THE CENTRE FOR APPLIED DISABILITY RESEARCH

The Centre for Applied Disability Research (CADR) is an initiative of NDS. CADR aims to improve the wellbeing of people living with disability by gathering insights, building understanding and sharing knowledge. CADR’s applied research agenda is helping to build the evidence base and support stakeholders to better understand what works, for whom, under what circumstances and at what cost.

RESEARCH TO ACTION GUIDES

Our objective is to build a comprehensive online collection of disability research and translational resources for the Australian context. Our Research to Action Guides are based on the best available local and international evidence and put together by subject matter experts to support research end users to engage with the evidence. We gather and analyse evidence about what works, and package that information into efficient and practical resources.

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This Guide was authored by Dr Jennifer Smith-Merry from the Centre for Disability Research and Policy at the University of Sydney.

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SUGGESTED CITATION


ABOUT THIS RESEARCH TO ACTION GUIDE: INCLUSIVE RESEARCH

This Research to Action Guide is a suite of resources produced by CADR on inclusive research. The suite includes a rapid review of the research evidence and current practice. It also comprises practice guides for research practitioners and people with disability undertaking research (all available at the CADR Clearing House, www.cadr.org.au). This Research to Action Guide is intended to promote and support best practice in inclusive research, ensuring that end-users of services and policies are key in decision making.

FEEDBACK

Do you have feedback, or a suggestion for a Research to Action Guide? We welcome your thoughts and ideas. Please contact info@cadr.org.au.
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INTRODUCTION

Inclusive research developed out of the aim to include communities in research as a response to critiques that the end-users of services and policies were not included in decision-making. It is underpinned by the often-used catch phrase of the disability rights movement: “Nothing about us without us”¹. Recently, however, inclusive research has become more formalised, with some grant funders making the involvement of people with a lived experience of the subject under investigation compulsory for securing funding².

In 1969, Sherry Arnstein drew attention to community participation and prompted the consideration of inclusion through the publication of her ‘ladder of participation’, which describes involvement from manipulation to citizen control (see Diagram 2, below).

**Diagram 2: Arnstein’s ladder of participation**

This provides a continuum of least-to-most involved in service planning and calls to account service and policy makers who do not genuinely involve those communities with which they work. A similar focus drives inclusive research. A 2015 review³ of inclusive research in intellectual disability found that many researchers conceptualised inclusion in relation to Arnstein’s ladder.

This review corresponded with the findings of previous research, which showed a wide variety of terms describing approaches to ‘inclusion’. Bigby et al categorised the literature into three types: “advisory, leading and controlling, and collaborative group.”⁴ These various approaches can be seen as a spectrum of inclusion with advisory at one end and co-researcher-led at the other.

Along this spectrum, a number of key models emerged. The main ones identified were emancipatory research, participatory action research, inclusive research and collaborative research.

**Diagram 3: Spectrum of models**
Others have also identified inclusive research as:

- Advisory committee guiding research;
- Planning groups designing research;
- People with a disability employed as researchers; and
- People with a disability participants in the research.

This last type would not generally be seen as co-research. However many papers described themselves as ‘inclusive’ or ‘participatory’ and did not include people with lived experience, except as research participants. This demonstrates the broad application of the term ‘inclusion’.

Inclusivity is usually characterised according to what extent co-researchers are actually involved in the research. Rose states that there are three types of co-researcher involvement in research: “consultative, collaborative, and user-led”.

‘User-led’ research is that in which co-researchers are in control of the whole research project. This contrasts with ‘collaborative research’, which is based on collaboration between co-researchers and other members of a research team. Abma et al (2009) describe the roles that co-researchers take in research on a hierarchy. This is shown in Extract 1, below:

Table 1 – Overview of the Roles and Tasks of Patients in Health Research

<table>
<thead>
<tr>
<th>Roles</th>
<th>Tasks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Object or respondent</td>
<td>Cooperating in a clinical trial; sharing information in interview or survey</td>
</tr>
<tr>
<td>Advisor</td>
<td>Bringing experience; discussing new developments; evaluating scientific articles and research proposals (as referent); advising; managing research projects as members of scientific commission</td>
</tr>
<tr>
<td>Interviewer/moderator</td>
<td>Jointly composing surveys and topic lists; conducting interviews with patients; preparing and/or leading a focus group</td>
</tr>
<tr>
<td>Research partner</td>
<td>Jointly developing a design; gathering, analyzing and presenting data; writing publications; evaluating articles and research proposals; participating in scientific congress</td>
</tr>
<tr>
<td>Research principal</td>
<td>Initiating research; developing and maintaining a knowledge base; joining established research networks</td>
</tr>
</tbody>
</table>

Consultative research, whereby co-researchers are only involved in an advisory role, is viewed as tokenistic. As Epstein states, “It is not just about adding a pinch of consumer to unchallenged research assumptions, and stirring like mad.” As the review of papers in this report progressed, a decision was made to exclude papers that only included consumers in an advisory role. This was done because of the very small levels of involvement in most of those studies in the face of no physical limitations on consumer involvement in these ways. Generally, the earlier papers had less actual inclusion in the inclusive research – e.g. advisory roles only. This may be due to growing expectations about more sophisticated levels of inclusion.
AN AD-HOC MODEL OF INCLUSIVE RESEARCH

Most papers did not use a particular model of inclusive research, but developed an ad-hoc model to suit the demands of their project and the co-researchers that they were working with. This was viewed as preferable to highly-structured models. Several papers reflected on the demands of a model and what this meant for both researchers and co-researchers. Woelders et al, for example, felt that inclusive research “...can be a rigid concept, guided by the ideal of social justice, expecting the same things of the academic researcher and the person with intellectual disabilities without a critical look at the added value of including people with intellectual disabilities.” 10

Difficulties in implementation of the model necessitated the development of a less structured approach. “As a community of researchers, we continue to juggle balancing principles and pragmatics.”11 Diagram 4, below, shows another, more flexible way of considering inclusive research with different levels of involvement of consumers from support to interdependency within a formalised or improvised framework. The key message here is the importance of keeping inclusive research practices open to meet needs of both project and co-researchers. 12

Diagram 4: Model of ad-hoc working, Nind and Vinha, 2014.

Several papers comment on the need to work with co-researchers’ particular needs and strengths13. In some cases, this meant the development of completely new methods for data collection. For example, Rome et al (2015) developed a new methodology which suited their research context (co-researchers were young people working with young people). The new method centred around ‘research spaces’ consisting of ‘agenda’ events where research knowledge was more likely to emerge for this group than by using traditional data collection methods. Others adapted research methods so that co-researchers could manage them more effectively14. The challenge here is to adapt the method without losing the academic rigour of the project and making results meaningless to others. This is discussed further below.
EMANCIPATORY RESEARCH

Emancipatory research is a model of inclusive research which actively challenges dominant hierarchies of knowledge. It is shaped by the ‘British social model of disability’ and evolves from the disability social movement in the UK. It is underpinned by an explicit social justice framework:

“Emancipatory research wants to redress these exclusion processes in society and is deliberately and explicitly emancipatory driven; empowerment of people with disabilities is an important goal. From this starting point, emancipatory research is not only a way to contribute to the co-production of knowledge but is also a form of political action.”

The aim is therefore not just to include or even partner with co-researchers, but to emancipate or free them from a social context which has invalidated their experience in the past. Boland et al (2008) make a distinction between ‘emancipatory research’ (which occurs in partnership) and ‘true emancipatory research’ (research led by those with a disability). Within an emancipatory framework, some researchers have gone so far as to state that only those people who have a disability should actually carry out research on disability.

INCLUSIVE RESEARCH

While used as a very general term, inclusive research also represents a distinct model of research. The term came to be defined as something specific in the work of Walmsley. While including some of the same concepts of control and social justice as emancipatory research, it allows more scope for other interests to enter the research process. It also prioritises collaboration rather than the necessity of co-researcher project leadership. Walmsley and Johnson defined the following components of an inclusive research model:

a. “Having ownership of research questions;
b. Being collaborators; that is, involved in the doing of the work;
c. Exercising some control over process and outcomes;
d. Being able to access questions, reports and outcomes; and finally
e. That outcomes will further the interests of people with intellectual disability.”

This provides a good framework for understanding the core inclusive elements of research and can be used by researchers to understand their own inclusive research practice. For example, these components have been used by Bjornsottir and Svensdottir (2008) and others to test the inclusiveness of their own research. However, what is termed inclusive research in not always inclusive. Because of the diversity of papers that sit under the term ‘inclusive research’ in the literature – only a small number of which fit within this model – caution should be used when speaking about this model. Nevertheless, the framework provided is useful for conceptualising an inclusive approach to research.
PARTICIPATORY ACTION RESEARCH

Participatory Action Research (PAR) was very frequently cited as a model of inclusive practice in the studies included in the review. However, as with inclusive research, its application could manifest in a very broad range of practices. The PAR approach mixed inclusive research defined above with a more dominant focus on the emancipatory principles of emancipatory research. Stripped to its elements, Selener and Balcazar et al developed four principles of PAR:

1. “Disabled individuals articulate the problem and participate directly in the process of defining, analyzing and solving it”;
2. “Direct involvement of disabled people in the research process facilitates a more accurate and authentic analysis of their social reality”;
3. “The process of participatory research can increase awareness among disabled people about their own resources and strengths”;  
4. “The ultimate goal of the research endeavor is to improve the quality of life for disabled people”.

As this demonstrates, there is a strong element of ‘equalisation of power’ in a PAR approach, with some stating that PAR cannot be implemented without a focus on the emancipation of co-researchers.

COLLABORATIVE GROUP

The ‘collaborative group’ approach defined by Bigby et al is an approach to which many inclusive research papers aligned with without naming it as such. Extract 2, below, demonstrates the components of the collaborative approach.

Extract 2: Bigby et al 2014a ‘Components of a Collaborative Group Model’.

As this graphic shows, this model is built on principles and flexibility rather than a structured approach and strict requirements. Its application is pragmatic and context-dependent rather than directed by the model, yet it still seeks to critique and level power imbalances. This fits well with the ad-hoc approach discussed earlier.
INCLUDING CO-RESEARCHERS:
PRACTICALITIES AND EXPERIENCES

Taken together, the papers included in the review show that including co-researchers necessitates not just a willing co-researcher but a detailed understanding of the model for inclusion, an understanding of the value that working with co-researchers brings to the project and an understanding of their talents and needs with regards to project tasks.

Several papers spoke about the need to consider the ‘added value’ that co-researchers provide rather than just including them because it was the right thing to do or a funder required their inclusion. There was a need to include not just people with a disability but people with a disability who had the capability and interest to be able to do research. Timmons et al, who were conducting a project on the employment decision making of people with an intellectual disability provided the following list of requirements for their co-researcher:

- “(a) have an interest in learning about how people find jobs,
- (b) have the desire to participate as a member of a research team,
- (c) self-identify as someone with intellectual and developmental disabilities, and
- (d) have the capability to work with team members.”

Other papers reflected on the need to acknowledge and work with the unique skills that co-researchers had, rather than to meld them into a preconceived idea about what the co-researcher could offer. In the paper by Koenig (2014), three different people with intellectual disability were included in their research to bring in a range of different types of knowledge. They included people with intellectual disability who were politically active, those with skills in research, and those who had life experience of the matter being researched. Each of these individuals would bring something different and important to the research project.

PROJECT DEVELOPMENT

Very few of the projects originated with the co-researchers themselves. Those that did were mainly projects which arose from existing groups of co-researchers who were already involved in research. One project developed by co-researchers within an existing activist group of researchers brought in a ‘scientific advisory group’ of academics to advise on aspects of research. One such group is the Irish Inclusive Research Network.

Most of the models listed earlier take for granted that co-researchers will be involved throughout a project. This was the case for more than half of the papers in the review. For others, their involvement was restricted to only one or two stages of the research, such as data collection or analysis. While this restriction usually came from academic researchers designing a project, it could also come from co-researchers who had no interest in being involved in aspects of research that were not interesting or were too difficult for them. Hart developed a ‘ladder of participation,’ measuring the levels of participation of children in research similar to the table by Abma et al. For Ajodhia-Andrews (2016) it was clearly in the ‘best interests’ of those co-researchers in their project to co-research less intensively (lower on the ladder).
CO-RESEARCHERS INVOLVEMENT IN DATA COLLECTION

Several projects employed ‘supporters’ to work with and assist the co-researchers as necessary in project tasks. One co-researcher with an intellectual disability commented, “It’s also very good to have a research advisor I think, because she can advise us on what to do and what not to do, and help us make our decisions.”34. In Gillard et al’s (2012) study, co-researchers experiencing mental ill-health were paired with other researchers. They found little difference in interviewing style between researchers and co-researchers except in the way that probes were used35. In another project, co-researchers adapted focus group methods to suit both co-researchers and participants – e.g. a round-robin approach so everyone gets a turn36.

CO-RESEARCHER INVOLVEMENT IN ANALYSIS

Many papers included co-researchers in all areas except analysis, which was seen as a more complex or subtle process which involves more training. However, those that did include them found that co-researchers brought out elements of the data not picked up by others37. One paper looking at the use of co-researchers in data analysis found that co-researchers were more likely than other researchers to code the instances of ‘experiences and feelings’ where other researchers coded ‘processes and procedures’38.

For some of the projects, consumers were not included in the data analysis but were consulted in depth about the results. For co-researcher involvement in reviewing analysis, Buettgen et al used three questions based on Cashman: “In reviewing results, what do you think they mean? What is your understanding of what the data says? Are there any surprises, that is, findings that you did not expect? If so, how do you make sense of them?”39

CO-RESEARCHER INVOLVEMENT IN DISSEMINATION

For a significant number of papers, co-research extended to dissemination. 42 papers were co-written by people with a lived experience of disability. Co-writing took different forms. In some papers the co-researchers write alternate parts of paper40, but in most others they were just involved generally. In other papers, co-researchers were not included despite the project representing research at the most inclusive end of the spectrum. This can be problematic as “questions will arise as to whether the co-researchers have legitimacy in claiming authorship”41 when they have conducted so much of a research project.

Dissemination also included a broad range of formats beyond traditional reports or academic journal articles. This included theatre performances, lay publications and art exhibitions.42 Accessible dissemination is also important so that project outcomes may be shared and consumed by the co-researchers and their communities.
CO-RESEARCHER EXPERIENCES OF THE PROCESS

53 papers included reflection on the co-researcher experience of the research. Those that did reflect on the co-researcher experience (through the lens of either the co-researcher or the researchers writing up the paper) generally commented that the experience was a good one for the co-researchers and that any difficulties were overcome by positive experiences. Co-researchers felt proud of their research, developed new skills, felt valued or part of something important and enjoyed contributing to the community through the research. This aligns with the findings of the systematic review by Frankena et al (2015) which found that co-researchers “were empowered; gained skills; gained confidence; gained experiences; employment; felt they could contribute; felt respected; experienced personal development; and experienced mutual understanding”. The process could also be hard at times with several papers commenting that the research could also be emotionally difficult when the subject matter was confronting or close to home for the co-researchers or if the data collection was practically difficult.

Several papers evaluated in this rapid review speak about the co-research being therapeutic for co-researchers. Here, there is a mixing of research and “community development work”. Some of the co-researcher reflections bring out the emancipatory aims of inclusive research. For example, one co-researcher did “not want to take part in a research project where she has no say.” Involvement could indeed become a turning point in an individual’s life:

“IT was fantastic to come off benefits, and to get my first proper paid job. But I didn’t expect to get a job, because I expected to be on the scrapheap for the rest of my life. That’s the important part of it for me personally. And I’ve built my confidence through being on this project.”

One co-researcher provided a perspective on what factors in the development of a project enable co-researcher participation:

Extract 3: Co-researcher reflections on successful co-research.

While this reflection applies in particular to co-research with people with intellectual disability, it provides a clear explanation of co-researcher needs more generally.

The people who you work with:
- You need to be able to trust them
- You need to be comfortable with each other, respect each other, be honest with each other
- They need to be organised, skilled, reliable
- Be able to get you involved – not do the work for you

The project:
- Something you are interested in and have some experience of
- Something you care about
- Something you can do

The job – what you need:
- A clear job description
- Someone to do the paperwork
- Work out the pay and get paid the right amount at the right time
RESEARCHER EXPERIENCES

A number of papers reflected on the impact of involvement of co-researchers on the other researchers in the project team. Chappell et al (2014) stated that all researchers (both co-researchers and professional researchers) developed an altered understanding of themselves as a result of the involvement in the project. While it was therapeutic for co-researchers, one paper stated that it could also be therapeutic for researchers54. For researchers coming from an academic or practitioner background, co-research involves a reconceptualisation of the researcher’s own values – e.g. towards a human rights perspective to become an activist social researcher55.

Inclusive research can also be challenging. The models listed can bring with them quite strict processes and ideals which place pressure on researchers. One researcher stated that they felt they “could not live up to the ideals of inclusive research” and that they faced multiple difficulties and challenges in the process56. Co-production with co-researchers also challenges traditional hierarchies of academic knowledge, involving:

1. “a move away from academically led research institutionalized within the university
2. a transdisciplinary approach involving a range of scientific and nonscientific expertise
3. nonhierarchical, heterogeneously forms of undertaking research...
4. an increasing reflexivity and social accountability of knowledge production
5. a challenge to what is counted as ‘good science’”57

Kidd and Edwards reflect that engaging in a research project involving those things can challenge a researcher’s own position within academia:

“These actions come at a professional cost, even reaching into our personal perceptions of whom we are and what we have to offer. Relinquishing power to people who are socially excluded and stigmatised, such as mental health service users, comes with the very real risk of attracting those same consequences to oneself. Co-production is a political act of courage, presence, authenticity, and reflexivity”58

BENEFIT FOR RESEARCH

Co-researchers should not be included in research unless there are specific benefits for the project. A scoping review of inclusive research (using more narrow terms than this current research) looked at reasons for including co-researchers in research. It found that they were included because of their “expertise, experience and their ability to build meaningful relationships” with other co-researchers59. Frankena et al stated that research involving co-researchers experienced the following benefits: “increased quality and validity; developed appropriate research materials; facilitated research with people with ID; safeguarded ethical standards; developed relevant research and outcomes; learned new skills; improved data analysis; facilitated recruitment; improved data dissemination; and experienced mutual understanding.”60
These findings were reflected in this review where co-researcher involvement was shown to break down power differentials between research subjects with disability and researchers in several studies. Co-researchers hold “‘experiential knowledge’ which is increasing in legitimacy” in disability related research. The difference in approach brought about by co-researchers also enhances the validity of data produced by making it more multi-dimensional.

DIFFICULTIES AND CRITIQUES

Inclusive research does not operate in a context free of critique. Some people have accused inclusive researchers of using people with a disability as ‘puppets’ to promote their own interests. Others have labelled co-production as a “buzzword which does not produce as much benefit for research as is made out”. It was clear that in some projects, co-researchers were involved in the research, but it was hard to see how their research and understandings were included in the project findings.

Chappell et al (2014) state: “The medical model of disability constructs persons with disabilities in terms of ‘deviance, lack and tragedy’ as victims of impairment and as objects to be studied rather than as subjects and agents of research.” Inclusive research challenges this. However if researchers feel that they are ‘giving voice’ to people with a disability by including them in research, this can also reinforce the problematic medical model. Inclusive research must be genuinely collaborative. This should also be a warning against an empty ‘emancipation’ that makes co-researchers feel good but does not move knowledge forward.

Power is a problem that needs to be dealt with continually in collaborative research. Researchers need to consistently question their relationship with co-researchers and assumptions about their needs, interests, knowledge and abilities. There is also a need to make sure that co-researcher ‘supporters’ don’t take over or influence the co-researchers. The danger here is that co-researchers will be co-opted into expressing someone else’s interests rather than their own.

Several papers spoke about the different timeframes operating in different worlds (co-researcher vs. academic or clinical) which could make researchers or co-researchers frustrated. Time for physical health problems also needs to be foreseen, and built into the design where it is likely to be a problem encountered by co-researchers. Extra time should also be built into projects as lead-in time for working out issues such as power dynamics, training and so forth.

In two projects, the time limits of the project meant that a truly collaborative approach between co-researchers and academic researchers could not be reached. For Mcclimens, this was just one aspect of difficulties relating to a shared writing project with co-researchers which had stalled. He wanted to draw attention to the difficulties inherent in timing and communication between co-researchers and researchers, stating that these were often ignored in accounts of inclusive research:

“I wanted to write this separate account because I felt that some of the grittier and messier aspects of collaboration were being glossed over or perhaps ignored in the publications I was reading. I found it hard to believe that other people in other
places were not experiencing similar frustrations and yet to read their narratives the collaborative research process was no more taxing than a walk in the park. The published product did not, to my way of thinking, reflect the protracted process.”

Where there is tension between lived experience and researcher needs, Gillard et al (2015) promote a ‘dialogical’ approach where tensions are discussed and worked through openly.

There is also a question 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, and the project ending can mean a big adjustment or let down. Dorozenko et al (2016) say that this can be problematic, and that, in their project they had a ‘closure’ photo exhibition. Grayson et al (2013) also discuss this issue, and note that they marked the end of the project with a presentation and ‘celebratory lunch’.

Other specific difficulties:

- In three projects, it was not possible to make the project fully inclusive because the PhD researcher needed to own the project, not the co-researchers (because of the requirements of the qualification). This called for pragmatism where the “constraints of the academic system meant that the aims of the research had to be recalibrated”;
- Including people who it is difficult to co-research with in person (e.g. study where co-researchers with autism collaborate online);
- Limitations of consumer-led inclusive research – Some important parts of the story are missing. In only understanding the consumer perspective on what is interesting, research might not have value for others who can use the data too;
- Paying people who are otherwise on the disability support pension could be a problem;
- Risk of moving from ‘genuine’ co-researcher to “becoming a “super user,” meaning that the service user experience and perspective have been replaced by a frame of reference that is more like an academic researcher’s.”

VALIDITY ISSUES

Critics state that co-research means that the researcher loses objectivity. Hancock et al (2012) also state that those opposed to consumer involvement cite a “perceived lack of objectivity and capacity and lack of research knowledge/skills”.

However, some of these issues are real, and there can be significant validity issues involved in inclusive research. For example, bias issues can arise where those who design or are described as co-researchers in the study are also involved as participants. This was the case in a significant number of the projects included in this review. In one project, co-researchers were participants who then wanted to have a go at interviewing and so were then included as co-researchers:

“This development is acceptable in the context of PAR approaches. These young women effectively challenged the traditional binary positions of the ‘researcher’ and the ‘researched’ and the corresponding potential for replication of oppressive social relations therein” (Stevenson, 2010).
The involvement was justified in terms of the aim of PAR being emancipation rather than other forms of validity. Other projects involved co-researchers in evaluating interventions that they themselves developed. Bigby et al state that, “For some people, their closeness to a topic might impede their ability to provide broad ‘advice’ about the direction a study should take or appropriate methods.” There are also issues when co-researchers are unable to collect data in a rigorous way.

The practices involved in some of the models mentioned above might be emancipatory for the co-researchers involved, but would mean that the research was not acceptable as a form of evidence in some arenas. For example, journals may baulk at publishing research with these types of inherent biases and funders may not fund projects that exhibit these limits to validity. These issues need to be carefully worked through and safeguards put in place so that the research remains valid and findings are able to be transferable and change practice.

**TRAINING**

There were significant differences in the involvement of co-researchers in training. One paper stated that training was ‘essential’ for participatory research, and conducted before the project began. In other papers, training was either provided on the job or gradually as the project progressed. This can be difficult, particularly if the research follows a very structured design, such as with a randomised controlled trial.

Different models of research training for co-researchers include “apprenticeship, lifelong learner, challenging inequality, addressing deficits and formal models”. Nind et al developed further models: inclusive immersion (more equal than the apprenticeship model) and the dialogue model – where different ideas are talked through (like in the seminars). They wanted to involve people in research, and therefore wanted them to be familiar with research, but didn’t want to train them in such a way that they lost what is unique about their own approaches.

A program by Salmon et al (2013), called the Research Active Program (RAP), trained people with intellectual disability to be co-researchers over eight weeks with topics including Research: What is it? Why do it?; Make research work for you; Your rights in research; Being a co-researcher; Making it count: telling people about your work; and do a public talk. This training teaches more about the context of research rather than the actual ‘how to’ of data collection and analysis.

Research training can be very intensive. In one paper, co-researchers were examined by the principal researchers on their knowledge of research and data collection. This followed very intensive research training, up to 15 weeks long. The problem with training co-researchers to be ‘researchers’ is that in mirroring the work of other researchers, they may lose contact with the added value that they bring in terms of their lived experience. ‘Failure’ of training may also lead to a feeling that their knowledge is not valid. A more appropriate approach may be to work with their existing skills; drawing on them and enhancing them through the project.
ETHICS

Ethics approval for inclusive research can be long-winded and difficult due to ethics committees not understanding the context of inclusive research – for example, needing competency of researchers to be assured\(^95\); and concerns about ‘capacity and objectivity’\(^96\). Ethics committees also had concerns about the skills of co-researchers to both conduct interviews and get the participants to validly consent\(^97\).

An ethics committee in one Australian study made co-researchers with intellectual disability read a long participant information sheet which was not accessible despite the need for accessibility.\(^98\) This meant that they couldn’t fully participate in the consent process and needed to rely on parents. It was also difficult to get the co-researchers to participate from the beginning of the project when ethics has to be gained before the project starts and co-researchers employed. This means that power imbalances will exist as they have not been involved in the project development, including important choices about methodology\(^99\).

Northway et al (2015) state that ethics committees have problems with participatory research because it develops as it progresses through dialogue with co-researchers, blurring the boundary between co-researcher and research participant. Their research focused on abuse and because of the sensitivity of this topic there were concerns about the ‘vulnerability’ of the co-researchers with intellectual disability. This is a real concern and steps need to be put in place to assure the safety of the co-researchers but not disempower them in the process. Conversely, not including people in research makes them more vulnerable because their perspectives are not heard. Ethics process can thus lead to further disempowerment for co-researchers\(^100\).

MEASURING THE INCLUSIVENESS OF RESEARCH

Several authors provide criteria against which to measure the inclusiveness of research\(^101\). Kidd and Edwards identify steps for ensuring true co-production as:

1) Is co-production right for research and team?
2) How should team communicate?
3) Who will lead the different stages of the research?\(^102\)

Dubois et al (2011) provide three questions to determine the extent of community engagement in research. These are adapted here:

- “[Are] individuals from the community ... provided with a voice (e.g. one representative, a small group of gatekeepers, or a random sample)?
- Do community members have authority to advise on the research protocol or to make key decisions regarding the research protocol?
- Are community members elevated to the level of co-investigators? Do they share resources and play an investigative role in the conduct research? Do they participate in data interpretation and dissemination?”

If the answer to all of these questions is yes then the research could be fairly considered as inclusive in nature. However, these still cover a wide range of research.
CONCLUSION: ESSENTIAL ISSUES TO CONSIDER FOR ACADEMICS EMBARKING ON INCLUSIVE RESEARCH

This review shows that, while the literature describes several models, there is no consistently-used model of inclusive research. Given this, and the differing needs of projects and co-researchers, the ad-hoc model based on the ethical principles of inclusive practice may be most appropriate. This approach would be well-suited to an Australian context.

The following issues are presented for consideration.

<table>
<thead>
<tr>
<th>Element of research</th>
<th>Issues to consider</th>
</tr>
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</table>
| Co-authoring publications | • Academics involved in co-research should consider how they might approach publication of results. Some journals (e.g. JARID) state that only those that have contributed to the writing of the paper should be named in a publication. However, if the co-researchers have devised the project and contributed to a significant part of the data collection and/or analysis which is reported in the paper, it may not be ethical to exclude them from authorship.  
• Only one third of papers in this review included co-researchers as authors. In some papers, co-researchers had written alternate parts of an article. In others, they were more generally involved. |
| Accessible outputs | • Co-researchers should be able to access, share and make use of research outputs for their own purposes. They should also be able to direct the creation of their own outputs if they choose to do so.  
• Several papers spoke about the development of non-standard outputs such as exhibitions and performances. This link provides an example of different forms of dissemination by Brookes et al (2012): http://www.thistle.org.uk/riskresearchproject/adultprotectionresources |
| Payment of co-researchers | • Co-researchers should be paid for their time, if possible. The impact of payments on disability support payments should be considered. |
| Timelines | • Extra time needs to be built into projects in case of ill-health, difficulties in data collection, accommodations for disability, training and deliberations. |
| Project finalisation | • The end of the project may be a time of sadness for co-researchers who may have developed skills, used their knowledge and built new friendships. It may be difficult for them to transition into a life where they are no longer researching. They should be supported in this process. |
| Research quality                                                                 | • Much of the co-research included in this review was of low quality when considered against standard quality scales such as that produced by the NHMRC. In order to justify the effort put in by co-researchers, the research should be constructed in a sound way where the research can be used by others.  
• Unless the research is purely a therapeutic or training exercise for the co-researchers, it is not ethical to involve people without a concrete aim for the research. For the research to be used by others, it should be constructed with a sound methodology that adheres to academic standards about validity as much as possible. |
| Researcher skills                                                               | • Consider the existing skills, interests and needs of co-researchers that you are working with and match to research tasks. Co-researchers do not have to be involved in every part of the project but should be included in ways that fit with the needs of the project. |
| Training of co-researchers                                                      | • Training may be necessary depending on the tasks that the co-researchers are involved with. This can be formal or informal.  
• Formal training described in the research in this review ranged from a small number of sessions designed to teach core aspects of the method being used to more extensive courses which offered in-depth research training. A benefit of this approach is that the co-researchers then have a set of skills that may be transferable to other projects. The training is also standardised.  
• Informal training happens ‘on-the-job’ and may take the form of an apprenticeship model. This approach may be preferable as it will allow the co-researchers to draw on their lived experience rather than modelling an objective researcher ideal.  
| Research training of academic researchers                                      | • Academic researchers should receive training throughout their structured university education which assists them to feel comfortable embarking on co-research.  
• This could involve co-researchers coming in to provide accounts of their lived experience of doing research. |
| Communication                                                                  | • Several papers in the review showed that research could stall because of communication problems. Communication structures between members of the research team (co-researchers and academic researchers) should be worked out at the start of the project and thought through as necessary throughout the project. |
APPENDIX A: SEARCH STRATEGY

The research developed from the following questions:

1. What fully-described models of inclusive practice have been developed for research with people living with a disability?
2. What models of practice do consumer accounts of inclusive research practice describe?
3. What practical ethical frameworks have been developed to support research with people living with a disability?
4. Which of these are most relevant in an Australian context?

In order to answer these questions, a search of the literature on inclusive research was conducted according to the following criteria:

- Inclusion criteria: Disability as defined by the NDIS Act 2013
- Exclusion criteria: Language other than English. Age of participants 65+
- Databases searched: Medline, Cochrane Reviews, Scopus, Cinahl
- Date range: 2006 to 2016

DESCRIPTION OF THE FINDINGS

The search of the academic literature resulted in 123 full papers being included in the final analysis (see Appendix A table for list of papers by stages of search). Of the papers identified, 109 described at least one inclusive research project, six were reviews of inclusive research, four were commentaries on inclusive research, including commentaries co-authored by co-researchers, and four were classified as ‘other’, including two papers that focused on training of co-researchers.

AREAS OF RESEARCH

Most of the inclusive research was conducted in mental health (41 papers) and intellectual disability (54 papers). There were four papers including children or young people as co-researchers. This aligns with the findings of a review of systematic reviews on public involvement in research which found that most work had been done in mental health (Boote, Wong, & Booth, 2015). Several papers focused on more than one type of disability and six focused on a much larger range of disabilities. Only one paper reported inclusive research with people from ethnic minorities and one focused on indigenous people. Four papers included a focus on carers or family members and two took place in a prison or forensic facility. Generally, the co-researchers were people with the same ‘type’ of disability as the subject of the study, but this was not uniformly the case (e.g. Nicolaidis et al. (2015), which included people with a range of physical and developmental disabilities on the research team although the study was on developmental disabilities). Box 1 below shows the variation of papers by type of disability.
Box 1: Paper count by characterisation of disability of co-researchers.

GEOGRAPHIC ORIGIN OF PAPERS

Papers were most likely to come from the UK (48 papers in total: 37 from England, six from Scotland, three from Wales and two from Northern Ireland). The next largest group of papers came from Australia (24 papers) and the third largest from the USA (20 papers). A small number of papers were cross-national and seven had no geographical origin but spoke generally about inclusive research (e.g. systematic reviews).

Diagram 1: Graph of papers by geographic area in which research conducted.

Around a third of the papers (n=42) were co-written by people with a disability. Three of these co-written papers were from Australia.
**RESEARCH TYPES**

Most of the papers included in the review focused on co-research in the fields of health or social sciences and focused either on service development, consumer experiences of health or social care, or identity. Most papers used a qualitative methodology. Most involved interviews and focus groups, however 14 studies involved surveys including several with quantitative components. There was also one randomised controlled trial and two framed around user-acceptability testing of a computer program. Non-traditional data collection methods including performances and art were also used. Theatre was used to collect data in three projects via ‘Theatre of the Oppressed’ or ‘Forum Theatre’.

**RESEARCH QUALITY**

Generally, the paper quality was low to very low in terms of generalisability and strength of methodology. Papers reporting on inclusive research largely comprised of reflections on the research process without a structured methodology. Those papers that compared models of inclusive research provided opinions rather than direct comparisons based in data. There were six systematic reviews which included discussions of inclusive research but none of these evaluated models of inclusive research against each other. Only one review provided a structured comparison of the use of co-researchers in research versus research without co-researchers and found no difference in research outcomes (Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2013). One of the systematic reviews emphasised that the inclusive research included in the review was of low quality and that all studies showed research bias (Anderson et al., 2015).

The research methodology and the exact nature of participation of co-researchers was not described well in the studies. For example, a significant proportion of the papers state that co-researchers were involved, but do not say how they were involved, what this involvement meant for the research, or how this involvement impacted on the co-researchers (e.g. Karban, Paley, and Willcock (2013)). This has been highlighted elsewhere (Bigby & Frawley, 2010). One of the systematic reviews discussed this as a serious limitation of inclusive research studies (Jivraj, Sacrey, Newton, Nicholas, & Zwaigenbaum, 2014).

**SEARCH TERMS**

- coprod* co-prod* co-design* codesign* co-creat* cocreat* co-develop* codevelop* co-research*
- “participatory research”; “emancipatory research”; “inclusive research”; “partnership research”; “people led” (all previous as OR) AND “disab*” or “mental health” or “mental ill*”
**PAPER COUNT AT EACH STAGE OF SEARCH**

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<tr>
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<th>After abstract review</th>
<th>Duplicates removed</th>
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<th>Final #</th>
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<td>Cinahl</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>1471</strong></td>
<td><strong>410</strong></td>
<td><strong>296</strong></td>
<td><strong>285</strong></td>
<td><strong>138</strong></td>
<td><strong>123</strong>*</td>
</tr>
</tbody>
</table>

**APPENDIX B**

Resources arising from the ‘grey literature’.

**GENERAL GUIDES FOR INCLUSIVE RESEARCH**

Guidelines for including people with disabilities in research – National Disability Authority 2002  

Melanie Nind and Hilra Vinha, University of Southampton National Centre for Research Methods Methodological Review paper. Practical considerations in doing research inclusively and doing it well: Lessons for inclusive researchers  
http://eprints.ncrm.ac.uk/3187/1/Nind_practical_considerations_in_doing_research_inclusively.pdf  
This is an excellent resource which includes sets of questions for researchers to ask themselves when embarking on research to ensure that it is inclusive. Focuses on intellectual disability.

Melanie Nind and Hilra Vinha Doing research inclusively, doing research well?  
https://www.southampton.ac.uk/assets/imported/transforms/content-block/UsefulDownloads_Download/97706C004C4F4E68A8B54DB90EE0977D/full_report_doing_research.pdf  
Full project report.

Inclusive Research Practice Guides and Checklists for Autism Spectrum Research  
Updated November 2014, Autism CRC  
Centre for Disability Studies – Disability Inclusive research principles – quality statement

Research Toolkit for Disabled People’s Organisations: How to undertake and use applied research. Leonard Cheshire Disability and Inclusive Development Centre, University College London

This is an example of an accessible guide to inclusive research.

Elena Jenkin, Erin Wilson, Kevin Murfitt, Matthew Clarke, Robert Campain and Lanie Stockman

Martin Farmer and Fraser Macleod Involving Disabled People in Social Research. Guidance by the Office for Disability Issues

Centre for Charitable Giving and Philanthropy. Co-producing research: working together or falling apart?
This is a report based on a roundtable event and focuses on co-production in social care.

TRAINING MATERIALS

Training materials 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

OTHER RESEARCH GUIDES

Ethical Guidance for Research with People with Disabilities, NDA:
Provides advice on ethical issues in research related to people with disabilities (not specifically inclusive research).
Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges Melanie Nind University of Southampton
http://eprints.ncrm.ac.uk/491/1/MethodsReviewPaperNCRM-012.pdf

EXAMPLES OF ACCESSIBLE OR EASY READ OUTPUTS

Inclusive Research Network reports:
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

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15. Bjornsdottir and Svensdottir, 2008
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18. Bigby et al 2014
19. paraphrased in Bigby and Frawley, 2010, p.53
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22. Clements 2012
23. Conder et al 2011
25. From Bigby et al 2014a, p.56
26. Tuffrey–Wijne and Butler, 2010
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29. e.g. Brookes et al 2012; Makdisi et al 2013; Nikolaidis et al 2011
30. de Wolff et al 2009
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82. e.g. Azzopardi Lane and Callus 2015; in the base project referred to in Bjornsdottir and Svensdottir, 2008; Brooks et al 2013; Bryant et al 2012; Hollinworth et al 2016; Clements 2012; McDaid, 2008; Morgan et al 2013; Ollerton and Horsfall, 2013; Tee et al 2007; Tilly, 2014)
83. Stevenson, 2010
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89. Hassounih et al 2011
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94. e.g. Strnadoova, 2014
95. Grayson et al, 2013
96. Hancock et al, 2012
97. Lincoln et al 2015
98. Morgan et al 2014
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100. Northway et al 2015
101. e.g. Kidd and Edwards, 2016; Bigby and Frawley, 2010; Dubois et al 2011; Nind and Vinha
NDS gratefully acknowledges the support of the NSW Government in establishing the NDS Centre for Applied Disability Research.
RESEARCH TO ACTION

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

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-research 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:


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:

Box 2:

Box 3:
NDS gratefully acknowledges the support of the NSW Government in establishing the NDS Centre for Applied Disability Research.
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 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:


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


REFERENCES


NDS gratefully acknowledges the support of the NSW Government in establishing the NDS Centre for Applied Disability Research.