The Received Wisdom

Episode 36: Electric Cars, the Problems with Tech Biographies, and Against Technoableism ft. Ashley Shew

Teaser

Intro

Shobita 00:00:37 Hi Jack.
Jack 00:00:38 Hi.
Shobita 00:00:39 Happy fall. Happy October. How are you doing?
Jack 00:00:42 All fine here. Weather's closing in. Term’s starting. Back onto the treadmill. What about you?
Shobita 00:00:48 Well, we're well into the term here. We're at the point where I, I have to do a lot of work to keep my students still <laugh> on track and energized, uh, managing with that. Trump and Biden came to town recently, so that was extremely weird…
Jack 00:01:05 And especially European listeners might have forgotten that you are in Michigan, in ground zero for America's auto industry.
Shobita 00:01:15 That's right. Yeah. So I live – Ann Arbor is pretty close to Detroit and of course right now we have the United Auto Workers who are on strike. It's so interesting, just generally as a point, I don't think we've really talked about this on the podcast, but so many of the labor strikes this summer have been kind of accelerated by AI and in fact the Writer's Guild just was able to get some concessions and the Screen Actors' Guild are fighting for concessions around AI and technology.
Jack 00:01:49 It's a really interesting, actually to see some resistance, right, and to, and to see some concession.
Shobita 00:01:54 That's right.
Jack 00:01:56 You do start to think, oh, okay, okay. This is changing the story a little bit. So, how's AI figured in, if you work for one of the big car makers, how is AI scaring you and what are you doing to push back against it?
Shobita 00:02:09 I mean, in some ways the history of labor strikes, back to Luddism, is about automation and technology, but in this case there's concerns about, you know, more automation in the car – automated vehicles, your area of expertise – but also the rise of electric vehicles and that's also rendering the cars more technological. And if that happens then one of

the concerns is that the parts will no longer be made by the people in the factories, that they will require a skill level that the people in the factories may not have. And the secondary concern is that the, uh, manufacturing will continue to move outside of the U.S. Of course, so much car manufacturing is done outside of the U.S. already despite the efforts of the auto workers. But yeah, they're worried about that. And so basically you had – very strange, I mean within a 24 hour period – you had Joe Biden, the labor president, the certainly the president who considers himself a great friend of labor and who the United Auto Workers haven't endorsed yet – they haven't endorsed anyone – but Joe Biden came and he talked to the workers and he walked the picket line and he held a rally sort of event with the union workers, and the head of the United Auto Workers was publicly photographed and seen with Joe Biden.

Shobita 00:03:39 So that's sort of Joe Biden as an ally of the union. And then within 24 hours Trump was here too, <laugh>. But what was interesting about Trump's visit was that he didn't go to a union shop, he went to some other, you know, we have, because of the big three, we have all these other car companies in town, you know, car parts manufacturers and other laborers involved in the auto industry. So Trump went to another car parts dealer, car manufacturer, I don't remember, and basically said, you know, the reason that the auto workers are in such bad shape is because of electric vehicles and no matter what – like he basically said, the union is not gonna exist anymore. There are gonna be no jobs if there are any more electric vehicles. And of course Biden on the other hand, has been a huge proponent of electric vehicles in recent legislation.

Shobita 00:04:32 A lot of that has really focused on electric vehicles. The other thing to keep in mind is that, you know, Michigan is a swing state of course, which is why they are running here to try to make these different arguments and calculations. Meanwhile, the head of the United Auto Workers didn't have anything particularly kind to say about Trump, as you can imagine. 'cause he didn't come and actually endorse the union. The union leadership in the US tends to be Democrat. And it used to be that union workers were also reliably Democrats. But Trump kind of shifted that and more union workers became Trump supporters. So that's why all of the politics are a little bit up in the air and weird around this.

Jack 00:05:16 We see a sort of politicizing of manufacturing of the technological transition to electric cars, which – at least according to the Biden camp – are the future. It's sort of, you know, you're either making electric cars or a flood of Chinese electric cars will take over, but the sort of inevitability of the transition is there. Whereas for, for Trump it's been really interesting seeing the sort of politicizing of electric cars as bad for American freedom. I mean they are an interesting challenge to the ideal of the American dream and the internal combustion engine giving that sort of freedom. Rather than depending on a network of petrol stations, gas stations filled up by American oil, you are dependent upon some sort of sinister electricity grid that might fail. You are also dependent on Elon Musk's software that might just, you know, where he might choose to brick your car at any moment.

Jack 00:06:13 So are you ever really truly free if you have an electric car? So in Britain we've had the last couple of weeks the conservative and labor party conferences. And one of the odd moments for those people who aren't following British politics, we basically have what look like the death rows of a conservative administration. And as the conservatives go down in the polls, they're sort of flailing about for things that look popular. And one of the things they've

done is try to politicize transport as well. So Rishi Sunnak has declared war on the war on cars. Classic sort of culture war <laugh> language to imagine that you're under attack and then to fight back, which for Britain, there's a sort of urban-rural dimension to this. It's things like low traffic neighborhoods that have sought to get rid of cars very successfully in areas like where I live in London. And occasionally some sort of toying about with fringe conspiracies as well. So conspiracy theories about 15 minute cities and that sort of thing, being part of some central bank digital money surveillance state that will stop you from moving about.
Shobita 00:07:27 Can you explain what a 15 minute city is?
Jack 00:07:30 So a 15 minute city, this is a big deal if you live in a European city, it's the sort of philosophy that basically says, wouldn't it be nice if you lived somewhere where all of the things that you needed, like schools for your kids, a local doctor, local shops were within 15 minutes of you walking or cycling so you don't have to get in a car. And it's, you know, that clearly is a political move because how people get about is always political, but yeah has been absolutely weaponized by people on the right, including there was this gigantic showdown in Oxford, Oxford, you'll know – big university town – where they handled the imposition of new controls on cars very badly and started restricting where cars could go. And this was seized upon by the sort of Brexit-y fringes of the British right of politics. Which means that the whole thing is – you've basically seen a culture war about transport. You know, in places like London, how you get about has always been political because there's so little space and so many people who need to move around just like in Manhattan.
Shobita 00:08:41 And there's long been a congestion tax, right?
Jack 00:08:45 Yeah. So the congestion charge, the congestion charge is a extremely successful policy. I think most people would agree. But if you wanted to introduce it now, I don't think you could, because the politics of it have got so nasty.
Shobita 00:08:59 It sounds like it's becoming more American in some ways. Certain kinds of restrictions, quote restrictions on quote freedom of movement are not tenable I think in the U.S. And so yeah, any of those kinds of restrictions or perceived restrictions are often just off the table when it comes to thinking about –
Jack 00:09:19 Well it's interesting isn't it? You know, if you live in Manhattan, I guess the big restriction on your freedom of movement is the fact that you'd be mad to drive through the city <laugh> many times of the day. So, you know, the restriction on your freedom is the sheer amount of traffics and the fact that there are other options available. So obviously it's always freedom for whom and, and we would say, you know, those of us in London who use public transport, that we have the freedom to choose a whole bunch of different options, which is an extraordinary privilege that means that you don't actually need to have a car. But sometimes the accusation would be that people in London forget that the rest of Britain doesn't work like that. So there's a sort of metropolitan elitism type accusation there as well.
Shobita 00:10:04 Right. I mean I don't know about this dimension of U.K. politics as well, but I know that in the U.S. it's so interesting because the history of electric vehicles, if you think back further than the current history, is actually one of the car industry preventing the development of electric vehicles for many years until relatively recently. And there's no freedom frame for that, right? Which is interesting as you just suggested. Like one could imagine a freedom frame around that in terms of choice. But because of the politics of climate change in

the United States and the way that that's been bifurcated, it doesn't get overlaid in the same way.

Jack 00:10:49 The other really important thing to remember about Britain – and this is certainly clear when I talk to friends in Germany – is that Britain doesn't really have a car lobby anymore because Britain doesn't really have a car industry anymore, which sort of eases the politics of those transitions a little bit. A little bit. So it's more about how you get about than what the future economy looks like. Now listen, I want to ask you about your part in facial recognition. So we've talked a bit about facial recognition in earlier episodes and there have been various developments. And it's a really interesting discussion because it's one of those technologies where lots of people in lots of places are actually seriously considering banning it, which is sort of a heretical for many technology discussions. And yet when it comes to facial recognition, a lot of public authorities are saying, no, this thing stinks, right? It looks really bad and the risks seem to massively outweigh the purported benefits. And there's been a development in New York that I understand you've been a part of. Yes?

Shobita 00:11:51 Yeah, and and I also think, I mean obviously I'm a little biased here. You know, we certainly, I certainly talk a lot about the complexities of evidence-based policymaking or the difficult relationships between sort of knowledge and the process of policymaking. But this was an interesting example of how it was a relatively straightforward process in, in New York. And I think what's interesting to know – and this is again a, in some ways a uniquely American phenomenon – there have been over the last five years or so, constant conversations just like in the U.K. and Europe about facial recognition technology and its potential risks and benefits. And it's been creeping in in various ways. I think we've talked on the program about how, unfortunately from my vantage point, Detroit has sort of jumped into facial recognition technology with some level of gusto when it comes to law enforcement. Other cities in the country have banned its use – again, primarily for law enforcement.

Shobita 00:12:52 But a few years ago, in 2020, I led a team working on a report on the use of facial recognition technology, specifically in schools. And at the time, this was before the pandemic, when we started anyway, there was some evidence that schools were starting to use it. And at that time they were talking about it really as a tool for school safety. Since then you've had a few things happen. Of course there was a pandemic which increased the rise of use of facial recognition. I mean there were facial recognition technology companies promising that they could tell the temperature of people entering and exiting a building. So it could be used as a public health measure. There of course, has been a rise in the use of facial recognition and allied biometric technologies when you're taking exams, again virtually. And in the US unfortunately there has been a number of mass shootings, including school shootings. And so facial recognition technology companies have really capitalized on this. And they have been trying to convince schools to purchase these technologies and a bunch of other similar kinds of technologies that really – beggar belief. So three years ago, and I'll just tell you one quick story which I think is telling, which is that they were going to do this in Langley, Virginia, uh, a school district in Langley, Virginia.

Jack 00:14:20 Home of the CIA, yes?

Shobita 00:14:22 Correct. Okay. So it should be telling to everyone that the parents in the school district quickly got rid of that proposal. So that should tell you something. If presumably many of those parents work at the CIA, they did not think that that was a good idea. Anyway, so in 2020, New York State became the first state at the state level to issue a moratorium on facial recognition technology use in schools. They then commissioned a report from their Office of Information Technology, which came out a few weeks ago. That is the report that cites our work. And that report says basically the risks of this technology outweigh the benefits and the way that they define risks includes consideration of things like civil rights, concerns about surveillance and the impacts of surveillance on children in the long term, the concerns about privacy, not just the common argument, which is, oh well it's not very accurate.

Shobita 00:15:25 And pretty quickly the New York legislature passed a ban and the governor signed it. So that's a pretty interesting turn of events. I mean I really hope that other states follow suit because one of the challenges here, there are at least two other challenges that I don't think get discussed enough. One is that when you're talking about school districts purchasing technologies like this, the vendors are obviously coming in with an interest. They're selling the technology in a particular way to officials who usually lack any detailed knowledge about the technology. They may have some technical knowledge, but they certainly wouldn't have any kind of knowledge about what the impacts are. And so these companies are really taking advantage of that lack of knowledge. And one of the things we tried to do in the report was offer appendices of sets of questions that school districts could ask to try to arm them with knowledge.

Shobita 00:16:22 So that's one thing. The second thing, which is probably an obvious STS point to most people, but I think bears mentioning is that there's always the characterization of accuracy. And okay, if it's not accurate now it can become accurate later. But the problem is that a human, to use the lingo in the field, the human is always in the loop. So there's always gonna be a human who has to interpret whether the match that the technology has indicated is correct. And then there's a human who has to decide how to act on the basis of that purported match. And those are human decisions based on human biases and assumptions about people. And there are also all kinds of assumptions. For example, there was just a news article that talked about how often when law enforcement uses facial recognition, they're supposed to go through specialized training, but most actually don't go through that training at all. There's also evidence that, for example, when judges use algorithmic risk assessments to aid their decision, they only use it to make more punitive decisions, never in the benefit of the defendants. So they're sort of using it in a biased way. So these are things that are never gonna go away. And when you're talking about a vulnerable population of children, they're far more important. Right?

Jack 00:17:49 Congratulations on managing to shift the needle in that discussion because as you say, it's easy for people without the capacity to make those sorts of decisions, without the capacity to interrogate those technological systems to say, oh, this is a balance between does the technology work and the benefits, which are hard to argue against if you don't know anything about the technology, because there are people saying this will save kids' lives. It's a hard thing to push back against. And the sort of counter arguments are about, I mean they're really hard. They're about saying, no, we need to recalibrate what we consider as risks. We need to think about questions of burden of proof. So there's civil liberties groups in Britain have started to use the phrase automated suspicion to refer to facial recognition technologies, which is the introduction of these technologies just completely upends the conventional calculation.

Jack 00:18:44 So rather than being innocent until proven guilty because of how data science based approaches work, you're basically, everybody's guilty, everybody's surveilled all the time. And then we will do our best to exonerate people one by one, sweeping away bits of hay from the haystack until we find the needle. But it's a really, really difficult argument to win. And maybe the companies selling this stuff, I mean there's one, Clearview, who've got into a lot of controversy. Maybe they're just rubbish at it, maybe they're just not very good at making the argument, but it's gonna be an argument that will have to keep on being made.
Shobita 00:19:23 Yeah, I think that they don't have to be very good at the argument in the context of schools because you know, if it's framed as a problem of preventing a mass shooting at your child's school, who wouldn't say yes to that? So they don't have to be that good. But I think, I suspect that in most school districts they haven't even begun to see it as a problem. They see it as a procurement issue. As Chris Gillard said on our podcast long ago, and that has really stuck with me, “procurement is policy,” especially when it comes to technology.
Jack 00:19:59 I was told by one of the computer scientists that I work with who does a lot with the police, and he was saying to me, well the trouble is that the police just buy stuff. Right? There might be all sorts of reasons why we don't want the police accessing stuff, but they're dealing with emergencies. In, in Britain, school shootings are not an issue, but terrorist attacks in public spaces mean that the police will just scramble around, reach for something and it's probably not that expensive. They will just buy stuff.
Shobita 00:20:29 Well, speaking about the promises of technology. On our last podcast episode we promised to talk a little bit about the promise and perils of technology when it comes to atomic weaponry. But since then there has been the publication of at least two books, which I have to say I find interesting, not just in their publication but also in their reception. So Walter Isaacson, famous biographer of tech bros published a biography of our friend Elon Musk.
Jack 00:21:05 Friend of the show, Elon Musk.
Shobita 00:21:07 Definitely he counts as a friend of the podcast <laugh>. And then um, Michael Lewis, whose books have turned into movies like Moneyball and The Big Short and who also tends to write, hey, geographies of dudes, white dudes in particular, published something to coincide with Sam Bankman Fried's trial about Sam Bankman Fried. And both give these figures more airtime and space than I might, uh, <laugh> cred- credulous airtime and space. So I'm wondering what you have thought about – not just the publication of these things, I mean that's the common thing, we want to admire these sorts of figures and see them as not like us and wanna understand the genius – but I feel like the public reception has been kind of a little bit different than the way we've usually…
Jack 00:22:01 Yeah. So I think in both cases you sort of see the authors trapped in the bubble of their subject's ego. And a lot of the interviews that the authors have given to explain why it's worth writing a book about these guys and the sort of positives and negatives. They've been trying to sort of explain and apologize for the downsides of their subjects. I think Michael Lewis is quite interested because it's very clear that he originally got interested in Sam Bankman Fried before Sam Bankman Fried was exposed as a alleged fraudster. Look how professional I am saying alleged.
Shobita 00:22:40 Yeah, <laugh>, I like the idea that we're important enough that somebody would, would sue us.

Jack 00:22:47 No, exactly. We'll, we'll be drawn into the trial in some, in some complicated way. And Sam Bankman Fried, now he is the subject of a fraud trial, but Michael Lewis can't change the story and he is sort of stuck in the story. And I think the same with Walter Isaacson. My guess is that Walter Isaacson probably got involved with Musk a long time ago when it might have been more tenable to hold onto the idea that Musk was a sort of great man of history for all his flaws. You know, he is an awful person to live with, an awful person to work with, but he's the sort of person that bends the direction of history in some way. And now has to sort of explain the thing that came out almost exactly as the book was published, which was the thing about Elon Musk deciding unilaterally to change the direction of the Russia - Ukraine war by switching off his starlink, whatever it is, wifi network. The sort of retreat from and explanation of why the ambivalence I guess, that they know now that the public does have about these people.
Shobita 00:23:54 Yeah, I guess the biographers here have slightly more self-awareness and in that you could also say that Christopher Nolan's movie also betrays a little bit more self-awareness in terms of how he portrays the story of Oppenheimer. Right? In the movie, there are scenes that demonstrate the horrific consequences of the atomic bomb and dropping it on Hiroshima and Nagasaki, to my mind, not nearly enough. But on some level it's interesting to think that maybe biographers have to think differently. I think they're not thinking differently enough. It's interesting to think about it as a time of change because I feel like all of these sorts of figures, or maybe the biographers, and in this case Isaacson and Lewis are in a different category than Nolan, but Isaacson and Lewis are biographers or serious nonfiction writers with a long history. And they are used to producing, hey, geographies. They're used to producing these kinds of celebrations of generally white male genius. And so they're now at this moment where there's not the same kind of audience for that and there's growing social awareness that it is a more complicated story. So they're trying to contend with that to different degrees. So
Jack 00:25:14 I think maybe you are being a bit generous. I think there would still be a huge number of people that think we need more Musks in the world.
Shobita 00:25:24 Oh, I mean, yeah, of course.
Jack 00:25:25 Right, that we need more special people and that we need to tell more great man stories about special people. I'm also duty bound to defend Christopher Nolan because he is alumnus of my university and often films his films on my university campus.
Shobita 00:25:44 Isn’t that a conflict of interest? Aren't we veering to <laughs>
Jack 00:25:46 <laugh>? Yeah, just you know, full disclosure. But also he's a storyteller and if you are telling stories about something like the atomic bomb, I'm guessing a screenwriter would say you can't tell a sort of sociological story about that sort of thing. You have to tell a character story about that sort of thing, which means that you have to center powerful people.
Shobita 00:26:09 Uh, right. But why does Oppenheimer have to be the central character? I mean there are ways I think to tell different kinds of character stories that would tell –
Jack 00:26:18 There would be, but nobody would go to those films, Shobita.
Shobita 00:26:21 I know.
Jack 00:26:22 Well, you and I would, but that would not compete with Barbie.
Shobita 00:26:26 Well, but now we're getting into a slightly different subject, which is the kind of precision media and targeting that I'm likely to be exposed to. Because I have been surprised that the New York Times, the New Yorker, number of podcasts that I've listened to,

um, have made charges about at least the latter two books that we're talking about, that seem closer to the kinds of things that we regularly talk about in the podcast, than what I've heard before. And that was striking to me and quite surprising. This idea that Michael Lewis's biography didn't quite measure up because it was too credulous. Now maybe if we take that into account, maybe there's a different story to be told, which is that there are certain kinds of audiences that are not interested in this anymore. That don't see their stories represented, don't see the complexities and the realities represented. So both of us can be right in the sense that there are huge audiences still and they may be still the majority audiences, but now the minority audiences have media sources that might amplify their concerns in ways –

Jack 00:27:50 Well, I think, and there's something else as well, which is that it's not just that other stories are not represented, but also people I think have become more willing to see, the problem with putting somebody like Musk on a pedestal is not just that he's a problematic, awful person personally. But that actually having him on a pedestal, imbuing somebody with that much power is disastrous when it comes to high stakes situations like the war in Ukraine. Where actually one completely unaccountable private individual is able to make decisions that affect whole states. So just the act of putting somebody on a pedestal and raising that pedestal up even further is gonna be an issue.

Shobita 00:28:36 Yeah, I mean I think that's a good point. There's not ever going to be a shortage of these kinds of biographies, at least not in the short term. So I'm sure we will have more data points to continue this conversation in the months and years to come. But maybe we should talk a little bit about our guest for this episode. This month, we have a really interesting interview with Ashley Shew. She's a professor in science, technology and society at Virginia Tech, but she is also the author of a brand new book called Against Techno-Ableism that just came out. And she's really one of the world's leading experts on the intersection between technology and disability. She comes to this both as a scholar but also with her own experience of disability and she really makes important points about how we tend to use technology to try to improve ourselves and kind of make everyone the same. And she, I think, makes a really important argument about how we really need to think differently and transform our built environments to accommodate differently-abled people rather than to locate the problem within. So I hope you all enjoy.

Interview

Shobita 00:29:58 Ashley, welcome to the Received Wisdom podcast.

Ashley 00:30:02 Oh, thank you so much for having me. Hello.

Shobita 00:30:04 It's really wonderful to have you and I am so excited because you are such a crucial voice on issues related to technology and disability and I was wondering what drew you to this set of issues, this work?

Ashley 00:30:21 So it's a topic I've been interested in longer than I've been working on. I was already teaching about some disability topics in my STS classes – we have a medical dilemmas class – and teaching on some disability, like, controversies around technology. I didn't feel like I could write scholarly work on this because I wasn't disabled and you know, my voice and what it would carry there is a little bit different. But I did become disabled and that wasn't like my goal in life. I uh, I had bone cancer, I was treated in 2013, 2014. I was in my second year on the tenure track at the time. So I did all my education without receiving, sort of the ableism that might've kept me from getting that education, in fact. And I became an amputee. But I also have a lot of disabilities from treatment with chemotherapy.

Ashley 00:31:10 I have chemo brain, so I take a long time to answer any questions 'cause I have to think of the words – you can cut that out, right? And then I have, like, tinnitus, I have some hearing loss, and I became infertile. All of these things, due to chemotherapy and you know, in some sense I'm very lucky I'm alive. I've had two recurrences of the cancer, so I've had two different operations to remove little chunks of my lungs, you know, no big deal. Just little chunks, <laugh>. And I'm on the other end of this in some ways. Um, and so many of the narratives that got reinforced on me as I was going through these things, the things people would say to me. You know, and just reading about disability history and seeing where we are today from sort of a context of the past has been really meaningful to me in my, in my work, you know, in terms of STS but also very much, you know, in my life in sort of what I read to my children and what we focus on. My sort of community engagement is very much centered on disability in many ways. And I'm lucky we have extremely great disability organizers here at Virginia Tech. So Martina Svyantech, Liz Spingola, Elizabeth McLain. These are people who I have worked with, continue to work with on disability issues, locally. So seeing this not just as interesting scholarship, but something that I'm engaged in in a myriad of ways.

Shobita 00:32:29 I really appreciate your honesty and telling us all of that. I just wanna say.

Jack 00:32:33 The thing that just comes through all of your writing actually is, it's the ideas and it's the power of your voice. You have a new book, Techno-Ableism, you know, if you can get the idea into one word then publishers are delighted. Tell us what does that word capture and what does it do sort of useful work for you?

Ashley 00:32:55 Yeah. I mean I don't know if publishers are delighted because it's a popular press book and I've made up a word. But the title is against Techno-Ableism. So I know I don't want us to be techno-ableist. And first I have to explain what ableism is to tell you what techno-ableism is. And ableism, there's lots of really great writing on it. Michelle Nario-Redmond has written a whole book called Ableism, the Causes and Consequences. And it's a wonderful book. And techno-ableism spins off ableism. So ableism is this deep rooted bias against disabled people, against disabled ways of life, against looking disabled, against being understood as disabled, right? So not everyone claims disability, but more people than that are understood or at least culturally treated as disabled. And I think about the ways in which this has structured society in so many ways. So it plays into white supremacy.

Ashley 00:33:43 Well who is the most fit, right? Who is the most abled? Uh, it plays into our ideas about like who is appropriate to immigrate to different countries. It’s actually really hard to become a citizen of another country if you are disabled. You know, when, when my liberal friends say I'm gonna move to Canada, I'm like, well good luck. I am disabled. I will be viewed as a burden upon their system. I can't become a Canadian citizen, even if I wanted to. Just because of the way in which disability is always understood as economically costly, as burdensome. You know, the way even I as a highly privileged white disabled person receive discrimination in particular institutional contexts is very real.

Jack 00:34:24 And how does technology meet those prejudices? There are various ways in which by smashing those two things together, you can imagine either the exacerbating of some of those inequities or maybe the alleviation of some of them in some domains. I mean, what sort of encounters are you most interested in?

Ashley 00:34:41 In the book I talk about when we talk about technology in terms of disability, it's usually a redemption story. That's the story people want. You build this technology, these great scientists and engineers are gonna help you out. But what it is to be the object of that, to always understand that you shouldn't be disabled, that you should try to pass as non-disabled as possible, that disability is painted as such a bad thing that you can't exist as a regular person existing. People want to interfere with your life in particular ways. And sometimes that is a matter of discarding you. That you don't belong, you don't deserve housing. We talk about the lack of accessible housing. That you don't deserve the same rights as everyone does. When we talk about how disabled people are surveilled at a much higher level than non-disabled people. You know, all of these things mean that disability is like institutionally written in, but there is this sort of technological element.

Ashley 00:35:34 So many tech projects are meant to save us. But the question is save us from what? Save us from the disrespect that we're receiving in a social context, right? That the sort of fix that you're aiming continues to paint disability as a bad thing. And it reifies ableism in a lot of our tech projects. This isn’t all tech projects. I like some technologies. I mean I'm sitting here. I own hearing aids, I'm not wearing them. I can turn up the volume on my laptop. It's beautiful. And then I'm wearing a prosthetic limb right now. I have some like hardware, you know, that's inside of me at the moment. I have a port which is a fantastic device that helped me get chemotherapy and I still haven't had it removed, but we didn't burn up my peripheral veins. So I think there's lots of good tech.

Ashley 00:36:15 I think technology that seeks to normalize disabled people is really problematic because it keeps on telling us disability is a bad thing. So meanwhile people talk about, oh I wanna build this technology to empower disabled people. And you see this with a lot of like exciting PR from universities about their great engineering teams. You know, I see those stories, and rarely are disabled people interviewed. It's always the engineers. If they interview anyone else, it's usually a caretaker who is having to deal with, and I use scare quotes here, having to deal with that disabled person. And they talk about how great the technology is. I mean most of those projects will never be fruitful in the marketplace for a whole myriad of reasons. <laugh> Like it's just not gonna make you because most people don't understand what it is to be disabled. So like how we even get these devices. Disabled people like have less disposable income than most people. Like how we would even get the devices that they're, they're seeking. But then also just like what it is to be always viewed as a project and never okay by yourself. It wears people down.

Shobita 00:37:16 I was just thinking about how this is also about for whom disability is a problem and what kind of problem it is. I mean so frequently these technological fixes are from the perspective of someone who sees the disability as a problem. And as you said, often the disabled person may or may not see it as a problem or they may see something else as a problem that is something that can't be fixed by technology. And so it sort of connects to something we've talked a lot about on the podcast, which is viewing the problem as a simple one and thinking that one can just solve it, and then all of the other requisite problems are solved. But I'm also reminded that, I don't remember the exact statistic, but most of us in fact are disabled in some way.

Ashley 00:38:12 It's hard to get a good estimate of who counts as disabled outside of sort of medical benefits offices which have very narrow definitions that don't really map onto our social demographics. It’s just like, I'm an amputee, I'm disabled wherever I go. That doesn't mean that I get counted as someone needing social benefits or payments of some sort. So sometimes there's some leakage between those things and how people end up being framed. You know, I think issues of disability are more important than ever in the wake of long covid. More people are recognizing themselves as disabled or will very soon. And we don't know what covid looks like 20 years in the future. I think about all the people who get shingles decades after their chickenpox infection. We actually don't know how disabling covid will be at this point. We know that long covid exists for a large number of people and you're more likely to have long covid symptoms the more often you are infected with covid.

Ashley 00:39:06 What we're seeing right now is just gonna be world changing. And that was, you know, even in the absence of things like climate change impacting like how malaria and Lyme disease are located on the globe. I mean I was reading this morning about four cases of malaria in Florida, uh, which hasn't had malaria, just sort of, so climate change we can expect more disabled people and the wake of long covid. I mean I think these issues about making the world more accessible to everyone, about inclusion are, are even more important than they've been in the past because of the wide number of people who will need some of the lessons of disability organizing and disability design about making things flexible in use, about modifying schedules, about how we value and judge people. Because so much of how we value and judge people is ableist already.

Shobita 00:39:59 So just to follow up on that, one thing that is sort of implicit in what you've said is that when we look to technology as a solution, we tend to locate the sort of object as being the individual and of course also the responsibility as being in the individual and – as opposed to a social solution. So in the case of long covid, thinking very differently about our policy infrastructure or our work infrastructure, our expectations. And one of the things you talk about in your work and I think is related to this conversation, and I wanted to introduce the concept and maybe ask you to talk about it a little bit, is the medical model of disability. Which often when people talk about that they don't explicitly connect it to technology or this individualization. But I was wondering if you could talk about that a little bit. What is the medical model of disability and why is that a problem?

Ashley 00:40:54 So there's a lot of work posited against the medical model of disability and what that results in is there's lots of other models of disability. Not that we all subscribe to all of the models. But the medical model of disability looks at disabilities as individual health defects. That there is something located within a person that is impaired or abnormal and what the medical system wants is to give a diagnosis and then a treatment. There's a clear plan with the medical model O. We seek to find out what the impairment is and I think about all the ways in which our bodies are recorded and tested and measured to find our impairments, right? I have chemo brain so I have some cognitive impairments. You know, but even like talking about measuring them like where you hit me on a particular day might matter to like how, how my cognitive function looks and I'm happy we're interviewing in what is my morning, which is my best brain time of the day.

Ashley 00:41:47 Also the Adderall has hit my system. Some people are using Adderall for chemo brain now. So I'm also very excited to be with you. So there, there is a sense in which I play into the medical system. We all do. It's impossible to resist the medical model in so many ways. The thing is the medical model works really well for some types of disease. It doesn't particularly work well for disability as a category. So there are ways in which the problems in my life are not medical but are social. If we change how things are located, change how things are structured, we can permit more people's participation. There's the social model of disability which says that the disability isn't located in me. It's located between me and the world. Somewhere in that interaction is where the impairment is located. And then you look, I I think about universal design being one of the answers to the social model, right?

Ashley 00:42:46 They're gonna design things that will fit more people and this is where the social model also fails. Like for some people, they will have chronic pain no matter what you do in this social environment. You can make it better for them to participate. You can be less judgmental when they don't show up for a particular event, right? There are social ways to address that, but that doesn't mean that you've solved the problem of pain. People also talk about like relational models of disability and they have to do with how we're structured together. You know that there's a lot of different alternatives to the medical model. The social model is sort of like the first, the first wave of these, but it really points to how our medical system has a particular idea of how we have to proceed and it's very much focused on individual shortcomings.

Jack 00:43:35 Can I ask you Ashley, about autism? Because I think autism, maybe this is an overly optimistic take, but there appears to have been certainly in my lifetime, quite a successful reframing of autism. And you write about the fact that it's more likely to be referred to in terms of neurodivergence and things and less likely to be treated as a problem to be fixed. And that many institutional settings are better at understanding autistic people and autistic people's needs. Is that overly optimistic or is this actually a case of where there has been a successful reframing away from this medical model towards something more understanding?

Ashley 00:44:16 I wish we were, as you described, I think most people who get their diagnosis of autism, which is often as children – what individual doctors and parents seek is normalization of behavior. I think we have new models from the adult community of autistic people who critique heavily the way in which autistic children are treated in this system. But I think the dominant paradigm is still about normalizing behavior, which is sort of the wrong thing to seek when it comes to autism, right? The problem is not a behavioral one, the problems are often witnessed as behavioral ones as children, but often have to do with sort of, when I think about like audio processing disorder being part of an autistic diagnosis. That it is overwhelming all the noises that you can hear. And often autistic people as well as people with ADHD can hear fluorescent bulbs.

Ashley 00:45:13 Like when we talk about like what they're wired to hear, <laugh>, it's you know, sometimes they're hearing more noise in the ambient environment than people realize. And that it can be really disconcerting. You know, what we should be looking for is making existence easier for autistic people and creating environments where it is easier to just be autistic in yourself instead of thinking that every problem is a behavioral one. I have a whole chapter on neurodivergence in the book. I'm so grateful. Um, the thing is I can't tell you the DSM, like any of the DSM criteria for autism. One of the lovely things about being in community is that everything I know about autism I've learned from autistic people, <laugh>. Um, so sometimes I don't even feel like I'm speaking the same language as people who are caught up in the medical model. As people who like work in centers for autism research and things like that.

Ashley 00:46:01 Because so much of what I've benefited from in disability community has been led by autistic people. The concept of neurodivergence is one that is developed within autistic community but is meant to cover even people with chemo brain, even people with traumatic brain injuries, people with bipolar people with schizophrenia. Anyone whose brain doesn't work, people imagine brains should, right? I won't even say like normal because I'm not even sure what a normal brain would be. I find a lot of help in community, sort of what I've learned from some of my autistic colleagues. But even like just some tiny life hacks. My chemo brain acts a lot like ADHD, which is to say I don't know what time it is any given point in the day. And this was a big problem for me. You know, I've forgotten to attend my own classes, which means that I am constantly worried that I will forget meetings.

Ashley 00:46:55 And I do. That I'm constantly like vigilant. You know, one of my friends with ADHD, this is like, Liz Spingola was like, oh you can just set alarms for that. I can just bring my cell phone and just set alarms and that's how I pick up my kids every day from school. My alarm goes off, I get in my car. You know, oh I need to get to a class on time at the beginning of every semester. I enter in which days of the week this alarm needs to ring you know, at this time. And at the point that I had done that, I was still experiencing chemo brain. But it didn't count as an impairment. If I've set things up in my life from this life hack that Liz taught me, where I have a lot of alarms and I do those things. It's fine.

Ashley 00:47:33 And also like being in disability community is great because I can be open about my chemo brain, which I felt for years after. I'm a university professor. You don't mention that you have cognitive impairments to anyone, right? Um, so I didn't, I, you know, I went through ADA paperwork, you know, on my hearing disability, but I did not mention the chemo brain. And I asked my doctor not to mention it in my ADA paperwork. And the reason for that is I know that that is the thing I'm more likely to be discriminated against at work on. I can be open about it now because in fact, well A) I got tenure, thank you. But then you know, I also, you know, I think about what it is to be in community and be vocally out about it. And I think that's really important.

Jack 00:48:17 The way that you talk about that sort of neurological divergence reminds me of how you also write about deafness. Which is one of these things where to people with no experience of deafness, they might imagine that as an obvious sort of deficit as the absence or the impairment of a thing that the rest of us might take for granted. But there've been lots and lots of studies about deaf communities and how they reframe their disabilities. And in particular, I wanted to ask you about cochlear implants. A technology that I imagine at the time of the invention of the cochlear implant promised something miraculous, which was the ability to restore a lost sense. But can you just explain how a lot of deaf people don't see it that way?

Ashley 00:49:03 I feel like of all the topics I teach on, it's hard to select the material for this because there are like multiple documentaries. Sound and fury is one of them that actually deal with this particular controversy. This was something I was teaching on before I became disabled too. So this particular controversy I think is really interesting to people who are interested in STS to recognize that many deaf people, many culturally deaf people – so people who grow up in deaf community, who participate in deaf cultural institutions who use signed language with each other – that they think about themselves as a cultural group, a linguistic minority rather than as disabled people. You know, I know some of this has changed and that not every deaf person holds one opinion here. But when cochlear implants were announced as a cure for deafness, if you think your deafness is not a disability, and you're told there is a cure for something that is actually offensive, right?

Ashley 00:50:04 That people presumed that your problem was not being able to hear. Although many deaf people will tell you the experience of not being able to communicate is different than not being able to hear. And they talk about – there's lots of benefits to community, and people talk about Deaf Gain as an important topic. And there's a book by that name on the shelf that I can see from here. There's ways, uh, you know, even the idea of hearing loss, like this hasn't always existed as a concept. There's been really excellent work on like the history of different professions where we frame a problem and different professions get created around that problem. And then reify particular ideas. So even the idea of hearing impairment of hearing loss in earlier eras, um, you know, we might talk about – those are just all deaf or going deaf. It doesn't – like linguistically talking about it as an impairment –

Ashley 00:50:56 You know, not that these ideas haven't persisted in particular ways. I think about uh, Jaipreet Virdi's work on Hearing Happiness where deaf cures have been sold throughout history. You know, there was a real belief in cochlear implants as sort of the engineering and scientific miracle for deaf people that deaf people didn't necessarily share. And that a whole bunch of professionals about deaf people – audiologists, speech and language pathologists – bought into, without consultation or without real knowledge about deaf community and deaf history. Because deaf history has a long history of people trying to eliminate deaf people. This has its own name. It's not ableism, it's audism. A U D I S M. And there's a whole tradition. Like Alexander Graham Bell was part of a eugenic cause to get deaf people to not marry deaf people. Rules against deaf people marrying each other so they wouldn't produce more deaf children. About eliminating deafness from our stock.

Ashley 00:51:53 It is a eugenic project. And then about – there's this whole tradition of oralism that the goal is to get deaf people to pass as hearing people, to basically read lips. Which is really, really hard and a cognitive nightmare and not everyone can be able to do it. And to produce speech. And this is where speech and language pathologists come in. To produce speech without a deaf accent. You know, and people who are forbidden from signing language. So if you're looking at a culture that has been constantly put up as problematic, and all of these professions agree, all of these scientists agree, but they have no idea about the culture. It is another attempt at cultural genocide when you look at the history of deafness. And then you start to see how inflammatory the rhetoric around cochlear is. And the thing is, the cochlear implants aren't the same as what the rhetoric tells us anyway.

Shobita 00:52:43 Well that's always the case. <laugh>, I feel like with every technology, right? I mean, one of the things that you're saying that I think is so important. You know, the importance of enabling social formations that allow people to engage with one another, to learn how to live and thrive and be confident and to see their conditions as not necessarily a deficit, as you said, but in fact perhaps a benefit, in certain kinds of ways, or at least a particular culture as is the case in the deaf culture. As you were talking, I mean, you were implicitly saying that this is a clear place where it's important to bring disabled people into decision making. And presumably that means decision making about whether there should be a technology, what it should look like, policy, etc. But I'm wondering how you think about the fact that, as you said, for example, in the case of deafness, there's controversy, right? Not every deaf person believes that it's a culture or a community, and not a problem to be solved. You know, every so often there's a viral video of a baby who gets cochlear implants. That of course helps to reinforce a particular image of solving deafness. And so when we think about disability expertise, how do we think about, I guess, the controversy or the differing positions within a particular disability community?

Ashley 00:54:19 Yeah, I mean some of these will turn out very differently. I think there's a parallel history between deafness and disability that's a very different history. The deaf case is interesting, especially from a techno-ableist viewpoint because of so many narratives that have been set upon us. And I think about this as a very STS topic, right? Because we have different technologies and people claim they're gonna make all of these changes. And in fact, it's not as if anyone in the deaf community is against cochlear implants for late-in- life deafened people. So if you're an adult who experiences hearing loss. Okay, so not all deaf people experience hearing loss. Sometimes you're born in that particular way. But if you're an adult and you have experienced hearing loss, no one in the deaf community is saying cochlear is wrong for you. Right? You're an adult and you can make your own decisions.

Ashley 00:55:03 So much of how this has played out is because of the early recommendations for implanting children at very young ages before they would have any understanding of themselves as deaf people or any relation to their community. So it takes out community members early on and then kids who are implanted are encouraged not to sign. Their parents are told not to sign to them and they're mainstreamed. For most disabled people, the move to be mainstreamed in education is a good one. And it is a little more controversial in how we think about deafness. And part of that has to do with disabled people. You know, for so many deaf people, different institutions existed, but disabled people were just left out <laugh> for a period of time, at least in the United States. And then in the seventies, disabled kids could attend school, but you could be bused across town.

Ashley 00:55:54 And it wasn't until 1990 with the Americans with Disabilities Act that you could go to the school that other kids in your neighborhood were going to. So people who are my age sometimes will say, what to me is just wild stuff. Like, yeah, I remember the day when I was allowed to go to school with all my friends from the neighborhood and I'm like, I am not that old for us to be having these kind of reminiscences. But it points to like, there are these different histories here. So it's harder to navigate that coming from the deaf case. But I think there is this talk about individuals with disabilities that really isolates disabled people. So when I talk to

anyone who works in services for students with disabilities or an ADA sort of accommodations office or anything like interfacing with the ADA – that's the Americans with Disabilities Act.
Ashley 00:56:41 So much of it is about, oh, this individual person provides you the paperwork. You know, if we're not talking about like specs for places, but about accommodations processes, we're pushed apart from each other. I think about how people like keep saying individuals with disabilities. And I know when you start out with individuals with disabilities, we're probably coming from different frames of reference. What it is to be an individual is to be like being forced back into the medical model like that you're not like anyone else, you're abnormal. You need to be treated in weird and special ways. Where when I think about what it is to be a disabled person, what it is to be in disability community that is speaking to a larger demographic group. And it's about all of us and not just one of us.
Jack 00:57:24 I mean, Ashley, you've already talked about universal design, if universal design exists and, you know, there might be trade-offs and all the rest of it. But as a sort of ideal, it's one of these ways in which technologies might be empowering, but also you've described that technologies – one of maybe the more insidious things that they do is change our collective sense of what we consider normal. Mm-hmm <affirmative>. And there was a really grim story, I dunno if you've heard this, about cochlear implants, about planned obsolescence.
Ashley 00:57:54 Oh yeah, yeah.
Jack 00:57:55 Yeah. About people that had, you know, got one of these things, got used to it, reshaped their lives around it, and then found out that they could no longer afford the upgrades or that their particular generation of device was no longer supported by the tech company. And so they were sort of cast adrift without being able to afford the alternative. Which is another way, <laugh>, that technologies create these forms of dependence that's extraordinarily powerful. And one can't imagine anything more disempowering than reconfiguring your life around something and then suddenly it's taken away from you.
Ashley 00:58:28 Maintenance is such a big topic in the world of disability. In a way that's completely underrecognized by scientists and engineers and the general public. Like what it is to depend on companies, corporations, for say, your ability to walk or your ability to hear and different platform turnovers. I mean this has happened to the blind community over and over again. Oh, you get a new operating system. None of your text to voice software works anymore and you can no longer read anything on your computer. Like this has been happening for, since computers were accessible, I mean since the 1970s, 1980s. You know, every new upgrade, they often fail to test whether important software will work. Being upgraded can also come at the costs of you're no longer covered. This planned obsolescence with cochlear implants is one case. There's a recent case of a woman who um – a human subject in this like brain implant group that would stop particular types of seizures. It worked really well for her. It did not work as well for many other people in the study. And they took her brain implant away. She had to get brain surgery to remove the thing that she really loved and that really improved her quality of life and she wasn't given any alternative. And she says her life is like far worse because she has all these seizures and can't go out. And she felt like she was living her life again
Jack 00:59:48 To have something dangled in front of you and then snatched away. Yeah.
Ashley 00:59:52 And there's also this case of like the bionic eyes that are no longer – like the company went belly up and these people who got bionic implants in their eyes are screwed.

They have no recourse. So I think about all of these things quite a lot. And of course The Cyborg Gillian Weise talks about being careful not to get too many or too few steps because size bionic leg counts steps. And they have this worry that if they take too many steps or too few steps, the insurance company will judge them not a good user for this knee. And it's like, oh, we're gonna help you or we're gonna maintain this. But then they're keeping records. And sometimes they're keeping records just like, oh we wanna, you know, gather this data to improve our product. Right?
Jack 01:00:32 Oh wow. So they’re surveillance technologies as well.
Ashley 01:00:35 When it's at the interplay with systems that determine what we get and what we need. Every amputee is rated. They're called K levels and it determines what sorts of equipment you're allowed to get.
Jack 01:00:47 But they're judging whether you are a good user, yeah.
Ashley 01:00:50 Activity level is a big part of that. But I think about how different demographic features may play into whether people are seen as deserving of technology, whether they're rated as capable of sort of having an active lifestyle. I think about the way in which particularly, uh, fat studies has talked about this quite a bit. The sort of presumption that certain bodies are less active bodies is not always a good one. But what that means for disabled people who won't have access to the right sort of equipment to maintain an active lifestyle can be sort of terrible. What that means for them in the long run. I think a lot about who has access to these technologies and it's not just a matter of, oh, I wanna try something out. We're never allowed just to try something out. <laugh> That is rare. Um, the sort of places where you might be able to do that are few and far between.
Ashley 01:01:37 I mean wheelchair repair in the United States is basically covered by two companies only. And you can wait months. And we hear about this a lot because airlines are always breaking wheelchairs and then it takes months to get the wheelchairs fixed. And in the meantime if you get a pressure sore or something like that – I mean you can die from having a pressure sore. If you're someone who's paraplegic and can't feel that sore, um, you can go septic and die real fast. So this isn't just like, oh, I wish we had better maintenance, like as if I had some more alternative. And some of these cases the lack of maintenance is deadly to people and not just a matter of inconvenience.
Shobita 01:02:10 If we could shift a little bit to the question of what do we do? And who needs to do it? Part of it seems to me to be a project of sensitization at the very least. But I'm wondering how you think about how do we shift this? What are the best steps to take?
Ashley 01:02:26 I teach a class on technology and disability. A lot of my work in the classroom is just to get non-disabled people and even disabled people to see disabled people as experts. So we don't read from a lot of non-disabled people. I mean in some cases we do, but it's mainly because they have really bad takes that we're gonna break down. Um, that's when we read non-disabled people and disabled people can be ableist too. I don't wanna say that that's not part of it as well, but really to get a lot of these students who wanna go into therapeutic professions, who wanna go to engineering professions, who are gonna be speech and language therapists, to actually see the people that they wanna work with as people. I know that seems like a low bar. But for so long non-disabled people have gotten to be the experts

about disabled people that it really messes them up when you start framing everything from disabled expertise.

Ashley 01:03:16 I have students who are like shocked to learn what people in the deaf community think about some of these approaches. I have people who are going in to like autism-helping specialties who are reading autistic writing for the first time and recognizing that the way in which autistic people view autistic care providers, view therapists in this realm isn't as helpers as they thought. And it isn't with gratefulness that they thought that the community should have. So we're working through a lot of that. My group, I have a NSF career grant – we're at the end of it. And my students and I – Hannah Hurtogan's a major graduate student on this and she works on disability diagnostic technologies. But she and I have been editing materials to introduce people to the realm of disability and technology and to have other narratives than the ones that they've been given.

Ashley 01:04:13 So we've been sorting a lot of disability narratives and this is just things written by disabled people. And then we've coded them when we're interested in the technological topic that they're talking about, because of course not all disability narratives are about technology. But really sorting them and then looking for different narratives than people expect. So we have that that we'll be publishing later this year and that'll be open for anyone to use in their classrooms to sort of summarize some of the material from disabled people talking about technology. And you know, we had to look beyond memoir because, who has access to memoir? Well it’s usually white, disabled, privileged folks, um, is who we have memoirs of. So we've been looking at blogs and YouTube videos and a lot of poetry and it's been really fun. But some of it's really surprising for my students to read and learn about.

Shobita 01:04:58 I can imagine, as you were talking, I was thinking how rare it is. I mean I know a little bit more about engineering schools, but I suspect also in therapy programs, occupational therapy, physical therapy, working with special needs kids, for example. That's not part of the usual pedagogy, it's not part of of the curriculum to actually read from or learn from these kinds of folks. So that's incredibly valuable. One of the things I know you do, 'cause I know you talk about it on Twitter with your students, is to have them literally in some ways walk in the shoes or try to manage at least the built environment in the way that a disabled person, in this case a physically disabled person does. And I'm wondering if you could talk a little bit about that and what students get out of it.

Ashley 01:05:48 So, um, this is actually a challenge developed by Martina Svyantek, who was my teaching apprentice for some time and we were co-chairs in the Disability Alliance Caucus at Virginia Tech. And her idea was, well it's not like we want people to do disability simulations 'cause there's lots of problems with disability simulations, which I won't go into today. But they are problematic and the disability community in general does not want people doing disability simulations, but we need some other activity to sort of demonstrate how hostile the built environment is. So her idea was – she had lots of ideas in this vein and she works at University of Virginia right now in Disability Services 'cause she's a badass. She, uh, was like, just take the accessible route, see where it takes you. Part of our problem is like signage. Like I can take an accessible pathway and not know where I'm going because they've built things in such weird ways.

Ashley 01:06:37 So her thing was just like, take the elevator. Take the accessible path. See if you can find where you're going on these accessible paths because, in terms of figuring that out, it’s actually very hard on the ground to do that and just to like record your thoughts about that. And so we do that as a classroom exercise. You know, lately I've been taking us out on like infrastructure walks where – I mean I think this was Bess Williamson's idea where we just go and point to things as a group. I'm noticing what we're seeing in the built environment in terms of like features for blind people, like tactile pavers. But also a lot of just routing access that's invisible. Like if you can do one step, you can get around much more quickly. Like one step. You know, where you put in the curb cuts really matters and to continue putting them in.

Ashley 01:07:19 And we've protested particular built environment things at Virginia Tech a couple different times and a lot of times we don't need to anymore. I tell someone what's messed up. We have a barrier reporting form where we can tell people what's not working in the built environment and that was the thing our group lobbied for. But it's also really convenient. I get my students who are newly walking around the long way. Of course, why would it always be longer for disabled people? They're taking the long route to get around, to get into buildings and they're very frustrated by it. Seeing that like even as a non-disabled person, to take the accessible route is to put on so many more steps a day. That doesn't make sense. But then also to show them the barrier reporting form and they're doing this job of reporting all the problems for the disability community. You know, people who want to be helpful but don't necessarily know how. This is a really fun exercise that I think does good work on our campus too.

Shobita 01:08:12 And you just got a very large grant for the Mellon Foundation. Congratulations. And I'm wondering, uh, one of the things that seems really innovative about that work called “Just Dis Tech” is the inclusion of artists in that project. And I'm wondering if you can talk a little bit about, you know, we've talked on the podcast about the importance of the humanities in addressing issues around technology and science and I'm wondering if you could talk a little bit about what role you think artists can play and that you're hoping that they'll play and how you imagine this project going forward.

Ashley 01:08:48 Yeah. Um, so this project was dreamt up between me and my colleague Elizabeth McLain as Elizabeth was recovering from surgery and I was hanging out with her. And she was on a lot of painkillers and we dreamt up the perfect marriage of our work and then pulled in some collaborators who we really enjoy working with. So she's managing a whole bunch of artist residencies as part of this. We're bringing in disabled artists with a bent for disability justice. So a lot of the theorizing around disability justice that's happened has been from disabled artists, not disabled scholars. So we see a lot of this work as being really exciting. We also think that disabled people are never given the means to do what they need to, which is to say disabled people are always expected to work for free to educate people. So we have this Mellon Foundation that will let us pay our artists and residents really well to come give some performances or exhibitions to spend time in a residency situation that they normally might not be able to access.

Ashley 01:09:47 So we have a lot of accessibility features built into the grant. We have money to pay for interpreters if we need interpreters or to bring in equipment that we might need to actually make a disabled artist residency happen. One of our residencies will be fully offsite, knowing that some disabled people can't travel for various reasons. So we have things that we're doing in that vein, and part of it is about community education. We live in a sort of rural part of our state and we're working with Damien Williams who's at UNC Charlotte, as well as Keresh Afsari, who is in construction engineering. She's sort of our first test case. What I'm doing with the grant has to do with disabled people consulting on tech projects. So we have so many people who are like, oh, I would love to hear more from the disability community about this idea I have.

Ashley 01:10:36 And they don't get to talk to anyone from the disability community until they're recruiting human subjects. That's far too late. They are already committed to a certain idea. And then at that point, if the human subjects, like, disagree with the research, like how that gets recorded – how that gets understood – is really problematic. So we hope to do community education around disability justice. And some of that has to do with talking about disabled expertise. Developing groups of people here who are willing to have hard conversations with scientists and engineers sometimes about their work. And will be able to pay disabled people to be consultants on these projects. It's amazing to me that the Mellon Foundation is like, is on board and letting us support our community members at the rates, um, that we're able to. Um, it's a really fantastic project that really speaks to trusting disabled expertise. And part of having artist performances – some of it's just having disabled joy together.

Ashley 01:11:33 Some of it's, we're just gonna enjoy some wonderful music from, uh, Kalyn Heffernan of Wheelchair Sports Camp. She'll be one of our acts in the fall. Very excited. And she'll be here for a good number of weeks to radicalize all of our students. And it's hard to even fathom that we have the means to do this. Like I'm so grateful to the Mellon Foundation and Justice Tech. You can say Justice Tech, it's fun. And, and so we're also just doing like community stuff, community gaming and narratives. We have a whole group on sort of tabletop gaming with Alice Rogers and VT Libraries and Taisha Thompson from our English department. Some of it's just about building community around disability narrative, culture, history, which is something that's really hard to find in like a rural part of southwestern Virginia or western North Carolina. So we're just really excited to have – have the means to get people transported here to do that. Right? Transportation's a huge issue that stands in the way of a lot of disability community when you're not in a city.

Jack 01:12:27 I mean, it totally sounds like this is the sort of template that all projects should follow, but what it genuinely sounds like is innovation. We've sort of let the word innovation get privatized, but you can just imagine the sheer quantities of novel insights that will come out of these interactions. They're just not the sorts of innovations that we tend to devote huge amounts of our money and attention to normally.

Ashley 01:12:53 No, I really appreciate that. I mean, we're trying to provide different models. Like part of what this money is letting us do is to provide different models of what this might look like. And we expect like every artist visit will be slightly different. What it means to be in disability community is we don't all need the same things or want the same setup. So it's just sort of left the artists to have a lot of self-determination over what events they'd like to do, what things they don't wanna do, and how they wanna spend their time here too. We're still getting that roster of people set up. Kalyn Heffernan is one in the fall. I'm very excited about that. And if you don't know her music, you're gonna love it.

Shobita 01:13:27 Well, thank you so much Ashley for speaking to us and for leaving us on a somewhat more hopeful note. I'm excited to hear about how this work that you're doing with this new Mellon grant evolves. And also, of course, really looking forward to the launch of your book and the various events that go along with that.

Outro

Shobita The Received Wisdom podcast is edited by Edward Waisanen and produced with help from the Shapiro Design Lab at the University of Michigan. We would love it if you would subscribe and rate us on your favorite podcasting platforms. You can also find all the recordings, transcripts and links to the books, articles and other stuff we discuss in this episode at our website, thereceivedwisdom.org. That's thereceivedwisdom, one word, dot org. Talk to you soon!