

It's our project! People with learning difficulties managing and doing research

We are a group of people with learning difficulties called the Learning Difficulties Research Team. The Department of Health asked us to find out all about good ways to involve people with learning difficulties in research. We are doing this by looking at what's happened in 12 research projects funded by the government through the Valuing People white paper. We want to find out:

1. How people with learning difficulties got involved in these research projects.
2. What works and what doesn't work about involving people with learning difficulties in research.

We are travelling around the country to meet people and ask them questions about their views and experiences. After we finish interviewing people we will put all our information together and publish a report, run a conference and do other things to tell people what we've found out.

This is an exciting project because we are the researchers and we are also running the project ourselves. We manage the money, make all the decisions and do the research.

We would like to tell people how we set up, manage and run a proper research project as a group of people with learning difficulties. We would like to tell people how we have learnt to do good, inclusive, empowering and accessible research and how we have overcome challenges and difficulties.

We can do this in the paper format, with questions and discussion or we can run a workshop. Both formats will be

fully accessible. The workshop format would focus on what people with disabilities or other 'service users' can do to have more control over research and what non-disabled researchers can do to support us.

Making decisions about how to apply what you've found out: Involving people with learning difficulties in a European research project

'I like, I love' is a research project that covers 6 European countries, looking for a new resource for people with learning difficulties around sexual health that is useful in all partner countries. This report from the researchers involved in the project will consider the professional involvement of people with learning difficulties. The report will address undertaking and implementing research with people with learning difficulties. Joyce Howarth will talk about the importance of people with learning difficulties being employed on the project. Sally Hillman will give her experience of being a researcher with learning difficulties. Kerrie Ford and Val Williams will talk about meeting all the partners in Mallorca and how Kerrie helped to decide on the way forward.

Issues for discussion will be:

- The importance and added value of including service users in research about sensitive topics.
- Methods for including service users in professional,

mixed teams of researchers.

- Doing research in an inclusive way in Europe.

Knowing how: a guide to getting involved in research

Authors: Lisa Thorne, Rachel Purtell and Lisa Baxter

The aim of the project was to find out how much lay people are actively involved in research outside the health service, and to use what was learned to make recommendations for health research.

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