Disability Visibility Podcast

Episode 93: Disabled Indigenous Creators

Guest: Johnnie Jae

Host: Alice Wong

Transcript by Cheryl Green

For more information: DisabilityVisibilityProject.com/podcast

Introduction

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

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

ALICE WONG: Hello, my dear friends. Welcome to the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host, Alice Wong. 2020 is about to end and good riddance! Now that a vaccine is about to become available to the public, what does that mean for the communities hardest hit by the pandemic? Today's episode features an interview with Johnnie Jae who is from the Otoe-Missouria and Choctaw tribes of Oklahoma. Johnnie is a journalist, organizer, creator, futurist, and the founder of A Tribe Called Geek, an award-winning media platform for Indigenous Geek Culture and STEM, and #Indigenerds4Hope, a suicide prevention initiative designed to educate, encourage, and empower Native youth. Johnnie will talk about her experiences accessing healthcare and staying safe as an immunocompromised person, the pandemic's impact on disabled Indigenous people, the systemic inequalities facing Indigenous communities, and the movement to remove racist imagery and terms in popular culture. Please note there will be discussions about hospitalization, death, genocide, settler colonialism, medical racism, and racist mascots. Are. You. Ready?! Away we gooooo! [electronic beeping]

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

ALICE: Johnnie, thank you so much for being on my podcast today!

JOHNNIE JAE: Ah! Well, thank you so much for having me.

ALICE: Please tell the audience a little bit about yourself or your background and just anything you'd like to share.

JOHNNIE: Well, my name's Johnnie Jae, and I'm from the Otoe-Missouria and Choctaw tribes of Oklahoma. I'm the founder of a Tribe Called Geek, a media platform for Indigenous geek culture and STEM. I'm also one of the co-founding board members for Not Your Mascot and Live Indigenous OK. And I've just been doing a lot of advocacy work. I do a lot of speaking. I also do a lot of artwork, a lot of digital artwork mainly. And that's kind of been keeping me sane during this pandemic as well. And let's see. I guess, what else can I say about myself? I was born and raised in Oklahoma. I lived in New Mexico, and for a while moved back to Oklahoma. And somehow between those two states, I ended up out here in Los Angeles in Hollyweird. And I actually really can't imagine how I was ever anywhere else. I just seem to fit in really well here with the weirdos! But yeah, that's little about me.

ALICE: So, we are talking on the last day of September 2020, which is hard to believe because this pandemic has changed my perception of time. Sometimes it goes really slow, but I feel like this September has been really fast for me. How are you doing right now?

JOHNNIE: Oh! That's a loaded question. [laughs] 'Cause it has. Time has been passing so fast, and I don't know if it's because, you know, like we have this pandemic going on, and I've been in my apartment since before they were doing the shutdown. 'Cause I have like, I'm immunocompromised because I have lupus, and so I wasn't going out much anyway. I started off this year sick. In January, I was really sick, and it took a couple of weeks to kind of recover. I had a really bad case of bronchitis, which in the back of my mind, like I know it wasn't COVID, but with some of the symptoms that I had and everything, you kind of panic. And you're like thinking back like, did I have COVID already? But I was already kind of in a lockdown situation, not as strict as I am now, but still kind of not going out as much and just kind of being mindful of where I was at because I was scared of getting sick again.

But then COVID happened. And boy, did it change the world so quickly. 'Cause I remember just hearing about it, about them talking about potential lockdowns. And I live here in Los Angeles, and it almost seemed like a panic at the beginning. And I remember telling my partner that he needed to go grocery shopping because I said, "Everybody's starting to loot everything and just kind of hoard." And he's like, "No, no, it's not that bad." And I was like, "It's that bad." I said, "I'm watching it on the news. People are running out of toilet paper and paper towels. And he was like, "No, no, it's not that bad. It's people are just being dramatic." And I guess on his lunch break, he went to the grocery store. And sure enough, everything was being wiped out. And he was like, whoa. [laughs]

And just from there, you know, it just kind of went down really quickly where we were just being expected to stay home. And with my health, that became an issue. My partner ended up quitting his job because there was just a risk of me being infected and not being able to protect himself at work either. So, it's been kind of like an adjustment period. So, and we've been stuck together, just the two of us. [chuckles] And we kind of go crazy a little bit in just trying to find out how we're gonna survive in this new reality. Because it's just like, we can't go to work the way we used to. The things that we were able to do before, we just can't do that with my health. It's just so volatile that it's kind of hard to find a way forward when we still have this pandemic, and it doesn't seem to be getting any better anywhere. We have no leadership, so it just keeps, it just seems to get worse. So, [laughs] I think I'm doing as well as could be expected in this situation.

Because it's scary when you are chronically ill, when you're disabled, and you have a pandemic that is so contagious. Because even my doctors have been really stressing like, "You need to be careful. You need make sure you wear your mask. You need to make sure that you're not exposing yourself," because my chances of survival are very low. One of my doctors told me that I have less than 15% of surviving COVID if I were to be infected just because of the way that my lupus attacks my lungs. And there's just so many little nuances that happen with the way that lupus affects my body that COVID would just devastate my body. So, ,that's kind of terrifying, too. But so, I think I'm doing OK. I mean, I'm still here, so that's good. [laughs]

[mellow music break]

Consequences of the early pandemic run on lupus medications

ALICE: Just to get into conversation about epidemic, I think I'm super curious, as somebody who has lupus, what were your thoughts about, you know, during the early or middle part of the pandemic where there was a run on medications that are typically used for people with lupus as an unproven treatment for the coronavirus? Because this, again, left a lot of people out in terms of just out of panic and fear for people actually need those medications.

JOHNNIE: Absolutely! And I think that's one of the things that has boggled my mind the most, because one, a lot of the medications that were hoarded at the beginning, like Plaquenil, for example, you only could get those medications if you're prescribed those medications. You can't just go to a pharmacy and be like, "Give me a three-month supply of this." So, I was really surprised that so many people were getting prescriptions for it when they don't need it, especially given how toxic it can be. Because I know, as someone with lupus, I've been on Plaquenil. I've been on Benlysta and a lot of different medications. And when you start on those medications, they watch you for a good week to a month to see how your body is gonna handle those. And so, I was really surprised that people were just like, "Oh, we're just gonna take this, and we're good." And I'm just like, whoa! [laughs] Like how?

But one of the things that I did learn is that it wasn't that they were actually being prescribed to a lot of people. I'm sure there were people that were getting those prescriptions. But at the same time, a lot of research facilities were preparing these medications for them to start testing how effective they would be on COVID-19, so Plaquenil. And surprisingly enough, there were a lot of diabetic meds that have been used as well and that were, still, I have to call in my prescription for Alogliptin, which I use for my diabetes, because it's another medication family that is being used to see how well it can help in the treatment of COVID-19. So, Saxagliptin, Alogliptin, and there's one more that I can't remember right now off the top of my head, but all three of them that are really popular diabetic medications have been really hard to come by.

Pharmacies, the one that I went to here in Hollywood at La Rousse, I went to go pick up my prescriptions for Saxagliptin at the time, and they were like, "Well, you need to, when you need your prescription, you need to call it in because we are only able to give out one prescription." So, they were only getting one prescription a month. So, if you weren't the first person who needed that medication to get in there at the time, then you weren't getting that medication, and they would have to special order it for you. And even then, it was kind of iffy. So, I had to switch over my pharmacy because I found that it was easier to get it through CVS than it was to continue getting it through them. And even then, they have to call it in every month to make sure that and special order so that is there when I need my refill.

And I also had to change from Saxagliptin because it became a medication that was no longer covered by insurance because of how popular it was becoming at the time. So, I ended up having to change my prescription and be prescribed Alogliptin, which honestly, it doesn't seem to work as well for me as the Saxagliptin. But I can't afford the Saxagliptin without the insurance. So, it's really left a lot of people out just wondering, like, OK, what are we gonna do? There's so many people that are having to switch medications to generic brands or to trying something different just because they don't have access to the prescriptions that they need because of COVID-19 and people thinking, oh, well, maybe this will work, maybe that'll work. And that's fine to do the research. We need that research to figure out how to combat this virus. But at the same time, they really need to be mindful of the people that need it. That this medication is proven to work for these different conditions, and we need to make sure that the people with those conditions have access to them. So, I think that's one of the things that's really been not really discussed when it comes to talking about COVID-19, 'cause we we've all heard them talking about Plaquenil, but we haven't heard them talking about other medications that have been harder to come by as well.

ALICE: There's so much uncertainty, and I think that's, for a lot of us, that's always been kind of one of the underlying things, but I think it's been really amplified in this time. I think it's definitely true.

JOHNNIE: Oh, especially now, because it's almost like too, and I worry like, OK, what if I do have COVID? Am I gonna get the care that I need, or are they gonna be like, "Well, she has lupus, so let's not waste the resources on her. And let's give it to somebody who might stand a better chance of survival." And I worry about that quite a bit because, one, I'm a Native woman. And so, I also have to combat medical racism when I go into the hospital. And it's something that's always on the forefront of my mind when I go in, because I'm worried about am I gonna get the care that I need? Am I gonna have to fight for my care? Because of the misconceptions that they have of Native people, are they thinking that I'm just an alcoholic or drug addict? What are the excuses that they're gonna try and give to not give me care or to withhold care from me, because they think, oh, well, maybe she's just an alcoholic? Or just all these judgments that they have about Native people, that's always on the forefront of my mind.

And now with COVID, it's just a whole nother layer because it's like now am I gonna be discriminated against because of my disability, because I'm chronically ill? And it's terrifying when you think about that, because we do have policies in some states that are dealing with high outbreaks of COVID where it's like, well, if you have a underlying condition, they have all these lists. And they're just like, well, we're just going to make you comfortable, and that's it.

[mellow music break]

Impact of the pandemic on Native people and intersections with settler colonialism and medical racism

ALICE: The other day I saw you tweet about how so many Native communities have been ravaged by COVID-19. And I was wondering, if you're OK with it, just sharing a little bit more about your thoughts on how Native people have been impacted by the pandemic and how all of this intersects with settler colonialism, with clearly the long-standing history of genocide, white supremacy, and medical racism that you just mentioned.

JOHNNIE: Yeah, you know, it's really hard to talk about COVID in the Native community specifically because it's hit us so hard. My cousin and his wife were infected with COVID-19, and they recovered. My aunt and uncle both had COVID-19, and they were intubated. My aunt, like me, has lupus, and my uncle had a lot of health conditions as well. So, when they got COVID, it was very scary, because their chances of survival were really low given their health conditions. And they were intubated right away. Like they weren't sick long before they had to be intubated. My aunt was in a coma, and she was intubated for about 36 days. And my uncle was intubated for 61 days before he died. And my aunt recovered. And when they say "recovered," I don't think they don't mean like you're just all well; you're good. My aunt had to relearn how to walk. And she has lupus, so a lot of the damage that was done because of COVID also impacted the way the lupus started attacking her body. And she's still recovering it, and it's been about three months. And the progress that she's made is still very marginal compared to what healthy people that have recovered have made.

And it's really hard to talk about that because, in my opinion, none of this should be happening. We shouldn't be being as hit as hard as we are, and especially when you consider that Native Americans are less than 2% of the entire U.S. population. We're a very small population. And you start looking at the numbers, and it's terrifying. The CDC found that Natives were testing positive for COVID at rates three and a half times more than that of non-Hispanic white people and were hospitalized at rates five times that. And what makes it so horrendous is just that we're already at higher risk for the more severe COVID symptoms because of the health disparities that we face in our communities. We have a lot of Natives who have underlying conditions, whether it's diabetes, obesity, but we also have a lot of chronic illness and disability within Indian country. A lot of our communities that have been hit by environmental disasters due to uranium drilling, oil spills, they already have high rates of cancer in those communities and other illnesses and birth defects. And that all plays a part in the survivability of COVID-19. So, we're already at risk for the more severe symptoms. And we've seen that risk really just become a reality because it's devastating our communities right now.

In July, the Cherokee Nation lost 13 fluent language speakers over the course of one month. The Mississippi Choctaw have roughly about 11,000 tribal citizens, and 10% of the entire population has tested positive. And there have been 75 deaths. The Navajo Nation has been hit really hard. They've had over 10,333 cases. 555 deaths have been reported, and that's just a few tribes. There are over 573 federally-recognized tribes in the U.S., and there are hundreds more that are just state-recognized. And every single nation is being impacted by COVID, and it directly correlates to the racial inequity and the ongoing genocidal policies that we've been combating since first contact. Like there's no separating the two right now. And a lot of that has to do because Indigenous people have a right to healthcare under the treaties that we've signed with the U.S., but the U.S. has failed to live up to those treaty obligations. Our healthcare has been defined by shortages in access, the quality of care, and even funding. Not once in the history of the Indian Health Services have they been fully funded ,and every year they just face huge funding cuts over and over again.

And what makes that hard for Indian country is that many IHS clinics and hospitals, especially in urban areas, with COVID and with the lack of funding, they've had to cut our services, and we've had some that had to shut down altogether. And 78% of Native people live off-reservation in more urban areas. But a lot of the urban area IHS clinics have been shut down. Here in Los Angeles, we don't have access to IHS services. There's a nonprofit here, the United Indian Involvement Group. They run a little clinic out of their offices, and they serve the entire Native population for Los Angeles County. And Los Angeles County has one of the highest population rates for Native people. So, they're basically, right now, they're just overwhelmed with having to care for so many Natives with what resources they do have. And they do get some IHS funding, but most of their funding comes through grants and also donations. And that's kind of scary to think that the level of care that we need isn't being met because of funding, and it's just, oh, there's just so much that goes into it.

Because even if you do have access to IHS in an urban area, you still have to figure out how are you getting to your appointment? Do you have money for transportation? Where is it? Are you gonna have to take off work? Is there somebody to watch your kids? If you're disabled, is there someone to help you there? Because sometimes accessibility to buildings in urban areas are lacking. And I think that's an understatement to say! But even for the tribes that do have IHS, for Natives who live on the reservation, it's the same struggles. Because not every Native community has access to an IHS clinic, and some Natives have to travel one to six hours in order to be seen at an IHS clinic. And again, it comes back to the lack of money for gas, food, lodging, lack of transportation, someone to drive. And all of that makes it nearly impossible for Natives to access an Indian Health Service clinic.

And it's just when you look at the impact of it all too, aside from the funding for IHS, we just, many of our communities just don't have access to the resources we need. And the U.S. government has intentionally delayed resources, and that includes funds through the CARES

Act. Many tribes have had to sue in order to get the funds released to them. Tribal health programs that requested PPE for their health workers were instead sent body bags and supplies that were unusable because they were molded over or expired. Many of our more rural communities also lack access to running water. And with COVID-19, that puts us at a huge disadvantage when they're telling you you need to make sure you wash your hands and make sure you wash down surfaces. If you don't have access to running water, that kind of poses a problem to that. And all of that is intentional because the goal of the U.S. government has always been to eliminate the Indian problem, and it hasn't changed. And COVID-19, it doesn't care about race or class, and it doesn't choose who to target. But our government does.

[mellow music break]

Surviving and thriving

ALICE: This brings in a perfect segue to something you wrote on your website, which I'm gonna quote. You wrote, "Survival is our superpower, but I've learned that it's not enough to just keep breathing. You have to live with a purpose beyond surviving a day in front. You must always consider the extraordinary measures that you're willing to take to be well, to be happy, to not just survive, but thrive." And this is, I think, especially resonant right now, but it's been resonant, I think, for a long time. So, how do you reconcile with the dynamic between surviving and thriving under such a bleak and violent environment? How do you take care of yourself and the people around you and find joy every day?

JOHNNIE: That's a good question, and it's one that, I look at that quote, and it kind of haunts me. [laughs] Because when I said this, it was at a time when my life was going pretty good. I kind of felt like I had broken out of the cycle of poverty, where everything seemed to be on the right projectory, and I wasn't having to worry about just surviving. My lupus was in remission at the time. My work was going good. I had steady paychecks coming in. I was doing what I love to do. Everything seemed good. Like everything seemed like, oh! This is what it was all leading up to. I did it. I arrived [chuckles] at that place where I could start worrying about how do I thrive now? Because survival mode and thrival mode, it's very different, because the things that serve you well when you're just trying to survive day to day, they no longer serve you when you're trying to thrive. It's a totally different mindset.

And so, with everything that's been going on this year, especially, it's really hard to reconcile with that because it's like, whoa. Because you wanna be kind of, it's really easy to get overwhelmed and to just see that violence and to just see the bleakness and the hopelessness. But at the same time, as bad as things have been, there have been these moments where it's like, oh, this is what life should be. [laughs] If we're not stressing ourselves out, having to work or worry about the things that we were worrying about before that now just seem so petty and unimportant because now we're literally having to fight for our lives, [laughs] it's a whole different world we're living in. But there are still these moments where you're like, oh! We don't have to exist this way. It's possible to do better and to be better. And we've seen that because as somebody who's disabled for a long time, we've been asking for more accessibility in terms of being able to work from home or to be able to do teleconferences instead of meeting in person because we're immunocompromised. And they've always said, "Oh. Well, that's impossible." Like even taking classes online, they've always made these excuses as to why we couldn't do it. Like, "No, you have to come and be in person. It has to be in person." And then with COVID-19, it seemed like overnight, that whoa, all of a sudden, it's possible for us to work at home, to take classes online, to not have to do everything in person. Even our doctors' appointments we can do over Zoom or a telephone call. And it's like, see? That wasn't so hard. It's possible.

We've also seen that, like they always tell us, "Well, there's not money to do this. There's not funding in order for us to help other people with this problem or that." But at the beginning of the pandemic, when they first started talking about the CARES Act, then they're pulling funding out of there butt it seemed like. It's like, wait a second, you said there is no money for this, but here you are putting billions of dollars towards this? So, it kind of shows that it's possible for us to take care of each other in different ways as well, not just through our government making sure that we have accessibility or funding. But we've seen it on a community level where there's a lot of mutual aid efforts and people really being mindful of the people in need in their communities and making sure that they have food or that they have water, that they have cleaning supplies even, that they have masks. That's a huge one that's been going on.

And I really love that because right at the beginning when people learned that there were hospitals that didn't have access to their PPE or they were running shortages on masks, people stepped up in their communities and were making masks for people, were making sure that they could try and figure out a way to get these people what they needed, even if it wasn't necessarily the medical-grade equipment they were used to, but just something in order to help them take care of people and keep themselves safe. So, we've seen a lot of positive things come out of this as well. And so, it's really hard for me to reconcile with that. Because it's easy to get overwhelmed, especially when you're struggling. But at the same time, even when you are struggling, you still have to be mindful that you aren't just existing in that moment. You still have to think about what extraordinary measures that you need to take in order to be well, to be happy, and to not just survive, but thrive. That still stands even when you're struggling.

And it's really hard to reconcile with that, because you have to take the good and with the bad. And I think especially for someone like me, I am bipolar, and I struggle a lot with depression. And this year has been really hard for me, not just with the health issues. But at the beginning of this year,. I've lost so many people. I mean, just recently, I had a cousin who passed away in a car accident. So, for me, it feels like it's loss after loss after loss, and all I'm seeing is the devastation and all I'm feeling is that devastation. But at the same time, I'm still finding these moments that, to me, are beautiful.

[mellow music break]

Fighting against Native imagery as mascots

ALICE: So, I wanna pivot, if that's all right with you. Because you are journalist, a speaker, a podcaster, a technologist, advocate, community builder, and you are one of many Native activists who have fought against the use of Native imagery and words as mascots. And what's your take on how things seem to be slowly changing? For you, what is the ultimate goal in terms of eradicating all sorts of harmful images of Native people?

JOHNNIE: I think it's about time. And I'm really glad that change is starting to happen, especially for a lot of our elder activists who have been working on various issues, whether it was changing the name of the Washington football team, the Cleveland Indians, the Chiefs. You know, we have a lot of elders who have been working on this issue for close to 50, 60 years. And a lot of them felt that this is something that they may never see in their lifetime, and they were just hoping that the groundwork that they were laying would help benefit future generations that were picking up the torch. And so, when the football of Washington team announced that they were changing the name, finally, it was a shock. I think a lot of us knew it would happen eventually, but again, not in our lifetime. So, it was a shock. And it was a good shock because it was just like, whoa, what?! [laughs] And it made me happy for a lot of the elder activists who have been working on this issue because they got to see the benefit.

Because so much of the work that you do, we constantly have to remind ourselves that it's not for us; it's for the future generations. Because we know the likelihood that it's something that yes, we're gonna make some progress with the work that we do. We're gonna start laying some of that education down, but it's something that is just gonna be ongoing, because these problems didn't happen overnight. So, the solution and the change, it's not gonna happen overnight either. So, it takes a lot of patience.

And this is one of the cases where I was just so happy. [laughs] I mean, I'm still like, when I think of it, of the fact that my nieces and nephews are gonna get to grow up in a world where it was the Washington football team, that's amazing to me. Because the ultimate goal when we're trying to change the name of these racist teams and monikers and the racist mascots, it's not that we're trying to erase ourselves or to even create a monopoly on Native imagery or use of it. It's that the imagery that exists, the monikers that are using, have led to a very toxic misunderstanding of who Indigenous people are in reality, because there's just no education on Native people. When you go to school, you're fed a very whitewashed, very short version of Native history and usually only during November, which is Native American History Month. And so, there's not a lot of comprehensive understanding of who Native people were in the past, much less who we are now in more contemporary times. And a huge part of that is because we have literally been made invisible by the hyper-invisibility of those mascots and team names. Because when people think Native American, that's where they go. Their mind goes to these mascots. They go to these tropes that are so prevalent in pop culture. And that's who they think Native people are.

And that's one of the reasons why so many people have just this really defeated idea that Native people are just poverty-stricken, that we're pitiful, that we have no value to society. Like, people actually believe this. And then there's also a lot of people who don't believe we exist now. They think that we were extinct. So, it's so vital that we remove this imagery that kind of contributes to that erasure of Native people and kind of start letting people see us as more contemporary and real, full, actually fallible human beings that we are and seeing us in other roles. Because we are just like everybody else. [chuckles] We're human beings. We're not perfect. But at the same time, all these issues that we face in our community, whether it's poverty, alcoholism, drug abuse, these problems exist in other communities as well. But because of the prevalence of the tropes and the mascots and stereotypes, everything, they've really made those issues synonymous with our identity as Native people. And that's where the problem is. And so, eliminating that kind of takes out one obstacle. And it's honestly like the lowest hanging fruit.

It's the easiest thing that people can do to help Native people: to change the names of their football teams or sports teams that are using Native mascots or Native-themed monikers like the Chiefs or the Indians. It's the easiest thing that you can do to change that in order to help Native people because it creates a toxic environment for Native people, no matter where they are. And it does. It impacts the self-esteem of our youth. And it also impacts the political realities that we face as Indigenous people, because a lot of people will tell us, "It's just a mascot. It's just a cartoon," that is not real. But the impact of those things are very real, because the people in Washington, DC that are creating policy, or even on state and local levels that are creating policy, that impacts Native people, if they don't know who we are and they can't see us beyond those tropes, then that policy is always gonna reflect those misconceptions and prejudices. And that's not good for any of us.

And so, that's one of the reasons that we really work to eliminate the use of harmful Native imagery and get rid of these tropes. Because we no longer wanna live with the impact that it has on our communities, the very real and harmful impact that it has. We wanna be seen as who we are: human beings who are fallible, who are also resilient, strong, and we're absolutely brilliant. And that's one of the hardest things, I think, for me as a Native person to really reconcile with, is that people are more willing to stand and fight for these mascots and these stereotypes than they are for actual living, breathing human beings that we are. So, I think that's one of the reasons, the ultimate goal. That's why we're looking to eradicate these Native mascots and imagery just because we wanna be seen as human beings.

ALICE: Johnnie, thank you so much for being on my podcast today.

JOHNNIE: Oh, thank you so much for having me!

Wrap-up

[hip hop]

ALICE: This podcast is a production of the *Disability Visibility Project*, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast.

You can also find out more about Johnnie at my website.

The audio producer for this episode is me, Alice Wong. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

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Thanks for listening! And see you on the Internets! Byeee!