



**Season 1 Episode 9:
How can we make the arts accessible for patrons?**

Transcription possible by Wreally. Transcribe.wreally.com

www.disarmingdisability.com

[Upbeat intro music]

Nicole:

Whats up? This is the reflection episode about for media. For media, and this is disarming disability and you've hopefully have just listened to the three shows all about media it really intense and we had crazy amazing experts. So please go back and check out episode 6, 7, & 8 if you haven't listened to those the stuff we're about to talk about probably won't make sense to you. But hello, that's what we're going to do. Sarah and I are going to chat it out.

Sarah:

Hey, I'm Sarah Tuberty.

Nicole:

And I am Nicoel Kelly

Sarah:

I know it's just it's really fun thinking about media again because like yes, I consume media, of course, right and like yes, I think is important but I'm not like in on like I don't know lots of things about it. I sort of see it as it comes. I like maybe see this movie here and there maybe I watch a TV show, but truthfully I'm doing so many projects that that's like the one big joke of my life is like, I don't watch TV. So people like oh Game of Thrones and like sure that's been like a very what pivotal thing and like American culture that I like don't know anything about like there's people and they cried over things. I but really I literally can't tell you nothing about it and I don't know actors names. I don't know movies. I don't know if they like it. So this is just a world that like yes, I see things but I don't know it as intimately as I suppose like an average consumer would. So it's been really like it makes me want to engage in a more in like really like understand where disability is because I know that that's something that isn't being seen on TV, right because I'm even in the like little glimpse of things that I do see I'm not seeing people with disabilities there. But then just even thinking that it is important to be active in this and and to understand what is happening because really media is shaping a lot of our social understanding of what we're viewing and how we perceive different things. I think we learn a lot of social scripts in media right? I and I say that in the context of this just reflecting on being like a kid and learning how to go on a date. So I feel like I learn how to go on dates via whatever TV shows or movies that I saw like you hold hands on your

date or something. And this is what middle school looks like. Whereas like those aren't things that my friends were telling me necessarily and those weren't things that my parents were telling me necessarily. So these are some social scripts that I'm learning as a young adult and again dating is one example. I just thought it was a funny one to put out there but just like how important media is and understanding what I'm seeing why I'm seeing it and why I'm not seeing other things.

Nicole:

It totally makes sense. I weirdly, this area in particular kind of is one of my interests and so it's something that I have always been kind of particularly clued into but also even though I was clued, into it clueless. So my antidote for you is literally my life story. So I did I did go to, I have a degree in directing and theater management. That is my undergraduate degree. Entering into school, I had a choice to make I knew that I wanted to act but when I was looking at the world, I did not say a single body on stage in a movie in a TV show that looks like my body. So I quite literally thought it was impossible to do the thing that I wanted to do. I didn't think it was even possible to be an actor. So I got my degree in something that was not at all acting. I totally if I had two hands. I 100% would have had an acting degree like that facts that's facts. So it's funny because then I went to New York City and I was working Backstage on Broadway shows and I still have that itch be on stage and I was like, I can't be on stage here. I want to be on stage here, but I can't I can't I can't wear can I be on stage? Where can I be on stage? And that's, honest to God that's how I ended up in pageants is that was an opportunity for me to audition for a part where all I had to do is be myself. I got to be on stage. I got to think I got to sing I got to do all of the things that I wanted to do in the acting world but literally couldn't do or thought I couldn't do so I went and I did it in this parallel universe that was pageantry, which is crazy like that is in real, although I didn't realize at the time maybe as maybe that was a lot of suppressed things and it can't work through the reality of "yes, this is because I have one hand" you know, I might have I probably was living in a space of denial where I wasn't really admitting that out loud but a hundred percent that's that's what it is now is a very self-aware person and as somebody who on the emotional homework, that's totally what it was.

Sarah

And I think it also comes in line to that doing something especially like "groundbreaking" in that sense and being like, I don't see anybody. I let me back up. I think that in that path we need mentorship. We need to see a path. We need to see some sort of steps to get from A to B. Right? And I think that that's just whatever. I don't know how to say hold on. I we may need to edit that out my need to start over again. But anyway, I'm trying to think of like seeing a path and so like if you are if you want to be an actor or an actress and these are things you want to do like you there need to be tangible steps to see so if you don't see anybody at the end that has any body that's remotely similar to yours then how can you make up those steps to get there? If we don't have that end goals? and I think and I think in both of our lives and I think that you probably receive these messages and I receive these messages to that like we are both very empowered women and that we both take on lots of projects and we are doing new things in the world and we are big advocates and we are really confident in our lives. Yes, and it's really beautiful but there was times where that wasn't true. So I think that it's important to be like, yes, like I am feisty

like, yes. I do work hard. Yes, I can see these things but it also gets to a point where I need to see that end goal and I can make up steps and I can push myself forward and I think we go all makeup steps and push ourselves for words, but there has to be something helping us and guiding us along that way. So whether that be the program's whether that be mentorship whether that be even just seeing a picture of somebody doing something and you're like, yes, I know that that exists. I know that I can get there I can make up the steps in between I can build my own path. But if we really we don't have that end destination, then we're just sort of wandering around and and then choosing other things where that end goal seems more tangible.

Nicole:

So this makes me think of Barbie almost when we were kids and that was when Barbie suddenly was getting jobs and you know, you could get by Barbie as a doctor. You can find Barbie has a NASA astronaut all these different jobs that that we want. They wanted kids to start visualizing and seeing themselves in these roles and you know as somebody who is interested in arts and media and theater like I I was looking for people who had differences and not seeing them. So yeah, I think it's really exciting that we're entering into this space where where our bodies are becoming more mainstream, but also I think building up and making the resources that that Talleri and Lawrence and Christine talked about all of the organizations that exist specifically to support people with disabilities those please seek those out. Those are the places and the people in the community who are doing the things that that you want to do that you want to be involved in that you could be in the middle of so yes and make the girl yet again. Oh, go ahead. I was just gonna say all the links on our website. So check that out.

Sarah:

Go ahead ask please do and I think it's cool because like this is this has been actively building for a long time and I feel that we're coming up on the sort of big push where it becomes mainstream and and I think that we're you working on uniting all of these different silos of communities were working on uniting both the people who have disabilities and who don't have disabilities have disabilities to really build that this becomes a "yes and" to use Christine's words there where this is this is normal and I think about this a lot like as a child going back to Barbie being a doctor and Barbie have holding jobs. Like I had a mother who was a career mother she did lots of really incredible things. She was in an administrator of nursing home. So in my mind, like feminism wasn't a thing or like job inequality wasn't a thing. So like how because as a four-year-old that's what I saw. I saw that my mom was working in these roles. Like I didn't think anything of it. And so how beautiful to live in a world where that's what I perceived to be truth as. And then to learn that we're still working through that struggle. Absolutely. But as a child, that's my "yes and" like please tell me something I don't know, like please this should be something that should just exist and be normal. And so I think that that's really beautiful advantage we have now to raise our children in a post ADA world to raise our children our world where they do see themselves in media represented and that extends beyond disability that extends word of any minority group that exists and all types of bodies all types of bodies disability or not and and showing them there, and so that then we raised a kit raise

our children our world where. They see these things and they're like, yes, and I think it's beautiful.

Nicole:

Yeah agreed. I totally agree if you. Yeah, if you don't if you are looking for your Idols, if you are looking up and looking for the people that that are you but 10, 15, 20 years older than you that people you want to grow into becoming but you don't see them there. Then then what are you supposed to do? Right and and so I'm just thankful that we really are entering into a world where it is becoming mainstream and it's thanks to the work of literally the three people the three experts we had on our show in addition to of course a whole crew of other people but really those three are majorly at the forefront of this work. Yeah and just yet again the idea of of seeing it is making it is normalizing it and I know a lot of people in our community when we talk we talk about words a lot and how to use them. I know a lot of people hate using the word normal and but at the same time, all I want to do is normalize the word disability,

Sarah:

Right, right!

Nicole:

We should be would be a part of conversation. It should be a part of identity. It should be not more than a second thought right? and we're a long ways away from that being a reality and that's okay, but that should be the goal, right?

Sarah:

Where these are things to expect and I think that comes back to things we've said before where we looking at our hands and our arms and like these are options like these are these are all parts of human variation. We are all humans here on this planet. Yes, and that these are things to expect and not be surprised when we see them.

Nicole:

So I'm just thinking back. Now. The first part of this chapter of media specifically Lawrence and Lawrence really was discussing his light bulb moment when he actually woke up and realized that he was a part of the community that that people thought we are better dead than actually alive and you know go back and listen if you didn't hear it, but essentially he was in a movie theater watching *Million Dollar Baby* and when the audience cheered at the end because because they actually kill the main character he is light bulb turned on and he said, oh my gosh, this is there's so much stigma attached to this there so many ideas attached to this that just aren't true. I have to get active. I'm wondering can you share with us what your lightbulb moment was? I know probably in various forms, we've talked about it, but I don't know if we've used it in the terms of "light bulb moment." So I'd love to hear that from you.

Sarah:

Yes, so my lightbulb moment was when I was in school to be an occupational therapist. And again, this is I'm probably 27 years old maybe 28 years old when I'm

reading this and my big light bulb moment was the social structure of disability that I read. It was an excerpt from a book called stigma by Goffman that was written in 1963, which is it's been around for a little while and it's been circulating in our world for a little while and it sort of talks about this "in group" and "out of group alignment" and how people with disabilities are perceived to be less than because they have these bodies if you will that are like not seen as being helpful and then there is this assumption that they're not able to do things. Therefore they get put in this sort of outcasts category and then have all these social limitations put on top of them and then that's what everybody thinks people with disability are and then that Outcast group is then those social if we're talking about social scripts again, those social scripts of that outcasted group are only reinforced with the media that were consuming because again, we're writing the social script saying that yes, there are better off dead or like oh it's so wonderful that they're able to put on their shoes and this is so powerful but whatever they woke up and we should praise them for waking up and I can't believe that they're living the world and the bodies that they do and they're so inspirational, right? So it's those two different things we did talk about with warrants, but I feel like those social scripts are reinforced. So then we're teaching mainstream society that that's the truth of people living with disability and that it only reconfirms that "out of group" alignment. So then people with disability that's the images that they're receiving about themselves. Do those are the social scripts their learning and then they take on those limitations and then they don't pursue acting because they think that they can't be there. I mean that's something that we just talked about existing in your life as well. And that there are those perceived limitations that I know I'm not able to do X, Y, and Z because I don't see myself doing it because I've been told by these social scripts not super knowing that this is what was happening that I can't I can't be there and I shouldn't be there and I should be somewhere else or I should exist somewhere else. And then people in that out of group can either take on that idea identity which we sort of talked about or they can reject it and then become this like heightened social awareness and then use that in turn to teach the larger society that actually the social scripts that were currently existing are not helpful. They're not true. And so we need to stop them and rewrite what truth is. So I feel like that was a big light bulb moment for me to and where I really took on being somebody with a disability because again my life and your life and if we talked about that before has been I I don't I not disabled disabled as a bad word. Those are people that can't do anything their quote unquote helpless their quote unquote broken. Like we need whatever, they're not something you want to be there less than normal. And so that way I am not going to be a part of them. I don't wanna be associated with any of that. But at the same time all of that negative stigma, I've experienced my whole life too. I just didn't know that that's what it was. So it's been this really empowering moment to take on like yes! I am somebody who identifies with the disability community and I just feel so much more empowered and I think like it's again another one of those like duh tag lines that we learn as children is that knowledge is power and so really like learning that and having that knowledge that like, yes, I am a part of this disability Community. I know that these social scripts are not true. Now I have the power to rewrite them and help build a more inclusive world all together. So I know that that's what we're doing with our podcast or what we hope to do with our podcast and being able to talk through and dissect these further but also really work to rewrite those social scripts that were putting in the media that we're consuming so that what we are putting out there does

accurately reflect the live experience of people with disability and knowing that again, everybody's lived experience will kind of be a little bit different here and there but but there is these larger overarching themes that do transcend everybody that does live with a disability and we can rewrite them because they're not true and it's simple if you will like it's not that hard I mean air quotes here, but these are absolutely tangible things to do. We've got lots of social barriers that were facing that makes it really hard work but it's not unattainable. We can do it.

Nicole:

Totally we can't do it. We totally can do it. Yeah, and another thing which we talked about is is the word inspiration porn. And so, um, I for those of you just as a refresher inspiration porn is the news, media, TV, whatever whatever outlet. It is telling stories about disability in the disability experience. But telling it in a way to make themselves feel better. So here is Johnny who asked Sarah who has Down syndrome to prom isn't Johnny the best boy that's ever existed because he's taking this little girl to prom? like those kinds of stories being told from that lens are just the worst. I was going to try to think about like more educated way to say that but they're just the worst.

Sarah:

They're worse.

Nicole:

They're just the worst and when you don't give the person with a disability seat at the table to talk about that experience and just to share it in an educational way. All you are doing is perpetuating the idea that people with disabilities are less than and that is exactly what you do not want to be doing right. That is the wrong message for the 21st century and within which we live in and I would like to think that people are starting to wake up to that idea. But you don't see it being completely gone. In fact the so I when I went back to grad school was for journalism, and I only did stories on disability the whole time I was there because I was so so so angry about literally the term inspiration porn. I hated I hated inspiration porn. So I was convinced. I was going to learn all the ways to undo inspiration porn. And and so we had to be studying different Nightly News shows as part of our graduate school and one of the shows we had to study was the Nightly News with Lester Holt, which is one of the main steak television shows that happens at night and Lester Holt every night ends his show with I'm not going to be able to say what the segment is called. Specifically but it is 100% always an inspiration porn and story that he's telling where he is going into a camp and many of our Sarah, many of our friends in our community of of amputees. There have been a couple of organizations that have been highlighted and it hurts me every time it happens because they actually go in and they talk about yeah, they talk about It's absolutely inspiration porn. So I say that getting better, but

Sarah:

I also that feel that there's a lot of very sad dramatic music that's gets played with it too.

Nicole:

Always, well, and it's always taking the spin on look at how less than they are and look at look at how other people who are normal are doing something to make their lives better, and that's completely the exact wrong message of what to be sending and what we want to be receiving. So, so just I guess if you're one of my news media friends on here, just remember that I'm watching you.

Sarah:

Nikky is going to come after you! that's gonna help

Nicole:

But also start start being a smart consumer right Christine with Christine we use that word a lot and we talked about that a lot be a smart consumer you get to choose where your money is going where where your views are going and don't don't consume the media that you know is not helping our community. You have the power to do that.

Sarah:

Yeah, absolutely. Yes, and and and and I think that comes in to what we talked about with tolerate as well is that to be like get ourselves at the table. So working on how to make places accessible so that like, yes, we are choosing not to consume this media, but we can also choose to be a part of changing the story. Some people may feel called to do those things but help rewriting all of those things as well. So so like helping to support theaters that are accessible like helping to work and be on boards or whatever provide feedback, and to help make theater spaces accessible or to believe in that conversation or to help include disability at the conversation when we are working about building different spaces for people to be able to access the media that they want to access in ways that can authentically portray it and then also work to be like, we need you. We need you as writers. We need you as directors. We need you as actors. We need you as actresses. We need you as costume designers. We need you as makeup artists all of these components that get involved.

Nicole:

Well and I feel like the important part of that though is is many of us who are that perhaps are filling these roles. We just aren't filling these roles with the understanding and intention that we bring the disability lens. And so what good is that doing for our community when we're trying to to push it forward and and when we have brothers and sisters who who do need more Tools in order to break down the barriers, you know, you might not be somebody who needs closed captioning and when you go to see a movie but you know our brothers and sisters do so, if you're working in that industry that issue is your in issue as well. And just be mindful and open to the fact that that voice and these issues they're a part of the fabric of who you are in the culture of who you are. So to be okay with owning that and taking that on and having those conversations with people not not only in our community but in your workspace as well.

Sarah:

Yeah. No that is absolutely really important because again, we're humans. We are all part of this Human Experience together and there's lots of different kinds of humans

and I think it's really wonderful to help make sure that we are providing things that humans can be able to access.

Nicole:

I totally agree. I totally agree. So now I'm thinking back to you. Yeah, the episode with Talleri .We really talked about about being the consumer and going into these spaces and what organizations are doing to make live events in particular places that are comfortable and welcoming and I loved that in that conversation Sarah. You likened it to just being a good host. Like when you have a friend come over to your house, is that chair comfortable for you? Would you like lemonade or would you like coffee would you you know like you were throwing out these examples that we do every day in our everyday life when we like a person and want to hang out with them and invite them to our house. That's all like that thought process is the thought process that should be happening at not only these live event spaces these media consuming and spaces but literally across the board and all corporate offices and in literally whatever situation you're going into hopefully if you are hosting people it that that's the thought process that we want people to have. We won't we don't want it to be we don't want want to have to be aggressive and be like, “these are my rights and I'm standing up for them” We will do that. But also we would much rather be greeted at the door with Welcome to our space. Would you like coffee or would you like lemonade?

Sarah:

and and that that's we're welcoming everyone to that space. It's not just people with disability. It's anybody that was welcomed into that theater that yes that we are people and that we have that we are people just that's it where people

Nicole:

We are people that's it. We're people yes people we're not we can eat. This is my favorite thing to tell people is when we're talking about just disabilities in general and probably it comes up when I'm talking about inspiration porn. I'm like people with disabilities can be really good people. They can be really horrible people. They can have really sad days. They can have really happily happy days. They can be complete assholes to people they can be the kindest humans. Like literally we are experiencing the same emotions as everybody else. And so tell our stories and that way as well.

Sarah:

Yeah, that makes me think of something I was learning in one of my occupational therapy classes were talking about we had a whole section on assistive technology was of course that we took and we talked about communication boards there and I appreciate BU, I went to Boston University and I appreciate Boston University so much and adding this the conversation that it's like if we have a 37 year old male who wants curse words in on his communication board like we should put them there because yes, he's 37 and like he has the right to use curse words if he wants to and he has the right to write the language. It doesn't have to be very eloquently like proper English because who speaks like that on a day-to-day life, but because he is unable to produce the words himself via his body. Whatever, that doesn't mean that he's not thinking them. That doesn't mean that these the way that we use our words

shapes who we are as people what we believe in our personality. So like of course, we should integrate slang we should integrate curse words because that's who he is and that's who he wants and he's a person who has the right to use them and it was such like a duh like duh moment, but so powerful to underline that that's really important. So like yes build this communication board for what is going to work for this person because oh my god, he's a person

Nicole:

Because he's a person who wants to say shit again.

Sarah:

Who was a lot of effing shit to say.

Nicole:

That's a really good. Yeah. That's a good example. Yeah, what else what else is on your mind from that whirlwind of a of the three weeks with three awesome guests?

Sarah:

Right side note. I am losing power on everything. I one of my earbuds just died. I'm like to percentage is down here so we can continue talking later date.

Nicole:

So if we want to be finished with this is we have like a half an hour of content. So we're cool.

Sarah:

Cool. Okay. So yeah.

Nicole:

Let's give a closing here guess so yes Sarah anything else on your mind then?

Sarah:

I think I mean I have so many things on my mind, but I feel I think this is I think we are good. I think we recovered it for this moment. Um, but yes cool.

Nicole:

So yeah. I mean, I feel like we could talk about this specific medium so much, but I feel like the big overarching themes, is just number one freaking show us we are here we are a huge part of the percentage of the population

Sarah:

Twenty! Twenty! twenty percent!!

Nicole:

Twenty percent of population. Number two, there are resources and community and people who exist who are working in this space there people doing that work so you can reach out and you can find them they are experts they are bridging those gaps. And number three is we are just people I feel like that's always going to be the number three on every list that we made we are just people yeah, that's what's on my brain. So I feel like hopefully after listening to that those were the kind of big picture

items that you took away to let us know what thoughts that you have. Remember to check out our website because there you will not only find the episodes but you will find the coloring pages that we have from our artists you will find actual questions prompted questions for you to fill out along with the episode to get thinking and then of course, there are all those amazing resource links there for you. So if we talked about it, it's there. It's clickable. You can reach see those resources yourself. And also there is a transcription posted up there of every episode as well if you're wanting to read through, so, please please use that and make sure you're checking that out and investigating that world.

Sarah:

Yes. Yeah, great. Well, thank you so much for being a part of everything that is going on and on this whole world and we're so appreciative if you taking the time to listen and then taking the time to think and taking the time to have conversations with people on the street or people that you love anywhere to just just move all of this forward.

We want to give special thanks to our Network public-house media for our intro beef Jason Barn. It's cybernetics for our logo art Patrice. You can find them at [normal person's.com](http://normalperson's.com) and Matt Meldrum and Ryan Lewis are two-handed technical team.

Subscribe on Apple podcasts or Public House media.org follow us on Twitter at [disarm disabled](https://twitter.com/disarmdisabled) follow us on Instagram and Facebook at [disarming disability](https://www.facebook.com/disarmingdisability) and check out our website [disarming disability.com](http://disarmingdisability.com). See you next week. Bye!