



Hannah:

Hello, my name's Dr. Hannah McPherson and I'm author of Inclusive Arts Practice and Research.

David:

Hello, my name is David and I'm a co-researcher.

Pedro:

Hello, my name is Pedro and I'm also a co-researcher with Heart n Soul at The Hub.

David:

That was spot on. I think what we wanted to say in the video was said.

Hannah:

I'm glad you think it spots on David and representative of some of the really great work you've got involved in during the course of the project. I think this is a very interesting project and it builds on a diverse and complex history of doing research inclusively. This isn't the first inclusive social research that's been done with people with learning disabilities. Was there... Were some things about the project that you particularly enjoyed?

David:

I enjoyed all of it. Everybody contributed, everyone felt relaxed, asked each other questions and sit around and actually answer the questions ourselves before we asked the public.

Hannah:

I think surveys generally are very boring, but one thing you managed to do, alongside some of the computer tech people that you worked with, was make a survey very interesting, I thought, and very novel to a new to interact with. And I thought that was a real achievement of the project.

David:

I think it's because some of us can't read and write so we actually need a survey like that because we need step-by-step video, we need audio to read. We need easier ways to understand the graphs for ourselves. So we want to make it easy for ourselves so we can understand it ourselves.

Hannah:

And there what you've got is one of the best bits of inclusive design, which is universal design, which is design that appeals to everyone.

Pedro:

I agree with David that being a co-designer of the survey, it was about making it accessible or as accessible as possible with the videos and the audio. But I think it was also very creative and innovative because you have the co-researchers themselves explaining the reason why they wanted to ask those questions and they were speaking directly to the audience. So there was something about honesty and something about those voices wanting so badly to be heard that I think this also had an impact on how people answered it. So instead of a normal, boring survey, you've got a survey which is colourful, which is multimedia, which you have some real people really asking some very important questions in a very creative way.

So then when you take the survey, you see this narrative from question one to final question and you see all those people, those characters, those co-researchers telling their stories. And it really builds up because at the beginning, "Okay, it's a survey." But then you really get involved. And then when I was doing the transcription of other people's answers, you can really tell how having a survey like this affects how people answer. And I think this led to people being more open, trying to connect with the subject. So independence, trust, overprotection, and so on. So I think this was really like an outstanding achievement.

Hannah:

I got an impression at the beginning of that film that clearly Heart n Soul members have learned a lot about the conventions and quite conventional social research, actually. Because they were speaking at the beginning about sampling strategy and survey design and the first cohort of answers and things, which I thought was interesting. Part of inclusive research is working with people with learning disabilities to develop social research, but also sometimes challenge the conventions of social research. And I think you've achieved a bit of both in that project

David:

Demographics, going through the demographics and things like that. That was interesting, people who took part are mostly doctors and carers and students. Finding that out it's like people who we actually wanted to get to, because they go into social care or they been into being a social worker or a doctor working with people with learning disabilities. Like trying to say that we can do stuff, like doing things

what challenge us and find out what goes on behind the scenes where people do make papers about people with learning disabilities. Then coming from a medical angle.

Pedro:

A learning process, as well, throughout. Because I mean in the video they're saying we want to know what people say, but who are these people? And how do we analyse who... So the demographics and the age and the level of education. So it was really about... Before we look at the answers, like what they said, we look at the 'who are they' and why is it important to know who is answering this? And to have a variety or a diversity of people answering to these questions. So I think it was really breaking down and learning how to make science, really, or scientific methods or social research methods accessible as possible and taking ownership of that.

It took us some time. We did use a lot of artwork and creative design and reimagining the graphs, reimagining those variables so that, "Okay, so now I get it." This is our way of understanding. So then we can move forward and look at the actual answers.

David:

Yeah. People redoing the graphs and understanding it in a way they can understand it. But our way.

Hannah:

I think more broadly what Heart n Soul, I don't know if you'd agree, but what Heart n Soul... Achieve more generally Heart n Soul as an organisation achieve kind of all sorts of things around asking ourselves what is a question and what is an answer? I'm sure some of the music

workshops and thinking about questions and answers in terms of musical questions and musical answers, it doesn't have to be words, the fact that you could embed in your own survey design, pictures and things, and you showed the role of creativity in inclusive research design is really important. But also I think what's really important is not forgetting the role that Heart n Soul play in kind of pushing at the boundaries of what we think of as questions and answers in the world. Cause yeah, surveys can only ever tell us how much... A certain amount about what one person thinks of another. We can never really truly know that, there's an unknowability to those sort of questions as well. And I think sometimes those other artistic methods including your music and artwork can also grasp at what questions and answers really are.

David:

We built questions as a conversation and people gave really long answers and it was like that's a story. One thing we all got in common, we've all got different stories to tell. And it's like, "Tell me the story." And some people really long thoughtful answers. So it's what we want.

Hannah:

I think what you were saying there David, about people being able to kind of reply in stories is interesting.

Pedro:

The actual answers were more honest and positive, overall, than we expected at first. And I think part of the reflection for the group was also kind of making amends with that. "Okay, we expected the world to treat us as we thought or as we were used to in the street. But because

we did all this research and survey, well actually the response was different. So there is hope"

David:

Society is changing. And the number of people with learning disabilities is more apparent. Cause I've got a son with learning disabilities. It's like he's well looked after at school cause he goes...I see that things have changed.

Hannah:

Certainly in our recent research at the University of Southampton, the self-build social care project. There were still a lot of challenges for the older generations in terms of people's attitudes and general access to community activities and inclusive activities that were available.

Pedro:

And I want to ask David a question. How to be objective? Looking at the answers like, "Okay, I'm a scientist, I'm a co-researcher, I'm just going to look at this very coldly, very rationally. But at the same time I'm reading this and it sparks an emotional response. It resonates to my own lived experience." How do you manage or how do you think we've been doing... Trying to separate or not? And how far have we got in this?

David:

I don't really think about it because I don't really care what people think of me. And I don't think the others really care as well. They could switch off as well. They know it's research.

Hannah:



Projects like this tend to be successful if they travel at the speed of trust and clearly this project has done that. So, that's great.