Doing research inclusively, doing research well?

Report of the study:

Quality and capacity in inclusive research with people with learning disabilities

Melanie Nind & Hilra Vinha, 2012

Acknowledgements – Thank you!

Contents

Summary – key points

- This report is a story of our research for anyone interested.
- The idea was to bring together people doing **inclusive research**[1] to share and develop their learning.
- We wanted to work together on a better understanding of what it means to work together on research and to do it well.
- Our method was talking together in **focus groups**.
- We made **audio recordings** and **transcriptions** and looked for important themes.
- We found out:
  - About how people research together - approaches can be

Inclusive research is research that matters to people with learning disabilities, involves and respects them	

Focus groups are small groups who talk about ideas on a research topic	

Audio recordings record voices so they can be listened to again	

Transcriptions are written records of what was heard on audio recordings	

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[1] Applying the definition of Walmsley & Johnson (2003)

planned or responsive; they can stress giving support, negotiating practices, or trusting each other.

o Inclusive research is particularly good at developing knowledge about people's lives.

o There are many different ways of doing research inclusively.

o Being involved in inclusive research leads to new friendships and networks, new skills and experiences, and feeling confident and valued.

o When people with learning disabilities are involved in research the questions can be more relevant, the methods more **accessible**, and the **findings** more rich. There is potential for social inclusion and social change.

o There are barriers that still need to be addressed for inclusive research to have a good future.

o Research is seen as good in terms of inclusion *and* good in terms of generating knowledge when it:

Accessible is when something can be used by people of all abilities.

Findings are what we find out and learn from a study.

- ✓ addresses questions that require an inclusive approach
- ✓ answers questions in the best way
- ✓ makes use of insider knowledge of what it is like to live with learning disabilities or a label of learning disabilities
- ✓ is genuine and meaningful
- ✓ has **impact** on the lives of people with learning disabilities.

- We conclude that we are still learning about inclusive research. Everyone wants it to do a lot for the people involved. It is important that we keep exploring and talking about how we go about doing research inclusively and doing it well.

> **Impact** is making a difference or making something happen because of the research

1.   Introduction – How to read the report

This report tells the story of the research. We hope to share this story with everyone involved and anyone who would like to know more about what we have done. This report is available on our website www.doingresearchinclusively.org.

We want this report to be self-advocates, researchers and funders who are interested in how research can be done inclusively. It is hard to write a report that is right for everyone, but we hope this works for you.

For some, jargon is a technical language that they use in their profession.

For others, jargon is the unnecessary use of difficult words.

Jargon
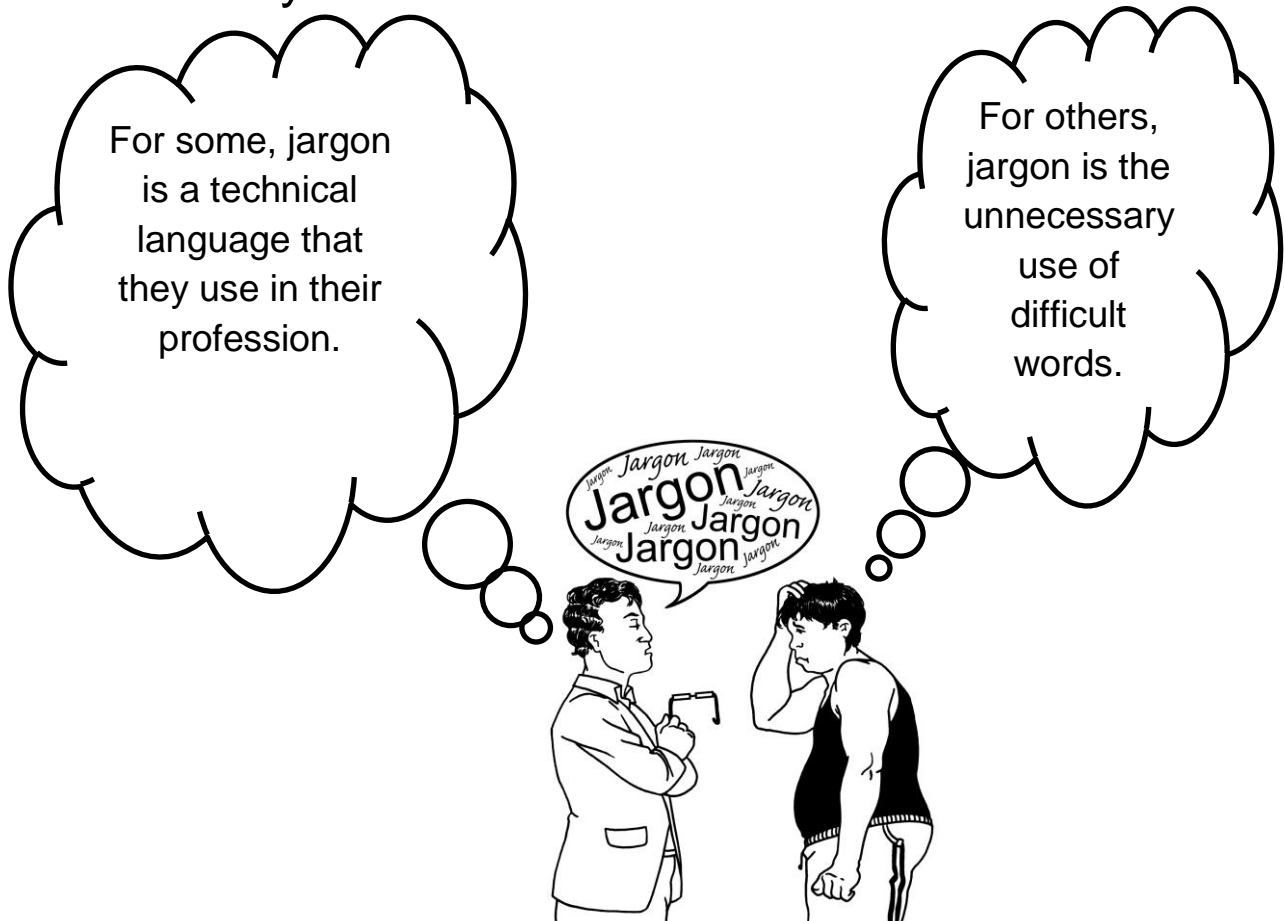
We know this report has some hard words, but we use plain English as much as we can. To help with some of the hard words, we include a list of what they mean here. We have added pictures and examples to make it easier to read. Change (2009; no date), The Learning Difficulties Research Team (2006), The Plain Facts Team at Norah Fry and others have produced reports that we could use as good examples. Some of our **participant-researchers** with learning disabilities also guided us as to what was important to them.

Research terms and what they mean

Academic: activity in universities or a person doing the university activity

Accessibility: refers to ways of getting to places, communicating, and doing things that have fewer barriers and more help to make them open to everyone

Capacity building: improving the ability of people and groups to do things by improving skills, knowledge and support

Conclusions: what you can say at the end of the research based on what you found and thought was important
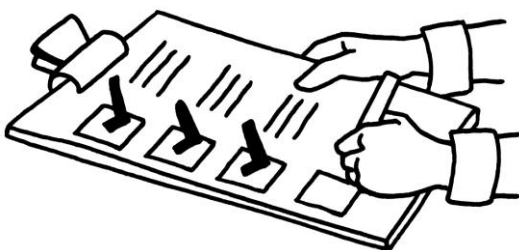
Consent: agreeing e.g. to take part in the research or to be named

Example
I then got involved in the work Jan and others were doing at the OU and realised there was a whole world of people with learning disabilities out there exploring their history and that's why I got involved in participation. (Duncan)

Critical incidents: turning points that make people change how they think or act

Example
Becca: This is how we do it isn't it Michael.
Michael: It is yes, yes
Becca: We go from pulling out ideas & stuff and then somebody goes away writing …

Data: the information you gather through research such as people's words

Example
Research process – funding
RP/costing forms
RP/getting funding
RP/allocating funding
RP/contract
RP/deciding on funding criteria

Data analysis: working out what information gathered through research means, what is important and what is interesting
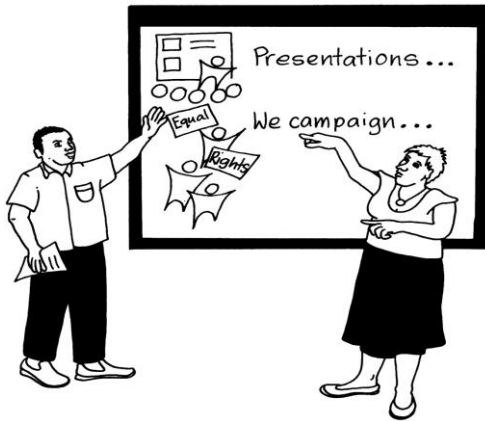
Dissemination: telling people about the research and what you found e.g. through reports, conferences, websites

Easyread: a method of using words and pictures together to make the message easier to understand

Emancipatory research: research that helps those involved make good changes to their lives by being in full control of the research

Ethics: doing the right thing in research, treating people well and not doing anything to harm them

Example
Again Helen created a welcoming feeling as people arrived.

Fieldnotes: notes a researcher makes about what goes on while they are collecting data

Findings: what the researchers find out and learn from a study

Focus groups: small groups brought together to talk and share views on a topic

Inclusive research: research that matters to people with learning disabilities, and that involves and respects them

Informed consent: agreeing to take part in something like research, based on understanding what is involved and what will happen to you and your information

Jargon: academic or special language which is not used in everyday life

Methods: the ways you go about finding things out (such as interviews) or doing analysis (such as finding themes)

Objectives: What you want to achieve or complete

Example

I can remember when we … did the workshop … people signed up to it and we ended up having to …

Narrative: A story of events and how the person experienced them

Participants: the people that researchers get their information from

Participant-researchers: Participants who are also researchers or co-researching with you

Agreed!

Participatory methods: methods where the participants are involved in decisions about the research and the research activity

Policy: Statement about what is important and how things will be done

Policy-makers: People who develop policies in organizations.

Research literature: Books and papers in journals about research or explaining findings

Self-advocacy: Standing up for yourself and taking control of your life

Stakeholders: people with an involvement and interest in something

Theory: A way of thinking about or explaining information or things happening in the world

If a word in the report is in **bold type** you should be able to look back at this list for help with it. If you would like something explained please phone Melanie on

023 8059 5813.

2. Beginnings – Our aims and plans

The idea for the study

We know that it matters to people how research projects begin (and who came up with the idea!). Therefore we are honest about this here. The idea for this research came to Melanie when she was writing another paper (Nind, 2011). The idea, though, was influenced by others. She was reading a lot about how people with learning disabilities get involved in research. It seemed that although many people were working on this they were not getting together to share what they were learning. There were examples of interesting projects that were breaking down barriers to research for people outside universities. There were papers written about what was important and challenging when people with learning disabilities and **academics** do research together. (We list some of papers at the end - see Appendix 1.) But Melanie thought it would be good for everyone to come together to talk and to get an overall picture. This would help us to think together about the next steps too.

Within the **research literature** some writers make it clear that some things need particular attention.

Simone Aspis (2002: 4), a self-advocate, argues, 'How many times have we heard that we are working in partnership with people with learning disabilities? We need to think about what that really means.'

Jan Walmsley & Kelley Johnson (2003: 12) reflect on a 'stifling of debate about the real difficulties of including people with learning disabilities in research'. They called for more honest discussion.

Gordon Grant & Paul Ramcharan (2007) concluded that we have enjoyed a first phase of learning practical things about doing inclusive research. Now, though, the time has come to find out more about the kinds of knowledge we can develop through inclusive research and how we can know that knowledge can be trusted. They put on the agenda: 'what forms of partnership make inclusive research effective, and whether good science and good inclusive research practice can be brought together' (p.12).

The importance of the research

This led Melanie to see the value of

- exploring the nature of partnership in research
- discussing the things that are difficult to do and difficult to talk about, and
- looking at when and how inclusive research becomes good research.

She thought a research council might want to support a project like this because of **policy** changes. The UK government had written about their vision for people with learning disabilities as active citizens enjoying rights, independence, choice and inclusion (DoH, 2001). The Department of Health had, between 2001 and 2003, spent £2 million on 13 studies. These were part of the Learning Disability Research Initiative (LDRI) following the Valuing People white paper. Therefore it would make sense to fund this research to help make sure money spent on inclusive research is spent wisely.

Aims and objectives

The aim of this research was to build knowledge and capacity. Our steps, or **objectives**, were to:

Take stock of what we know about people with learning disabilities taking part in research about them

Produce guidance to help when people with learning disabilities are workiing together with others and on their own doing research

Develop materials and case studies based on new practices

Produce criteria for judging quality in inclusive research.
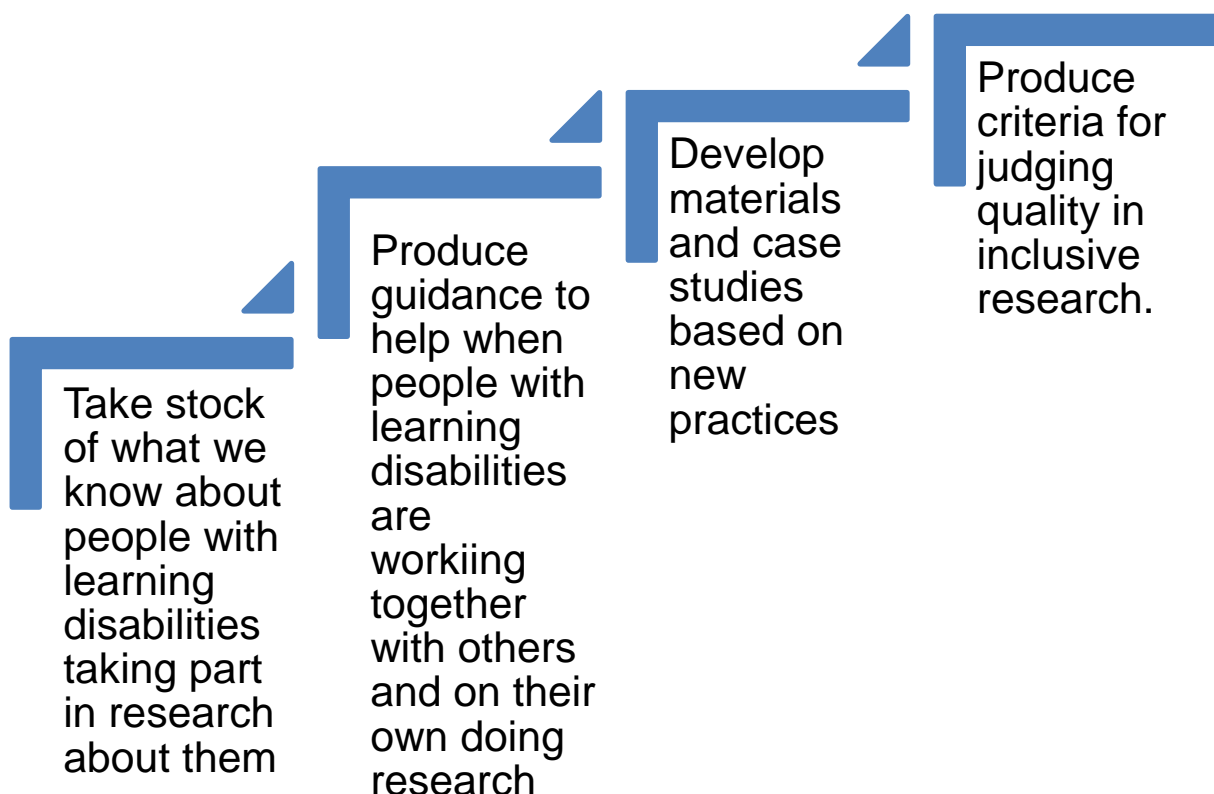
Guiding principles

We did not want to end up just repeating what others have already said about **inclusive research**. Instead, we wanted to bring together people with experience to:

- talk
- work through points of friction
- create new knowledge from sharing knowledge.

We wanted to bring about the kind of talk that changes things. Gergen (2009) calls this transformative dialogue. We were convinced of value of this by the work of Paulo Freire (1970).

Freire, a Brazilian educationalist, was passionate about dialogue as creative and liberating. Freire challenges oppressive practices (the emancipatory principle) and calls for the liberation of oppressed groups by themselves (the participatory principle) by consciousness built collaboratively in dialogue.

This **theory** influenced the research. It led us to see **focus groups** as a powerful way to connect the **emancipatory** and **participatory** principles important to inclusive researchers.

We did not want to research **inclusive research** in a way that was against the spirit of **inclusive research**. Yet there were compromises we had to make and with

more money we could have done more to make the research more inclusive. People with learning disabilities were not involved at all the stages, but their ideas and published work did influence the decisions we made throughout. The bid for funding said we would answer these research questions:

1. What does working in partnership with people with learning disabilities as researchers really mean?
2. What kinds of knowledge are attributable to **inclusive research**?
3. How can **inclusive research** and the outcomes of inclusive research be assessed and authenticated?
4. What are the benefits of inclusive research to people with learning disabilities and other **stakeholders**? Where do the problems lie?
5. How might good science and good inclusive research practice come together?
6. What can be added, from sharing and interrogating practice, to current understanding of what **inclusive research** is?

Put more simply we set out to find out:

1. How do people work together as partners doing research?
2. What kinds of things do they find out about?
3. How can we know whether the research is good?
4. What good things come from doing inclusive research? What makes it difficult to do?
5. What makes a piece of research good - for people judging it for its research and its inclusive qualities?
6. What we can learn about inclusive research from coming together to talk about it?

3. Research process - How we did the research

Plan for the methods

We designed the research for maximum dialogue. This meant a series of **focus groups**. The idea was that the focus groups would involve people coming together who do research from a common position. This would help create a safe space to talk in. This idea was borrowed from Madriz (2000) and Haw (2010) who had found it effective for research involving hearing the voices of groups with little power. We wanted to ease the process of sharing and generating knowledge among the people participating in the study. We refer to them as **participant-researchers** to recognise their role as **participants** and researchers.

We planned for a series of focus groups as shown below. The idea was that the first 3 focus groups would meet 3 times, and involve the same people so as to build trust. The focus groups would be **audio recorded** and there would be gaps between to give time

- for them to be **transcribed**
- to reflect on the data
- to plan the next line of questioning
- to prepare visual materials and ideas to stimulate the talk.
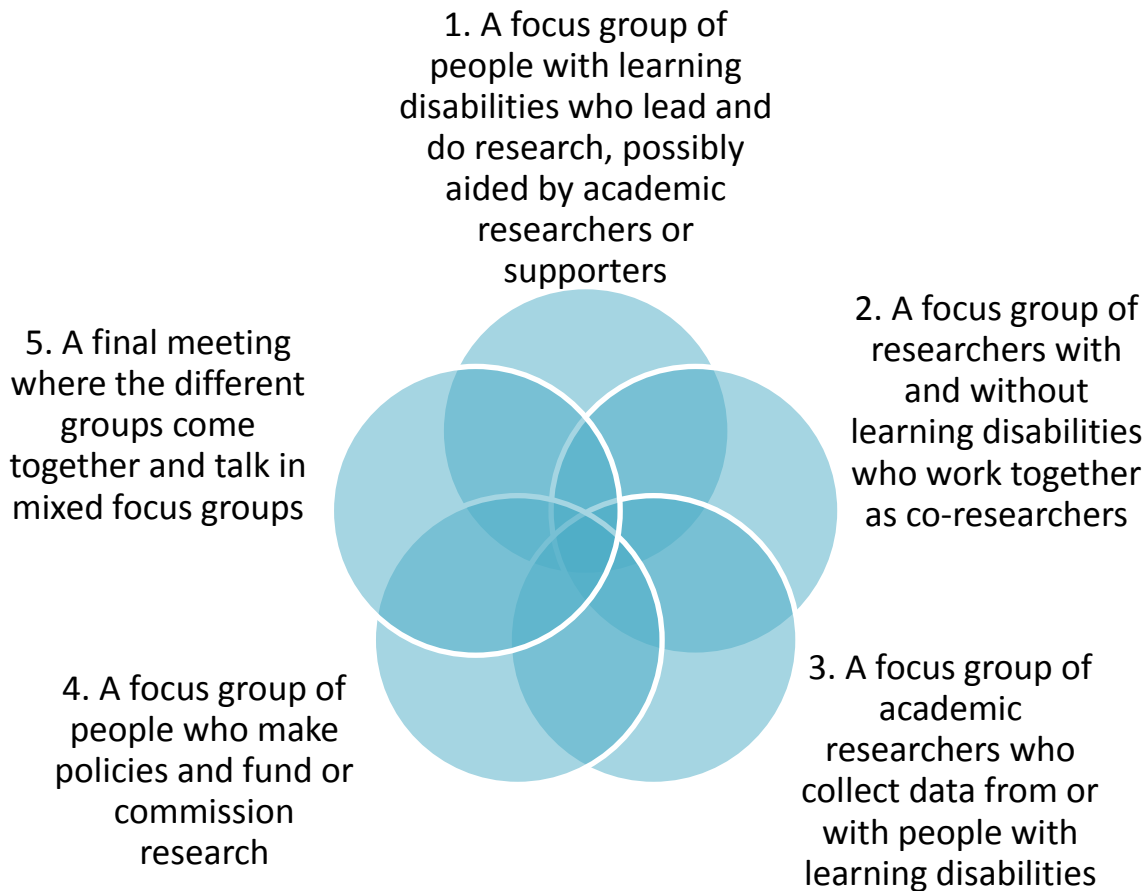
Plan for the focus groups

We thought of the time and tasks as 'dialogic (talking) phases' and 'reflective (thinking) phases'.

The **policy-makers** and funders would meet once to reflect on the ideas of the other groups and share their own views.

The final meeting would be a chance for all the **participant-researchers** to meet and form new networks. They could pick out the findings that were

most important to them and challenge anything they were uncomfortable with.

The methods in action

The realities of putting this plan into action meant that there were some changes.

We invited people to take part who we knew, whose research we had read about, and who other people suggested to us. Some of them said that as they do research in different ways they could fit into more than one group – this is a problem when putting labels on researchers! When this happened we asked them to choose which group they joined. They did partly based on what interested them most and partly on which group was nearest to get to.

The first focus group became 2 focus groups, one meeting 3 times in Leeds

We were very glad to have the involvement of participant-researchers from:

- Carlisle People First
- Central England People First
- Change
- Looking into Abuse research team from Wales
- Heritage Lottery Fund
- Joseph Rowntree Foundation
- My Life My Choice
- National Development Team for Inclusion
- Voice Group at Norah Fry
- Work in Progress team from Cornwall
- Wigan & Leigh People First
- York People First

and 1 meeting twice in Bristol. This was partly so we made sure we heard from people with learning disabilities with different experiences of research, and partly because travel from the south-west to the north of England was costly and difficult.

The main groups were bigger than we first planned because so many people were interested in taking part. The same people did not always come every time as fixing dates that everyone could make was impossible. The thinking phases between the talking phases were sometimes a bit short.

The focus group of **policy-makers** and funders was smaller than we planned as some of the people who said they would come could not make it at the last minute.

The **ethics** of the research were important and ethics approval was given by the University of Southampton. The process of getting **informed consent** began with the same materials for all **participants** explaining the project in plain English. Mostly this was straightforward, but 1 group challenged our assumption that people in support roles would help with access to the information where needed. In response we made some of our materials more in line with the **easyread** that these **participant-researchers** were more familiar and comfortable with.

Each **focus group** lasted about 2 hours. The conversation started with sharing experiences and led into questions about what makes **inclusive research** challenging, possible, and of high quality. They ended by agreeing themes to be returned to in a later meeting or taken forward to a different focus group. (See Appendix 2 for the questioning route.) The questioning included topics under-developed in the literature:

- how are people with high support needs/ profound impairment involved in research?
- what inclusive ways do people use to do **data analysis**?
- how do inclusive researchers use or develop **theory?**

Data analysis focused on what would help to build **capacity** in **inclusive research**. The **transcripts, fieldnotes**, reflections and the materials produced were all analysed. Key ideas, **narratives**, and **critical incidents** were identified.

The findings were then shared, reflecting the different voices involved.

We work together as a team … we practise on it

Gareth

Actually, disabled people should be paid for the research they do

Elizabeth

I think that any research, as long as [it's] conducted ethically, is good in its own right

Ann

4.   Findings – What we found out

1. How do people work together as partners doing research?

Researcher-participants described how they worked together and what was important to them in this. This showed the importance of dialogue for all the researcher-participants and not just to us in this project.

> We sat down together to talk about it, what has been done and what hasn't been done. (Craig)

There was some agreement though that the quality of the teamwork or partnership was important, and that this involved trust, openness and finding ways of working that suit everybody.

Funders/**policy-makers** who judged research applications looked for a healthy partnership, shared understanding of inclusive research and shared purpose.

> Some projects would come as partnership say between a People First group and some researchers locally or the university. And this is where you see them working best. (Emma)

Lots of journal articles have included the prickly issue of the power dynamics when **academic researchers** and researchers with learning disabilities work together. This issue had not gone away for the people in this project.

Research teams worked using agreed principles, customs or even rules.

For some it was important that ideas came from people with learning disabilities. Who initiates and who leads was important. **Participant-researchers** from cooperative research

> Ideas have to come from members of the group and there's this research cycle we go through. (Rohhss)

groups spoke of needing to agree group decisions.

The processes involved in researching together inclusively were sometimes informal, such as being social, having fun, and doing research in your spare time. They were sometimes formalised, such as dividing out tasks, doing training, or using a steering group. Informal and formal processes could go on alongside each other in the same team. Similarly, **participant-researchers** operated in a very principled way *and* a

> I went away and put it [the proposal] together then took it back to say have I got it right. It was part of what I did, but I checked out how I did, just to make sure it of it. So I had the method bit about how to do it but the ideas came from self-advocates. (Julie)

realistic way rather than just one or the other. Some talked of taking risks, learning from mistakes, adapting and compromising. Some talked of the hard slog of getting their research funded and working as they wanted.

There was much talk of the processes group members went through together: selecting interesting articles to read together, running **focus groups** together, writing together, reflecting together, and working closely with the funder. There were also times when tasks were divided out with some research group members reporting back.

> We make that decision as a group then … in an ideal world it would be great if all the ideas came out of the group, but that would mean we would lose an awful lot of things that were not our idea (Chloe)

Researchers from inside and outside universities and the people who supported others worked together in various ways. Any one of them could be in the role of bringing knowledge, skills or practical support.

An important idea to come from the focus groups was that academic researchers, researchers with learning disabilities or people offering support could provide a bridge into new worlds.

Carl's demonstration of the bridge idea

To make sense of the different ways of researching together we developed a model – a kind of mental picture as shown below. Formalised ways of working together and improvised ways are very different, so they are at either ends of the model. Formalised approaches involve doing things in a pre-planned or rule-bound way while improvised approaches involve co-working and co-learning worked out 'in the moment' and in response to specific challenges.
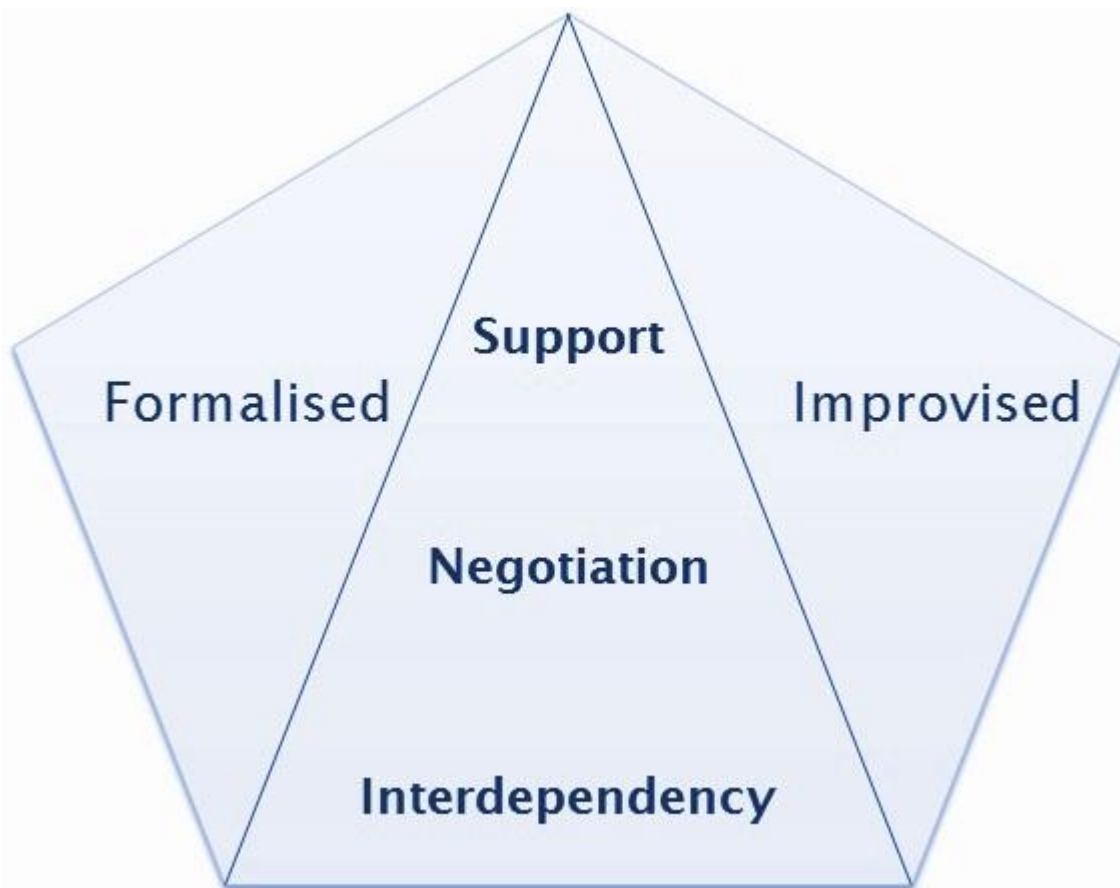
Model of different ways of researching together

Ian's People First group had a formalised approach, while Will valued something different. Another researcher describes this in practice: "but when I get in the field … I start adapting my methods".

> I am the one basically cracking the whip. Got to get things done. …You know the format. You know what is going to happen. You've got to make it happen. Sometimes got to be flexible but you are answerable … You set out your stall. You have to ensure that you try to deliver. Steering group, we meet every so often. Report what you've done. (Ian)

> I view improvisation as the greatest possible skill which could be developed and shared in terms of inclusive practice. (Will)

Support, negotiation and interdependence are at the core of working together. In a model that stresses support some people work in support of others. People with learning difficulties may be seen as doing the research work; they are the experts by experience, the decision-makers and leaders supported by support workers or academics. Support may be with writing, transport, making arrangements, understanding jargon and so on. People holding support roles may be unsure of their right to speak for themselves and sometimes borrow the power of the person they support to make

their voice heard. Equally, academics may see themselves as doing the main work and recruit people with learning disabilities to support their research with their insights, access to networks, help with making research tools accessible and so on.

In a model that stresses negotiation put effort into agreeing how to work together. The negotiation may be between people whose power and right to speak are very unbalanced or on more equal terms.

Lisa: We are one big team. So I think it's a good idea to ask the support workers what they think.

Gareth: …because at the end of the day it is how Kerrie and Lisa, it's their lives.

Mel: Yes, but they're saying what do the support workers think.

Gareth: Yes, but the thing is they're only there for support. They can only make any judgement on if they've achieved something.

In a model that stresses interdependency model there is support and negotiation, but more crucially people working together enjoy cooperation in what they see as teamwork. There are high levels of trust and communication and much work is put in to ensure all voices are heard and none are dominant. Knowledge is

shared and value is placed on listening to, and learning from, each other.

What kinds of things do inclusive researchers find out about?

The research answered this second question in two ways:

- By bringing so many researchers together we could see the range of topics being researched (see Appendix 3) and the range of knowledge they are likely to produce.
- By talking about what makes inclusive research special we could see it as good for getting particular kinds of knowledge.

Together these suggest that inclusive research generates knowledge about and for people with learning disabilities, and knowledge that is based on lived experience. The lives of people with learning disabilities was by far the largest focus of interest. On the whole, researchers with learning disabilities did not get funded

to do research unconnected to their lives but had some interest in doing so.

Some **focus group** discussions covered ways of knowing and what counts as knowledge. These discussions pointed to different ways of knowing rather than better or worse ways of knowing. Knowledge for academic researchers might be different from knowledge 'for' and 'about' people with learning disabilities.

Sometimes studies might lead to knowledge new to the inclusive researchers involved but not new in terms of the **research literature**. This makes it difficult to get published in journals. Mostly though, what makes the knowledge distinctive is that it is based on people's lives. It is grounded in experience. It is authentic or meaningful and uses and extends knowledge of the culture of learning disability. This makes it useful rather than just interesting knowledge.

What counts as knowledge? And what knowledge counts? … We are still stuck in this thing about hierarchies of evidence, peer reviewed, non peer reviewed, journal ranking, and all the rest of it … the inclusive research project is to me very much about relational practice, it's about pluralities of knowledge and people valuing and recognizing that and not putting one set of voices above another. (Gordon)

How can we know whether the research is good?

The third research question was about how we can know the value of **inclusive research**. **Focus groups** discussed how to recognise quality in inclusive research. Examples were research that was relevant and interesting to people with learning disabilities, involved them meaningfully and throughout and made their lives better. These things were valued particularly by researchers with learning disabilities and their supporters.
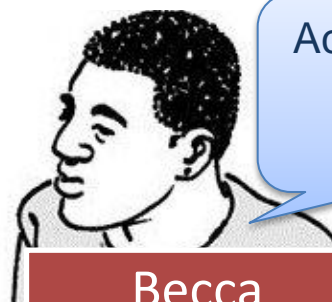
Quality was also talked about in terms of research that generated the best evidence and used the best methods, that was enjoyable, new in some way, honest and clear. **Participant-researchers** were aware of what was valued in universities – impact and publications. The **policy-makers**/funders particularly valued the quality of the partnership and its impact and benefits.

> Emma: There is something about you wanting to invest and see it as process through people getting involved as co-researchers shaping all aspects of themselves, part of bringing around changing their own lives, the lives of the group, life beyond the research output, that is added value that comes of something that is co-produced
>
> Tony: Yes, certainly one of the things that we look for in an application is that it is not just a project that has a beginning and an end, and that's the end of it, but it's the sustainability it's what happens afterwards.

They look for researchers asking the right questions, clear and flexible plans, value for money, and money reaching all the partners. Other funders might look for a track record and good evaluations in previous studies.

It became very clear that everyone want sinclusive research to do a lot of things:

- create knowledge (the research goal)
- give voice and build self-advocacy (the political goal)

- bring funding to organizations (the practical, sustainability goal)
- provide training, skills, jobs, networks, and friendships (the wider agenda)

The funders and **policy-makers** who support inclusive research were as interested in the wider agenda as the researchers themselves – they wanted more from their money than the generation of knowledge. This may separate them from other funding bodies who do not yet fund inclusive research and who may have a different vision of what they what to fund. The **participant-researchers** had received grants from a small number of funders (see Appendix 4).

We need to think about the broad and varied goals when judging the quality of the research. In Appendix 5 we suggest a series of questions to ask yourself to aid this process. This helps us to avoid imposing ways of judging research that are important to just one group on to everyone.

Some **participant-researchers** struggled with meeting quality criteria associated with funded research that was not inclusive while still trying to be inclusive.

What good things come from doing inclusive research?

For many **participant-researchers** the benefits of doing research were about making friends, learning new skills, doing something useful, feeling valued, gaining confidence and experience. Doing research could also bring much needed funding to their self-advocacy organizations. The benefits extended to the difference the research could make to improve other people's lives and to change practices.

Making lots of friends and all that

We feel valued *and* they learn something about us

John

Kerrie
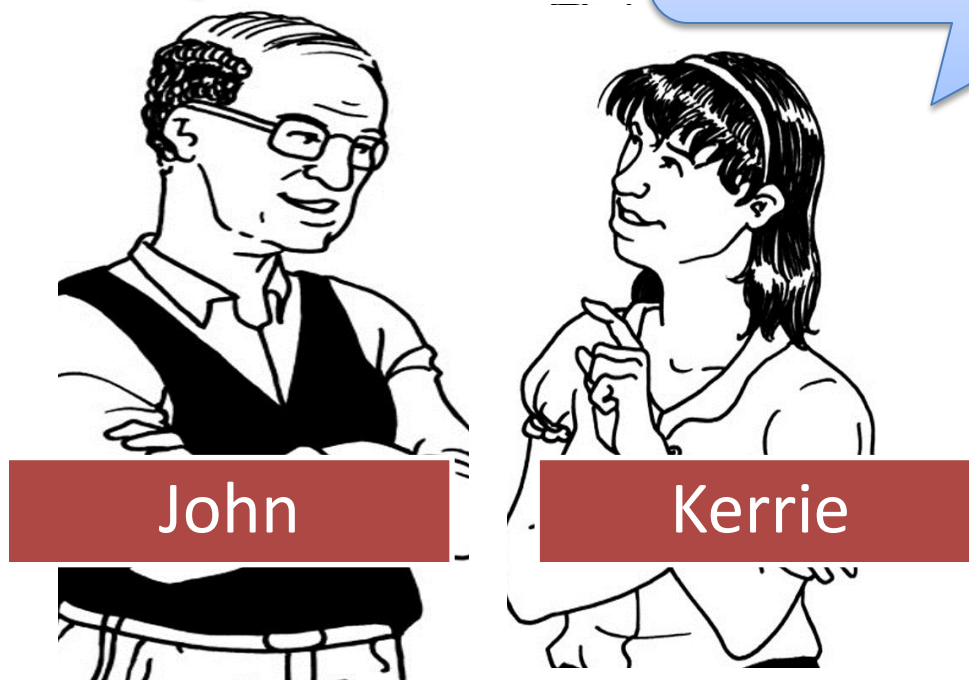
We talked about where inclusive research had more value compared with other kinds of research. Often the value added by the researchers with learning disabilities: their voice, experiences, thoughts and feelings, and cultural knowledge of things like day centres, institutions and personal assistants. Also important was their ability to connect with, and create a comfortable feeling for, research participants with learning disabilities.

One line of argument was that to address some research questions inclusive research was the only way to get to the data and do it properly. Another was that people reading the research might be more likely to listen and take note.

There was also awareness of the limitations of inclusive research – the questions it could not answer.

I think people don't listen to you because they think, oh well yeah yeah ok that's just another birdie talking off on a roof top, whereas if people with learning difficulties are doing the research people from the older generation might think, shock horror, these people should be in the institution but they're doing research, we better listen to them because it's like, shock horror (Kerrie)

What makes inclusive research difficult to do?

Many barriers to doing **inclusive research** were identified. We grouped these barriers into:

- Attitudinal barriers, such as funders' lack of knowledge or understanding, their inflexibility, their low expectations of what people with learning disabilities can do, and their failure to learn or change. There were also general attitudes about protecting people with learning disabilities or not valuing their input.
- Barriers in the social process, such as the barriers put up by universities protecting their territory, inaccessible calls to tender for projects and few routes into research for people with learning disabilities. Some barriers were put up by individuals and some were rule-based such as rules about tenders, formal **ethics** and governance requirements, online submission to journals, and the need for police checks.
- Material barriers, such as of transport and information, lack of funding for preparatory work (which was important to the cherished value of involving people with learning disabilities at all stages), inadequate funding more widely, and rules associated with people's benefits payments making short-term paid research risky.
- Within-person barriers, such as literacy difficulties.

Mostly people were reluctant to discuss barriers as existing within people. **Academic researchers** did admit gaps in their skills that they got help with, e.g. Irene reflected "if I want to get my statistics analysed I talk to a statistician". Curiosity, though, was identified as crucial for research and lack of it as a barrier for anyone. The strong message was that problems associated with inclusive research do not lie with people with learning disabilities.

Accessibility was a big issue. Making the research process accessible includes:

- accessible application forms/ electronic paperwork
- feedback on bids
- information from funders
- ethics and consent forms
- methods
- transcripts
- ideas
- theories
- language
- acronyms (like ESRC) and jargon.

> The literature review … was written so people with learning disabilities could understand it (Joyce).
>
> We've done easy read information sheets, easy read information DVD, and a testing (Karen)
>
> People with visual impairments … were saying that our electronic paperwork is not as accessible as it should be (Tony)

Ways of achieving this were similar to ways of making the research products accessible (see box below). Taking people's preferences into account and allowing

Accessible products of research included:
- accessible title, accessible report (with pictures, plain English and avoidance of jargon), accessible post-research resources, easyread versions, versions in different formats, languages and font sizes, multimedia outputs (video/DVD/drama / websites/ YouTube).

time for learning about research and to gain understanding were also stressed.

Most importantly, in terms of where the problems lie, there was concern about the sustainability of **inclusive research** – its future. The funders/ **policy-makers** spoke of the cultural shift associated with policy support for inclusive research. They suggested there had been a creeping, positive influence. The people doing research, though, identified some of the on-going challenges involved in bringing together researchers from different backgrounds. This includes tackling tokenism, rigid governance, and low funding odds. The pleasure of doing inclusive research was clear to see, but so too was the hard work involved with discussing difficult things, negotiating sensitive ground, keeping relationships going, finding ways to get published, and learning the unspoken rules of the research community. The future for inclusive research was seen as threatened by lack of funding, lack of capacity in the system, and lack of support for People First groups.

What makes a piece of research good - for people judging it for its research and its inclusive qualities?

After doing inclusive research for many years, Val is clear: "there is no right way of doing it". We could see that what makes good research from a funding council point of view differed from what makes good research from the point of view of self-advocates. A research proposal from an **academic researcher** might look very different from a research proposal from a self-advocacy group or research cooperative. This would apply to research reports too.

This can leave whoever is awarding the grant, or grading the research, with an impossible task. Each approach has its own merits and they are difficult to compare. Through dialogue we found our vision of good social science research practice meets with our vision of good inclusive research practice when:

1) The research answers questions we could not otherwise answer, but that are important.
2) The research reaches participants, communities and knowledge, in ways that we could not otherwise access.
3) The research involves using and reflecting on the insider, cultural knowledge of people with learning disabilities

4) The research is authentic (recognised by the people involved)
5) The research makes impact on the lives of people with learning disabilities.

What we can learn about inclusive research from coming together to talk about it?

In some ways the answers to the other research questions above already answered this one. We know that individual accounts of inclusive research are important, but the big picture from this study tells both of how far inclusive research has come, and how far there is yet to go.

People with learning disabilities are

- shaping and judging research proposals
- managing and conducting research
- writing, editing and reviewing papers and books.

But while some researchers are pushing forward into new territory:

- many continue to be involved in arguments about accessibility and power dynamics
- the number of funders who support inclusive research is limited

- if you are someone who is learning disabled the routes into becoming a researcher and building a research career are very much reduced
- the future of inclusive research is not secure.

This study brought these tensions into sharp relief.

The focus group dialogue also generated knowledge not fully discussed above. This includes the various identities and relationships with research. **Participant-researchers** spoke of themselves as:

- team member
- co-researcher
- inclusive researcher
- advocate for inclusive research
- proper researcher
- lead researcher
- expert by experience
- research supporter
- research coordinator
- research advisor.

There were research teams, groups, partnerships, a cooperative, and a whole set of terms being used as people involved in inclusive research struggled to explain their work.

The focus groups also exposed some of the differences between academics and researchers with learning disabilities. For example, there were different routes into

research, career paths and opportunities, different job titles, roles and rates of pay. Networks were often different and the relationships with research might be different - for people with learning disabilities the research could be more personal and overlap with advocacy work and campaigning. Sometimes the differences were about working for a university or not. On balance though, **participant-researchers** preferred to stress that which they shared in common.

5.   Conclusion – What we think now

This was a very stimulating study. It provoked a lot of new thinking, though sometimes the difficult areas remained unspoken about. We were challenged, enthused, and inspired by the many different ways in which people strive to do research inclusively. In this report we have focused mostly on the knowledge aspects. In the appendices there are some materials and case studies that we hope will be useful, but the website provides many more (see www.doingresearchinclusively.org).

In conclusion, we make three main points:

1. We have made great strides, but we are still learning about **inclusive research**. There are people we can learn from who have years of experience. They have taken bold steps and they carry the status of expert in some ways. But they are still learning too. This means that the dialogue about what good inclusive research means to us needs to carry on.

2. Inclusive research has taken hold in pockets, but the argument for the distinctive contribution that inclusive research can and does make is still in development and yet to be heard by many. This

means that we need to take our dialogue about inclusive research to new audiences. We need to talk with children, older people, people with mental health problems, and many others who are doing participatory/emancipatory/inclusive research and learn from and with them.

3. There are many different ways of doing and understanding our research practices as inclusive. We also want different things from this research. This means it is not wise to try to fix one way of doing things and call that, and nothing else, inclusive research. We know the danger of putting labels on things. So, we see the way forward as talking more about recognising when inclusive research is good quality, and at the same time keeping room in our ideas about this for differences in approach.

We wanted this research to be about dialogue and different voices. Therefore we end the report with some different ideas about what inclusive research means to people in pictures and words. We completed this report 3 months after the last focus group and we see it not as the final word, but as a new basis for dialogue.

Ingredients of inclusive research
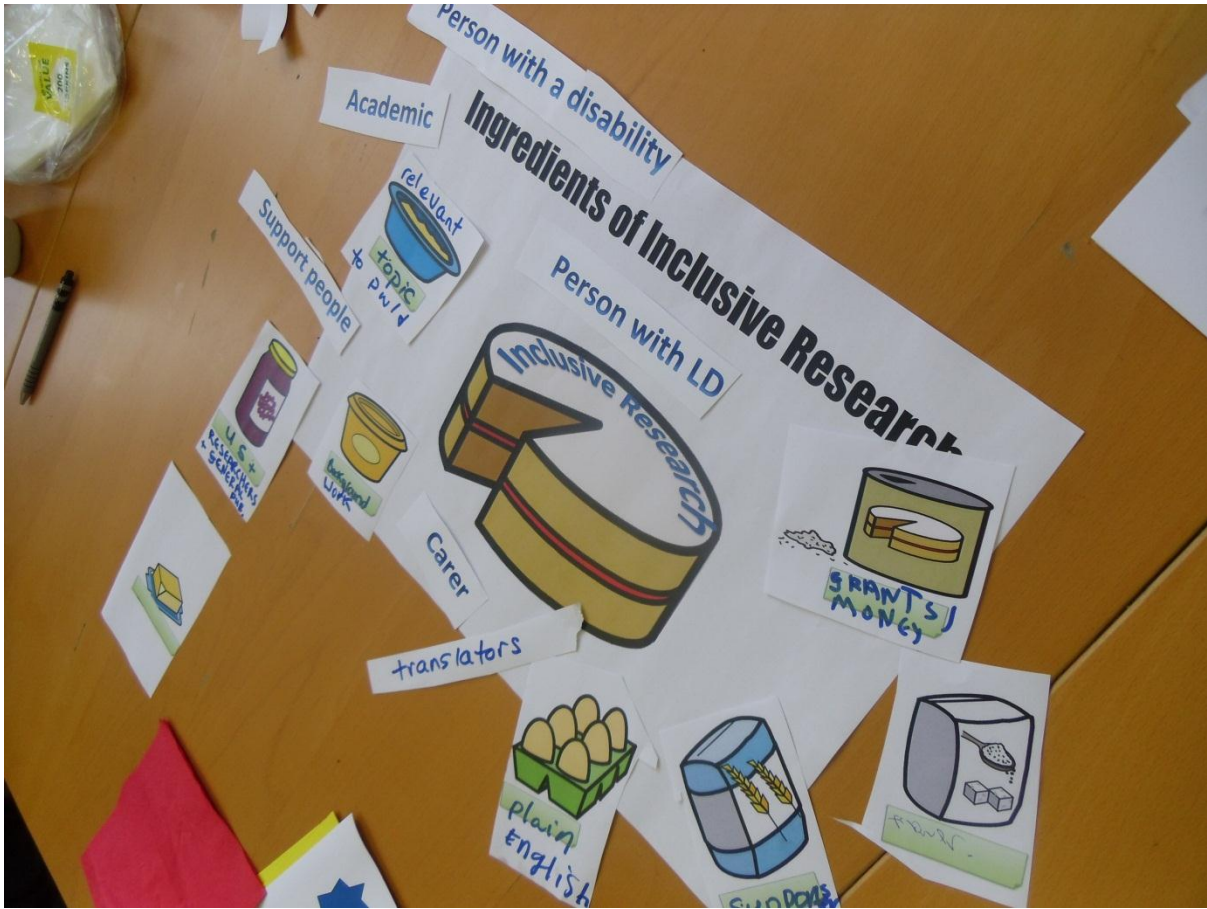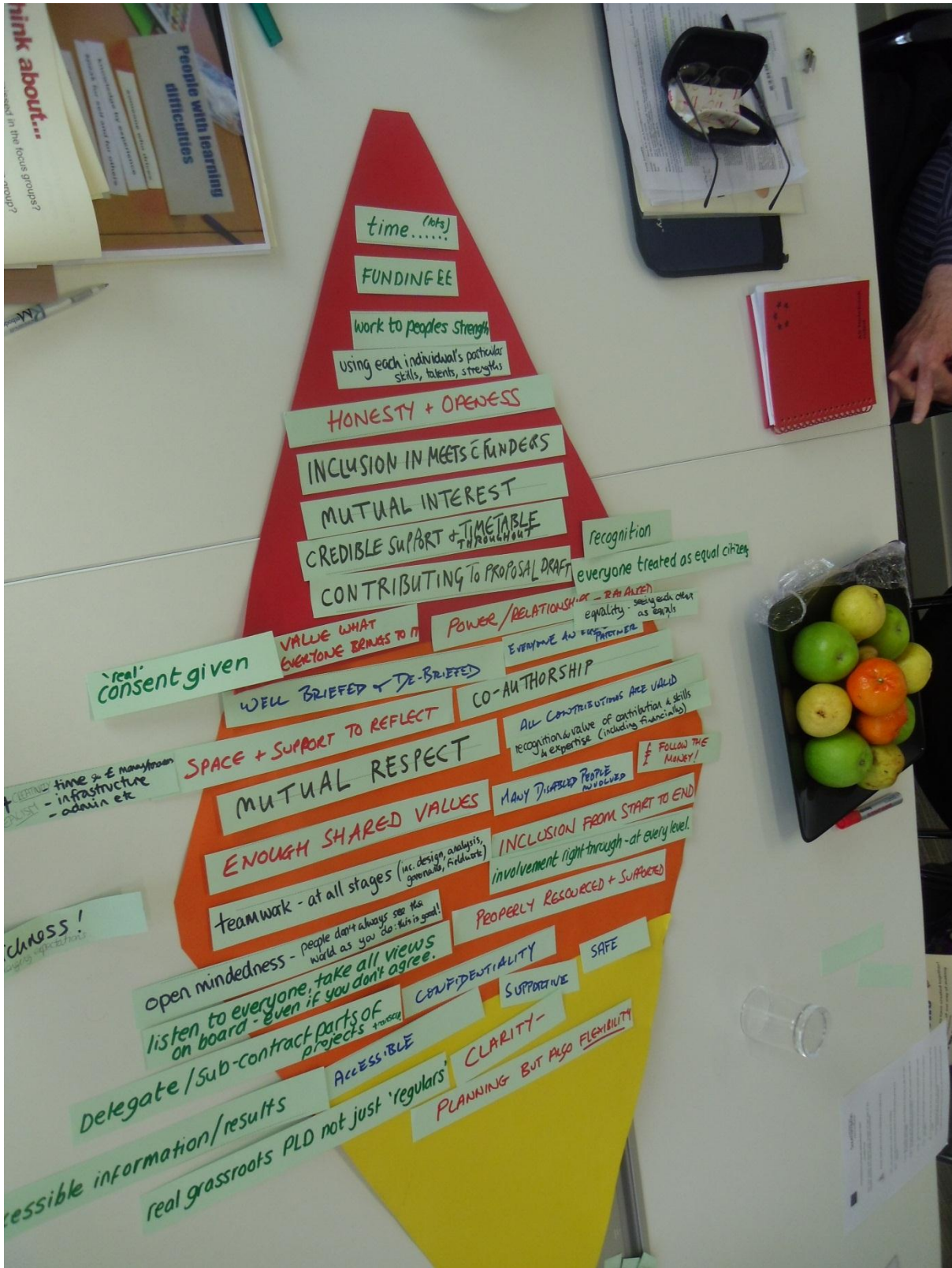
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Appendices – What we produced

Appendix 1: Suggested reading

At the time of writing this report some of our **participant-researchers**, with their colleagues, saw the publication of their special edition of British Journal of Learning Disabilities, the first to be fully edited and peer reviewed by a partnership of learning disabled researchers and academics. The challenging of established practices and breaking down of barriers was happening all around us! We therefore recommend the whole of BJLD volume 40, number 2. Our other suggestions for further reading are just a handful of what is available but they show a range of approaches used by participant-researchers in this study and some of the issues they have been writing about.

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Williams, V. and Simons, K. (2005) More Researching Together: The Role of Non-Disabled Researchers in Working with People First Members, *British Journal of Learning Disabilities* 33: 6-14.

Appendix 2: Focus group questioning route

Encounter 1 Story-based	Encounter 2 Reflecting	Encounter 3 Gap areas
Opening invitation 'Please go round and say who you are and how you became a researcher; share any material you've brought along with you' *(round robin to warm up so all voices are heard and audio recorded with name; research stories/life stories/gaining some context)*	*Opening invitation* 'Please go round and say who you are and something nice that's happened since we last met – can be about your research or something else' OR 'and respond to X stimulus from last time/FGX)' *(hearing each voice; re-forming the relationships)*	*Opening invitation* 'Please go round and say who you are and what you think about X stimulus material' *(hearing each voice, opening up ideas about analysis)*
Main section • What research are you doing now and how did you come up with the idea? *(prompting research stories; getting at rationale, goals, early processes)* • How did you go about designing the research? *(prompting research stories about process, collaboration, free form comments on what went well and what was challenging; leading into specific prompts)* • What has worked well? • What have the challenges been? *(then getting deeper into stories motivations about motivations and personal success criteria)* • What did you hope to get out of the research? *(follow up)* • Did you get what you wanted? (Why/How?) *(trying out abstracting from the stories)* • What made it good research?	*Main section* • What different kinds of research have people in the group done? *(opening up diversity of topics and methods)* • What have you found out about? *(clarifying topics and probing types of knowledge)* • Were your projects successful projects – what made them successful? *(using success to help clarify criteria and link back to goals/purposes)* • Would you judge this to be good research? *(getting at own quality criteria; prompt to reflect on own project and interesting projects that have arisen; use prompt)* • Why? • Who else might judge your research? Would they see it as good? *(getting at different audiences/purposes/quality criteria/knowledges)*	*Main section* • When you analyse/make sense of the findings how do you share out the tasks? • How do you check your interpretations with your research participants? • What concepts or theories do you find useful? *(may need to differentiate PMLD topic for FG1)* • Can everyone be a researcher? • Can everyone give research data? • What do you need to be a researcher? *(or for FG3, or mix)* • Has anyone done research involving people with profound and multiple disabilities? • What were you trying to find out? • How did you go about it? *(addressing the gaps outlined in the bid)* • What has not been covered in the focus groups that you would like us to discuss?

End section – going forward • What would you like us to take forward for next time? • What would you like us to take to the other focus groups to discuss?	***End section – going forward*** • What would you like us to take forward for next time/ take to the other groups? • What has not been covered in the focus groups that want included?	***End section – going forward*** • What would you like us to take forward to the policy makers focus group? • What would you like to see go into guidance?
Potential stimulus materials: • Anything the researcher-participants have brought with them about their work • Our digital story • Participant info sheets & consent forms • Powerpoint slides • Quotes from participants from prior work	***Potential stimulus materials:*** • Anything the researcher-participants have brought with them about their work • Powerpoint slides • Quotes/ digital story from transcripts of first encounters	***Potential stimulus materials:***
Open areas for analysis: • Key concepts (and how we know they are key) • Core narratives • Critical incidents • Emerging patterns	***Open areas for analysis:*** • Key concepts (and how we know they are key) • Core narratives • Critical incidents • Emerging patterns	***Open areas for analysis:*** • Key concepts (and how we know they are key) • Core narratives • Critical incidents • Emerging patterns
Key areas for analysis: 1. How is working in partnership described and understood? 2. What are the processes for generating and co-constructing research questions and research designs? 3. How do participants from the same research team function together? 4. What do the focus group dynamics tell us about partnership work? 5. What kinds of knowledge are referred to in relation to these participants' research? 6. What benefits from doing the research are described? For the researchers? For their participants? For other stakeholders?	***Key areas for analysis:*** 7. Qs from encounter 1 (particularly (i) & (iv) plus: 8. How is good research conceptualised? 9. Which research purposes are referred to and emphasised? 10. What success criteria are suggested? 11. How are the needs of different audiences understood and balanced? 12. What agendas emerge from the researcher-participants themselves?	***Key areas for analysis:*** 13. Qs from encounters 1 & 2 plus: 14. What does working in partnership mean in terms of analysis? 15. How is analysis understood? 16. How is analysis conducted? 17. How do participants talk about the role of theory in their research? 18. What does more profound impairment mean for working inclusively?

Appendix 3: Research topics of participant-researchers

Lives of people with learning disabilities		Lives of others
People with learning disabilities Our lives and communities My life/life stories Life in institutions People's lives Relationships Friendships Social lives Dating My family Family trees	Health, wellbeing, lifestyle, opportunities Sterilisation Support around cancer Breaking bad news Patient safety What people with learning disabilities understand about abuse	Support workers Personal assistants Experiences of people without learning disabilities How able-bodied people see us
Self-advocacy Self-advocacy groups & social media Advocacy Resistance songs Direct payments	Wartime memories Hidden heritage History of People First Groups	
People with learning disabilities or all people? Autism Access for people with visual impairment Children's lives, friendships, participation		
Services		**Other**
How to change services Services for BME groups Support Bereavement support Health checks		Musical instruments Access Work Research agenda Identity History (of an institution) Research development

Appendix 4: Funders

Funders of research in which people with learning disabilities led or were major collaborators	Funders of research in which academics or people without a label of learning disabilities led
Heritage Lottery Fund National Lottery Joseph Rowntree Foundation Northern Rock Foundation Advocacy Sparks Oxford Council	Disability Rights Commission Economic & Social Research Council Arts Council National Children's Bureau BBC Children in Need Epilepsy Action
Department of Health	

Appendix 5: Questions to ask yourself when judging the quality of inclusive research with people with learning disabilities

1. Is the topic relevant to the lives of people with learning disabilities and interesting to them? Could it become relevant?
2. Does the research involve people with learning disabilities in a meaningful and active way?
3. Are the participants in the research treated with respect?
4. Is the research communicated in a way people with learning disabilities can understand and respond to?
5. Is there honesty and transparency about everyone's role and contribution?
6. Were the ways of working carefully thought through and adapted in response to needs?
7. Does the research create worthwhile knowledge?
8. Are there likely long-term wider benefits for the people involved e.g. new networks, skills, funds, roles, social inclusion?
9. Are the research questions the kind that inclusive research can best answer?
10. Does the research reach participants, communities and knowledge that other research could not reach?
11. Does the research use, and reflect on, the insider cultural knowledge of people with learning disabilities?
12. Is the research genuine and meaningful?
13. Will the research make impact that people with learning disabilities value?

Note: These are questions to provoke reflection and discussion. They could be answered 'yes', 'no', 'yes but', 'possibly', 'in some ways', 'it depends'. Any overall judgement will be informed by ideas generated by the researcher-participants in this project. This approach (rather than specified criteria) reflects our conclusion that there are many ways of doing research inclusively, different perspectives on what makes it good, and a need to keep our thinking flexible while we are still learning.

Appendix 6: Questions to ask yourself when working out how to work together in inclusive research

1. Why are you working together on the research? Do you have a shared purpose, or do you want different things from it?
2. What do you each understand inclusive research to be?
3. What values guide the way you want to work together? How will you put those values into action?
4. What terms will you use to describe yourselves? (co-researchers, partners, team members etc) What does your choice of the terms say about you?
5. How will you talk about the research? (How often, where etc)
6. Who is setting the agenda?
7. Does everyone have equal right to speak? How will you make sure everyone is heard?
8. What skills, knowledge and qualities do each of you offer?
9. What will you do together and what tasks will you need to divide out?
10. What can you plan in advance and where might you need to adapt as you go along?
11. What kinds of support are needed?
12. How will you work through differences of opinion and challenges?
13. How will you learn from each other?
14. Are you placing most importance on support, on negotiation or on interdependence?
15. What will work best for this particular project at this time?

Note: These are questions to provoke reflection and discussion. The research indicates that there are many different ways of working together rather than one right way. Many research teams have developed their practices over time and work differently on different projects and so the research context and the research question are important.

Appendix 7: Case studies – Teaching and learning materials for helping to guide practice

The following case studies are drawn from the data. They are not case studies of individual projects as there are plenty of those in the research literature already. Reflecting the particular nature of this research they are case studies of dialogue that we think shed light on inclusive research in useful ways.

We suggest that among the questions to ask yourself when using the case study material you might like to think about:

1. What does this tell us about what is important in inclusive research?
2. What does this say about how the differences in power are managed?
3. What values seem to be guiding this way of working?
4. What practical lessons can be learned from this example?

Case study 1: Identities

Hilra introduces the focus group (made up of self-advocacy groups who get involved in doing research) to an activity about who they are and what they do. They have visual materials to work with including prepared labels, blank cards and pens.

Carl points to the label *person with a learning disability* and comments, 'I could agree with that. Individually we are that.' Durbali then reflects, 'You have to think what you are doing. Are you campaigning for learning disability or not?' Becca asserts, 'I want to be a human being', which is met with good-humoured cheering. Durbali asks, 'Can you do a black person with learning disability or not?' Exploring the available labels further Becca observes that the professionals say *learning disabilities* they say *learning difficulties*, and Julie points out that their group use *learning disabilities* more. Then Carl picks out a new identity for himself, pointing the label *researcher* he says 'I am one of these'. Hilra asks if anyone is a *co-researcher* and Durbali responds that she calls herself a *member*, and Carl that he calls himself a *researcher* or a *team member*. He goes on, 'I know this is so wrong now, but I don't want you to laugh at me, but, I suppose that one (pointing to the label *inclusive researcher*) sounds better, it makes you look clever … it sounds better if you have *inclusive researcher*, it sounds clever.

Case study 2: Research funding

This focus group of people with learning disabilities doing funded research projects and people who are involved in the research with them are discussing their work. It is their first meeting and the group is rather big. Their talk includes how they work together and how they secured their funding. One group are at an exciting stage of their project, Looking into Abuse. Davy describes himself as part of the project and Karen, his personal assistant confirms that he is one of 3 co-researchers employed on the research. Joyce, a researcher who has been involved longest, tells the story from the beginning: 'The idea for the project came from a group with

learning disabilities who advise the teaching nursing section of the university, where they have a session on what research is and they said well we want to do research'; abuse came up as the most important thing to look at. It took them 7 years and lots of attempts to get research funding after their first application to the Lottery was unsuccessful. They were encouraged to keep trying by a person with learning disabilities who chairs the research advisory group. Joyce explains, 'We also got money from an organisation in Wales to pay me, luckily, to write the project outline with people with learning disabilities, so people were involved from everything from the very first thought of it right through to the co-researchers and people are still involved on a voluntary basis.

Tracey talks about the campaigning work they do in My Life, My Choice, but Kerrie wants to know why it took so long to get funding for the abuse research. Joyce explains 'it also took seven years because people with learning disabilities were involved in writing it, who could meet once a month, and it took a long time to write everything that you have to write for a research project, including the literature review which is when you look what was done before it, all that was written so people with learning disabilities involved could understand it.' Tracey explains how they won funding from Oxford City Council after doing a presentation with role play.

Suzy, the research co-ordinator for another group of co-researchers and their project, Work in Progress, tells their story: 'I heard the Lottery were funding research projects and … we knew that from the research that Norah Fry had done before that employment was important to people, we also knew locally in Cornwall it was important to people … I desperately wanted to do inclusive research … so we wrote, well you [referring to Val – experienced colleague] wrote most it'. She continues,

much to our amazement, we just got it and I was expecting a huge telephone interview and interrogation. I remember calling you [Val] saying we got it and you said 'what do you mean we've got it?' [laughter].

Tracy says that someone helps them get money in My Life, My Choice and a supporter tells the story of how a professor from the Open University identifies funding opportunities and asks if they want to get involved, which goes to the trustees to discuss. Ideally they would prefer to work from the grass roots, but as a charity they weigh up whether what is proposed will get people with learning disabilities involved, get them paid, improve their skills, and so on.

Case study 3: Academic voices

Members of the focus group of academics introduce themselves and their work. Liz reflects back on her PhD on the history of Mencap: 'three or four months in I explored whether I could make it a more inclusive project and realised that I was too late and really that should have been something that should have informed the proposal from the start'. Irene talks about her work at St George's Medical School where they employ two people with learning disabilities on training and research as advisors initially, now as co-researchers, and that they couldn't do their work properly without them. Will talks about his PhD using inclusive participatory design making bespoke musical instruments for disabled players. Hazel describes her efforts to involve people with profound and multiple learning disabilities and Jane recounts convening an inclusive seminar series. Another (anonymised) researcher explains the necessity of involving people with learning disabilities to find the answers to her research question about resistance songs in long stay

institutions, and her use of mobile interviews as a method. Sarah talks about her starting point being her interest in hearing disabled children's voices and moving on to participatory design. Gordon says, 'I think I stumbled into more inclusive forms of research by making mistakes'; he reflects back on how at first he was not translating inclusive policy principles into his research practices until 'the penny dropped'. Ann relates feeling her way through particular projects that pushed her to consider what were 'authentic, trustworthy, credible approaches'. The group talk about obstacles for them: the expectations of certain disciplines, funders, ethics boards and universities, and how the money is rarely enough to be as inclusive as they want to be. They discuss their personal integrity and also what they gain from their research, which may not be the same for the people they do their research with. The quality of the relationships with those learning disabled people is very important to them.

Case study 4: Roles and contributions

Amongst academics and people with learning disabilities who collaborate on research projects and who mostly know each other already, those involved in researching the history of their self-advocacy group are discussing the different contributions people have made to the study. Self-advocates had been telling their stories when, as Catherine describes, 'our support worker come to us [with] this beautiful long list of all the things we forgot to mention and Ian said were vitally important about our history'. Ian reflected on why they had been missed: 'the things he said - our support worker - are more the backdrop. The most important things are those that people [have] personally been involved in and things they've achieved'.

It transpires that, Jan, an academic, is doing the project background work on self-advocacy. She reflects: 'the interdependency is very important. It's a team, what comes out has to be the contribution of different people and I think the missing bit is why we haven't analysed, why you flourished so much in the 1990s and why life is much more difficult since 2000/2001. We haven't looked into that and I don't think that inclusive research will be very good at that.'

The conversation moves on to the need for research to gather experiences, and to offer interpretations about why those experiences were like they were, different people's interpretations, informed by different research and life experiences. Ian relates this to the National Survey experience, 'I sat with you and Karen and the entire purpose was not to dispute what Eric said as an academic, but in front of each chapter [we added] some paragraphs, and those paragraphs are "we recognise this in our experience from our own research or we are a bit surprised by this".'

Case study 5: Accessibility

The focus group combining self-advocacy groups who also do research are concerned with the subject of accessibility and Julie, a main supporter introduces stories of barriers to their involvement in research: 'The office for disability had some money for disability groups but the form on their website were really complicated, and we did email them and asked for an easyread copy, but we still haven't got it, they acknowledged it, but… The money they've got is supposed to be used with groups, and … they did not adapt their papers at all. We were reading it and looking up the words on the internet because some of the language was really difficult.' Self-advocates, Carl

and Becca chip in about the font size and the conversation shifts to their experiences of using dance and drama to communicate to audiences, the problem of jargon and not assuming that everyone speaks or understands English. Durbali adds in how at Change they use a lot of pictures in their reports.

Becca anticipates that the focus group of policy-makers and funders will 'be full of jargon'. The group suggest they won't know easyread, but they will be interested in budgets and what the research is about. They agree that making the research accessible means it costs more. Mel explains that 'we will ask these people [funders] what is important to them as well' and Becca responds, 'that will be really different'. Later they talk more about their use of accessible media and Michael proudly recounts, 'We made this video about what we do, then I uploaded to YouTube, so if someone goes to our website they can see it on YouTube'. Later, he takes up the invitation to make videos for this project website too.

Case study 6: Co-analysis

The group of self-advocates, academics and supporters have worked together over many years and several research projects. They are comfortable with doing data analysis together as a collaborative process. Lou explains one of the lessons they learned: 'I remember on one of our projects we transcribed tapes and I helped with that and we realised that rather than doing the transcription, [if] we actually just sat down and actually listened to the tape interview rather than to transcribe it all, just listen to the tape and that worked a lot better. It's actually finding ways that suit everybody.' On another occasion she expands on this: 'some people in our

research group can't read so what's the use of transcript in word form when you could just listen to them as tapes. So we went through the tapes using flipcharts around the room and people would pick themes that came up. It was not one of those, like right we've analysed it that's it, we kept adding to it. So we did copies of tapes for people so they could bring home and listen to it at their leisure.'

The focus group are immediately interested, and someone comments on how the analysis is done is often skipped over in the research papers. Ian describes the data analysis process for the National Survey where Eric (the lead academic) analysed the data first and then Ian sat down with the researchers with learning disabilities: 'we went through what Eric had done and they picked up things they recognised … we could pull out quotes using one of the tools for qualitative research. That made them think about the topic because they were coding the topics not me.' Members of the group suggested that while transcription could be boring and just done to please the funders, the things they did with coloured pens, and using the idea of different coloured panels of an umbrella, and trying to put themselves in the shoes of the person being interviewed, and the person reading the research, was a good part of the research process.

Case study 8: A conversation with policy-makers/funders

The focus group is small, the people involved with policy and funding are in senior roles; they are joined by two experienced people from a research cooperative whose focus group has already met three times. Melanie asks for their views on the defining features of inclusive research. Margaret suggests mutual interest is key – 'subject matter that engages all

participants' – plus mutual respect. There is agreement and Emma takes up the theme: 'For me there is something there about having enough shared purposes. Because actually people might have different things [they want from the research] and people might have different perspectives but it is about having enough that is shared … that holds everyone together. It's about being clear, everybody being clear and honest about why they are part of it.'

They discuss whether there is one way of defining inclusive research and Lou and Chloe respond that their cooperative have discussed this at length without coming to an answer. There is agreement that everyone's full commitment to the topic is important. Emma talks about the spectrum of approaches and terms and reflects, 'what worries me is if we receive proposals that are over-claiming or using words almost because they are designed to be words to appeal for a funder rather than actually describing the processes'. Tony says he doesn't mind where the idea starts from as long as there is high involvement of disabled people in the development of the idea into a proposal and project.

They discuss what has driven policies to fund inclusive research: families wanting research that is credible, the availability of lottery money, the push from disabled people, greater valuing of research about people's lives generally. They talk about what they look for in funding proposals including a realistic budget and timetable. Chloe and Lou express interest in hearing this as their projects cost more and take longer. The funders reassure them that this is to be expected, as Tony says, 'being truly inclusive you accept, you want to be inclusive so you accept that there is going to be a cost'.

Case study 9: Inclusive research and theory

Melanie has posed the question to the participant-researchers of whether they use theory when they are interpreting data. She has worried about whether this concept will be accessible to everyone. This group of academics and people with learning disabilities who research together are experienced, no-one expresses discomfort with the word and the academics pick up the theme. Some have used hypotheses and existing theories and developed them further within their inclusive projects. In one project the academic researcher held back any theoretical material because it was meant to be user-led.

Jan reflects that inclusive research is based on a theory or hypothesis, 'which is if you break things down enough then people who are not accustomed to think about research can learn about it'. She also identifies a post-modern theory underlying inclusive research in that 'we're saying there are different voices and we don't need to weave them together, they can stand for different things'.

Catherine suggests, 'you can work within a theory without naming it as a theory'. Rohhss recalls reading the work of Simone Aspis 'and bringing it back [to the research cooperative] and then talking about the social model. People know all about the social model, it is just not expressed the way academics express it but it still there.' They discuss how Dan Goodley has written about this.

Case study 10: Ingredients of inclusive research

The focus group of self-advocates and their supporters enjoy a relaxed atmosphere, sitting round a table in a familiar informal venue. The question posed to them is about the ingredients of

inclusive research, imagining it was cake what would need to go in. They have visual materials to work with.

Becca begins, labelling one of the ingredients 'the topic we are going to research'. Carl picks up on the metaphor: 'The jam is going to be us, because we're on the middle of the cake'. Becca adds 'background work'. Mel asks if the topic can be any topic, Becca isn't sure but Carl is: 'it must be a relevant topic', clarifying relevant 'to us'. Julie, in support, gives an example of researching farming in Greenland to help explain Carl's point. Not everyone is following the metaphor but Carl and Becca are enthused adding, 'plain English', 'translators', 'supporters', 'money' and 'accessible buildings'.

Hilra probes further to explore the people dimension, asking them about who they mean by 'us'. They are represented by jam and there are jokes about raspberries and strawberries before Becca offers, 'we the researchers'. Julie, interested in this theme, tries to prompt thinking by asking, 'What if there was 10 people from the university as researchers and there was 1 self-advocate. Would that be inclusive research?' They respond no, talk about partners, and that 'everybody has to be involved', with the same numbers. Durbali adds volunteers to the mix and Carl makes a new ingredient label 'Researchers, and the general public'. Mel checks they know the word 'academic' and Becca responds, 'People from university?' They confirm they are happy with academic being an ingredient – 'university jam'.

Later the conversation turns to whether the ingredients of inclusive research always need to be the same. Becca thinks yes but Carl disagrees, 'sometimes you put something else in your cake', or 'you make the same cake and it turns [out] different'. Michael agrees with Carl that asking the right questions always has to be in there.