Purple Orange Podcast, Episode 4:

The burden of low expectations: Challenging disability stigma across cultures

**SPEAKERS**

Belle Owen (host), Carey Scheer (narrator), Esther Simbi (guest)

**Belle** 00:00

Hello, and welcome to the purple orange podcast where we shine a light on the stories of people with disability in our community. I'm your host, Belle Owen, and this is Episode Four in our series, this podcast was recorded on Kaurna land. More often than not, the stories that we hear about disability from people who have a similar experience to our own. So it's so important that we understand that disability as an identity intersects with other identities, including coming from a culturally and linguistically diverse background. In order for the disability rights movement to move forward, we have to listen to people who have experiences other than our own, so that we can understand the ways in which they experience oppression, exclusion, discrimination, and then work together to solve those problems, to change those barriers. In this episode, Esther Simbi shares her powerful journey with us of challenging disability stigma across cultures. Carey Scheer brings us the story.

**Carey Scheer** 01:05

After 19 years in a refugee camp, Esther and her mother sat down for their final interview for resettlement in Australia. Esther had a sister who was already living there.

**Esther Simbi** 01:18

When you get that immigration interview, it's like you win lottery. I was so happy. The thing is, you don't know if you will go through the interview or not.

**Carey Scheer** 01:30

Did you know Australia excluded refugees with disability from their resettlement programme until 2012. Only on rare exceptions was a refugee with disability accepted. Esther's immigration interview was 2005.

**Esther Simbi** 01:49

My mum was so worried about the disability. My sister had told her some things that we might not succeed because they have a disability. And I knew it was going to be a problem. They were even neighbours of mine in the refugee camp. There was a girl that had intellectual disability. They applied to come to Australia and straight up was a no.

**Carey Scheer** 02:17

it didn't surprise her. She was no stranger to being rejected for disability, first in her birth country of Sudan, and then Uganda, why would Australia be any different? And yet Esther still held hope.

**Esther Simbi** 02:31

The lady that interviewed as well as Australian, white Australian woman that came there to interview us. She said that I would be a great asset, regardless of my disability that I would contribute to the Australian society.

**Carey Scheer** 02:46

Esther found out she would be the lucky rare exception.

**Esther Simbi** 02:50

I was mums interpreter. So I looked at her mum and I said, mum, she said we are successful. And she's like, can you repeat that? I said, Yes, she said was successful. She actually went down on her knees said thank you. She got up and ran outside. We had tears, screaming. And I followed my mum, we were crying. People were told that we lost the interview, that's why we're crying. But we were happy. (phone rings)

**Carey Scheer** 03:23

You can answer if you need.

**Esther Simbi** 03:24

Hello?

**Carey Scheer** 03:25

As Esther was telling me the story, someone rang from university, asking if Esther's organization, Zion disability services, could offer work experience to students.

**Esther Simbi** 03:36

So you're asking about placement opportunity? Yeah, we do. Can you send me an email? All right. Thank you. Bye.

**Carey Scheer** 03:45

And so here's Esther, just as the immigration officer predicted, giving back to Australian society. But to get here, it took a whole lot of work to shrug off her own cultures low view of people with disability. How do you think disability is viewed in Australian culture?

**Esther Simbi** 04:05

In Australian culture? I think it's not perfect. People are struggling every single day because of people's attitudes, and inclusion is a big problem. Acceptance is a big problem. But in Australia is a little bit of acceptance. But in my culture, it's not like that you will be viewed as, like a taboo like something bad. When I was four and a bit years old, nearly five years old, when I contracted polio, and then I noticed that now I'm being treated differently. The same neighbours children that we used to play with and are laughing at me. And yeah, from that time on, I realised that I am different and being different is not accepted.

**Carey Scheer** 05:06

Motivated by fear, love and a desire to protect Esther's mum place the first burden of low expectations upon her.

**Esther Simbi** 05:15

She didn't want me to go to school because she knew I was going to be bullied. And when I'm at school because you will be at home, where will I go? Always when I'm crying, I come back to her. The second reason was that the school was very far. And she didn't think that I was going to be able to walk to school every single day. Third reason was that she didn't have money to pay for my school fees. And also the other thing was, there was no point educating someone with disability. They're going to end up on the street begging anyway. So the little money she had was to train the children that do not have a disability.

**Carey Scheer** 06:03

Esther desperately wanted to go to school. She spoke to her cousin who was only in the first grade and asked for her help.

**Esther Simbi** 06:10

So she said, Okay, let's plan to escape then. And she came very early. She hid behind a tree and then she waited and waited and she my mum went to the farm. And then she came slowly calling my name slowly. I said, yes, I'm ready, let's go.

**Carey Scheer** 06:30

They walked slowly to school taking breaks as often as Esther needed.

**Esther Simbi** 06:35

When we arrived, the year one students were already in class under a tree. So my cousin dragged me, come and sit next to me, so I sat next to her. She had a book and a pencil, but I had nothing. So I was writing on the dirt. So the teacher came and he checked, like one plus one. Oh, how many would they were? And he checked all my answers were correct. And he just did a big tick with his stick. And then he asked, who are you? What is your name?

**Carey Scheer** 07:09

And just like that, Esther was a student. Her cousin and her were thrilled with their success. But as they made their way home to face Esther's mother, their mood changed.

**Esther Simbi** 07:20

My cousin was alive. She's going to beat both of us. You go. You go and if there is a problem, let me know. So she walked with me closer to my house, and she went back to her house. And I, when my mum saw me, she was like, Where have you been all day? I said, I went to school. And she's like, so you were able to go to school? And you come back? I said, Yes. And I was so excited. I said, I got all my answers correct. And just like, okay, so you want to go back to school? I said, Yeah, I want to go back to school. And that was it. I continued going to school, there was no problem. She wasn't angry, she didn't give me any punishment, nothing.

**Carey Scheer** 08:06

Had you not gone to school at that age, what do you think the effect would have been?

**Esther Simbi** 08:11

I would not have gone to school at all. I would have not been where I am today. But education has opened so many doors for me. And all thanks to my cousin who helped me make that possible.

**Carey Scheer** 08:27

Education has been Esther’s just gateway to everything. But her mother wasn't wrong, in that she had a rough journey.

**Esther Simbi** 08:36

Disability, in my culture, and in most African cultures, is perceived as associated with something bad, evil. They believe that you're a curse, that your parents might have done something wrong in their previous life. And that's why they had a child or children with disability. And they believe that you're possessed by evil spirit.

**Carey Scheer** 09:04

Was there ever a time where you took that on board and believed that for yourself?

**Esther Simbi** 09:11

Yes, I did. I didn't believe that I was evil, but I believed that I would not make it in life because people were telling me nothing good will ever come out of me, people with disabilities should be sitting on the street and beg for food. When people constantly put ideas into your head, sooner or later you're going to make it your own and you will live like that thinking that’s you.

**Carey Scheer** 09:48

While Esther was battling disability stigma, another battle was unfolding. Sudan descended into civil war and her family fled.

**Esther Simbi** 09:58

I left Sudan when I was seven, and I spent 19 years in three different refugee camps in Uganda. My faith in God helped me get through that.

**Carey Scheer** 10:17

We aren't going to delve much into life in the refugee camp. But it was, of course hard. And if you're interested to know more, Esther writes about it in detail in her first book Beyond Calamity. What's important to share here is that Esther got to leave the refugee camp to go to school.

**Esther Simbi** 10:36

When I get out of the refugee camp to go to school, I can see light. When I go back to the refugee camp, there is no light.

**Carey Scheer** 10:44

She went on to finish primary school, high school, and then a Diploma of Social Work. All while living in the camp.

**Esther Simbi** 10:51

Studying social work also opened up my thinking. So I started challenging those beliefs that because I have a disability, I can't make it in life. I don't know something in me told me I was much more than being in that box that other people created for me.

**Carey Scheer** 11:14

It was with this newly formed self-acceptance and determination not to be limited by others any longer, that Esther made the journey to her new home in Australia. After nearly two decades as a refugee, she was finally free. But shortly after arriving, she realised she was not free from her culture's view of disability. After a joyful reunion, Esther says her eldest sister insisted that she share a bank account with her and their mother. Esther says this was because they thought she can't do it on our own.

**Esther Simbi** 11:52

And I said, Okay, so if we have a joint account, does that mean if I want anything, I can just withdraw money and buy whatever I want? She said no, that account will be managed by mum, mum will do everything. That was the moment I told my sister no.

**Carey Scheer** 12:14

This led to a fallout that lasted years. After Esther had her first daughter, they reunited.

**Esther Simbi** 12:21

I never held any grudge against my sister. Everything she did was from a place of love. Culturally, on her own side, it was the right thing she did. It was her own way of protecting me, like financially and all of that. But I want to be independent. I want to do things by myself. And so when I said no, she felt really hurt. I wouldn't say I did the wrong thing. I did the right thing for me, because if I didn't do that, I would not be as independent as I am today. I’m so grateful that we had that conflict and it's resolved. And now we can sit together and talk and tell each other secrets and all of that.

**Carey Scheer** 13:16

Do you think her view has changed on disability?

**Esther Simbi** 13:19

Yeah, I think so, yeah. Definitely I think so. Because I've done all these things and I think that has changed her own perception of disability.

**Carey Scheer** 13:28

So after standing up for herself, Esther thought she won't stand for others limiting beliefs any longer. But turns out that she still had a few of her own to contend with. She was studying a Bachelor of Social Work. She kept missing classes because it took her so long to walk from one class to the next. When she complained to the uni, they organised a wheelchair for her. And it was incredible. She hadn't used one before. She was never late again. But she wasn't ready to embrace the wheelchair.

**Esther Simbi** 14:02

I was kind of hiding it. Most of the time, I didn't want to go because of that stigma and shame. I was okay, using the wheelchair at the university. And then when I go to my community, I struggle to walk. For me if I was to go in the community back then, in my wheelchair, it was kind of confirming that I have a disability, I can't do anything.

**Carey Scheer** 14:31

The irony of this was that without the wheelchair, she was limited. But with it, the world was open.

**Esther Simbi** 14:38

I have to learn to know that my wheelchair is one of my strengths. And it's actually nothing to be ashamed of. And I'm happy now. It's part of me. That was one reason why I started Zion Disability Services Incorporated, because I became aware so many People are living with a disability in culturally and linguistically diverse communities. They don't want to apply for disability support pension, they don't want to apply to the NDIS. Because of that stigma and shame they don't want to be seen differently.

**Carey Scheer** 15:18

And so with Zion Disability Services, Esther aims to help individuals seek the support they need to live a good life, but also to educate migrant communities about disability.

**Esther Simbi** 15:29

I'm not saying people should abandon their cultures, but those practices, those cultural practices that are not fair things like this stigma, and shame. So I want to use my own experience that look, here I am, I live with disability. There's actually nothing wrong. I live with disability I went to the university, I graduated with two degrees, a bachelor degree a master degree. And here I am doing these things in the community contributing to the community, giving back. People look at the disability as a weakness. It's not, it’s strength.

**Belle Owen** 16:11

You can learn more about Esther's organization, Zion disability services, by visiting www.ziondisabilityservices.org.au. We want to hear more stories from people who might not often get to share their perspective. If you have a story you would like to share, or you have feedback on this episode, be in touch. You can reach us on Facebook, by emailing us at stories@purpleorange.org.au Or by calling 0883738388. Visit our website at purpleorange.org.au. Join us next time for the Purple Orange podcast where we meet Lauren Spear who has rebuilt her identity after acquiring a brain injury. I'm Belle Owen and thanks for listening.