu and Netflix and arguably Prime Video, kind of, but a lot of these streaming services are also saying, "We need to differentiate ourselves, because we are never going to be able to ..." Apology. I'm sure all of the Netflix studio execs are listening to this and I'm going to apologize to them right now. But you're not going to be able to compete with a Marvel Avengers film. You don't have the budget, you don't have the capacity. You are not going to be able to compete with a big budget film.

Jeff Preston:

And so what that means is that you're going to need to dominate in different spaces, spaces that aren't driven by money as much. And I think that's why when you look at Netflix and their attempts to do a blockbuster style movie, it always falls flat. But where they do really well is in niche content that is driven to make a lot of sense and connect deeply with smaller groups of people. And I think that the disabled population has then found a home in some of these platforms because suddenly there's actually a space for us, a space that is interested in us, interested in what we want to watch, and interested in the stories that we want to tell. I think that is actually really changing things in the ways in which we represent.

Jeff Preston:

So there's a lot of people that talked about how the internet was basically blowing up those big demographic segments and resulting in a world of highly niche content and how that's probably a bad thing. I think it's only really a bad thing for the big studios. I think it's a phenomenal thing for minority communities who otherwise were never even invited to the dinner party because it was believed that we just didn't deliver a big enough demo.

Beth Haller:

Right. And I think if we think about YouTube also as a social media and a media platform, I mean, back in the early mid-2000s, stuff like that, there were things like My Gimpy Life, Teal Sherer's two season series that's about her life as a actor who's a wheelchair user. I make my students watch the first three episodes of season one. They all finish both seasons. And I actually interviewed her for a book I'm writing. In 2019, I interviewed her and we're talking about everything she'd done. And she was kind of a pioneer because she was doing stuff before there was the streaming platforms.

Beth Haller:

And somebody from Netflix, if you're listening to this podcast, please contact Teal Sherer, because it's just perfect. If you were watching Special and it suggests what else you should watch, they should be buying her series from YouTube and putting it on Netflix because it's a natural fit. I mean, none of my students who are watching her series, maybe one is a wheelchair user. All of them probably identify as non-disabled and they're majority female, because that's what a lot of colleges are these days. They love the series. And it's again, a short series, short timeframe. I mean, each episode is like 10, 12 minutes, but you don't feel like it's 10, 12 minutes. You feel like you've seen a whole lengthy episode of something.

Beth Haller:

It also shows how we don't need these really long, 22 minutes sitcoms or these really long, 42 minute hour dramas with commercials all in them. But I think that that's also another reason why people are going to the streaming. It's just a control over your media. You're not the butts in the seat anymore. You're the person with the remote deciding what you're going to do. And I think all of this, now that we're seeing the big releases on streaming, also in theaters, they're going to have the data to show the studios that, yeah, for some of those movies in the future post pandemic, yeah, some people are going to want to go to theaters for that. But I mean, just across the street from me, if he has his shutters up, he has a TV that I swear, the people are like human size. It's so big. It's one whole wall. The inches, it's like, I don't know, six feet long and five feet high or something. I mean, when I can see it at night, I'm like, "Wait, there's people playing football in his living room."

Beth Haller:

So people have these home studios now too. People are getting these massive flat screens and even the smaller flat screens are so cheap these days that everyone ... And also the fact that we're stuck at home now because of a pandemic. I happen to be in Texas right now because of a disaster with our power grid. It's unbelievable how much more time we're all going to be at home. And people are going to get, if they can afford it, all kinds of more things and hardware in their house to watch and do what they used to go out and watch and do.

Keith Casebonne:

Well, this has been very interesting. I've really enjoyed this conversation. Thanks to both of you so much. I really appreciate your insight on this really, really deep subject with a lot of history and a lot of changes right now. So thanks again to both of you. I appreciate it.

Jeff Preston:

Absolutely.

Beth Haller:

Thank you.

Keith Casebonne:

Thanks again to Beth and Jeff for being our guests today. To learn more about disability representation in the media, I'll have links in the show notes to our guests' publications as well as some other sources. Thank you for listening to the You First Podcast or reading the transcript online. Please email any feedback, questions, or ideas about the show to podcast@disabilityrightsflorida.org.

Announcer:

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