Wheelchair Activist S2 E3
AI and Disability

Emma: In this episode of the Wheelchair Activist, we are exploring all things AI and disability. We are talking to Christine Hemphill, who has done amazing research into the ways that AI is impacting disabled people in all areas of life. Everything from education, to employment, to healthcare. And I am very, very excited to learn more about AI and the ways that it can both positively and negatively impact disabled people.I hope you enjoy this conversation as much as I do.

[INTRO MUSIC] 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, Christine, thank you so, so much for joining me on The Wheelchair Activist. I'm so excited to talk to you today and get into an issue that I've never covered before, but I have a huge amount of interest in. But first, would you mind telling our amazing listeners a little bit about you and the work that you do?

Christine: Well, thank you Emma. It's lovely to be here, um, I'm Christine Hemphill. I'm the founder and managing director of Open Inclusion. Open, I set up a decade ago to be a research organization that's specifically looked to listen to and effectively understand the diverse perspectives of the disability and older community to inform better design and more profoundly useful innovation.

That's what we were, that's what we are, and that's what we will be for as long as I'm here. At the center of this organization is a beautiful community that is now just over 3000 people, um, both in the U.K., U.S., Canada, and a little bit in Ireland and Australia, um, of people Pan Disability, who share their insights with us to inform the work that we do.

So that is the gem at the heart of Open that allows us to be useful. Um, we also have reached through community partners, um, into other countries. So when we've had the opportunity and privilege to do work around the world, we don't have the cultural fluency to understand the disability informed experience, for example, in Kenya or South Africa or Latin America.

But we have global partners that allow us to do research there with their understanding informing that work. So, you know, we have reached, I think

about 400,000 people in 28 countries around the world when we have the opportunity to, you know, do, uh, multi-country research.

Emma: Wow, that is a huge amount of people and it sounds like a really important, really important organization.

And I think what's so wonderful is that rooting lived experience at the heart of research also then that research will, if it goes on to inform policy or government decisions or briefings that decision makers get, they're getting that lived experience of disability instead of people making assumptions about what disabled people want or need,

which I think as we touched on before I pressed record, there's a lot going on right now in terms of the policy landscape that impacts disabled people at the moment, sadly, in very negative ways. But I'm sure we will get into that amongst the conversation. But what I have been so, so interested in talking to you about his disability and the rise of AI, so artificial intelligence. And it's a really big area of interest for me, but I think it's becoming more and more mainstream to be using AI.

At the time that we're recording this for people who may have seen this on social media, um, for the past few days there's been a trend going on socials where you can use Chat GPT to make yourself into a little action figure and have, you know, your little action figure accessories. And there were so many videos saying how do I do this?

And it's through AI. And so I think that's one of the ways that AI is becoming so, as I said, mainstream, so used by people. But what I'd really love to ask you is how do you think disabled people are feeling about the rise of AI? Do you think it's somewhere in the hopeful or the cautious or sort of somewhere in between?

Christine: As a researcher, I'll answer that with some evidence as opposed to here's Christine's view. We had the privilege last year of doing some research in the UK, so just to say this is grounded in UK consumer experience, where we asked 500 people, you know, nationally representative across the UK in terms of age, gender, and region.

Um, and then 300 of whom didn't have a disability or didn't identify as disabled

and 200 of whom did. And across a really wide spectrum of disability. And we asked them about their perspectives around AI. And what was really interesting, in general, people with disabilities and without disabilities are positive about AI.

So if there's a kind of minus five to plus five, I'm just looking at my data here, they were marginally positive on both, uh, disabled people and non-disabled people. So it was, this was a, scale from zero to 10. So five being, if it's below five, it's negative. If it's up, you know, 10, it's extremely positive.

In terms of the disabled audiences and respondents, they were just positive. So, you know, they were kind of 5.1. So just on the positive, not negative. Which means some people would've been strongly negative, some would've been strongly positive. Non-disabled people were still not far off,

um, but they were 5.6, so more positive than the disabled people. And I think what was really interesting is we did the quanta research and we looked at a number of use cases, so biometrics, voice ui, and adaptive media. Biometrics was the most positively seen by disabled people. Then voice UI then adapted media.

But there were a lot more concerns. And the concerns when we looked at specifics, in terms of what, what, what are the benefits and what are the concerns? There is less benefit and more concern to disabled people consistently across all three use cases. And the concerns were more specific.

So things like, you know, marginalized groups will be left behind because the data sets might be distorted and so on. So in short, there is more concern and less benefit seen by disabled people in the UK, of this particular survey, than non-disabled people. When we did a little bit of qualitative research to kind of unpick that and understand that in a slightly richer way, one of the things, um a number of my colleagues were sharing this research earlier this year. And one's wheelchair user and one is blind, and they both talked about how both, they might get more positives with AI. So the benefits might be greater because the ability to adapt inaccessible environments, tools, approaches, information to their needs might actually provide greater benefit to the disability community than to non-disabled people.

The other side of that is when they're left behind, if you think about when digital first came in or when mobile tech first came in, if there is a, a gap between the disability informed experience and the non-disabled experience. And yet AI is being applied in increasing areas of our society and increasingly fundamental

rights-based areas like education, employment, health, political rights and and so on.

Then the implications of that are greater. So I think even though there is a marginal difference and there is a difference between these communities, what's interesting is when you blow that up in terms of there are probably greater benefits, but also greater costs and fears to the disability community. And I think they're very well founded and, and we've done some work on, on how well founded they are.

Emma: So interesting. Because in terms of AI... I mean, going back to what you said about digital and mobile experiences, we've seen and we're continuing to see inaccessible websites, inaccessible phone applications, whatever it might be, that excludes a huge number of disabled people, you know, when particular, you know, web content accessibility guidelines aren't being met. Or you know, those standards aren't being reached, it shuts people out of using

that service or whatever, whatever that may be. But it's interesting you say about AI, and again, it goes to what we were speaking a little bit about before we, we pressed record, which is around co-production. And I was saying how I really enjoyed your research because it was all rooted in that lived experience of disabled people.

And I think as we're developing new technologies, whatever form that is, we absolutely need to be including in disabled people and those lived experiences in that development. Otherwise, we're going to be shut out of another medium and you know, we're going to not be able to receive those benefits. But i'm really curious about the different ways that AI is being used and if there was anything in your research that disabled people were particularly concerned about over other things. And I, I have a few things that I've seen in terms of, you know, concerns online, but I'd love to get your take on

what are some of the specific areas of life that AI either is being used or could be used that disabled people said they were most concerned about?

Christine: Yeah, and I think, disabled people, let's just start there. You know, it's a community of 1.3 billion people. So there are consistencies, but there are a lot of inconsistencies along that community as well.

And depending on people's personal experience, not just due to their disability, but all their other characteristics. You know, what other privilege or marginalization have they got in their characteristics that means their experience

of disability is completely differentiated? Even from someone else with the same,

you know, functional differences as them. Even the different assistive technology or adaptive approaches we might use can mean that our experiences, our barriers, our enablement is quite different. So, you know, just by saying I'm, I'm really conscious of not speaking for a community because there are so many beautiful subcommunities within that community.

However, there are some quite consistent barriers and there are some quite consistent areas of fear that I think impact many people and actually beyond the disability community, but marginalized communities. Marginalized in power, not necessarily in volume of, of people in many ways. The most obvious of these is around, what I was talking about before, in rights-based areas. In areas that can really fundamentally impact someone's ability to live independently with agency and with, you know, confidence and capability in the society around them.

So some of the most important areas where exclusion would fundamentally impact someone's life, let's just start there. They're the areas we need to be very conscious of applying AI to in a way that might discriminate against someone with disability. So that includes employment-- well start with education.

You can't be employed if you're not educated. So education, fundamental right, and we've seen some really challenging implications of AI in the education system. And in fact, in the research that we shared, one of the women who came as an expert to that research brought quite a personal story to it. Which her son is, uh, neurodivergent and had been excluded in the school system by an AI enabled technology that had basically rated his reading at a certain level and therefore, you know, was going to give him a very different opportunity for education on that basis.

Where, you know, a little bit of adaptation, a little bit of human in the loop could have had such a positive impact. Instead you hit a child's confidence right at a moment that that was critical and that doesn't go away. You know, I'm parent of neurodivergent children as well. Understanding that once you have, particularly in that very sensitive period of education, impacted a child's confidence, you know, that can be a lifetime worth of impact.

It's really, really challenging. So education, critically important. Employment, the kind of flow on from education, critically important. And Susan Scott Parker

has done some remarkable work in Disability Ethical AI. She's got a website, links to a whole lot of information there.

The OECD also did some really good work on AI being used as assistive technology in the labor force, but also some of the negatives in there. Chloe Touzet was the lead author of that. So there's been some amazing work in this space that I'd really kind of point people who are interested in that to look to.

Um, then health, obviously health data is already significantly gendered. What's happening politically means that's probably gonna become even more so, especially when a lot of that research is done out of the states. But disability informed research around health is really under understood. The disability informed experiences.

So if you've got data sets that exclude disabled perspectives or don't exclude them, but don't actually include them in a way that you can correlate the disability experience to the impact on people's health, or do correlate it, but also correlate bias in the system that is actually accurately reflecting today's reality.

There are a whole lot of layers that because we're applying data through AI to get to outcomes, we can distort the outcome for disabled people in a very negative way. So health does concern me significantly as well, as AI is applied. Equally on health, I think there's some amazing applications of AI to be able to understand better what's going on and faster than humans could possibly move our brains across if it's set up successfully and in a very conscious way to start with.

So there is such value and productivity to be gained from ethical AI. I just think the awareness and understanding of what that is and the misinformation around selling products and services that someone's going to benefit from selling that service that has AI embedded in it to be more efficient,and yet the buyer is not aware of the implications that come with that. This is a very new technology and so there's some very, um, unequal pressures and knowledge that can impact how people might wish to buy a system and apply it and recognizing the potential implication of that system, whether they're a government, whether they're an organization. You know, it might be a government thinking about using it in a justice system.

It might be an organization looking at putting it in an HR system. Or it might be a health organization thinking about how they can, you know, hold and manage health data to, to get to faster outcomes. You know, all of these could be very positive and very practical and they can be very problematic,

given our understanding of the challenges in the data sets that underpin these.

Emma: There's so much within that that I desperately want to ask you about. But I think I'll start with-- and please, I'm not an expert, so please feel free to, to correct me wherever I'm wrong. But the data and sort of the resources, the sources that AI is using is very much based on averages and sort of volumes of content that it sees. And so it's, it's using the resources and the sources, like I said, that it has available and it's very much about averages and norms. But I'm wondering in terms of disability, where, as you said, it's this incredibly diverse community and as you said, with all different access needs or communication needs or whatever it might be, is there an inherent risk with AI, just at its very core, that it could be already excluding disabled people or the way that disabled people communicate or lived experience or, or sort of anything like that based on what AI has at its disposal?

Christine: Absolutely. And it's really interesting that the, the very nature of AI, as you've kind of--

But firstly, can I just say nobody's an AI expert, even if they pretend to be. This technology or set of technologies, 'cause it's not a technology, this suite of technologies is coming at us so fast and you know, it's self transforming so rapidly.

You know, none of us is an expert and I most definitely am not. I'm listening actively in this space, but it's most definitely a space that I feel consistently uncomfortably comfortable in. And I think I mention that because I think we all should. It's a space where it's very easy to go, "I'm not an expert here,

how could I have a useful, valuable voice or perspective to put into the debates that are happening around it?" Here is my first thing-- I'm being the politician here. I'm not answering your question. I'm answering the thing I want to share first, which is please everybody step forward into this space and bring your perspectives and bring your views and ask good questions and challenge what's going on.

Nobody is an expert, despite what they say. And we need a more diverse set of voices involved in the debates around AI, how it's used, where it's appropriately applied, what sort of constraints and guardrails and guidelines are required around it, and how that might be implemented to minimize harm and maximize the benefit of this very powerful tool.

So I just, you know, urge everybody to lean forward and be uncomfortably comfortable or comfortably uncomfortable because no one's going to be confidently comfortable in this space. And if they are, they're just kidding themselves.

Emma: There are a few people that are springing to mind in the global stage, so absolutely with you on that.

Christine: Yeah. So, you know, it's, it's just a space we need more voices and I just want anyone listening to this, get curious and bring your perspective because it's needed. Your question around averages, um, in order to make data usable by an algorithm, you basically need to synthesize it, simplify it, codify it.

it's taking data and making it usable for an algorithm. The practice of doing that strips the data of a lot of its meaning. And that's that kind of averaging and normalizing what is not a norm-- you know, it's the, the knowledge and the experiences often at the edges that are the particularly powerful ones,

yet that process often strips those out. Trisha Wong spoke, um, she actually wrote a beautiful article in 2013 about thick and thin data. And if you just use thin data-- and she was working at Nokia at the time. And they were looking at how they might understand the Chinese mobile market, using very big data, but very thin data.

And that's exactly what AI does. It's using big but quite thinned out data. That becomes very problematic quite quickly because you can see patterns, but you can't know why. It's the what without the why. It is the same when you strip data of it's, you know, a lot of that very contextual information. For example, context of disability, context of the other characteristics of that individual with a disability, context of quality of life implications, not just behavioral implications or what people did or what they got out, you know, how they felt.

All of that gets stripped away. It's not qualitative data. It becomes very, very quant, very quickly, very numeric. Um, because essentially it's got to be put into zeros and ones. So that very process of turning it into useful data for AI actually can make it quite harmful, especially to people who have more atypical experiences.

And in fact, again, I'm just gonna keep throwing references in so people who are curious can read from people who are much better than me at speaking about this. Jutta Treviranus from OCAD in Canada at the Inclusive Design Center

there, speaks beautifully about AI and about stripping down of the atypical experience and the implications of that.

And in fact, just a, a very simple example that she's used about that, when you've got autonomous vehicles that use AI to understand from sensor data to moving a vehicle through space safely. They had an autonomous vehicle in Canada moving through a space where somebody was using a wheelchair. They were using a wheelchair in an atypical way.

They weren't moving forward. They actually used their feet on the ground and moved backwards. So it allowed them with the mobility that they had to move through space in their way, but the car didn't recognize that as a human and would've run over them had there not been a driver still in control, and therefore human in the loop to protect that individual.

That's the cost of an algorithm, not understanding that complexity of humans that you were talking about before. And the fact that we don't all fit naturally into very clean little boxes of particular ways of moving or acting or seeing. And just a less impactful or life threatening, but still impactful,

example, you were talking about representation before and about everyone making their little action figures at the moment and how fun that is. Well, it's a lot less fun if you've have got an atypical body and it won't make it in a way that reflects you. And you're looking at all your friends getting their little characters and going, well, that's great for you, but why haven't you been able to make me, that looks like me because you are underlying data set didn't work well enough for me.

And the most obvious perspective I've seen on that was if you ask an AI to generate an image of a disabled person or to have a crowd with a disabled person in it, or then you get a bit more specific and you say, can we have some people with these characteristics and some people with those, and it just can't do it really well.

And Jeremy Davis, a comedian in the US who's an autistic gentleman himself, looked at one of the image creation AI sites, and said, please show me autistic individuals, you know, give me some images of autistic people.

Emma: Mm-hmm.

Christine: And he got a hundred images, and I'm gonna get the stats wrong 'cause I don't have them in front of me,

but it was something like, 90 of them were teenage men. You know? Interesting. And they were all white, very few women. Very few people who weren't white, and most of them looking quite pasty and quite unhealthy. You know, so what AI does is when there's a trend, it doesn't just play it forward, it amplifies it forward.

And I think that's a critical point for us to understand is when AI picks up on patterns in data, in underlying data, and that underlying data is quite distorted because, for example, our representation across society is remarkably distorted in terms of, you know, just think about who's in ads, who's in films, who do we see in society in the, you know, images and imagery of humans, and who doesn't get equivalently represented in that?

All of that distortion doesn't just get played forward, it gets amplified forward because the algorithm picks up on that trend and goes, "oh, great. I got something. Yay me. I'm gonna play that forward." You know, in this case it's still harmful because representation is harmful, but it's not life threatening.

But it can also be rights threatening. And we've seen this happen in, um, the justice system, for example, in the US. Where AI has been used to support sentencing. And it plays forward to trends from the past in, in very negative ways, particularly for people of, um, marginalized ethnicities.

Emma: Again, there's so much in there that I think really resonates, but really, really clearly explains the way that, like you said, stripping that data and you know, removing the outliers from from data sets and trying to find that norm, really excluding disabled people and the ways that they interact with, with everything. I mean the autonomous vehicles example, so my, my day job, um, is working at Transport for All, which is a disabled person's organization focusing on access to transport and street space. And with the emergence of autonomous vehicles and in the previous parliament, various debates around autonomous vehicles in legislation, we were very heavily campaigning for there to be a requirement to have developers and manufacturers of autonomous vehicles work with disabled people to be designing these in a way that, like I mentioned earlier, isn't going to shut us out from this new mode of transport.

But I think what you've really greatly touched on is that safety concern and you know, that example of someone using their wheelchair differently and that ultimately being then life or death. And how incredibly important that is. So I'm almost making a mental note to myself, you know, for work to be pushing for that even stronger. And that, you know, at Transport for All we, we call for everything, all policy to be co-produced with disabled people. But I think

particularly around this, your example makes it so clear why that is absolutely needed and why there needs to be legislative requirements for developers and manufacturers to work with disabled people so that they can then plan for as many of those eventualities as possible.

But when you were saying about the action figures, um, it actually just struck me as you were talking, mine... I uploaded a picture of myself. And for those of you who are listening, instead of, you know, watching this on YouTube, I have a ventilator that I use through a tracheostomy. And now thinking about it, none of the versions of the little action figure that it showed me had that. It had me in a wheelchair because again, it probably has enough ideas of what wheelchairs look like. Even powered wheelchairs as opposed to, you know, the manual ones I think are first used. But it, it didn't pick out my ventilator, my trache. And I was thinking beyond that and those fun, you know, image generation things, uh, apps or websites that I know friends of mine have used. They'll upload a selfie of themself and then they'll ask it to essentially give them a professional headshot that they can then put on their LinkedIn.

And I, you know, like my friends, I tried that, but it didn't recognize the ventilator or the tracheostomy. So I thought, well, this is completely useless to me because it's, it's not picking up something that's so identifiably me. And something that I, I wouldn't ever like Photoshop it out. But as you were talking there, I thought I did post my little action figure, but I didn't ask for it to have the ventilator.

And I, that just completely didn't cross my mind, which is so bizarre, um, given what I just said. But I think you're, you're absolutely right about these kinds of perceptions that AI is using. And I, I talk a lot on this podcast about media representation, and I think that is so incredibly important for awareness of disability across so many areas of life.

But when those perceptions or those portrayals of disability are being used to inform AI, it's going to... I think we can safely say that, you know, in the UK at least, there's this perception of disabled people as the para Olympian or the benefits grandeur. And if those are the examples that are being given to AI-- or there's a bonus fun, third one, which is, you know, the tragic disabled person.

Christine: The pity porn, the inspirational porn or the superhero.

Emma: Yes.

Christine: And these are the, you know, they're mythological creatures that yes, there will be people that, you know, like any other community will fall into being truly inspirational. Actually, we were talking about Tiffany Yu just before this.

Emma: Yeah.

Christine: And I've just recently had the privilege of having a chat to her and she says, you know, if you can take away the word disability and the person's still truly inspirational, use the word inspirational. Like there are amazing people doing amazing things that have disabilities just as there are in every other community. But if it's, oh my gosh, and you got up and went to work, really? And you got your lunch as well?

Emma: Yeah.

Christine: You know? Right, good day. So, you know, there's these caricatures as opposed to characters that media tends to overplay and they're these mythological creatures that we've got used to hearing about, whether it's through fairy tales or like through lots and lots of cultural experience, we've overplayed these mythologies. And the reality of the disability community, like any other community, is there's every spectrum of interesting, curious, and quirky human beings in the middle.

Emma: Absolutely and I'm just thinking about, you know, some of the research that I did in, you know, preparation for this episode and there was a lot of commentary around AI being ableist.

And I think that that makes so much sense to me based on what we've talked about, about how it's getting information about disability and how it's stripping away that nuance, that diversity, that huge range of what, you know, like we've said, you know, someone with the same condition can look completely different to another person with their condition and have completely different needs.

So would you say that there's a genuine risk that AI is being ableist?

Christine: AI is a set of tools underpinned by sets of data and empowered by being applied to solve problems. None of that has a conscience. So it's essentially zeros and ones all the way through. However, there are a lot of people involved in the making of that, and there are a lot of past and current experiences that are fueling that data set that feed into that, and making

decisions on how that data set is applied, where it is used, and what the implications of different outcomes.

You know, you hit channel A, B, C, D, you know, and you're gonna get different outcomes. Maybe it's different insurance prices or different offers or different, you know, opportunities or whatever it is. They're all the humans in the loop and our society is clearly quite ableist. Our data sets are even more ableist, I think, than our society because our practices around research and data are actually fundamentally exclusionary.

You know, as a disability inclusive research agency, we work really hard to try and offset that, but standard research practices actually exclude disabled people in many different ways from intent, tools, skills, understanding even once you've got that insight, and application. So right across the ecosystem of research, there are layers of disability exclusion that are impacting how research accurately and appropriately reflects disabled people's experiences.

Given that, that sits in all our data sets, our actual reality is quite ableist. You know, we know that, we know that people with disabilities don't have equivalent opportunity to those without, in lots of different ways across lots of different parts of society. So the data could have gaps in it, firstly, and those gaps could be very meaningful.

Secondly, the data could reflect our reality and reflect our current level of discrimination forwards. The application of that through a process, if you're not doing what you are, you know, trying to get everyone to do at Transport for All, involved right the way through this practice and process of designing and applying AI and hopefully also monitoring and verifying that it's working as it was planned, that if people with differentiated experiences aren't involved in that, it will

by its nature and by the nature of the environment that we live in, it will exclude. There is no question. So for all that I say, zeros and ones are zeros and ones, and really don't care which way they flip, the way in which technology is created, the way in which it's informed, and the way in which it's applied, and the implications of that application all will discriminate.

Emma: That makes a lot of sense. And you're absolutely right. Uh, and I think we've, we've all heard similar arguments before about, "well, it's technology, so how can it be discriminatory?" But as you say, it is, it's created by people. As much as it does get, you know, stripped down into those zeros and ones, those zeros and ones come from real people collecting real experiences about real

society. So I think that there's a lot to, to take in with all of that. And I think all of the risks that are immediately jumping to mind in those areas that you mentioned of education, employment, and healthcare. But what are some of the positive ways, I suppose, that disabled people could be using AI or if disabled people were to get more involved in the development of AI, or like you say in the debates and conversations around AI, what are ways that it could potentially support disabled people to be more independent or to achieve whatever it is they want to?

Christine: AI has a lot of power, and that power can be used for good. And we have seen some really beautiful examples of AI enabled technologies that are specifically designed for disabled people and communities that can transform people's capability, independence, and experiences. So, you know, for all that, I've gone to some of the risks of particularly broadly applied,

not specifically in considered AI, there are some incredible and positive powers of AI to enable people. You know, as an example, the Scott Morgan Foundation is doing work on voice UI to enable people who are losing their voice, say through ALS or through Huntington's, or, you know, other conditions that people can lose progressively lose their voice, so that their assistive communication devices actually are embedded with their own voices in the future.

Now, the quality of life implications of that on someone being able to communicate with their family and read a story for their children or tell their wife they love them, or, you know, speak at a, an event and do their work in their own voice. That's incredibly positive and powerful.

Emma: Yeah.

Christine: You know, if we think about transport, you know, you were talking about, you know, Transport for All. We've been doing some really interesting work, you know, with the Royal National Institute of the Blind around understanding how technology can enable blind and partially sighted individuals to navigate transport systems, you know, urban spaces and public transport systems. And there is such, both mainstream technologies enabled underneath by AI and specific technologies designed for people who are blind or partially sighted or even designed for other purposes that can be co-opted by people who are blind and partially sighted, to make things so much easier for people with low vision or no vision to navigate spaces confidently, independently, or safely.

Or hopefully all three. So there are really powerful and positive use cases of AI enabling people with disabilities to independently navigate things that are more complex and have more barriers in them today. Even little things like being able to pick up on prosthetic designs in one part of the world and 3D print them in another part of the world using AI and computer vision to say match on a child's arm as it's growing.

You know, this is reducing the cost enormously of getting to the assistive tech that can enable and empower people.

Emma: I mean, those are some really wonderful examples. Your example of the voice particularly resonates with me because when I contracted the swine flu when I was 15, I did lose my voice for a full year, really. 345 days I wasn't able to speak. And at that time I was so incredibly grateful to Apple. Not just saying this because I hope that they sponsor me, but maybe one day. Um, but I had an iPad touch or an iPhone. But I think the iPad Touch was my main one because it was a bit lighter.

And I was able to communicate using that. It was through, you know, me typing and then people reading it. But when I think about now how I think on all of Apple's recent products, um, there is that personal voice. More or less you read a bunch of sentences to it and it then is able to use, you know, AI to then use your voice to read out whatever it is that

you've written or like you said, you know, saying, I love you, or reading a story, or whatever that is. And when I think about what that would've meant, not just to me as the person who lost their voice, but to my family. And, you know, I remember my mom so clearly saying that, you know, she was just calling my voicemail on my mobile at that point over and over to get to my voicemail

because that was the only recording of my voice. But now, you know, technology like that, it makes that assistive tech that much more personal and that much more...

I don't wanna say easy to use, but I think for people who might struggle with internalized ableism and not wanting to rely on assistive tech or assuming that, you know, I think we've all seen various, you know,

comedy interviews or real interviews with Stephen Hawking, for example, and sort of have this idea of that robotic voice with that very long delay between someone asking him a question and him being able to respond to that. I think

people have that as a little bit of a, you know, a point of reference for what assistive technology could look like.

Christine: Interestingly, he could have changed his voice into a much more, uh, naturalistic voice towards the end of his life.

Right.

Christine: And because people so identified that sound as his voice, it became part of his identity and he chose not to. He actually, that is his voice. And you hear that and you go, that's Stephen Hawking.

Yeah.

Christine: So it's, you know, you were talking before about, you know, having your trache and, and that being part of your identity. You know, different assistive technologies can become part of our identity. And that's actually, to people that don't use assistive tech, it's like when people use the word wheelchair bound, clearly never used a wheelchair, because they don't bind you, they enable and empower you. So it's just that, um, recognition that identity can come with assistive technology and can be an incredibly enabling, empowering and actually identity informing part of people's characteristics. And that does depend on where they are in their disability journey, how long they have lived with it.

Yeah.

Christine: You know, all these other things that play into it. I wanna pick up on two things that you just mentioned. One of them is the incredibly positive power of mainstream technologies that have disability adaptive-- not just disability adaptive, human adaptive capabilities.Capabilities that allow, whether it's because of disability that's permanent, that's situational, that's temporary, that's just, it's my preference, allow us to use technology in ways that better suit us.

And whether it's Apple, whether it's Google, whether it's more specific technology like, I don't know, a Bose headphones or what have you, so many technologies that we use are building in mainstream capability. We're seeing this actually increasingly in white goods as well, mainstream products that have adaptive capability.

Now as they do that, and as you have more in inverted commas, smart products that have AI enabled or things like touch screens on a fridge and so on. Back to

your comment before thinking about autonomous vehicles and cabs. Who was involved in the making of that product and what diversity of people and of their experiences and of their engagement approaches were involved?

'Cause if you take an Apple type approach, which has worked pretty well for them, to be honest, start at the edges and you get the center for free. Work with people with really differentiated experiences right at the beginning of the innovation process. And you are gonna create a mainstream technology that's going to be so much more human and adaptable.

Obviously not excluding people with disabilities, but more importantly it will delightfully adapt for humans who do and don't identify as disabled. And you know, if we think about an aging population and people not necessarily identifying as disabled, but having increasing kind of age related quirks. Um, this is just gonna make for much more human products as we go forward.

And just little things. It can be very mundane, as well as very profound. You were talking about autonomous vehicles before. We did some work on them a few years ago, and one of my colleagues who's blind said, well, what if there's no mirrors?

You know, there's no wing mirrors required on autonomous vehicles because they're using sensors, not sight. You know, you're not using human sight, so you don't need rear view mirrors, you've got sensors facing all directions. As someone with sight loss, that's the affordance I use to know where the door handle is. Huh. So who thought of that and who has thought about what the equivalent tactile affordance is that we are gonna offer people with sight loss to ensure that they are enabled when they're trying to find the handle? And just a little add-on to that, we were in Italy actually at the assistive tech conference a couple of years ago.

My husband and I were sitting there on the pavement on a, this is when a heat wave was hitting Italy on a very, very hot evening. And a son, or son-in-law came around to pick up his mother or mother-in-law, who was quite an aged lady and trying to get into his car. The car was this very modern, very sexy beast. Owned by someone who's, you know, currently got a lot of political power in the states. And she could not find the door handle for love or money. You know, the door handle was obviously kind of, didn't have this obvious tactile affordance of your standard door handle. It was kind of built into the door and she was there trying to find this thing to get into the backseat of the car.

Could not. Eventually the son had to come around and open the door for her because they'd taken away that affordance that allowed someone who had more limited dexterity in sight to be able to know where that door handle was. So something as simple as getting into a car, they'd just taken away her independence.

Emma: I mean, that's fascinating. And what I think is so interesting-- you know, without going full transport nerd, um, uh, in all of this. But what I think is so interesting about autonomous vehicles is that I feel that they are really being pushed towards the visually impaired community because there is this assumption that, you know, that will open every single door possible.

You know, I mean, metaphorically, every door that, you know, if a visually impaired person wants to go to the shop, then clearly the only barrier they have is driving themselves to the shop. But what I think is so interesting is the ways that they're not even being designed as, as that example you just mentioned, but I could think of some of the others, they're not being designed for an actual blind or visually impaired person. It's based on an idea that someone has of a blind or visually impaired person.

Christine: So someone who–

Emma: Yeah, exactly.

Christine: – who's not blind or visually impaired would go, of course this is gonna be useful technology.

Emma: Exactly. But not thinking--

Christine: Who's designing it.

Emma: Exactly.

Not thinking about, like you said about the wing mirror being an indicator for someone or, you know, there, there are so many little things that I've learned about autonomous vehicles and the way that they're being developed right now that I can just spot problem after problem for so many impairment groups. And unless we bring disabled people into that conversation and make that a requirement of manufacturers, because I think we've all seen not many manufacturers are going to take that step themselves to engage with the disabled community because of various, there are so many reasons that I agree with none of. But unless it's a requirement to consult, I think it's unlikely that that

consultation is going to happen and therefore that end product is going to be pitched towards a blind or visually impaired person.

And like that friend that you mentioned, they're going to say, well, how do I get into it, because the wing mirror is gone? And again, it's, it's just this big flashy piece of tech that is not actually going to benefit the disabled community because it's not designed in that way. But I think what we were saying about the different ways that AI can enable, I think that's so interesting.

And, you know, beyond the, the voice, which you know, as I mentioned really strikes with me, but as we're talking about with Apple, I do think that-- and again, I'm no accessibility expert at Apple, but I have used an iPhone since the first one came out, and I now really use the whole Apple ecosystem because of the accessibility features that are built in and are so easily

built in. You know, they're, they're right there in the main settings page. You don't have to go into some, you know, advanced fourth option page to find, you know, how do I change the text size? But the, the way that Apple has built in so many accessibility features, that not just I use as someone with a, you know, physical impairment or I use things like the assistive touch,

I use Siri who's probably gonna yell at me any minute because she hears herself. But, um, you know, I use all of those and they're so readily available that I do feel that Apple does seem to care about disabled consumers. I, again, that's my own perception.

Christine: I think it's a really interesting point, Emma. And I think I would challenge designers of autonomous vehicles to learn from those who have gone before and been incredibly successful in technology development.

So don't look at current practices of, of vehicle design. Don't start with our flawed, you know, process of, you know, design crime everywhere I look. I mean, I always say when I talk to young designers, the thing about inclusive design is it's such a joy because everywhere you look there's opportunity.

And it's so frustrating 'cause everywhere you look, you'll see bad design. You know, our current level of design across our society is really pretty poor because we've just anchored in quite an inaccessible and quite a, a narrow target audience for design. And that's not just disability, it's actually across a lot of characteristics.

But I would really challenge innovators and people wanting to be successful, look at those that have gone before and used the, you know, approach of starting with people with really differentiated experiences to inform more creativity, more adaptability, more mainstream enablement of broader target audiences, so that you're actually useful, as you've talked about.

It brings huge loyalty with it because if all the other products are falling behind and this one step forward because it started with that understanding of the reality of human diversity, you're just going to get a much better product and it's gonna be so much more sustainable. And quite frankly, in a market like autonomous vehicles, there's not yet leadership because it's such a, a immature market.

If you think about Apple, this, I find it really interesting because they were ahead of the curve. Now Google have worked really hard to catch up, and Android actually has an amazingly adaptive mainstream ecosystem now too. But it's very hard to challenge a leader when that leadership was one fair and squarely, and they were ahead of the curve.

Now there's space for leadership in these new spaces. So here is a wake up call to anyone who works in an autonomous vehicle organization or anywhere else where you know you're thinking about how might we differentiate and create sustainable competitive advantage in this market, come talk to the disability community because there's some really good knowledge there that'll help.

Emma: Preferably, please come to Transport for All because we would love to get involved in that. That's me putting my workday hat back on. But no, I think you're, you're absolutely right in, in looking at good practice examples of engagement and design around that. And I would love to ask you one more question.

We've talked a lot about encouraging disabled people to get involved in these debates and in this conversation, what advice or what channels would you suggest to disabled people who maybe have listened to this and either have more questions or they want to learn more, and then how would you direct them to get involved in these conversations?

Christine: Well, a bit like you, I'll wear my day hat firstly and say, please come and join Open Inclusions Insight Community, because we would love to hear your perspectives. And we make sure, one, you're well remunerated for perspectives you share. But secondly, we work in spaces where the clients are listening. And so the power and influence of your voice, you know,

3000 people do not represent 1.3 million people, or even, you know, we've got, I think, just over a thousand in the UK, do not represent the, you know, 16 million people in the UK. But it actually means your voice is over amplified because you're the one being heard. So, you know, I'd really, um, welcome anyone to come and join the community and get involved in research 'cause we are listening and we co-create that research with people with different disabilities so that we design it right from the very start.

In fact, you know, quite often, even at the proposal stage with people with different disabilities informing us to make sure we are looking the right way and asking the right question to make sure that that understanding is shared appropriately and, and usefully. I think there is also, this is a time where we need community to step forward. There's a lot going on and I recognize that not everyone will have that energy, time, and space to do so.

So whether it's you doing it or supporting someone else who's doing it or just, you know, amplifying other voices when you don't feel that you have the time and space for your own. You know, this is a community and this is a community where we can support each other. And I think one of the things we've just been talking to our community leaders, both in the UK and US in the last two days, about some of the things that are going on at the macro level at the moment.

It feels like people are pouring water of division between the community and across communities. This is a time where we need to support each other. You know, make space for each other, make space for our differences, and find those points of commonality where we can work together.

And when you don't have the energy, support those that do. And when you do, you know, make space for other people to support you because we need to lift this roof. And in whatever way you are curious and interested and want to be involved, follow that. Because there are so many ways that people can get involved. Whether that's in a community group, whether that's in a campaign that's going on, whether that's in policy and trying to, you know, advocate for change at the governmental and guidelines. And you know, whether it's things like AI guidelines, whether it's policy around social services, there's so many spaces. Pick one that suits you. Again, just before we started recording, Emma, you and I were talking about, it can be really exhausting. Do what you can in the moment you're given with the time and energy you've got, and don't beat yourself up beyond that.

Because if we all just did that, oh my gosh, could you imagine what the world would be like?

Emma: I am going to have my producer clip that, and then I'm going to play it to myself whenever I feel like I need that little bit of empathic motivation. Um, so thank you so, so much. And I will make sure that we have the link to your organization in the episode description,

um, so if anyone is interested, they're able to, to get directly there. I just wanted to say Christine, again, a a huge, huge thank you for joining me on this podcast episode. It's been incredibly interesting and hopefully not too self-indulgent in my interest, but hopefully other people will, will really be interested in this area that, like you said, no one is an expert in and that it's, it's an exciting and really important time

to be having conversations like this. So a huge thank you for taking the time to talk to me.

Christine: Oh, absolute pleasure. You know, and thank you for making space. Because these spaces are important and you know, I talked about some of the big ways people can get involved in things, sometimes it's just listening, getting curious, getting critical, thinking.

You know, there's so many micro things we can do to progress our society as well. This space is, is not a micro one. This is a macro one. So thank you for holding that space.

Emma: Thank you so much for listening to this episode of The Wheelchair Activist. If you want to stay up to date and catch all of our previous episodes,

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