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No Research About Us Without Us

Our easy-read summary of a review on inclusive research

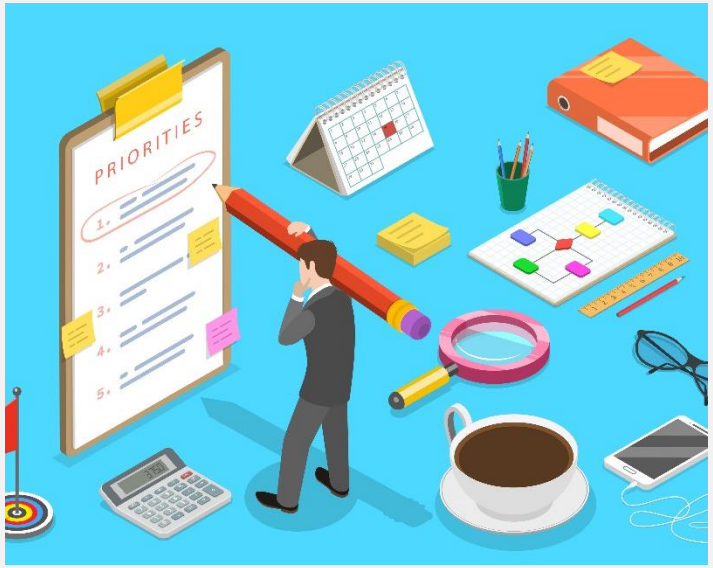
Our team from the project 'No Research About Us, Without us' wanted to look at the written evidence of what was happening in other research about inclusion.

WARWICK
THE UNIVERSITY OF WARWICK

Aston University
BIRMINGHAM UK

Researchers from University of Warwick and Aston University have written an article we found interesting.

Researchers looked at any research project that was about health or social care...



...and involved people with a learning disability in making decisions about how the research was run.

The researchers looked at research from the year 2000 onwards.

The researchers found 17 journal articles that wrote about this topic.

A systematic review and narrative synthesis of inclusive health and social care research with people with intellectual disabilities: How are co-researchers involved and what are their experiences?

Peter E. Langdon | Katherine Tapp | Michael

Abstract

Background: Using inclusive research methods with people with intellectual disabilities is increasingly common. A recent consensus statement identified key elements when conducting and reporting inclusive research with people with intellectual disabilities. This review identifies the range of health and social care research topics using inclusive research methodologies, systematically appraises the involvement of researchers with intellectual disabilities, and identifies facilitators and barriers to inclusive research. Researchers' experiences of engaging with inclusive research are synthesised.

Method: Seventeen empirical studies focused upon inclusive health and social care research were identified. The associated inclusive research methodologies employed, and the stages in which researchers with intellectual disabilities were involved, along with the experiences of researchers with and without intellectual disabilities were synthesised.

Results: Papers focused on a broad range of health and social care topics and largely employed qualitative or mixed-methods designs. Researchers with intellectual disabilities were frequently involved with data collection, analysis and dissemination. Facilitators of inclusive research comprised sharing power, team working, having sufficient resources and making research methodologies accessible.

Conclusions: Researchers with intellectual disabilities are involved in a wide range of methodologies and research tasks. How the added value of inclusive research is measured and its impact on outcomes, require consideration.

KEYWORDS

1 | INTRODUCTION

The research paper has a very long title. It's called:

A systematic review and narrative synthesis of inclusive health and social care research with people with intellectual disabilities: **How are co-researchers involved and what are their experiences?**

Inclusive research means people with learning disabilities are included as active partners.

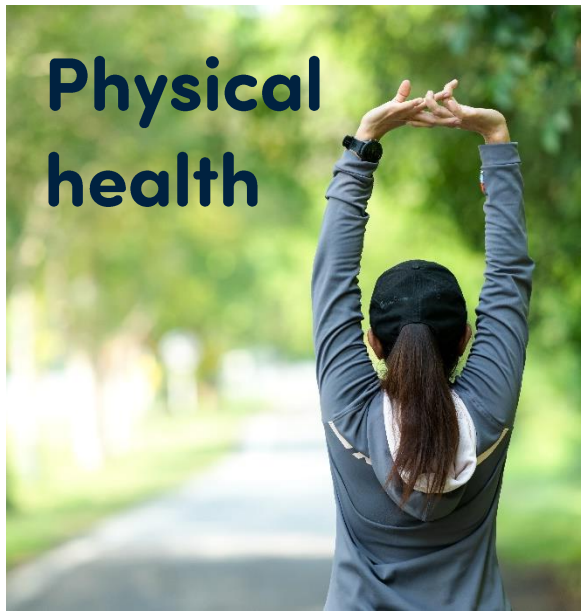
This study was a review to look at how researchers in health and social care involve researchers with learning disabilities in their projects.

The review also looked at what helps to make this research work well.

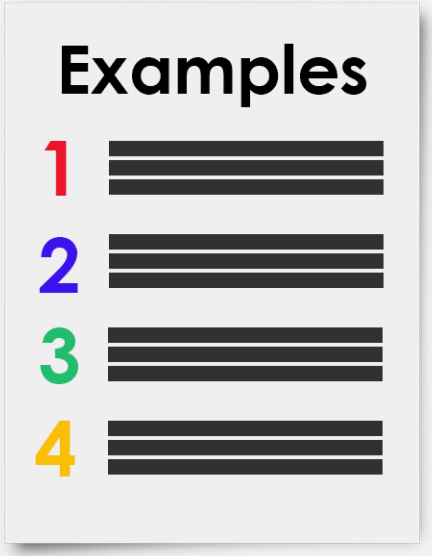
The review found that:

1. There were studies including researchers with learning disabilities.

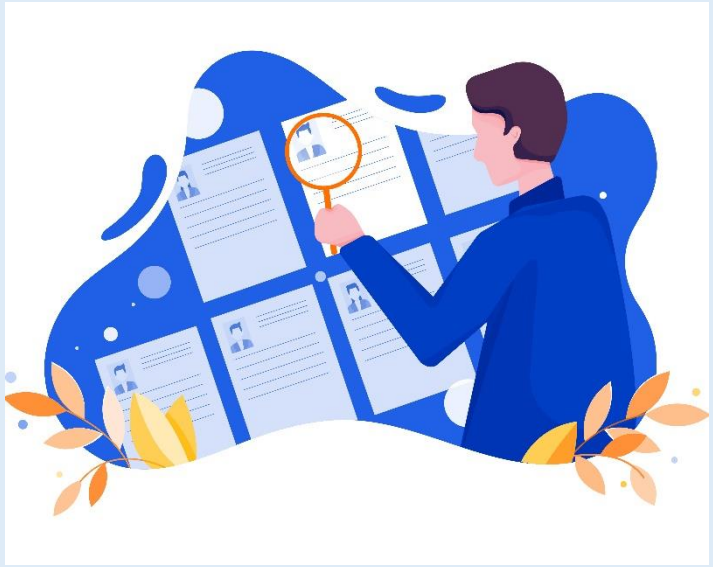
Together they looked at:



2. Researchers with learning disabilities were involved with lots of different research activities.



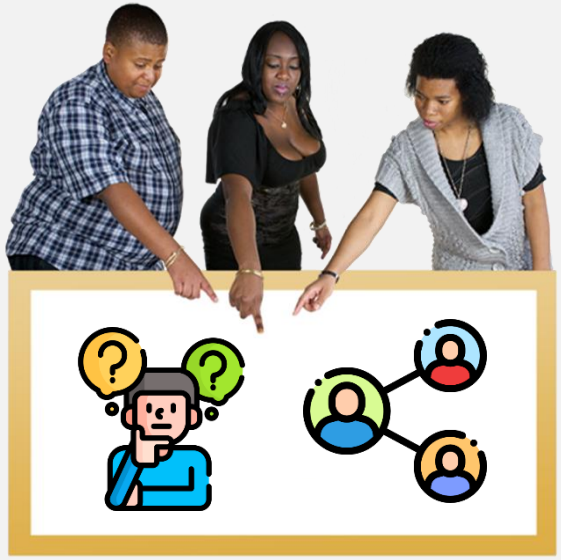
Examples are...



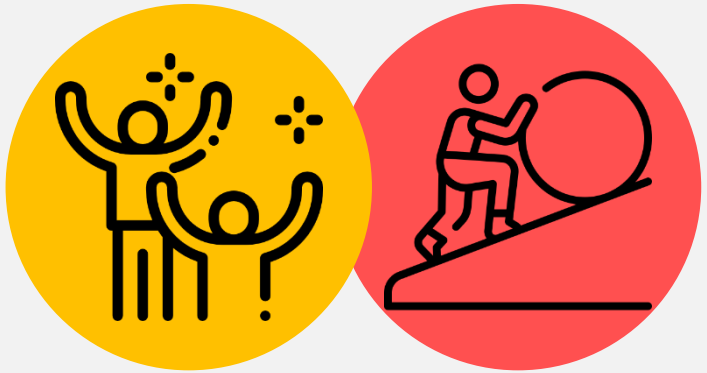
Helping to find people to take part in studies

Applying for research money

Deciding what the research should be about and how to do the project



People with learning disabilities also helped to think about what the findings mean and how best to share the findings with others.

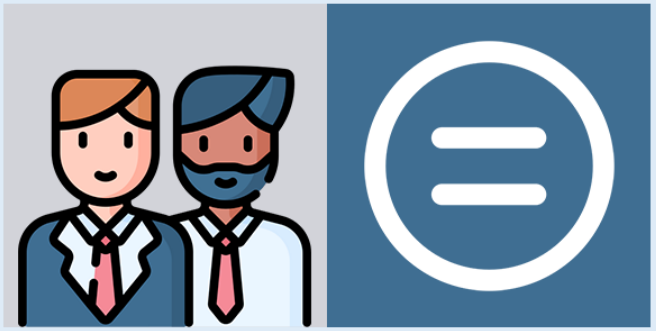


3. Research can be enjoyable, but it can also be challenging.

Inclusive research can work when...

Researchers with learning disabilities hold real control and power to make decisions.

The project is jointly owned between researchers with and without learning disabilities.



Everyone is equal.

Each person is clear on what their role is.

Researchers get training and learn new research skills.

Researchers with learning disabilities get the right support.

It starts from the beginning of the project.

Future research should...

Be clear about how researchers with learning disabilities are involved in projects.

Include people from different backgrounds.

Make sure people get the right training.

This summary was created by the project team from "No research about us, without us“ to share with our project team so we could talk about the article together. We decided to share it with the authors of this article to help other people know about their research. This project is funded by the NIHR Programme Development Grant ‘Developing Innovative, Inclusive and Diverse Public Partnerships’ (NIHR PGfAR – NIHR205211). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

An accessible summary like this would make it much easier to share the findings of your research. This was intended as a brief summary and introduction to the findings and as another entry point into your research. It should be viewed as part of a potential suite of accessible resources.

Hewitt, O., Langdon, P.E., Tapp, K. , & Larkin, M. (2023).

A systematic review and narrative synthesis of inclusive health and social care research with people with intellectual disabilities: How are co-researchers involved and what are their experiences? *Journal of Applied Research in Intellectual Disabilities.*

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TOTAL COST: £355

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