

‘Can you tell me what ethics means?’: collaboration, voice, and consent in (inclusive) research with people with learning disabilities

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Summary

Introduction

Research has often ignored the experiences of people with learning disabilities. There has recently been a push to do ‘inclusive research’, which involves disabled people as active participants. But there are few stories about what doing this work is like. In this paper, I share my reflections of doing research with people with learning disabilities. I discuss using an advisory committee, the issue of ‘voice’, and the ‘consent’ process. By doing this, I reveal how my attempts to be inclusive were not always successful. I suggest people doing similar research should tell such stories so that lessons can be learned.

Research Aim

The aim of my research was to consider how people with learning disabilities and their allies (for example, parents and carers) share positive stories about their lives through their involvement in different activities. In this paper, I reflect on my research with two groups that were run for and/or with people with learning disabilities: 1) a professional theatre company; 2) a community café. I spent my time ‘hanging out’ with the theatre group and café team members. I talked to them about their lives and what the theatre group/café meant to them (among other things).

Summary of main findings

My argument is that doing research with people with learning disabilities is important, but it can come with problems and challenges. I provide three examples of this in the paper. Doing this shows how my attempts to be inclusive were not always successful.

1) Advisory Committee

I formed an advisory committee with three people with learning disabilities from a self-advocacy organisation, one member of a learning disability charity, and two academic researchers with experience of doing research with people with learning disabilities. Committee members offered advice on the research and specific issues raised during the project. The committee were enthusiastic, supportive, and incredibly helpful. But I still had some anxieties about its use in the research.

One was that the advisory committee was more led by me than intended, because I set the agenda and chaired the meetings. There were also problems with co-producing research materials (such as information sheets and consent forms) with the committee members. This was because of University requests to include more information, which made the materials longer and much less clear. One committee meeting also exposed my assumptions and limitations as a researcher. This became clear in my use of words like 'ethics', which were not fully explained to committee members.

2) 'Voice'

Hearing the 'voice' of people with learning disabilities in this research was complicated in two ways.

Firstly, the way that I did my research was not effective for all people. Some were very comfortable having one-on-one 'chats' with me. However, others were not. I realised that my decision to have one-on-one chats could have excluded people who were not happy to communicate in this way.

Secondly, my method of 'hanging out' with people and reporting on these experiences meant that I often rely on my own voice. I had conversations with people with learning disabilities, but I still report on these conversations from my position as a non-disabled academic researcher. I also discuss this in the paper relating to concerns I have about publishing (such as the possibility of harm and ensuring that people are anonymous).

3) 'Consent'

The consent process was given lots and lots of thought. It was mostly successful, with many people confirming that they wanted to take part. However, the way that I tried to get consent from people raised some issues.

This included: some people did not seem to understand the project (at least at the start of the research); I had worries about people feeling forced to take part; some people did not seem bothered about the formal consent process (but they still wanted to take part). I worried some people were confused about my role in the theatre group and the café too.

In conclusion, have not suggested solutions to the issues raised in the paper. The main reason that I raise them is to show how research can be messy and unpredictable. It is important to tell stories about doing research and this includes describing moments where things can and do 'go wrong'.

Summary of main implications

My paper finishes with four lessons that I have learned from doing this research.

Firstly, researchers should share stories about doing this type of research so that we can improve our own practices.

Secondly, we must define what we mean by 'inclusion' when doing inclusive research and outline how we have attempted to include people with learning disabilities.

Thirdly, we must work hard to ensure our research does not exclude people, including people with profound and multiple learning disabilities.

Fourthly, we should try to create networks, where possible, for people to offer guidance and support when doing inclusive research.

Find out more

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You can read more about me here (<https://profiles.cardiff.ac.uk/staff/thomasg23>).

Thank you for reading this summary!