Jillian Curwin: Let's listen to the little people telling us what they want to see, let's listen to the community when they say that this is wrong, this is offensive, this is perpetuating harmful stereotypes, which the community has been trying to challenge and change,

Emma Vogelmann: Welcome to The Wheelchair Activist, a podcast hosted by me, Emma Vogelmann, and every month I interview amazing members and allies of the disabled community who are quite literally changing the world. In this episode, I am chatting to the amazing Jillian Curwin. Jillian is the host of a podcast called Always Looking Up, which I highly recommend you check out.

Now let's jump into this really interesting conversation.

Jillian, thank you for joining me to open season three of my podcast, The Wheelchair Activist. It is such, such a pleasure

Jillian Curwin: Thank you so much. I'm excited to be here. Congrats on season three, and I'm honored that you, chose me to open this new season.

Emma Vogelmann: As a seasoned podcaster with over 100 episodes under your belt. I'm excited to chat to you about all things disability, disability representation, fashion, and of course, what is disability like in America? And that's something that we haven't really I've talked a huge amount on this podcast before because other than my childhood best friend all of my guests have largely been from the UK and we've never really delved into what it is to be a disabled person in the States, other than my own experience because I grew up there, but yeah, really interested to get into all of those Things, but could you give a little intro to our audience on who you are, what you do and all that good stuff?

Jillian Curwin: So my name is Jillian Kerwin. I am a little person with dwarfism, dwarf, all the above are acceptable terms. I'm just a person of short stature. I have shorter arms and legs supporting an average height torso. And like you said, I am a podcaster, so I have like a daily 9 to 5 like kind of corporate job, and then I am the host of the podcast, Always Looking Up, where I talk to other people in the dwarfism community, as well as people in the disability community, those that are disability adjacent, as well as those who are allies to the community.

About living in a world that is not necessarily designed for us. I also write. I have a blog, which is in a bit of a hiatus for the moment, but I'm hoping to bring back this year. I have a couple ideas for pieces I want to write. I also do some

freelance work talking about different events happening and how they relate to the disability community, whether that's in pop culture, real life, et cetera,

Emma Vogelmann: Tell me about Always Looking Up, like what made you want to start your podcast?

Jillian Curwin: So Always Looking Up came, the podcast came from a series I was doing on my blog, also entitled Always Looking Up. And the blog I had started in January of 2020.

I've always been interested in fashion and finding ways to speak up and out. Um, but it wasn't necessarily calling myself an advocate yet. Um, but seeing and so in 2019, Sinead Burke was featured on the cover of British Vogue as one of the 15 forces for change. I was able to get my hands on that issue and I remember seeing it for the first time, in fashion, which is an industry I love, but doesn't include me.

I felt seen. here's someone in the UK doing this. I always wanted to, but never thought I could because I didn't see anybody like me really doing it. I. I had a lot to learn, about being an advocate in the disability space, what the disability rights movement was. I really didn't know, , and we can go into that and that kind of will play into like the differences between the US and the UK a little bit.

But I was like, I'm going to do this. So I started the blog and the beginning, so January 2020 was when I launched it and it was purely from a fashion focus. so it's talking about trying to find jeans and looking at the Oscar looks and seeing could this dress theoretically work on a little person where you wouldn't lose the dress?

Same thing with Fashion Week and talking about the lack of dwarfism representation. and so like very much from a fashion lens. And then COVID hit. And obviously the fashion industry, like many others, shut down. And I didn't know what to write about. And so I, you know, the only logical answer was to start writing about other issues outside of fashion.

And through that, I think that's where my disability education came in because I didn't really identify as disabled. this is also around the time when Crip Camp came out. and everybody was talking about that within the community and I learned.

A lot about our history that wasn't taught in schools. So getting that education and one of the things. then at the time like I wanted to do was talk to other

people, because we were all so isolated and so spread out. So I started this series on my blog called Girl Talk where I would like as we're doing right now have a zoom interview with a friend.

I talked to dwarfism community. I talked to. I remember talking to one of my best friends who is a fashion designer and was designing for disability in the disability design space, I would then transcribe our conversations, try to edit them down as best I could, without losing what was being said and publishing it and I love the conversations I was having, I didn't love the process of The transcribing and at the time, because I think we were missing their voice for me.

I was like, I want their voice to come through. having that transcription is very important, but I still felt like something was missing. And so I was like, Why don't I start a podcast? nobody was in that space that I really saw doing it. I reached out to my younger brother who was majoring in radio, television, and film at Northwestern.

I said, Hey, would you want to do this? I know you have this technical skill and he said, sure. that was the easiest. Yes, I was able ever able to get out of my brother for help.

Emma Vogelmann: Oh my God, as someone with a brother, I hear you.

Jillian Curwin: Yeah. So May 2021, we launched the podcast it's been a wild ride I love doing it. I'm proud of the growth, the conversations. That I've been able to have, and this year I really just want to keep doing more and more with it.

Emma Vogelmann: There's so many things about what you said that I want to ask you about. But, the first thing is, when you talked about fashion, you said that it was a world that you loved, but it didn't include you. I really, really resonate with that, but that also just strikes me as something really profoundly sad that, you can love this world and love this industry, but feel so excluded from it. I just wanted to know if you wanted to say a bit more about, your relationship with fashion if, as we all know, the fashion industry isn't inclusive to all types of disabled people.

Jillian Curwin: Yeah, I think that whole Concept of loving an industry, but not feeling loved back or not being seen applies to a lot.

Jillian Curwin: It doesn't just apply to fashion, but for me, I think, I mean, my love for fashion has always been there. I remember when I was younger, there was a store limited to, and it was like the coolest store.

Emma Vogelmann: My God. I spent hours in that store.

Jillian Curwin: For young millennial girls in the early two thousands, it was the store like that.

And Delia's those were the two. Top tier stores and I remember the first time I was able to buy a shirt that fit me there and it was just like a t shirt like that was a huge deal. I wore that as often as I could and every time that I go to the mall and go shopping, I would Look at the mannequins and try to copy their outfits to the best of my ability and often what that meant was copying them from the waist up and it wasn't something I truly recognized that I was doing, but it was something that I knew that from the waist up.

More or less, I could replicate that outfit and try to be, one of the cool girls or be on trend. the problem was, though, finding pants or finding shorts or finding skirts that fit me. I'm 28 years old, limited to, sadly does not really exist. I don't think it exists anymore. I still have that problem, though. There's that, and then I remember being in my parents bedroom and they had, cause there was the only room in the upstairs that had a TV in it. And I was just like flipping through channels and I had to hit, I couldn't find the remote. So you had to hit the buttons on the screen.

And there was no guy that tells you what channel you're on. I had stumbled across this fashion show it was when they were doing the runway show. And I had no idea what show this was, but I was entranced. I was, I was mesmerized. I could not believe that there's a show where people were getting judged on design. I had no clue what they were talking about in terms of fit, in terms of style, in terms of taste. I knew that I was like, I, I was like obsessed with it and I couldn't find it for the longest time.

I could not find that show again until I discovered it was Project Runway on Bravo, Bravo is one of the guiltiest of guilty pleasures. so very thankful for Project Runway in many ways. But yeah, since so watching that show and seeing the design process and how clothing is actually made. Disability was. never a client on Project Runway until relatively recently and it was treated like a one off. And, but still just like seeing that I think just like fuel this passion for fashion and then growing up obviously Trying to find jeans, trying to find clothes, trying to find prom dresses, trying to find shoes.

That's kind of like the lens where I understood my disability even though I didn't understand that I was disabled was that nothing fit that I didn't fit into this world and that's kind of like why, when I was like seeing Sinead Burke on the cover, like that was my entry point into disability advocacy was through fashion.

Emma Vogelmann: That's so interesting. I mean, weirdly, I guess I grew up in the States and I grew up living in limited to with my friends. but the first time that I. As a wheelchair user was able to wear jeans was when limited to came out with an elasticated waistband jean. So I really remember feeling like I felt so cool.

I felt like I, just felt like a normal teenager, wearing jeans and a cute top and it seems so insignificant to other people, but I really get what you mean about this, The sort of moment that you just, yeah, you just want to be able to express yourself through your clothing. But yeah, the fashion industry just doesn't allow us to do that.

Jillian Curwin: Yeah. And it's I always look at jeans as like the example because I remember writing one of my earlier blog posts. That I wrote was about like finally owning multiple pairs of jeans that fit me, which I really didn't do. I really had one pair of really good jeans that fit me that I liked and then the others were like, they fit, but I didn't like the fit.

But that was like the best that they were ever going to fit on my body. And, it's the fashion industry, whether you consider yourself into it or not, it is one of the few industries. that affect everyone, that truly affect and impact everyone, because we all get dressed in the morning. We all have to put on clothes, and whether it's, we want to be comfortable, whether we are like dressing to go to work, go to the gym, go wherever we're going, we have to get dressed for it.

And disability, it's still for the most part left out. There's been strides since I first became interested in fashion, but for the most part, disability is still left out and isn't considered, in that. In that process.

Emma Vogelmann: Yeah, I couldn't agree more when I have become more aware of fashion and designers fashion weeks, etc. Anytime that there is a disabled person included, it does very much feel like a one off or sometimes it can feel quite. Tokenistic in a way. Yeah. Which we really, which isn't real inclusivity. And so I think it's really impactful when, like you said, you saw Sinead Burke on a, you know, a Vogue magazine cover, and I remember seeing her on the cover as well, and she was wearing.

This, it was a really cute white like shirt dress and I saw that it was from Alexander McQueen which was, is my favorite designer in the entire world. I love Alexander McQueen. I love McQueen. Remind me after this to send you some pictures of these shoes. I just got for Christmas that were Alexander McQueen and they like what this is so interesting that right that we're talking about this because I look at McQueen's clothing.

And I think, God, if I had a body where I could wear these pieces, I would wear nothing else. I would have zero money whatsoever, but it feels so unobtainable. To me, to wear those pieces, but when you find a piece of clothing, whether it's jewelry, whether it's shoes, bags, whatever it might be, that fits you so well from a brand like that.

It's so powerful, right? And yeah, I'm just, I'm so curious about what you've learned since doing a podcast about disability, because exactly like you, I didn't call myself disabled for a really long time, and I think a huge part of that was growing up in America, which is a lot newer of a country, like relatively than the UK.

And it's better for physical accessibility, at least from my perspective as a wheelchair user. But just sort of like, yeah, what, what has been your sort of disability discovery journey since maybe moving away from fashion a little bit. I think

Jillian Curwin: it goes back to, again, when Crip Camp came out. And I, that was in the summer of, I believe like 20, I think it came out actually like in the winter of 2020 before COVID.

I could be completely wrong about that. But it was like that summer. I watch it, and I watch it because, oddly enough, Sinead was like, posted like something like, wanted to do like a group chat talking about this film. and so we all, signed on,said hi, introduced ourselves, then we all went to separately go watch the film, and then we all logged back on to talk about it.

And I think I was the only American on the call. I could be wrong about that. And it was interesting for me to say, because I remember, like, saying, like, at the time, like, I didn't know this, and, I felt ashamed as an American not to know, as an American with a disability, not to know this part of our history.

And I think someone had asked why, like, wasn't this taught in schools? And I was like, no, we never, Judy Heumann's name, for the best of my memory, did not appear in a textbook. The 504 Citizens was not something we studied. We

didn't study the history of the ADA and how that came to be. And I think that was a real wake up call for me to say there's a lot here that I don't know.

I tried to figure out why don't I know this. Why wasn't this taught to me? Why don't I identify as disabled? Because I still didn't. It took me really to moving to New York City the next year and finding a group of friends that were differently disabled, that were wheelchair users, that used different mobility devices and being a part of that community where I really started to say and embrace that I was disabled.

So I think that's like the lens through which I studied disability was. Talking to other people who weren't just little people and talking to them and understanding their experience, their access needs, and then seeing You know, we have things like, we have laws like the ADA and Section 504, and seeing how they're effective, but also how they are still, 30 plus years later, rather ineffective in protecting the rights, and truly the bodies of disabled people in a way.

One of the things I've been, like, exploring wanting to talk about is, like, how, we say that, things obviously, since the ADA, like, we say, like, it's, it's great that we have it, but at the same time, is it enforced always? No. Is the ADA perfect? No. Is, you know, but also like, is this just being taught? Are we learning about this? Are not younger, not the next generation learning about the history? No. And that's a problem.

Emma Vogelmann: Yeah. I couldn't agree more. I, the same as you was. I was really blown away by learning about Judy Heumann, which I actually only did last year, really in the past like six months or so, when I, came across her book, Being Heumann.

And I, I knew nothing about what she did, who she was and the sit ins, like you said, and all of this amazing campaigning and advocacy work that led to me as a young child in the States, being able to grow up and not have any barriers to my day to day life. Like I was in A mainstream school mainstream education, the only place that I wasn't able to physically access in the town where I grew up I think it was a bakery for dogs, which is the most random business. That happened to be in my little suburb at the time, but everywhere else was accessible to me. And then learning about the people who allowed that to be my reality, it was really incredible to hear about, but equally. When you look at Judy's story and the other advocates at the time, yes, there weren't laws in place to protect them, but were their experiences of discrimination that different from the instances of discrimination that I face all the time?

I don't know if that resonates with you at all.

Jillian Curwin: That does in many ways and I actually don't think that's a question that I've really considered because I think you are 100 percent right. I think that in terms of the discrimination that we still face, I think a lot of it is the same discrimination that the older generation face and was fighting to get those laws to protect again it shows that like the ADA a isn't perfect, isn't, and it isn't the easiest law to get enforced, and that there's still, it did, the disability rights movement didn't end with the passage of the ADA.

Emma Vogelmann: So in terms of growing up as an American, you said you're 28 right now. Like, how do you find, this is such a big question, so please take it wherever you want to take it, but what do you what do you feel is your experience of being a disabled adult in now, 2024, do you feel that there are still so many instances of discrimination, microaggressions, and all of those things, or do you feel the opposite

Jillian Curwin: very much the former. I still feel very frustrated. I think the only difference between how I grew up and how I see the world now is I understand why I think, and I've talked about this a lot in saying like I learned how to be An advocate in terms of like the actual skills from my parents. Both my parents are average height, non disabled, and they're both lawyers, which I think definitely played a part in it as well.

But like, I remember going to school with them at the beginning of the school year and just watching them, not fully understanding what I was seeing, but just watching them advocate for me and making sure that the classroom was as accessible as it could be. And. There were fights that they lost in the sense that they, in some ways, the school gave me too many accommodations that my parents wanted and in other ways we didn't get the exact accommodations that we were asking for, but watching them do it, and Because it got to a point where the onus was on me to make sure that these needs were met.

I was the one to make sure that I got my second set of books in that, I would be the one who every class would have to take the second set of books down to the guidance counselor's office to make sure that they were ready for my mom to pick up for me because they wouldn't do that anymore.

The school would like it was on me to make sure that got done. And it was interesting because at the same time. first, like my parents got accommodations that I didn't necessarily need, and they didn't necessarily want me to have

because they wanted me to still maintain independence, and I then had that resistance in middle school, and I think it was like trying to fit in.

And be like everybody else and I saw these accommodations and I think the way the accommodations are kind of viewed now still as special treatment as a way to make you stand out in a way that's not positive. And I didn't want it. I truly like in some ways refused I said like with the next like I don't want this, I would rather sit in a chair on my feet dangle if it meant that I got to sit in a normal desk, like everybody else,

There's some things that I couldn't give up because I like I had to make it to class on time, so I had to leave a couple minutes early when needed, I had a different desk with a different chair, and it was different than everybody else that also meant that I couldn't move like my desk was there.

Everybody else switch seats every now and then. My chair stayed in the same spot. And so I didn't want that. And I said, no, I don't want this anymore. And it wasn't because I didn't need it. It was because I didn't want to stand out. I didn't want to be more different than I already was.

And I think even now it's, you know, with like this, it's kind of like more like in the lens of asking for help. I don't like doing that. I don't like asking for help. Even if I need it. I don't like doing it because I don't want to reinforce what somebody else already thinks about my disability. Or My dwarfism because I think I that's a whole other conversation of whether or not I do I think people see actually see me as disabled.

That's a whole separate of the conversation. but I think that's how I was like I became more aware of what it was, I needed what it was I was asking for and really like how the world. saw me and treated me because of who I was physically.

Emma Vogelmann: that's so interesting. And I do want to ask, what other types of accommodations did you sort of push back on? Because I think a lot of my listeners were UK based. I would say. From my knowledge of the UK school system. So I, I did the first two years of high school in America and I moved to the UK I did two years of school here before I went to uni and I don't think that the UK integrates disability into mainstream schools all that well.

and I'm just sort of. Thinking, yeah, that people might be wondering, what type of accommodation did you get? And this mindset that people might, listeners might have of going, in the UK, it's so difficult to get any sort of adjustments

and. Some, I, this is absolutely no criticism, someone who's getting the adjustments and doesn't want it, I couldn't resonate with that more because I so often, to this day, and it's stupid, but I do it as well, push back on help because you don't want to be a fuss. You don't want to be a bother. You don't want to, like you say, you don't want to stand out, even though we quite obviously do because our disabilities are very visible, but that sort of, yeah, that difference is, it feels so big sometimes. Is there anything we can do to push back on that?

I totally get why you do that.

Jillian Curwin: Yeah. And it was like, and I recognize that. With my disability that I had the privilege of being able to push back and it's interesting because I Pushed back on you when I was younger on the same accommodations. I now ask my employer to give me one was getting a certain kind of chair to sit at my desk and when I was younger that meant I had to have again like a different desk than everybody else and oddly enough, though, if I, if my memory serves and if my mom's listening, I'm sure she'll tell me I was wrong, because I, that's what mothers do.

Emma Vogelmann: Yeah, you're never right.

Jillian Curwin: The chair, so I got this chair that we saw that like, LPA, Little People of America. we have an expo every year. They also provide resources for different adaptive products. So that's where we learned how to adapt our home to the best of our ability. So that way it was accessible for one little person and three people of average height without fully like inconveniencing one. someone, either myself or my brother or my parents, although I did leave stools everywhere. so they recommended that this chair that had a built in footrest and was more suited for supporting our body, making sure our back was supported and our feet were supported, which is like the two biggest things that we really want to try to make sure of with our disability that happens.

In third grade. We take start taking keyboard in class and it's a computer lab. And so that was the best chair that they could provide for me to have in that classroom because I think in the other chairs, my feet would have still dangled. Without like, even if there's a stool underneath, I don't think my feet would have been able to touch because for the most part in elementary school, I just sat with my chair and I had a stool under my feet.

so the chair was a solution for that. And then in middle school, my vice principal at the time, who was truly one of the greatest, nicest, kindest people

who was so understanding and so caring and and very much listened to us and was very much. made sure that what I needed was, my needs were met.

I think, though, he, took upon himself. I don't remember the exact details, but then suddenly I had, that meant I had a chair in every, that chair in every classroom. And I get, but like I saw it as like a way for me to stand out in a way that I, you know, in middle school where you're really trying to fit in.

Same thing with like trying to fit in with fashion. I didn't want that. I truly didn't want this. I was like, I think the biggest thing that I really pushed back against and said, I want to sit at a normal desk. I want to sit, I want to be able to, if a teacher is moving everybody's seats around, I want to be included in that.

And so seventh grade, I didn't have that chair anymore. and I think that was like the big one. And then like in middle school and high school, again, was like with the books, it was like me making sure that, that I got the books that I needed, that they were provided that I would go to the teachers and have to say, I need a second set of books.

And, they'd be like, okay, fine. Take it down to the guidance counselor and have my mom pick it up. And that's what she did or my dad. but yeah, I think it goes into this. It's not, it's hard like with wanting to, and again, recognizing that I had the privilege to be able to do this, trying to fit in when you were literally born to stand out, it's very hard to do.

And I was at the point when this is like showing that I didn't fully understand that I was disabled and that I really did need these things, that my body needed these things. It was. just wanting to be as normal as I possibly could be and not feeling that I was protected by these laws, not understanding what these laws were, and also not understanding what had to happen in order for me to get these accommodations.

Emma Vogelmann: Yeah, I completely see that. I think. And I wonder, as an adult now, do you feel like you're better at accepting what your body actually does need?

Jillian Curwin: Yes, 100%. I'm much better at accepting what it means. I'm not better at accepting its limitations. I think that is something I may never fully get.

I'm always like wanting to challenge and wanting to test my own capabilities and see, obviously recognizing that there are limitations that I really do have to accept. But also, like questioning limitations and why are they in place? And is

it really something that I can't or shouldn't do, or is it something that people believe I shouldn't do?

Because if that's the case, then I'm like, no, let's challenge that. but I think now it's, with coming into my identity as disabled, I'm much more, again, like, in the workplace, I'm now asking I was able to ask him to receive that chair and the and also recognizing that it is appropriate , you know, in some ways, it is while yes, by law, they were required to make those accommodations like the easiness with in which that process happened.

I do recognizes. It's a privilege for, at least in the States that it was like that my supervisor was immediately like, okay, let's get this done, put me in touch with the right people. And they went above and beyond what I was asking for, like what I knew we could do. So that was, again, unexpected, but I think now, especially with the podcast and everything when you talk about like, I'm much more willing and able to accept accommodations and also recognize that there are things I can't do and that, I'm not going to always fit in and that's okay.

Emma Vogelmann: Do you feel like there's a distinction though between asking for accommodation and advocating for yourself more in the workplace than in day to day life and like, and with social lives as well?

Jillian Curwin: Yeah, I think it goes into, I think, I see asking for accommodations and asking for help, in some ways, are different, because I think, in the sense that,in social situations, I'm very reluctant to ask my friends for help for something, or even strangers, in a grocery store, I'm very reluctant to ask for help.

And there are some places where I'm in like public spaces where accommodations can be made where I'm still reluctant to necessarily ask for but at the same time I will also point out how they are very inaccessible. So I need to work on that. But

Emma Vogelmann: I get that, right? Like I, I really do get, wanting to challenge things that could make things easier but also not wanting to accept help which also makes things easier.

Jillian Curwin: Yeah, and it's In those situations, it's more seeing that my accommodation would be an inconvenience to those around me. And I did this a lot, like using it an example. And it's interesting because I taught again, this is an industry that I love that I say all the time is very inaccessible, which is like the theater, which is like Broadway.

And I love Broadway grew up going to theater. Still waiting to see myself on Broadway. but that, we'll continue advocating for that. But I,

Emma Vogelmann: one, one day I will be in that front row.

Jillian Curwin: Yes. But it's, there's one accommodation like I can get is like getting a booster. So I can see more of the theater, which oddly enough, I was having conversations with somebody about this, I think on my podcast, or like in general, who someone else is like in the theater community, realizing that my accommodation helps me see but doesn't necessarily help my body in the sense that it makes my feet even higher from the floor.

Jillian Curwin: Which I didn't think about because someone, because someone pointed that out to me and I was like, Oh, that's something I'm gonna consider for a little bit, but I would, for a long time, like, go with, I wouldn't ask for a booster because I thought that I would be too tall. I would be blocking other people's view, but my view would still be blocked.

Just before I see who's around me, just go in and say, I need this. it's like something like that. So yeah, it's it's very interesting in situations, but I think accommodations for the most part, more willing to ask for it's asking for help. and even just like simple social situations of like asking somebody to slow down.

Asking a friend to slow down. I am really bad at doing that, and I get called out for that by people who rightfully should call me out for that. But I think, it's very interesting how, with what things I will be okay with asking for, and in what situations, and what help I need, I won't ask for.

Emma Vogelmann: Is it the impact on other people that you think is the factor? Like Like you said, sort of inconveniencing someone by being now the person who might be obstructing someone's view or having a friend change their walking speed. Do you think that's the fact? Like a big factor in that?

Jillian Curwin: 100%. I think it's feeling like an inconvenience.

Feeling and I think part of it is because, like, that's happened to me, it's, there's been instances of that in the past where I have asked for it, and then I was treated a certain way that I didn't like, so not wanting to feel like that again, I would, I'm more reluctant to do it, or not feeling like not knowing how they're going to react if I do ask for, or also like, in some ways, it's like a frustration that like, I shouldn't have to ask for this, like you should like in certain

situations. So they're not wanting to ask for it because you feel like you shouldn't have to. So it's like the whole concept of, Ooh, that could be like having to ask for help when you're disabled or ask for accommodations.

It's not as simple. As it seems, from many perspectives, it's not even just simple, like, just true, like, does the law allow you, should you be legally required to get these accommodations met? It's a lot more than that, that I don't think is necessarily talked about, really.

Emma Vogelmann: And I want to go on from that, but talking about, like you said, how these things should already be in place.

There should be, you shouldn't have to ask. For things and worrying about other people's reactions and reading your blog and sort of like looking at the conversations that you've had. And I particularly, you know, was reading your transcript of your solo episode about turning. 28. And you talk a lot about representation. And we've talked about that, right? You know, in terms of fashion, but also you talk about it in terms of the media, like you've, I've talked about the Wizard of Oz, which I really want to get into. And other ways that your disability is represented in media. And I want to ask you, because I think, there are some people who will think that inclusion is sometimes, and I don't agree with this, at all, but there are some people who think oh, that's going too far in terms of inclusion, so having a little person during New York Fashion Week, or, having a, disabled character in a TV show and yeah, I just wonder, like, how do you feel About it, because, I could imagine in your example of the theater with the booster seat, and you said about worrying about other people's reactions with that person behind you, who might be annoyed and think, oh, this is, going too far by accommodating you with any inconveniences, me, but yeah, what are your thoughts on that?

Jillian Curwin: It's interesting you ask this question, because I had, do you know Sophie Morgan?

Emma Vogelmann: I do, yeah. Okay. not personally. no, yeah. But I know of her incredible work, yeah.

Jillian Curwin: She's incredible. I had her on the podcast, and she had said something that started this conversation in terms of, the differences between the US and the UK., and I think disability representation, because, I see the UK. From a disability perspective as being ahead of the US, at least in terms of real representation, and she like, because she was saying like how like in the US

things are more accessible, like from like the league like from with the ADA and everything like that.

So, and why I said that is because we don't have. There isn't like a Sophie Morgan who's a presenter, like a normal, like in terms of like normal in terms of like frequent presenter on mainstream television. We don't have that. We don't have, British Vogue had Sinead Burke on the cover. British Vogue had their disability issue last year.

American Vogue hasn't had that. And so like in terms of representation of just seeing it and having it just be more normalized, from my perspective, I'm not going to speak for everybody, like I saw is like the UK is ahead of the U. S. on that and like seeing, like with Doctor Who with Ruth Maidley's character, I don't watch Doctor Who, but I'm like supporting her 100 percent and like seeing that representation, like we, the U.S has made strides. But I think there's a lot of catching up to do and also like so that's kind of like this was interesting that you say because like I think You know, that's, really where, for me, those differences lie. but yeah, it's, I never thought of, being, like,going, that's too far, but I think that's exact, I think that is 100 percent true.

I think with, like, being, when, like, when we ask, say, we want to see this, a lot of the pushback is, that's too far, or that's too complicated, or that's too hard, or we don't want to do it wrong, so they decided the answer is to not do it. And I want to be like, no, that's never, that should never be the answer that should never in terms of in the conversation around representation and never be the answer just to say, well, out of fear of doing it wrong.

I don't want to do it. However, there are some instances of disability representation, and I'm specific representation of little people where it's clear and it's been made clear that this isn't okay. When that happens, then it's don't do then say rather than continuing to go in this wrong direction.

Let's pivot, let's listen to the little people telling us what they want to see, let's listen to the community when they say that this is wrong, this is offensive, this is perpetuating harmful stereotypes, which the community has been trying to challenge and change, I got in trouble for saying this then when I said, on something like representation and is everything, but I do stand by it, because I think if we don't see disability on our screens in the magazine, if we don't see it, then it allows it to be ignored in spaces where it really can't be.

So I think having that representation in that sense is everything. And I think representation is not just limited to the entertainment and fashion industries. I

think disability representation is lacking in a lot of areas where it really needs to be present.

Emma Vogelmann: Yeah, I completely agree because I think, like you said, if disability was everywhere, which it is, because there are so many disabled people, there's no way that you have no interaction with it, but by having it everywhere and by seeing it, it, like you say, it's not possible to There Like claim ignorance for not doing something that is within your power to improve a situation for disabled people.

And I think, that goes, particularly, the first thing that's come to mind is politicians, right? if we can't get Politicians aware of disability and they're choosing to not engage with it, and they're not seeing it, then how are they ever going to legislate or put in place schemes, programs, whatever that serve disabled people and allow us to have equal chances, opportunities, and all of that.

So I think that's incredibly important, but I'm so interested that you think that the UK is better in terms of representation, because I think. I think I agree, in a sense, because there are instances of disability, like you say, in Doctor Who, and, other places, but what I wanted to ask you about is the inclusion of people with dwarfism, because I, can only speak as a wheelchair user, and I think when people think of, inclusive Representation, when it comes to disability, it's sort of a ghost like a wheelchair user in there because it's really easy or it's also really easy to fake.

And, when we've seen those pictures where we know that , stock photo, that person is not actually a wheelchair user. But what do you feel are the perceptions in terms of the ways that dwarfism is depicted?

Jillian Curwin: We are either seen as tools for education, and I'll say that in a positive way. I think the show, the reality TV shows, Such as Little People, Big World, The Little Couple, Seven Little Johnstons, I think are examples of positive dwarfism representation because they show what it is really like to be a little person in this world. it's not every dwarfism experience. I myself resisted watching those shows at first because I said those shows don't reflect my experience as the only little person in my world. but I do think they show Without necessarily putting an inspiration porn lens on it. What it's really like to be a little person. but we're either, so like it's, but it's like education. So we're either that or we are with several exceptions. I will say that and obviously the one notable one being Peter Dinklage.

we are objects. of entertainment, of amusement, we are human like rather than human, and I mean, we're seeing it right now, uh, well, I guess we could talk about it because, like, the strike is over, you know, the Wonka movie came out, and we saw Hugh Grant as an Oompa Loompa, and I will say, I'll confess I haven't seen the movie, but I don't want to see the movie based off of the trailer and based off of what I heard both Hugh Grant and the director say about decisions that were made, as well as some other behind, like not interested.

Emma Vogelmann: what are those comments for people who aren't familiar?

Jillian Curwin: That basically, like, there was no, it was made to seem like it was no possibility that they were actually going to cast a little person. The director made it seem like, of course, we're going to cast Hugh Grant because he is. I think he said like little shit or something funny little shit or something and that was what they were looking for with this character and then knowing that to make Hugh Grant laugh, which Hugh Grant talked about the director during like the renderings of like developing the character, sent a nude version of this character just to kind of like for amusement and it's just like What?

Like, I like to be open, like that open to just talk about it, and think that there's nothing wrong with that, or that the little person community, because in essence you're saying you're sharing, even if it's AI generated, like, nude pic of a dwarf body, what are we doing here? so there's that.

And then there is Snow White, which is coming out now next year. And Peter Dinklage said when it was announced who was going to be in, who was going to be Snow White, that Rachel Zegler was going to be Snow White. Peter Dinklage had gone on a podcast and said, called out Disney for trying to score diversity points. And I want to make it very clear. He had no problem with Rachel Zegler being cast as Snow White. He had absolutely no problem with it. That was not the issue. The issue was that they were trying to score diversity points while at the same time, telling a story that was going to continue to perpetuate harmful stereotypes of little people.

And he's like, that is just, that is uncalled for. And what he said, Got very much misconstrued. so I do want to kind of like make that clear that he did not take away jobs from little people. He did not do that with what he said. Not at all. but then fast forward to, last year, a picture went viral that was leak from the set, unofficial, it's not clear what it was of the Snow White and the Seven Dwarves except there was one little person and the rest were all of average height.

And the internet did not like that at all. And for me seeing that and seeing the reaction to it, again first having to say like Peter Dinklage, because then a lot of little people actors were like blaming Peter Dinklage for this when he does not deserve any of the blame for it. But also like, failing to recognize the true problem here.

And I'm like, you're mad because this challenges your belief system of what the seven dwarves could be. And if you don't want to challenge it because you want to be able to keep this perpetuated. You want to keep it going. It's hard, It's hard to make fun of the seven dwarves if six of them look like non disabled average height people.

It's hard to do that. so like that photo was leaked. Disney said like it's unofficial. It's it's not clear what that photo was. But then I think when they announced that they were pushing the film release back a year, they released a photo, like an official photo. And the seven dwarves Look animated look like not great in my opinion CGI And I'm just like because Disney tried to say like we're going in a different direction We consulted the little person community before doing this like in terms of how we approach these characters and I saw this and I'm like, so what exactly did you learn?

that's my question, but seeing what the, what this one result is, obviously the film hasn't come out yet, but I'm just like looking, I'm like, so what exactly did you learn from these little people that you consulted? Because it's, it's, I'm like, it's reinforcing what Peter Dinklage was saying from all along, that, you're telling a story that is going to continually perpetuate this harmful stereotype that, Dwarves are these like, they're not, they don't have names, they like, it's just like, what are we doing?

It's like, in terms of dwarfism, it's just what is, what is happening? I guess that's like my question.

Emma Vogelmann: Something that's just come to mind as you were talking is that I never realized was Being a little person and using the term dwarf dwarfism when a dwarf can also be thought of as this like mythical creature, right? like a leprechaun, a dwarf, a goblin, a unicorn, like it's like you say, it's something that's not human, but there are Humans who live for dwarfism. So it is, how did that happen? Was it, like you say, when little people and all of these like freaks for lack of a better expression because of freak shows, right?

Like, you know, the greatest showman Phantom of the Opera, like those types of scenarios did happen where people would come and look at people who look

different and laugh. But. How do you feel as someone living with dwarfism when a dwarf can also be this, non human creature? Is that the right term?

Jillian Curwin: Yeah, that's, I think that's correct. And, it's frustrating, and like, that's why I said, like, when I introduced myself, I kind of explained, like, I said I'm a little person or dwarf, and that's really how I explain myself in general,

I always say both because I know that people have a concept of what a dwarf is, and that concept is often not human. And I will say, like, the objectification and dehumanization of people with dwarfism goes back centuries. This is not new. and, there's a really great podcast and content creator.

Aubrey Smalls, he has a podcast, Dwarfism History, and a lot of his content does really examine it, and it's really great, and I highly suggest people follow and listen, so that's not new, but, so I'll say, I'm a dwarf or a little person, because dwarfism is my diagnosis, I am medically a dwarf, but because of these preconceived notions of what a dwarf is that aren't human, I have to say little person, and the problem is, Not a problem with that, but like something that someone pointed out recently is like they'll say I'm a little person or dwarf to Challenge what it means to be a little person in the sense that we refer to children as little people Children are little adults are not little so having to describe ourself as a little person what does that mean?

And I never thought of it like that. So it's like how do we define ourselves in a way that doesn't get us treated like a child or like a mythical creature or less than human and that shouldn't be a question that we as humans have to answer like that shouldn't be a debate like it shouldn't be and that's also something that shouldn't be on us. To have to try to explain, that shouldn't be on us.

Emma Vogelmann: I'm just sort of like mulling over the conversation and this realization of you know what it means, and I hate it when people try to weaponize your own self identifying language and try and make you feel like you should be using a different term to describe yourself, because it might make them feel it might make them clearer, it might make them more comfortable, whatever it might be. And I've had that a lot with, living in the US where you would say a person with a disability, I use that term in a tweet when I was relatively new to the disability activism space and someone sent me a long, not very nice email about why I shouldn't be using the term person with a disability, I should be using disabled person because that follows what the language that they use in the UK, which is around the social model of disability.

And I, I respect that is the terminology, but I was also describing myself. So I feel like give us the freedom to describe ourselves and our impairment, how we want to without trying to turn it into something that reflects on you in any way.

Exactly, I'm just still, I'm just like baffled at that because like to me I see that like the person with a disability versus disabled person like that's just how you, that's like more of a language issue of whether you identify as, use identity first or person first language like that's not like they both mean the same thing.

Emma Vogelmann: It was a huge surprise. To me to receive that email and I've been extremely conscious of it since and now it's become second nature because of the field that I work in, which is disability in the charity sector. So I will now try and correct people on that language or educate them rather, I should say, instead of correct, it's sort of correct, but here's why, but to describe yourself.

I think you should be given the freedom to use the language that makes you feel comfortable. And, yeah, I think it's just so interesting how people will interpret, try and dance around language with disabilities. we've all seen the, you know, the memes like differently abled, or less able and it's I feel to try and make other people more. I feel like they're saying the right thing because they're not outright saying that you have a disability when like you say, we do we have a medical diagnosis, a condition, we can call it what we want in terms of.

you say person first, identity first, language, but ultimately, we do have a disability, so let's not pretend like we don't, or that it's not a part of who we are, because it's the same, that and the other, but if your identity impacts who you are.

Jillian Curwin: Exactly, calling us disabled is not an insult.

Emma Vogelmann: So what do you, if you were the director of the new Snow White movie? How would you want to see? That approach, which I know is a huge question that is, outside of probably your scope. I don't think you're a famous film director, but if you were, that'd be sick.

Jillian Curwin: I would say I'm not making this movie.

I think I would say this movie has, we have, one, we have Snow White, which, like it or not, the original, like it or not, that movie is cinematically important is the first animated film. It's you know for the time. It's well done in my opinion, I would say I'm not making this film, I think that's, but I recognize, I'm saying that as a little person, as a little person director.

If I was approaching it, though, assuming that I was the director from this, I would try to, I would say, fine, but I'm going to treat these characters as human. I'm going to cast little people actors.

They are going to have names. They can have the emotions that these characters have, so whether that is dopey, which I might change that one, happy, grumpy, they can have those emotions, but they're going to have real names. They're not going to be these helpless, individuals, we're going to really humanize them and say, like they are minors, explore that, like really show the humanity in these characters.

If we're saying that they are human, then we're going to treat them as humans. I feel like with the seven dwarves from the 1937, they're humans, but they're not treated like humans. So there again, that's like human like so yeah, I think that would be the approach I would have to it but I would then also say you know, it's 2024.

It's so weird, I keep wanting to say it's 2023. It's not. Yeah, me too. We have seen what happens when we diversify our concept of who a Disney princess is. We saw it with, Little Mermaid. With, Halle Bailey as Ariel and the reaction that got from young black girls who were able to say like we have our princess, we see ourselves and the power that we're seeing it with Asha in Wish, which I will confess this movie hadn't seen, but I've seen the reactions to it.

We saw it with the live action Mulan was like when we see these. roles that we typically see as one way of being cast, saying that there isn't really a limit to who this person can be, like, I would say that needs to apply to disability too. We need our disabled Disney princess, because there are young disabled girls who are still waiting for their Disney princess, who want to see disability be royal, be regal.

what are we waiting for? There's tons of disabled talent out there who would love to do that part, who would love to tell that story, who know how to tell that story. Give them the platform instead of retelling. a story where you're perpetuating harmful stereotypes.

what, it's like, again, like referring back to what Peter Dinklage, you can't want to try to score points while at the same time doing harm. It doesn't work like that. It shouldn't work like that.

Emma Vogelmann: And that's what I was thinking when they were talking about Snow White is that they, and I know, The actress got like a bit of flak and

that is probably an understatement, but for saying oh, it's 2023, she doesn't need to be rescued, all of that type of stuff.

So if they're going to try and quote unquote, like rev, not revolutionize, but modernize what Snow, who Snow White is, then why can't they do that? In a sensitive way to disability and disability representation and I feel that I and I talk about this on my social media a lot and I've mentioned this with Peter Dinklage characters as well is that so often disabled.

People in media, if they're in a mainstream movie, it'll either be as an object of pity, which I think is probably, and please correct me if I'm wrong, but I feel like that leans towards the wheelchair users, and I think, or they are depicted as a villain. And I know that he, and I haven't seen the new Hunger Games film, but I know that Peter Dinklage is a villain esque kind of character, and I didn't see it.

Jillian Curwin: I think I haven't seen it either.

Emma Vogelmann: Yeah, he, I think I read somewhere that he creates The Hunger Games, which, is creating a TV spectacle where teenagers kill each other. And I don't know if that sort of rings true to you.

We've talked about how dwarfism you feel is represented as either human like. Do you feel like those two representations of disability resonate with how you view media?

Jillian Curwin: I do, and I completely agree. I think that often the just, disability, and I'm not referring to just dwarfism, oddly enough, I'll say dwarfism is rarely seen as more of like the pitiful character. rarely, I'm not saying that it's not often. but I think in terms of like when we see like when it's disabilities treated like that, it's very rarely a little person in that role. I think you're 100 percent right. And Peter Dinklage is an interesting example of just a disability representation in general, because he has said from the beginning, and I don't think people with talking about him now, fully understand that he said from the beginning he was not going to take on roles that played into the stereotypes.

That wasn't something he then was able to say once he became Peter Dinklage. That was his mindset from the beginning. He just got incredibly lucky with the roles that he was able to get. And the one role that comes to mind where I think the character I don't want to say falls into that victim category, but is treated in some ways like, is like victimized or is, but it's it's very real, is the station agent,

which is like his big break character is really treated the way people with dwarfism are treated in the real world where they are, in some instances, humiliated, they are insulted, they are mocked, and Yes, that character is in some way being victimized.

It's very real. And that role really made him, and, but he said from the beginning, I'm not gonna take on parts where I'm playing an elf. I'm not gonna play one of the seven dwarfs. I'm not going to do these roles. He'll be in fantasy, but he's not going to do those kinds of roles and.

It's interesting because I know that I didn't read all of the books. I tried and I just couldn't do it. with like Game of Thrones with Tyrion, I think that the representation of Tyrion that he portrayed is different from the books in the sense that he Took away some of those more stereotypical parts to the character as he's portrayed in the book and made and grounded him more.

but yeah, he's still a character who will call himself an imp, who, but he says I do that so people can't use it against me. And so I think that it's just, it's a very interesting. His career is like just very interesting to see from like the representation perspective, but it's always lost that people think that he was able to take the stance that he takes all the time.

Once he became Peter Dinklage like once he got Tyrion but it's like failing to recognize like no that was always his approach to his career that he was never going to take those roles he just got incredibly lucky and it's also incredibly talented that he was able to do that.

Emma Vogelmann: Yeah, he is a fantastic actor, like there is absolutely no denying it, but I personally didn't know that about his, his stance when he started it.

In the career because when you said he's not going to play an elf. Of course, Christmas was fairly recently and Elf is one of the big Christmas films and he plays a character who gets called an elf and, by Buddy the Elf who, you know, not a real human, but he physically attacks him for calling him an elf, which I think is really, it's really interesting, but it's now thinking about it a bit more seriously, is making a point, isn't it?

It's that, yes, there, this is the joke of the scene, but the point is that he is this incredible children's book author, illustrator, whatever, and he's being taken incredibly seriously by the other non disabled characters in the scene. But, he gets called an elf, attacks him, and then leaves because he's gonna not be treated

that way. I've never analyzed sort of his inclusion in that film in a serious way, but does that sort of feel like how you've understood it?

Jillian Curwin: Yeah, I saw, cause Elf is interesting, and Elf I think people try to bring up to say no, he did this, like he's called an elf, but it's like, he doesn't accept that, like he stands up for himself.

Yes, he does it in a way that is somewhat comical, but I do think that anyone pushed to their breaking point, if that was an average height actor getting repeatedly insulted and then decided like, nobody would throw an issue, even in a comedy, nobody would have an issue with it, or would still think it's funny, but people like to, you know, I think with Elf that, he stands still firmly in his humanity.

He's like, I'm not an elf. Don't call me that. Don't, I'm a human. I'm the boss in this situation. I'm in the, like, he's the, has the most power in that room. Um, so, yeah, elf is always like, people try to, like, say, like, well, like, he didn't, and it's like, no. No, watch the movie. He doesn't allow himself to be called an elf.

He doesn't allow himself to be treated like an elf.

Emma Vogelmann: No, he, you're right. He is the one with the most power in that room so much so that they are Begging him, paying him, whatever he wants to come in and, save their asses, essentially, and he does leave, and they, they end up ripping off his idea, which, or they try to, which is not great, but it shows that what the non disabled characters in that scene did not value is his mind, his expertise, and his career. And I think that's really quite interesting when you think about it in light of what you've told me about Peter Dinklage as an actor.

Jillian Curwin: Yeah, I think it's the idea of like representation as a whole, I'll say like in every, for a lot of instances of this, there's the one, it's we have our one, so we're good.

Yeah, no, don't stop at your one, one is not enough, it's not enough and, you know, and representation in other ways so it should not be enough and how you see disability. In the U.S. we really need to see disability in our media in the sense of not just reality TV, but more like news, TV, more normalized and like the present, like we don't have that here and I think that is, and same thing like with fashion, like in that like sense of like just seeing real representation of disability where they're not a character is something that we need to really see.

Yeah, like we need to catch up because we're not there yet.

Emma Vogelmann: Yeah, I love seeing a disabled actor in a role when their disability isn't the point. Like it's not a factor of the scene. They just happen to be an amputee that just happened to be a wheelchair user, and it's not the point of their inclusion because, we, it's not the entire point of our existence. Why should it be for media.

Jillian Curwin: Exactly, like being disabled, as a whole, being a disabled person is only a part of, I think, like of who we are as individuals, but there are disabled activists, disabled writers, disabled people, doctors, disabled lawyers, and they see themselves as doctors, lawyers, etc, and it's their job title here, and they recognize that a disability is part of them, but it doesn't define it. Them. And in some ways, in some instances, like that's not their main identifying trait or how they really wanna see themselves and identify themselves as it's more of what they do. What they're capable of.

Emma Vogelmann: Yeah, I, I completely agree. And that brings me to what, sadly probably our last. Question, although I'm aware, like I could easily talk to you for, for hours.

Jillian Curwin: But that just means you need to come on my podcast. That's what's really going to happen next.

Emma Vogelmann: Oh, my God, I would love to. And this beautifully segues me into what you said that you're going to do a bit more broad interview or, solo episodes, et cetera, with always looking up. But what are you hoping to do in 2024 with Always Looking Up?

Jillian Curwin: I think the main goal with going into this year is I think with last year it was more getting guests and like having conversations with people diversifying my guests in terms of like different disabilities, different fields, different professions.

And I think with this year, it's really diversifying my topics that we talk about and also really being less afraid to talk about subjects that I think, in some instances non disabled audiences aren't necessarily ready to hear, but also instances where maybe disabled audiences aren't ready to hear or also maybe not necessarily examining conversations that are happening, but coming at them from a different perspective.

so I think that's my big goal in terms of letting those limitations and it might have. Unconsciously put in place around like what we talk about, letting those go and really being more open in what we talk about and in doing so being able

to continue diversifying who we get on the podcast and talking to people who really have a different life experience than I do and having a conversation, having a debate and really amplifying those voices like I always tell my guests like my podcast really isn't my space, it's theirs.

Emma Vogelmann: Well, I am just, yeah, beyond excited to see what you do with the podcast this year and would highly recommend it to absolutely all of my listeners, because I think it would just open them up to new, amazing disabled people that they haven't heard of and hear some incredibly important conversations.

And so. I just want to now say a huge, huge thank you to you for spending your Saturday with me and recording this. It's been just so much fun getting to know you.

Jillian Curwin: Thank you so lovely coming on. Thank you so much for inviting me. And yeah, you're gonna have to come on my podcast and that's not a question.

Emma Vogelmann: I would love nothing more. So everyone that stay tuned for that episode where we flip the script. Exactly.

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