

Opening Doors, Season 1, Episode 1

Kameko Thomas: The Invisible Disability

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 first season, we aim to amplify the voices of Black, Indigenous, and People of Color with disabilities, and to learn how race and disability impact their access to arts and culture. Here is your host, Elizabeth Ralston, founder of the Seattle Cultural Accessibility Consortium.

Elizabeth Ralston: Hello, I am here with Kameko Thomas today. Kameko Thomas is a writer, founder of Vonem Creative Media and a disabled black woman veteran, who understands the unique relationship between storytelling and hearing. She believes that hiding the truth of one's mental health journey in a misguided attempt to shield others from its impact actually causes more harm, not only to the person dealing with the mental health concern but to those around them. Recently, Ms. Thomas has shared the details of her journey to storytelling panel and events with UW Medicine, the Institute for Sustainable Diversity and Inclusion, and the 2020 Artist of Color Expo and Symposium. She has helped audiences learn about the realities of invisible disabilities for black women, how art and creativity help in the healing of trauma, and how to recognize the biases and stereotypes that falsely center themselves in narratives that aren't theirs. Ms. Thomas has a B.A. in English from Wiley College, an M.A. in English and Creative Writing from Southern New Hampshire University, and describes herself as a black woman living and working at the intersections of race, gender and invisible disability. In this case, her Post-Traumatic Stress Disorder known as PTSD, welcome Kameko!

KT: Hi! Thank you!

ER: Great to see you!

KT: Thank you, great to see you too!

ER: Now to kick things off, I'd love for our listeners to understand what it means to have an invisible disability. So, can you share what it means to have an invisible disability?

KT: For me having an invisible disability, it's multi-layered in the fact that. . . you know we do- we do live in a very ableist society and I feel that the- the number one thing when you have an invisible disability is of course the automatic assumption that there's nothing wrong with you, right?

KT: So then, when the conversation comes up and this has happened to me so many times before, well I say "Well, I'm actually a disabled veteran" and I'll- you know, get these incredulous looks like "Oh really?" and then, the next one is "Oh, you don't look like disabled," and then I have to say, "Okay, well what is- what is someone with a disability look like to you?" Like, what is disabled look like to you that you really do believe that it has a look and if it doesn't look the way you think it's supposed to look, then the automatic assumption is that it must not as bad as you're making it out to be or you know- or "Are you really disabled because you know, you're not ticking off any of my boxes." So, to have an invisible disability is a struggle and a fight in itself because you know, there is a way that people are treated when you see that they need wheelchairs or when you see that they need walkers, when you see someone on crutches or even in a cast. There are certain things that automatically happen because they have those visual cues. But when you don't have the visual cues, it becomes [chuckles] it becomes a completely different issue. And, I deal with that like every day. It's actually kind of exhausting but-

ER: I can totally relate to that because as a person with a hearing loss, I also have an invisible disability and so when people find out that I'm deaf, they're like "What? You speak so well for a deaf person?" [laughter] So, I totally get where you're coming from and-

KT: Yup.

ER: And, you know, I actually looked up what invisible disability means and according to the Americans with Disabilities Act, the ADA, "an individual with a disability is a person who has a physical or mental impairment that substantially limits one or more major life activity, has a record of certain impairment or as regarded as having such an impairment. Now, furthermore, a person is considered to have a disability if she or he has difficulty performing certain functions like seeing, hearing, talking or walking, etc.

KT: Yeah.

ER: Or, has difficulty performing activities of daily living or has difficulty with certain social roles.

KT: Mhm.

ER: So, when you consider that one in five Americans has a disability, it's so easy to see how incredibly difficult it is to make invisible disabilities more apparent and critical to helping so many people who are overlooked but also, is so daunting in this scope.

KT: Yeah.

ER: And you know, like you can continue to think about it as having symptoms of a debilitating pain, fatigue, dizziness, cognitive dysfunctions, certain impairments. I mean, these are not always obvious-

KT: Yeah.

ER: to the onlooker. So, can you tell me a little bit more about your day-to-day life experience, how your invisible disability has provided a chance, that you and others around you hadn't anticipated. How- how do you handle that?

KT: Well, having dealt with this for 22 years now, so we're basically talking about my whole adult life. So, now unfortunately, I will never know what it is like to be an autonomous adult and not have to deal with Post-Traumatic Stress Disorder. Like, so that ability, that experience is totally closed off to me. So, it makes me sad when I- if I think about it too much, it makes me a little sad. But the challenge that I face, and again this is just after 22 years of trial and error, is- is learning what my max is, learning when I have days that I- that I really just can't do a whole lot of anything and not wanting to overcompensate for my disability because I used to do that a lot. I used to do a lot of things in spite of PTSD, so I used to- I would- I would often fight against it instead of working with it. And I would end up crashing all the time so, what I've had to learn how to do is, again trial and error, because this isn't anything that would be obvious to anyone else, but I had to learn how to do. Pay attention to my energy, pay attention to my moods, be mindful of the traumas that I knew about and also be mindful if something happened and I ended up being triggered. And the thing about the triggers are, there are some that I absolutely know about and there are others I don't know are triggers until I'm having a response. And there have been times where I've been in public and I've seen something or heard something and then I'm having a panic attack. And you know- then I have to- then I'd go under fight or flight mode, I tried to find some place or somewhere to go where I can feel safe and kind of get back to center and I've got all these peoples around me and I think, you know to the untrained eye, I just look like I'm having a fit or something. But for me, it's like okay, I'm- I'm in the throes of something right now and I need to figure out what I need to do to be safe and you know- maintain some sense of equilibrium. It's a- it's also difficult because PTSD is very mentally taxing, and it ends up physically exhausting, so I said this once, at the actually at the Institute for Invisible Disabilities, I said this. I said, "There are days," I said, "My max on a good day, my battery meter is at 50 percent." That

means if I- if the insomnia wasn't bad [laughs] you know, if I was able to get decent sleep, like with all of the conditions okay, the max- like the best I'm at is 50 percent and I have to do with 50 what other people, you know, can do with 100 or should be able to do with 100, should be.

KT: And again that's on a good day, sometimes really, I'm averaging really more like between 25 and 30 percent. 50 is like my ideal, I don't always hit that.

ER: And it becomes even more exhausting, I would think, when you have to deal with the ableist society's perspectives or perceptions of people with disabilities, especially people of color.

ER: so that leads me to my next question is what made you decide to speak more publicly about being a black woman with PTSD, considering all that?

KT: there are a few things that made me decide to speak out. The first was, I personally get tired of other people telling me what you know- like they want- performative disability. Something that fits this narrative that Hollywood has put out about Post-Traumatic Stress Disorder, even though that narrative overwhelmingly centers white men and is always tied to something extremely violent and unbelievably irrational. And it's like okay, honestly for PTSD sufferers, most of us are more of a danger to ourselves than we could ever possibly be to other people because there's a high ideation for suicide that comes with that. So, that's part of it. And I got tired of- of that and then it's the- the other part of it too, is I got tired of you know- as a black woman being told how resilient I was always supposed to be, you know, when dealing with, you know, when dealing with a challenge. It was like well, you know, your ancestors were slaves and if they could deal with that, then you could deal with this. Or- or my favorite one, mental health issues are for white people, which is probably the most ignorant thing I [laughs] I think anyone can say-

ER: Mhm-hmm.

KT: this upon its dealing with a trauma or the fact that so many of you know- because PTSD is a mood disorder, then it stops being PTSD and then it starts being "Oh, I'm a black woman so I just have an attitude." I'm upset about everything all the time and those things are very damaging because I look at it this way too, and- and I see this as a responsibility. I've- I've even said this, "You're gonna say that to someone and then the next you know, they're gonna go and eat a bullet." Because they're gonna start feeling you know- hopeless. Like nobody cares and no one understands, or you know- they're gonna- you know- because it's unintentional gaslighting and I felt like if I don't get out and start speaking on this, then you know- the next person might not be so lucky. So. . . [laughs]

ER: Yeah.

KT: So, yeah so, it's hard. It's like- these conversations are never easy, but they are 100 percent necessary, which is why I do it.

ER: Well, I so admire for speaking up about this issue because I think this is an issue that doesn't get very much attention and I think it's really important to explain as honestly and candidly as one possibly can about how this effects one's own being in everyday life. And you have listed a bunch of stereotypes and biases that come into play, tell me more about the race and gender piece. You know, we talk often about intersectionality and how-

KT: [mumbles in agreement]

ER: that plays a big role in how people with disabilities are able to access arts, for example, and civic life. So, tell me more about that.

KT: [sighs] Well, you know as I said before, from the racial perspective it's, you know, I have an attitude because I'm a black woman. Like I just want to be mad about everything all the time like, I just, you know,

I want to feel like I'm always being persecuted, like I'm always being victimized because that's where I'm the most comfortable and no, it's not because I personally don't like how vulnerable I feel when I walk out into the world and that's without PTSD. So now, with PTSD, so there's a vulnerability that I feel as a black woman and there's some vulnerability that I feel as a black woman with a mental health concern because if I'm not catching it on the race and gender end, I'm catching it on the disability end because again, not only is this an ableist society, it's a very racist and sexist one [laughs].

ER: Yeah.

KT: I'm fighting a war on three fronts all the time and it is exhausting. Like before the pandemic, there were days to fight you know, woke up and just knew that I was having a bad day. I wouldn't even leave- I wouldn't leave my house. I'd be like, you know, like when I know that I feel like the act of interacting with people is likely to trigger me, I stay home. Like, these are the things I have learned to do but then I walk out you know- I go out into the world and I look at the people who take for granted that they don't have to think about these things and still feel comfortable putting their expectations on me and then wanting to persecute me for not living up to whatever ideal they have painted in their head. And it's really hard and it's very, very painful. I- you were talking about, you know, the accessibility in the arts as well. Well, there are a couple of things because I feel that just as a black person who appreciates the arts in all of its forms, I actually- a friend of mine took me to a performance of the dance theatre of Harlem one birthday. It was like, probably one of the greatest experiences that I've ever had-

KT: When the Seattle Art Museum had the Basquiat on display like, just being able to be in that environment was wonderful.

ER: Mhm-mm.

KT: and the flip side of that is, I walk into spaces like Seattle Art Museum and I get these looks like, I'm not supposed to be there or I'm not supposed to know, you know, understand the significance of so many of the works that are you know, that are there. And I'm like, why is there such a paternalistic attitude toward the arts? Like, that should be for anyone that connects with the work, not "well, you know, you're black so you can't possibly really understand what any of this means" and it's like okay but Jacob Lawrence was black. [laughs]

ER: [laughs] Right.

KT: Basquiat is black! Like, why are you talking- so it's okay for you to essentially colonize works by, you know, prominent African American artists but African Americans themselves can't even know it exists? It's, you know, that's extremely frustrating and then you know, that's the one part. Then, the other part of it is as a writer, I- and as a non-fiction writer, as a disabled non-fiction writer, I feel that there are no opportunities for people like me. I see the same people get the same money all the time and I actually feel that I've been locked out of some opportunities because I've been so forthright about having PTSD. I feel like it's one of those things that people want to understand or they- they want to create the impression that they understand but when they're actually faced with it, it's too much for them. So, they kind of back off. It's like, it's a responsibility that they don't want to have that's like, I'm not asking you to be responsible for my narrative because you don't know my narrative. I would never center you in my narrative because you wouldn't know what to do with it any way. I'm responsible for my narrative, I need an opportunity to be able to share it in a way where it's safe and I don't feel like I'm encroaching upon, you know you know, earmarked territories, so to speak.

ER: You have such a rich story to tell and it makes me sad that's not appreciated, and I think one of the things that, we need to work harder-

KT: Mm-hm.

ER: as a society to be more welcoming and inclusive of all people with disabilities, especially BIPOC-

KT: Yeah.

ER: with disabilities, right?

KT: [mumbles in agreement]

ER: And you have just touched on an essential part of what that welcoming, and inclusion could look like. So, I'm all about thinking about well, how can we educate other people in making their spaces and their events and their programs more welcoming and inclusive? What would it look like if you had the perfect experience accessing any kind of arts program?

KT: I will say this- I- when I, you know, spoke about seeing the Jacob Lawrence migration series- the full migrations series, I wasn't going to miss that. But what I noticed was that it was pretty much standing room only so, if you had mobility issues, if you had, you know, some sort of spinal injury, that would've been a very painful experience for you because, you know, it was a line that stretched around but it was a line. So, if you start to feel fatigued or whatever, that was gonna be a bit much. Now, if you factor in, you know, you know, you know, in my case having PTSD and sometimes a huge crowd of people like that, that I don't know, triggers my anxiety. So, I had to work really hard not to freak out because I was in an environment- I was surrounded by people I didn't know and they were- well, this is obviously way before social distancing, they were way too close to me. So, I'd- you know-

ER: Mm.

KT: I'd be like, why are you so close? [laughs] you know?

ER: [laughs] Yes!

KT: I feel that honestly the first part is, there should be a, you know, whether or not people will agree with me when I say this, I think that there should be a times or a space that's earmarked for okay, look today is the day where this is- we're opening the floor for people with disabilities, invisible and visible.

KT: Mm.

KT: Like, this is their day. Like, you abled folks, however you are abled, like the rest of the world is yours like almost all the time, let the disabled have this space and this time for this day. So, I think that's one way to do it. [laughs]

ER: Yeah, I love it! I love that! I think that is absolutely essential, especially when you talk about having to stand so much of attending arts performances or exhibits, you have to stand-

KT: Yeah, you're actually-

ER: and wait in line.

KT: There are no spaces to sit-

ER: Right!

KT: and- and after a while, I also have an injury from a car accident so sometimes, I can't be standing for like, you know periods, unending periods of time, you know because my pain will flare up. And then if there's nowhere to sit-

ER: Yeah.

KT: Then, I'm forced to leave a lot sooner than I had planned because I'm not comfortable and there's nowhere for me to go where I can be comfortable. And I don't think that that's anything that anyone does

intentionally but it- the impact is still the same. Like, I still feel like nothing is being done to make sure that I can also be comfortable in a space and I think that people feel like when you're asking for accommodations, you are asking for "royal treatment". You know, as a ,you know, like you know, it's- and it's like, no because saying like okay if you went to a restaurant and you ordered a steak well done and they brought it to you raw, no one would accuse of wanting special treatment because you wanna get what you paid for.

KT: You know, so there's that and I also think that a part of it, I noticed that there are a lot of people in the Disability of Diversity and Inclusion Space, it doesn't really include disabilities but I noticed that there are a lot of people in the DDI Space that aren't really very diverse. And I feel that the opinions of people like me- like, no one ever asks me. You know-

ER: Mm-hm. Right.

KT: It's all- it's always like, abled people who don't really understand that are being given the space to speak on behalf of people like me and I think that that's highly problematic. So, the solutions, such as they are still suited for people who will never have that experience and will never know what that's like. And I think that, you know, I think that bringing us in to consult and be like, okay well we wanna do this, what's the best way for us to do that in a way that is inclusive, you know, to you because everybody else, they already have what they need. [scoffs]

ER: Yes, and I think-

KT: Yeah.

ER: Mm-hm.

KT: So, are you being overly concerned about people who are going to be able to access it whenever they want to be able to access it, why are you so concerned about how they feel, especially if they're the majority of the population? Like, what you said one in five, that's 20 percent! So, that means that 80 percent of the people. . . don't need it! And I feel like the 20 percent is always being forced to consider the perspectives and the needs of the 80 percent. You know, in any other circumstance, that would be considered grossly unfair so why is it that in this instance, there are all these aspersions? Like, there was actually a woman who asked us at a panel on invisible disabilities, "how do we know you're not faking?"

ER: [sighs] Yes!

KT: [bursts in laughter]

ER: You know what, Kameko? You have just touched on so many amazing and important issues and I think part of the problem is that there's so many generalizations that so many different needs within the population of disabled people. So, it's not a cookie cutter approach.

KT: Mm-hm.

ER: You have to meet the person where they are at.

KT: You have to meet the person where they are. And I think-

ER: Yeah.

KT: The first part of it too is like you know- the talk that I gave at Aces' earlier this year. There are people who. . .they didn't understand the concept of an invisible disability. Like, that was [noise] that was new to them, like invisible disability? So, there were people there who had to be educated on what it meant to have an invisible disability and you would think that invisible would kind of be like, the key word. Like, okay we're talking about disabilities that are present, but you can't, you know, but they're not

immediately recognizable. But no, they had to be educated on that. Then, they had to be educated on Post-Traumatic Stress Disorder, then they had to be educated on- I even had a part where I said, "How many of you in the audience, have called someone that you knew had mental health concerns, crazy because you were mad at them?" And there was like one guy, he was sitting in the front and he- [giggles] he did his hand like this.

ER: [chuckles]

KT: And I said- I said, "You guys have to stop that because what you're- when you do that, it's very damaging because it's already hard to process that and then when someone is vulnerable enough to trust you with that kind of insight into themselves and you throw that back at them; not only do they feel foolish for trusting you, now you have re-traumatized them and you have made them a stigma when they already understand the stigma-

ER: Mm.

KT: that surrounds mental health and that stigma is double, if you're black because of the- you know- the stigma of getting help for mental health concerns in the black community. Then, I'm a black woman so then it becomes how much of this is PTSD versus I'm just an angry black woman. And it's like-

ER: [sighs]

KT: You know, it's like- well I get to be angry because you're walking around trying to gaslight me about my own experience and it's not your narrative to center yourself in.

ER: Kameko, I have learned so much from you and I really appreciate you taking the time to share that amazing story and very important story-

KT: Yeah.

ER: and I would like to close by having you share a little bit about-

KT: Mm-hm.

ER: embarking and your journey of healing.

KT: Yup.

ER: Because I think this would be a great place for us to understand what that looks like and what that looks like for you, especially.

KT: My healing journey, it was bit of a process because for about 15 of those 22 years, I wouldn't even consider the possibility that I had any kind of mental health concern. I remember the first time I was told "yeah, you- you sound like you have PTSD," I was like "Hmm." Like, even when I filed my disability claim for PTSD, I was still in denial. Like- I- I felt-

ER: Mm.

KT: I felt like I was lying about it because that's how much in denial I was and it took me 15 years to even say to myself, "yeah, this is PTSD." And then it took more time for me to say "well, I can't expect to deal with me based on information I know they don't have." So, I had to first learn how to get comfortable with that for myself, which took a lot. And then after I did that okay well, what's the next step? It's like you know what? I might actually want to, you know, start going to therapy because sometimes, I kind of go there with people without meaning to. Because I'm constantly being triggered and re-injured and I don't know how to process that, so that was- so that was the other part. And the third part, what is really then helpful is, you know, forms like this where I get to say, "hey, look. There's nothing wrong with me as a human being for having a challenge. I am not less valuable because you have decided that what's going

on with me makes me damaged. That's not your call to make. I still have things to contribute to the world, I have to be mindful of how I do that now. There are a lot of things that I have to consider that you don't have to consider but it doesn't make me less valuable. It doesn't mean that I get to be ignored and that what I have to, you know, what I have to say gets to be discredited and- and I'm not going to let abled people and people who don't know what this is like, tell me or the rest of the world what this is supposed to look like." I'm- I'm not gonna do that anymore so speaking up and claiming it has been probably one of the most empowering things about this journey that, as I said. It took almost 20 years to get here so [laughs] so that was- it took a long time, cause I had to get past my racial pride, my racial identity, my identity as a strong black woman, you know, all that nonsense. Like, there was a lot of stuff that I had to clear out just to get to a Kameko space, where it's like all of these things are me. Not just the little parts that everyone can deal with like, all of this stuff is me. And I even like, tell people when I- when I meet them, this is who I am and- and this is the stuff that I'm dealing with. And that might be too much for you and if it is, I can totally respect that but if it is too much for you, you need to go now because you're not going to sit here and expect me to hide things so you can be comfortable. Cause I tried that and it made things worse so, I'm not doing that anymore. So, I mean some people, you know, they've been able to hang on and others have fallen off and [laughs] I'm like, okay-

ER: Mm.

KT: If you can't do it, you can't do it. But it's not harder for you than it is for me so I'm not gonna, you know, sit here and be concerned about well this so-called person with no issues. And most- more- and there are people who have more mental health issues than they think so like, this so-called person who just believes he's totally normal is saying that you know- I'm too much for him. Well if I am, if dealing with me and me holistically is too much for you, then the only thing you can do is exit stage left and I'm okay with that. [chuckles] Like, I have to get to that point where I could say that and mean it and know that that was true for me, and that took a lot of work. And while all this is going on, I'm raising a child solo and- and-

ER: Mm.

KT: dealing, you know, the single parent thing. And trying to find a- ways to give my life meaning because like, a 9 to 5 is just not going to work for me because of all of the challenges that I have. So, I've had to put in a lot of work to get here so, when other people feel they can just jump in and start telling me what that looks like when I know the pain of that journey, it does make me angry and that was the other reason to start speaking out about it. Like, you guys need to be quiet cause you really don't know what you're talking about and you really are the quintessential [laughs] like, the quintessence of ignorance here. And- and what you're doing isn't just ignorant, it's dangerous. And it's-

ER: Mm.

KT: very irresponsible and I feel like I'm at a point where it would be equally irresponsible of me to see that and not do anything about it.

ER: Thank you so much, Kameko for those amazing, wise words and I cannot wait to read your writing. I've read some of it and I cannot wait to see what else you produced, and I would imagine that all of this, as hard as it is to be vulnerable, in some way it's freeing.

KT: Oh, yes!

ER: So, thank you so much for sharing your very personal story. I'm very humbled to have spent this time with you and thank you so much for your time and-

KT: Thank you for-

ER: speaking up.

KT: Thank you for the opportunity like really, really. To use this platform to give a voice to people who typically don't have voices, I think that it is so amazing so thank you so much for doing this because we need more forms like these, absolutely, so thank you for that really.

ER: Thank you so much!

Narrator: Opening Doors is produced by the Seattle Cultural Accessibility Consortium and Jack Straw Cultural Center. This podcast was made possible by The Awesome Foundation, Seattle Office of Arts and Culture, and individual contributors, with in-kind support from Jack Straw Cultural Center, Sound Theatre Company, Jennifer Rice Communications, and the SCAC steering committee. Music performed by William Chapman Nyaho, produced through the Jack Straw Artist Support Program. The mission of the Seattle Cultural Accessibility Consortium is to connect arts and cultural organizations with the information and resources to improve accessibility for people of all abilities. SCAC's fiscal sponsor is Shunpike. To learn more, go to seattlecac.org. Jack Straw Cultural Center, producer of the Blind Youth Audio Project since 1997, is committed to keeping art, culture, and heritage vital through sound. You can learn more at jackstraw.org.

Join us for our next episode, featuring an interview with Troy Coalman, a passionate leader, fundraiser, and tireless advocate for the disabled community.

Troy Coalman: The same cultural attributes that exist to create racism exist for someone who can't see. And so we have to break down those walls and we have to break down those barriers that may exist whether they have to do with language or they have to do with behavior, or whether they have to do with access. They don't work separately; they work hand in hand.

Narrator: Hear the whole interview on the next episode of Opening Doors, available at soundcloud.com/OpeningDoorsPod and wherever you get your podcasts. Thanks for listening.