29. Disability and…SciFi with Zuleika Lebow and Kyla Harris

**Ian Rattray**

Welcome to the Graeae and Disability Arts Online podcast Disability and... bringing together thoughtful discussion and debate. This month, Zuleika Lebow, guest editor of Disability Arts Online chats with artist Kyla Harris about science fiction and her wheelchair Edna. This podcast contains references to ableism and strong language.

**Zuleika Lebow**

Hello everyone and welcome to this special edition of the Disability Arts Online podcast. My name is Zuleika Lebow, and I am the guest editor for essentially the month of October for Disability Arts Online. And today I am joined by the wonderful, phenomenal Kyla Harris, who is an artist, activist, blogger, filmmaker, writer. Any more adjectives you want to you want to add to that Kyla?

**Kyla Harris**

I don't know, culinary wizard? I don't know. I mean, there are just so many facets to everyone's personality.

**Zuleika Lebow**

Audience members, Kyla has probably never cooked for you, but I hope one day you get the chance to sample her amazing culinary skills because they are truly, truly brilliant. I have never left her house without my tongue practically exploding with joy.

**Kyla Harris**

I hope that's a good exposure.

**Zuleika Lebow**

Oh, yeah, very much so. Very much so. So today, we're here to essentially talk about you and your relationship with technology and all things Sci-Fi and fantasy. And I'm going to chime in a little bit. But really I want to kind of get started with the theme of this guest editorship, which is the relationship that disabled women, femmes of colour, have with sci fi and fantasy. And I think this is a very important topic that often gets whitewashed and man-washed, if you can say that?

**Kyla Harris**

You just did!

**Zuleika Lebow**

I just did! I made it official.

**Kyla Harris**

You made it official!

**Zuleika Lebow**

So yeah, I'd love to hear your kind of early inspirations from Sci-Fi and fantasy, like what has...

**Kyla Harris**

Oh my gosh. Well, okay, I'm not a Sci-Fi or fantasy writer, and I was a tUniversity and I wasn't able to complete a course. So essentially I had to go to a Summer school at Uni, and take one of these kind of courses that you don't actually want to take. And it was on Sci-Fi. And I was like, 'Oh, this is gonna be the death of us...!' One of the assignments was to read HG Wells' The Time Machine, and it completely changed my view on Sci-Fi and the genre and how it can be such a incredible tool as a genre to mirror and reflect back society, like current and contemporary society. And I love how evocative, specifically The Time Machine, it just really opened my eyes like your tongue exploding with joy. My new Sci-Fi brain exploded with joy and and I wouldn't say that I'm even a diehard sci fi fantasy lover, but there's just such a wonderful escape within that genre, whilst also being able to reflect back on why we need it and how it's still relevant to what we experience today.

**Zuleika Lebow**

So you weren't raised Sci-Fi, you're a convert.

**Kyla Harris**

Yeah, yeah. Hell no, it's definitely not raised Sci-Fi. No. I was raised like, Shakespeare.

**Zuleika Lebow**

Okay.

**Kyla Harris**

I was raised like, American literature; Of Mice and Men, I was raised To Kill a Mockingbird, and very kind of like gritty American literature and then the English Lit that... You know, like there was always something about Chaucer and like how you described boils, that really ignited my imagination.

**Zuleika Lebow**

Have boils made a reappearance in your writing since Chaucer?

**Kyla Harris**

No, just in my nightmares. I mean, I'm such a visual person that when I read Chaucer, I really see that boil. I see. I see how ready it is to erupt. Like how many there are in the surrounding skin. Like, I'm just I'm there. I'm there in the Canterbury Tales on the journey, with the boils.

**Zuleika Lebow**

Absorbed in the boil! Well, I think that's a really interesting point because I was raised Sci-Fi. So yeah, I definitely was raised Sci-Fi. So my Mum... Essentially, this is a story that she tells, and every time she tells it, she gets tears in her eyes. So, she was a kid when Marvel first started releasing the X-Men comics, and she collected all of them. And at that time, that was not really something that girls did particularly. And she went away to university, and she left them in her room, and my grandmother threw them all away.

**Kyla Harris**

I mean, you have a horrified look in your eyes. Yeah, like a piece of your heart has just broken, crumbled into ash, and you've had to sweep it up yourself and put it in the bin.

**Zuleika Lebow**

It really... I mean, I have second hand trauma from this.

**Kyla Harris**

Yeah. Intergenerational trauma

**Zuleika Lebow**

It really is because I mean, first of all, they're first edition, they would have been worth so much money. But just the fact that my Grandmother, thought they were worthless -the X-Men were worthless and just chucked them away. So yeah, my Mum told me this story practically every time she was annoyed with my Grandmother. She did this!

**Kyla Harris**

Was it a weekly occurrence?

**Zuleika Lebow**

At least once a month. Once a month, yeah. I grew up watching X-Men, which probably I shouldn't have actually been watching it quite a young age. But we watched X Files together, and saw Terminator at quite a young age, and lots of cartoons. All of the X-Men, definitely the X-Men cartoons. And so yeah, definitely raised Sci-Fi. It was always around, always talking about time machines, Doctor Who, and so I'm quite confused by people who aren't raised Sci-Fi. It's one of those things.

**Kyla Harris**

Am I a confusing species?

**Zuleika Lebow**

Well, not now because you've kind of come into it. But you know when people say, 'Oh, I have no idea about any kind of Sci-Fi reference' I just sort of think, what rock have you been under? But that's because it's been so much a part of my life since I was young.

**Kyla Harris**

I didn't know that. I didn't know that it was so kind of ingrained in your upbringing. I mean, it does make sense. And it does make sense how you kind of transfer and reflect your own experiences to these kind of Sci-Fi characters. So thanks for making sense. I try!

**Zuleika Lebow**

So actually, you saying that brings me on to a neat point, which is, is there a Sci-Fi fantasy character now that you really do kind of identify with?

**Kyla Harris**

Well, it's funny that you mentioned X-Men because I always loved Storm. Storm was just such a radical boss bitch that always held it down, but was also still able to be vulnerable. And like that, she just looked fucking great. She just also killed it with her looks. So I also, yeah, just going back to to HG Wells and The Time Machine, I just really relate to how he really explored like the class divide. And the division between the subterranean species and the earthly species, and I can't remember what they're called, I should have revised HG Wells before we started talking. Well, at least The Time Machine! But I really relate to this kind of idea of having something happen in the world that changes the course of humanity and dividing it. And I feel like that is so relatable today, because I feel like there can be a stark division between disabled people and non-disabled people and our experiences of life. And so sometimes it makes me wonder, like, what would that be like, if we divided into two species based on disabled and non-disabled? What would that look like? What would our community develop into and be, and what would it feel like? What would it taste like? Like, you know, all of those things and then would we be at war with non-disabled people? Or would we be able to live in harmony? And then there's also the divide as well to me of class. And you know, currently, it's like so many disabled people are... we're just not paid anywhere near the amount of non-disabled people. I can't remember the statistics for that now, but you know that creates a huge wealth and class divide as well. So I guess there are all of these kind of ways that I respect and contemplate more of the environments and the scenarios in Sci-Fi, and less, potentially with characters. More with the circumstances.

**Zuleika Lebow**

Yeah, I see exactly what you're saying. And audience, I have been nodding frenetically the entire time. I had to stop myself because I felt like my head was gonna bobble off. I think yeah, that raises a very interesting point. Because a lot of people think that Sci-Fi fantasy, it's not real. It doesn't reflect anything of real life. But when you get shows like say Game of Thrones, you get shows like The Walking Dead, you get like Doctor Who, any of these shows that so kind of capture the imagination of people or HG Wells, who obviously was hysterically popular in his time that captured the imagination. I think that idea that it's not real is actually so... I'm just going to say it's quite basic really. It's quite basic, because you're just seeing, you know, wizards and things and you just think 'Oh, that's got nothing to do with me' But 10 seconds of a deeper look and actually there's a lot there, as you said.

**Kyla Harris**

Yeah, I think there are also like, it's a great way of looking at like archetypes, as well. And I think that there's something that, like I always identified with Morgana in the kind of Merlin fables and tales, and I think that there was always something about this, like the archetype of the witch and what kind of effect they have on on men, -there's no way around saying it- and their kind of sexual power and that being seen as a threat. And also just being like kind of... Morgana was always kind of cast out from society and always very... seen as being kind of being othered and I think that there's something that I really relate to with all of those things.

**Zuleika Lebow**

Yeah. Well, she had a disability as well. Yeah, so in the Morte D'Arthur, because I'm also obsessed with Arthurian legend, I got got really into it. She's not necessarily partially sighted, but one of her eyes looks different from the other. And throughout the book, they just kind of talk about how hideous she is, and if you look at one side of her face, she could be very pretty if only she didn't have that eye, kind of thing. And I think a lot of representations of witches, of anybody who is othered, there's always that kind of caveat of 'Oh, if only they didn't have that thing, they'd be so great.' I think that's probably why we relate to them the most, because they're others like we are. Also, we've heard that phrase so many times, 'Oh, if only you didn't have this thing, or that thing would be so perfect.'

**Kyla Harris**

What?! Yes, oh you have such a pretty face!

**Zuleika Lebow**

Yeah. Yeah. Particularly if you identify as somebody who's fat or chubb, you've probably heard that a lot. Like, 'Oh, if only you lost some weight, you'd be really great.' Yeah, it's a pretty horrific thing to hear. But I think it also, you definitely relate to the outcast and Sci-Fi as written by outcasts and so it's full of outcasts.

**Kyla Harris**

Yeah, that's really interesting about Morgana. I think the other thing that I identify with is the use of, and don't agree with because it does perpetuate ablest narratives, but the idea of disability as a metaphor. Like Morgana is seen as a bad person and her disability reflects that. Her facial disfigurement, perhaps or partial sightedness reflects her morally corrupt character, and therefore, she deserves to be disabled. And that is a negative thing and could not be a positive thing and disability is seen as kind of like retribution.

**Zuleika Lebow**

Yeah, and it was for such a long time. And it is something that I think when we as disabled people are talking about Sci-Fi, it's such a strong thread throughout the genre, just because it's been such a strong thread in society. That I think our, or at least me with this editorship, what I'm trying to do is actually take that back and say 'No. It does belong to us. There is room for us in here and it should be ours.'

**Kyla Harris**

Well, it's also like in a way, a refreshing way of exploring disability too. It's out in the open, it's talked about it's a part of, you know, the X-Men is a really good example of like, all of the characters having some kind of a disability that is their superpower. Although I don't want to go into like an inspiration porn, superhuman disabled disability kind of thing. But, you know, but that it's an attribute to them. I mean, I know that wider society's afraid of X-Men but they are our heroes, you know, they're who we follow. They're who we explore. They're who we relate to and connect with. So I think it is ours for sure. It's just that in the same way that it's not written by us and should be, but it is ours and it's our history and it's our current... I was actually wondering, what do you think of Frankenstein? Because I feel like Frankenstein is something that needs to be explored within disability.

**Zuleika Lebow**

I think Frankenstein is such an under utilised metaphor.

**Kyla Harris**

Yes, exactly!

**Zuleika Lebow**

Is such an under utilised metaphor, and I think not enough credit, although there is more now, particularly with Reddit threads: history Reddit threads and Sci-Fi Reddit threads, where people are saying 'Oh, you know, the earliest Sci-Fi novel was written by Mary Shelley and nobody is talking about it. Why is nobody giving this woman her flowers?' And I think it's such an unde rutilised metaphor because the first question that came up for me when I read it, and you know, watching all the movies, and everything was who is actually the monster?

**Kyla Harris**

Yeah, I think it's must be like society's monster, right?

**Zuleika Lebow**

Yeah, right. First and foremost. And you know, Dr. Frankenstein creates this creature that again, he has all these aspirations of the creature being beautiful. He takes the most beautiful parts from all of these corpses and meshes them together, and instead of it being beautiful, just like he wanted, it comes out as not beautiful. And I think that's such an interesting metaphor for how we kind of think about things like having children, things like what we create as artists, our flexibility around what we want to happen and what actually comes out happy accidents and things like that. But also like in a wider societal thing, our expectations of what is beautiful, or what is the thing to do, or the way to behave or the way to look and the reality often don't, for me in my mind anyway, they don't match match up at all.

**Kyla Harris**

Ooh. I'm just going to turn towards you for a sec. Okay, because turning Edna on turning towards you so I can properly get even more into the combo. Yeah, so I was kind of, not reintroduced... I came to Frankenstein again recently, during the pandemic. There was a National Theatre production online, and it was starring Benedict Cumberbatch as Dr. Frankenstein and what's that hot guy's name? That was married to Angelina Jolie?

**Zuleika Lebow**

Which one? Brad Pitt? Johnny Lee Miller?

**Kyla Harris**

Johnny Lee Miller!Johnny Lee Miller played the creature and it was such an unbelievable production. It was so stunning and it was so well cast and so interesting. But it struck me for the first time of the creature being disabled, the creature being the metaphor for not only physically but also the creature kind of almost being born with a learning disability.

**Zuleika Lebow**

Absolutely.

**Kyla Harris**

And it was just so shocking to me, that I felt like viscerally, I felt that Johnny Lee Miller should not be playing the creature. I felt a disabled person needs to be playing the creature and it needs to be put more in front of our face that this is our story and our narrative as well, because we are so hunted by society. And you know, often killed by society. Yeah, I'm not fucking around with my words with that one, because I was going to be nice about it, but now we are so often hunted by society and our lives are at risk because of ableism. That's what struck me with the killing of a preacher at the end of Frankenstein. Oh, it was so heartbreaking. It was so heartbreaking.

**Zuleika Lebow**

It is a very moving story and I would say that anybody who has not read Frankenstein, to try. I think a lot of it as wel, is that we think about books written at that time as being very difficult to read and actually, it's not.

**Kyla Harris**

Oh it's such a page-turner.

**Zuleika Lebow**

It's very much a page-turner.

**Kyla Harris**

It's so beautifully written. So well crafted. And so... it's a stunning, stunning piece of work.

**Zuleika Lebow**

There's so many ways that you can read it, but I think the way that you presented it just now Kyla is really poignant for obviously this conversation and the wider editorship and just how people, especially now during the pandemic, and this whole mask wearing/not mask wearing, our relationship with technology and the track and trace app...

**Kyla Harris**

Yeah, and vaccines

**Zuleika Lebow**

And vaccines, yeah, and the misinformation, being what people think about the creature versus how he actually is and what his actual intentions are, just because he's not pretty is so you know... And I often think about that, about the kind of the face of disability and who our representatives are. You know, they're usually 'acceptable' disabled people.

**Kyla Harris**

Yeah, there's this really incredible... One of my favourite pieces of disability literature is by Mia Mingus. And she wrote this essay called Beyond Desirability and it's about really embracing ugly and accepting magnificence. Like, you know, she goes on to kind of be like 'I don't want beautiful friends, I want magnificent friends.' And I think that's what I think of my disabled friends that you know, really embrace disability justice. They are magnificent. You are magnificent.

**Zuleika Lebow**

Thanks mate! Thank you. Yeah, but definitely I think I would much rather be magnificent. Well, you know, what's that line from Bianca Del Rio? Pretty fades, dumb is forever! Well, I mean, obviously dumb is an ableist word, but you know, that kind of thing about investing in something other than looking good, especially as a woman is a very powerful thing. Very powerful thing. So you kind of touched on Edna a little bit when you moved yourself around to stare in my boat a bit more. I'd really love to know about your story with Edna? How Edna got her name?

**Kyla Harris**

So for people who have not had my meals or seen me in person, Edna is my power chair. She's very... she's a beast. She's an absolute beast of beauty. She looks very wheelchair-y. There's no hiding that she's a wheelchair, nor should she hide that she's a wheelchair. I got her, maybe eight years ago? Yeah, eight or nine years ago, and she absolutely changed my life. I've never had a relationship with technology to the point where I wanted to make... you know, name something. Name an inanimate object. And yet, Edna just presented herself to me and became so much a part of my identity and joy and way of living that she deserves a title: Dame Edna.

**Zuleika Lebow**

So is she named after Dame Edna?

**Kyla Harris**

No, no, she isn't. That was a happy accident. So what happened is basically the first time, the first... I had used a manual chair up until that point for kind of like, over 10 years of my having a disability. And I was 26, I think, and I somehow gotten to this charity, which was like Whizz Kids, which I did not feel like a kid and it was very bizarre. I was married and had three stepchildren at the time. Like, I was not a child, but thanks for the free wheelchair. And they had recommended that I use a power chair and I think, you know, I kind of avoided using power chair beforehand because I'd had so much internalised ableism and being Canadian, there's such a living in Canada, for most of the country culturally, it's so ableist. Ugh, it's just so based on the physical and that as being someone's biggest asset, whether it's looks, whether its ability to chop down a tree, you know it's very Canadian. So I had so much internalised ableism that I never saw myself as wanting a power chair, but also in a way needing it. Because I felt like 'Oh, well I can wheel for quite a bit. Oh, but I do need assistance with someone wheeling me whilst I'm outside.' There wasn't this whole idea of you could get a power chair and like you would be independent. And so when I came to the UK and lived in London, and happened upon Whizz Kids being an adult, I kind of went in and it was like this moment of absolute, like, just such excitement, such excitement. And I remember, I was living in Bethnal Green, and went to Columbia Road flower market, and it was my first trip out with Edna and a bunch of friends. And they were like 'Oh, we're gonna stay out for a bit, and you know duh-duh-duh...' That I was like, you know what? I kind of just feel like going home. And I went in Edna, you know, to the flower market, but also back home by myself for the first time in 15 years. I had been by myself outdoors. And I arrived at my front door and just burst into tears, because of the sense of freedom that she gave me. And the sense of absolute autonomy and joy, and excitement, and possibility and potential. And all of these things were wrapped up in my ugly beast of burden and beauty. You know? And I had a PA of Eastern... at the time, and she was very, very much involved in my life and a very big support whilst I was going through an incredibly difficult time. I said, I really want to name her. I was in bed and kind staring a it lovingly. AndI said, I don't know, what should I call her? And my PA turned to me, and it was just a dead pan thick Eastern European accent and I was just like, 'Yes.Yes.!' I've never looked back and neither has Edna. I mean, Edna is ... Yeah, I would say if she was a car she'd kind of be like a hybrid between a Jeep and a Rolls Royce. Oh, wow. I love that. Yes. She's also like part Transformer. Yeah. Because I can use this function which I think they're no longer allowing on the NHS...

**Zuleika Lebow**

Right.

**Kyla Harris**

...which is raising Edna, so the seat raises to what I call barstool heights. I often bring my own barstool to the bar in the form of Edna. And that was transformative as well, because I was always like... I'm five foot 10, and I remember one of the first things that happened after my accident, I was out in a gallery in my manual wheelchair, and my Dad wheeled me right in front of a group of people right in front of this painting. And I started ducking, and I went 'Dad, Dad! No. Like, what are you doing?!' Because I was so used to being so tall and being the kid at the back of the photo, never the front, that I've always had that in crowds. I always kind of made sure that other people that were shorter, kind of stood in front. And I didn't realise that physical change in height because of sitting down. And so now when I raise up, it's close to my actual height and that's really important socially. And I love being able to be at the same height as people and talk to them in their eyes when they're standing. And yeah, so she's just been transformative in that sense too.

**Zuleika Lebow**

It's also like a really great power move. You know, somebody's trying to throw their weight around, you can just raise Edna up a couple of inches and then it's like, okay, yes.

**Kyla Harris**

Yes. I mean, she does weigh a lot as well. so I could literally throw her weight around.

**Zuleika Lebow**

Yes, and run over people. I'm sure you've wanted to do that a few times.

**Kyla Harris**

Maybe it's like a tank-Rolls Royce hybrid.

**Zuleika Lebow**

Hybrid. Absolutely. I mean, there's so much in what you just said, and that amazing story you described as like having independence for the first time, in a long time.

**Kyla Harris**

I do want to have a caveat around the word independence, because I don't think anyone is independent. And I think independence is absolutely a myth. So when I say independence, I do suppose I more mean autonomy. Yeah. Because I believe everyone is interdependent.

**Zuleika Lebow**

Yeah. I mean, that kind of brings us neatly on to 'It's Personal' doesn't it?

**Kyla Harris**

Oh, are we going there?

**Zuleika Lebow**

Yeah, we can go there. Do you want to go there?

**Kyla Harris**

You go there, this is your your gig.

**Zuleika Lebow**

This is my gig. This is my show. Well, I remember going to a talk that you and Lou McNamara delivered a couple of weeks ago,

**Kyla Harris**

A workshop

**Zuleika Lebow**

A workshop.

**Kyla Harris**

God, it was months ago now...

**Zuleika Lebow**

Yes, it was months ago. About interdependence, and about It's Personal. And obviously Edna is a big part of It's Personal.

**Kyla Harris**

She has her own title card.

**Zuleika Lebow**

She does. She does. As she should...

**Kyla Harris**

She should because I mean it's what she deserves

**Zuleika Lebow**

...she should, I mean, Edna as herself.

**Kyla Harris**

Yeah, yes. Edna was starring as herself

**Zuleika Lebow**

Because nobody else can play her, it's very hard...

**Kyla Harris**

Yes, absolutely!

**Zuleika Lebow**

But thinking about It's Personal, and one of the things that struck me is both you and Lou have this fascination with reality TV?

**Kyla Harris**

Yes. I think that maybe you should describe what It's Personal is, for people that don't know It's Personal.

**Zuleika Lebow**

So, It's Personal is an incredible... would you call it a short film or an episode?

**Kyla Harris**

I'd like to say both. At its current state it is a short film but it also acts as a proof of concept for an episode, episodic series.

**Zuleika Lebow**

An episodic series about Kyla and her personal care, and the difficulties that Kyla had finding personal care during the pandemic. But also asking Lou McNamara, who is a good friend, and an amazing filmmaker to come in and train as Kyla's PA, for a period of what was it -one week? Or was it five days?

**Kyla Harris**

It was one week.

**Zuleika Lebow**

One week. As an experiment to see if Lou, well both of you, to see if you could train Lou in that time to be a PA, and if Lou could actually do it.

**Kyla Harris**

And if Lou could be trained!

**Zuleika Lebow**

And if Lou could be trained, yeah!

**Zuleika Lebow & Kyla Harris**

Sorry Lou!

**Zuleika Lebow**

I remember hearing you talk about it and you said, both of you said, you had such a hunger for reality TV and such a love for it. And I think that really speaks to... in a different kind of way, the love of Sci-Fi, and this idea of it being like a hyper-reality, but too much of reality. We definitely consume reality TV because even though it's supposed to be real, it's on the edge of real. There's an uncanny-ness about it that is not actually, you know, we know it's not real. We know these fights are not real. They're obviously scripted.

**Kyla Harris**

I think more staged, staged. Yeah. Yeah.

**Zuleika Lebow**

So, I think in terms of It's Personal, one thing that I'm curious about, is how real it got versus how scripted it was?

**Kyla Harris**

Ooh, I'm sure I've answered this question before, but for some reason, it's eluding me and it feels very fresh. I think maybe that's just time as well. It's been, you know, It's Personal came out in February, and there was a lot of kind of hype around it then. It's kind of settled a bit, which is great, because we took it off the website to try and pursue actually turning it into a TV series. So it's no longer available online. I think, well, the scenario was and wasn't real. I did have personal care. It was more of the idea, because that's what happened when the pandemic first hit, is that I didn't know whether I'd have personal care in England or not. And there was this moment, which was probably only a few days, but felt like an eternity, where I didn't know whether I was going to be able to stay in England, and have all my care covered or if I needed to risk my life by flying to Canada to be with my family. To have them cover my care and potentially risk their lives if I bought COVID as well, because several of you know, my grandparents live with my parents and at the time my grandfather was dying. My Dad is a very... well he's disabled. He doesn't identify as disabled, which is another podcast. So that in a sense was manufactured. I had care covered. Loretta, who is in the series/episode, she offered to stay with me for three months.

**Zuleika Lebow**

Wow.

**Kyla Harris**

Yeah. Yeah. Yeah. So, I knew that I'd have that care covered and that Lou wasn't actually going to have to cover my care.

**Zuleika Lebow**

Okay.

**Kyla Harris**

But,it was a very real scenario for me during the pandemic, and, you know, could have been a solution to try and have Lou. But also not, because there's this odd, on boundaries, what do you do when you are thinking of hiring a friend to do your personal care? How does money change that dynamic? How does long hours spent together alone, change it? How does someone helping you pee or assisting you with peeing, how does that change your sense of vulnerability and equality? So, we explored all of those things and I suppose, in a way, I don't feel like It's Personal is about me. I think it's about disability and I think it's about vulnerability and equality. And Lou and I are just almost the stand-ins to kind of explore those topics, and topics of interdependence and what friendship really means. You know what friendship truly means.

**Zuleika Lebow**

It's such an important point that I think a lot of people didn't really think about in the pandemic, is what happens to people who need care?

**Kyla Harris**

Mm-hmm. Yeah, yeah.

**Zuleika Lebow**

And it felt, I think, for a lot of disabled people, even still now because it's not over. And I think for disabled people in particular, it feels really dystopian.

**Kyla Harris**

Oh, yeah. Yeah. Absolutely.

**Zuleika Lebow**

And it's what I really found interesting is that you and Lou managed to make this slice of dystopian reality TV.

**Kyla Harris**

Haha ha! I want that to be our brand.

**Zuleika Lebow**

Yeah, but it was fun and it was fresh, it was exciting, it was vulnerable. It was all of the things that you need from a show. I was so engrossed in it and then it was over and I wanted to click... I wanted that Netflix bar to come up and it just didn't happen. So please, somebody come and fund It's Personal.

**Kyla Harris**

Please Netflix!

**Zuleika Lebow**

Please Netflix, ahem! But I think for me, it did feel -it's not directly a Sci-Fi reality TV show. Yeah, but just because it's located within this very dystopian but strange time

**Kyla Harris**

I love that. I love that can be related to Sci-Fi and fantasy because it is, it is dystopian, it does feel very dystopian. And it felt like we did create our own world like that between Lou and I and in that household. It was almost a lab for community as well, and what community means and what the purpose of community is and can do.

**Zuleika Lebow**

I do think you know, speaking about community, and relating that kind of back to what you were saying about the class system in HG Wells' The Time Machine. Having our silos of community and our different pockets, I think is so important because especially now when certain political regimes are trying to kill us, and don't seem to care. Having, almost having an underground society where we do take care of each other is so important. And I'm just kind of wondering, you know, what do you think would be the first steps to creating such a criptopia?

**Kyla Harris**

Oh my God, I love criptopia! I love that word now that you've presumably just coined?

**Zuleika Lebow**

I don't know, I might have read it somewhere.

**Kyla Harris**

Well, we're going to co-opt it if it does exist for the purposes of this episode. Yeah, I think criptopia is based on communication and boundaries. And I think it's based on openness and equality, and I think non-disabled people are very welcome as long as they adhere to those policies.

**Zuleika Lebow**

Right...

**Kyla Harris**

Boom.

**Zuleika Lebow**

Boom. You don't have to go home, but you can't stay here if you cannot adhere to these very basic rules.

**Kyla Harris**

Yeah, yeah. Because I think being a crip is so much about communicating, and being creative, and being really creative with what you have in the scenario that you're in. And that's like a method of survival. And I think communicating you know, certainly my life is... hinges on communication. To communicate what I need, to communicate what I like and what I don't like what you know. For some reason, it's now going into sex as well but it's like that's also important too, you know, because it affects every facet of life, communication. And I think that as crips to be able to communicate to other crips, there's this level of, well access intimacy, also bringing it back to Mia Mingus. Yeah, it's really recognising another person and seeing them for exactly who they are, what they are. And how you can support them, and they can support you, but without you depleting yourself.

**Zuleika Lebow**

That's a such an important point. And one of the things when I first met you, and I think I think I remarked upon this at the time, is that you have such an amazing way of communicating what you need and asking for help in such a wonderful, open way. And it's... I, when I saw you communicating like that, I realised how I had never been taught to communicate like that. And even when I became disabled, I was not ever taught that I would... You were an interdependent being before, and you even more will need people now, and you will need people to understand you and you'll need people to relate to you in a different way. And I definitely knew that there was some kind of something going on in my communication, because I was not letting people into that, I guess that inner sanctum to, you know, to think about Superman, that Fortress of Solitude, and it did feel quite lonely. And I think a lot of disabled people, especially when they're newly disabled or chronically ill, do feel lonely because we as a society, we haven't been taught those communication skills that you've graciously learned over time. I think it's, you know, it's obviously quite an unfair place to be put in. But one of the things that I really found was that communicating through kind of Sci-Fi, it definitely helped to giving people like an allegory. Going back to Frankenstein, using him as an allegory, or in my case, werewolves as an allegory for my disability definitely helped me to get people on the same page of like, 'Oh, wow, that's really what she's going through. It's not just like, she's got the flu.' Which I think a lot of people do think especially with chronic illness, 'Ah, you're you just...you know' Yeah, it's a different breed entirely. So, I definitely see you communicating and how you communicate, and I think maybe you should give classes. You know, when is the book coming out?!

**Kyla Harris**

Like, I write a handbook on how to be disabled?!

**Zuleika Lebow**

Yeah. How to communicate properly with people, and ask for what you need in a way that isn't, you know, asshole demanding: I want it now! That conveys all of that emotion without being horrible.

**Kyla Harris**

Well, thanks. And I've been nodding emphatically as well, to everything you've been saying before about just like how necessary it is and how, yeah, essentially, like I say, it is so essential to survival, I think. And I think it's really difficult for people to admit that they're vulnerable, for varying reasons. Like a lot of internalised ableism in society and blah, blah, blah... and even people not really be okay with the term vulnerable. And so, I think that can stop people from really divulging what they need or what they want. I think it's a complex subject. I think the complexity also comes with it perhaps not being choice.

**Zuleika Lebow**

Yeah.

**Kyla Harris**

Like, you don't want to have to do this. And so, there's an internal resistance to communicating perhaps for people. Because there's this idea of unfairness and this idea of why should I have to share this part of me with someone else? Which I get, and I have as well, you know. I think something that I've realised in the last couple years is that I have to be professional 24 hours, seven days a week. And I mean 24 hours, so that when in the middle of the night, if I'm calling personal assistant to help me pee at 4:13 AM, I still have to be pleasant. And I think that our survival shouldn't depend on our kindness, but I think our survival does depend on communication.

**Zuleika Lebow**

That is such an important point and I think most people don't really think about that. Because even me, you know, I don't have to... As much as I am invested in the disability sphere, as much as I am an activist, as much as I want to support my fellow crips, you know, everybody has different access needs, and you don't know what you don't know. So, until encountering somebody who needs 2- hour personal care, you're not gonna think, wow that person at 4:13AM when they have to get up to use the toilet still has to mind their P's and Q's.

**Kyla Harris**

Yeah, yeah.

**Zuleika Lebow**

...and communicate effectively. And also, you have to wake up and think there's a lot of forward planning involved in that as well. Because you have to... You, particularly, I've seen this happen, you have to get your phone and call your PA, and then your PA has to wake up, make it upstairs. There's so many processes involved in that, mental processes, before we even get to just do the job...

**Kyla Harris**

Empty your bladder. Yeah, yeah.

**Zuleika Lebow**

...and have a piss. I think, you know, we don't really necessarily realise that it is so important to our survival, not just as disabled people, but you know, society in general, we definitely overlook it.

**Kyla Harris**

Yeah, yeah. And I think that there's such a culture of repression here as well, and lack of communication. That I think it's something that people really are afraid of, like there's a lot of fear around communicating feelings and needs and wants, and it's not seen as desirable to do that perhaps or, you know, or to feminine, you know, is a massive thing as well, right? Like, yeah, communication is seen as a soft skill, which is often kind of relegated into the idea of awful woman-ness. You know, deviant female territory!

**Zuleika Lebow**

Ugh, she wants to talk to me, eurgh! I mean, thinking about that, you know, I've always wanted to get your perspective or just like a window into your experience of being a disabled woman of colour in a wheelchair, and how that is for you on a day to day?

**Kyla Harris**

Oh fuck, on a day to day? Yeah, it's difficult. I am also queer too, so it's like I have, you know, apart from being trans, I have all of the kind of, all the intersections. And an immigrant as well.

**Zuleika Lebow**

Yes.

**Kyla Harris**

An immigrant too. I suppose I have... I'm more middle class so I don't have a lot of... I'm very privileged in that sense. I've also come from a working-class background, but because of my accident and getting my settlement, I have funds and that has allowed me to have a really good quality of life. And I'm aware that like a lot of my disabled community doesn't have that. And yeah, I think it can be really lonely. I think it can be really lonely. Because a lot of my time, although like, most of my closest friends are disabled, my day-to-day existence is around white non-disabled women, as my personal assistants and as my partner. I love you, Angie!

**Zuleika Lebow**

We love you, Angie!

**Kyla Harris**

And it can be... while, like definitely I think my partner Angie is one of my biggest supports, and she's so empathetic and she has such a hunger for equality as well and understanding and supporting me, that I do feel less lonely because of her. And because she just appreciates me, and it's just so nice to have a partner that appreciates you! Revolutionary! So yeah, so it just feels like there's something... and also, I kind of have a bit of a... I don't know if I fully identify as a woman. I'm trying to work out that out, because I'm just having a lot of conversations with myself and a few friends and well, and now everyone here in this episode, listening to this and all of you strangers! Because I feel like 'woman' doesn't fully encompass my experience because gender to me is very much constructed.

**Zuleika Lebow**

Yeah.

**Kyla Harris**

That I feel like no pronoun really defines, like even being non-binary or being considered a man, or strictly a woman, and that doesn't really feel quite right. And so, I'm kind of figuring that out, and I'm not sure that there will be anything to figure out. I think it's just... I might have to sit in this unknowingness for some time, and that's okay. I mean, I am very femme. I do look very femme and have, and read as a woman, and so I'm treated as a woman. So, I think, you know, I was at this event last night, and I met a queer disabled woman of colour, who was a wheelchair user, and I was like, 'Wow, you are a unicorn. We are unicorns together.'

**Zuleika Lebow**

Two of you in the same room?

**Kyla Harris**

Yes! Sitting side by side.

**Zuleika Lebow**

Wow.

**Kyla Harris**

And I can't... I don't know if I've actually ever met a disabled queer woman of colour that's a wheelchair user before. And it was like -I see you. I see you.

**Zuleika Lebow**

Did her chair have a name as well?

**Kyla Harris**

We didn't get that far.

**Zuleika Lebow**

Damn.

**Kyla Harris**

No.

**Zuleika Lebow**

That is a real shame. Well, if you ever do find out the chairs' name, I think they should have a play date. I mean, obviously.

**Kyla Harris**

And you will be the mom, and we'll be the children that we're taking out to the park?

**Zuleika Lebow**

Yeah, exactly!

**Kyla Harris**

Yeah, why not?!

**Zuleika Lebow**

I'm up for it. I'm up for it. But that's exactly why I asked that question, because there are a few wheelchair using women of colour that I am aware of in the sphere, the disability sphere, but not many that I've met, or have a friendship with as I do with you. And not to say, you know, that kind of sounds a bit collect-ory. That's not what I mean, but I think obviously...

**Kyla Harris**

Put me in a cabinet!

**Zuleika Lebow**

Yeah. You know, but obviously, the disability sphere is so dominated by white femme appearing people.

**Kyla Harris**

I would say white, straight, cis men.

**Zuleika Lebow**

You think?

**Kyla Harris**

Yeah, yeah. Yeah.

**Zuleika Lebow**

Yeah, it's a weird thing. There's so much erasure, so much erasure.

**Kyla Harris**

I mean, that's where the Disability Justice Movement really kind of stemmed from or spurred from was women and non-binary and trans people feeling really erased from the Disability Rights Movement and not seen. And I feel like that in a lot of spaces that I'm in around advocacy. Try not to say too much around those spaces, but yeah, and and the work that I do.

**Zuleika Lebow**

Yes, yes. And I think that's a really important point and obviously I keep coming back to it, but it is my podcast, so whatever, I'll do it. Even in the Sci-Fi sphere you know, Mary Shelley invented the genre, Octavia Butler, -all of these women of colour kind of coming in. I think about Michelle Nichols almost every day. Shout out to you, as you are original Uhura. And then you have these kind of neck beards, like white cis neck beards on the internet just trying to erase and sanitise this, you know, amazing genre. And also, just in general, going back to disability, the disability movement as well. Sanitise and erase women of colour and trans people for really no good reason. Yeah, that's the reason.

**Kyla Harris**

No reason.

**Zuleika Lebow**

No reason. Well, we know the reason, but we won't say it. I think we're rounding off the hour. but I want to end with one last question, which is, aside from Edna, what is your favourite piece of technology?

**Kyla Harris**

Oh my gosh, well, I mean, it's undeniably my laptop. It's just my right hand, it really does feel like a part of me. Often an avoidant part of me, but definitely a part of me. I live and work on my laptop so much. Especially, like, you know, points of connection through zoom and stuff. Over the pandemic, it was a lifeline, and it's how I connect with my family: we're all in Canada. It's how I relax, it's how I learn. I think it's pretty integral too in terms of technology. But I also would love the idea and very much I've had times where I've not been with my phone or my laptop for a week, and it's been a very happy, connected time as well. So, I could do without my laptop, however, I could not do without Edna. So, no-one compares, nothing compares, as Sinead O'Connor says.

**Zuleika Lebow**

Edna, nothing compares to you. Well, thank you both so much for joining me today on this episode and sharing so vulnerably and being so open about your experiences. And is there anything else you'd like to say to our listeners before we sign off?

**Kyla Harris**

No, I just want to thank you. And for those of you who don't know Zuleika, she is currently wearing a purple snake-skin print dress with some neon-tipped long fingernails and her fiery locks are being backlit with Trafalgar Square behind us. And I think she's just a vulnerable powerhouse, and I appreciate you.

**Zuleika Lebow**

Thank you so much Kyla, I really appreciate that. And I'm going to describe Kyla for anyone listening now because Kyla is wearing a full-length woollen midnight blue number that looks cosy and squishy and elegant, with two chunky pieces of gold jewellery and her hair is... I don't know, like sort of tumbling around her face and she looks, she looks like a witch really!

**Kyla Harris**

Ha ha ha!

**Zuleika Lebow**

Maybe that's your pronoun. A witch?

**Kyla Harris**

Yeah, maybe. Maybe it is.

**Zuleika Lebow**

Okay, well, I think we're going to leave it there. Thank you so much to everyone at home for listening in and joining us today. Do remember to sign up to the Disability Arts Online newsletter that comes out every week. You can find that on the Disability Arts Online website. And yeah, stay tuned for the rest of my editorship. We have some amazing pieces of content coming up for you and I don't want you to miss a thing. So, make sure you subscribe. Anyway, ciao for now.

**Ian Rattray**

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