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Episode 25 – Disability inclusion in the workplace (Part 1): The lived experience, with Samantha Renke

Ellie: Before we share today's episode, we wanted to give our listeners a quick content warning. We'll be discussing some challenging themes relating to disability discrimination, which some listeners might find distressing. With that in mind, we would advise listener discretion as to whether you feel comfortable listening to this episode.

Hi and welcome to the Work Couch Podcast, your fortnightly deep dive into all things employment. Brought to you by the award-winning employment team at law firm RPC, we discuss the whole spectrum of employment law with the emphasis firmly on people. My name is Ellie Gelder and I'm a senior editor in the employment equality and engagement team here at RPC and I will be your host as we explore the constantly evolving and consistently challenging world of employment law and all the curveballs that it brings to businesses today. We hope by the end of this podcast that you'll feel better prepared to respond to these people challenges in a practical, commercial and inclusive way.

At this time of year, we're marking a number of disability awareness dates, including [Disability History Month](#), which started on the 14th of November, the theme of which this year, is disability, livelihood and employment. And we also look forward to [International Day of Persons with Disabilities](#) on the 3rd of December. So today, in the first part of our three-part Disability Inclusion at Work mini-series, we are looking at the world of work from the perspective of our colleagues in the disability community, including the day-to-day challenges and the lived experiences of living in an ableist world. And with me to share her own experiences and insights, I am really excited to welcome actress, broadcaster, writer, and disability rights campaigner, Samantha Renke.

Ellie: I know many of our listeners will know you from the fantastic work you're doing to campaign for people with both physical and hidden disabilities and how you're just totally rewriting the narrative around disability. So thank you so much for joining us today.

Samantha: No, thank you. And I know that I've worked with your wonderful team on a few occasions now. So it's always nice to be back and it's always nice to be back around this time of year. It's always my busiest time of year because as you mentioned, there's a lot in the disability calendar that we celebrate but I will a little bit of housekeeping I had a bit of a technical issue so I hope that everyone can hear me nice and loudly I used to be a high school teacher so I will remember to project my voice but also I'm having and I've been renovating a little bungalow I recently moved from London back to my hometown of Lancashire that's another story for another day however and I've had the builders in at the moment and they they're replacing all the internal doors because they've all warped so I can't even I can't even close them so the reason the reason why I'm sharing this with you is because I've got two very loud and cheeky cats and essentially apart from the bathroom I don't have any doors so ...

Ellie: Wow. OK. Okay, so any feline noises we've explained.

Samantha: Yeah, I can't lock them away. I mean, but to be fair, they often have quite some interesting points!

Ellie: Okay I can imagine, yeah, well, I'm keen to explore their opinions on this as well. Thank you so much. wonderful. So Sam, can we just start off by hearing about your own story and also the work that you're now doing to amplify the voices of people in the disability community?

Samantha: Yes, I was born with what would be perceived as a relatively rare genetic condition called osteogenesis imperfecta. It's more commonly known as brittle bone condition. So essentially I don't produce type one collagen in my body and that, you know, impacts, you know, my body as a whole. So it impacts mostly my bones, hence the term brittle bone condition. I've probably fractured over 200 bones in my life. As a child, I would fracture so frequently as an infant that I would be carried around on a pillow because obviously I couldn't be, I couldn't be cuddled like a, you know, a typical child. And I always kind of laugh because now I work in the entertainment industry and I am quite cheeky and I'm quite brash and tenacious and, you know, I don't mince my words and I definitely don't shy away from really taboo kind of subjects.

I just say, when did I get this kind of diva? It's like, maybe it was because you were carried around like a chihuahua. Essentially, so I was born in Germany and I grew up in Lancashire. I sadly lost my father when I was nine years old. And we're going to be talking a lot about disability and some of the tropes and some of the stereotypes that linked with that. One of which is like, you know, just tragedy narrative. But I always say when I'm delivering a keynote or when I'm talking about my life journey, is that actually losing a parent at age nine, if we really want to talk about tragedy in life, if we really want to talk about, you know, if anyone wants to feel sorry for me, then don't feel sorry for me because I'm a full-time wheelchair user and because I've, you know, got this condition. Feel sorry for me because you know what? At times my childhood sucked because I didn't have a father. You know, so I think it's really important that we listen to the stories of disabled and neurodivergent people like myself, because ultimately we can often, you know, just talk solely about their condition, their difference, their impairment, and forget that we're actually just human beings at the end of the day, and we've probably got a lot more in common than a lot of people may first think.

Ellie: Thank you Sam, that's a really important point to make - to focus on the person as opposed to their condition. Tell us about how your career has evolved so far and how you first became involved with activism and campaigning for disability rights.

Samantha: This is probably where I should plug my book because you can, yeah, "You are the best thing since sliced bread", there you go, you can read some memoirs, you can read about my life.

Essentially, I went to mainstream school, I went to college, I went to university, I did a post-grad, I became a language teacher. And then because I was really experiencing a lot of challenges in the place that I worked, I quit my job. I was a trustee for the Brittle Bone Society, so I kind of gravitated to the world of charity and I was like, hang on a minute, I like this, I like this world. It was a world where up until my early 20s, I actually pushed away from anything associated with disability and I'm often kind of quoted saying that I'm not ashamed to say that for a very long time I hated all the disabled people. And maybe we can touch upon that in terms of how I... internalised those kind of ableist views on disability. You know when I was, I think it was 2010 I became a trustee for the Brittle Bone Society and that really changed my trajectory because all of sudden I recognised that not only could I make a difference in my own life.

You know, we talk about, why did you get into activism? Why did you get into campaigning? And people tend to not take my answer seriously, but the truth is I did it because I was, for quite selfish reasons. I was sick of experiencing ableism, disability, barriers. I was sick of being treated differently. I'd worked really hard all my life to be successful in the eyes of society. You know, I conformed. You want me to do that? You want me to go to university? Yep. You want me to be a model student? Yep. You want me to, you know, kind of be a celebrity in my local town? Yep. Like I did everything that, you know, society would want from someone who is, you know, put on a kind of, pedestal. And still, even though I did all these things, you know, I still experienced a lot of barriers. I mean, a really good example would be at university, one of my lecturers. Even though I was one of his highest performance students, he would like pat me on the head or he wouldn't be able to give me eye contact. He felt really uncomfortable. And I was like, and it came to a point where, you know, that I think in your 20s, I'm in a very different place now that I'm getting closer to 40, but I guess my 20s and early 30s were just constantly battling that. What do I need to do for you to accept me? How many hoops? How much do I need to succeed?

For you to see me as my non-disabled peers. I definitely let go of a lot of that external validation and the need for external validation. But I think at the time it was a driving force for me to fight for social change. So I initially went into that world of talking about disability issues. I went in there with very selfish reasons. I wanted a better future for myself you know, in my twenties, I wanted to be a parent. I wanted, you know, if I would have children with disabilities myself, I want them to grow up into a different world. And actually, through the work that I did, I started to connect with my community, so the disabled community. And I then, you know, the sociologist that I am at heart, I then realised that actually, for one thing or another, I had quite a strong voice in the community that maybe not everyone was afforded, perhaps because they'd been infantilised, perhaps because they physically couldn't get out into their community. Although it doesn't seem that long ago, technology's come a long, long way in the past decade.

So I think I kind of was at that cusp of the technological kind of turning point. So I think I got a lot of notoriety because I didn't mince my words. If you wanted to talk about things like disability and sex, I'd talk about it. If you wanted to talk about disability and discrimination in the workplace, I would talk about it. And I wouldn't hold back. And I think that was a...that was my selling point.

Ellie: It's so interesting to hear that trajectory that you've been on and we'll explore that in a moment. You recently gave a fantastic talk to some of our clients and one quote that really resonated was when you quoted this quote, "When a flower doesn't bloom, you fix the environment in which it grows, not the flower" which I love. And I just wondered if you could just explain for us the social model of disability and why it's so important for everyone to bear this in mind when we talk about disability inclusion.

Samantha: Absolutely, and that was a quote from Alexander Den Heijer, think I pronounced his name correctly. And essentially, you know, I grew up in this world, in a disabling world, I grew up, seeing myself as a problem, a problem to be fixed. And I mean, a problem to be fixed as in anatomically, like, you know, if I, you know, I had operations with a child purely not because I needed intervention, but I had operations because the caregivers in my life, and I don't just mean my parents, mean occupational therapists, doctors, physios, social workers, all these people that were in my life as a minor, all these people fed into that narrative, that harmful narrative that disabled people need to overcome their disability. And if you don't conform, if you don't become more able...or whether that means getting rid of your wheelchair. Because we all applaud, don't we? We've all seen these videos of someone getting out of their wheelchair. What is your first reaction? Almost likely as a non -disabled person, it's like, my god, amazing, look at them. And I look at those videos and I go, actually, I know for a start that they are probably more independent in their wheelchair than they will be on crutches hobbling around. But non -disabled people go, my god, they've overcome their adversity, you know, they've overcome their disability, isn't that wonderful? And looking at my own life now, I'm like, my goodness, if I was to be walking around now as a three foot something woman with brittle bones in my home, first of all, I'd have to spend a fortune to adapt my home even more, because I won't be able to reach everything, at least in my wheelchair, as I can reach them, you know, but also I'd be so much more susceptible to falls. You know, I probably wouldn't be able to do the work that I do because, you know, menial tasks like loading up the washing machine would take me twice as long as it would if I'm, you know, safely in my wheelchair. So again, I grew up believing that I was a problem. And, you know, even at my birth, you know, the doctors just say, I'm so sorry, you know, there's something wrong with your child, you know, and that that was kind of the outlook for everyone. Everyone, you know, saw my birth as a tragedy. even spoke to my mum. I interviewed her when I did write my book and she said, you know, your birth was more like a bereavement. People didn't even come to visit her when I came into this world because they thought like, you know, I might as well have been dead. That was the attitude, you know, and I'm pretty sure a few people were probably like, well, it would have been better if she would have died. And I don't mean to say that for kind of, you know, effect, but I've had strangers kind of approach me and say, you know, if I were like you, I'd rather not be here. So again, disabled people are fed this picture that we have to change. If you and I, if we went out for drinks after this podcast, which I'm sure we should do, I know right? It's a good excuse for me to come back to London. You booked the restaurant and then the lift was out of order.

Ellie: We should, if it wasn't virtual, we could. Absolutely.

Samantha: And then you go, shame that Sam, isn't it? well, we'll see you later, Sam. We're going to go and have a drink. So again, I just grow up like, OK. And I guess because I fed into this idea, which we often refer to as the medical model of disability, which is, even the word medical, it's about fixing people, isn't it? It's more on what you can't do as opposed to what you can do.

And I guess before my activism, before I became a trustee, I believed that. So if I was to rock up somewhere and they turn me away because, I mean I've even been turned away because I've been called a fire risk at one point, I would just go, okay, that sucks. I'd go somewhere else.

But I would never challenge it because I'd grown up believing that that's just the way things were. And then when I actually became a trustee for the Brittle Bone Society, and we started to meet other amazing badass disabled people, you know, they taught me, they were like, hang on a minute, you're not the problem. How dare the world say that you're the problem? You know, disability is actually social constructs. Like so, for example, in my flat in London, it was completely bespoke, completely adapted for me. What did that look like? I had automatic windows, I had an automatic front door, light switches were lower, plug sockets were higher, door frames were wider, my kitchen was on hydraulics, know, et cetera, et cetera. So yes, I had my condition, I had my impairment, my difference. I had brittle bones.

But depending on where I was or who I was with, that's when I became disabled. Because as soon as I got out of my front door, my automatic front door, which was wonderful, but if I, as soon as I got out that front door and someone had, you know, vandalised the lift, for example, or a taxi driver refused to pick me up or the pavement had been dug up and they hadn't put temporary ramps down, you know, instead of the drop curves. That's when I became disabled. So essentially the social model says, you know, very similar to what that quote says, know, let's stop blaming disabled people for something that they have no control over. Let's understand that, you know, these barriers are systemic they're institutionalised and actually it's up to everyone to work together to remove those barriers.

Ellie: And being an employment law podcast, we can't explore this topic without making reference to the legal definition of disability, which you'll find in section six, the Equality Act 2010. That states that a person will have a disability if they have a physical or mental impairment that has a substantial and long -term negative effect on your ability to do normal daily activities. I think we've...

Samantha: Yeah, yeah. Yeah.

Ellie: We've touched on this, but I would be interested to hear your views on that terminology because it seems pretty negative.

Samantha: Yeah, so let's remember, so the medical model is you're a problem, can't, can't, shouldn't, wouldn't, couldn't, that's you. So it's your problem. But I just think the equality act as it stands, let's have a look at that. It's, that has a substantial and long-term negative effect on your ability to do normal daily activities. Listen, the social model isn't perfect because there's a lot of disabled people out there that will say, actually, so let's use me and my condition as an example. Actually, when I fracture an arm, that's nothing to do with there not being a ramp. That's nothing to do with wheelchairs being expensive. That's to do with your body being different and in that moment, letting you down. And so there's a lot of disabled people or chronically ill people out there that will challenge a social model and will say, Well, hang on, it's not the black and white. It's not about external barriers. It's not about external attitudes. Sometimes it is actually me. It is my body. However, I have a bit of a flip, a counter argument, shall we say. My counter argument is, even if I have a fracture, yes, that is, you know, directly my body restricted me. However, so long as I can call in to work, and have reasonable adjustments, so ask to work remotely because I've got a fracture, so long as that will not impact my ability to continue my role. So, you know, my boss doesn't give my role to someone else or project to someone else, you know, in that way, like discriminates me in that way. So long as my support assistant, so my PA turns up to work and supports me. So, so long as the government...invest in disabled people so that they can have equipment like wheelchairs. You know, I don't see my condition as being the greatest barrier. Does that make sense? Yes, in that split second, that fall or that fracture, yes it is. But as long as I'm able to vocalise my needs and have my needs met, then I still strongly believe in the social model.

Ellie: How does that social model of disability, which you've just explained so coherently, fit into the wider global legislative landscape when it comes to disability rights?

Samantha: It's really interesting because very quick history lesson. The US and the UK are very much world leaders in terms of disability civil rights. The US kind of, created the civil rights movement, disability civil rights movement. In the 1990s, the ADA, Americans with Disabilities Act came about. And then in the UK, that came a little bit later. So we ended up getting the DDA, the Disability Discrimination Act in 95. And what's interesting is when we had the DDA, was very much, well, groundbreaking for one, but it really leaned into the importance of understanding individual needs. And that's obviously often referred to as equity, understanding individual needs. Because obviously, it's it's estimated 1.3 billion disabled people. We're all on a different path even if we have the same condition, we're going to have different lived experiences. And in 2010, when it got merged with the Equality Act, it was a very bittersweet moment, I think, for a lot of disabled people, in the civil rights movement, because... on the one hand it was like, hurrah we're seen as humans, we're protected like everybody else, But then on the other hand it was like, but now we're just a bit of a statistic, now we're all bunched together under this umbrella term of disability and that's why you get things like, you know, normal daily activity, well what's normal? It's a normal daily activity because a normal daily activity for me is going to be very different from a Paralympian, know what I mean? And it really, think at the moment it really puts the onus onto the disabled person again. And just, if we can just take a moment, I've got it here. If you look at the United Nations definition of disability, it essentially goes like the term person with disability is used to apply to all persons with disabilities, including those who have a long-term physical, mental, intellectual, or sensory impairment, which in interaction with various attitudes and environmental barriers, hinders their full and effective participation in society on an equal basis with others. I don't know about you, but I kind of prefer that, don't you? It's so different.

Ellie: Yeah, it's so different, isn't it? It's so much more inclusive.

Samantha: It is, all of these, know, unfortunately, when you're dealing with a community that is so vast, you know, we are so different, we're not going to embrace and accommodate everyone's feelings and sentiments. So even, even though I absolutely love the United Nations definition, because it definitely is more social model language, you know, it identifies external barriers.

There has been some criticism saying that it actually doesn't include people who have, for example, a dynamic disability. So dynamic disability is someone who wouldn't identify always as being disabled. So sometimes if they've got a chronic illness, they'll have a flare up. And only in those flare ups would they say that they are at an unequal footing with non-disabled people. Does that make sense?

Ellie: Yeah, yeah, so it's not perfect, the UN definition.

Samantha: No, and I think this is why it's really interesting, you know, people get so hung up on language and disability and I think this is, you know, just a really important point to make. It's like there's no hard and fast rule. So yeah, be kind for anyone listening who gets a little bit bogged down with semantics, be kind to yourself because actually,

Samantha: I get it wrong and I'm a disabled person. You know what mean?

Ellie: Yeah, yeah. And what does the term ableism mean to you? Just wondered if you could share examples of ableist actions in the workplace, which you've either come across personally or you've heard about from others in the disability community.

Samantha: Yeah, let's bring it back to what ableism means. I think it can be a word that scares people. Just to be completely honest, it's probably only in last six years that I've become aware of the term and use it. So ultimately when you're disabled you can experience disability discrimination in two ways. You can experience disability and you can experience ableism and there's a very slight nuance, a very tiny tiny difference. So disability is discrimination against disabled people. Ableism is discrimination in favour of non-disabled people. I know you're probably thinking, hang on a minute, what? That still doesn't really make sense. And there's a bit of a chicken and the egg situation here because if you prioritise non-disabled people, surely that will then in turn, create disability. All you need to know is both are bad. Let's avoid both of them. So I kind of differentiate them in two ways. So this is a scenario for you. I have just got a text message from a group of friends and they have a free ticket to a concert. This was back in my London days. So I jump in a black cab, so accessible black cab, hurrah for accessible black cabs. Jump in there and I get off to the venue. part of me is like, I probably should have checked if it's accessible. But the other part of me is like, actually under the Equality Act, a concert hall should be accessible so I kind of just leave it. I start chatting with a taxi driver. Anyway, I arrive at the venue and lo and behold there's no step-free access. So straight away I revert to feeling like I'm the problem. You know, I don't want to mess up my friend's night. I feel like a bit of a burden. I'm a bit embarrassed. Now I won't be able to get in. And you know how that plays out. All your friends are going to be nice and they're all going to be like, well if you're not going in, we're not going in. And then you're like, you've ruined everyone's night. Anyway, I end up calling over one of the organisers. And I say to them, look, this really isn't great. Like, what are you going to do about it? And the organiser is clearly embarrassed. And they go, my goodness, I'm so sorry. Yeah, you're right. This should be step-free access. Listen, there is an accessible entrance. It's around the back. It's not very glamorous we're going to have to move a lot of bins and garbage and so on and so forth. It's going to take us a while to get that access point available to you. But once you're inside, you know, we're going to give you complimentary drinks, et cetera, et cetera. And we would love to invite you back because we will endeavour to make sure that access is better. I'm still being discriminated against. Like even though they were courteous and even though they tried to make things right and even though there was kind of an alternative, it's still... discrimination, is disability. Let's run that scenario one more time. So yeah, get there, I call over the organiser and the organiser goes, well, I mean, like how many people like you come out? I mean, I've probably only seen another wheelchair bound person. And do you know what? We did look at getting a ramp put at the front, but it was quite expensive and we decided the bar inside needed a bit of a makeover so we invested in the bar inside because more normal people use the bar on the inside so yeah sorry about that but we'll take you round the back. That for me would be ableism because what you've done you've prioritised those members in society that are deemed as typical or normal and it's really important to understand that disability is a disability centric discrimination, so you have to be disabled to experience it. ableism, other members of society, so underserved members of society can experience ableism. an example would be, you know, transphobia, so not being recognised as a real male or female, or if you are a cis female and you choose not to have children, well, you can't have children, for example, like people will be like, well, you're not a real woman, are you? If you don't have children. Migrants can experience ableism, being kind of labelled as a burden or a drain on society. So throughout society, we always have this idea of what is normal or typical. So ableism essentially is, you know, anyone in society at that given time who is seen as normal or typical, they will always be prioritised as anyone who deviates from that pedigree of normality.

Ellie: Okay, that makes a lot of sense, thank you. Such a helpful explanation of how disability and ableism might play out in a common everyday scenario, and important to bear in mind that, as you say, ableism can be experienced by all underserved members of society.

Ellie: Well, Sam, we've come to the end of the first part in this mini-series. Thank you for giving us such an informative deep-dive into some of the language and terminology used in relation to disability, and for sharing your own lived experiences, which really give pause for thought when we think about what disability inclusion should look like. I'm delighted to say you will be joining me on The Work Couch again next time in part 2, when we will explore the narrative around disability, the financial pressures facing the disability community, making reasonable adjustments, and why disability inclusion should be a priority for the C-suite and business leaders so I really look forward to talking to you again then!

Samantha: Thank you again for having me.

Ellie: For anyone listening who would like further information or support, a great place to start is [Scope's](#) website, which has lots of brilliant resources for people who are facing some of the challenges that Sam's talked about today. Also, [Disability Rights UK](#) and just informal chat, solidarity with your online communities is a great place to start.

If you'd like to revisit anything we discussed today, you can access transcripts of every episode of the Work Couch podcast by going to our website www.rpclegal.com/theworkcouch. Or if you have any questions for me or Sam, or perhaps suggestions of topics you'd like us to cover on a future episode, we'd love to hear from you. You can email us at theworkcouch@rpclegal.com

Thank you all for listening and we'll see you next time.



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