Creative methods for enabling the participation of people with disabilities in research

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Overview

- Describe a range of creative methods I have used to try and capture the experiences of people with disabilities in ways that are inclusive and meaningful to them. These methods include memory boxes, sculpture, body-mapping and i-poems
- Consider the extent to which research participants with disabilities were able to shape and adapt the methods to meet their own goals
- Evaluate what researchers can learn when using these methods that they might not learn from other methods

Why the need for creative methods

- Inclusive and accessible
- Trigger dialogic interactions



1. Memory Boxes



Was inspired by my attendance at an end of project conference run by the Inclusive Archive project (OU, UEL, Reading)

 People with learning disabilities had been supported to collect together objects that were important to them and place them in a box, which could be carried around and shared with otherstaking an object out and explaining why it was important.

Examples: adults with learning disability



2. Body Mapping





I had seen a presentation by a group of inclusive researchers (with and without learning disabilities) who had used the method to express their feelings <u>about good</u> and bad support

Find out the method had originally been used as a method to enable undocumented immigrants in <u>Canada</u> to tell their stories

The mapping process

Trace an outline of your body that represents your positive and negative experiences (e.g sleeping, jumping, waving hands, dancing, curled up in a ball)

Pick a colour for the body outline that best represents how you feel

Draw one or more symbols or pictures that represent your experience

Think about where you would like to put this symbol on your body- on your head, your chest, your ears?

You might like to create a slogan, a statement or a saying that describes your current thinking about your experience







Example: Disabled university student

Example: museum visitors with sensory impairments



3. Sculpting as an alternative to body-mapping

I have used the idea of a totem-pole or sculpture as an alternative to body-maps- originally intended for visually impaired participants

The carvings on totem poles may symbolize notable events. They may embody a historical narrative of significance - a different way of story-telling



The sculpting process

 Shape the modelling clay into a shape that represents your positive and negative experiences (e.g. flat, body-shaped, a pyramid, an arch)

You might want to create a number of shapes or levels to represent how your feelings/experiences have changed over time

Add extra details to your shape to represent your experiences of (e.g. lots of hands, spikes)

Think about how you might use texture and feeling the clay to represent your experiences

Think about where you would like to put extra details on your sculpture

Example: museum visitor with hearing impairmen t



Example: University student with mental health problems



4. I-Poems

- I-poems were originally devised as a specific method for analysing interviews in longitudinal research projects.
 - The process involved four main sequential readings of an interview transcript in order to ascertain "who is telling the story"; how do participants represent or speak about themselves; how the participant talks about relationships with others and how to specific political and cultural contexts shape their sense of self (Gilligan et al. 2003).
- Edwards and Weller (2012: 205) describe how they have focused on just the second stage in order to develop a case study of a young person's sense of self over time.
 - They describe the process of creating an I-poem as reading through an interview transcript and highlighting each use of the first person 'I' (and associated verbs or text). They then cut and paste these highlighted phrases ' in the exact sequence that they occur originally in the interview, and placing them in separate lines, like the lines of a poem'.

Example: From this....



I think it is lovely

I would definitely like to have some colour

I like it, it is really beautiful.

I wanted to read everything on the signs and boards, but because of the pace of the tour there was no time.

I want to go to many places, but I'm held back because I can't speak very clearly and the staff are very ignorant.

I was really happy because the entrance was very accessible

I was able to walk independently with the walker

I felt very independent; it was amazing.

I was very happy about that

I wanted to buy a drink, but because my speech is not very good, they asked me to write it down, which was great!

I wish there were more places like that.

I got the feeling that when we were being filmed some got more time than others.

I wonder what the point is, some people here need to learn more about people's needs

I don't think people understand the effort it takes for me to come to ARCHES.

To this....

How do participants shape and adapt the methods to meet their own goals?



Example 1: From body-mapping to art installations







to tapestry

Example 2:Trees not body-maps







Example 3: Body maps turned into tapestry

Re-usable and shareable artefacts that create spaces for dialogue



What do researchers learn when using these methods that they might not learn from other methods?



Learn to ask different questions about peoples' experiences

Tell me why you drew yourself like that?

That looks interesting, tell me more about that.

Why did you choose that colour?

What does that symbol mean?

Why did you put that symbol there?



 Re-evaluate what counts as data

 Different relationship with 'data' and the participants who 'gifted' it

Learn about the 'painful' stuff that is hard to hear but important, particularly in relation to evaluating the 'success' of a research project.



Thank you





References

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