Disability Visibility Podcast

Episode 13: Autonomy & Disabled People

Guests: Kim Sauder

Host: Alice Wong

Transcript by Cheryl Green

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

Introduction

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

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

ALICE WONG: Hey hey! It's me, Alice Wong, the host of the Disability Visibility Podcast, conversations on disability politics, culture, and media. Today's episode is about autonomy with Kim Sauder, a blogger and PhD student in Critical Disability Studies.

Earlier in the summer of 2017, Kim published two blog posts about the sexual autonomy of disabled people, and it sparked my interest to have a broader conversation on autonomy. You'll hear us talk about privacy, sexuality, decision-making, disabled bodies on display in health care settings, the delights of non-compliance, and of course, ableism. Basically, a lot of good stuff.

Are you ready? Away we go!

[electronic beeping]

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

ALICE: So, Kim, thank you so much for talking with me today. Would you like to tell me a little bit about yourself, if you don't mind?

KIM: Well, I'm a PhD student in Critical Disability Studies, and I blog about disability rights and disability in society. What I plan on studying primarily is disability in media. It's kind of my generic focus, and I certainly write a lot about that on my blog. And I've been in Disability Studies now for around four or five years.

I didn't even realize Disability Studies existed until like 2010, and it changed my life. And so, that's basically what I've been doing ever since.

ALICE: Yeah. You know, I think you write so well about popular culture, media about the depiction and representation of people with disabilities. So, I'm really excited that you're gonna be researching this and working on this as your dissertation. Is your idea later on to teach or to be a professor?

KIM: I mean, I would love to do that, although it is a difficult field to get into. But I would love to do anything that would allow me to do activism. And I think that teaching is a huge form of activism, and Disability Studies basically exists as an activist field to question and push back against being defined by everything else but us.

ALICE: Yeah, it is really interesting that Disability Studies is really still kind of on the sidelines, not really seen as an actual discipline or a field, which is really unfortunate. It's often aligned with Cultural Studies or other interdisciplinary areas.

KIM: And I think, too, is Disability Studies, particularly outside of academia, people have no idea what it is. When you have those generic sort of conversations with strangers, and they're all like, "So, what do you do?" "I'm a PhD student in Critical Disability Studies." And they're always like, "Oh, that's so great. We need more of that. You're gonna be working with disabled children, right?" "Um...no. It's not a medical-type degree. It's actually a sociological degree." And they just don't understand at all.

ALICE: Yeah, it's really sad that we're still kind of, despite decades after the Social Model, everything is so entrenched in this very rehabilitative set. I think right now, just a very active pushback by people with disabilities on social media about representation.

KIM: Oh, yeah, definitely. And that's something too is particularly around media representation of disability: There is very little actually done in academia itself at the moment, but there's so much going on online, on blogs. It's both interesting and sort of frightening when you're doing research in an area where there is so little foundational academic work. Because suddenly you're using blogs as primary sources, and you're just like, are my supervisors going to be OK with this, that I'm citing Twitter and not journal articles?

Social media, disability representation, sexual autonomy, and paaaaarents

ALICE: Yeah, and I think this is where emerging phenomena, emerging conversations, and communities, they're using what they have in front of them. And I think for so many people with disabilities, social media has been the real tool and having their own platforms that are not filtered by the media or other lenses and without any gate keepers. It's also been a way for--I can speak for myself that--I've really connected with so many people thanks to social media that I learn so much from. And I think that's where-- I think I discovered you on Twitter. I love your Twitter handle, @CrippledScholar. That caught my eye! And your blog, also known as Crippled Scholar, I think you have been very good about talking about these things that are happening in media, in our society, and really getting to the heart of it.

So, the reason why I wanted to talk to you today is that there were two recent posts that you published in July that really interested me, and they were about disabled sexuality, relationships, and of course, paaaaarents. So, what prompted you to write about these two?

KIM: Well, the original, the first one was a response to the fact that a British-Australian author had written a piece, I think it was originally in The Daily Mail, about how she had considered hiring her Autistic son a sex worker. And I mean, these stories, they actually pop up relatively frequently. They're not uncommon, and we always hear stories about how, in Holland, sex work is legal and how there are actually sort of, there's funding for disabled people to go to sex workers so that they can have sexual experiences. So, that whole idea is not new or particularly shocking. But the way that this woman wrote this piece, it became very clear that at no point was her son involved in the discussion, and he didn't know it was going on.

And it was just this woman sort of freaking out about her son's sex life and her consideration of hiring him a sex worker without his knowledge or consent. And basically, her reaction to the bullying that he had experienced and the sort of conclusion that she came to all by herself. Which luckily, she did not follow through with, because I think the ramifications of that would've been pretty horrific. Because she was living in the UK. Sex work is very illegal. And she even points out that around the same time, a man was arrested for hiring a sex worker for their disabled child. The fact of the lack of consent and involvement of her son at the time, I mean, really, I'm just hoping that she made this whole story up. She was using it as a sort of jumping off point to market her newest book. She's a novelist, and she wrote a book about a mother who was arrested for trying to hire her disabled child sex workers. Because the narrative and the way she went through it is absolutely appalling and horrifying.

ALICE: Yeah, and I think it was really interesting that this overwhelming concern is often so based on these really strange, obviously ableist, ideas that by this time, my son who's a young man, should be hitting these milestones, right? Parents of disabled children, I think sometimes they're really obsessed with these developmental milestones. And it continues: A young man at this age should be engaging in sex, but he isn't yet. And therefore, I must facilitate that.

KIM: Exactly. Because she talks about, I believe he is now around 26 years old, but in the piece, she claims that she was considering doing this around the time that he was 20 or 21. It is absolutely pretty normal to get to that age without having a long-term or meaningful relationship. I mean, she talks about the bullying that he experienced, and I think that is relevant. But I also question this third-party assumption that the best way to deal with someone being told repeatedly over and over and over again that they are unattractive and undesirable is to then hire a sex worker without their knowledge [chuckles]. To me, that's just reinforcing the point. It's like yeah, we had to pay someone. You are definitely undesirable. And because I just did this behind your back without even talking to you, I definitely agree with all those people that bully you: This is the only way you're ever getting laid.

ALICE: And that very interventionist mindset so many parents of kids with disabilities are so used to throughout their entire life. It also robs that person of the who's responsibility is it to take care of the bullying? I mean, the parents, it's obviously, when you have a young child, that makes sense. But clearly these two examples in your blog post, they talk about how disabled people's sexual autonomy and their privacy is not respect at all.

[laid back keyboard music]

Disabled people’s sexual and bodily autonomy being violated or dismissed

ALICE: What are some other ways that you see in media, or in other areas, disabled people's sexual autonomy is either violated or dismissed?

KIM: Well, I mean, disabled people, it's like our lives are often we don't seem to have the right to privacy, generally. On the occasions where our sexuality is sort of generally acknowledged, if BuzzFeed does like one video about dating in a wheelchair or something like that, there will always be that sarcastic question: Can you have sex? It's so common and ubiquitous. And so, it's just idea like everything around being disabled, if you are noticeably and visibly disabled, where suddenly your body and your life experiences or people perceive that they are public property where you can go up and ask random questions. And sometimes they do get very personal.

But also, there's just this trend of people that aren't disabled talking about the disabled people they know. Of course, parents are the big example of mommy bloggers and what not who just overshare about their children's live. But it's also sort of perpetuated by the medical establishment as well, because I see on Facebook, I can't even tell you how many times I've come across rehabilitation centers that will post videos of very small children going through physiotherapy. And oftentimes, so that the doctor or therapist can see what the child is doing, the child is often wearing only a diaper. And these videos are posted online to be like, "Look at what we do!" That child should have the right to privacy around not having those sorts of things put on the Internet, particularly by medical professionals.

Because I remember as a child, when I had to go to specialists, having to walk around in my underwear so that they could check my gait and what not. That was sort of just a part of my medical care. But luckily, I grew up in the '90s before the Internet is what it is, and there was never any sort of conception that I would ever be filmed or put on the Internet.

ALICE: Yeah. I've also had similar experiences where I've been in a body cast because I'm being fitted for a back brace, and you're there for an hour or two at the orthotics place. And people are just, you're just an object there. All these technicians are working around you. I'm pretty much in just a very flimsy undershirt as a child, and they're squeezing my breasts, and like they squeeze. This is so, I felt like such an object. I was worked around, always been this very zoo exhibit feeling often in the service of medical education, right?

Some of the media that you talked about has to always kind of explain disability as if we're still at that place in our, I guess, popular culture where we still have to be in this explanatory mode.

KIM: And so, it sort of becomes this idea where disabled people, in order to have a space in the public sphere, have to center their disabilities, or they will be denied a place in that public sphere. So, there's this real, they have to privilege these stories of how you become disabled. I know that one of the things that I was hearing around after *Mad Max: Fury Road* came out that people really seemed to like about the character of Furiosa is the fact that she simply existed as a disabled person. The fact that she only had one arm was really never mentioned. She didn't have a backstory for it. It just was.

ALICE: Yeah. And I think it was really great that there wasn't ever a flashback to when she lost her arm. You know, they could have b-roll or flashbacks of how they became disabled, as if that is needed to explain--

KIM: Who they are as a person? It's like character building, how they became disabled.

ALICE: Yeah, and often I think the, like you talked about privileging the people who acquire disabilities later in life.

KIM: There's also the fact that it's often used to justify the casting of an able-bodied actor. It's kind of like, "Oh! We're going to have flashbacks. So, they're going to need to be able to walk."

ALICE: Yes. We could get into the, that could be like a whole other episode. Goodness. Oh, my goodness, yes. That is true.

What does bodily autonomy mean to you?

ALICE: So, you mentioned a little bit about your own experiences as a child. What does bodily autonomy mean to you as a disabled person?

KIM: So, for me, it very much means being able to not only make your own decisions about your own body, but also kind of being able to decide when you require assistance and when you can figure out how to do something for yourself. 'Cause I know growing up, and you still hear them now, disabled people will give TED Talks where they're like, "Oh, I owe all of my stuff to my parents because they never let me lay around and pity myself. They always said I had to figure out how to do things." It's good to an extent, but it's also sort of problematic: This idea of disabled people not being able to decide for themselves when they require assistance or if something would be easier for them if they had an accommodation, even if they could theoretically figure out how to do it without the accommodation. 'Cause I know that was very much the way that I was brought up is, you have to figure it out yourself. And oftentimes, that meant that I would maybe figure out how to do it, but if I had had an accommodation, it would be easier and more comfortable.

I remember as a kid really wanting what's called a rocker knife because I have difficulty cutting my food. And I can do it the proper way with a fork and a knife, but it's genuinely painful for me to do it. And so, as soon as I became an adult, I started just buying myself accessible things because it made my life so much easier.

ALICE: Yeah. I think a lot of it is about having control and having the freedom and the power to make decisions about how we wanna live. And also, just being able to put up our own expectations in terms of our interactions with other people, like having boundaries, having the sense of how we wanna protect ourselves.

Have there been other times in your life where bodily autonomy was ever at risk or disregarded, if you wanna share?

KIM: I mean, I'm in the position where I can do most, like, I don't require a lot of assistance doing things or that I can get around without having an assistant around. So, one of the things too though is, a lot of the time, because disabled people are assumed to be sort of helpless, there have been positions where I've been put in where I've been given tools that I can use by myself. And because I don't have assistance, I know I went to the doctor, and I needed a wrist brace. They sent me off to the Occupational Therapist, and she gave me one option. This option was something that i could not use by myself. And I tried to explain this to her, that I couldn't use this particular brace by myself, but I still needed a brace, but I needed one that was different from this because I couldn't use it myself.

She's like, "Well, who's around to help you?"

And I'm like, "No one! I live by myself."

And she's like, "But someone is around to help you, right?!"

"No. I live by myself, and this does not work for me. And I'm not gonna wander around my apartment complex asking random strangers to strap me into a wrist brace because that is not something I should have to do. So, you need to find a different option."

ALICE: Yeah, it is really funny because people are utterly stunned. They just can't wrap their minds around that I would like to do this by myself, and that we shouldn't presume at all that each person has their own support network or people are readily available at any time of the day!

[chill music]

KIM: The irony around that situation too was that the doctor that I was seeing at the time didn't wanna actually give me the brace. He wanted me to have Botox, and I didn't want to have Botox, and I wanted the brace. He got so angry with me that he dropped me as a patient. That's also a big issue of bodily autonomy, particularly around medical issues: If you disagree with your doctor, regardless of whatever reason, then you become "non-compliant," and they don't help you anymore.

ALICE: Yes. I've definitely been through some tense conversations with doctors. I've had doctors suggest, for example, a feeding tube because at one point in my life, I was losing a lot of weight. And I saw a nutritionist, and they were putting a lot of pressure on me to get a G-tube. They kept saying, "Oh, it'll be so much more convenient for you. You're gonna be able to gain a lot of weight, and you don't have to worry about hydration." I basically tried to explain to them that it's so easy for providers to suggest these things, but once the disabled person goes home, they have to be the ones responsible for everything that's entailed, getting the assistance. It's not easy to have a new feeding tube when I myself may need assistance with getting all the stuff together. I already do my own personal routine. I already have so many steps and things I have to do every day just to get myself taken care of. And they were stunned!

I said, "You know what? I don't think things are dire. Give me some time to see if I can regain my weight in non-invasive ways."

And I think that was something that was just considered radical to them, and I really needed them to respect my choices. I think that's really still considered bizarre to a lot of providers. And sometimes I do have to push back. They seem to have these options for us, but they're very limited, and there's not much thinking about all the work that happens and all the labor taken for granted.

KIM: Yes. And it's just this idea of disabled people not being, this perception that we should never refuse care even though I know in both Canada, where I live, and in the United States, where you live, there is this sort of idea that people are supposed to have autonomy over their medical care. You hear stories about people who have refused care. And oftentimes, if they're perceived to be non-disabled, they're sort of seen as heroic or brave for refusing care. But if you're disabled, regardless of your reasons, regardless of the impact of refusing care, you're perceived as being unreasonable. We're not considered to have that same right to refuse care or to question or offer alternate care solutions.

ALICE: Yeah. We're seen as ungrateful that we dare! We dare to propose other ways or that we reject the way the care is provided or the way the care is constructed. And I think this is where how narrow the ideas of what is really available to us and that for so long, this whole power dynamic between patients and providers, this is where the heart is, where they're still seen as the experts versus disabled people who've lived and adapted and found ingenious ways to use what they have around them to make their lives better. And yet, that expertise is oftentimes unrecognized and devalued.

KIM: Exactly. And it plays very much into the medical model of disability and this assumption that doctors are coming in to care for us and then to fix us. And it's sort of this very benevolent idea, and the idea that we would either actively refuse care or want to have an alternate form of care basically flies in the face of the entire way that disability is constructed within the medical industry.

ALICE: Yeah. And I think there isn't even space to critique care. If you actually have a real critique and opposition to the ways some care is provided, somehow, that is seen as way too extreme.

[bright piano music]

Gene editing, designer babies, and fear of disabled bodies

ALICE: So, I was wanting to ask you one more question. I am curious about your thoughts on the latest breakthrough in human gene editing where a researcher was able to delete a genetic mutation in a embryo. And most of the media coverage was centered on this fear of designer babies and also this discussion of the removal of preventing suffering and pain from disabilities with this technology. In many ways, I think it's a pre-emptive strike against even the discussion about bodily autonomy and integrity because it wipes out the existence of certain disabled bodies. So, what are your thoughts on this issue, and why do you think people fear disabled bodies so much?

KIM: Well, I mean, in terms of why people fear disabled bodies is because actively, people have been taught to for a very long time, particularly in the last century and a half, around when we had discovery of the theory of evolution. Which of course, then gave birth to the eugenics movement. And so, there is a long and sort of very clear history of actually creating systems to say disability is bad and horrible and should be eradicated.

There's so many things to comment on around gene editing because, of course, I've seen news articles where they're asking well, what do they consider a disease, and what are they gonna consider to be too horrible to exist are two very big questions. But there's also the fact I have Cerebral Palsy, which is not genetic. So, you cannot stop me from existing. I'm also Autistic, and that is probably genetic, but they haven't figured out how to test for that yet. Although, I know they're trying. So, what do you do in a world where gene editing is possible, but not all disabilities are genetic? What does that mean for the people that are left behind or because no technology is perfect? You know that disabled children are still going to slip through the cracks of that technology, and what does that mean for them? And you know that parents are gonna start suing doctors for wrongful birth if they pay for that technology and still end up with a disabled child. They are absolutely going to sue.

And then, of course, the fact that that technology is going to be very expensive and is almost certainly going to end up privileging wealthy white people and thus reinforce systems of poverty and racism. And I mean, I brought up some of these issues a while back after Bill Nye's Netflix series came out because he did an episode on designer babies and very much sort of ignored any of the social ramifications that might come from gene editing. And he very much spoke about his sister who has a genetic disorder and how he wishes she wouldn't have had to live with that genetic disorder. So, he was clearly coming from a very personal space, but also, as a result of that, very much ignored any of the social ramifications. He had a panel on, and one woman did bring up the, "This is going to end up privileging wealthy white people," and another white man on the panel immediately interrupted. And he was like, "But, choice!"

And the thing is, is there really going to be choice if it's expensive? Because it's not going to be available to everyone. So, who actually gets the option, and who doesn't? And what happens to disabled people who are left behind without actually even getting into the complications of the eugenic aspect of this technology.

ALICE: Mmhmm. I do foresee that this is gonna create another underclass of people who already this cultural idea that health and a good life are so steeped in ableism that of course, why would anybody who has that choice or access would not wanna do it? And those who choose not to are gonna have this new kind of stigma, right? That those who actually actively reject it, it's gonna create this new kind of underclass of people.

KIM: Well, it's definitely, because I mean, we have this history of eugenics, and I expect it'll be very similar to that, this idea of where they clearly didn't understand either genetics or disability at the time. Which is why they started targeting poor communities of color, because they didn't understand the correlation of disability and poverty. Not that there was a genetic inferiority but that living in poverty has its own additional set of risks that make you more prone to disability.

So, I expect if this becomes available and is expensive and not available to everyone, I expect that they will recreate the same sort of, that same narrative of, "Oh, look at those people. They have more disabled people in that community. Therefore, there must be something wrong with that community."

So, it's absolutely going to reinforce stigmas not just around disabled people but the entire communities in which we live.

ALICE: Mmhmm. Yeah. I'm gonna really look forward to the day where disabled people are not seen as exceptional. I just don't wanna be this unicorn out there, and I think that we've got a ways to go until that happens.

KIM: Well, as Stella Young said, we're congratulated for getting up in the morning and remembering our own names. And until that's not the bar, where the bar is much higher than that, then we have a lot of work to do until that point.

ALICE: Well, you are definitely one of the forces in counteracting that. I think your writing and your social media presence really does a lot of in terms of visibility and telling people exactly what's what. And I think that's what I really appreciate, and I learn a lot from you. So, I really wanna say thank you in terms of what you do and your voice out there.

KIM: Well, thank you. You know, when I started that blog, well, a) I didn't even really think that I would still be blogging three years later. So, the fact that people are actually reading what I'm writing, it's always wonderful to hear that people are reading it and getting something out of it.

The role of social media in getting readers to the blog

ALICE: Do you feel like social media's had a real role in getting more readers to it?

KIM: Well, I think I actually would credit you with my first initial, when people actually started reading it regularly. I think it started after you started sharing it. So, I think part of it is having other disabled people who are respected within the community, such as yourself, were giving it credibility. And I started having pieces shared by the Autistic Self-Advocacy Network, and that was really good at getting basic readership from within the community.

Well, social media has completely changed the way I looked at how I interacted online. 'Cause when I started out on Twitter, I just sort of assumed Twitter would be for people who I didn't know at all, and Facebook would be friends. And then suddenly, half of my Twitter followers are suddenly my Facebook friends. I had no conception of the fact that I would actually find community online, and I think that that's really amazing and important.

ALICE: It is amazing. I am thankful every day of discovering, finding people and just seeing the wealth out there of disabled people creating culture and media and just sharing their stories, whether it's in a tweet, just a post, whatever. But I think it just really shows the diversity and just the huge range, and I think that's what really drives me to keep doing what I'm doing, is that so much of that is undiscovered and unacknowledged. And in a way, I'm just delighted to be able to share your work as well.

How can people reach you if they wanna learn more about you?

KIM: The best way of directly contacting me is probably via Twitter. My Twitter handle is @CrippledScholar, but I'm also under my real name, which is Kim Sauder.

ALICE: And how can people support your work?

KIM: So, I have, if people are able and willing to support me financially, I do have a tip jar on my blog. But also, if that isn't possible--which I do understand, considering most of my readership is disabled, and we are a disproportionately impoverished group. So, I do understand that people are frequently not able to support me financially that--just share my work. And the more people that read it, the better I get.

ALICE: Well, I can't wait to read what you write next. So, thank you again for all that you do and for talking with me today.

KIM: Well, thank you for having me.

Wrap-up

[hip-hop music]

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 find links to the blog posts mentioned in the episode by Kim on our website.

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Thanks for listening, and see YOU on the Internets! Byeeeee!

♪ knees up, toes down, lets dance

romance, hat’s off

knees up, toes down, lets dance

get as low as you would if you were in sweat pants ♪