

Opening Doors, Season 2, Episode 4

Tatiana Lee: Blackness & Disability Intersecting with Art

Narrator: Welcome to Opening Doors, a podcast about accessibility in arts and civic life. Brought to you by the Seattle Cultural Accessibility Consortium and Jack Straw Cultural Center.

For our second season, we continue to amplify the voices of outstanding individuals with disabilities of all kinds. Here's your host Elizabeth Ralston, an accessibility consultant and founder of the Seattle Cultural Accessibility Consortium.

Elizabeth Ralston: Hello, this is Elizabeth from the Seattle Cultural Accessibility Consortium, coming back to you with our wonderful guest today. So happy to have you join us. We have Tatiana Lee, who is an actress, international model and activist born with Spina Bifida.

Growing up in Pennsylvania, Lee felt unseen in popular media. She learned to harness social media's power to speak boldly about accessibility and inclusion in mass media, due to the lack of access and opportunities for herself and others with disabilities. She has become a sought after speaker in the entertainment and media space and volunteers her time as a disability advocate for Women of Color Unite.

Some of Lee's award-winning film credits include *Footloose*, *Jade*, *Together and Better*. She has appeared in modeling campaigns for companies like Target, Zappos and Apple. Lee is the 2018 recipient of the Christopher Reeve acting scholarship for her contribution to further disability inclusion in media.

She is the lead consultant for RespectAbility on various TV and film projects and conducts training for studios and production companies including, NBC Universal, Netflix, and the Walt Disney Company.

Wow, you've done a lot so far in your young, brief life; that is amazing. I'm so happy to see you today. Thank you for joining us.

Tatiana Lee: Thank you so much for having me. I was like wow, reading that I'm like, "Who's that girl?"

ER: [laughs]

TL: My name is Tatiana Lee, thank you so much for having me. I am a Black woman with curly, dark hair. I have on glasses. I'm wearing a tank top, it's hot, I'm in sunny California and I have a grey studio backdrop behind me [laughs] and my pronouns are she/her/hers.

ER: Thank you so much that. So let's dive right in. What was it like growing up in Pennsylvania, as a person with a disability? Do you see any improvement and access to opportunity, even now?

TL: So for me, I grew up in a small town. I recently read something and people call it "The poorest city in the richest county in Pennsylvania," a small town called Coatesville. I grew up there. And I was raised by a single mom and had lots of family and love around me. But I was

oftentimes the only person with a disability. And even in school, sometimes, the only person of color as well.

So, that was at times very isolating. I spent a lot of time, you know making friends but then also being teased, being picked on, and really struggling a little bit. I did really well in school. But sometimes it's challenging because I also have learning disabilities. So sometimes not getting the support I needed at certain times, so that was quite interesting and it was definitely a battle.

But one of the things that, you know, my mom and my grandmother—they're very strong women—and really always taught me to, you know, keep pushing keep fighting. And then when I got to 10th grade I was pushed out of school.

So that was quite interesting and figuring out navigating life after that, and not getting the support that I need. And to answer your other question of do I think things have changed.

Um, there, I don't know. I haven't been there. I left, almost 11 years ago and I kind of never looked back. I mean I still have family there and I go back there to visit—actually been back there since the pandemic for a cousin's wedding.

And I don't know how much has changed there but just as a society, we're getting there but we have so much more work to do, which is why I'm very passionate about the work that I do, because there aren't a lot of opportunities for people with disabilities. And people with disabilities—we make up 20 to 25% of the population.

But if you just think of, in terms of media representation, we only make up 2.3% of what you see. And then when you think of unemployment, graduation rate, things like that, the numbers are stacked against you from someone who does not have a disability. And then when you add on the other intersections that you could potentially exist in: being Black, being Hispanic, being, you know all these other marginalizations, being from the LGBTQ community. All of those things are stacked against you. When you look at those numbers, the numbers are even smaller.

So it's important for me to do this work. And I feel the industry is getting better, the industry is shifting, we're starting to see more disability representation and we're starting to see more writers in the room with disabilities.

And I would like to say I play a small part in that. But we still have so much more to go, just even when you think about representation of disabled Black women. The Geena Davis Institute recently did a study, and they did a study on representation of specifically Black women. And I don't know who made sure this happened but they included stats of representation of disabled Black women, which is the first time it's ever been seen. This was the first time any study has acknowledged that there's a lack of representation of disabled Black women specifically. And that number was 0.0%.

So, it's sad that that's the number, but I'm glad that it was acknowledged. I think that's a step in the right direction

ER: There is so much to unpack in what you just said, and I want to go back to something you said earlier about how you were pushed out from school in 10th grade, and it made me think of Julie Heumann, who I'm sure you've heard of

TL: Mm-hm

ER: and how she was denied entry to school, simply because she was in a wheelchair. Was that a similar experience for you?

TL: Yes. So getting accommodations, in itself, is a headache. Sometimes it went well, like once I got to high school they had a ramp outside because it was a newer building and they had an elevator, and I was granted access to the elevator key.

But other schools that were a lot older built weren't always that great. And in my childhood I went between walking on crutches to being in a wheelchair depending on what was going on with me during that time. I've had numerous surgeries on my legs and stuff. Have been in and out of the hospital pretty much my entire life, from various surgeries to illnesses. So sometimes I was in a wheelchair, sometimes I walked on crutches, but sometimes even access to class was a lot, and then you know living in Pennsylvania in the wintertime, you have to think about snow. And if you have to deal with snow. Snow is not accessible for, if you're on crutches or definitely not if you're in a wheelchair, it's not that accessible. So during the wintertime I missed a lot of school.

And so that was a barrier, and then actually just getting the support I needed was a barrier. I jumped between being in what they call alternative classroom to mainstream because my school system didn't quite know what to do with me.

I excelled really well, and were in classrooms that were the more higher level, academic students, but then I struggled a lot. And they didn't know exactly why I was struggling or how to help me. I was diagnosed at that time with ADHD and dyslexia, so I knew I had learning disabilities but I didn't quite know what that meant or was given the proper resources to be able to still excel in school, while understanding what it means to have ADHD and dyslexia, and how to navigate getting an education with that. That wasn't readily available to me.

And so what happened was when I got to 10th grade, I had missed a lot of school. By that time, I had over 10 surgeries on my legs, and I had got like meningitis twice, and was out of school, and I came back from—I was just home because my meningitis – I had viral meningitis, and they said there's no medication, we can just give you—put you on IV medication, and we just have to wait for it to go away. So I couldn't be in a classroom because there was a chance that I could pass the meningitis on to other students. And I wasn't feeling well so I literally had to just do school from home, but all I had was a teacher just dropping me off packets of work once a week and that was it.

ER: You were kind of home-schooled in some ways. And I'm just thinking back to my own childhood too and my hearing loss, and how you had to work so hard to get access and I think for people with disabilities, especially in education, you kind of have to overcompensate in other areas.

Did you feel like you had to overcompensate in another area of your life?

TL: I'm that person, I feel like I have to overcompensate in every part of my life. Like I just, I don't know, I mean I know I had to do well and I had to push myself and some days I didn't even care and some days I really, really tried hard.

So, I think, to answer your question, I went back and forth with that, with feeling like I had to overcompensate but I always wanted to push myself because I always knew I wanted more from my life than where I was.

And I think one other thing was, as a kid, you just want to feel seen and you just want to feel heard and you want to, you just want to feel like how anyone feels. You just want to feel like people see you. And I guess going through school at that time I didn't feel like people saw me, you know.

ER: Yeah, I mean you have a visible disability, you know, you can escape that.

TL: Yes. [laughs]

ER: But for me I could kind of escape from that, as long as I didn't open my mouth. I mean as soon as I open my mouth, you know that I have a disability, so there's quite a difference between visible vs. invisible disabilities.

And so this brings me to the next point about you mentioning that you felt invisible in some ways, you know, the lack of portrayal of people with disabilities in the media. And you mentioned the Geena Davis Institute doing that study and that's really great that someone was actually thinking about that.

TL: Mm-hm.

ER: So what do you think we need to do? Like, where can we go as a society to make a change in this arena?

TL: I think we have to . . . First, from the audience, we need to be heard in what we want to see. And I think people need to be vocal about the kind of content they want to see and should really want to see media reflect what is real life in society. Because we definitely do not reflect that, what we see.

Like I said, people with disabilities make up 20% of the population. That is not even close to what we see in film and TV. So I think from the audience, you know, asking to see that kind of content.

And from the industry side, creating opportunities, creating access, and that doesn't just happen by accident, especially including people with disabilities.

I was just explaining to someone the other day, I said, "You know, there's this concept of the ideal of inclusion vs. accessibility." And it's like, you know, people can say you want inclusion. But if you are not giving someone the option to request accommodations to, you know, get a job, or not having your website or your application accessible, explicitly saying, you know, "people with disabilities please apply." And including that in all the other diversity statements because there's so many diversity statements. If you're part of, of, you know, the LGBTQ and the Black community or the brown community or the Asian community, you know, we

encourage you to apply, also include disability. Oftentimes in these diversity statements disability is left out.

ER: Oh, we could talk for hours about this.

TL: [laughs]

ER: I mean, I am constantly talking about, “Where is the ‘A’ in DEI. Where is the accessibility?”

TL: Yes

ER: How can you make things equitable? How can you be inclusive if it's not accessible? How is that possible?

TL: So I think making spaces accessible for people with disabilities to come in and have access to be able to tell their own stories. Because it's not gonna be fully told authentically unless people with disabilities are actually involved in making the content.

The same thing with any other community. You can't tell a really great queer story without people from the LGBTQ community involved. Same thing with, you know, the Black community and the Asian community. I think the only people that can tell their stories authentically is the community that experiences it. And I think that is the most important and once we have the opportunity for everyone's voice to feel heard and to be able to tell their stories, that's where we can get and then society will reflect . . . media will reflect what is in society and everyone will feel seen, heard and valued.

ER: Yes, and I think maybe part of the issue is that some people don't know how to advocate for themselves. Maybe many people are tired, and they think that no matter what they do, it's not going to make a difference.

So how can we change that perspective? How can we change the perspective of people with disabilities to say, look, if you speak up more and talk about who you are because people are afraid to ask those questions sometimes and people are all curious, but they don't know how to ask that question, speak up more.

TL: Yeah, I will say, yes, people are tired. I have days where I am exhausted and I'm thinking, “What am I doing this for? I'm not getting anywhere, what is this all for? What does this all mean?”

And then I have days where there's a huge breakthrough, and you know, then it's like you know it becomes worthwhile. So you have to hold on to those moments that make it worthwhile.

And then for people that feel they don't, or they're not gonna be heard. One of the things that I can say is, and I think I had to do this for myself, find something that you love. Find something that no matter what, if you feel heard or not, you feel joy and stick to that. And you will push for it, and you will become an advocate whether you thought you were or not.

Because I feel like that's what happened for me. I was never intending to be an advocate or an activist, I never thought about that. All I knew was that since I was seven years old, I wanted to act and model. I knew, I knew that from seven years old.

And that's what I continue to push for because that's what I wanted. That's what made my heart sing, and so I was willing to fight for that, and still willing to fight for it. And I think that's where my activism has come into play because I'm not gonna let anybody's ideals or misconceptions about me stop me from creating the joy that I want in my life. And being in front of the camera brings me joy, and also playing characters and creating stories and all of those things, and bringing visibility to the beauty of disability is what brings me joy and so – that turns into activism, that turns into activism, and so be it. [laughter]

ER: That's wonderful. That's a beautiful story, and I'm really glad that you shared that because I want to talk with you about the media and entertainment sector, and how receptive they are to people with disabilities. And you're clearly a strong woman who loves to do what you love to do and you will not let anybody or anyone or anything get in your way. So you go right ahead and you do it.

The media and entertainment sector, though, is not very kind to people with disabilities. So tell me a story about how you deal with accessibility as a wheelchair user, particularly in this sector.

TL: I have to speak up and say something. I have to use my voice to know what I need, and be able to own that and speak up and ask for it. And that hasn't been easy. My activism started out in that way. I started, I created a blog called Accessiblehollywood.com and I started just sharing my stories of accessibility, because I would go to networking events and I literally could not get into the room.

And so that was my way of starting to use my voice, because I was like, "Well maybe people don't realize that someone who's a wheelchair user wants to work in the entertainment industry and actually can't even get in the room."

So that was the start of me using my voice. And I think that – I had to find it and that's where I found it. And then I think since then, realizing that, you know, my voice had an impact, because I was getting responses from people where businesses in different places started putting accessibility accommodation requests and things like that on their website and creating or moving events to somewhere that was accessible.

So I was like okay, it's not that people, maybe, maybe necessarily don't care. It's maybe because it's not right in front of them, they don't know. So that's why I set out to educate and just let them know like, "Hey, this is a thing. This is a problem. You need to do something about it."

And I think a fair amount of people are receptive. And I think that's what keeps my heart open. It gets hard at times because not everyone is receptive. But a fair amount of people are receptive and I think that's what keeps my heart open and continues to give me glimmers of hope that we are moving slowly in the right direction. And I just think about when people say you know, "Rome wasn't built in a day but . . ."

You know so just keep pushing on. [laughs]

ER: Yeah, exactly

TL: Literally and figuratively.

ER: Exactly and I talk a lot about dismantling ableism because we were born, and we live in an ableist society, whether we like it or not. And so, if people thought more about inclusive design and universal design, then those ableist structures, I think will start to crumble—

TL: Yes

ER: —and start to disappear over time. It's going to take a long time, but I'm feeling hopeful that with people like you and continuing to advocate for stuff like this, it will happen. And I want to talk a little bit about pandemic. Bringing up some a-ha moments for you.

When we spoke recently, you were grappling with the realization that your blackness and not your disability was the cause for discrimination and exclusion, and you mentioned that briefly earlier, when you talk about intersectionality.

Can you tell me some examples of the way this is showing up in your life?

TL: It's interesting, you know, living at the intersection of being disabled and also Black. You know, I thought about the two because you know, I have my identity. But to me, they're all a part of my identity. I identify as a disabled Black woman or a Black woman with a disability which every day, I'm feeling that day, I use them interchangeably.

But this past year, with the Black Lives Matter movement, and the pandemic, and it was like, I saw a lot, and it opened my eyes to so much, which led me down a rabbit hole really educating myself about, you know, ableism and racism and all of those things, and I never could pinpoint a lot of discrimination I've experienced in my life. And I've experienced a lot of discrimination.

I guess I never really thought about which one certain things were coming from, whether it was ableism, or if it was racism. Sometimes it's both of them at the same time because you know people have their own misconceptions about, you know, definitely a Black person with a disability.

But I think this year, this past year, I had to advocate for my blackness more than ever. And that was interesting because I obviously always felt it was my disability that got in the way or that was contributed to a lot of discrimination I felt in my life.

But I think this year I've learned a lot about like, it's not always your disability, it's your blackness. And that was eye-opening for me in understanding how important it is to advocate for not only disability but blackness within disability. And I think, yeah, that has just opened my eyes so much more than ever. And so I'm very conscious of that now and – yeah, just realizing how much that representation is needed and how much that voice is needed. Because a lot of people don't understand or think there's a difference.

There are all forms of discrimination but you experience them in different ways, and this year has taught me how you experience them in different ways. And like I said, sometimes they can be compounded and sometimes one over the other. You just never know. But that's a part of intersectionality. [laughs]

ER: Yeah, absolutely. And that's something that the pandemic did for me as well with the Black Lives Matter movement and everything. I've realized that I have been advocating on behalf of my White privilege for White people with disabilities, and I had those blinders on and not

realizing, even though I was thinking in my head, it was all people with disabilities, I wasn't being an outspoken advocate for that intersectionality piece. And so it's been really eye-opening and humbling for me as well, and also thinking about my life and how I experienced microaggressions, primarily from people who are ableist, you know—

TL: Mm-hm.

ER: —as opposed to racist. So it's an interesting and different way of looking at things.

TL: Yes, exactly. I've experienced that too with realizing people, you know, being around people and it's like, “oh, you're not ableist, you're just racist.”

And, you know, okay. Now I know. And you know, okay. I peep you. [laughs]

ER: [laughs] O Tatiana, we could talk all day about this. I'm so thankful for just a glimpse of your thinking into your life. And just talking about your background and how you are such a strong advocate, we are so lucky to have you advocating for all of us for the arts and culture sector. So please keep doing the great work that you're doing, and thank you so much for joining me today. And I'm sure we will be in touch very soon.

TL: Thank you so much for having me. I really enjoyed talking with you. Thanks.

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