

Emma: 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.

Well, welcome, one and all. Thank you so, so much for joining me on this very special episode of The Wheelchair Activist. I'm joined by three incredible disabled people who also are members of the LGBTQIA + community. And I am going to ask them to introduce themselves. We're joined by Jasper, who is being interpreted for by Carol, so I will ask Jasper, can you tell our audience a little bit about you?

Jasper: Hi everyone, my name's Jasper, I'm a profoundly deaf male. I'm also a wheelchair user. I identify as queer and also as a trans man and I live in the northeast of the UK, with my husband.

Emma: Wonderful. Well, welcome. And if you don't know Jasper by name, you probably know the Instagram page and website Wheelie Queer, which is one of my favorite names. So yeah, thank you so much. And I will go to Annie. Can you tell us a little bit about you?

Annie: Yes. Hi, my name is Annie Segarra. I use she and they pronouns. I have classical Ehlers Danlos syndrome and co occurring conditions like POTS. I'm an ambulatory wheelchair user, meaning that I use a wheelchair sometimes and other times I can use a cane or sometimes even walk unaided, but I do have difficulty with being on my feet.

Annie: I'm also autistic and I identify as queer, lesbian, non binary, and gender fluid. So as I mentioned, I use she and they pronouns mostly, but any pronouns are fine by me.

Emma: Great, thank you. And Annie's wearing a shirt that I need to buy after this that says the future is accessible.

Emma: Can I pass to Ezra, who, for people who don't know, Ezra is a colleague of mine, so I'm super excited that I perform well enough as a manager to convince him to do this. So Ez, over to you.

Ezra: Yeah, no convincing necessary. My name's Ezra, I use he, him pronouns, and I identify as a gay trans man. And in terms of disability, I have chronic pain, for which I sometimes use a stick, but often it's just, will kind of stop me being able to speak for a minute, or move, and so sometimes throughout the podcast, you might notice me.

Ezra: kind of stopping and clicking or having to pause for a minute and I also have epileptic and functional seizures, so I kind of identify as chronically ill disabled person with a kind of number of fluctuating conditions.

Emma: Amazing. Thank you. So the biggest question that I want to ask you all about is how do you feel accepted or not accepted by the disabled community, but also the LGBT community and sort of what has been your experience as someone who occupies both spaces?

Emma: Annie, do you want to go first?

Annie: Sure. Yeah, this is something I think about a lot. I really struggle with the intersection of, like, being queer and disabled in terms of community because I feel very excluded by the abled queer community a lot of the time. Specifically regarding pride events and LGBT spaces.

Annie: Accessibility tends to be an afterthought, and sometimes there can just be a lot of ableism in the spaces throughout. I think that it's something commonly known that, like, specifically in gay men's spaces, there tends to be a very, like, high beauty standard. I won't claim to have noticed that in, like, sapphic spaces, but that's something that I commonly hear about, the high, uh, beauty ideals of, like, the gay male body and the pressure to, like, keep up with that.

Annie: Um, so, like, ~~my~~, my experience includes one where prior to becoming a wheelchair user, I would go to this gay bar a lot, target audience for that bar was gay men. But it was like one of the only queer spaces in the area, so I loved being there and I didn't notice the inaccessibility until I became a wheelchair user and I absentmindedly entered the space and realized there's no elevator to my favorite dance floor, which is on the second floor, but because I'm ambulatory, I'm like, okay.

Annie: It's worth it to me. I'm going to park my wheelchair and like get my cane and hike up the staircase. And when I get up there, I'll have a little tachycardia attack, which is, um, when your heart rate becomes over a hundred beats per minute, and it can cause like chest pain and dizziness and all these things, I'll deal with that for a moment and then find a place to sit and enjoy myself for the rest of the evening.

Annie: And I did that about like five times, I think five different days. And one day randomly I did my routine. I parked my wheelchair. I made it up the stairs. I

calmed my heart down and I just hung out there with my friends and a security guard approached me and said, Your wheelchair can't be where it is.

Annie: And I was like, Oh, okay. It's never been a problem before, where do you want me to move it to? And he said, I don't know. It just can't be there. I said, okay, well, I have a condition and if I go downstairs to move it, I don't think I have it in me to get back up, so essentially you're asking me to leave. And he just shrugged his shoulders, like, I don't care, your wheelchair can't be down there. And in that moment,

This one person represented the entire space to me, and while it doesn't literally do that, it does symbolically do that because the space is inaccessible, because there was no way for me to safely, without pain, without risk of injury, to access the same spaces as everybody else. And I felt really humiliated, unwelcome, and like, the assumption was either your wheelchair is ruining the vibe, it's bringing us down, or it just is ruining the aesthetic, it's not the look that we're going for. So either way, I felt really excluded from the space.

And since the pandemic, I don't really go to bars anyway, at the moment, but bars are one of the few spaces that we have. And that needs to be remedied, but also the inaccessibility and the ableism within LGBT spaces needs to be addressed because we are such a huge part of the community, and we constantly get left out. Even with Pride events, Pride happens in the summertime for so many of us, and with my vascular condition, I can't be in the heat very long without getting very sick. And there's not often a lot of spaces for us to Navigate those things. So overall, I definitely feel a big social segregation between my LGBT community and my disabled community.

Emma: Thank you so much for sharing all of that. I'm so angry on your behalf for that experience and Jasper, I saw you looking as angry as I was. As someone who's also in both communities, how's your experience been? And do you sort of feel Annie's story is something similar to what you've experienced?

Jasper: Absolutely. Yeah. I have a lot of similar disabilities to Annie. And I remember when I was at university going to a gay bar and I was using my wheelchair and a gay man approached me and said, Oh, I'd never date you cause I don't want to be a carer. And I think, I think that's a huge assumption within the community that disabled people need to be cared for and need carers. You know, the assumption was because I'm disabled, oh, you know, it's impossible to get a date because you're disabled. But also, as a deaf person, that's an additional barrier because a lot of sign language is really focused around gender.

So, that means when people come for the first time, oh, they'll say, that woman, and they'll describe the one with the dress and it's the way things are signed.

Emma: That's fascinating. I mean, I remember my very distraught French lessons for a few years, how gendered that language is, and I don't think we think of English being so much. Gendered, but of course, you know, BSL is a, it's a different language and that's fascinating that it is so gendered, even though it's based on spoken English.

And I think your point around the carer and people's assumptions over dating a disabled person. I would definitely say that that's something that even I really resonate with, you know, as a wheelchair user on a ventilator myself, even though I'm straight, I very much feel like that's... it's a huge pressure and a huge misconception that people have about dating someone with a disability.

Ezra, I'm really curious because I know your disability and chronic conditions more manifested later in life, but how do you sort of feel in both the queer space and the disability space?

Ezra: Yeah, I was going to say, because I feel like I've got kind of a view to different parts of it, because I became physically disabled, at least in my early 20s, and very, very suddenly, kind of overnight. Whereas I came out as trans and gay in my teens. Um, so, up until I was kind of 20 and stuff, I generally found myself in more kind of typical queer spaces, and that manifested a lot as nightlife, and kind of what you'd associate with kind of like the typical gay scene, with the kind of added complications of being a trans gay man.

But when I got ill, when I was about 21, I was really out of action for about eight months. I was not really able to leave the house too much and kind of lost all of my usual hobbies, but even now, um, as my condition stabilized a little, I still have a lot of fatigue. I still have a lot of pain. I just can't pace myself like I used to. And so I find. The kind of community that I had established or the lifestyle that I had kind of built for myself, or where I felt that my community was, is no longer hugely accessible to me in the way that it once was. You know, I can't stay out as late, I really can't drink very much, I have to kind of look after myself a little bit more.

And so, I've kind of had to re learn what the queer community looks like for me, what kind of spaces I can access. And even though I have managed to kind of build that up a bit and kind of find a new way of negotiating my relationship to the community, I still feel a little bit left out. I still feel there's not as much space for disabled people in the queer community. But I do want to kind of flag that I

know there is definitely a lot of intersections between our community. I think the kind of rates of disability among queer people are higher and likewise, I think in the disabled community, more people are likely to identify as queer. And so I have found that queer nightlife spaces, always, you know, far from perfect as all of your stories and some of my experience is evidence as well.

There's a lot of issues, but I find that often they can make a little bit more effort than straight clubs and straight bars and straight events and stuff. I think there is some attempts, maybe, because we are both communities that exist without the world being built for us with stigmatized bodies, with stigmatized relationships, stigmatized ways of being. I think there is some kind of degree of mutual recognition and some, you know, attempt, at least from my experience, for queer venues to cater a little bit more to Disabled patrons. But still it's far from perfect and there's a lot of work to be done in making sure that both of our communities can kind of access each other.

Emma: In terms of awareness, I think for both the disabled community and for the LGBT community. So, of course, you know, this episode is being done for Pride Month, which is June, but there's also Disability Month. There's Disability History Month, and there's also International Day of Persons with a Disability. And I'm really curious how all of you feel seeing, I suppose, the public's response to both. I think we can all agree that Pride is much more prevalent in terms of, you know, companies will change their social media logo to rainbow for a month. And, you know, there's a lot of, I think, Corporate push as well around equality, diversity, and inclusion, particularly for the LGBT community. And I'm curious how that's felt as a disabled person as well. Maybe not seeing the same recognition for disability as an identity that deserves its own celebration. Annie, did you want to...you look chomping at the bit.

Annie: Yeah, I just kind of got hit with a big emotion in my chest. Um, because like, as you mentioned, celebrations of disabled community, my brain started already moving, connecting some dots and remembering how, like last year when it came to one of our celebratory months, it was probably disability month, July, that maybe I saw one Instagram account that wasn't disability related create a it's disability pride month kind of a post on their grid.

And then that kind of like, pulled me back to something that I experienced for the past few years, since the Pulse Massacre is like I tend to have this a bit of, like, seasonal depression during the summertime and, like, part of that is in regards to grief from these massacres that we experience. I'm Floridian, Pulse was a place that I went to a lot, so I feel very connected to the space. We're recording this on the anniversary of the massacre, actually, so I just got hit with,

like, a lot of big feelings, a whoosh of, like, memories and feelings just, uh, came upon me, of, like, The night of, the morning of, and like having to call friends to make sure that they weren't there, and that they were safe, etc.

So, in relation to like, celebration and representation for our communities, I felt a sense of gratitude for the global response to the Pulse Massacre, which was to respond to it as a mass hate crime and buildings around the world were lit up as rainbows and things to show like we see you we want you to know that you have allies out here and that you are wanted here. Which was so necessary. It's so scary for all of us when something like that happens. I remember that week that people were scared to go out to any gay bar that week, scared that a copycat would occur and that no gay bar was safe after, um, the Pulse Massacre. But something else that happened that very same month, something that a lot of people don't know about, which was the Sagamihara Massacre, where at least 19 disabled people living in a disabled housing were murdered, um, for being disabled, um, by someone who believed that if he could murder a majority of disabled people, that it would help the economy of the country. This is from a letter that they wrote.

And, um, once again, I echo the feelings that I just mentioned about the Pulse Massacre that like when a mass hate crime happens like that, you feel so vulnerable and all of a sudden the bigotry that you face in the world is, is right there in your face. And I can't speak for all of us, but for so many of us, it makes us a little scared to walk out our front door. Like that anytime you are out of your house, you may confront somebody who hates you for being you. And so for me that month, it was doubled after the Sagamihara massacre. Because I was like, people hate me for being queer. People hate me for existing as a disabled person. But regarding the Sagamihara massacre, like there was just so much silence. It was barely in the news, so that solidarity that I saw for the LGBT community, it wasn't there really for the disabled community. It was just kind of disabled community being there for one another online, uh, and that felt really lonely and that isolation felt very scary.

It felt like an affirmation of how little we were cared for as a community. Um, and I think that we get, uh, unfortunate evidence and affirmations a lot. We get punched down on so much like including with the COVID pandemic and how little we were regarded in that way. The news said it's chronically ill and disabled people that are more vulnerable to this disease. And people said, well, I'm not one of those people. I don't really care. I'm gonna just live my life the way I want to. That's another emotional hit that we as a community had to take on the chin and continue moving forward with. Uh, I'm so grateful that we have each other as a community because I don't know how else you would

emotionally survive things like that. Like, just masses at large, society at large, constantly throwing these emotional punches of erasing you, neglecting you, forgetting you, or at worst, like wishing that you didn't exist. So, I think it's important that we have those celebratory months. And I really hope that as time passes, that it's not just us celebrating our community that, but that we can be celebrated by others as well.

Emma: I mean, I'm not sure if you clocked when you were talking about both of those instances in Florida and in Japan. I mean, I got, I felt really emotional because I remember both of those very vividly as well. And I remember the news coverage around Pulse and it truly broke my heart as someone who has so many people that I love in the LGBT community and like 100 percent consider myself an ally and want to be the best one that I can be. That was destroying. And then I also remember the deafening silence around Japan and what happened, I think I wrote a blog at the time about that and how our Prime Minister at the time, Theresa May, didn't make any sort of public statement. There was no statement of, you know, recognition of how disabled people might be feeling, because I, like you, took that extremely personally, and it's not easy to sit with that.

And I just want to thank you for raising both of those. And I think they're both incredible examples of the way that those different identities are thought of by other people. And I think with Jasper and Ezra, something I'm really interested in as well is, we also know about the hate crime, the hate speech towards trans people, and how does that inform your experience, you know, how do you feel that the various aspects of your identities are celebrated or vilified by sort of society and public opinion? Ezra, I don't know if you want to go first.

Ezra: Yeah, I guess, um, I guess you probably hinted at, like, there's a difference between the ways that, you know, queerness, uh, or traditionally, you know, homosexuality, gayness is celebrated during things like Pride Months, and then where transness sits in that as well. And it goes without saying to people who exist within the community, but it's worth restating to people who aren't, that the political situation for trans people in the UK, specifically at the moment, is completely horrific. And it's become pretty commonplace among all major political parties to use us as a political football, as a joke, and in a way that is not nearly so acceptable for the kind of LGBTQ kind of parts of our community.

But I think that, there's probably a kind of similar vilification of trans people and disabled people in politics at the moment in terms of just the kind of using us as a wedge issue, as a scapegoat, it's something I recognize very, very

potently as members of both of those communities, like the policy focus at the moment on scrapping, uh, the welfare state as much as is human, you know, to the bone, past the bone, and, the way in which disability is framed as a complete burden on the taxpayer, that it's a minority that's draining the productive majority, and in the same way, trans people are vilified in, you know, being a tiny minority that are kind of wrenching the rights out of the hands of, you know, the good normal majority.

And there is just this outrageous disproportionate focus on our communities that are beaten down and vilified constantly. It's just one of those parallels where there is this maddening focus on presenting both of our communities as somehow like, you know, the cause of all of the world's ills. And it's just a parallel that has felt more and more pronounced in the past few years, which is, I guess kind of counter to the view that, you know, history is inherently a kind of arc that bends towards justice and that, you know, progress is inevitable. Because over the past few years, the kind of public and political attitudes towards Trans people and the broader, you know, I think that's being used as a wedge issue to kind of like vilify the broader queer community, but specifically trans people in the UK and disabled people is getting worse.

The political situation here is getting worse over time, which is something that I didn't expect when I was a teenager. I remember starting to kind of realize my identity as a teenager and thinking it's bad now, but you know things get better. It's like it was in the 80s, you know, inevitably things move forward and it moves me to tears sometimes thinking about how it's definitely worse for teenagers now than it was for me 10 years ago, which is horrific. It's horrific that it's getting worse and the same with disability, you know. We went from disabled living allowance being chopped down to pip which is now being chopped down even further to voucher schemes. So as a member of both communities, it's frightening and I think there's a lot of potential for allyship and obviously there's a lot of intersectionality between our communities, but you know, it's really fertile ground for allyship between our communities as, people who are punched down on and treated as being the kind of source of the end of the world when actually like we're just equally stigmatized groups.

Emma: I mean, my first thought is, God, I feel really bad that I make you read all of this political stuff every day as part of your job. But I couldn't agree more in the way that the disabled community is being treated in British politics at the moment. Every day, we're hearing more and more horrific stories about, you know, plans to reform welfare, to cut people's eligibility to that financial support, and I know how difficult that feels as someone who works adjacent to politics, and we have to read this all day, every day. And our job is to actively

fight against that. But that doesn't mean it's not an incredibly heavy emotional toll.

I think in terms of trans hate, and I, I'm really curious, Jasper, your opinion on this, but to me it seems like it's becoming more mainstream to be hateful towards trans individuals. It's becoming socially acceptable to write horrific opinions and I think we can all think of a certain celebrity who really should just stay in their lane and stop talking about these issues to which they have no lived experience, but it's I think it's a really good example of someone who probably all of us grew up loving. I mean I'm not trying to say that being a Harry Potter fan is like anywhere near like a huge part of identity, but it, it's a core part of I think a lot of people's childhoods and for that to now be tainted, I think is... it's horrific. But Jasper, I don't know if you sort of identify with that.

Jasper: Absolutely, yeah, um, she has become, he will not ever be named.

Emma: She who must not be named?

Jasper: Thank you, yeah. I remember when I was at university, I was the first person to be voted as trans officer. So there was a lot of fighting going on to change attitudes and that meant, you know, making sure that we were changing policies to be more accessible. And at that time, they were also in consultation with politicians for, how can we change the GRC process? So, that was when this specific, you know, experience started for me, and I think the hate that was experienced was, when she started to become, you know, more equal to the public, it was very specific things linked to trans people and that was a really difficult time.

And it's still going on today. I mean recently I got married and when you live in the UK as a trans man you have to get a GRC if you want to get married as a man. And I remember being so scared of the political system, banning that, which meant that I wouldn't be allowed to get married. It was like, what happens if they say, no, we're not going to do it, we're going to ban it. It was a scary time. It was a really difficult time for me because a lot of people, from the disabled community know me, um, I'm very open that I am a trans man. And that makes me also very vulnerable because I am so open. So a lot of the time, I was getting lots of emails and death threats, it was unstoppable, it was an absolutely horrific time.

Emma: I think that's disgusting that you received that hate online. I wish I was surprised, I think is what I'll say. I think for all of you, though, you know, all of you are activists and sort of campaigning or trying to influence, in albeit

different ways, but we're all putting ourselves out there to create change. And I'm curious how is that experience of being so public with who you are as an individual and with the public opinion of you. We're putting ourselves in the public eye for a reason, but that also comes with unexpected drawbacks, shall we say. So, Annie, how has the public sort of received you and your work?

Annie: My experience on the internet has been such an up and down roller coaster ride. I remember prior to even becoming like out as disabled, really online, um, that I was creating lots of Feminism, misogyny focused, uh, content and also anti-fatness, uh, fat phobia, and informing around that because that was a big focus of mine when I was doing eating disorder recovery.

And through those lenses being anti anti-fatness and being anti misogyny, you know, basically slews of misogynists and fat phobic people would come through in the comment sections and harass me. At one point hacked into my account and deleted it from the inside. That really sucked. And now like present day, it is a really difficult internal debate and that I sometimes have with my partner who's also a very private person, um, regarding like privacy on the internet as someone that is very public and someone who is very passionate about being visible and being the representation that I needed when I was younger, because I long to do that.

And I've seen, fortunately, as recently as today, the impact that that can have on somebody else. I was so honored today, like my eyes just got watery thinking about it, just today someone shared with me that prior to them becoming disabled, they were familiar with my disability content online, and that because of the way I put myself out there and because of the things that I created, I couldn't believe that this sentence came out of someone's mouth, they said, because of your content, I wasn't scared to become disabled. I knew that it wasn't something to be afraid of. And I started sobbing when I heard that because that's really the impact that I've always wanted to have. I know that for so many of us, how could you not, in the society that we live in, you know, fear disability and fear joining the community and, fear the community when you're not part of it. There's so much that stigmatizes us, that excludes us, that tries to paint us as undesirable and unattractive, etc. So you can stop a random person on the street, ask them, would you want to be disabled? And they're probably going to say no. But the least I can hope to try to change in public opinion is that one is not scared to become part of this community.

So I am looking for a way to try to continue to do that kind of work while maintaining safety as well. And figuring out where that line is in regards to, like, the privacy of my personal life and privacy for a sense of safety. Especially

with the way things are. I'm in the U.S. and if you're aware of the political things we have going on, it's, uh, very scary right now for people of color, LGBT people, disabled people, and I'm in Florida of all places. So, being someone who is in a T4T relationship, who is a person of color and a wheelchair user the majority of the time that I'm out in public like it's been feeling very vulnerable. I've been having lots of anxiety nightmares about how vulnerable it is to exist in my body at this point in time, but the Internet has been both a haven, such a portal into community, specifically disabled community, because people chronically ill like myself who may sometimes be home bound or bed bound, the internet is where we live and where we find each other.

But at the same time, the internet has also become more dangerous than it has in the past. Years ago, when the internet was just, you know, a newborn, we were like, don't talk to strangers on the internet. But now we're talking to strangers on the internet all the time. And we've forgotten how dangerous it actually can be. So yeah, I'm in the midst of like, trying to find that balance, because I love the internet, and I'm scared of the internet, and I want to continue doing the best work that I can while keeping myself safe.

Emma: I mean, I really resonate with so much of what you said. I mean, the wheelchair activist is a play on words for armchair activist, which is a term that's largely criticized, and associated with keyboard warriors, you know, and all of those people. But that is where I found that as a disabled person, I could get my experience out there and get change, hopefully. So I completely see what you mean, but I'm just so struck though, about your comments of feeling vulnerable in your own body and again, I wish I didn't empathize with that and I can only imagine the added components that are making you feel that way.

I mean, you're living in a state where someone is running for president and they can't vote in that state because they are in fact a felon. That is the he who must not be named for this episode. Ezra, I mean, you more or less joined both communities, you know, later in, in life, you know, the LGBT community in your teenage years and then joining the disabled community, you know, in your early 20s. I think, you know, it's something that you and I say a lot in our work is that disability is the only marginalized group that anyone can join at any time. And I'm just really curious how it felt for you entering both of those communities and which one felt safer, which one felt more comfortable for you, what represented you better.

Ezra: That's such an interesting question. Ooh, I don't even know where to start. That's so... yeah.

Emma: I have good thoughts sometimes, just not at work.

Ezra: No, it's just like, yeah, I hadn't really considered that question. I guess the link between those two is I think that when you first join them or realize that you're starting to join them, especially the kind of trans community specifically and the disabled community, They're both ones that, when you join, you kind of don't really want to be the kind of person who's, you know, starting to belong to those communities. They're both quite scary to join, and they're both communities that really pose the question about what your life is going to look like from this point. They're both communities that, when you join them, your idea of what your life was going to look like, potentially what you had envisaged for yourself, really has to start to shift.

And they were both quite lonely for me to join. You know, joining the community is something that happens gradually. You, you know, the identity becomes part of you first and then slowly you kind of find your community. So when I was a teenager, I was dipping in and out, kind of trying to figure out what was going on and then, you know, after a little bit of resistance, you know, slowly conceding that I was trans and that I was a gay man and it, took me quite a while to be able to kind of accept that about myself.

I had a lot of internalized transphobia for a lot, you know, many years and a lot of internalized homophobia with that as well. Whereas, you know, when I joined the disabled community in my early 20s, again, I had a lot of internalized ableism. Um, because I joined the disabled community very suddenly and, you know, my life really did change very overnight. You know, I went from kind of working a full time job and having particular views of what my life was going to look like to immediately kind of losing my job, not knowing whether I was ever going to kind of get better, like it looked, my prognosis wasn't great in terms of like, whether I was going to be able to do much independently, whether I wasn't going to be having seizures every day, like, constantly.

So it really, like, took me aback. I was, I was... it knocked me for six, but as well as just the kind of physical health impacts, there was a kind of thing of like, oh, I've built my whole life around this idea of what I'm going to be, what I'm going to do, what I can do, and suddenly that shifted in the same way that it did when I realized I was trans.

Like, you know, I've got this whole kind of life set out for me. I've got this expectation of what I'm going to look like, what I'm going to do, what I'm going to be, and suddenly that has to change. Um, but with the disabled community, I think the thing that made a difference, and that made me, allowed me to accept

myself quicker than I did with being trans, is actually starting to work at Transport for All, which allowed me to not only find a community of disabled people much quicker than I did with the trans community, but just the kind of foundational belief, and shared experience, and the kind of you know, reframing of what disability is and that it exists in the environment, that there's nothing wrong with you, that it's, you know, it's not that I couldn't work or couldn't do things that I wanted to or couldn't live a fulfilling life, it was barriers in the environment were preventing me from doing so.

And so that kind of like framework and sense of shared community and relationships with other people that allowed me to reframe like what disability meant to me meant that I... I could accept my disabled identity much quicker than I could my trans identity because the trans community is out there, but it was much more difficult for me to access as a teenager than through my work where I got to be around amazing disabled people all the time and work on the kind of issues that pertain to our community and I don't know it just really helped me build my life around that identity much quicker and find other people who were like me and who could show me a vision of what my life could be.

Emma: That's so interesting, the sort of community that you felt in in very different ways. Yeah it's fascinating and I think so much of those years as well, when you entered these two very different communities, there are times when, you know, you are majorly figuring out who you are and what is your place in the world, what does your future look like, and to have, you know, those curveballs is incredibly difficult.

Jasper, I'm thinking about your work and the fact that you work, you know, with disabled people to provide support when trying to access benefits and, you know, other financial support, but you also do work in terms of training for LGBT related training. And I'm wondering how that experience is for you, because you work in those two communities that you are a member of.

Jasper: It definitely feels complex a lot of the time. Currently, especially with the government, you know, big time, the attitude, do I need to say any more, you know, disability benefits, fit to work, all these things. A lot of people are really scared at the moment so there's lots of discussions going on and it is very emotional and I'm really bad at hiding my emotions. But at the same time, when I'm a trainer, I feel a lot of the times that I have to be... I feel like I'm performing because I feel like I am representing the whole community. So when a person asks me, you know, a questions, they're not always nice.

And I have had TERFs. I was managing the training session and I said, well, actually I am a trans man, so, you know, I'm comfortable in that. So basically I had to say, if you don't like trans people, then there's the door.

Emma: I really hear you with the performance aspect and it's really not easy. And I feel I tried to represent the disabled community during the pandemic and did a lot of media type work around the impact of lockdown and lack of vaccines and all of that. And it was highly emotional, like your training material is, and you almost have to emotionally disconnect from it, because if you took on the full weight of what you were saying and the importance of what you're trying to do, you would never be able to actually effect change.

And of course, there needs to be a balance between providing a safe space for people to ask uncomfortable questions, but it doesn't give anyone the right to be so openly hostile towards you when you're coming in to provide them with knowledge and expertise that only you have that will benefit them in no matter what role they're performing. And I'm just so angry on your behalf that you had to experience that. Again, I'm not terribly surprised. There's something that I really wanted to cover in this episode. I'm really interested in the medical space and conversations that you may have had with health providers in terms of any intersections between your identity and your disability.

Jasper and Ezra, I think, particularly being trans and having health conditions, I'm wondering what barriers, if any, have you come across when trying to access treatment from healthcare professionals? Jasper, you were nodding so I'm hoping I can pick on you to go first.

Jasper: Because I'm profoundly deaf, healthcare is a nightmare to be honest. So, for example, I have a consultant appointment and every time it needs to book an interpreter and it's over nine months because the hospital, they just don't know how to make a booking, when to book an interpreter, and the situation, it's really stressful. If I'm going to a GP appointment, they will talk directly to the interpreter and not to me. So if that GP is talking to me, for example, about my transgender, a lot of the communication is discombobulated because the interpreter is trying to be professional. But it's not their role to manage the GP and that situation.

And they don't know I'm transgender, so a lot of times they just don't realize, cause it's not clear when they look at me. The GRC isn't there in my records, which means, you know, it doesn't say that I'm transgender. It has me down as being male, but a lot of the time, if I'm going to the GP appointment and it's specifically linked to a transition, for example, HRT, a lot of the times they'll be,

"um, why are you in a wheelchair?" And it's like, "um, no, the issue is the injection and I don't need to talk about my wheelchair. That's irrelevant. That's not what I'm here for."

Emma: I have to admit when I asked you that question, I completely didn't think about the interpreter aspect of your disability and that communication between the patient and healthcare provider is crucial. There can be no misunderstanding because any misunderstanding can lead to very bad outcomes. And when you've explained your experience, it's so obvious, but I am so interested in that example that you mentioned, where you go in for something to do with your transition, but it just goes back to your disability.

It's incredibly frustrating, I can imagine, when they are separate things, one doesn't inform the other in any way, but it's what they see first, I suppose, and I can only imagine how frustrating that is. And Ezra, how has navigating the relationships with medical professionals being a trans chronically ill man, how has your experience been?

Ezra: It's usually... It's such a lovely surprise when someone knows what they're talking about. And so I always kind of start explaining like I'm explaining to someone who has no idea what they're doing. And when someone's like, "oh, top surgery," I'm like, "oh God, you know what that is? I thought I had to explain that like to a toddler, but oh, fabulous."

But yeah, no, it's been a real mixed bag. Like one time I went in for a scan, ultrasound scan of my kind of abdomen. And I just wanted to notify them because my medical records say male and they, lots of people don't read me as being trans initially. So I just wanted to say to the doctor straight away, I said, I'm trans. And before I could even explain what I wanted to say, he went "from what to what?" Like, you know, it's just like, just so deeply insensitive. You know, I was just like, I would have told you, I just wanted to, you know, notify you that there might be some organs you weren't expecting.

But, um, I mean, as well as there being those kind of communication issues, just in terms of medical transition, it's caused barriers in some of my other health care, and likewise other health care things have caused barriers in my kind of transition health care. So, um, because of my seizures then that really complicated my hormone therapy. I had to get everyone to sign off on a load of different things, because even though I was several years on HRT by the time I started having seizures, because, you know, there's some kind of warning on the box that particular kinds of HRT might have an effect on this, everything has to be signed off by a neurologist, every kind of change in medication, and it made

the process really, really slow, and so it's made it quite difficult to access care at times.

And likewise, I think a lot of the kind of, um, neurology team when they were prescribing certain medications or looking at particular treatment programs didn't really know how to handle the fact that I was trans, whether that affected things, because there are certain kind of medications or treatment options where you can't have it if you're at risk of getting pregnant, for example. And they had to kind of ring colleagues or ask me being like, "so can you get pregnant? What does that mean? Like, can we prescribe you this? I don't know. I need to consult with like six different people." And then every single time, you know, they'd write it up wrong. I was prescribed things I shouldn't have been or not prescribed things that were absolutely fine because they didn't really, kind of, know how to handle what seems to be kind of like a really important, you know, part of any of their patients care.

And the same reason in kind of just wards, when I've been staying in hospital, you know, they might say my old name, if it's written on my records for some reason, and then, you know, my old name is a feminine name, and so you would have kind of thought they could put two and two together, really. But then, you know, might announce it and say, "Are you transgender?" In the ward because, you know, because they're like, "We noticed an old name on your file." And it's like, just shut up. Like, you know, I'm in the middle of a ward, I can't really move if someone decides they want to have a go. So, like, just cool down, you know, so it's, it's difficult.

There are all sorts of these kind of barriers, like there are social barriers and then there are also medical barriers. But yeah, it's definitely complicated and it hasn't really, again, gotten any easier over time. You know, there are some people who are great and that really surprise you, but you know, I guess it's the kind of exception that proves the rule.

Emma: Again, I'm just in a bit of disbelief, I suppose is the best word to use for it, that you've had such stark experiences of what I think we can all agree is just incredibly inappropriate questions and behavior, not just from a human being, but from someone who is providing health care for you. And just that complete lack of respect and acknowledgement for your identity is horrific, and I can only imagine how slow it is to get anything signed off when it does have to go through so many people. And Annie, of course, you're U.S. based, so it's a very different healthcare system, but I suppose from your Identity, how is trying to access health care?

Annie: Yeah, I- oh my god. If I could generalize our health care system, uh, we pay a lot of money, and we have to wait a long time to see a specialist, so like, we get to do both. Uh, it's, it's incredibly unaffordable, and it'll be months before we can see anybody, so if you're sick, and you can't work because you're so sick and you're stuck in bed for months, it sucks to be you. And then you're going to be so much more in debt after your doctor's appointment, because you're going to have to spend the money on that. Um, it's pretty tough.

I was thinking about that and thinking about first, just as LGBT people overall, that medical spaces are so vulnerable. I think being perceived as a woman in medical spaces and then being LGBT+ in medical spaces is so vulnerable because there's a power imbalance. Like medical professionals have so much power over patients and patients go in there sick, vulnerable to the power of their hands to look at us, have whatever prejudices they have about us and make decisions based on those prejudices, dismiss us, and then we leave with less money in our pockets, in my experience, and still sick and still suffering and, um, without any kind of treatment or help. And those kind of things, like, they come up so unexpectedly.

I just had like a gynecology appointment this past week and like, they asked me questions about my sex life and my partner. And like, they asked me, are you sexually active? Is it homo or hetero? And I'm like, It's homo, but are you asking me the gender of my partner for funsies, or do you need to know the genitals of my partner? Is that what your question is? Because that can get confusing. What's the specific information that you need to know about what is bumping with each other? Because we're here and we're like focusing on the genies, the genitals. Uh, I'm thinking that that's what you're referring to. So I don't know. But, uh, when questions like that come up, God, you're in such vulnerable hands. You don't know if the person that is asking you these questions, how they're going to respond. I was very lucky that like in that stammering moment, um, because I was unsure of what this nurse was asking me, and it's a complicated answer depending on what she's asking me with such a vague question, uh, because my partner is trans. Luckily her response was, oh, I don't know how to log this then. See how scared I am of bigotry that like I say luckily her response was just and I, I like embarrass Lee responded. I know I live a colorful life, I guess. And, and, and she goes, "mm hmm. Well, as long as you're happy" and like, okay.

Emma: Oh my god.

Annie: But that moment scared me. I'm like, I'm in a room with somebody that has so much power over like my access to health care. And if they disagree with

my identity and/or who I'm partnered with. They have control over whether or not I have access to the health care that I need. So that is something really vulnerable that, like, people neglect. I think people believe that we're in a space where, like, things are more progressive now and people are more accepting. But definitely all over, UK, US, politically there's a lot of fear mongering happening about our communities, it's been very shocking.

This pride month on the internet I've seen so much more-- I feel like it has to be bots doing this, but it's just, there's just so much more comments of disgust regarding the LGBT+ community and I'm like, where's this coming from? And why do y'all have no lives? Why do you care so much? But it does, unfortunately, truthfully, scare me when I see stuff like that. I'm like, is it safe to kiss my girlfriend in public? Is it safe to be overheard talking regarding our romantic life?

All these things have a role in how safe we feel and specifically in medical spaces, what a rough one, because to like circle back to what I was saying earlier about even just being perceived as a woman is a detriment in medical spaces. Um, because you're often believed less about like your pain levels or any symptoms that you describe because if you're perceived as a woman, the, the prejudice that most people have is that you might be over dramatic or exaggerate and that whatever complaint you have about your body shouldn't be taken seriously, that you're probably just too weak to handle whatever you're going through. So when you complain about pain, you're probably just being very weak about a minor pain and you're exaggerating what you're bringing up. So, whether you're perceived as a woman, whether you're LGBT+, person of color, whatever marginalized group has tremendous prejudices against them, it is so vulnerable to go into medical spaces and to try to receive care for your chronic illness and or disability.

Ezra: I just wanted to come in because that kind of being scared in medical settings and them having kind of so much power over you really resonated with me and it's something I became a lot more aware of after I became disabled and had a lot more frequent encounters with medical settings. I've become very aware of unconscious sadism as a concept in medical settings. The kind of best analogy for that I've heard is Trixie Mattel saying something like if you really want a good hygienist clean for your teeth, then go to someone who's a little bit homophobic, because they'll just really kind of scrape it, you know, they won't quite care how much it hurts, they'll really go for it.

But that kind of made me aware of like, oh yeah, like, if they perceive your identity or have a particular prejudice, I don't think they'll consciously try and

give you worse care all the time, often they will, you know, but they might not consciously be trying to give you worse care or trying to be causing you more pain, but just a little part of them might not really care so much if something goes wrong or if something hurts a little bit too much or if you don't quite get what you need straight away. And so it's something I'm kind of aware of, like, oh, do I kind of let this professional know, like, these particular parts of myself? But is it relevant in this setting? Because I don't want to give them any ammunition that might mean that I receive worse care for some reason or another.

Emma: The fact that that has crossed your radar is horrific to me. I mean, I think like you've both said really well, there is a huge power imbalance between patient and healthcare provider, but, you know, I think we talked so much about unconscious bias. I think, you know, we've all probably done that training session with a company at some point around how, if you submit two identical job applications, but one says disabled, one doesn't, you know, the odds are that you're going to pick the candidate who doesn't have a disability. And we talk about that so much, but I think really too much in the hiring, recruiting workplace space, but not enough in other areas of life.

I mean, Ezra and I, for example, work in transport and, you know, we have heard from individuals who are sometimes thinking, I don't know which part of my identity led to this behavior from, say, this driver or, you know, this person getting the ramp out for me, but something about me made this situation worse, or, you know, they didn't get the support that they needed, and it's, it's horrific that that is a reality. And Jasper, I saw you... it felt like you resonated with that,

Jasper: Yeah, again, definitely. I think also there's like various levels of healthcare where there are different attitudes within that levels. So for example, in emergency care, a lot of the times they won't allow my partner to come with me. The only time they allowed it is when you say, Well, there's no interpreter, so, you know, how are you going to communicate? You're going to have to have him in the room with me, and we have to do it that way. But that is, you know, a basic human right. That basic level, you're just facing barriers and constantly fighting. Because recently I was in hospital, and I was there for about three weeks, and there was only one time I had access to an interpreter. The rest of the time, they would say to me, Oh, you can use your husband. And ask him, ask him to come [01:02:00] in after work and he can interpret. And it's like, well, he's not a qualified interpreter. And he's my partner. You know, if I want my partner to visit me, then yeah, that's fine. But I don't want to rely on him to give me medical information to see if I'm okay, you know, in, in emergency

situations. So I, I don't know why they're doing things or tests they're doing, and it feels very scary.

Emma: Again, it's that added layer of vulnerability and reliance as well, and it's incredibly inappropriate and I'm sure very emotionally difficult for your partner in that situation as well to have to communicate something very potentially private or, you know, hard news, whatever it might be, to the person that they're spending their life with. And that's not the role that they should be playing. They should be there as your husband, like you said, not as your interpreter. There's so much of a power imbalance, but it's just compounded when you have, you know, a disability, when you are a person of color, when you are trans, and all of these aspects of identity that we've talked about.

And I'm not going to do the what would you tell your younger self and I'm not going to, you know, ask you to talk about it gets better because we have talked about that and we know that it doesn't always get better and I'm not going to be that cliché straight person who's gonna ask you for words of wisdom for, you know, other people who might be listening to this. But what I do want to ask you is a positive experience that you've had either as a member of the LGBTQIA + community or as a member of the disabled community that has particularly surprised you where you felt seen, you felt heard, you felt included.

Annie, you look like you might have an idea.

Annie: I don't have a specific one in mind, but I just want to... I guess what did occur to me is how I have kind of curated my life to have friends and a partner who are very affirming in multiple ways, um, both in my LGBT identity and in my disabled identity. And that is something that has been surprising after, like, years of isolation, being chronically ill, like, I never predicted that I could find, like, in person community in that way, and I still struggle to believe it sometimes, that I have people around me that, like, want to help me, and that I'm not seen as a burden to them. And that like, when I have to cancel plans because I'm not feeling well, like they understand.

And my joyful thing is that like, if you are a person that doesn't believe that people like that exist, that friends like that exist or partners like that exist, that they do. In my relationship, like, I'm constantly being affirmed in my gender fluidity. My partner uses multiple names and pronouns for me, uh, and it constantly feels very affirming for me. And my friends are very inquisitive and ask me like, is it okay if I offer to help you or does it feel a little infantilizing?

And you know, I try to walk on my own as much as I can. I've done physical therapy and my walking ability has improved some, but I still need my wheelchair for long distances. But it's very scary being in this, like, middle place with my walking ability because sometimes if I'm attempting to walk unaided, my Disability feels so invisible and I'm like, at any moment, my knees could give up and I'm on the floor and people are going to be like, what happened to that person who looked totally normal a second ago? It's very scary. And I feel like sometimes my efforts to, uh, walk, people forget how fragile my body is and how disabled my body is. So, like, I'll tell my friends, like, no, I really appreciate it when you, like, reach out your hand to, like, support me going up a step and when I'm getting my wheelchair out of the car, extending your hand to make sure I don't fall off the ramp or whatever, like, I appreciate from my friends, from people who know me, a little bit of, um, abuelita treatment, a little bit of grandma treatment, because the truth is, my body is fragile, I am disabled, and I love to feel seen and cared for and protected by the people around me. And I'm very grateful and joyful that I've created a life like that for myself, so I like to give people some hope that people like that exist.

Emma: I really want to say that that's beautiful, but I don't know if that's the most cheesy thing in the world to say, but I, I think everyone at some point, whether you're disabled or not, or LGBT or not, we all want to believe that those people for us are out there and I'm incredibly happy for you that you have found those people. So thank you. Ezra or Jasper?

Ezra: I think it's probably the same. I mean, in a different way. Actually, this is going to turn into advice hour now, but, um, yeah, I, it's what I would implore anyone who's finding themselves kind of joining both of these communities or either one of them is find people who are like you wherever you can. And I think it's something I resisted for a really long time because to seek out other trans people, to seek out other disabled people felt like, it felt like conceding that. It felt like conceding that I was trans, that I was disabled and that had to be such a big part of my life when I was just trying to reject it. I didn't want to be defined by that. I didn't want it to be a part of me.

But actually like, never is it less an intrusive part of my life than when I'm around other people like me, you know. When I was so worried about my transness defining me or my disability defining me, nowhere does that define you less than when you're with other people who are around you. It's kind of counterintuitive because you're just kind of like each other in different ways. And it just alleviates so much of the kind of stigma and self stigma and confusion that can come with finding yourself joining both of these

communities. Yeah, find other people like you in wherever and whenever you can and stick by them.

Emma: I loved that advice. I think that recognition in other people around you is huge. That peer support is incredibly important. Jasper, what's been your surprising, pleasant experience?

Jasper: I think mine is very similar, but slightly different. And so it's parallel, but slightly different. Uh, last time I went to Trans Pride Parade in Brighton, when you're a deaf person, language is always a barrier for the first time so when you go to a hearing event, it can be stressful. So if it's the LGBT community, it's like, you never know if you're going to have access there. So I remember, uh, I was on the train for nine and a half hours, uh, because obviously I live in the Northeast. So I had to get all the way down South.

And I went to Pride with a group of my friends. Some hearing, some were deaf. And I remember being so excited by the anticipation, waiting for the, uh, parade to start and seeing an interpreter as well. I think, I think there was maybe five interpreters around the event and they saw that I was using sign language. Um, and so they came over and said, um, you know, here's our number if you want an interpreter, text this number and one will come to wherever you are on, on site. And for me, that was so relieving to feel included.

But also I agree with what's previously been said a lot about community. When I was at the parade, my hearing aids fell out and you know, it was a big queue, it's like, Oh, I've got the wheelchair. And my deaf friends saw somebody catch the hearing aid before it fell and actually put it back in for me because I was struggling with my wheelchair. And that was a really special time that they just saw it happening, put it in, and carried on as if nothing had happened.

Emma: I mean, I'm still not over the fact that it took you over nine hours to get to Brighton from where you are. I feel for you so much. But I love that experience. And I think it shows why it is so important for spaces, events, workplaces, hospitals, whatever it is, to be inclusive because it makes a huge difference to the people that you're providing for. And when it comes to disability, that can be any person at any time. And it's so important to provide equal access, particularly in spaces that are celebratory of other identities, so thank you for sharing that.

But from the absolute bottom of my heart, I just wanted to say thank you for joining this episode of The Wheelchair Activist, it's been incredible to do the first episode with multiple people and have it be such a special episode. And I

want to thank you all for being so open and vulnerable. I know that this is not new to any of you to do, but that doesn't mean that it's easy. So I appreciate that so much. I want to say thank you so much all of you for joining and for Carol for providing interpretation.

Thank you for listening to The Wheelchair Activist podcast. You can learn more and stay updated by going to my website, TheWheelchairActivist.com and following me on social media. We will be back next month with a brand new episode.