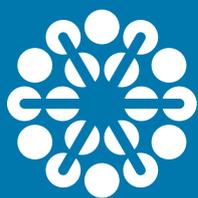


RESEARCH TO ACTION

>> 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:

Disability worker
good practice guide



ABOUT THIS GUIDE

This guide provides advice on conducting inclusive research with people with disability. It will be useful to you if:

- You are interested in doing an inclusive research project;
- People you support want to be involved in a research project; or
- People you support are invited to be part of a research project.

WHAT IS RESEARCH?

Research is a structured way of finding out about something to understand more about it. A researcher is someone who is involved in this finding out.

Research projects usually involve collecting information about people and their experiences. There are lots of different ways of collecting this information, such as interviews or surveys.

Research is often done by universities. It can also be done by organisations that work with people with disability, or by people with disability themselves.

Research is important because it tells us:

- What the experiences of people with a disability are;
- What is important for people with a disability;
- More about particular types of disability and effects on people;
- How to better services in ways that meet people's needs.

WHAT IS INCLUSIVE RESEARCH?

Inclusive research is research that involves people with disability in the finding out process. The people with disability involved in research projects are sometimes called 'consumer researchers' or 'research partners'. In this guide, we use the term **co-researchers** to refer to these people.

There are different ways that people with disability can be part of research, including:

- As part of the administration team who organise and run the research project;
- As providers of information for research projects;
- As advisors – for example, to advise on how the research should be conducted;
- Making decisions about which people should be involved in the research;
- Assisting with how data is collected and actual data collection;
- Providing opinions on what the data means;
- Working out what information means for the way different services work.

DIFFERENT TYPES OF INCLUSIVE RESEARCH

We can think about inclusive research as a spectrum of involvement. This ranges from advisory involvement (the lowest level of involvement) at one end to consumer led involvement (maximum level of involvement) at the other.



Advisory research: This is research that involves people with a disability as advisors. It is not generally thought of as inclusive research because people with a disability do not usually have control over the project or input into the actual research process in this type of research.

An example of this type of research would be a project where people with a disability do not take part in the actual **data collection** (interviews, surveys etc.) or **analysis** (working out what the data means), but have some guiding role in the project design and/or data collection methods. People with disability are not normally involved in research **dissemination** (telling others about what the research has found out) and are not normally named on **ethics applications** in this type of research.

Collaborative research: Collaboration means working together. Collaborative research projects develop research partnerships between researchers and people with disability. They create the research together as a research team. Co-researchers are often involved from the start of a research project and are included in most parts of the research, including data collection, analysis and dissemination.

You can find examples of different types of research throughout this guide. Examples of collaborative research are given below in Box 1 and Box 3. People with disability were involved in most parts of the research, but the way they were involved differed according to the needs of the organisations, the type of project and co-researcher interests.

Consumer-led research: Consumer-led research is research in which people with disability make a decision to create a research project on a topic of their own choosing. They may work with other researchers to help them conduct the research, but they will generally have control and be involved in all aspects of the project.

An example of this type of research is described in Box 2. People with disability who were all part of one advocacy organisation decided to complete a project. They contacted an academic researcher who could help them with their research by guiding the process. Co-researchers then worked together with the academic researchers on data collection, analysis and dissemination.

Other types of inclusive research: Other types of inclusive research might employ people with a disability as researchers but not include them on the project research team.

Box 1: Example of Good Practice in Inclusive Research: Involving people with intellectual disability in research

This study was started by university researchers who wanted to know what life was like for people with intellectual disability.

The research team included university researchers, co-researchers with disability and people who worked as assistants to help the co-researchers do the research.

The co-researchers with disability carried out 23 focus groups (group interviews) with people with intellectual disability across the country. Some parts of the research project were changed by the co-researchers so that the questions would make more sense to participants. The university researchers looked at all the data and analysed it. Then the co-researchers said what they thought of that analysis. The co-researchers and the university researchers wrote the report and presented the research together.

The co-researchers needed support from their organisations to be involved in the research team. This had not been thought about at the start of the project so made the project harder. Being able to be flexible and adapt the research project was important in making the project work.

WHAT TYPE OF INCLUSIVE RESEARCH WORKS BEST?

The three basic types of research described here are key ‘models’ along the spectrum of inclusive research shown above, but most projects will develop their own approach which aren’t exactly like these models but are somewhere along the spectrum.

The level of inclusiveness you have in a project will be determined by a number of things, including the topic of your research, your organisation’s needs and the co-researcher’s interests and abilities.

WHAT ARE THE BENEFITS OF INCLUSIVE RESEARCH?

You will probably know the statement, “Nothing about us without us.” This helps us to remember that people with disability should always be included when thinking about disability policies, programs and services. This applies to disability research too.

When people with disability are included in research, it has been shown to have several important outcomes:

1. The research is more likely to mean something to people with disability. If people with a disability are included from the start of the project, they can make sure that the research goals meet the needs of people with a disability. They can also make sure that the research questions are worded in ways that other people with disability will understand.
2. Inclusive research is able to find out things that academics might not understand. This is because they might not know what it is like to live with disability. By including researchers

with disability in the process of analysis, the results of the research are more likely to highlight those things that are important to people with disability.

3. Other people with disability will be more likely to be involved in the research if people with disability are involved as researchers. This is because people with disability might trust and feel more comfortable talking to people who have had similar experiences and understand their perspectives.
4. People with disability usually speak positively about being involved in research. Being involved in research can also provide people with good work experience.
5. It is right to include people with a disability in research. “Nothing about us without us” is ethically right. Many people involved in inclusive research get involved because they have a strong belief that it is important to do so. They believe that researchers should work to include the voices of people with disability in everything they do.
6. Inclusive research helps to build research capacity in the disability sector. This can then be used to start or be part of other projects. Training people with a lived experience in research makes it more likely that they will be involved in or lead research projects in the future.

Box 2: Example of Good Practice in Inclusive Research: Consumer-led research

In this project, some people with disability wanted to create a history of the People First organisation in England. The co-researchers were all people who had intellectual disability who had been part of the People First organisation.

People with disability led the project and controlled all of the decision-making. An academic researcher without disability was employed to create the history and another worker was employed to manage the project and assist the co-researchers.

The project used interviews and created a ‘talking event’ where different ideas and memories were collected from a group. They also collected documents and photographs. These were brought together into a history of the organisation.

The co-researchers enjoyed the project and felt that they produced work of great value. The project successfully delivered its aim to create a history of the organisation. The group also produced guides for how to do inclusive history research. It was felt that the co-research worked well within the organisation in which it took place because the organisation was already co-led by consumers.

There were also some challenges for the project team, however. For example, they felt uncomfortable about speaking on or writing research results about difficult relationships and bullying within the organisation’s history. Some of the interview participants saw the co-researchers as too close to the organisation and did not want to be interviewed by them. They therefore got someone else to do those interviews.

They also had trouble with a university they approached who were not willing to include people who could not read in research. Overall, however, it was a very positive process for the co-researchers, who felt that they had created something very meaningful.

WHY SHOULD YOU BE INVOLVED IN INCLUSIVE RESEARCH?

There are three main reasons disability workers might be involved in inclusive research:

1. The people with disability that you work with might like to start their own research project about something that is important to them. They will likely need some help from your organisation to do that.
2. You might want to share information about something you are doing in your work. You might also want to improve practice where things are not working so well. Developing research in partnership with people with disability can help to produce evidence of that good work, which can be shared with others or develop ways to fix current problems.
3. University researchers might ask your organisation if the people with disability you work with would like to be involved in a research project. If that happens, it is important to know what this would involve for your organisation and the people with a disability that you work with.

The questions below should help you to think through the reality of doing research in all of these situations. Not all questions or steps will apply to your research, but you should work through them in order to determine if they do.

WHAT DO I NEED TO CONSIDER IF PEOPLE I SUPPORT ARE ASKED TO BE INVOLVED IN INCLUSIVE RESEARCH?

Do the people with disability want to be involved in research?

This should be the most important factor in deciding on involvement. You should speak to the people with disability that you work with, and they should make up their minds themselves. People with disability should have the proposed research explained to them in ways that they understand so that they can make a fully-informed decision about whether to take part in it.

To what extent do the people with disability you work with want to be involved in research?

People with a disability should be allowed to choose which parts of the research they want to do. This includes the right not to be involved in parts that don't make them feel comfortable. Examples might include meetings, training, writing up findings, and presenting.

Is there a strong communication strategy set up between the people with disability, the other researchers and your organisation (as relevant)?

A communication strategy is necessary so that everyone involved in the research project (as researchers or supporters) can communicate effectively. This can take the form of regular meetings or catch ups where progress is discussed and delays identified. A formal process should be decided on between your organisation, the researchers, the co-researchers and their supporters, but is important that your organisation takes a lead on this to ensure that it happens.

What practical support will you need to give to the research?

Your organisation will probably need to provide practical support for the people with disability

you work with to be involved in the research. This may mean prompting people about their involvement, tasks to be completed and explaining things like confidentiality. Depending on the research, people may need to have emotional supports in place to deal with difficult subject matter. People may also need financial support to be involved in the research, either as a payment of money or through providing other funding such as transport vouchers or meals. You need to consider whether your organisation is able to be involved in this way.

How long will the research take?

Inclusive research can take quite a bit of time to produce. Your organisation needs to make sure that it can support people for that much time.

Has the research received ethics approval?

It is important that all research has been approved by an ethics committee (or will be) to reduce risk that people with a disability will experience anything negative from the research. (Ethics is discussed in detail in the next section).

Will the people with disability receive something in return for their involvement in the research?

People with disability bring unique skills, perspectives and expertise to research. This should be recognised in some way. A monetary payment might be agreed, or an equivalent credit or gift voucher. Other forms of recognition might also be explored. The impact of payments for co-researchers on their disability support payments should be considered. Expenses for travel, accommodation and disability-related supports should also be factored into your budget planning.

WHAT ARE THE STEPS TO CONSIDER IN AN INCLUSIVE RESEARCH PROJECT?

Inclusive research should take the lived experience of people with disability seriously and involve people at all points of the research. However, the actual process of putting this into practice can be quite complex and will take commitment.

The diagram below sets out the 10 steps of an inclusive research process. While these steps will differ according to each project, they provide a useful guide if you or people you support are considering becoming involved in an inclusive research project.



STEP 1:

Is inclusive research right for these circumstances?

Think about both the research question(s) being answered and the co-researchers that might be involved.

If the research question is too complex, it may be very difficult to involve co-researchers in all aspects of the project (e.g., if it needs special research skills that co-researchers do not have and which it would be difficult to teach). In these cases, it may be better to break down the project into smaller parts that the co-researchers can control or that enable their meaningful involvement.

Inclusive research should always seek to benefit people with disability. This is an important ethical idea to ensure is included in inclusive research.

You should also consider whether there is a genuine need to conduct the proposed research. Involving people in research that is not necessary but asks people to invest time and effort is also unethical.

STEP 2:

Speaking to people with disability who might like to be involved in the research.

People with disability should be involved in projects as early as possible, preferably in the beginning discussion stages when the project is decided upon.

You may work with people with disability who would like to be involved. This can be a good option if you all get on well and already know each other.

Be aware that existing power dynamics between service providers and people with disability might influence the way your

research team works. People may be more likely to agree to what you think rather than sharing their own ideas.

Other options are to speak to an inclusive research group that is already operating, or to try and partner with an advocacy organisation to see if there are members of the organisation who might be interested in research.

STEP 3:

Think through the capacity of your organisation and all the people on the research team.

The capacity of your organisation and the members of your research team will impact on the scope of the project and your ability to complete the project once you begin.

Check that you have all permissions from your organisation for the research to take place. You will need commitment from your organisation as a whole or you may find that your project stalls at key points.

Start projects with an understanding of how long the project will take. Many people writing about their experience of inclusive research projects comment that the projects take much longer than expected. This can be as a result of extra training, ill health, or negotiations about process.

Some co-researchers will only be interested or able to participate in some aspects of the research. This should be their choice.

Depending on the research design, a project can be expensive. You should consider the research expenses for data collection such as travelling to interviews, providing travel costs for focus groups and the cost for transcribing (getting someone to write down everything said in an interview or focus group).

If your organisation is conducting the research, you will also need to think of the organisation's ability to pay co-researchers. While some people are happy to volunteer in projects, this should not be assumed.

People with disability should be recognised as experts contributing time and effort in the same way as other members of the team. Sometimes the disability support benefits received by people do not allow paid work, so this needs to be checked before payments are accepted. These factors need to be weighed against each other.

STEP 4:

Research design – What methods should be used to collect data?

Research methods should be chosen to suit the research topic.

A survey can be a useful 'method' to get information from a large number of people. However surveys are limited in how much you can explore what people have said. Focus groups are a good option if research is interested in understanding shared group experiences, for example of a group of people accessing your service. They are also useful if there is limited time to conduct the research and there is an existing group of people that can be brought together quickly.

To get an in-depth understanding of a person's experience, researchers can use interviews. Interviews can also be used alongside the other types of data collection discussed above, or with visual methods such as photographs or videos.

The choice of these or other research methods will depend on the skills, interests and abilities of the co-researchers working on the project. Think through how you can include people with disability in data

collection. This may include adapting standard research practice: for example, working face-to-face where possible.

STEP 5:

Ethics of the proposed research

Ethics ensures that research takes place in a way that respects the decision-making of everyone involved in the project – researchers and participants.

Ethics includes thinking about confidentiality (keeping personal information private); consent (people agreeing to the research and knowing what they are agreeing to); the benefit of the research; and possible harms that might result from the research.

Ethics approval involves a group of people not involved in the research assessing whether the project has been created and will be run in an ethical manner.

Many big organisations or universities have ethics committees which will judge the ethics of your project. If your organisation does not have its own ethics committee, you can use any one of the committees that have been approved by the National Health and Medical Research Council (NHMRC). Find them at <https://www.nhmrc.gov.au/health-ethics/human-research-ethics-committees-hrecs>

Keep in mind that ethics approval is often not easy when it comes to inclusive research and may cause difficulties for your co-researchers. Ethics committees sometimes have difficulty understanding the true capacity of co-researchers by either under- or over-estimating their capacities. For example, they may make them read and say that they understand long documents, or ethics committees may feel that people with disability do not have capacity to respect ethical processes such as consent. You may

need to educate or explain capacity clearly to the ethics committee so that they understand your project.

STEP 6:

Training people with disability to do research

It is important that co-researchers are able to develop the skills to collect data and participate in a genuine way.

Training can be conducted formally through a structured program or informally as the project progresses.

Formal training can vary from a small number of sessions designed to teach core aspects of the methodology, to longer courses with in-depth research training. A benefit of this second approach is that the co-researchers can develop a set of skills that may be transferable to other projects.

Informal training happens 'on-the-job', and may take the form of an apprenticeship model (where a co-researcher is taught while working on the project with a more experienced researcher). This approach may be better as it will allow the co-researchers to draw on their lived experience of doing the research rather than modelling an idea of research learned from a course.

Click below for examples of training developed by Hancock et al (2012):

- Trainee version - <https://ses.library.usyd.edu.au/handle/2123/9318>
- Trainer version - <https://ses.library.usyd.edu.au/handle/2123/9319>

STEP 7:

Carrying out the data collection

Collecting data (the information you get from people) involves carrying out activities which are designed to get people (participants) to

provide information that will answer your project research questions.

Co-researchers with disability may be better placed to engage participants with disability because of their similar experiences of disability. This needs to be managed carefully however because people may agree to do the research because they know the person or are anxious about offending them.

Research data must be collected in a structured way according to a system or methodology. This helps to make sure that the data is not 'biased' (influenced by someone or something) which could happen if different ways of getting the data was used with different participants.

Ways of collecting data can be changed to meet the needs of co-researchers/

People with a disability may also need assistants to be employed to help them carry out the data collection. This can take the form of advisors who may remind the co-researchers about important steps in data collection which they need to remember.

Other members of the research team can also partner with co-researchers in data collection, for example carrying out interviews in pairs.

STEP 8:

Analysing the data you have collected

People with a disability can bring new ideas to research data analysis that might be missed by people who do not have disability.

It is ideal to include co-researchers as much as possible in the analysis. While some types of data analysis are too technically complex to be conducted by people who are new to research, most research data will be able to be analysed with training.

There is great variation amongst what is currently done. In some projects, data analysis is done solely by people with disability. In other projects, it may be a collaborative effort where all researchers work together to analyse the data as a group.

Another approach is for researchers without disability to do an initial analysis of the data, and for co-researchers to systematically check or add to the data analysis through a different set of eyes. Choose the approach that is best for your research team and topic.

As with data collection, it is very important that the data is analysed in a structured and systematic way. This will limit bias and help to ensure that your research findings are a true reflection of the things that your participants told you in the research.

STEP 9:

Telling others about the research you have carried out

Research dissemination is about sharing the lessons from your research. Results should be presented in a way that can be understood and used by a range of people. This can include academics, service providers and people who use disability services. Co-researchers with disability often provide valuable advice on making sure information is accessible and can be easily understood by different groups.

Research is usually shared through publication in academic journals or in reports. These can be co-written by people with disability. Usually, co-writing publications is done either as a group or with sections of publications written by co-researchers with disability and other researchers. Sometimes there are restrictions by the publishers of academic journals about who can be named as an author, so this needs to be checked.

Research findings can also be shared through

events, performances, art exhibitions, videos, podcasts and displays. Think about the ways the project results can be best interpreted for people with disability who you work with.

It is also important to think about how people with disability can be involved in research dissemination events. The participation of co-researchers in public events provides recognition for their work and sends a strong message which may encourage more people to do inclusive research.

STEP 10:

Project closure and next steps

As a project team, you should think about what happens when funding or research finishes.

Often co-researchers have made friends, support networks or received paid employment as part of a project, so the project ending can mean a big adjustment.

Some ideas used in previous inclusive research projects include a 'closure' photo exhibition or a presentation to the co-researchers, or a lunch to celebrate the project experience.

Many projects however will keep the inclusive research group meeting with the aim of thinking about future research projects. An ongoing meeting of the research team every couple of months, where skills and research are shared on an ongoing basis, may mean that the group is able to develop their interest in inclusive research and be more able to take on new research projects when they are appropriate.

Box 3: Good practice in inclusive research example: How are services being experienced by those who use them?

This research project was funded by a service who wanted to know how people with mental ill-health felt about using their service. People using the service were employed by a researcher from a university to collect information from people with mental ill-health through 14 focus groups. They then analysed the information from the focus groups to find out what people thought about the service. University researchers helped out with the focus groups and the analysis. They all worked together to create a report of the project and have since been involved in other research together.

For the service, the other services they worked with and academic researchers, involvement of people with disability as part of the research team was important because it helped the participants to open up in the focus groups and share their experiences more freely. The people with disability had a better understanding of the issue spoken about than the other researchers. Their position as researchers was also important because it helped to make people with disability more respected by the staff in the organisation.

This research has been written about in an article which was also co-written with people with disability.



WHERE CAN I GET FURTHER INFORMATION ABOUT INCLUSIVE RESEARCH?

THIS GUIDE IS SUPPORTED BY AN IN-DEPTH REVIEW OF RESEARCH.

This guide has been developed as part of the Research to Action series. It is accompanied by [other resources]. The literature review provides much more information about inclusive research with references for all of the concepts discussed. [Insert text re the guide for people with disability]. You can access both documents here: insert weblink

LINKS TO OTHER GUIDES

The following are links to online resources that might be helpful in thinking further about inclusive research:

Disability Inclusive research principles by the Centre for Disability Studies: <http://cde.org.au/wp-content/uploads/2016/04/Inclusive-Research-Principles.pdf>

Research Toolkit for Disabled People's Organisations: Shows how to undertake inclusive research. By University College London: <http://globaldisability.org/wp-content/uploads/2016/02/Research-Toolkit-for-Disabled-Peoples-Organisations-Leonard-Cheshire-Disability-Published-Version-1.pdf>

Learning Difficulties Research Team. Let me in – I'm a researcher! (Accessible language version). Getting involved in Research. By the Department of Health, UK Government: <http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/assetRoot/04/13/29/79/04132979.pdf>

Inclusive practice for research with children with a disability: a guide. By Elena Jenkin, Erin Wilson, Kevin Murfitt, Matthew Clarke, Robert Campain and Lanie Stockman: http://www.voicesofchildrenwithdisability.com/wp-content/uploads/2015/03/DEA-Inclusive-Practice-Research_ACCESSIBLE.pdf

ABOUT THIS GUIDE:

This guide to inclusive research for disability workers was written by Associate Professor Jennifer Smith-Merry from the University of Sydney Centre for Disability Research and Policy.

CASE STUDY REFERENCES:

Box 1:

- Garcia Iriarte, E., O'Brien, P., McConkey, R., Wolfe, M., & O'Doherty, S. (2014). Identifying the key concerns of Irish persons with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27(6), 564–575.
- O'Brien, P., McConkey, R., & Garcia-Iriarte, E. (2014). Co-researching with people who have intellectual disabilities: insights from a national survey. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 65–75.

Box 2:

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

Box 3:

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

