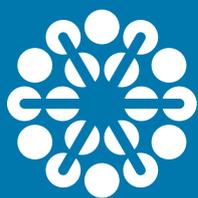


RESEARCH TO ACTION

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



Centre for
Applied Disability
Research

An Initiative of National Disability Services

NDS National
Disability
Services

INCLUSIVE RESEARCH:

A review of current
practice



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.

ACKNOWLEDGMENTS

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SUGGESTED CITATION

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ABOUT THIS RESEARCH TO ACTION GUIDE: INCLUSIVE RESEARCH

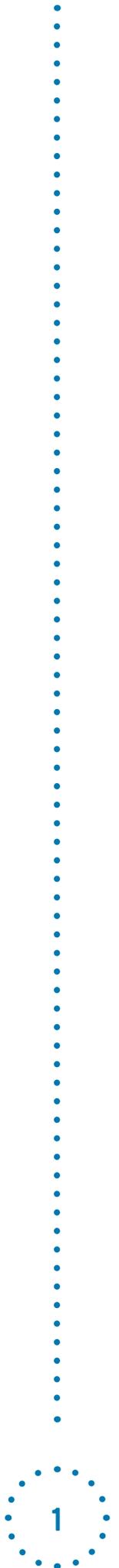
This Research to Action Guide is a suite of resources produced by CADR on inclusive research. The suite includes a rapid review of the research evidence and current practice. It also comprises practice guides for research practitioners and people with disability undertaking research (all available at 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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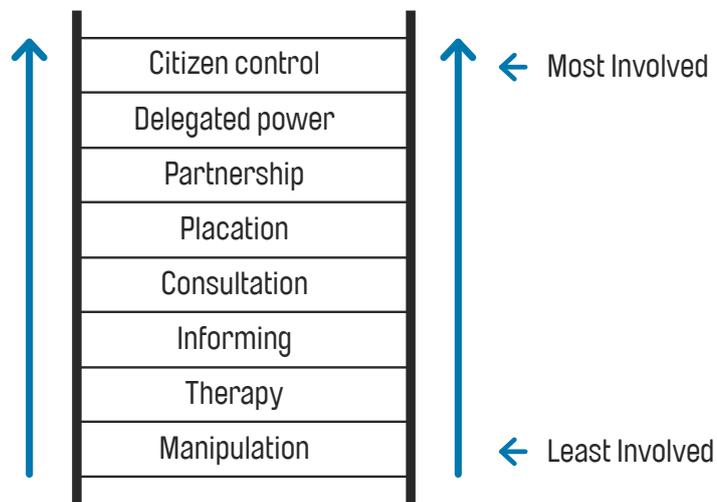


INTRODUCTION

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

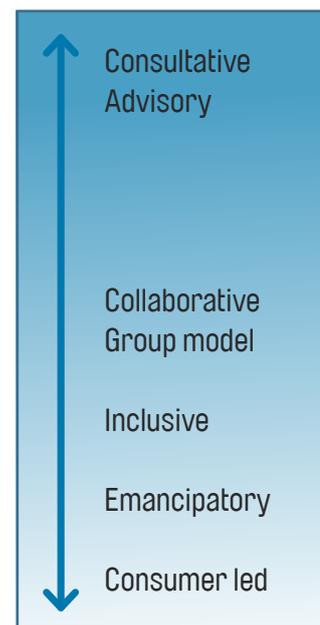


This provides a continuum of least-to-most involved in service planning and calls to account service and policy makers who do not genuinely involve those communities with which they work. A similar focus drives inclusive research. A 2015 review³ of inclusive research in intellectual disability found 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 research⁵.

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”⁶.

‘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 team⁷. 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

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

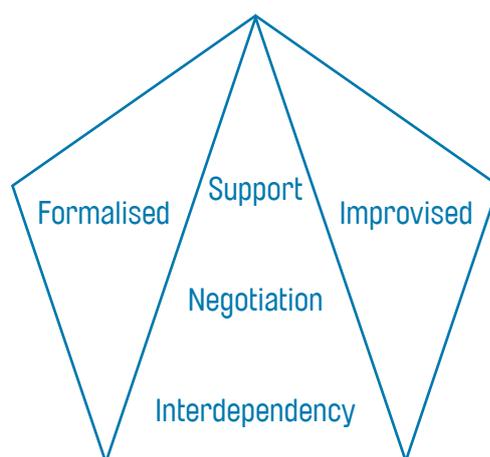
Consultative research, whereby co-researchers are only involved in an advisory role, is viewed as tokenistic⁸. As Epstein states, “It is not just about adding a pinch of consumer to unchanged and unchallenged research assumptions, and stirring like mad.” As the review of papers in this report progressed, 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 only⁹. 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 UK¹⁵. 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.”¹⁶

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 disability¹⁷.

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.¹⁸ 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.”¹⁹

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 Bjornsdottir and Svendsdottir (2008) and others to test the inclusiveness of their own research. However, what is termed inclusive research is not always inclusive²⁰. 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:

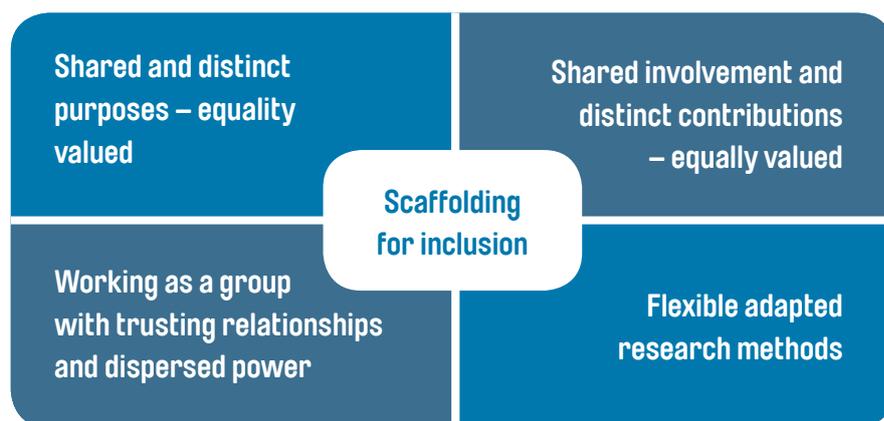
1. “Disabled individuals articulate the problem and participate directly in the process of defining, analyzing and solving it”;
2. “Direct involvement of disabled people in the research process facilitates a more accurate and authentic analysis of their social reality”;
3. “The process of participatory 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”.²¹

As this demonstrates, there is a strong element of ‘equalisation of power’ in a PAR approach²², with some stating that PAR cannot be implemented without a focus on the emancipation of co-researchers.²³

COLLABORATIVE GROUP

The ‘**collaborative group**’ approach defined by Bigby et al²⁴ is an approach to which many inclusive research papers aligned with without naming it as such. Extract 2, below²⁵, 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 inclusion²⁶. 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 research²⁷. 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.”²⁸

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.²⁹ 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 research³⁰. One such group is the Irish Inclusive Research Network.³¹

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 them³². Hart³³ 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 research⁴³, developed new skills⁴⁴, felt valued or part of something important⁴⁵ and enjoyed contributing to the community through the research⁴⁶.

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-researchers⁴⁷ or if the data collection was practically difficult.⁴⁸

Several papers evaluated in this rapid review speak about the co-research being therapeutic for co-researchers⁴⁹. Here, there is a mixing of research and “community development work”⁵⁰. 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.”⁵¹ 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.”⁵²

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.⁵³

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

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.

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 process.⁵⁶ 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 studies⁶¹. Co-researchers hold “‘experiential knowledge’ which is increasing in legitimacy” in disability related research.⁶² The difference in approach brought about by co-researchers also enhances the validity of data produced by making it more multi-dimensional.⁶³

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 interests⁶⁴. Others have labelled co-production as a “buzzword which does not produce as much benefit for research as is made out”⁶⁵. 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 findings⁶⁶.

Chappell et al (2014) state: “The medical model of disability constructs persons with disabilities in terms of ‘deviance, lack and tragedy’ as victims of impairment⁶⁷ 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-researchers⁶⁸. 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 frustrated⁶⁹. 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-researchers⁷⁰. Extra time should also be built into projects as lead-in time for working out issues such as power dynamics, training and so forth⁷¹.

In two projects, the time limits of the project meant that a truly collaborative approach between co-researchers and academic researchers could not be reached⁷². 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.”⁷³

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 finishes⁷⁴. 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)⁷⁵. This called for pragmatism where the “constraints of the academic system meant that the aims of the research had to be recalibrated”⁷⁶;
- Including people who it is difficult to co-research with in person (e.g. study where co-researchers with autism collaborate online)⁷⁷;
- Limitations of consumer-led inclusive research – Some important parts of the story are missing⁷⁸. 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 problem⁷⁹;
- 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.”⁸⁰

VALIDITY ISSUES

Critics state that co-research means that the researcher loses objectivity⁸¹. 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 review⁸². 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).⁸³

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 developed⁸⁴. 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.”⁸⁵ There are also issues when co-researchers are unable to collect data in a rigorous way⁸⁶.

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 balk 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 research⁸⁷, and conducted before the project began. In other papers, training was either provided on the job or gradually as the project progressed⁸⁸. This can be difficult, particularly if the research follows a very structured design, such as with a randomised controlled trial⁸⁹.

Different models of research training for co-researchers include “apprenticeship, lifelong learner, challenging inequality, addressing deficits and formal models”⁹⁰. 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 approaches⁹¹.

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”⁹² 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 paper⁹³, 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 long⁹⁴. 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 assured⁹⁵; and concerns about “‘apacity and objectivity’⁹⁶. Ethics committees also had concerns about the skills of co-researchers to both conduct interviews and get the participants to validly consent⁹⁷.

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 methodology⁹⁹.

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-researchers¹⁰⁰.

MEASURING THE INCLUSIVENESS OF RESEARCH

Several authors provide criteria against which to measure the inclusiveness of research¹⁰¹. 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.

Element of research	Issues to consider
Co-authoring publications	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Co-researchers should be paid for their time, if possible. The impact of payments on disability support payments should be considered.
Timelines	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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. • 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
Research training of academic researchers	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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

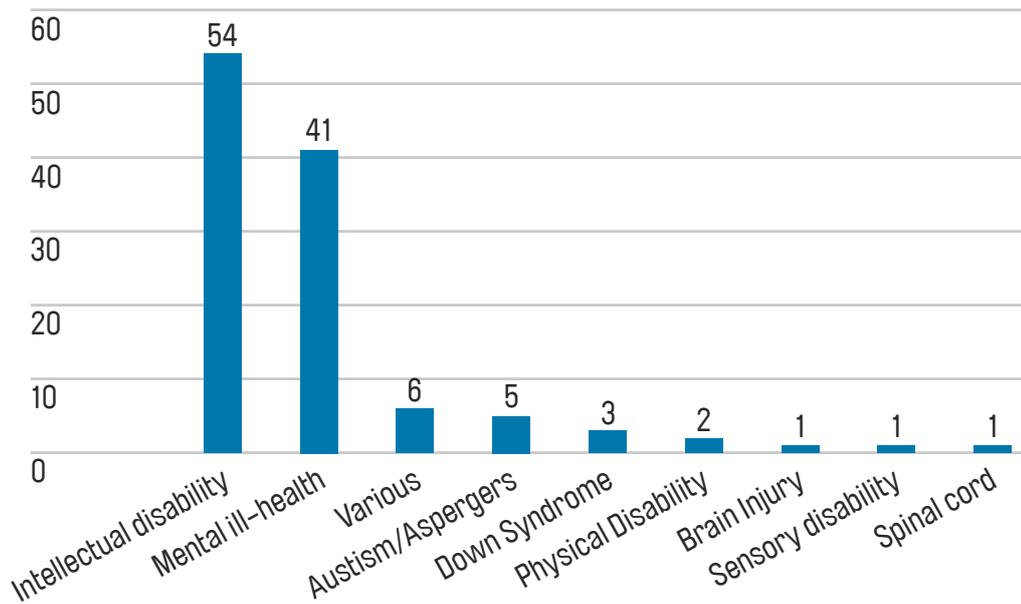
DESCRIPTION OF THE FINDINGS

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.

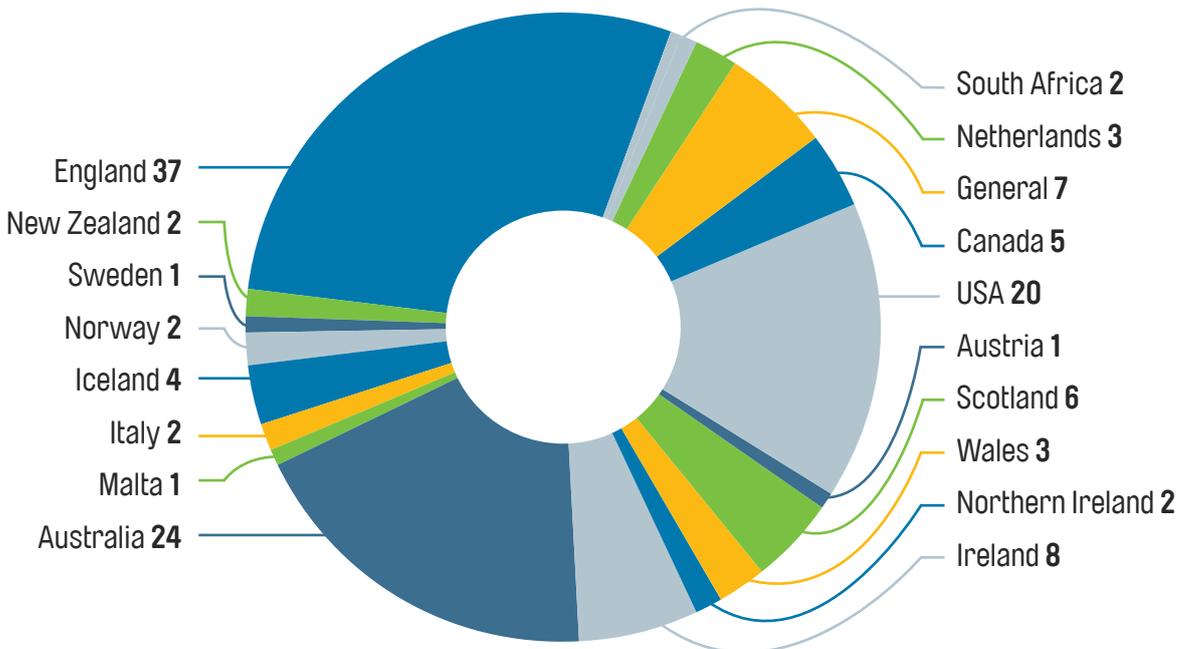
Box 1: Paper count by characterisation of disability of co-researchers.



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

Database	Initial search result #	After abstract review	Duplicates removed	Downloaded full text	Final #	Adjusted total (removal of advisory group only papers)
Medline	407	106	75	73	33	
Cochrane Reviews	145	2	2	2	2	
Scopus	498	154	80	73	41	
Cinahl	421	148	139	137	62	
TOTAL	1471	410	296	285	138	123*

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
<http://nda.ie/nda-files/Guidelines-for-Including-People-with-Disabilities-in-Research.pdf>

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
<http://www.autismcrc.com.au/sites/default/files/1.%20Autism%20CRC%20Inclusive%20Research%20Practices%20Final.pdf>

Centre for Disability Studies – Disability Inclusive research principles – quality statement
<http://cds.org.au/wp-content/uploads/2016/04/Inclusive-Research-Principles.pdf>

Research Toolkit for Disabled People’s Organisations: How to undertake and use applied research. Leonard Cheshire Disability and Inclusive Development Centre, 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! Getting involved in Research. Department of Health, UK Government.

<http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/assetRoot/04/13/29/79/04132979.pdf>

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

Elena Jenkin, Erin Wilson, Kevin Murfitt, Matthew Clarke, Robert Campaign and Lanie Stockman Inclusive practice for research with children with a disability: a guide.

http://www.voicesofchildrenwithdisability.com/wp-content/uploads/2015/03/DEA-Inclusive-Practice-Research_ACCESSIBLE.pdf

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

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/321254/involving-disabled-people-in-social-research.pdf

Centre for Charitable Giving and Philanthropy. Co-producing research: working together or falling apart?

<http://www.cgap.org.uk/uploads/Briefing%20Papers/CGAP%20Briefing%20Note%208%20-%20Co-producing%20research.pdf>

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:

<http://nda.ie/nda-files/Ethical-Guidance-for-Research-with-People-with-Disabilities.pdf>

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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4. Bigby et al 2014
5. Boland et al 2008
6. Horsfall et al (2007)
7. Arthur et al 2008
8. Horsfall et al 2007
9. Magliano et al 2009; Lewis et al 2008)
10. Woelders et al (2015, p.538)
11. Nind and Vinha (2014, p. 108)
12. ibid
13. e.g. Martin, 2015
14. e.g. Garcia-Iriarte et al, 2009
15. Bjornsdottir and Svendsdottir, 2008
16. Woelders et al (2015, p.529)
17. Bjornsdottir and Svendsdottir, 2008
18. Bigby et al 2014
19. paraphrased in Bigby and Frawley, 2010, p.53
20. Bell and Mortimer, 2013; Bigby and Frawley, 2010
21. Cited in Buettgen et al 2012
22. Clements 2012
23. Conder et al 2011
24. Bigby et al (2014a; 2014b)
25. From Bigby et al 2014a, p.56
26. Tuffrey-Wijne and Butler, 2010
27. Strnadova, 2015
28. Timmons et al, 2011, pp.286-7
29. e.g. Brookes et al 2012; Makdisi et al 2013; Nikolaidis et al 2011
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31. http://www.fedvol.ie/Inclusive_Research_Network_IRN/Default.241.html
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102. Kidd and Edwards, 2016

