Serenity Isaiah

Profile:

Serenity is a playwright, motherhood practitioner, carer and social activist with a penchant for baking.

She was diagnosed with CPTSD in 2012. She also is AuDHD and, as such, is an advocate for neuro-inclusive practices and trauma-informed approaches within institutions. She believe in the importance of forging our own networks outside of the scope of what is considered normative so that we receive validation, support and reflective community, which equally pushes the social and cultural elements of change.

She has come to see disability in a different way; it is neither a matter of sickness nor of superpower, as some will have us believe in relation to ADHD. It is complex and nuanced in that it is human.

Transcript:

[00:00:00] So I'm Serenity and I am autistic ADHD also have CPTSD. So I guess from a lived experience perspective as many autistic women around my age would probably say is the same experience or similar experience in that as a child I didn't know that I was neurodivergent. And then, you know, well into adulthood then recognising these traits in myself.

[00:00:28] Predominantly through my son, actually, because my son has his diagnosis, and it was through that that there was kind of this journey of self-discovery and realising, oh, I might also be neurodivergent. So yeah, I do feel like we're now, thankfully, in an era where there's a lot more self-awareness around these things.

(Voiceover) Why is it important to have diverse inputs in research?

[00:00:58] Well, the first thing that comes to my mind is adequate representation. I feel like from, from a disability standpoint anyway, there's not a lot of visibility. You know, just, just by the nature of how disability operates is that we're very often not included or hidden, you know, from the scope of everything in society really.

[00:01:19] So when it comes to research in particular, it's so important that we have an accurate portrayal of what disability is because it's so vast reaching and yeah, that there's visibility.

(Voiceover) Have you been involved in contributing to co design or as a research participant?

[00:01:42] Yes not to do with disability specifically, but actually to do with local authority, co-production stuff and consultancy work around lived experience and trauma informed practices.

[00:01:51] So I have done these, these kind of things.

(Voiceover) What advice would you recommend to early career researchers to create inclusive settings when co creating or conducting research?

[00:02:06] I would say inclusive settings is again very wide reaching because everyone's disability is unique to themselves and their own experiences.

[00:02:12] I think the biggest piece of advice I would give is to be open minded. Because. Very often our portrayal of disability, even as a disabled person ourselves, is very narrowed. Just because again, there's a lack of visibility. There's a lack of you know, talk about these things. So just understanding that we likely wouldn't have picked up on everything.

[00:02:38] And just to ask questions, I think, around what's needed and just be open and emphatic, really.

(Voiceover) In terms of your lived experience, what have you seen done well? What has worked well for you in the past?

[00:02:51] Honestly, just people being open minded because I don't think anyone can get everything right from the get go ever.

[00:02:57] There's always grey areas and the best people that I've worked with are people that are more flexible and open to making adjustments and changes where they're needed. Because there does tend to be quite a rigid, you know, tick box culture with a lot of things of, you know, this is the way it's done.

[00:03:20] And actually a lot of these changes, they're not huge changes that need to be made. They're not huge adjustments that need to be made. So. Yeah, I found the best people to work with are just people that are open.

(Voiceover) Can you share any common mistakes that researchers should avoid?

[00:03:41] I think making assumptions, you know, with regards to, just to give an example, with access. So there's an assumption that access is a narrowed scope of physical disability, for example, of things that we see, things that are tangible, whereas there's so much more to access than that because there are people that also have mental health issues. You know, or for autistic people, as an example, we have issues with information processing.

[00:04:06] And one of the biggest ones is filling out forms. That's one of the biggest issues actually. So yeah, again, like just don't make assumptions and just ask questions and be flexible.

(Voiceover) Is there anything else researchers should be mindful of when working with the disabled community?

[00:04:34] Yeah, again, just an example perhaps give more time for them to answer you or to provide feedback. Some of us have delayed processing, for example, some of us might say no when they mean yes or yes when they mean no. So I guess like that leads to the realm of consent and things like this and boundaries in the not everybody will present in a uniform way when it comes to that. And just allowing more time, more time to process.

[00:04:57] And yeah, just giving a little bit of space, I think is really important.

(Voiceover) Do you have any final tips or recommendations you would like to share?

[00:05:29] Not particularly, just, just that this is such a good project that you're doing, and to keep going and keep bringing representation and visibility really. Yeah.