Disability Visibility Podcast

Episode 38: Food Accessibility and Hunger

Guest: Shona Louise

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: Hey there, friend! Welcome to the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host, Alice Wong. Today's episode is all about food accessibility and ableism with Shona Louise.

What is your first reaction when you think of pre-packaged peeled and cut fruit? Do you think it's a frivolous waste? Do you think it's for lazy people? I've learned a lot from activist Kim Sauder about food accessibility from her blog crippled scholar. And earlier this year, Shona Louise, a writer from the UK, came out with a piece in response to criticisms of these products from her perspective as a disabled person. We also talked about the proposed ban of plastic straws in the UK that are also happening around the world.

Are you ready? [electronic beeping] Away we go!

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

ALICE: So, Shona, thank you so much for being in the *Disability Visibility Podcast*. Why don't you introduce yourself and just share a little bit about yourself.

SHONA LOUISE: I'm Shona Cobb, and I have a blog. And I talk about anything to do with disability really: stuff about ableism, accessibility. I do a little bit of that kind of thing in the media in the UK as well and generally just try and educate people and raise awareness of some of the issues that affect disabled people.

[mellow guitar break]

Getting started in writing and journalism, then moving into disability writing

ALICE: Tell me a little bit about how you got started in writing and journalism, if you don't mind.

SHONA: Yeah. So, I started my blog coming up about seven years ago now. I started it when I was 14, and I was in high school and feeling quite isolated and like I didn't quite fit in. When I started my blog, I had the genetic condition I have now, but it didn't really affect me. It was sort of mild symptoms like pain and joint hypermobility. And then I started my blog, and I started talking about beauty because that was the community that I came across first. And then over the course of sort of two or three years, as my health got worse and I found myself having surgeries, and I ended up having to leave school at about 16. My blog ended up being sort of the thing that saved me really and kept those social connections up and gave me something to do in my free time. And then ever since then, it's just sort of evolved now, and the main thing I talk about is disability.

ALICE: And what was that transition like from writing more and more and talking more about disability? Because there are a lot of writers and journalists with disabilities that don't really wanna talk about that or wanna cover that. So, what was that transition like for you?

SHONA: So, it started off quite naturally for me. When I had my first operation, and I was searching online for information about people's experiences, and I really wasn't finding the answers to the questions that I had, sort of the really personal questions and things that people don't really talk about when it comes to the surgery I was having. So, I thought well, why don't I just document my experience and be completely open so that people like me in the future can read this and have those answers that I was looking for myself? And it just started off like that really, that I was just talking about these just sort of surgeries at first, sort of like my milestones, you know. I wasn't as such talking about disability because it took me many years to even consider myself disabled, you know, fighting off that internalized ableism.

And at first, when I started going from just talking about experiences to actually tackling bigger subjects to do with disability, a lot of my readers were quite sort of disinterested because they were mostly non-disabled and came to read about beauty and talk about that kind of thing. So, at first, I did find that I was losing a lot of readers; views were going down, and it was quite disheartening at first. And then when I came across the community of disabled people and saw that I wasn't the only one talking about these things, and in fact, I could probably build up that readership again with new people who were interested in what I had to say, I just sort of continued. And eventually, I sort of found a happy medium where I still have a lot of non-disabled readers, but I also have this new community of disabled people who can relate with me.

ALICE: Yeah, and I feel like disabled writers—however they identify—write about whatever they're passionate about. But I think, as you probably also might feel, disabled people really need to see disabled writers and disabled people creating media and be part of media, be journalists and people on the telly, people on the radio. Because there really isn't that representation that's out there. Do you feel that way at all?

SHONA: Yeah, that was a problem I had at the start. I couldn't see anyone else talking about what I was talking about because the community that I was within at first, you know, I really was one of the only few disabled people within that community. So, at first, I really felt like an outsider. And then when you come across this whole community of people doing their thing, creating media, showing their stories, just doing what they feel they're passionate about, it really sort of sparks something inside you. And then further on in the past few years, when I've seen disabled journalists and more and more disabled people on TV, things like that, it really just motivates me more and makes me think yeah, actually that could be attainable.

ALICE: Yeah, I feel the same way too. I think the more folks I discover and come across, it just really invigorates me and makes me feel like oh my goodness: our community is so vast. That's really just the tip of the iceberg, and we have so much interesting perspectives that I really feel like mainstream media doesn't really know about.

[mellow guitar break]

Shona's opinion piece on how banning pre-packaged food is ableist

ALICE: One of my friends Tweeted one of your articles recently about pre-packaged foods. And you wrote an article earlier this year about the criticisms that people have had on social media about pre-packaged foods, and you wrote an opinion piece about how that really is ableist, and it leaves out a lot of people who need these things. So, what prompted you to write about this?

SHONA: Yeah, so, it's an issue that, I think last year, really kept coming up again and again. And I think the first thing I saw was about the pre-peeled orange in a little plastic pot, which I think was over in the US that kept popping up. And people kept making new tweets and keep getting shared. And this sort of anger inside of me just kept building and building. So, when the issue came up more in the UK with this, I think it was called a cauliflower steak, which was just sort of a sliced piece of cauliflower, and I just thought you know, I've had enough. I need to write something about this. And I really thought that no one would be interested. So, when people actually started listening to what I had to say, I was quite shocked, really. Because I see disabled people, friends, again and again bringing up these issues but not getting anywhere. We have these call-out tweets that mainly non-disabled people do about these foods to say will people respond, sort of put in their opinion, and then it just sort of gets pushed down again. And then a few months later, it might happen again. So, I just, I felt like I wanted to do something to at least try and break that cycle and introduce this side of the topic to my readers, especially my non-disabled readers who really had no idea and had joined in, in this sort of calling out thread of tweets and things like that.

And yeah, it was just one of these things that sometimes these topics just really get to you, and it latches on to something personal inside you. Because I really do rely on pre-packaged food a lot, especially for lunches. So, it really did just sort of spark something inside me that I thought, I've had enough. I really need to start discussing this.

ALICE: That's wonderful. And I think you were even on Channel 4, a video segment about it. So, what was that like? Because that's also really exciting too, to see that it gets picked up, and you start being kind of like a go-to person to talk about this. What was that like?

SHONA: Yeah, when I first got the message, I was shocked, and not in a sense that it was TV. It was more shocked that such a big media platform was interested in a disability story like this. And I was really shy as a child, so I've sort of over these years builded up my media stuff and slowly done more things that terrify me. And that was one of those things that really did terrify me, but I thought I can't turn down this opportunity to get this issue out there to mainly non-disabled people who have no idea that this is a problem. So, yeah, it was amazing to get that email and to be asked, and also terrifying.

ALICE: Yeah. I think a lot of people just don't realize all the privilege that's behind all the criticisms, you know: whether it's cooking or eating nutritious meals or just preparing meals. Because people with disabilities, they may need devices or equipment. They might need an accessible kitchen. They may need time and energy. And we may be poorer than others or live in a place that doesn't have easy access to food.

SHONA: Yes. So, that was a big thing, and I think it's one of these issues where people literally don't realize it's not that people are intentionally—I mean sometimes people are intentionally saying, you know, "You don't deserve access to these foods; get someone else to do it," etc.—but most of the time, people just really have no idea about these kinds of problems and no idea about the privilege they hold. And sometimes it's great when people put their hand up and say, "OK, yeah. I accept that. I had no idea. From now on, I will think differently. I will look at this issue differently." But it's when people get annoyed when they're being called out for their privilege and the way they're using their privilege.

That's what I find quite frustrating, that people have taken this idea of privilege and think it's like an offensive thing to say, to say that someone has privilege now. And I find that really frustrating because it's just sort of recognizing your privilege, and there's nothing wrong with that. We all, most people, have some kind of privilege, and it's not the end of the world to recognize that and to go one step further and try and use that to raise other people's voices.

ALICE: Absolutely.

How Shona currently accesses food and eating

ALICE: And how do you currently access food for yourself, if you don't mind describing your day-to-day activities regarding food preparation and just feeding yourself.

SHONA: So, currently, I'm living with family. So, sort of for evening meals, I'm covered, and my family will make them. But for lunches and things like that, I heavily rely on things like pre-made salads, packaged sandwiches, and especially fruit is a big thing that I really heavily rely on, pre-cut fruit. And stuff like when I saw the peeled orange, I thought, I wish we had that over in the UK because that would really help me out. So, for sort of breakfast and lunch, I'm heavily relying on pre-packaged foods, and then for evening meals, I'm covered. But I'm hoping to move out on my own eventually this time, sort of around this year. So, when that happens, I will have to try and figure out even more ways to stay independent and how to access foods. Because social care is being cut so much in this country, you know, and everywhere, really. It's a big issue. And so, ideally, whilst I would love and need that sort of support from another person to access food—and especially good and healthy food that I will enjoy—I just, I'm not 100% sure if I will be eligible for that help.

ALICE: Yeah. I live with family as well, and they do the majority of the cooking. But I also wanna do things that are convenient for me as well. I think sometimes I get things that are takeout or delivered to my home because I want to kind of, I guess as somebody who relies on other people for assistance for a lot of things, any way I can kind of make it a little bit easier for all of us is always a nice option to have. And I think we all need those kind of choices.

SHONA: Yeah, absolutely. And that's one thing that I kept repeating to people. People would say to me, you know, "Well, just get your family to do all of it, or get them to make you something before they go to work," and things like that. And you know, we have the right to have as many choices as possible, really. And whilst it might be easier to get someone else to do it, a lot of us wanna retain that independence. And if this food can give us that option, then we should have it, you know? It's a right.

ALICE: Yeah, and I think some people don't realize, again, another aspect of lived experience is when you ask people to help, it's like you know there's kind of a limit. So, any way to try to decrease the number of times you need to ask the same person to do something, it's always kind of like a really good thing. So, if I don't need somebody to cut my apple slices for me, that's one less task for them, and that's better for all of us in a lot of ways.

[mellow guitar break]

Lazy, scroungers, and other oppressive, shaming labels for disabled people

ALICE: And speaking of privilege, I think there’s this other flip side. There’s a lot of food shaming, particularly of poor people and poor, disabled people. I think I follow a lot of things that are happening in the UK, and I know about the term “scroungers.” And it seems to be a lot of victim blaming, accusations of people with disabilities as lazy, as trying to cheat the system. Do you think those kinds of conditions also feed this environment, in terms of this kind of critique toward these pre-packaged foods?

SHONA: Oh, absolutely. There’s just this kind of assumption, and words like “lazy” and “scrounger” just sort of automatically get connected to disability. And it’s really fed by the media in this country, the government. And it’s almost this idea of you’re guilty until proven innocent, and especially when it comes to things like the benefit system in this country. Especially we’ve got this huge issue right now: people being assumed to be lazy and cheats and all of these negative words that people have just sort of learned to connect to disability, really. And that definitely does feed into more of these problems like food and access to food, and especially when it comes to people’s idea of like if you don’t have much money, people have this idea of well, if you don’t have much money, then you should be using it in this way or this way. And I think I read a piece recently that talked about how if you don’t have much money, if you’re poor, then you shouldn’t be getting things like McDonald’s, the saver items at McDonald’s because you should be, it’s cheaper to make food from scratch. And it’s like well, actually, at that time, when you’ve only got, say, five pounds, you don’t have the money to buy all of the ingredients you need for enough meals for a week. You’ve only got enough money for that day to feed you for that day. And you know, that’s a big problem that we have: people dictating what they feel others should spend their money on, especially if you’re on benefits.

ALICE: And for people who are kind of unfamiliar with the politics going on in the UK, would you say that a lot of these attitudes and cuts to benefits and social programs, is this basically because of the Tory Party? How would you describe this trend toward this really crushing oppression for disabled people in the UK?

SHONA: Yeah, absolutely. And it’s coming from the party that’s in power currently and has been in power for the last sort of many years, really, the conservative party, also known as the Tories. And the benefits system is really constantly being changed and cut again and again. And then when you mix that with social care being cut and the National Health Service being cut, you get this sort of system where disabled people, especially, are being hit from so many different sides. And it is our current government that is pushing out this idea that disabled people are cheats, they’re lazy. There’s a number you can ring if you think that a disabled person is lying to get benefits, and that’s misused a lot, especially people with variable conditions where they’re able to walk one day or need a wheelchair the next day, you know. There’s a lot of fear about being reported for simply living your life.

And it’s a big fear, and especially when you’re on several benefits. There’s the Employment Support Allowance benefit, which is for people who can’t work due to sickness or disability. And there’s two different groups for that, and if you’re in the lower group where the Department for Work and Pensions decide that you might be able to work in the future, that payment has been cut again and again the past three years. I think it was recently £30 less a week, which is a lot of money to lose.

[mellow guitar break]

Thoughts on the plastic straw bans

ALICE: Yeah, you know, I just wanna talk about another kind of related topic. There's been a lot about this recent campaign by a lot of restaurant groups or other industries against the use of straws. And I was wondering what you thought about that, because I think it's really related in terms of this kind of environmental idea to really stop waste. And plastic straws are something that a lot of people with disabilities use every day because they need to. Do you have any thoughts about that?

SHONA: Yeah. So, in the UK at the moment there's this sort of running campaign that in recent months, a lot of people sort of jumped on the bandwagon almost, and it's built up momentum quite quickly. And we've got a lot of restaurants and cafes that are pulling plastic straws really quickly without putting in place any safe alternatives. And we're seeing the effects of that already. And yeah, there's just this growing campaign really that has completely forgotten disabled people because it's being pushed forward so quickly that there's not even been time for us to put in our opinions or our voices. And it's only now, once these restaurants and these cafes have made these decisions that disabled people's voices are starting to be lifted up and actually listened to. Because whilst there are alternatives to plastic straws, some of them aren't great. Things like metal straws can be quite dangerous. And plastic straws, whilst yes, they do contribute to some environmental problems, are some of the best straws for people to use, especially disabled people. I've found I've tried a different amount of alternatives, but for me, plastic straws are still the best for me currently. And whilst I wanna do everything that I can to do good for the environment, I have to think about my independence and my rights and other people's rights to do the same things as everyone else.

ALICE: Exactly. And I use plastic straws when I'm out, but I use glass straws when I'm at home. But I can't carry around glass straws around with me all the time. Once in a while, it's a tradeoff, and I think this is where I think, like you said, people with disabilities are left out of these conversations or even the ideas of creating these campaigns. What are some of the ways that you would suggest that environmentalists can really engage with disabled people and really go in solidarity? I think we all wanna reduce waste, but there must be ways we can do that without isolating or blaming or shaming disabled people.

SHONA: Yeah, so, throughout this whole time, I've done a few interviews about the plastic straws things and the packaged food thing. And really, the message I've just been putting out there is we just need to be included in the conversation, especially like campaign groups need to be bringing in disabled people to put in their opinion so they know about these issues before they rush through with their campaigns: removing straws and removing pre-packaged food and things like that. I'm currently working with an environmental group in the UK, and I'm just simply writing sort of a document that just runs through ableism, really, just the basics of that and then also how ableism runs through a lot of these environmentalist groups just so they're educated. And so, before they put out their opinion and their plans, they're running through it and checking actually: does this affect disabled people, and in what way? And what do we do about it if it does?

[mellow guitar break]

Wrap-up

ALICE: Well, do you have anything you wanna share in terms of your thinking and writing and experiences with food and disability?

SHONA: I don’t think so. I think we’ve covered everything really, though. It’s quite a complex subject, but we’ve managed to sort of condense it down.

ALICE: Well, Shona, thank you so much for being on my podcast today. It was quite a delight to talk to you.

SHONA: Yeah, thank you for inviting me.

[hip hop]

♪ lets dance
get as low as you would if you were in sweat pants
How far will they go?
Oh, yeah yeah
How far will they go…. ♪

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.

You can also find out more about Shona on our website.

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Well, it’s been real! Thank you for listening, and see you on the Internets! Byeee!!

♪ rock it to the blast off
stop drop dance off ♪