



Selvie Hayward

Profile:

Selvie is a cochlear implant and hearing aid user. She has been hard of hearing since birth and when she received an implant later on, it helped her to hear more sounds.

She currently works as a TEFL English teacher, and previously worked in a market research company.

While she has lived experience of her disability, she also chose to undertake a Disability Studies masters, which helped her gain a more in depth understanding of different inclusive research methods and the barriers disabled people can face.

Transcript:

[00:00:00] Hi, I'm Selvie and I've been deaf since birth. So I've had hearing aids my whole life. And then in 2011, I got my cochlear implant on my left side. And that was mainly because I noticed a lisp in my voice. And we and obviously went for hearing tests. And I kind of gone from severe to profound again. I had the option of having two implants, but it was quite new technology at the time.

[00:00:22] And I have what's called a hybrid. Um, so I would just do one implant, I was still too young, I had to ask mum for advice, but I, I don't regret having one. And that's been a really great experience for me, so ever since then I've had the cochlear implant and the hearing aid. And in school that was really good, and at university I was able to access the support that I needed.

[00:00:40] Although I kind of largely did that myself, so I kind of worked out what the DSA was, how to apply for it and so on. And I think that was almost the time when I started advocating for myself and my disability, kind of getting up to that point. And the only other thing I would say is I got rejected for PIP just before university or something.

[00:00:59] But in the end, although that was like a negative experience at the time, I think it pushed me forward to like, get my own jobs and things like that, start earning some money, and kind of knowing what support I needed to be able to do that.

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

[00:01:14] Yeah, I think it's really important to have diverse input because so much of the population now is a mix of disabled people and able-bodied people and yet the research doesn't really have that balance and I think it's so important that they can.

[00:01:28] Any disabled person wanting to get into research especially can see those things and can see that and if it's not reflected, I think I see that myself. I didn't really learn about research as a career until university and even then it was my own research. So I think that's important. But I think to be able to acknowledge all kind of ways that that research can come into it as well.

[00:01:50] So whether that's co-production, interviews, whatever the most accessible means is. I think there's just a stereotype that a lot of research, it must come in a certain way. So the traditional form of interview or traditional survey, and so much of that is not accessible. So I think it just needs to have more diverse inputs so that actually the views we see in research that's published is more reflective of the society we live in.

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

[00:02:17] Um, I've been a participant in small-scale studies at university. They weren't specifically related to my disability, that was more just about student experience. Um, during my masters, which was disability-focused, I did learn about co-production and also kind of got to meet people who had been part of doing those.

[00:02:33] So I really got to learn about how that works. Um, so I thought that was a fascinating approach, but, um, no, I haven't specifically been part of like a co-production thing myself. Um, yeah, but been in a few participatory things.

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

[00:02:51] So definitely consulting disabled people. So actually I really do love this kind of co-production technique and just kind of seeing maybe like a pilot stage for research and actually getting them to get involved. What the questions are, are they clear? Uh, how would it be best for them to answer? So I think that pilot stage can be so crucial to just making sure that everyone's views are being accessible.

[00:03:11] But something I am a little concerned with in recent times is like the use of capture and robots, um, in terms of getting survey respondents through. And I just don't want that to have a negative impact on like assistive technology or anything, and kind of making that harder. It might make it easier, but it's a concern of mine. What does that mean? Yeah.

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

[00:03:35] I mean, when I've been part of, um, things, you know, they're very helpful in giving captions in my specific instance, and I've seen like BSL, use of BSL as well, um, providing questions in advance just to give people that preparation time, and then obviously just like the access into buildings as well, making sure that if it's in person that people have that access.

[00:03:57] So those are the kind of things I've seen that I think work well. Um, But I definitely think there's probably more to be done and also more consulting with them about what they actually need. Because I think sometimes you assume and you're like, Oh, we can provide captions or something. But if we just say, what support would you like? I think that would open it up a little bit more.

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

[00:04:19] Speaking for a disabled person, I would say make sure it's actually their voice coming through. And even if you're kind of hearing their voice, make sure it's presented in the way they want.

[00:04:26] So you could do that by sending them a copy of something afterwards just to check you've understood it correctly. Um, also just not providing that accessible input. So having someone to interview and then, you know, not giving them captions, not giving them space to consider things. I think that's where it can go wrong.

[00:04:43] Um, but I also think in terms of the recruitment. So I find that I don't think there's enough effort to actually reach unheard groups in society. So, especially when it's like an overarching thing. So I think there needs to be more of an effort there. Even consulting those groups themselves to try and do it.

[00:05:01] But there's definitely a problem where we're not reaching enough disabled people in the general research. So, so then you can be accessible to who you reach, but it's still not representing the population.

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

[00:05:16] Oh, um, I would say terminology is important as well. So actually, like, you know, um, some people like to describe their disability in a different way and we tend to kind of, like, generalise that. And so whereas one person might say, uh, for example, I am deaf or I have a hearing aid, I think there's like a subtle difference in that.

[00:05:35] And I think kind of acknowledging how people like to identify themselves is really important. Um, what else? Um, and also the value bring. So it's something I learnt before of like, don't introduce anyone in the research disabled or otherwise, if you're not adding value to them by taking part in that research.

[00:05:54] Because sometimes you can, especially co-production, it's a real sense of giving empowerment to whoever's involved in that. And then if you kind of completely eradicate that after the research that's not ideal. And then the final thing is the output. So making sure that that research is. easy read or, or text that's friendly for them, anything like that.

[00:06:15] But if they're taking part in a research and then can't access it afterwards, that doesn't seem like a, that doesn't seem like fair. So I think that's another consideration that people often forget and should consider.

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

[00:06:32] I think people probably don't utilise social media enough. There's so many groups out there. So if you're trying to reach disabled groups of people, I think there's so many ways that you could do that. Um, Just in a friendly manner, but also again, if you put a post out there making sure that it's using the correct kind of language that the post itself is accessible.

[00:06:46] So it's like making sure you think of all the steps before you try and promote that. Um, and again, maybe just seeking advice and lived experience. Don't rely on one disabled person to speak for, kind of actually listen to a variety of disabled people to get the different experiences. Because even like deafness, for example, there's a massive scale, you know, I don't use BSL, lots of people do entirely, but we all still have some shared experiences, but we can't speak, I can't speak for all deaf people, so those kind of things. Yeah.