



## How to Use this Document

This document summarises a recent paper published in the *International Journal of Disability and Social Justice*:

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

The person who wrote it is called Gareth M. Thomas.

This is an easy-read version. The words are supposed to be easy to read and understand.

For more information on the research, please contact:

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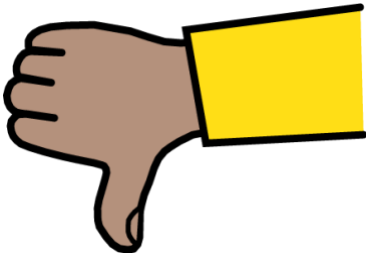
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Images for this document are provided by the ‘Learning Disability Service at Leeds and York Partnership NHS Foundation Trust’ and ‘Pixabay’.

## The Research Project



The experiences of people with learning disabilities are often ignored.



This has led some people to do what is called 'inclusive research'.



Inclusive research involves people with learning disabilities as active participants.

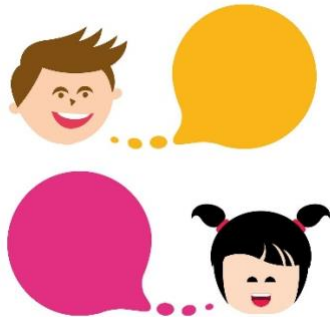
People with learning disabilities can give advice and be co-researchers on research projects.



But we know very little about there what doing this work is actually like.

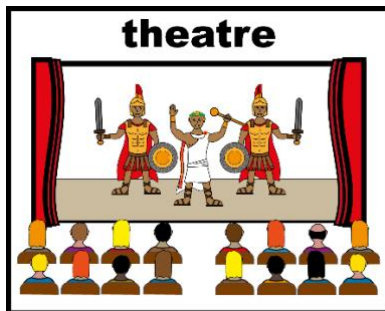


In this paper, I write about my experiences of doing research with people with learning disabilities.



The research looked at how people with learning disabilities and their allies (like parents and carers) share positive stories about their lives through their involvement in different activities.

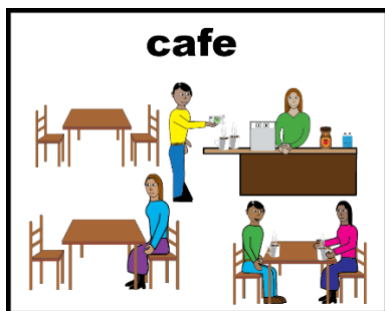
The research was funded by the [British Academy](#).



The research was done with two groups run for and/or with people with learning disabilities:

1) A professional theatre company

2) A community café





To do this research, I spent my time 'hanging out' with people and getting to know them.

I talked to them about their lives and what the theatre group/café meant to them (among many other things!).

## The Paper

### challenges



In the paper, I say that doing research with people with learning disabilities is important, but it can come with some problems and challenges.

### challenges



I describe **three** of these challenges and problems.

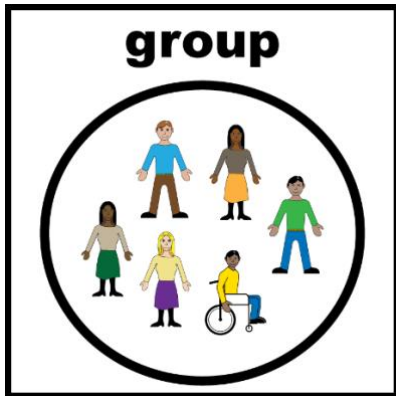
Sharing these examples show how my attempts to be 'inclusive' in my research were not always successful.

### group

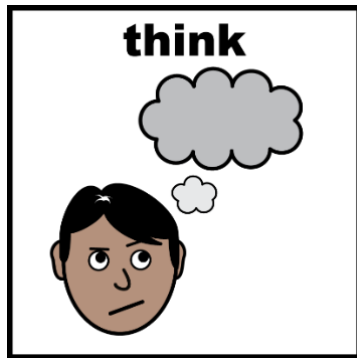


#### 1) Using an advisory committee

An advisory committee is a group of people with lived experience and expertise who offer feedback and advice to a researcher.



The advisory committee had 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.



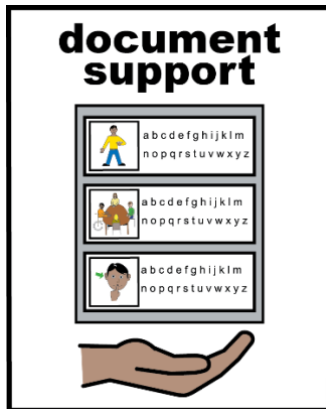
The committee were always enthusiastic, supportive, and incredibly helpful.

But I thought a lot about what could have gone better with the advisory committee.



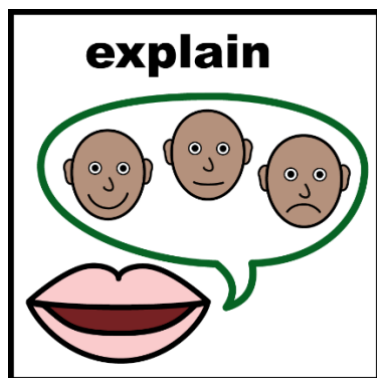
One worry was that the advisory committee was more led by me than intended.

This was because I made the agenda (so I decided what we would discuss) and I ran the meetings.



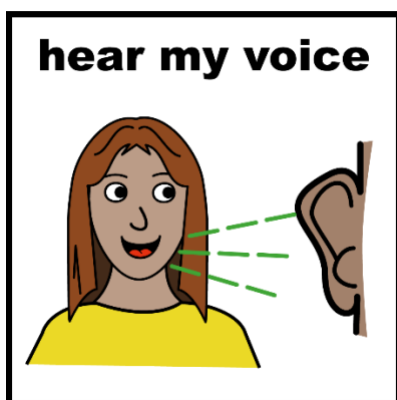
There were also problems with co-producing research materials (such as information sheets and consent forms) with the committee members.

This was because of University requests to include more information, which made them longer and much less clear.



I also did not fully explain to advisory committee members some words that they did not know.

The word 'ethics' was one example of this.



2) The issue of 'voice'

Hearing the 'voice' of people with learning disabilities in this research was challenging for two reasons.



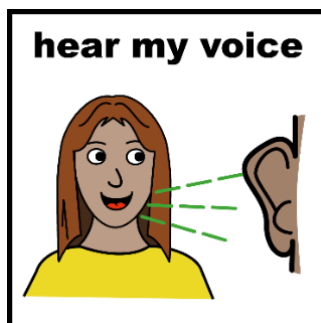
The way I did my research was not effective for all people.

Some were very comfortable having one-on-one conversations with me.

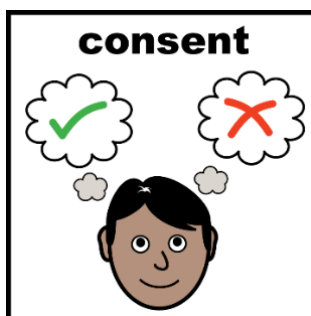
But others were not.



My decision to have one-on-one chats could have put off people who were not happy to talk in this way.



Also, the way I did the research (by 'hanging out' with people and sharing what I found) means I am relying on *my* voice, rather than the voices of people with learning disabilities.



3) The 'consent' process

Consent is when you agree to do something.

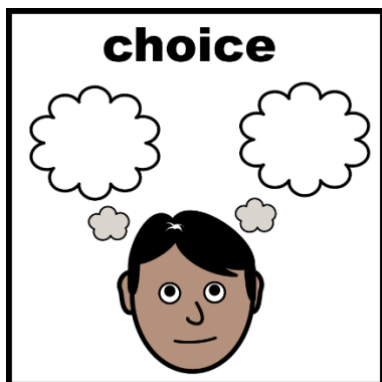
The way I tried to get consent from people in this research raised some issues.





At the start of the research, some people did not seem to understand the research.

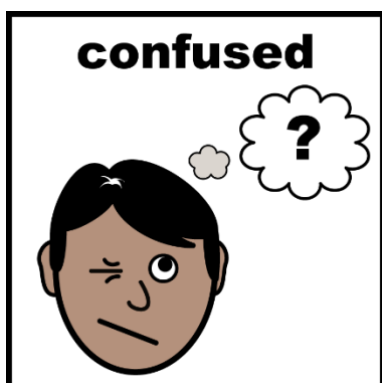
This was my fault as I did not explain it well enough.



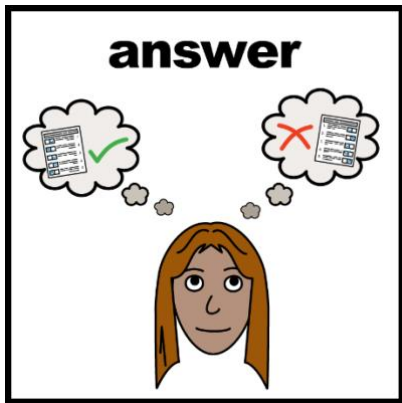
I had worries that people might have felt forced to do it.

I worried that they may not know that they had a choice about whether to take part.

Some people also did not want to go through the formal consent process, but they did want to help with the research.



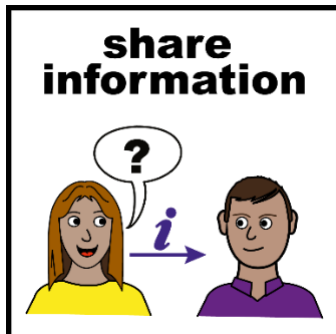
I also worried some people were confused about my role in the theatre group and the café.



I do not come up with answers to the issues raised in the paper.

The reason I raise these issues is to recognise how research can be messy and unpredictable.

## Lessons Learned

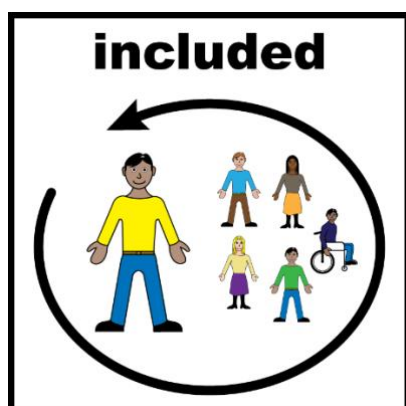


My paper finishes with **four** lessons that I have learned from doing this research.



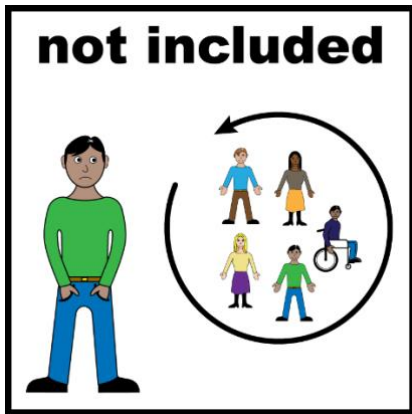
1) Researchers should share stories about doing this type of research so that we can improve our own practices.

This includes sharing stories of when things 'go wrong' – and that's okay!



2) Researchers must define what they mean by 'inclusion' when doing inclusive research.

They should also outline how they have attempted to include people with learning disabilities in their research.



3) Researchers must work hard to ensure that research does not exclude some people with learning disabilities.



4) We should try to create networks for people to offer guidance and support when doing inclusive research.



Thank you for reading this summary!