Episode 2 Internalised Ableism

**SUMMARY KEYWORDS**

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**SPEAKERS**

Belle Owen (host), Carey Scheer (narrator), Lily Durkin (guest)

**Belle Owen** 00:01

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 I'm thrilled to be bringing you the second episode in our series, which delves into the concept of internalised ableism. Ableism is something that is everywhere. When something is in the air that we breathe, of course, it's inside of us, I have to work every day against society's external views and understanding of my value and challenge that all of the time. So even though I would consider myself a proud disabled woman internalised ableism is something that I still challenge in my daily life. In this episode, we hear Lily Durkin’s story of internalised ableism, which she shares with Carey Scheer.

**Lily Durkin** 00:52

So internalised ableism means to me, taking on the negative thoughts and the barriers surrounding disability and putting that onto oneself, to just benefit the masses to just benefit society, which is so the opposite of what we should be doing. But it's such a battle for me, and for, I'm sure, other people with disabilities.

**Carey Scheer** 01:15

That's Lily Durkin, the first time she remembers experiencing internalised ableism, she was only in the second grade, though it'd be many years before she knew what that phrase meant. She was on a school camp, and everyone was heading out for a walk. But for some reason, she didn't have her wheelchair, and she couldn't go on the walk without it. She looked around at her classmates and her teachers, and she realised none of them were aware of her situation.

**Lily Durkin** 01:47

So I then started getting, like, internally, I remember that feeling of like, oh, but you know, if they have to go and get my wheelchair for me, then my friends aren't going to be able to go straight away. And I don't want to create this awkward situation for people, maybe I'll just stay behind, maybe I'll just say I don't want to, maybe I'll just say I'm sick, I don't feel well, and I don't want to go for the walk, I'll just miss out. That's fine. I think for me, that was probably the first time that I experienced what I obviously now know as internalised ableism but at the time, I was just this little person just trying to navigate the world and not upset anyone and, honestly probably try to shrink myself down a little bit so that I would fit.

**Carey Scheer** 02:31

Here's another example. She was about to start year 12.

**Lily Durkin** 02:35

In year 12, we were meant to have this really cool space where us year twelves could hang out at lunchtime, and all of that kind of thing. And it always used to be up in this building that didn't have a lift, nothing, was completely inaccessible. Until I came along. There hadn't been a disabled person who had gotten to year 12.

**Carey Scheer** 02:56

Just like a repeat of that camp and second grade, none of her classmates or teachers were aware of her situation.

**Lily Durkin** 03:04

Oh, it was so terrifying. Of the fear of missing out. And so, my mom helped me to advocate because at that point, I still need support, you know, every disabled person needs support, but she supported me to say hey, like, just FYI, I'm going to be in year 12 in a few weeks. If that's going to be where the twelves hang out, I'm literally not gonna be able to hang out with my friends for an entire year.

**Carey Scheer** 03:33

Once she brought it to their attention, the school actioned it immediately. But that's when internalised ableism kicked in.

**Lily Durkin** 03:41

They just said a blanket like we're moving at, this is where it's gonna be. And there was no mention of me. So then, this whole influx came of all my peers in my year level going, why did they move it? You know, it was so much better up there. You know, I hate that they've moved it. And so, for weeks, I was just sitting in class just like, pit in my stomach just so upset that I had caused this fuss. That I had made this change and that everyone hated it. And clearly, you know, why did I do that? You know, it was all, it was fine. I would have made it work. I would have just dealt with it. And yeah, that was a really difficult experience that kind of the feeling that I’d advocated for myself for once, but it'd caused an issue for my peers.

**Carey Scheer** 04:34

Moments like this are peppered throughout Lily's life, but there was one particular area where internalised ableism really stung.

**Lily Durkin** 04:43

I was one of those young teenagers that would always think I just, when I grow up I want to be a mum and have babies and everything, but then, I'd kind of stop myself. Every time I tried to think about, you know, daydream about having babies, because I'd always have that, that jump of thinking No. Why? Why think about that, because it's not happening.

**Carey Scheer** 05:10

And the reason she didn't see it happening for herself was that she didn't see any parents with disability.

**Lily Durkin** 05:18

If you don't see it, you don't think that it's possible. I would look up mum with a disability, you know, I tried to do my own research on Google, because I didn't see anything. And if there was even just an article that had a picture of a mum, you know, she was sitting in a wheelchair, and she had her son on her lap or something like that. There'd be comments being like, that's gonna be really hard life for that kid, he's gonna have to care for his mom, you know, that's so bad to put that on a child. Me being 12 or 13 at that point, I'd read that, and I'd be like, oh no, maybe I shouldn't put that on my child. Because clearly, if people are saying, it's so horrible, why should I have a baby? Why should I do it? And also, then, because my whole life had just been this medical model of, you know, protecting my body and making sure nothing ever happens to it. And doing all these surgeries to make it better and better and better. So I was always so concerned and so worried to talk to a doctor and be like, “Hey, do you think I could carry a baby?” Because I was just so scared that they'd be like “No, why would you even think about affecting your body like that?” And it's like, because I want a baby, because I want to be a mum and have a child.

**Lily Durkin** 06:42

I was not able to talk about disability and motherhood and having a baby until I got pregnant. Until it was a thing. *(baby crying)*

You’re not going to sleep, are you? Alright, come here.

**Carey Scheer** 06:59

That little baby you're hearing is Elsie, that's her second child. She also has a child Jack who is about to start kindergarten.

**Lily Durkin** 07:08

He was a complete surprise, then. As soon as I saw those two lines, all that maternal instinct and hope and love and wish to be a mum just took over, it just like broke free. I didn't even think about the fact that I was 20, so young and having a baby. I was just like, it's actually happened. No one can point me in a different direction now. That's genuinely all I felt. I did not feel any kind of fear.

**Carey Scheer** 07:39

Lily and her partner were super excited to become parents. Pregnancy was a happy time. And yet, internalised ableism still followed Lily there.

**Lily Durkin** 07:53

You can see my physical differences from the get-go. So, when I had a pregnant belly, the second time round I was a bit like yep, this is me, this is what it is. But when I was pregnant with Jack, although I was so connected to him and I was so in awe of us and what I was doing, at that point I was so internally ableistic that I didn't want to take pictures and share it because I didn't want to make people uncomfortable about the body that they were looking at. And that I looked different to the average pregnant body. With Elsie’s pregnancy, completely different, I shared it all. And people would message me and be like, it's really amazing to see pregnancy on a disabled body. You know, that's so cool when and I didn't think that would be the reaction when I was pregnant with Jack, so I didn’t do pictures. Looking back, that's so sad.

**Carey Scheer** 08:52

While the feelings of internalised ableism were heightened during pregnancy, it was nothing compared to the storm that would hit when Jack was born. All those years of reading negative comments about parents with disability, it was always going to have an effect.

**Lily Durkin** 09:11

I felt like I had something lacking for Jack that I needed to then overcompensate and be this incredible mum and have everything together the house always clean, zero ounce of any kind of struggle in order to prove that I could still be a good mum, even if I had a disability. I was burning out. I just ended up just keeping Jack and I at home, just in our own little bubble, so that people didn't judge us or judge me.

**Carey Scheer** 09:43

Lily was stuck in this dark cloud at home for three months when she finally forced herself out the door to meet her mother's group.

**Lily Durkin** 09:53

I don't know if it was just a longing to belong or just an intrinsic thought and knowledge that if I kept myself in this cloudy space that I wouldn't be able to get out without help. So I was just like, no, I need to get us to this place.

**Carey Scheer** 10:12

And the cloud started to lift.

**Lily Durkin** 10:15

I think it was the help of my mum's group to be honest. Of those experiences of sharing motherhood, and the struggles that they had too that I didn't even think that they could have. It really helped me open up and say, Hey, okay, you're experiencing this too. Okay, it's not just because I'm disabled. It's just because I'm a mum, and it's tough and sometimes motherhood’s really hard. So yeah, I think that's when slowly, it wasn't like a whisk away of the cloud, I think it was a slow drift away for me.

**Carey Scheer** 10:48

So currently, Lily is doing great. She loves being a mum. She's got deep friendships, and a loving relationship. But still, her journey with internalised ableism is far from over. She had a recent attack, in fact, it was when she went to Jack's future kindergarten,

**Lily Durkin** 11:07

We couldn't get in, because there was a gate, and it was too high for me to reach. So straight away, I was hit like I was back when he was a newborn. Hit head on with this intense feeling of internalised ableism, this fear. My heart was going a million miles per hour, I was so nervous, I was embarrassed. Like, does that then mean that I'm never gonna be able to take my son to kindy by myself? So then I had to text the director and be like, hello, I'm here, but I can't get in. She got to the door, she obviously noticed that I was short stature. She was like, Oh, I'm really sorry. Like, we will figure that out. You and me together, don't stress, we will figure that out. That's something, actually, that I'm still having to navigate. I think it's in my court to follow up, which is not ideal.

**Carey Scheer** 12:05

Lily says it's exhausting forever trying to shape society to fit you when it isn't designed for you. But to hit pause and take a break, it's just not an option she's willing to take because that's when internalised ableism will catch her.

**Lily Durkin** 12:23

I know it probably sounds kind of small to other people, because it's a gate, but I think this is something that I need to do for me. Because otherwise I think I might maybe go a step backwards and start fitting myself around the world again, instead of the other way around. So we'll see.

**Carey Scheer** 12:43

I think your child might be telling us that the interview is over.

**Lily Durkin** 12:54

I think so. Yeah? Tell me more.

**Belle Owen** 13:01

“I'll just miss out, that’s fine.” Those words resonated so strongly with me when I listened to Lily's story, because it's something that I have thought hundreds of times in my life as a disabled woman. You think that inconveniencing yourself more to inconvenience others less is the path of less friction. And so therefore the better option to take. And this is just one of the forms that internalised ableism can take.

When we're fine with missing out, it might be something as small as a family dinner, or a trip to the park, or something as huge and life changing as parenthood or a promotion or visible place in society. Challenging internalised ableism means we need to stop being fine with just missing out. It's not fine.

Join us next time for the Purple Orange podcast where we will dive deeper into the world of parenting with disability by chatting to parents, Mikaela Crotty and Mike Taggert will also hear the unique perspective from their kids on what it's like to be raised by a parent with disability. If you have a story you'd like to share or feedback on the podcast, please get in touch. You can reach us on Facebook, email us at stories at purple orange.org au, or call 088373838, or visit our website at purple orange.org.au. I’m Belle Owen, thanks for listening