Letty Raby

Profile:

Letty recently graduated from studying Biomedical Engineering at the University of Surrey. They are content creator and consultant mainly focusing on the Deaf and disabled experience and accessibility.

Letty is working towards a career in the disability design space and love using their engineering background to come up with innovative solutions that promote accessibility.

Letty wanted to be part of this project because without a disabled perspective, studies are missing out on unique insights and diverse data. The first step of which to gaining is to design accessible studies that disabled participants can fully engage in.

Transcript:

[00:00:00] My name is Letty. I'm a full time wheelchair user. I'm hard of hearing and I'm also autistic.

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

{00:00:10] I think if you don't have diverse inputs you're not getting the full picture of all of the people in the world.

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

[00:00:21] I've been a research participant. So I was, it was a questionnaire that I filled out that was rating different experiences from 1 to 10. And I've also done I've been a participant in like a physical test. I did struggle quite a lot with the 1 to 10 ratings. I really struggled to visualise what, where I was on the scale.

[00:00:47] Like, what did 1 mean? What did 10 mean? What would my answer actually mean to the researcher? Because they were just saying like, for example how easy do you find this on a scale of one to ten? But I didn't, couldn't really conceptualise what either end of those scales meant.

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

[00:01:11] I think it's because I've done two ones and one was like, a lot of just questions that I was rating. And then the other one was, was more like a medical test. They were looking at heart rate and things like that. So that was like less input from myself and more just kind of like my body's reaction to stuff compared to the other one which was sort of my opinions and things like that.

[00:01:39] With the questionnaire, I really struggled with the one to ten thing and also just how broad the language was. A lot of the time they would just use kind of open-ended words that, I didn't feel was specific enough for me to really understand what they were asking of me. And then also, they often repeated questions with really similar language.

[00:02:04] I couldn't really understand the difference between the two. Like, there was one that was like, how upsetting would that be? And then there was one that was like, how distressing would that be? And for me, I really struggled to understand my emotions to begin with. And then to be able to differentiate between those two things felt impossible.

[00:02:23] And I think they often ask the same question a few times to kind of like, like peppered in throughout the questionnaire to kind of, I don't know, see if it changes slightly with slightly different wording, but I just found that kind of made me feel anxious that I wasn't understanding it properly or I wasn't doing the questionnaire properly.

[00:02:44] I think that the study did do that well in terms of they explained why they were doing the research and what they were, not what they were trying to prove, because I think that would put it in people's heads to think a certain way, but kind of like what the two outcomes would be that they were trying to, you know, decide between which did help.

[00:03:03] Yeah, I think I would have really benefited from more information on the scale and then also maybe like a definition of the words they were using and because everyone using the same words could have a different reason for what they actually mean when they say distressed or what they actually mean when they say upset, which yeah, I struggled with that.

[00:03:24] I also struggled with the length of the questionnaire because there was no way of knowing how long it was. And that was quite overwhelming for me. Just sort of diving into a situation where I didn't know how many of these questions I was going to be asked. And then I couldn't go back to see what I'd written before as well.

[00:03:41] Like when this question came up that was like distressing versus upsetting. I kind of wanted to know what I'd said previously. Because you're dealing with these different scales and the scales kept changing. How upsetting is it? How distressing is it? How positive is it? How negative is it? And it was, I was just really struggling to, it took me a minute, like maybe 10 minutes to understand the scale and then put myself on the scale.

[00:04:04] And then the scale kept changing. So I had to keep doing that again and again. It was really mentally taxing for me. Made me feel like I didn't understand my own emotions which I do struggle with. So part of the testing was standing up. That was actually the main part of the testing was standing up.

[00:04:23] And I was never asked whether or not I could stand. And I, I had that as well with a different questionnaire I had where they were asking, it was about pain and they were asking how much pain standing causes someone, but there was no option on a scale of one to 10. There was no option for, I can't stand.

[00:04:46] And I think that's come up a few times as well, not in research, but more in just like my medical life that they'll, How difficult is it for you to cook? I am tube fed, so I don't cook. There's not really an option to say, I opt out of this question or this question doesn't apply for me. And then I wonder what my information is doing to their life.

[00:05:12] When I'm applying a different logic to the same question, when everyone else is thinking, okay, using a knife, carrying a saucepan, I'm thinking connecting a bottle of feed, like it's very different. And like, I often wonder if I'm affecting their data negatively because I just don't fit in the box in the same way.

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

(00:0:52) I have seen. I have seen when people have these scales where they have emoji faces to show, like, sort of, they might start with a green happy face and then go towards a red unhappy face, so you're kind of able to, it's like another layer of information to help people.

[00:06:03] If the 1 to 10 doesn't apply, then maybe the faces would, and then maybe text would for someone else. I guess it's just about having multiple options that makes it more accessible than just assuming that everyone can understand a 1 to 10 scale.

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

[00:06:24] I think potentially the energy required to contribute to the research. Like I said earlier, when I fill out one of these questionnaires, it requires a lot more energy from me Because of like the cognitive load of trying to understand the questions and maybe having to look up definitions of words or what they mean in this context because of how much I struggle to understand my own emotions in one to ten scales.

[00:06:53] If you have loads of questions and they're all one to ten scales and the one to ten scales are changing it just requires so much more energy that filling out a questionnaire that someone's written that they think oh that's a 10 minute questionnaire might take me hours and that can be really draining.

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

[00:07:32] I think when we're talking about the questionnaires, one thing that I have seen that people can do is, I also have dyslexia, is that they can have options to make the text clearer and easier to read and also to have one question at, like, one question at a time rather than, often it's like a scroll list that just has a lot of information, but it's just one question, it's got a dyslexia friendly front, it's simple I think that, that can be really helpful.