



Údarás Náisiúnta Míchumais
National Disability Authority

Research Partnerships between Researchers and Disabled People



This is an Easy to Read report

What is this report about?



This report is about a study called a literature review.



A literature review looks at all the information on a research topic.



This review looked at information on research partnerships between researchers and disabled people.

This information was from 2015 to 2020.



A partnership is when people work together.

Why did we do this literature review?



In the last 20 years, researchers and disabled people worked together more often.



This happened for a number of reasons:



- Ireland has been putting the United Nations Convention on the Rights of Persons with Disabilities into action.



- There are more Disabled Persons Organisations. These organisations may take part in research or help put policies together.

Why did we do this literature review?



- Research groups have been set up, such as the Inclusive Research Network.



- There is a Public and Patient Involvement Network called the PPI Ignite Network.
This group encourages people to get involved in health and social care research.



- Some organisations give money for research.
These organisations want researchers to work with people that use services.
For example, the Irish Research Council.

Why did we do this literature review?



It is a good time to think about how researchers and disabled people work together.



We need to put together a guide on doing research with disabled people.



This guide is for the National Disability Authority and the wider research community.

Our research questions



What are the best ways for researchers and disabled people to work together?



What are the good things about researchers and disabled people working together?



What are the challenges for researchers and disabled people working together?



What lessons can we learn from research partnerships?

How did we do the literature review?



We searched for information.



We did this on a computer.



We used databases.

These collect all of the research on a topic from books, journals, and other places.



We looked at 161 different documents on research partnerships between researchers and disabled people.

What we found



Disabled people work with researchers on lots of different projects.



Sometimes, disabled people are called co-researchers.



Co-researchers are involved in different ways and to different levels in research projects.



The most common job for co-researchers is collecting information.

What we found



Co-researchers may also be involved in planning research.

They might help to study information, or to write and share the research report.



In the projects we looked at, co-researchers did not usually help to get money for the research project.



In the projects we looked at, co-researchers did not usually work on getting agreement for the research to take place.



People with lots of different disabilities were part of the research projects.

In many projects, co-researchers had intellectual disabilities or mental health issues.

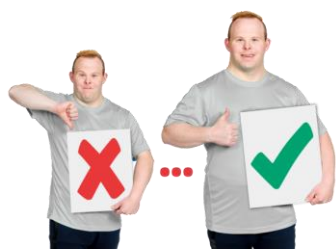
The good things about research partnerships



The research projects said there are lots of good things about researchers and disabled people working together.



Research partnerships give disabled people a chance to have their say, be treated equally, and use their rights.



The research can work better and have better results.



Researchers said they learnt new information and skills when they worked with disabled people.

The good things about research partnerships



Researchers learnt important skills for working with disabled people, for example, how to make information that everyone can understand.



Co-researchers with disabilities learnt new research skills and independent living skills.



Working in a research partnership gave people a sense of belonging and support.

Co-researchers often said they felt part of the team and were treated equally.



Co-researchers and researchers said that being involved in a research partnership was a rewarding and enjoyable experience.

Important things to think about



There are many ways for researchers and disabled people to work together.



Research projects where researchers and disabled people work together often take more time and cost more money.



These research projects might need more planning and preparation than other research projects.



There may be extra things to think about when it comes to getting agreement for the research.

Important things to think about



Researchers need to think carefully about who will be hired as co-researchers.

This is to make sure that all groups can take part.



We need to think about how we find co-researchers and how they are paid for their work.



Roles and responsibilities need to be clear from the start.



Researchers and co-researchers may need training for the research project.

Important things to think about



It is important that members of the research team trust and respect each other.

They must be honest with each other.



If you do not have good communication between researchers and co-researchers, it is difficult to have good relationships.



Another challenge is when power is not shared equally between the team members.



Co-researchers must be given the supports they need to take part.

Important things to think about



When co-researchers get the support they need, they can take part in every part of the research. This includes getting agreement for the research and getting money for the research.



Researchers must make sure that venues and information are accessible.



We need to think about any bad things that might come up for co-researchers, for example, feeling upset.

There must be support for people if this happens.



Some research projects were better prepared than others to meet the needs of co-researchers.

Important things to think about



It is important to record what happens during the research project.



It is important to check what has worked well and what has not worked.

This will help us learn the best ways to work in the future.



This Easy to Read report is from the
National Disability Authority.



Ace Communication helped to put
together this report.
Experts by Experience helped with this
information.

