Disability Visibility Podcast

Episode 17: Invisible Disabilities

Guests: Tiffany Marie Peterson and Linda Williams

Host: Alice Wong

Transcript by Cheryl Green

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

Introduction

[hip hop]

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

ALICE WONG: Hello my friends! Welcome the Disability Visibility Podcast, conversations on disability politics, culture, and media. I'm your host, Alice Wong. As a wheelchair user, I'm aware that many people think of disability as people who may have a service animal or may use a wheelchair, a cane, or a hearing aid. Whenever I get the chance, I try to share with folks that this is just small fraction of a much larger disability community.

Today's episode is all about invisible disabilities with my guests Tiffany Peterson and Linda Williams. Both Tiffany and Linda share their lived experiences as women with invisible disabilities, the misconceptions about invisible disabilities, and the need for language and symbols that we can all identify with.

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

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

ALICE: So, Tiffany and Linda, thank you so much for being on the podcast with me today.

TIFFANY PETERSON: Hey, my name is Tiffany Marie Peterson. I'm known most online as TiffanyAndLupus. I'm a professional patient. I am also a patient advocate and activist. I'm also a founder of LupusChat, which is an online health community that hosts conversations every other Sunday at 3:00 pm Eastern time. We have those conversations on Twitter using the #LupusChat, and our conversation is welcome to patients, healthcare professionals, caregivers, and just about anyone who would love to have discussions with us.

LINDA WILLIAMS: My name is Linda Williams, and I am founder of Invisible Disability Project, which is an online community. And we have projects that disrupt the silence around what it means to have an invisible disability, and we wholeheartedly believe that normal is a fantasy. By training, I'm a Clinical Neuropsychologist. My life now is proudly an activist, an advocate, a writer, and now a scholar at University of San Diego where we're looking at disability, equity, and leadership.

[mellow guitar]

How invisible disability impacts everyday life

ALICE: How would you say your invisible disability impacts your everyday life?

LINDA: I have a retina disease that affects the back of my eye. Sometimes straight lines look wavy. I'm now colorblind. I have dimming in my peripheral vision. It impacts my world in not just physical ways but psychological ways. But in my daily life, it's just impacted the ability to drive and not being able to go out at night because I can't drive anymore at night. It impacts the reading that I do, and I love reading. And it's getting worse. So, it's something that's progressive.

ALICE: And how do you I guess, experience or adapt to the changes as your disability progresses?

LINDA: So, in the short term, I make sure that I'm really compliant with the medicine that I'm given. But in the long term, I think about wow, I probably should end up in a walkable city because driving won't be an option for me at some point.

ALICE: So, Tiffany, tell me how your invisible disability impacts your everyday life.

TIFFANY: So, I have lupus, which is a autoimmune disease. For me personally, I don't look like I have an illness on the outside. I don't look sick. So, people are always assuming that I'm fine even though I'm really not. I would have to say that it becomes a huge frustration when I'm traveling outside, like on my own. In the event that I have a good day, and I do not have to use my accessibility device--which is a walker--say I'm on a crowded train, and my legs are really hurting, my body is just running low on energy, it's super uncomfortable for me to ask someone, "Hey, can I please take a seat? This is reserved for disabled passengers." And god forbid you're wearing some lipstick, or you dressed fancy that day. No one is trying to accommodate you.

ALICE: Or how dare you have fun!

TIFFANY: Exactly, you know? There was a time when I was like, I have a really crappy day. I have to use my walker. And so, I had my cute My Little Pony sneakers on, and I was wearing my favorite earrings. And do you know that nobody would move out the way? Nobody would help.

ALICE: There's emotional labor of having to explain yourself all the time.

[mellow guitar]

Biggest misunderstandings of people with invisible disabilities

ALICE: Would you both like to share a little bit about what you think are the biggest misunderstandings of people with invisible disabilities?

LINDA: One of the biggest problems we face in our society today is the perception of what a disability is and what disability means. I think about our universal sign, the blue placard. It signifies a disability that's related to mobility. I think it misinforms our culture that disability equals a mobility issue. I think our signs restrict the ability to even conceptualize what disability is. Change the sign, I think we make a huge impact in terms of what's possible in terms of understanding disability.

But for me also, I think it's the language that we use. So, whether we talk about it in person-first or disability-first language, showing our disability pride, I think that's important. And what's unique to invisible disabilities is that we really lack language to discuss the things that we cannot see. I can sometimes pass, and I don't have to disclose. But not everybody with a disability has the privilege to pass! And I think just recognizing that disability's on a spectrum, and disability, I always say, is not exotic. It's not this [laughing] exotic thing that happens. It's part of the normal human experience. If anything's going to be normal, we need to normalize what it means to be disabled.

ALICE: There's 57 million Americans with disabilities, and the majority of that 57 million have invisible disabilities. I think most people do think very narrowly based on the symbols and the language, whether it's visible signifiers like a cane or a service animal or a wheelchair. Really, that's only a very small fraction of the actual population that's so diverse.

How about you, Tiffany?

TIFFANY: There seems to be this negative connotation on what it is and what it means to be disabled. Like, god forbid you have some pride in being disabled, you know? And it's like, “Oh, no. You should be ashamed. We shouldn't talk about this.” And I was just like, “What? How can you tell us how to feel about something that defines us?” It's really hard to shed those negative feelings of shame. When people see you in the streets, they are staring, and there's these hushed tones and these whispers. And God forbid you walk too fast with your walker.

ALICE: No!

TIFFANY: All the sudden, like, "She's lying!"

LINDA: Right [laughs]!

TIFFANY: "How dare she!"

ALICE: Right.

TIFFANY: You know? It's like, "This is person is not really disabled! Arrest them!" And I'm just like-- I can always feel the weight of people's stares if I walk too fast with my walker. I know I don't owe them an explanation, but it's just so frustrating. Because you feel the weight of all these other people on you. And, you wanna sort of separate yourself from their negative narrative.

[mellow guitar]

Taking care of yourself and finding your own strength

ALICE: How do you both kind of take care of yourselves, and where do you find your own strength?

TIFFANY: There are moments when you're just like all right, I'm just gonna not say anything, you know. But there are moments when it's like, OK, what's not gonna happen is you're not gonna be disrespectful. You're not gonna be ableist in public. It's not happening. It's always a battle to have those moments because it comes a time when you put yourself in a dangerous position to violence. So, I always have to be conscious of that. And then the other thing is I have a therapist that I see every single week, and I've been seeing her just about as long as I've had lupus; I've had lupus for seven years now. And so, one of the most important things has been having a therapist that I can talk to on a regular basis.

ALICE: That's wonderful.

LINDA: That's great.

LINDA: It's exhausting to always have to explain my disability. You know, there's a lot of doubt. What ends up happening is that there's a group of people who are close who know. They know the thing that I can do and the thing that I can't do. And so, there's the areas of comfort tend to be more restricted. And then, like Tiffany was saying, [chuckles] the mob is out there. "You look fine!" But little do they know how I struggle and how, frankly, I've learned to cope in so many ways. You know, just because I'm coping well doesn't mean there's not a problem.

ALICE: And there's that weird expectation that constantly prove that we have difficulties.

LINDA: Right. But where does it stop? With people that care about us or love us, hopefully those are safe places where we don't have to continually prove or certify where we are in our illness or our disability in that moment.

[downtempo guitar]

Linda and Tiffany's online communities

ALICE: Both of you are carving out amazing online communities. Linda, would you like to talk a little bit more about the Invisible Disability Project?

LINDA: It starts from a lived experience, right? So, in addition to having an invisible disability myself, I have a son who's on the Autism spectrum. One day while he was in 2nd grade, he was in one of his therapy sessions, and his therapist reported him to the principal because during a turn-taking exercise where they had one die, she would have it and roll it, and then he would take it from her. Then it was her turn, and she would take it from him. When she took it from him, he, with his little 2nd grade hand, slapped the top of her hand. And she thought that was a reportable offense and took him to the principal's office. And that principal suspended my child for what he said was violence toward an adult staff member. I lost it as a parent. I quit my practice, and I started Invisible Disability Project.

ALICE: And what would you say is the overarching mission of the Invisible Disability Project?

LINDA: I think it's summarized in our hashtag, which is #DisruptTheSilence. We have various projects that we're focused on, but our main goal is to flip the light switch on the shame and to disrupt silence and to really empower what it means to be disabled in our society. One of our main projects that I'm working on, and especially in collaboration with University of San Diego, is what we call the PAL Project, which is about Pause, Ask, Listen. And I think it's far time that schools, the workforce, and maybe even law enforcement--we'll see--but we stop coming up with solutions that we address after the fact, after someone has been victimized by ableism or violated by ableism. But we solve how we even talk about disability before we can oppress, going in before the problems start.

[downtempo guitar]

ALICE: So, Tiffany, tell me about how you founded LupusChat and about the work that you do online.

TIFFANY: The LupusChat was founded back in I would say 2012, and at the time, I was participating in a lot of health conversations that were happening in Twitter. Some of the biggest ones are Health Care Social Media, Health Care Leaders. These are tweet chats that are heavily focused on just general healthcare, and there are a lot of healthcare professionals who are in those tweet chats. So, my thinking was how come there's not something like this for lupus? It would be really great to have these conversations. Back when I was diagnosed in

2010, there was almost no information online, and whatever I did see was not anything positive. So, I felt like I needed to contribute to the space and make something that didn't exist.

My goal for LupusChat was to have a conversation that was prioritizing lupus that would get patients talking about it. We would talk about those things that nobody wants to talk about. Nobody wants to talk about how illness has an impact on our sexual lives. I mean, I rarely see conversations about disability and sex or health and sex in general. But I really wanted to have these conversations. I wanted to make sure that healthcare professionals were also participating. It has been a really long and hard process to sort of open up our conversations to healthcare professionals and let them see that talking to patients is not this really big, scary thing. We can have productive conversations online. It's a great way for them to talk to the patient community outside of a clinical setting. And I believe one of our first guest rheumatologists was actually all the way from Mumbai, India. His name is Dr. Shashank Akerkar. So, I mean, it's like 3:00 in the morning over there, and he's popping into the conversation to talk to us about lupus and pregnancy.

ALICE: That's awesome.

TIFFANY: It was amazing. And so, I've been able to archive our conversations. Since then, we've had nephrologists, we've had more rheumatologists, we've had nutritionists. So, all of these healthcare professionals are being really supportive of our conversations, and it's doing such a great service to get other people with lupus saying like, "Hey, I'm not by myself. There's all these people who are talking about lupus." 'Cause I remember how I felt when I was diagnosed, and I felt very much alone. It was just a horrible feeling that I didn't want for anyone else. We've had community members from Africa, from Brazil, from Germany, from the UK, from Puerto Rico, all these people who are joining in to just talk about lupus. And then recently, we've been having something called the Chronic Coalition where we talk about other chronic and autoimmune conditions that don't really have a place to have these conversations. And so, we've talked about fibromyalgia, we've talked about scleroderma, we've talked about ankylosing spondylitis. And it's been such an amazing place for us to sort of have these great discussions because so many of us have these overlapping conditions. And once you have one autoimmune disease, it's sort of like a party for all the others to join in. So, and it's kind of a really great space to get everyone just being one open community so we're not being shut off into these different silos.

ALICE: Autoimmune party!

[party horns blare]

TIFFANY: Yes [laughs]!

Social media and finding community

ALICE: I do think the Internet, and especially social media has really given people with disabilities a tool to really find one another.

TIFFANY: Yes.

ALICE: You’re saying, "We are here, and you are not alone." We all need that.

LINDA: You know, you're hitting on something that's so powerful that I didn't expect with Invisible Disability Project in that, like Tiffany was saying, people from around the world really engage and talk and share and build community and solidarity around what it means to have an invisible disability. It's a tough world out there to share being disabled. I would say the most unexpected part of building this community is the friendships and the amount of people that I've come to know and respect and love and really be part of their lives. It's the best.

ALICE: I agree. And I think that it's there for non-disabled people to listen and learn. And also, it's for the people that may not identify yet who are kind of nervous or slowly getting to be comfortable with who they are. I think that's also, hopefully, reassuring folks that they are welcome.

LINDA: Yes.

[downtempo piano]

Tensions between invisible disability community and larger disability community?

ALICE: Do you ever feel invisible within what we think of us as the broader disability community? Because I try not to think in binaries, like invisible or visible, but do you think there are some strange kind of tensions or weird vibes within the broader disability community as a person with an invisible disability?

LINDA: Whether a person has a seen or an unseen disability, I think feeling invisible is kind of a universal experience. Because invisibility, from my perspective, is tied to feelings of shame, things we may feel inside but also how the world accepts or receives us. And invisibility has to do with disability, but think about so many of the other intersectional identities where invisibility enters the conversation. It's a complex, deep question.

TIFFANY: This is definitely such a complex and provoking question, Alice [laughs]. It really gets me thinking about the political climate for ones, and I remember seeing a lot of noise online. And I have so many different identities, and it was really frustrating to see some conversations go the direction of wanting an individual to take off their race and just focus on being disabled. And I really found that to just not be OK. Like, yes, we are disabled, but I am also Black and disabled. I am also Hispanic and disabled. There are all of these different layers. Being disabled, yes, I can face discrimination. But yes, I also face discrimination by being Black.

There was some people talking about a lot of issues and violence and police brutality. Then someone was like, "OK, but what about, how can you only talk about the discrimination that Black people are facing? How come you're not talking about the discrimination that disability is facing?" And I was like, "Whoa, whoa, whoa!" Like, it's not OK. It's not OK. So, I definitely have felt that there are times when I'm put up against being disabled and also being Black. And it's like I cannot separate those things. That is who I am. I've definitely felt a lot of tension online in the disability community. And it's something that I wish wasn't there 'cause I feel like we've all experienced being discriminated against, you know? We've all experienced violence. And so, there should be no discussion about wanting people to separate their race from being disabled.

ALICE: Yeah.

LINDA: And how can we? And how silly for us to use boxes and binaries to describe a human experience. I mean, these are inextricably bound, right? I'm just baffled by how we're supposed to unwind and extricate one identity from the other and then just have a conversation about one part of ourselves.

ALICE: There are some folks in the disability community who are so kind of single-minded in terms of talking about disability rights without thinking about racial justice or other aspects. It's like you just can't fight ableism without thinking about racism, sexism, and other forms of oppression. They're all intertwined. And I think there's also additional work that needs to be done, I think, in terms of the way we embrace and really include people with invisible disabilities in our activism. Because there are a lot of people who think of disability rights activists, and they think about people in wheelchairs.

LINDA: It's the sign, Alice! It's that sign.

TIFFANY: [laughs]

ALICE: Well, it's all back to the sign. So, getting back to the sign.

LINDA: [laughs]

Redesigning the universal access icon

ALICE: If we were like wizards at Hogwarts and could create an icon that includes all the multifaceted aspects of disability, do you have a idea of what that symbol should or would look like?

LINDA: It’s almost arbitrary, Alice, what that sign is. In some ways, we need a cultural mind shift, but when I think about that sign-- You know, we've seen the four parts that specify visual and hearing and mobility and cognitive, and I think that's progress. But it still leaves so many other disabilities that are not accounted for. I almost think we need an abstract symbol like a circle. And then we can have broader meaning around that. I think the real work comes with understanding that this whole idea of normal bodies and minds is just absolute rubbish. Just as important as the sign is the thinking behind the sign. And when we start connecting with what a normal human experience is, it's not perfection, people. It's diverse bodies, diverse minds. That's normal. Then I think we can reimagine a sign, but I don't think it needs to be broken out into the various parts.

ALICE: I'm all for an amoeba.

LINDA: [laughs] I love it! Let's do it!

ALICE: Right. A little blog that you could just make it really cute, you know?

LINDA: With a little smile on it and two round, dark eyes.

ALICE: Right. Like a little anime amoeba, you know? How about you, Tiffany? Do you have any thoughts about signage and icons that really kind of resonate with your lived experience and the broader disability experience?

TIFFANY: I think for one, it should be iridescent, just because I'm a fan of multicolors and holographic [chuckles]. And so, if it's shimmery then that sounds fun.

LINDA: Glittery and holographic with two little eyes and kind of a happy, or maybe a smirk. How about that? We'll put a smirk on it.

ALICE: Maybe with a side-eye, you know?

LINDA: Oh, I like it.

ALICE: Yeah, an iridescent amoeba with side-eye. Yeah. I love this idea.

TIFFANY: Maybe like some sort of iridescent equals sign that maybe is in another symbol that's sort of like just that we're equal. There's no this person is not that person, like this person's not normal, that not normal. I think I would really like that, and that would just be a much cooler sign to see versus this false impression of what disabled looks like, when that doesn't encompass us as a whole.

Wrap-up

ALICE: Great. Well, thank you both so much. This has been so fantastic. I appreciate you both so much for spending your time and sharing your stories with me. The work that you two do is so important.

TIFFANY: Thank you for having us.

LINDA: Thank you so much, Alice. Really.

[hip hop]

ALICE: Did you enjoy hearing us create this iridescent side-eye amoeba as the new disability symbol? That just made me laugh so much, and it’s a big reason why I love having these conversations.

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You can also find links about Tiffany and Linda on our website.

The audio producer for this episode is Cheryl Green. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

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Thanks for listening, and see ya on the Internets!

♪ It’s hard out here for a gimp ♪