Including Disabled People in Your Research: Transcript

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Gemma Lumsdaine: Hi there. My name is Gemma Lumsdaine and I'm the Disability Lead at Sported UK. Today I'm going to talk to you about including disabled people in your research and some considerations you need to make. So, why is it important to include disabled people in your research? Well, disabled people make up a significant proportion of our population, with one in four people in the UK being disabled. So, if you want your research to be representative and ensure that lots of different voices are heard, it's really important to include disabled people.

Due to the way that disabled people have to navigate everyday life and their unique and rich perspective of an experience, they can add so much insight and great, rich data to your research in terms of the way that they think about things, in the way that they look at the world and the way that they've had to experience different things, overcome barriers, challenges, so definitely adding some really great insight into whatever topic you're looking into. And finally, the disabled community is significantly underrepresented and often don't have an opportunity to share their voice and share their thoughts and experiences, so by enabling disabled people to take part in your research, you are giving this community a voice and a platform to speak up for what they believe in.

So, accessibility considerations in relation to data collection. So, the first thing to think about in terms of questionnaires is around the platform you're using, so often different platforms have accessibility guidance and this will show you what's feasible and what's not in relation to your questionnaires, so whether your questionnaire is screen-reader-compatible, whether you can change the colour contrast to black and white, which is often really

helpful for people who have sight loss, whether you can do speech to text, which can be really helpful for people with physical disabilities. And the last thing to think about is different versions of your questionnaire, so can you use easy reads, for example, which takes long, complex text and changes it into words and pictures so that people with learning disabilities and other types of disabilities can easily understand the process and engage with the information.

Length and wording is also really important because, for a lot of people, if something is really long in length in terms of questionnaires, the time that it will take to process the information and actually complete the questionnaire will be really fatiguing for them, particularly for those with physical disabilities, for example, if you don't have speech-to-text software and you have to type your thoughts and opinions, or simply just being able to complete might be really fatiguing. Wording is really important as well because you have to think about exactly what you're asking. So, neurodivergent people, for example, are very literal thinkers sometimes, so it's about thinking about how could your question be interpreted. Could it be interpreted in different ways or is the question really going to get the answers that you need. And also target audience is important because, unfortunately, there's not one method that suits every type of audience, so you need to be flexible in your approach and your methods to ensure that everyone's needs can be met. And again, it's non-traditional methods can really support with this. So, it might be as simple as actually using things like smiley faces or colours or pictures to ensure that people get their point of view across, or it could be that actually you work in collaboration with parents or carers to be or to ensure that the participant's voice is heard.

With all this though, everyone is different and it's not a one-size-fits-all approach. One thing about focus groups, in person versus online is important. Obviously, transport is a massive barrier for lots of disabled people, so in person might be too challenging. Similarly, online can also help people in terms of it causing less energy expenditure. But things like

online for a BSL user or in-person focus groups, if everyone else doesn't use BSL it can be challenging and time-consuming for them, so that's something that you need to think about as well is ensuring that you have BSL interpreters and looking at the nuances of conversation as well. Time considerations is another factor, so for some people it takes them longer to process information so it's about scheduling that into your timing as well to ensure that people don't feel rushed and that they have enough time to take their time to process the information and provide their thoughts and experiences. Again, what can support with this is questions ahead of time. This is particularly useful if you're working with autistic people or neurodivergent people who maybe need to have that element of structure ahead or need that additional processing time so that they've got the questions ahead of time so they can come into the group and be ready. And again, just about creating a positive environment to enable people to feel safe and comfortable to share their experiences.

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So, in terms of reporting, the way that we talk about disability matters. We always want to look at using social model approach, which identifies that actually it's society and accessible structures that disabled people, and it's not the disabled people themselves that are the problem. And I think the way that you frame disability and disabled people is really important. So often it's always in a negative light or as in their a complete inspiration, and I think actually they are just people, so finding how people want to be referenced and referred to is really important. Again, multiple formats for reporting is important because you want to ensure that the people who have taken part in your research have the ability to engage and see the finished product. And, again, sensitivity in relation to disability is really important. So, actually, people do not need to disclose their disability to add value into the research. It may be even an important factor within your results, so your findings around their disability, and just sensitivity around this, or particularly around if they're explaining about some of the challenges associated to their

disability is really important. But I think on top of this, it's all about having that conversation with the person and ensure that these sensitivities will be thought of from the beginning.

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