Disability Visibility Podcast

Episode 47: Design

Guest: Liz Jackson

Host: Alice Wong

Transcript by [Cheryl Green](#)

For more information: https://disabilityvisibilityproject.com/podcast/

Introduction

[radio static, voices singing with hip-hop beat]

LATEEF MCLEOD: This is the *Disability Visibility Podcast* with your host, Alice Wong.

ALICE WONG: Greetings fellow earthlings and cyborgs! Welcome to the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host Alice Wong. Today's topic is on design and disability with my guest, Liz Jackson. Liz is the founder The Disabled List, a design organization that engages in disability as a creative practice. Liz will talk about her work with the design community, how material objects are an important part of our self-identity, the limits of building empathy in design, and about a series of design fellowships called WITH that places disabled people with design studios and creative spaces for three-month fellowships. Are you ready? Away we go!

[electronic beeping]

ELECTRONIC VOICE: 5, 4, 3, 2, 1.

ALICE: Liz, I am so delighted to have you on my podcast today!

LIZ JACKSON: I'm so excited to be here with you.

Getting into design and being a design advocate

ALICE: So, Liz, this episode is about disability in design, and you are somebody that I first really to notice and learn more about when, several years ago, you talked, you petitioned with J Crew about coming up with their own cane. Do you mind if you talk a little bit about your origins in terms of how you got into design and being an advocate for better design?

LIZ: Yeah. It's interesting. So, I became disabled in 2012. Before then, I'd never really thought about disability before. And so, what happened for me was, is I ended up needing eyeglasses and a cane, and for me, the question was why I had so much choice with my eyeglasses and I didn't with my cane. When I got out of the hospital, I had the cane that was gifted to me from the hospital. It was this sort of a stainless steel cane with a rubber handle and a rubber tip. And as soon as I got home, I searched online for a cane, and the results astounded me. There was simply no choice. And it was actually that it was the struggle to find a cane that ended up causing me to fall into a deep depression.

I think people sort of assume in disability that I would have struggled with the fact that I was no longer able to choose my body, but that actually never bothered me, not even in the slightest. It was my inability to choose products that reflected my identity that I struggled so deeply with.

So, about eight months after I first got sick, I happened across this beautiful purple cane that changed my life. I'd been watching *The Girl with the Dragon Tattoo* movies at the time, and I decided I wanted to have a badass alter ego. And so, I made myself into The Girl with the Purple Cane. And immediately, I started using my blog to advocate for design. In the same way that I hadn't thought about disability until I became disabled, I also had never given much thought about design. And so, my blog was a process in really learning about Disability Studies but also about design. And so, I think that's where I…that's my starting point. [laughs]

What design reflects about people and need

ALICE: And why do products and the materials that we use every day, why does that matter so much? Because I think it goes beyond this idea of fetishization or being materialistic is that we all have intimate ties. We're all shaped by the objects around us. So, can you speak to that in terms of why the cane was so significant for you in terms of finding one that really reflected you as a person?

LIZ: Yeah. I think, well, I think what the cane really reflected was, what the cane meant is that— since I had lost the ability to choose—the cane only meant that I had a need. And so, suddenly, my identity had gone from something that I was able to kind of reflect what's on the inside out, and now it just became a symbol of the fact I'm now just simply, as society sees me, a person that just has a need. And that's, it's unrealistic.

ALICE: Mmhmm. Yeah, and I do think that it's really fascinating with durable medical equipment and assistive technology about how butt-ugly most of these products are because they're not considered— They're just, the central point is providing assistance, "restoring function," or part of the rehabilitation process, but these objects are so much more. We demand more. We want more.

LIZ: Well, I think sort of embedded within the idea of a product for a disabled person is this idea of fixing. I actually have sort of taken a great interest in what would an object look like that was made for a disabled person that actually does absolutely nothing, right? It's not that it's useless; it's that it doesn't strive to move us forward on the Bell Curve. And I think in that way, I think a lot in terms of the Bell Curve.

So, society sort of presumes that you're at the top of the curve, and so it markets to you. Aspirationally, it tells you, from the top of the curve, you can just slide into normal or into sort of super ability or super normal or whatever that is. But when you're disabled, you're actually at the bottom of the hill. And so, whatever is marketed to you is sort of saying it's this long slog, this hard climb up the hill just to get into normal. And who wants to fight to get into normal? And so, I think the basic premise of objects that are only set out to fix us is, I just, I find it, I guess, incongruous.

ALICE: Mmhmm.

[mellow music break]

Problematic aspects of designers' approach around disability

ALICE: In your mind, what do you think are the most problematic aspects that you've seen by designers in terms of their approach to designing? Because you've been in conversation and working with a lot of designers and the design community.

LIZ: Yeah. So, I've really started to dissect it down into two specific approaches to design. So, I'll start with the most commonly known, which is Universal Design. And I think much good has come with Universal Design, but I see something else. And what that is, is I look back, and I think, OK. Well, what created disability in the first place? What is that thing that really sort of set this trend of disability? And the way I see it is it happened during industrialization when suddenly there were bodies that couldn't conform. And so, I feel like it's this idea of "mass" and "normal" that created disability in the first place. And so, then when the 1960s, 1970s rolls around, and we decide, OK, we're gonna create a design system to meet the needs of disabled people, we come up with this idea of universality. And to me, the way I'm very curious about it is did we just not go to this idea of "mass" and "norm" to try and fix something that was created by "mass" and "norm?" And is that why it hasn't taken off like it has?

I think nothing is universal. I think that instead, what disability is, is expansive, and so things that come from us tend to grow. But this idea that…. I guess the thing I'm trying to get away from is this idea of normal. I'm worried that universal reinforces it. So, that's sort of the way I critique Universal Design right now, and I'm very curious about it. And I don't critique these to say that they're wrong or bad. Much good comes of it. But I'm simply looking for more.

So then, the lesser known—well, it'd be more well-known within the design community but probably less-known among the public—is this idea of design thinking. And this is the way I see it: design thinking was created in the 1960s, and it was created by, really, white men who had no equals. They were at the top of their professions. They were creating objects for millions of people all over the world, and they were connected to the most powerful institutions in the world. And what they saw is that design was not reaching everybody, right? Why wasn't design reaching everybody? Because they were white men. And so, they created this system to fill in the gaps, and they called it design thinking. And it focused on empathy.

And so, there's five steps to design thinking, and the first one is, is you start to cultivate empathy through a process of interviewing and observing your subject. And it's often disabled people. But so, I proposed this new approach to design thinking that I call design questioning. And what that is, is it's really looking at these steps from the users' perspective. And so, if you look at this process of building empathy from the perspective of a user, a disabled person, what you find is, is that oftentimes, the designers are a little bit less interested in building empathy and a little bit more in gleaning our lifehacks and our ingenuity and our ideas even though really, neither side of this is aware of it during the process. And so, what happens is you have the insights—our insights—gleaned by designers, and you go to step two, which is defining the problem. But because disabled people are not invited into the room during these processes, we oftentimes inadvertently get defined as the problem. Becomes about what we can or can't do rather than how something does or doesn't work for us.

So, you have our insights gleaned. We're incorrectly defined as the problem. And then you enter this iterative process of ideation, prototyping, and testing. And what I argue is, is that all of this builds up and leads up to what I call the unacknowledged sixth step of design thinking, which I call design thanking because we're expected to be grateful for this process. And so, for me, it's how do you sort of break down this system and determine who is in the room, and how do you actually start this process from the outside. And is empathy the right approach to design, or is it perhaps expertise instead? And so, these are the two ways that I'm really rethinking the design process.

ALICE: Yeah. I mean for me as a consumer, I'll be upfront: I'm not a designer. But as a consumer, I do think it's, in the end, all about power. And every time I hear the word "empathy,"

I kind of have to do a eyeroll because empathy does not go far. Empathy will only get you to a place where you think you know a little bit of the lived experience. And again, it places this weird power dynamic where disabled people or other marginalized folks are seen as the ones who share their stories, share their lives, and then the designers ultimately are the ones that profit from these stories, from this wisdom, from this expertise. So, how do we get to a place where there are more designers with disabilities who have the power?

LIZ: Well, I think for me, it's easy to, it's the easy thing to look at the system and say that it's the system is the problem. But the truth of the matter is, is that disabled people simply aren't entering design fields. So, why is that? Well, one of the things I fundamentally believe is, is that we're the original lifehackers. I know you've sort of discussed this idea before, but we spend our lives cultivating an intuitive creativity because we're forced to navigate a world that's not build for our bodies, right? We are wildly creative. But because the way that, especially design thinking, right, it separated the users from the designers. It separated those who have the insights from those who have the resources. And so, through this process of not getting credited, of not being included from the get-go in the process, we have stopped seeing our creativity as valuable.

And so, for me, the ways that I'm trying to carve pathways into design, it's not just about teaching an industry about our value, but it's actually teaching disabled people about our value. And so, I see it as sort of a double-sided conundrum.

ALICE: Mmhmm.

[chill music break]

The WITH Fellowship

ALICE: And let's switch gears and talk about something that you have been working on for quite a while, and this is about the WITH and your fellows. So, tell me, why don't you tell the listeners what that is and kind of the latest?

LIZ: So, I'm creating, I created something called the WITH fellowship, and there was a few things that led to it. I had a negative experience with a design museum called Cooper Hewitt. I felt that they had really—they created a disability exhibit—and I felt that they'd very much done so without the disability community. And I personally felt burned by the process. So, I think that was the driver. But there was this one particular day where I searched the term "design with disability," and what I realized was—or I searched the term "disability design"—and what I realized was, is that design for disability has more than twice as many search results, this idea that we're recipients of design has embedded itself into our language. And so ultimately, what I arrived at is, I wanted to create a pathway. I wanted to create a process where we could begin collaboratively working with designers.

And so, the WITH Fellowship is, it's really simple: we're partnering creative disabled people with— And for this first cohort, it's just New York City, some top design spaces in New York City. And it's really about getting, again, design spaces to see that we are valuable, and it's about getting disabled people to see that we are valuable. And the entire experience has been really powerful. Response from the disability community was powerful. Response from design organizations were powerful. And I remember I had this one conversation with a fairly prominent designer, and she was saying that within her company, they had been looking for ways to include disabled people and simply didn't know how. And what I had provided her is a way for

her company to start entering into this process and figuring out, how do we include? And so, it's been really exciting.

We're starting in New York. The first cohort starts on September 10th, runs through December, and then we'll be doing another cohort probably in New York and San Francisco in early 2019 and expanding. There's been interest in London and Toronto and Chicago and just all over the world. And so, I don't know how we're gonna grow it, but it seems like there's opportunity.

ALICE: Mmhmm. And you know, with all of these collaborations, it's gonna look different for each person. But I just wanna ask you, what do you think are some of the features of a healthy collaboration? What are some of the essential features of a partnership that's truly with us versus for us?

LIZ: I think for me, it always comes down to one word, and it's "mutuality," where two people are in it together. And I think, I just think we've so been lacking in that. And so, really with the WITH Fellowship, there's actually two sides to it. So, the disabled person comes in to the fellowship with a goal, something that they can use that organization's resources to further. And at the same time, they also go in, and they are the resident disability expert. And so, both sides get something out of it, and it creates a process of mutuality. It's not one doing for the other, but rather, they're both coming in, and they're both getting, and they're both giving.

ALICE: So, a lot of this work you've done, you've done a lot of, you've made a lot of inroads with the design community. The design community's really broad. It's not monolithic by any means. But what are some of the challenges you face making these connections and creating this kind of infrastructure to build a pipeline?

LIZ: Yeah. I think, well, so, I can give you an example that I've recently been navigating. There's a really big design organization. And I don't know if people outside of design circles know it, but it's called IDEO. And it's been around for years, and they are very much of the design thinking approach. And so, I got an email from them after I had launched the WITH Fellowship, and they said they were really interested in my work. And they asked if I would come in, and then they were like, "Oh, by the way, we sort of have this technology we wanna show you." And so, I was excited, though I was a little conflicted because again, there's no organization that's totally getting it right. And I wanted to make sure that we were on the same page, but I went in. And they were actually a lot less interested in my organization, and they were a lot more interested in showing me the technology. And they ended up showing me the technology.

It was something that they had created that was supposed to get disabled people hired. And so, I asked them, I said, "What disabled people did you hire to create this technology that's intended to get disabled people hired?" And they were like, "Well, none." And so, you know, I think even from the— And things really devolved from there, right? It was hard for me to kind of recover from that. But I think an organization like IDEO is so used to being patted on the back for doing this really good stuff, when in reality, nobody's considering the long-term implications and the messages that something like that sends.

And so, it's sort of this idea of we go back to empathy. And this is what I've really noticed in design is, is I think a lot of design organizations are more focused on how something feels rather than what something does. And if you can create something that sort of strikes that empathy/inspiration note, you could be totally unproductive and still be perceived as a success. And so, I think that's one of the greatest things that we need to combat as disabled people in this space.

ALICE: Well, I do think that there are so many creators and manufacturers and companies, especially in the tech space, that really believe in doing good. And their idea of doing good does not match with what the actual objects, the people they're doing good for. And I think a lot of times, this is such a equity issue, a social justice issue where I personally think one of the greatest ways to show empathy is to hire disabled people. And one of the greatest ways to show empathy is to have disabled people as your consultants, as your colleagues, as people that you see as your equals. And I don't think that's how people see, a lot of people don't see empathy. And I think people are very much interested in just getting that feel-good moment, those ally cookies, and that's something that's really tough.

LIZ: And I started to realize that there are sort of two ways to look at empathy. There's the historical interpretation, which is that we are moved to action. And there's the modern interpretation, which is that feeling it is just OK. And I've actually found the same thing with inspiration, right? Inspiration, it's a verb. People tell me I inspire them. I say, "I inspire you to do what," right? And they're like, "Well, I didn't really think about that." And so, I see these, the way the definition of both empathy and inspiration is changing, where people think it's OK just to feel it and not to actually act on it.

ALICE: And I think that that's a challenge because action requires something. It requires more than feeling. It requires sometimes people to feel uncomfortable, sometimes for people to share what they have. And I think that's sometimes the ultimate test of how far their empathy will go because they can give as much lip service as they want. As you and I know about, inspiration porn gets a whole lot of clickbait versus actual stories by actual disabled people. And again, it's like, what are you willing, how are you willing to back it up with actual change?

LIZ: Yeah.

ALICE: And I think that's on everyone: it's on me, it's on you, it's on the design world.

So, we're gonna be wrapping up soon. For people who wanna learn more about your work, where can they find you through your website or Twitter and other ways?

LIZ: So, my personal website is TheGirlWithThePurpleCane.com. My organization is The Disabled List, and it's DisabledList.org. You can find The Disabled List on Twitter and Instagram @DisabledListOrg. And I am @elizejackson on Twitter.

ALICE: Any final words you wanna share with us?

LIZ: I'm thrilled to be on your podcast, and I'm thrilled to be in your presence.

ALICE: Well, we will have this creepy moment of silence—

LIZ: [laughs]

ALICE: —as we sign off here! All right, thank you, Liz!

LIZ: Thank you, Alice.

Wrap-up
[hip hop]

ALICE: This podcast is a production of the Disability Visibility Project, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast.

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Well, thanks for listening, and see you on the Internets! Byeee!!

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