**“Young black disabled & proud”**

**Host: Leilano Fuimaono**

**Guest: Ngino Amum**

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LEILANI: All right. Hello, my name is Leilani. I'm here with my lovely friend and collaborator, Ngino Amum.

NGINO: Yes.

*[laughter]*

LEILANI: I've always wanted a podcast, so this is a dream come true. I am a chronically ill, Samoan, artist person. How would you introduce yourself?

NGINO: I'm Ngino Amum. I am an up and coming artist. I identify as queer black and South Sudanese... woman, was meant to be-

LEILANI: I'm non-binary. We came together through a show called Visibility. It's open now from November 27th until January…?

NGINO: Yes.

LEILANI: How was your experience with that?

NGINO: It was very eye opening. How I've evolved as a person and being vulnerable, I've shown a different side of me and I've more honed in into that positive aspect of me.

LEILANI: That's really exciting. It's really made me realize the importance of working with like other disabled and chronically ill people, and how vital that is for my mental health and wellbeing. Is that something that you felt as well or have always sort of known?

NGINO: Yeah. I definitely do see my artwork as therapy for me. Whether it's painting or drawing. Having that space of a group of people understanding me through my art helps me to ways people don't understand.

LEILANI: Yeah, absolutely. So Ngino, what was your experience growing up here in Australia as a disabled South Sudanese woman?

NGINO: I've definitely had different experiences being in different environments. Specifically at school, I was very... I was the odd one out. I didn't fit in. I was never part of any clique or group or whatever the other term you want to use in terms of revolving around groups of people at school. I was the ‘angry black girl’ to a lot of people or I was the shy, quiet, non talkative disabled kid, and that kind of affected me in a way in terms of, no one understood who I really was, because people never ever gave me the chance to express myself and actually talk about who I actually am. They just made assumptions of how they see certain people, so they stereotyped. Having to have that and society's view on how black people are, had a negative aspect on me, because even though I never saw myself as ugly or stupid or whatever negative term, it kind of hindered on me where I was like, "Well these people think I am, should I think of that of myself?"

LEILANI: Yeah. It's been consistently reinforced.

NGINO: So, all through high school trying to figure out who I am and what I want to do and who I like and things like that. I never had a safe space. It was always, "Oh, there's Ngino. She's just the girl in the wheelchair. Cool, who cares about her?" To then having to deal with all these things myself, and not because I didn't have a safe space at home or just I couldn't communicate that, and so having to figure all that on my own was scary, just because I didn't know what was going on. I thought half of the time I was going crazy.

LEILANI: Yeah. When no one extends themselves to reach beyond being boxed in like that. It's like, how are you meant to figure out yourself if you're just receiving everyone else's external realities and perceptions of you? What I was going to ask was, did online communities and things like that sort of help you find your way to a stronger sense of identity or was it just like, after school you met some people or started forming stronger friendships and relationships?

NGINO: It was kind of a mixture of both. In terms of my, I don't want to say queerness, but me identifying as queer, I definitely got onto online talking and whatnot, and socializing with other people who identified as queer online, and having that safe space of like, "Okay, they aren't going to judge me, we're all queer, who cares?" And then having a couple of people then ostracize me, and be like, "Oh well just because we're queer, but you're black though." And I'm like, "So much for a safe space." I went into this community I thought were going to be like, "Okay, you're one of us, you have that safe space," and then that be taken away from me was confusing. And in terms of having groups outside of school, well after I had finished school, I definitely got more in touch with me being South Sudanese once I finished school, because I was open to learning more about my heritage and where I came from, by talking to my mom or socializing with my sister more and her being able to open up different opportunities for me to engage in with people who are like me.

LEILANI: So you started having more conversations with your family members and stuff?

NGINO: Yeah.

LEILANI: That's awesome. Queers are ableist. It is a thing though, finding communities online, and it's a double edge sword of having some of your identity validated but some of it not being welcomed or understood or treated with validity. It's such an ongoing reality for disabled and chronically ill people, especially people of color and BIPOC. So, linking back to I guess queer, I hesitate to call it community because it's not really what it is.

NGINO: Group of people.

LEILANI: Yeah, it's a queer group of people. Linking that back in, ableism and racism is so inherently tied into these spaces, as well as classism and urban... Centering in the urban space rather than reaching out to rural queers and all of that. I guess I just want to talk about why I think disability justice and disabled people and chronically ill people are not listened to, are not having quite the “come up”as different marginalized groups that are... It's easier to lend that group of people to fashion or what's cool and having clout. I think disability at its core is anti-capitalist, and disabled people are fundamentally at odds with capitalism, and I think that's a lot of the reason that it's really easy to just ignore disabled and chronically ill people because... Yeah. I'm rambling, but what do you think about that?

NGINO: You did say a lot. I definitely think that when it comes to being in different spaces while being disabled, we're considered difficult or we have to be taken care of or, "It's so much easy to forget about that disabled girl who needs a ramp," then it is for other people to be invited into events. And I definitely think with accessibility, that's the main issue and it's like having to go into schools and different venues, and there not be any way for me to be allowed in is so unfair. It's so disheartening having to go into a space of like, "Oh, this is your educational space." Having to then be told, "Oh, well we didn't fix the ramp, we didn't know about it," or, "The elevator's a bit rickety, but it's fine."

LEILANI: I've always thought, how do people not see a double standard of saying, say there's a venue, you wouldn't say gay people can't enter this space, because then there would be uproar, community uproar. Like, "Oh, this place won't let gay people in." But a lot of disabled people can't get in anywhere, and there's no uproar about that, it's just like, "Well, that's just a reality." But if there was any other marginalized group having been barred access to a space, there would be more of a hubbub about it, and it's like why don't we look at disability in the same way? Why do we see access as an afterthought or a hassle to deal with, rather than a fundamental part of progress and the revolution?

NGINO: I've definitely gone into school events at certain TAFE courses and they've told me, "Get over it. It's your fault, you should've told us beforehand." Things like that. And it made me feel so guilty for being disabled, as if it's my fault and I'm like, "That isn't my fault. It's your job to fix things in a school or a building or whatever. It's your job, don't guilt trip me into feeling like there's something wrong with me."

LEILANI: It's literally the bare minimum of basic access and that should be met and not treated as disabled people are just angry or something.

NGINO: Yeah.

LEILANI: But yeah, I think that's a really big problem and maybe I am “at-ing” the queers a little bit and saying, ableism is really in our community or our scene, and it does feel like a lot of the time it's not prioritised because it's less easy to capitalise off. And I think that needs to change, I really do. Sad to say that.

NGINO: But going on to the whole queer and disabled aspect of it, I've gone to so many different queer pride events and then they'd be like, "Oh well there’s grass here." I'm like, you could have done something about that, there's a whole building and you're telling me I can't. You can't do anything about it? So I definitely think that it does target the queer group of people because it's such an afterthought. You have all these different events going on, but then say it's accessible and everyone's welcome, but then we get there and you're like, "Oh, sorry."

LEILANI: And maybe that's something we can say because we've got a microphone in front of us. An event is not accessible if the person has to personally contact the manager every time they need to leave the building to get the key to go to the elevator, which is at the back of the building.

NGINO: Or get the maintenance guy that has to apparently do something else.

LEILANI: If you have to ask permission before and after entering a building, then that's not accessibility, even if there's an elevator. I just want to say that. Yeah. What else is inaccessibility? If the building is accessible but the toilet isn't.

NGINO: That idea of us needing someone to take care of us. There's a difference of having someone ask you, "Hey do you need help?" And then someone assuming that you need help. And there's a different way of dealing with that and approaching that situation. Because there's been so many times, Leilani, where I've had random strangers attempt to push me because they've just naturally assumed that I need help.

LEILANI: Which is a life threatening thing, people. Do not grab people's wheelchairs. It's very dangerous.

NGINO: I've literally had so many... And it's usually grown ass men. Why are you grabbing my wheelchair? Personal space.

LEILANI: Yeah. Do you know what, my friend Frankie was telling me... Shout out to Frankie. We were discussing the other day, this is something that almost every friend of mine who uses a wheelchair has experienced. Religious people on the street coming up and praying on you. My friend Frankie was explaining to me that those people have a religious imperative, that they're actually taught that if they see a sick or needy person, they have to like pray on them, like it's their responsibility. And that really blew my mind. I was like, "Wow, the ableism is really like baked into their religious scripture."

NGINO: I've definitely had my fair share of people grabbing my knees and assuming that I need to be prayed for. And obviously, it has nothing to do with everyone, it's just certain people assume that I need to be fixed, when that's the complete opposite. I don't need to be fixed or I'm not broken.

LEILANI: Exactly.

NGINO: I remember I was in year 10 I think, and I had just come back from an excursion from the city and I was waiting with my teacher so I can be picked up. And this big buff guy, just out of nowhere, I don't remember what direction he came from, but he was just like, "Hey, can I pray for you?" And as I looked to my teacher who was on my right, I was like, "Please don't let him." Then he just starts praying, and then he grabbed my knees, held my knees. I tried to nudge him off but he like really glared at me. I was like, "Let's not do that." And having, once again that personal bubble be invaded is so uncomfortable. I know you're trying to do a good thing, but-

LEILANI: It's very weird.

NGINO: It's uncomfortable and unsettling.

LEILANI: It's really... Yeah. I find it particularly unsettling and violent, in that there's this imperative like you need to be fixed or something. So that's the thing that happens, that I think able-bodied people would be shocked to hear. It's like a frequent, often occurring thing. Stop that, religious people. We understand your texts might tell you to do something but stop doing that. PSA.

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LEILANI: Maybe a good topical thing we could discuss, which I think really encapsulates how inextricably linked a lot of marginalized identities and impressions are, is the viral Tik Tok that has been going around last week, the last couple days of a non-black nurse. I think the title of the Tik Tok was, “We Know When Y'all Are Faking”, and she is doing a fake hyperventilating thing. She makes a bit out of the hyperventilating and it's like mocking patients and that was a fun thing to have to see.

NGINO: Yes, very fun.

LEILANI: It's a lot to unpack.

NGINO: I don't think it's a lot to unpack. I just think people need to be more sensitive and understand that people go through traumatic experiences in hospitals.

LEILANI: Yeah.

NGINO: I've had multiple experiences being, I don't want to say locked up, but having to stay in a hospital for months on end, being on IVs and having multiple surgeries, and for someone to then assume that people are faking it is so offensive.

LEILANI: It's really scary.

NGINO: Having to see family members, friends fear for my life, and then to have someone take that as a joke, I can't comprehend it. I don't get it.

LEILANI: Yeah. It's definitely brought up like all the systemic issues, and I'm really glad that Twitter is the way that it is, even though I hate Twitter because it is the way that it is. But it's wonderful that when things like that go viral, there are so many different communities ready to explain and make the other side go viral and say, "Actually, this is so wrong. This issue affects so many people." I saw a lot of people being like, was it Serena Williams who nearly died in childbirth because of this exact issue. This is such an inherently systemic problem. Even though it was terrible to see it online, I was really glad to see how much discourse was going around.

NGINO: Yeah. I definitely do want to talk about my experience being about two years ago, two or three years ago. I had gone through having a back surgery done, and that was about two, three months that I was in hospital. And it involved having a halo put on my head and having one of the screws... For the people who don't understand what a halo brace is, it's several screws implanted into your skull, and then tightened for them to weigh water weight to kind of see how much they can stretch your back before pre-surgery. I had that done for about a month or so, and one of the screws had moved and it's not meant to move. Prior to me having these procedures done, I had asked, "Is it going to move, am I going to bleed?" The doctors said, "No, nothing's going to happen. You're going to be completely fine."

NGINO: I was like, "Okay, that's fine, surgery. Cool." A month in, one of the pins moved. I started bleeding. I remember waking up, this was when I was asleep, waking up in excruciating pain, screaming my head off, having to constantly press the buzzer and having one of the nurses run in and be confused as to why I'm screaming. For me, I was definitely one of the quiet patients, just because there wasn't really much that needed to be done for my procedures, and having her be so confused as to why I'm screaming and then realise that I'm bleeding. Everyone went into a panic mode. They had rushed in and got the doctors and they're just like... The doctors had dismissed it, like, "Oh, she'll be fine in an hour."

LEILANI: Wow.

NGINO: A doctor had literally just dismissed the fact that I was bleeding, that one of the pins had moved after they said that it wouldn't, and then having to take me in and out of the OR constantly without my family being there, and I was underaged. This was at a children's hospital.

LEILANI: That's messed. What ended up happening?

NGINO: Everything ended up... I had to-

LEILANI: Did you have to like advocate for yourself?

NGINO: Yeah, I definitely had to... I was lucky enough to be one of the eldest at the hospital and then the nurses around me being able to be supportive in the situation. The doctors were just like, "Oh yeah, just add more water into the bag, it's fine." The nurses were just like, "Hold on a minute, you can't do that, she's in pain. She's bleeding. She shouldn't be. Take that seriously." And they dismissed it. They just like, "It's fine, it's whatever." The whole water bag was meant to be around 10 kilos, it ended up moving up to 20. 20. Being pulled from my head in a head brace.

LEILANI: That sounds horrible.

NGINO: And the doctors dismissed it. They were just like, "She's fine."

LEILANI: So once the nurses were like, "No, you need to take this seriously." Did the doctors then address it eventually?

NGINO: No.

LEILANI: Wow.

NGINO: The nurses just had to be like, "We're not going to fill her water bag up."

LEILANI: Oh my goodness.

NGINO: "She's in pain. We can't do that. It's illegal. You're putting her in and out of the OR and she's underage. She's meant to have a family member there, she's under aged." Yes, I was 17 but still-

LEILANI: Yeah. That's an absolute mess.

NGINO: Constant doctors dismiss how I feel every time we had the morning run through doctors coming in, I would ask them questions, they wouldn't take me seriously unless someone else was there. I'm like, "Are you kidding me?" And I was like, "How do you expect me to explain my condition if you're not listening to me?"

LEILANI: Yeah.

NGINO: How? I don't get it. And then having... I remember there was another situation during that period where a nurse had scolded me in front of other nurses, because I was an hour late for my medication even though I had set the timer and I was an hour early, she then took it upon herself to yell at me in front of everyone, saying that I'm not taking my care seriously. Even though I was, I was an hour early, I knew what time I needed to be there by.

LEILANI: Yeah.

NGINO: What's so hard for you to comprehend? Once she had realised that she had gotten the times wrong, she didn't apologize, she didn't do anything. She just dismissed it and was like, "Well I have to work with multiple patients, get over it." I'm like, then don't work here.

LEILANI: Yeah. For me, I've always felt like people within the medical industry are just, of course doctors because they are in school for so long, but it feels like they've been through so much grooming in an industry that is just fundamentally extremely ableist and it's like a for profit industry as well. There's so much grooming by the time nurses and doctors have finished their schooling and their education, it's like built into them to disregard, to downplay patients' concerns, and I really do wonder why when there is so much blatant history of medical history being tied to eugenics, tied to mistreatment of Indigenous people, of black people, like medical science. It's just like, you would think that there would be more awareness in that industry of how there is some really awful history tied into the medical world, but there doesn't seem to be any kind of awareness of that.

LEILANI: That's just you're groomed into the system. You come out as a doctor or nurse. I'm not saying they're all terrible, obviously not all of them are ableist, but it just seems like such a systemic issue. I really think that there needs to be so much more done to acknowledge the roots of medical science, and how deeply it is tied into ableism and anti-blackness and racism. So I think we're going to wrap up here, so we'll just have last words, shout outs Nyama.

NGINO: My annoying lovely cousin.

LEILANI: I want to say shout outs to Tik Tok, which is a social media app. Even though the Tik Tok we were talking about was very ableist and problematic and racist. There's actually so many disabled people and chronically ill people on Tik Tok, a lot more than I've seen on say Instagram or whatever, which really encourages normative everything. On Tik Tok, I've just noticed that it's weirdly accessible to disabled people to be able to make three second or fifteen second long creative videos about their illness or disability. I've just seen like so many people on there living their best life. So shout out to Tik Tok. Shout out to my best friend Morag, who has been my closest friend for a long time. We've been through a lot of ableism together. I want to say shout outs to them. I love you so much. I'm so proud of you.

NGINO: That's it.

LEILANI: Thank you so much for listening.

NGINO : Thank you.

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