TRANSCRIPT – The Purple Orange Podcast: Language Matters

00:00 **Carey Scheer**

The Purple Orange Podcast: Language Matters

00:06 **Belle Owen**

Welcome to the Purple Orange Podcast. I'm Belle Owen, and today I'm here with my colleague and friend,Dr. Ellen Fraser-Barbour to talk about language.

Ellen participated in our Language Matters video a couple of years ago, but language is changing and so is the language that we're using.

Ellen, why is language so important to you?

00:25 **Dr Ellen Fraser-Barbour**

Well, language for me is really important because it’s a way of being able to communicate about who I am, how I identify in the world and what I need in orderto be part of this world as well.So, super important to me.

What about you, Belle?

00:43 **Belle Owen**

You know, the language that we use influences our attitudes, our understanding, our ideas.It influences other people, and it's free.It's a- it's an easy change that people can make to show that they're considered, respectful, and quite often in the disability space, when you ask people to make changes, their first thought is like, “Oh it's going to be so expensive.” But, language is free.

01:07 **Dr Ellen Fraser-Barbour**

Definitely, yeah.

01:10 **Belle Owen**

So, Ellen, have you always used the same language to talk about or describe your own disability or disability in general?

01:16 **Dr Ellen Fraser-Barbour**

Definitely not. I grew up in a very medicalised framing of who I was, and I have grown up surrounded by doctors and medical specialists and teachers who were specialised in disability as well. And so they used a lot of very deficit based kinds of labels like hearing impaired, vision impaired, craniofacial abnormality.

A lot of like learning assessments and things like that, that are very like heavily weighted toward analysis of all of the things that you don't do very well. So I grew up with that kind of framing, and it wasn't until I was in my early 20s and I was doing my own university degree and I was being exposed more to the idea that disability is a social experience. It’s not necessarily just a medical problem to be erased and eradicated. It's actually more of a social experience. And so that really helped me change the way that I think about how I communicate my disability.

So I now have a much more like nuanced way of being able to talk about my own disability, and I don't even really talk about body parts anymore. I just say I’m a person with a disability. Or I'm disabled. What about you? What’s your language been like?

02:49 **Belle Owen**

It's actually funnybecause mine has changedreally drasticallyin kind of the same way. But my experience was really different. So even though I didsort of have some, you know, more hospital appointments than probably your regular child, you know, and I knew I had this diagnosis of pseudoachondroplasia, but I came from a familyand from a broader circle where we didn't actually talk about disability.

I went to a mainstream school. I never was in conversations about going to, you know, segregated schools. And so, I didn't think about the word disability. I knew I was different. I started using my wheelchair when I was ten, but I still wouldn't have considered myself disabled.

03:35 **Dr Ellen Fraser-Barbour**

Wow.

03:36 **Belle Owen**

Yeah, and then, you know, in my twenties, I started to think about disability and start rethinking, you know, I would still consider the disability community and not consider myself part of it. And I started to think about what I was missing out on by not actually claiming that identity, that I was missing out on kinship or understanding and community and so many things and, you know, looking into the social model of disability started to really change my ideas in making disabled friends. And yeah, and so I didn't have medicalised things for myself, I just kind of had no words for myself until I started to identify as a disabled person or person with disability.

04:26 **Dr Ellen Fraser-Barbour:** But, you just reminded me that when I was young as well, if anyone had said to me, “Do you have a disability?” I would have said, “No, I don't have a disability,” because I was so against that medical framing and that really negative stuff that I was hearing, and was surrounded by. It was- it didn't sit well with me. I was really uncomfortable about it. And because that was my only framing, like I was always really against it. I would just say, “No. I'm not disabled.” “Don’t tell me I’m disabled.” “I’m not disabled. I’m not like those people.”

You know, I’d just be so against it. So, I'm not sure if that is similar, or if that is what you were saying before around how you didn't have any words, like you didn't have any words to describe it, as part of the disability community?

05:19 **Belle Owen**

Yes.

05:20 **Dr Ellen Fraser-Barbour**

Was it a denial or was itsomething else?

05:22 **Belle Owen**

In my childhood, I was embedded in this culture of well-intentioned, yet, I guess, uneducated people. And I mean that with a lot of respect. But, you know, my family, all the people around me, what they knew of disability is only from the messaging that they had received, which was that deficit model that you talk about.

So, you know, I was celebrated for, “Oh we don't even notice, you know, your chair” “We don’t, you know, you fit in with all the other kids.” “You don't make your disability everyone else's problem.”

You know, I mean, that's paraphrased, that’s between the lines. No one actually said that to me, but, you know, so then you because you feel celebrated for ignoring your disability, you don't want to give language to it. Even when I think about when I got my wheelchair, we would just refer to it as “my chair.” We never called it a wheelchair because I guess that was this medicalised model of it. And so, yeah, it just it took a big shift in my twenties of actually doing my own learning and re-examining what I thought, and the connections made with words around disability to actually start changing the way that I identified.

06:28 **Dr Ellen Fraser-Barbour**

I really relate strongly to what you just said. Definitely.

06:32 **Belle Owen**

Thank you. So you took part in our Language Matters video a couple of years ago. Let's have a listen to that, and then we can chat about it after.

06:40 **Dr Ellen Fraser-Barbour**

Sounds good.

* 06: 42 **Language Matters Video Starts**

06:45 **Carey Scheer**

Language Matters

06:47 **Tim Cahalan**

l think language shapes the way society views people with disabilities.

06:53 **Dr Ellen Fraser-Barbour**

Language can be used in a way that’s harmful, that communicates that we are lesser, and a person with a disability is a burden.

07:06 **Jae-Marie Jaensch**

I wonder how much journalism students are taught about how to talk about people with disabilities. I think there's still very much an angle of pity, and an angle of this will get readers.

07:20 **Esther Simbi**

“Wheelchair bound,” I hear that a lot in the media. It becomes a story about the wheelchair. It’s not about the person.

07:28 **Trevor Harrison**

I'm not bound to the wheelchair. My wheelchair is actually an enabler to my life. So yeah, I use a wheelchair.

07:40 **Tim Cahalan**

When they throw the word “suffering” in, it tends to bother me. Yeah, cause that does definitely tend to mean they should be pitied.

07:51 **Trevor Harrison**

I have cerebral palsy. I don’t suffer from cerebral palsy. There's nothing about cerebral palsy that I suffer from.

08:03 **Tim Cahalan**

It's usually just I find people talking to me in a patronising way, as if I'm a child.

08:13 **Esther Simbi**

When people are trying to replace the word disability with other words like “special”, to me personally, I wouldn't do that.

08:23 **Trevor Harrison**

Going away for a significant trip, that’s special. An anniversary, whatever.

08:31 **Dr Ellen Fraser-Barbour**

If you don't say the word disability, then some people will take that to mean that it’s a shameful word.

08:39 **Esther Simbi**

Disability is not inability.

08:46 **Jae-Marie Jaensch**

The words for me that are the hardest to deal with are the words that, like, “you're so inspirational.”

08:55 **Dr Ellen Fraser-Barbour**

The assumption is that you can't do anything in this world, so when you do that ordinary thing, somehow you’re defying the odds.

09:04 **Jae-Marie Jaensch**

I get it a lot when I'm like, “Oh yes, I go to uni,” or “graduated uni” and people like, “Ah such an inspiration.” Okay, but so many of us do that every day.

09:14 **Dr Ellen Fraser-Barbour**

One person came up to me and said, “A lot of girls, they may have all beauty, but they don't have it up here. Whereas you’ve got it up here.” She was intending it to be a compliment, but it wasn't a compliment at all.

09:29 **Jae-Marie Jaensch**

I've been told a few times, “It's a real shame you're in a wheelchair. If you weren’t you'd be so pretty.” Like those two things are not mutually exclusive. But now I know that you think they are.

09:39 **Dr Ellen Fraser-Barbour**

When you hear those messages repeatedly from the media, from people in the street, from your own family sometimes, it can really start to corrode your sense of worth.

09:56 **Carey Scheer**

So, what words should we use?

10:01 **Jae-Marie Jaensch**

I think when we talk about the incorrect language or the language we don't want, instead of being scared of that, I think able-bodied people and disabled people should be happy that we're finally getting a voice to say, this is what language we want.

10:20 **Dr Ellen Fraser-Barbour**

So, person-first language is the idea that you are a person before you are a person with a disability. So instead of saying “wheelchair bound” or “disabled person”, you would say, I am a person with a disability.

You also have identity first language, which is where your identity is something that you can claim, so I am disabled.

10:52 **Trevor Harrison**

I prefer to use the language of person-first, whether that be physical disability, intellectual disability, whatever, they’re people first. And I think that's the foremost that we've got to remember out of all this, is that we're talking about people.

11:18 **Jae-Marie Jaensch**

I use identity-first because I think disabled as a descriptor is only a negative descriptor if we give it negative connotations. It has negative connotations because society says being disabled is bad. Disabled isn't- The word isn't inherently bad. It's just a descriptor.

So, I don't say I'm a person who's a woman. I say I'm a woman because my personhood is already implied, whereas somehow then I'm saying disability, now my personhood is not implied. To me, that's more of a societal issue rather than the word.

12:04 **Dr Ellen Fraser-Barbour:** If you ask someone how they would like to describe themselves and you use whatever word that person has used, then there's nothing to worry about.

Create a little bit of a rule with yourself, which is that my job is to listen, and I’ll ask questions with good intention, without any assumption, and it's okay if I make a mistake.

12:34 **Esther Simbi** So if you make a mistake, don't shy away. Don't run away. There's no human being who is perfect. We all make mistakes. So, it's okay to make a mistake. If you make a mistake, you can learn from that.

12:48 **Carey Scheer**

Be a better ally, starting with language.

* 12:54 **Language Matters Video Ends**

12:54 **Belle Owen**

Ellen, how do you feel listening back to that? When you reflect on when you participated in Language Matters, has anything changed for you in the last few years?

13:06 **Dr Ellen Fraser-Barbour**

Not for me personally, because I remember in that video, I talked about language being interchangeable between identity-first and person-first language. And I know for me, that was something that I was already taking up. That idea that you can use it flexibly. There’s definitely people within the video who talk about different ways of describing themselves and that’s still the case. Like, in the community, we still have people that will prefer one term over the other term. That hasn't changed. So, for me, that’s still the same.

13:43 **Belle Owen**

For me,since that video,the only thing that has really changedis that I feel more averse to peopletelling other people what language to use.I feel much stronger about ushaving interchangeable language, about us allowing people the space and the time to choose language that they want for themselves, whether they identify as having a disability or not.

I think that we spent too long you know having our language policed and having- You know, being told why we need to choose one over the other. So, I feel really strongly and our recent survey that we did actually reflected that.

So, when we asked the community last year as an organisation, “Hey, what language do you use, what language would you like to use?” The community really came back and said, “Yeah, people should be able to choose how they identify and choose the language that they use.”

14:39 **Dr Ellen Fraser-Barbour**

Yeah, I agree. It's really important that people get to choose how they want to communicate about what their needs are and who they are. It really shouldn't be up to someone else to choose for them. It should be that person’s choice.

14:54 **Belle Owen**

I think maybe one thing that we're seeing in recent times is the death of the euphemism. It's a slow death. It's not happening probably as fast as I would like. But I think whether people use identity-first language, or person-first language, I think people are starting to realise the power in saying the word “disabled” or “disability.”

15:17 **Dr Ellen Fraser-Barbour**

Hugely.

15:17 **Belle Owen**

And, you know, we're seeing that these euphemisms that kind of came in place to protect people or to other them from this negative word, we're seeing the implication of the word disability change, and so we don't need those euphemisms anymore.

15:32 **Dr Ellen Fraser-Barbour**

Yeah. You're thinking of words like “differently abled” or “ability” type words, right?

15:41 **Belle Owen**

Yes. Yeah, anything that people use to avoid saying “disability.” “Special needs”. Yeah.

15:48 **Dr Ellen Fraser-Barbour**

Yeah, I think language is also about a sense pride and being able to be part of our community. And I know for me, I may not always have pride in myself, but I am proud of our community as an identity, and I hope that children with disability will grow up in a world where they're not afraid of disability.

16:13 **Belle Owen**

Thank you so much, Ellen. I think we should have this conversation again in another few years and see what has changed.

16:18 **Dr Ellen Fraser-Barbour**

There’ll be an ever-changing way of language, I think.

16:24 **Belle Owen**

You've been listening to the Purple Orange podcast. I'm the host Belle Owen, joined today by Dr. Ellen Fraser-Barbour.

16:35 CREDITS

**Carey Scheer**

We’d like to thank the Language Matters participants:

Tim Cahalan

Ellen Fraser-Barbour

Trevor Harrison

Esther Simbi

Jae-Marie Jaensch

This video podcast was hosted by Belle Owen, with guest, Dr. Ellen Fraser-Barbour. Filmed, edited and directed by Carey Scheer.

Music by Blue Dot Sessions

The original Language Matters video was supported by Government of South Australia, Department of Human Services.

We would love to hear your feedback, and ideas for future topics for The Purple Orange Podcast.

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