

Speaking of Research

South Coast Doctoral Training Partnership Podcast

Series 1 – Episode 8 – Elspeth Clark

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SPEAKERS

Catherine McDonald, Elspeth Clark

Catherine McDonald 00:03

Hello and welcome to Speaking of Research, a podcast from the South Coast Doctoral Training Partnership. I'm Catherine McDonald, and in this first series of our podcast, we're talking about impact and how researchers can achieve it. We're recording at the amazing Cumberland Lodge, and we're speaking to doctoral researchers about their research, who might benefit from it, and how they hope it will make a difference. In this episode, I'm joined by Elspeth Clark from the University of Southampton, who's researching occupational engagement, belonging, and people with profound, intellectual and multiple disabilities. Can you tell us a bit more about your research? There's quite a lot to unpack there.

Elspeth Clark 00:47

Absolutely yes. Thanks. So, I'm working collaboratively with students with profound intellectual and multiple disabilities to explore whether engaging in meaningful occupation can facilitate a sense of belonging. And there is a lot, there is a lot to unpack there, I totally understand that. So maybe if I go through a few of the key terms.

Catherine McDonald 01:05

Please, yeah.

Elspeth Clark 01:06

So, I guess the first one would be profound intellectual and multiple disabilities. So that is more of a description than a diagnosis, really. And people included in this group are highly heterogeneous. They have complex needs and very diverse abilities as well, but generally they have profound cognitive impairments, pervasive support needs and often additional physical and sensory disabilities. And they communicate without words, mostly, so they'll be using sort of facial expressions and gestures. There is an additional geographical nuance as well, because the study is based in the UK, so where, often in services, we use the term profound and multiple learning disabilities, or in education, in fact, it can be learning difficulties. So, there is a confusion of terms. However, in policy and practice worldwide, the term profound intellectual and multiple disabilities is much more commonly employed. Of course, there is the other key term, which is meaningful occupation, which, again, I understand can have multiple meanings for people, but my professional background is as an occupational therapist working in the

NHS on health teams for people with intellectual disabilities. And in occupational therapy, occupation is defined as activities that are described sort of value and meaning for people. So, the things people like to do, the things people need to do, or the things people are expected to do. So generally, the things you enjoy doing. And then alongside that is the idea that engaging in meaningful occupation can support a sense of belonging. That's key to the to the research.

Catherine McDonald 02:34

I see. And can I ask what motivated this research? What made you want to get into this and look into it in great depth?

Elsbeth Clark 02:42

Yeah, that's such a good question. I mean, I guess working with people with profound intellectual disabilities through my job in the NHS, and understanding that, you know, there's such a dearth of research working with this group of people, it's actually quite hard to find evidence for the work that you're doing. Also, there's a sort of misconception that they, you know they're too disabled to engage in research, or that you know if, because, if you don't spend a lot of focused time with someone paying close attention, you would maybe miss vital signs that they're enjoying themselves, or that they're engaging, and because their engagement is sort of can be idiosyncratic, it's not something that perhaps is obvious, unless you've spent a lot of time and have a relationship with that person. And so the opportunity to research this in more detail came along, and also because, you know, belonging is recognised as being vital to both mental and physical health, you know, something we can all identify with really, the idea that, you know, a sense of belonging is really important to us all, and it's really critical to investigate that for people with profound intellectual multiple disabilities, because, you know, they are much more prone to sort of mental health difficulties in the general population. And so, it's also because it's so very, very under researched previously. So, it's a brilliant opportunity to really bring this group of people who are very much on the margins of society in lots of ways, to sort of bring them back into the sort of the core of research, and also, like health service provision, I hope.

Catherine McDonald 04:07

Such valuable work. And so how are you actually conducting your PhD? What research methods are you using?

Elsbeth Clark 04:13

So, I'm taking an exploratory perspective, and I'm seeking an in depth understanding, and aiming to collaborate in the mutual process of co-constructing knowledge. And obviously, because I'm working with people who don't use words to communicate, I'm looking at different ways of, sort of working with them in a sensory and embodied way. And so, there's different phases to my research. And the first phase was, which I'm sort of, I've mostly completed that bit of field work now. It's work, working collaboratively with five students between the ages of 12 to 15 in the social, cultural environment of their special school. So, I started just by spending time with them, and, you know, really getting to know them, developing a relational connection, because I'm conceptualizing like the meaning that we're creating is through the interpretation of the stuff that we're doing together. And so, phase one, I'm also looking at using participant observation and in tech drawing on things like intensive interaction and from the field of Occupational Science, co occupation. And then in the second phase, which is where I'm just sort of starting that now, I'm focusing more on working collaboratively with two students, in particular, introducing sort of innovative audio-visual methods and using those to sort of try and amplify their voice and their presence within the research.

Catherine McDonald 05:30

Wow it sounds absolutely fascinating. You've already alluded to this, but what new insights do you hope your PhD will provide? And obviously, importantly, who do you hope those insights will benefit?

Elsbeth Clark 05:43

I mean, primarily, I would like to see them benefiting, you know, the students that I'm working with, because people with profound intellectual and multiple disabilities have been excluded from research, both as participants, and the research that has been done has been primarily done on them, rather than with them, whereas I'm working very much in a collaborative manner, trying to do research with these students. So, I'm hoping that the research sort of challenges that marginalization and offers some fresh perspectives about the relationship between engaging in meaningful occupation, belonging and young people with profound intellectual multiple disabilities. You know, findings can drive up standards of care and form statutory guidance and develop the evidence base in the realms of education, occupational therapy, but also disability studies. And I mean, I'm hopeful that findings will offer insight into how research can be conducted more inclusively with people who communicate idiosyncratically without words.

Catherine McDonald 06:03

So there's so much potential for valuable impact there. How are you going to try and ensure that impact happens?

Elsbeth Clark 06:44

I mean, there's different sort of circles within circles. So, to start off with, I'm working with the students. So, it's about the impact on the students, in the classroom, in the culture of their school, but also the people that support the students. So, they're their teachers, their parent carers. So, I'm looking to have, you know, I'm going to have like, disseminate the findings with the parent carers and within the school to sort of help to support the development of the attitudes of these students as being agentic within their own lives. And then also, there's lots of organisations that are linked to the school, but in the community that support, you know, people with profound intellectual multiple disabilities. So, I'll be disseminating the findings to them through like workshops. But then there's the more traditional approaches as well. So, through publication in journals, and I've submitted an abstract to present my findings at an international conference next year. And then also the sort of third sector organisations where I'll be looking to create, like, a more succinct and concise report of my findings, maybe using like a multimedia approach. And I'm hoping that social media will help me sort of share that further as well, just so to provide something that people can like a digested read of the findings, rather than the journal articles and things like that. So that's how I plan to make impact.

Catherine McDonald 07:59

Well, we wish you all the best with that. I really hope it gets the impact it deserves elsewhere. Thank you so much for talking to us today, and thanks to you for listening to this episode of Speaking of Research from the South Coast Doctoral Training Partnership. To find out more please visit southcoastdtp.ac.uk. Don't forget to subscribe wherever you get your podcast to access earlier and forthcoming episodes. This was a Research Podcast production.