**“Africans With Disabilities”**

**Host: Ayan Shirwa**

**Guests: Pauline Vetuna, Faro Musodza, Serious Meerkat, Hamile Ibrahim**

**Transcription by Leilani Fuimaono**

ANNOUNCER: The following program will feature discussion of domestic violence and child abuse. Listener discretion advised.

AYAN: You're listening to Africans with Disabilities in a one-hour special for 3CR's Disability Day podcast for 2019. In this program, you'll hear from Hamile Ibrahim who assists other African community members navigate the health system, employment and government services. Later, you'll hear from Faro Musodza on self-management of NDIS planning for her son with autism. You'll also hear from Serious Meerkat on non-Western modalities of healing from trauma. Stay tuned.

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HAMILE: I live in Dandenong area, southeast, so there's a lot of immigrant families there from different part of the continent, so we have a couple of… we have a huge Oromo population. We have Somalis but Somali from Somalia and also like Somali-Kenyans. And then we also have a couple of Togolese, Cameroonians, Malians. We also have families from Sierra Leone, Liberia, Senegal. We also have families from Gambia, South Sudan, and just one family from Guinea.

I mostly do forms, filling in forms, any forms to do with Centerlink, anything to do with taxation, medical forms, migration or immigration, anything that needs filling. If someone is trying to apply for something, including if they're trying to apply for jobs and things like that or if they are doing jobs searches, because most of them can't read and write, so anything to do with just reading and writing and they're like…

HAMILE: Or they get a letter and I need to go through the letters and be like, “Okay, this is what it says.” If there is an action that needs to be followed up, so I'll be like, “Okay.” These are the things that you need to do or these are the things that needs to be done. And I often also do all of that or whatever is required, and that role is from communities. It can be in Dandenong, I might be in Dandenong in the morning and then in the afternoon, I might be in Berwick or Narre Warren.

I can be in Nobel Park or in Springville, and sometimes I do also have aunties that come from the Werribee areas and they're just like, “Oh, we'll just go and take this semester Ha,” that's what they call me. They're like, “I'm going to go take this to *[inaudible]*,” and I say, “I will fill this, I will do this, I will do that.” Also, my mom is literally the community's mother *[chuckles]* so she is… she does a lot. Honestly, the woman's amazing.

She is babysitters or for anyone with kids in the communities, and this also varies and also our house is also some safe house for communities both here and also interstate. Recently, we just had a couple of aunties that was staying at our place and they were both running away from very abusive family, households, and really intense situations with domestic abuse.

So if they need refuge and things like that, most of them come to our house because the women shelter places are not also a safe space for them because most of them were in the intersection of a couple of things, being African, being Muslim and also one of a form of disability that they have, yes. They're diagnosed for a variety reasons mostly because when most of the families migrate here, what happens is, there isn't really assessment or things like that that happens.

They can’t go like “Oh let's do psychological analysis, or let's do,”… There's always the health thing that they do, which is they check if you have often malaria or diseases, sometimes even Ebola and things like that, things that are associated as endemic illnesses with the African continent. And unless you have a physical disability, let's say if you're a wheelchair user or if you can't… if you're blind or if you're deaf then they're like, “Oh, okay now, you can be in this category.”

But for most of them who come with authority… Also, most of the aunties especially the ones from Sierra Leone, Liberians and also the ones from Congo and places like that, they already come, sing like war, and they come being heavily militarized and there is so much trauma that they've seen and they already come here with PTSDs that don't get recognized.

And on top of that, also most of them come here when they haven't been schooled, and my mother is a very good example of that. There hasn't been any assessment to see, “Okay, they can't read and write. Let's see if there is any psychological thing that might be a barrier to that, or might be the reason why they haven't learned.” It's always, “Oh, they probably came from uncivilized place.”

And because of that and also because of patriarchy and misogyny and things like that where girls are not educated and there's all these assumptions about the continent, so that often leads to, “Oh, they were not… they didn't have a chance to be schooled and because of that, that's why they can't read and write, but if we put them… if they're here and we put them in an English school, that means they will be able to read and write."

Most of them have been here for 17 years, 20 years. My mom has been here for more than a decade and some aunties have been here for 18-21 and things like that. There's all this requirements that are needed in order for you to get, for example, centrelink. One of them might be like, “Okay, you need to do 20 hours of schooling.” They've been going to English class literally since they've been here.

Most of them can't read, can't write and can't speak English. And even when they speak, it's very basic and it's basic with heavy accent. Nobody goes in and ask questions like, “Oh, we've been teaching them English class for so long, it hasn't worked. Why is that so?” Why is it when this auntie writes, for example, when you ask my mom to write ‘cat', she would write T-A-K for example and things like that.

There isn't like, “Oh, why is this the issue?” The ‘why' is never present and it's never present for various reasons, which is anti-blackness and also afrophobia, and there's also this assumption that, “Oh, they just don't want to learn.” There's also like when ages comes to play, “Oh, when you're older, your brain slows down a lot, so because of that, you're not switched on.”

We just need to be slower and keep on just doing this repetitive blanking on words that we've been trying for so long, which haven't worked and are still not working until you are able to get it. But nobody goes in like, “Oh, wait, this is associated with dyslexia or this is,”… When for example you ask most of the aunties to write 17, they will write seven and then one, it's almost the opposite and I can never pronounce the word for it, but I think it's a learning disability. It starts with a C but I can never pronounce it.

But all those questions are not asked, so most of them have undiagnosed learning disabilities and they themselves don't even know that's what they have. On top of that, they also don't even know they're carrying so much trauma and they have PTSD, and it's not seen as… there hasn't been any support in place for even, for most of immigrant African families to be aware of what are the things they themselves are going through. Which we often… where the children who have been lucky enough.

We've been able to be educated and we've learned about mental illnesses and things like that, so because of that, we're able to be like, “Oh, okay.” So when auntie lashes out after a thing happens, we see stuff playing out. For example, my mom, when anything to do with abuse happens in the community, there is a way that she reacts, and it's a reaction before she even says it, and you know that, “Oh, it's a trigger.”

I now know that it's a trigger because I've been through the thing, but I did not know it was a trigger when I was growing up, I did not know it was a trigger up until five years or even last year, I didn't even know if it was a trigger. It is this year that I'm able to be like, “Aha, that's actually a trigger. This is what you're going through.”

“Oh, you are acting like this because of there is so many things that you're going through and you're suffering from, but you're not even able to see the suffering because there is nothing in place to tell you and to teach you that these are the things that you've been through.” Because of that, most of them just don't even know that they have disabilities. We have a couple of aunties who have children with Down syndrome, and one particular auntie who is also the one that was… she was unhoused. She was living with my mom for about two, three weeks.

For that auntie, she has children with down syndrome, autism, her other child has multiple forms of learning disabilities and cerebral palsy. For her, there is just so much that she is facing because it's not just… On top of dealing with the system, which is centrelink, healthcare, there is also family abuse that happens a lot that I don't think we often talk about it enough in the community, and most of them are also very financial, physical and also very psychological.

Often because also fear of the relationship that we have with police and the relationship that we have with the system in general, aunties don't feel safe about going and reporting it, so often the responsibilities of maintaining peace falls back on the elders in the community, who are all men. Often when the aunties come and they complain about the marginalization that they're facing within their own households, it leads to questions such as, “Oh, what have you done?”

And so the children who see that, who also… they have disabilities, they get to see their moms being beaten up. They get to see all this stuff that is happening, so the responsibility of caring for the children falls wholly on the mothers. That is one thing. And on top of that, there is also stigma from community because, “Oh, you have a child with down syndrome, we will pray for you. We will do dua’a for you. We will pray Allah *[speaking in arabic],* unburden you” because they are seen as burdens.

Aunties with children with disabilities don't feel safe going into community spaces because community spaces are also not safe for them. These children on one hand, the homes are not safe because of the abuse that is happening at home. On the other hand, the community is also not safe because when they go into community, they are othered in a way that it's very, very, very heartbreaking for the mothers to see.

When even they go into community without their children, they still are seen as, “Oh, you poor thing, how are you? We are praying for you, we are really praying for you,” because having those children are seen as a burden. And so there is all that and on top of that, aunties also having difficulties, not even accessing, having difficulties and even knowing what type of disability their children have.

It's only recently that one of them knew, “Oh, it's called down syndrome. Oh, it's called autism. Oh, it's a learning disability that is called dyslexia. Okay, so this is what they have.” It's often, especially for the ones that have cognitive disabilities, there is all this, “Oh, there's something wrong with their brain or there's something wrong with their head,” which is also automatically read as, “Oh, they're crazy. This child is crazy and there's something wrong with the child.”

They themselves also don't even know what form of disability their child has. The fault of this is mostly that of the GPs, because the GPs too, they don't even explain to the mothers, “Oh, these are the forms of disability that your child has. This is what caused it and because of this, this is how they are, and for you to be a supportive mother or for you to care for your child, these are the things that you can do, that you can fall back on in helping you care for the child. These are what they're called, this is where they're located and you can access them like this and like that.”

None of that happens, so when you ask questions like, “Well, what form of disabilities does your child have?” They're like, “Oh, I don't know, there's just something wrong with their head. I think that's what I was told.” They were probably told this when the child was born or like the rare times the child comes with disability, because of also incompetencies of the GPs and also because of again, them not being able to read, write, speak english to navigate the system and to know what are the things that are there for them.

It's hard for them to know what support is there for their children, so because of this, most of them don't even know what NDIS is. Most of them that have known very recently what NDIS is hate NDIS. The process has been so grilling and just so heartbreaking, and even when they get there, there is just so much anti-blackness, and afrophobia in the space even before applying for the NDIS in general.

Often, they themselves don't even want to go back to that place because they don't want to feel how they felt, because there's a lot of infantilizing, a lot of micro aggressions, a lot of just humiliation and disrespect that happens in those spaces, it also happens in centrelink], it happens at hospitals and it happens also at all other services that they try to access, so because of this they're like, “Oh, I don't want to go through what I went through there, so I'm not going to access it.”

That also leads to them not being able to do what's best for their child through whatever plans that is there for them to access, because they make it before they're even able to access it. The process is already so heartbreaking and you're already othered and you're already made… you're already made to feel so unworthy to be in that space, so because of that they don't even access it.

And most of them once they realize, “Oh, we need to access it because we can no longer… we can't afford this.” You can't keep on relying on the community's generosity to help fund and things like that, so they're like, “Okay, I'm going to get someone like Hamile, we're going to call up NDIS and you're going to know how to apply for this. The process is not clear. It's really not clear. They need to prove that their child has disabilities.

They need to prove that this down syndrome that they have or the autism that they have or the cognitive disabilities that the child has, it's permanent. I don't know how permanent is measured. It's not clear, and on top of that, after going through the process, going back and forth, simultaneously dealing with the anti-blackness and afrophobia, and the misogynoir in the space.

Often, they apply for the process, they apply for accessing NDIS. For most of them, I don't think they've still heard back anything from, most of them are still… they keep calling back every couple of weeks and what they hear about, “it's still being reviewed,” and when they ring back again they're like, “Oh, hold up,” and then the phone has been hanged. The rare times that it has been accepted, they often get letters again telling them that they need to reapply again.

Because I do most of the forms, I need to explain to them what it says. Even if I explain to them what the forms say or what is required of them, they get confused. The GPs being as useless as they are and as incompetent as most of them are, what happens is they haven't explained to the parents again, the disability of the child. When you're doing the forms, they also are learning about their children in the forms.

And so it's back and forth between centrelink, NDIS, GP and sometimes most of them need to go see a specialist, so you need to also book an appointment and because it's also most of them are public, they are on the waiting list. If you had, let's say a deadline because you're on the waiting list and you still haven't heard anything, you need to go back again and start… restart the process again, which is really, really heartbreaking.

And this is for people that can't speak, read and write the language. So you are explaining to them. It just makes them feel useless and most of them just… We are on a train and you will just see most of them just breaking down and crying and then just feeling this is, “If I knew how to read and write, I would have worked and my child wouldn't have needed to access this useless services and things like that.”

And they blame themselves for being incompetent parents and all that stuff. It's just, yes, it's intense, and this is also… For the children, I feel they suffer the most. And on top of that, often what happens is for some… for most of them, they have like carers, disability workers that come and this is to… it is supposed to relieve the carer, who are mostly like the aunties, doing the caring for a couple of hours or for the day so they can tend to other things or they can do chores and things like that and the child has someone that is caring for them.

There has been cases of abuse, not one, not two, not three, not seven, not 10. There has been so many cases of abuse. This does not include the fact that some of the children have been abused in shelters that are supposed to be safe for them and their families when they were unhoused or when they were homeless. Because often like the carers, there has been cases where a child has been “disciplined” by the carer and that is… and there has been marks, and this leads to, they already believed… how do I put this?

There's already this belief in the community that, especially for people… for families with children with disabilities, that nobody can care for that child except for them, because they cannot trust anybody else. And they have every right not to trust everybody else because over and over and over again, they have been proved they are right in not trusting anybody else.

When these carers “discipline” the child, because that's what they always say, they're like, “Oh, we were just… they were being… the child was being naughty or the child was,” …they don't even say naughty. They often say the child was being crazy. That's the word that they use. They always say, “Oh, the child was being crazy and I was trying to hold on and I got beaten or this has happened to me, and because of that… I was trying to just calm him down or calm her down and then this is how they end up getting the mark.”

And you're like, “Why were you calming them behind their thighs or on their buttocks? What calming down method or strategy is that? And most of the parents know their children and then they know their children that the only time their children… what's the proper language for this… Seen as difficult is when they have… when the person engaging with the child has done something to dishonor the child.

That has always been the case. It has always been the case where the child has been dishonored, the child… the carer or the person, whoever it is that is engaging their child has done something to trigger the child in a way that leads the child acting the way the child acts. But the responsibility automatically falls back on the child, and because also some of them, and in most cases, has been with those with… who are mute, and the parent knows their child, but when they explain this to whoever sent the carer, they often go, “No, you are lying, you're obviously,”… they gaslight them.

There's a lot of gas lighting that happens where they go, “No, you're not being rational or I don't think… you were not there, so how would you know?” Maybe sometimes we think we know our children but we don't really know our children, and the children… the child gets painted in a very particular picture or in a… and the onus gets placed on the child and the child bears the responsibility.

The issue doesn't become, “Oh, there is an abuse that took place.” It's seen as, “No, the carer was afraid for his or her life and the child is the one that was threatening and the carer just defended themselves.” It's not seen as abuse. There has been a lot of cases like that which has led to most of them, rightfully so, to feel not safe to leave their child with someone else that is not them or that they truly trust, and the child also knows.

And also this whole thing of, today the carer is a brown person, tomorrow the carer is a white person. The next day their carer, it's a black person. Every single time, changing carers with the children also has, for most of them, they're like “No, you're confusing my child. If it's one carer, let it be one carer so the child can get used to it, and they can earn the trust of the child.”

Often in most cases… actually in all cases, they see the babies as these monsters that needs to be managed and maintained, so it doesn't matter who they send, they don't see the child as a human being. They don't see the child as someone that has right to consent to whoever it is that is supposed to care for them and things like that. And there is all these assumptions that they already have about the babies.

Because of that, aunties are like, “No, we don't feel safe leaving our children with carers and strangers that we don't know, so we are going to care for our children and in times where it's necessary for us to be on a place without them, we're going to leave them with somebody that we trust.” Often in most cases, it happens to be someone like my mum, so they leave their child with my mum for some time, when my mom goes to the house and cares for them until the parent comes back.

The government and the department of human services, et cetera, they see this as, “Oh, you are telling us that you are fully capable of caring for your child? And also you're telling us that you're fully capable of not just caring for your child, but then also simultaneously being responsible for everything and also being responsible for, equipped with taking care of everything? You don't need our help? You have all this under control? Cool.”

They see this as “Oh, rejection of help.” They call it help, yes. They see it as a rejection of help, so often what that leads to is like, “Okay, so if you're telling us that you no longer require these services, then we're not going to give you these services,” which also leads to other services being cut from them because they see them refusing their child being accessed by strangers as them rebelling against the system.

Again, a lot of financial issues come up, again, a lot of things come up for them in terms of, “Oh, there is already this belief that my child is seen as and my children or my child is seen as a danger to society, and already my child is othered on fronts, on multiple fronts, fronts of being poor, fronts of being African or black, fronts of most especially, being a child with a form of disability or multiple forms of disability."

Because of this, they already just believe that, “Okay, no. Nobody cares about me and my child except for myself.” And they often, because of this, they're like, “Okay, I'm just going to say and seclude myself and just not interact with community because again, community is super ableist and also I'm not going to go outside, so I'm just going to protect my child and the best I know how to protect my child is to stay in this house, and this is what I'm going to do.”

And it looks like also them not getting care payment that most of them get taken off care payments and they're put back on newstart allowances or the family tax, I think from family tax benefit, that's the one that they get put back on. It's not enough, and once that happens is, especially for the ones that the kids that go to special school, this leads to a lot of things being cut off for them.

And one of those things is… I know like there's a school down at Dandenong where my niece goes, and they have art practices and things like that that they do, but there are things that… programs that you can access if you have… if your family receives a particular type of payment. So when that payment has been cut, that also affects the wellbeing of the child, not just in society and at home, but then also at school.

The child is othered on multiple fronts, so I often feel African children with disabilities or multiple forms of disability around the South Eastern part of the place, Melbourne, now, they suffer most, but it's just so layered and you don't even know where to begin.

*[outro music plays]*

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AYAN: Now, we'll hear of a very different experience of disability. Pauline Vetuna recently caught up with Faro Musodza at a community barbecue at Edinborough Park. In this impromptu interview, Faro discusses choosing self-management of the NDIS plan for her son with autism, culture and more.

FARO: My name is Faro Musodza. I'm Zimbabwean. I came to Australia in October 2006, and I have an 11 year old son who was born in September 2008, and I found out about his autism diagnosis when, let's see, after his second birthday. And how it came about was, I knew he couldn't hear me, so I thought he actually had a hearing issue, not so much autism. When we went to the specialists at Royal Children's Hospital, we went to the communications wing and they did their test.

FARO: And then after that they told me that, “Oh, your son is autistic.” But it hadn't really sunk in, because I still believed that he could still could not hear me, so I don't think I actually heard the diagnosis that he's autistic, I just believed that he cannot hear. It did turn out that his hearing is impaired. He's autistic, bilateral hearing impairment or senso-neural hearing loss, a lot of words. And after getting into school then I will say he's also got intellectual disability because of his learning processes, but that's where it's at the moment, yes.

PAULINE: And you were talking before about the fact that you're going to Zimbabwe.

FARO: Yes, right. Like I said, I'm Zimbabwean, there are traditional things that I do on my own and things that he's used to and unfortunately, the carers would be coming in, they wouldn't know how to do that. Some don't even know how to cook rice, so go figure. Going home because food is so central in our community, so going home is important and it's a wonderful experience because he gets to see… actually, he gets to be independent of me and I independent of him and I know he'll be okay because he's got people, one, who look like me, black like me and people will speak the same language that I speak to him with.

And he doesn't have to worry about being hungry because mummy's not going to be able to cook sadza for him or with the stew, or spinach and peanut butter, things like that. So it's wonderful because last year when I went, my mum literally took me out of the house and she took me to Victoria Falls, and I was not allowed to be on the phone or to find out if he's okay. She just said that, “No, we have to intervene because you're coddling him too much.” But it's that thing of me letting go of him.

Because children his age, they are letting go of their moms and they're going to play. But with him it's different. He's dependent on him and I'm dependent on him being dependent on me. I'm having to let go and just trust that he's becoming his own little adult, little boy or man, whichever. And yeah, just learning to let go and let him grow. Find out things and learn from other people, not so much mum… so it was beautiful when I go home, I'm looking forward to it.

PAULINE: You were talking about self-management and the NDIS.

FARO: Yes. Right. So initially we had early intervention, which is fussier funding, that ends when the child turns seven. And then after that you'd be reliant on donors and such. But after, I think some four years, that's when NDIS was being rolled out. So we're fortunate enough because it's just me and him. So I think it goes through certain tiers, like who are the people that urgently need it? So generally, yeah, it was quite taxing. It was quite taxing because it takes such a long time, you're having to chase up reports and things like that. Making sure that they're saying the right thing so that it can get the right amount of funding.

FARO: Because sometimes they might see him today, that's the thing with autism, they might see him today in he’s absolutely happy, beautiful and it's all wonderful, but then the next day totally different thing. It's like on the other end of the scale. So it's making sure that those things are accounted for and they're not just having a picture of him being happy all the time when that's actually not the case. So I think in that regard, that was great, and then the reason why I insisted on self-managing is whilst we were on the first year funding, I remember I requested for him to have an iPad to aid in his communication, because as I said, he has a hearing loss and is learning a bit of the Makaton type of sign language because it's very simple.

And yeah, the speech therapist, so many words, the speech therapists believed that he didn't need the iPad just yet because he was too young and it was unnecessary. But then the funding is for him, so it's them putting their personal or maybe personal professional opinions onto the situation. Whereas, when you're self-managing, I don't need that. If I feel that's what he needs, that's what he needs and I can just go out there and get it for him or get a quotation and get it done.

So I find that there's much more flexibility and even accountability on my part because I'm making sure that he's using those things to the maximum and it's not just something random for someone who's read in a book that, “Oh, autistic children need this when they're 12,” but yet I know he needs it now to familiarise himself first. And then you will have more range of use when he knows his way around the iPad. Yeah.

PAULINE: What does he like?

FARO: It's always a hard one because one day he likes this and he doesn't. He definitely loves food. And the reason why he loves Zimbabwean him food is because it involves using his hands when he's eating. So that's really good. Oh you should see him. You should watch him when he's eating. It's like, I don't know, he's eating this food that's out of this world. He's putting his hands into it and he's putting it in his mouth, and he's rubbing his lips. It is so cute. Like it's really…

Because he's… what is it? Like the sensory feedback of moulding, it's called sadza. It's a millet meal cooked until It's about stiff. Yeah, you know it. Yeah. So he's really working his hands on it like putty. So that's good for his hands and then he's eating it, and of course in his stomach, and it's just a wholesome feeling for him. So yeah, food is such a big thing. It's such a huge motivator. And he loves movement. So long drives, he enjoys that.

Like yesterday, I drove from home to Queenscliff, Geelong and then we got on the ferry, then we drove from Sorrento, stopped off in Rye. We went to the beach. There's like the back beach is… I think the waters are much wilder, I would say. They're not like the beautiful beaches in Mario. It's not soft like that. The waters are hard and they're rowing. He loves the sand. So that's a whole… that's a beautiful day for him because he's really happy when things are going well. He loves movement. And what else?

Did I say food just for emphasis? And of late, he's been enjoying navigating Netflix, especially with the touch screen. So you see the iPad touch screen, watching Shrek 2 is what he watches every night. So now thank god to NDIS and self-managing, I've managed to buy him even a portable DVD just in case Netflix is not working where we are or there's no electricity. I have a backup plan because with autism, if that doesn't work, I can't explain to him why it's not working. He wouldn't understand that. So I always have to have those things in place.

Yeah. I think for now that's about it. And collecting water bottles. I don't know how many water bottles I have in my house right now and I'm always having to throw them out. Yeah. It's just a thing, like he loves them. It makes him feel grounded when he's carrying things, so that's where it's from. It's always trying to ground himself. Yeah, yeah.

PAULINE: So you’re leaving soon to go?

FARO: Yeah, because we went last year and my mother's place, it's got, I think three toilets. He couldn't use any of them and it just felt unfamiliar for him. And he's someone who can independently use the bathroom and it's not the best feeling when you're wearing nappies and it's hot, and he just found a dish and decided to just use that as his bathroom. So in the end, we just use that. Although a lot of people are uncomfortable because majority of the time I'm not worried about him, but I'm worried about everyone else and how they perceive it, how they see it and their judgment of me as a parent, then also him having special needs and such.

So this time around I've done my homework, so I've managed to buy a toilet similar to the one we have home, which is under consumables. So hopefully, he'll use that. If he is not able to use that, I've got like a camping toilet so that I'm going to have to send separately. So with NDIS, it's great that I'm able to do things like that because I don't know if you understand dignity of risk, yeah. It's always trying to make sure that I am allowing him to be himself and have a dignified space the same way that I would want it, but making those little provisions for him.

And I also created a WhatsApp group where I have key people, like my parents, the two women who are going to be looking after him, and my partner and his sister, because I'm going to be visiting a lot of them. And just explaining to them what autism is, what are the things that he needs. And also explaining that the little discomfort that we might have personally, it's less than how he's going to feel and his experience. So it's so important for him to have a beautiful experience because he's going on a holiday, but I don't want it to become a thing where he associate that places being difficult and inaccessible.

So I think, yeah, having NDIS and self-managing has allowed me to do all that and having to have all those little things in place, it's been great. Yeah. So even getting waterproof bedding in case accidents. But yeah, I'm looking forward to this time around better than last year. It was a nightmare *[laughing].* Yeah.

PAULINE: I hope you have a blast time.

FARO: Oh I'm sure he's going to have fun because my partner, he's got a farm and we were there last year. He loved it. Just running later like we are here at the Edinborough Gardens. There's not much traffic compared to Harare. Harare, it's a lot of traffic. It's chaos. And he's used to a bus just going straight, not weaving through portholes or hooting here and driver just cutting through wherever. So I'm just trying to create a little itinerary for him where it's more predictable as well. So man, it's a lot of work, NDIS needs to start paying me too, this beyond mothering. I'm just kidding. Yes, we love you.

PAULINE: Thank you so much.

FARO: Thank you too. I'm excited. I hope this helps and inspires other black women out there and people of color because this is really good. Yeah.

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AYAN: Serious Meerkat joined Pauline Vetuna in the 3CR Studio to discuss her lived experience of trauma and non-Western modalities of healing.

MEERKAT: It's been a journey I'm realizing and I'm learning and I'm still going through it. I'm still uncovering new information and I'm still trying to navigate it. I found myself taking medication and at the time, I understand how when you're in crisis, it's something to help you get back to your baseline levels so you can deal with what's going on. And I don't deny the usefulness of that and I think we shouldn't be afraid to take that on and see how that's a negative thing. Because that was one of the things for me, I'm like I'm weak, I'm broken. There's something wrong with me if I'm going to need something external to help me get through this. And that's not a good relationship to have with anything really.

But I think in terms of medication, we have a complex relationship with it. And that comes with a lot of baggage and a lot of thoughts around what that means for you. Right? So if you're looking at it through a dichotomy of Western medicine, cultural medicine, and I put air quotes because that's already a vast discipline and that's shaped by so many things. If you look at it as like a binary, it can close you off to a lot of opportunities for healing and learning new knowledge. So for me, it was I had to get rid of that relationship that I had with medication and say, “Okay, I need to do this to help myself get through this. It's like an extra support. Right?”

But then as I'm taking this medication, I'm seeing a few things. One of which, for me, the side effects were worse than before I had it. And it was more, so say for example, the particular medication I was taking was called Pristiq. And if you look it up, it's been some very interesting results that came up in the clinical trials, and you look at the limited pool of people that they actually looked at. So I kept getting caught in this fight with my doctor because I would say, “Look, I'm feeling this, I'm taking this medication, I guess I'm a bit more stable, but there's these other things that are coming up.”

So say for example, one of the side effects is you feel like there's rocks in your head. So every time you can bend your head, it's like a swishing sound. So you're constantly trying to navigate your balance or if you miss a dose, sometimes by accident, which can happen, you get intense nausea and that suicidal ideation actually almost triples, like when they look at the stats. So you start to question and go, “Okay, so I'm on this medication, which is supposed to be helping me with certain things, but it seems to be exacerbating certain things.”

For me, the lesson in that was, that's when I had to learn to listen to my own body. Because the whole time I'd been functioning from a position of the doctor knows best, which is a very, I think, Western way of thinking about professionals and people with expertise. So I had to let go of that. At the time, I was also doing a type of therapy called CBT, which is Cognitive Behavioral Therapy. This is a massive distillation of it, but essentially, it looks at your thoughts and asks you to change them. And for me, I felt like I couldn't connect with it because I'm thinking I'm having these things come up and they're presenting in my body. These thoughts are presenting in my mind. I can't just switch them.

I felt like I had to understand why they were coming up because, for me, I think that was key. Because obviously, we all have a critical voice. We all have things that sometimes put us down or that we have difficulty facing or are challenged by. But I feel like if you just go, “Yep, change your thought. Switch a channel and you'll be fine.” For me, it didn't seem to capture the healing that I needed to do. And that was like almost, I'd say six years ago. And then I tried DBT, which is Dialectical Behavioral Therapy. That was massive in terms of transformation because it came from a place of understanding why you're having the thoughts that you are having and why you were feeling the feelings you were having.

And for me, that again, even emphasised that relationship that I had to have with myself and my body to trust myself and listen to myself. Because I think one thing that gets underplayed is how the body is so intelligent and it has its own memories, and everything we've experienced is embedded within ourselves. Right? The body remembers, which is one of the books that I've been reading to help with my healing. And so I was like, “Okay, now I've got a more holistic view,” and I think I've always had that. I didn't even realize, I was always interested in the bigger picture.

Because I'm like I'm not interested in just looking at the incident of this PTSD and how it's changed my life. I need to have context and all of that. So I think that was built into me already, I guess from my background, because I met… but it's not in an explicit way, I think. And that's why I started to see how cultural knowledge was really important in terms of healing because our ancestors didn't have words like DBT or depression. They didn't use those words as such and those specific terms as we know them. But they had mechanisms that always focused on keeping a person whole.

And I think that's something that maybe Western medicine overlooks, because you just treat the symptom of a problem. So medication to treat this particular symptom. And some people are on medication for all their lives and they don't feel as empowered. But I think it's more about the reason why you're doing something right and how it's actually helping you as a whole. So for me, I found if I can learn more and go out there, and tap into culture as part of my self-love and self-healing, that would help me understand more and know more, and help myself forgive myself more, and be more understanding of myself.

Because I think when you treat a symptom, it's almost like you're just looking at a robot that you expect to be working at full functionality all the time, and say, “Once you get the pills, you're back on.” But it's actually not like that, healing is like a zigzag journey. There's twists and turns and all of that. So the more I started yet to take on that self-advocacy role, I started to see the importance of culture as part of self-care and self-healing. And I think one of the biggest things also was learning about healers in the community and finding that healing is not just within the medical system. It's there, but it's also in other places too. So that's where I'm at right now. Trying to find the healers.

The colonial experience has disconnected Shona people from their culture quite a lot. So even look at how English is my first language and then you speak Shona at home. So even the educational system in Zimbabwe is set up that way. So it's hard to try and think of a specific thing, right? Like or a specific practice that we say we've employed for certain amount of years or that our family, or our heritage, or our lineage does. But I'll say it's inherent in every time we get together, we eat amazing food cooked by the wonderful matriarchs and sometimes the patriarchs as well. And I really appreciate that.

So everyone's involved in that process and we dance our asses off like crazy, and we sit around and we talk, we tell stories. There's this thing of, it's one of my favorite things about getting together with the family, it's like the elders talk and then us young people can ask questions and sometimes be a little bit controversial and like push the envelope, and watch their reactions. But this exchange of knowledge and interaction that we have with each other. And I see how some of that healing methodology may actually be present in that because, I mean, I always feel better after it.

But it's funny because when you're going through something like this, you don't always feel better. And I think that's an interesting dichotomy that when you're going through something like this, being in the West, communities viewed differently. But yeah, so there's like those things are inherent in the culture. But yeah, I'm very interested in kinesiology and that massage therapy style of healing because I think it's intimately connected. Absolutely.

Probably the biggest message for me coming out of this or the biggest learning coming out of this is learning to trust myself. And if we're coming off the back of the idea that the body remembers and you pass down this knowledge, then you could say you have your ancestral knowledge that lives within you and it's there. Like think of say for example crying, right? And how it's there's a negative connotation to crying. Women, if they cry, they're being too emotional. Men, if they cry, they being weak.

But if you think about it, that's the first language that you spoke and there's a reason for that. It's your body's way of communicating something, if anything. So if you can learn to work with that and not against it. Because I feel like if you're just looking at medication as a way to erase what you're feeling or therapy to get rid of what you're thinking and feeling, I think it's going to be a lot harder for you. Because if you can learn to speak the language of your body and what lies within it, I think that's been key for me. I don't always do it, but I'm learning.

*[outro music plays]*

AYAN: You've just listened to Africans with Disabilities in a one-hour special for 3CR's Disability Day podcast for 2019. I'm Ayan Shirwa, stay tuned for more Power from the Margins.