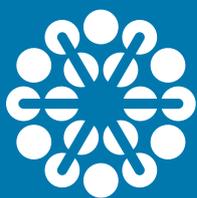


# RESEARCH TO ACTION

>> Bridging the  
gap between  
what we know  
and what we do



Centre for  
Applied Disability  
Research

An Initiative of National Disability Services

**NDS** National  
Disability  
Services

# INCLUSIVE RESEARCH:

A guide for people  
with disability





# ‘NOTHING ABOUT US WITHOUT US’

This guide is about research. It talks about what people with disability might need to know about research, and ways that people with disability can be involved in research projects.

## THINGS YOU WILL FIND IN THIS GUIDE:

- What is research?
- What is inclusive research?
- Examples of inclusive research
- How you can get involved in inclusive research
- Good things about being involved in inclusive research
- Some questions to ask if you want to be involved in inclusive research

This guide was written by Jennifer Smith-Merry, who is a researcher from the University of Sydney. It is part of a collection of ‘Research to Action guides’ about inclusive research for people who work in organisations and in universities.

## WHAT IS RESEARCH?

- Research is a way of finding out about something to understand more about it.
- A researcher is someone who is involved in finding out.
- Research usually involves looking for and collecting information.
- There are lots of different ways of collecting information. It might be:
  - Interviews (talking to people)
  - Surveys (– Answering questions on a computer or a piece of paper)
  - Taking photographs or videos
- The way you collect information depends on what you want to find out and who you are collecting the information from.
- Research about disabilities is very important. It helps us to understand the lives and experiences of people with disability, and to make things better.

## WHAT IS INCLUSIVE RESEARCH?

- Sometimes researchers use inclusive research to find out about disability
- Inclusive research is research that includes people with a disability
- Inclusive research is usually done by people with a disability working alongside other researchers from a university or another organisation.
- This means people with a disability work as part of the research team to find out information.

### AN EXAMPLE OF INCLUSIVE RESEARCH:

Some people with an intellectual disability wanted to tell the history of the organisation that they were part of.

The researchers with a disability spoke to people about their organisation in interviews and asked them for photos.

All the information that they got was made into a booklet and a guide to put on the internet. They also wrote an article for an academic journal about what it was like doing the research.

They worked with a researcher from a university to make their research project.

They were also helped by an assistant who did not have a disability who helped them organise the project.

## WHAT CAN PEOPLE WITH DISABILITY DO IN INCLUSIVE RESEARCH?

### The way you are involved in inclusive research depends on:

- What you are interested in
- Your skills (Things that you can do or are good at)
- Skills you would like to have (Things you would like to learn or be good at)

### Ways people with disability are involved in inclusive research include:

#### 1. Organising the research

This might mean making plans about the research, contacting people or helping to set up meetings.

#### 2. Collecting information

There are lots of ways to collect information. It might be talking to people, reading, asking people to do surveys, or taking photographs and videos.

#### 3. Working out what that information means

The information we collect is called data. After the data is collected, researchers need to think about what the data means. Sometimes, people with disability have a better understanding about what data might mean.

#### 4. Telling other people about the research

Sharing research is an important way to let people know what we have learned. This might be through talking to other researchers, or writing or making films.

### ANOTHER EXAMPLE OF INCLUSIVE RESEARCH:

In another research project, people with a mental health disability were asked by university researchers if they wanted to do interviews in groups (called focus groups) with people who use a mental health service. They wanted to find out what people felt about the service they were using.

The researchers with a disability were paid to do the research.

The researchers thought that involving people with disability as part of the research team was important because it helped people feel better about sharing their experiences. The researchers with disability had a better understanding of the things spoken about than the other researchers.

## WHY IS IT GOOD TO BE INVOLVED IN INCLUSIVE RESEARCH?

- Inclusive research is important because work about people with disability should involve people with disability.

Being involved in inclusive research can also make you feel good. You might:

- Learn new skills which you can use in other parts of your life
  - Feel valued for what you know and what you can do
  - Meet and work with new and interesting people
  - Be part of a team
- It is good for researchers without a disability to learn from people with a disability. [?]
  - Your research can also help everyone to understand what is important for people with a disability.

## HOW CAN YOU GET INVOLVED IN INCLUSIVE RESEARCH?

There are different ways people with a disability might get involved in inclusive research. These include:

- A university can ask an organisation if they know people with a disability and ask if they want to be part of a research project.
- A university can ask people with a disability if they want to do research.
- A researcher can make an advertisement looking for someone with a disability to be a researcher on their project.
- People with a disability can decide to do research about something that is important to them.

## QUESTIONS TO ASK ABOUT BEING INVOLVED IN RESEARCH

It can be difficult to know if research is something you want to do.

Use the questions below to find out more about the research you are thinking about or talking about with others. They will help you think about things involved in inclusive research, what parts you want to be involved in and what help you might need.

1. Do I want to be involved in research?
2. Am I interested in the topic of the research?
3. How is the research team going to work together?
4. Does the project have ethics approval?
5. How will we collect information in the project?
6. What parts of the research would I be involved in?
7. What training will I get to be part of the research?
8. What help will I get to do the research?
9. What benefits will I get from the research?
10. How will we share what we learn from the research?

## DO YOU WANT TO KNOW MORE ABOUT INCLUSIVE RESEARCH?

Great! There are some more places people with a disability can read about inclusive research.

This booklet describes a research project which included people with a disability as researchers:

- Let me in – I'm a researcher! Getting involved in research by the United Kingdom Department of Health Learning Difficulties Research Team.  
<http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/assetRoot/04/13/29/79/04132979.pdf>

These two reports are examples research by people with a disability:

- Inclusive Research Network reports:  
[http://www.fedvol.ie/Reports\\_by\\_the\\_Inclusive\\_Research\\_Network/Default.2084.html](http://www.fedvol.ie/Reports_by_the_Inclusive_Research_Network/Default.2084.html)
- Thistle Foundation. Risk Research reports:  
<http://www.thistle.org.uk/riskresearchproject/adultprotectionresources>

## REFERENCES

**Example 1:** Telling the history of self-advocacy: a challenge for inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 34–43. Walmsley, J., & Central England People First History Project, T. (2014).

**Example 2:** Stakeholders' perspectives on community-based participatory research to enhance mental health services. *American Journal of Community Psychology*, 54(3–4), 397–408. Case, A. D., Byrd, R., Claggett, E, DeVaux, S, Perkins, R., Huang, C, Kaufman, J. S. (2014).



