Understanding quality in inclusive research: a process of dialogue

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Abstract

The case for research by and with (rather than on) people with learning disabilities has been successfully made. Calls for emancipatory research have drawn attention to the ways that research owned by disabled people can better tackle social oppression. For learning disabled people moves towards a productive rather than passive role in research have largely retained some involvement of non-disabled people. This paper reports on a study in England which brought together learning disabled researchers leading their own research, learning disabled and non-disabled researchers working in collaborative research partnerships, and academic researchers using participatory design or methods. We adopted Walmsley and Johnson’s (2003) concept of inclusive research to recognise the overlaps between emancipatory and participatory research and the need for research that matters to the people involved, represents their views, involves them in the research process, treats them with respect, and may improve their lives. The intention was to work together in a series of focus group discussions to take stock of what we had learned about doing inclusive research and to answer Walmsley and Johnson’s call to ‘grapple honestly’ with the challenges. This is necessary if quality in inclusive research is to be understood. In the paper I reflect on the research process and the resulting model of ways of researching together and guidance in the form of questions to ask ourselves: when judging the quality of inclusive research; when negotiating how to work together in inclusive research; and when using the case study materials the project generated.

Preparation

This paper reports on a study conducted in England in 2011-12 to explore what was happening in inclusive research with people with learning disabilities and what quality means in the context of developing practice. The ground had already been prepared for this project in that the case for research by and with people with learning disabilities had been well-made by people with learning disabilities and their allies (e.g. Townson et al, 2004; The Learning Disabilities Research Team, 2006; Abel et al, 2007). There was already a range of research projects being conducted in which people with learning disabilities were leading, collaborating, or being actively engaged as participants or decision-makers by academics. Many had concluded with their findings being published in some way, and some researchers had also published reflections on their processes of becoming researchers, negotiating their collaborations or, occasionally, their struggles along the way. There was, therefore, a series of individual accounts and a sense in which each new project was discovering anew – each new research team was inventing the wheel for themselves.

The stimulus for the research was the recognition that it was timely to take stock of developments – to pause for reflection. Walmsley and Johnson (2003) had made an important contribution by offering a definition of inclusive research that moved on from the concepts of
participatory and emancipatory research to a new concept that embraced these but that was more open and meaningful to people with learning disabilities. For them, inclusive research ‘must address issues which really matter to people with learning disabilities and which ultimately leads to improved lives for them’, ‘must access and represent their views and experiences’, and reflect ‘that people with learning disabilities need to be treated with respect by the research community’ (Walmsley & Johnson, 2003, p.16). Walmsley & Johnson (2003) also presented critical analysis of the state of play in inclusive research and concluded that, despite the positive developments, there was nonetheless a failure to ‘grapple honestly’ with the inherent challenges and ‘a certain stifling of debate’ (p.13) about these.

A similar argument was made by Aspis, a self-advocate who has questioned the use of people with learning disabilities as puppets and the failure to really address the meaning of partnership. Also taking stock, Grant & Ramcharan (2007) accepted that much of the practical work around how to do inclusive research was well underway, but that work was still needed to better understand the benefits of the experience of inclusive research for those involved, the kind of knowledge it can generate, and ‘whether good science and good inclusive research practice can be brought together’ (p.12). It was timely therefore to bring inclusive researchers together to engage in constructive, hopefully transformative, dialogue (see Gergen, 2009) and to grapple with the idea of when inclusive research is also quality research. This is what I set out to do in this study.

**Action**

Having secured funding from the Economic and Social Research Council I set out to engage the participation of learning disabled researchers leading their own research, learning disabled and non-disabled researchers working in collaborative research partnerships, and academic researchers working in participatory ways. The research design involved each group meeting together in a series of three focus group discussions so that rapport could be built and open dialogue facilitated in a safe environment, preventing any defensiveness about the approach taken (after Haw, 2010). There was also an additional group of researchers with learning disabilities whose focus group met twice and a group of funders or commissioners of inclusive research who participated in a focus group to address this from their perspective. Key points from each focus group were fed into the questioning route of others to allow for exchange of ideas. Ultimately everyone came together in a final inclusive focus group to check back over the interpretations made about the core messages in our process of co-construction of knowledge.

This way of fostering cycles of dialogic inquiry followed Vinha’s (2011) methodological adaptation of Freire’s (1970) concept of dialogue as creative and liberating. The emphasis was on listening to and engaging with a range of researcher voices, reflecting on those voices to make best use of constructive friction within the field, and re-locating authority away from the individual researcher or researched and placing it in the interactive space between them. Focus groups can offer a non-hierarchical participatory approach ((Bagnoli & Clark, 2010) and they were chosen as a way of engaging us all in ‘deliberative, dialogic and democratic practice’ (Kamberelis & Dimitriadis, 2005, p. 887).

During the early stages of action in the project there were two important changes in language and thinking, one related to the people taking part in the focus groups and one to the project itself. In the democratization of the research we were mentally rejecting the idea of experts by experience [ref] talking with experts by training or profession, tending instead towards the
position proposed by Gallacher & Gallagher (2008) that such discourse of expertise is tyrannous. Instead we regarded everyone involved as what Gallacher & Gallagher’s (2008, p.511) refer to as universal ‘emergent becomings’, ‘always-unfinished subjects-in-the-making’, never ‘fully knowing, competent and rational’. Moreover we worked the hyphen (see Fine, 1994) by referring to participant-researchers and researcher-participants to acknowledge our dual identities and the interwoven process of being a researcher and a participant in the dialogue. The project name change from that used in the funding bid (Quality and capacity in inclusive research with people with learning disabilities) was prompted by a desire to have something less formal and more accessible to people with learning disabilities. In the new name (Doing research inclusively, doing research well?) the change to the active verb deliberately stressed the process of doing and took the emphasis away from inclusive research as a noun, as if we shared a concept of the thing. The question mark was important for stressing our shared process of coming to know what doing research inclusively and well might mean.

I had always intended that the focus group discussions would be supported by visual triggers or stimulus materials. As the project unfolded these materials reflected our use of metaphor when discussing the ingredients of inclusive research (see case study 10, Nind & Vinha, 2012 & powerpoint slide 11). Auditory materials were added when we started to create a form of I-poem (Gilligan et al, 2003), or rather ‘we-poem’ to provide narrative summaries of themes emerging from the dialogue in participant-researchers’ own words (see our video story on the ‘how’ section of our website http://www.doingresearchinclusively.org/). Analysis of the dataset (comprising abridged transcripts, fieldnotes, reflective diaries, memos to self and the materials we co-produced) took place in reflective phases interspersed between the dialogic phases. Themes were teased out related to (i) the issues involved in inclusive research, (ii) the process and lived experience of conducting inclusive research, and (iii) recognising quality in inclusive research.

**Reflection**

A major area for reflection in the analytic process was how learning disabled researchers, support staff and academic researchers worked together. We discuss the model that emerged in our full report (Nind & Vinha, 2012) and paper in British Journal of Learning Disabilities (Nind & Vinha, 2013) and I explain this here briefly. The dialogue clearly pointed to a rich diversity in the ways in which people work together across differences when conducting research. One metaphor that emerged spontaneously in one of the focus groups was that those involved in research together could form for each other a bridge to another world (see powerpoint slide 13 for the visual representation of this). For example, research could enable self-advocates a route into the world of academia, or enable academics to gain insight into the world of self-advocacy. This was a function of research that was universally valued by participant-researchers and even the funders of inclusive research expressed desires for the research to have wider benefits in terms of social inclusion that went beyond any new knowledge generated. Nonetheless, how such bridges were built and how research relationships were formed with participants in the conduct of studies varied enormously.

The descriptive model we generated from the data (see powerpoint slide 14) represents the ways in working together could be a predominantly formalised or improvised process. This reflected how much could be pre-planned or was bound by rules for conduct and how much researchers felt it appropriate to be responsive in situ. More centrally, though, were ways of working in which the emphasis was variously placed on support, negotiation or
interdependency. Subtle differences in emphasis spoke of the influence of discourses of expertise, legacies of power differentials/power battles, and journeys towards recognising mutual need, interest and purpose. For some research teams there were experts and there were supporters and each had very different entitlements. For some there was huge energy invested in negotiating who does what and how and who can speak for whom and so on, which was almost/more important than producing worthwhile findings from the research. When positions of interdependency were reached support and power were less of an issue and adopting different roles in an overall interdependent process was valued.

It became clear that research teams could work in different ways at different times in their research career, in different projects, or even in the same project! This diversity makes a mockery of attempts to pin down exactly what inclusive research is or should be. Thus, our co-produced overview of inclusive research was a picture of people doing things differently, but according to some shared values and concerns. Consequently, the research did not generate criteria for what constitutes inclusive research practices and we settled instead on some questions to stimulate reflection among teams setting out on a research project. This approach allows for diversity but avoids each new team starting entirely afresh. Instead they can build on the experiences of the (more than sixty) researcher-participants involved and discuss their responses to questions such as:

- Why are you working to together on the research? What do you each understand inclusive research to be?
- What values guide the way you want to work together? How will you put those into action?
- What terms will you use to describe yourselves

(for the full list see Nind & Vinha, 2012)

This approach of posing questions to provoke reflection and discussion was also one of the outcomes of our work on the quality question. Not only are there many valid ways of doing research inclusively, there are many ways of doing it well. We were able to explore what different groups appreciated as distinctive about doing research inclusively. Furthermore, we were able to grapple with the tensions between what people with learning disabilities value in a piece of research about them, and by or with them, and what social science researchers value in research that is of high quality. These discussions led to the production of questions pertinent to these issues, such as:

- Is the research relevant to people with learning disabilities? Could it become relevant?
- Does the research involve people with learning disabilities in a meaningful and active way?
- Are the participants in the research treated with respect?
- Is the research communicated in a way people with learning disabilities can understand and respond to?

(for the full list see Nind & Vinha, 2012)

It was always the intention that this research would produce helpful materials and an overview of the state of play that was polyvocal. I was less concerned with reaching consensus than with reaching an appreciation of different standpoints. Nonetheless, the study did generate answers to the research questions related to how inclusive research and its outcomes can be evaluated and how good science and good inclusive research can come together. These answers are tentative and have the status of ‘becoming’ knowledge, but they are based on where the different voices and standpoints coalesced. In sum, were able to
concur, based on careful analysis of dialogue among experienced researchers that inclusive research is also research of quality when:

- The research answers questions we could not otherwise answer, but that are important.
- The research reaches participants, communities and knowledge, in ways that we could not otherwise access.
- The research involves using and reflecting on the insider, cultural knowledge of people with learning disabilities
- The research is authentic
- The research makes impact on the lives of people with learning disabilities.

These criteria may not facilitate entirely the distinction between studies of high and low quality but they are a useful starting point. Funders and reviewers have been in the position of having to compare bids made in response to calls for proposals for studies that were required to be in some way participatory or inclusive. This has been an unfortunate position, even an impossible task when faced with comparing a proposal with high social science quality (marker by rigour, trustworthiness etc) but poor inclusivity or high inclusivity and poor research quality. So far the means to evaluate inclusive research bids and completed projects have been lacking, but these criteria provide an indication of what a study might look like when combining good inclusivity and good social science.

**Conclusion**

I finish with an additional complication to the question of quality in inclusive research. One finding from this project that shone through more strongly than any other is that we expect a great deal from inclusive research; put colloquially, it is a ‘big ask’. We expect it to offer something over and above ‘traditional research’ in terms of design and approach to knowledge generation, and we expect it to play a role in social inclusion; we ask it help sustain self-advocacy groups, provide people with new skills and networks, and even to empower people and change lives. When we look for the research to be of high quality we need to bear in mind these multiple agendas and the ways in which they necessitate an expansive and fluid concept of what it means to do research inclusively and do it well.

**References**


The Learning Disabilities Research Team (2006) *Let me in – I’m a researcher!* DoH.


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Background

- Case for research by and with (rather than on) people with learning disabilities has been successfully made.

Let me in – I’m a researcher!
Getting involved in research
Department of Health
Inclusive research has been defined:

- ‘must address issues which really matter ... and which ultimately leads to improved lives’
- ‘must access and represent their views and experiences’ &
- reflect ‘that people with learning disabilities need to be treated with respect by the research community’ (p16)

But!

- Different project teams each working it out for themselves
- Very little dialogue between them
- Very little discussion about the difficult stuff
So ... the need for dialogue

- learning disabled researchers leading their own research,
- learning disabled and non-disabled researchers working in collaborative research partnerships
- academic researchers working in participatory ways
- funders

And to move forward to ...

- ‘Grapple honestly’ with the challenges (Walmsley & Johnson, 2003: ?)
- Understand quality in inclusive research
- Build our capacity to do research inclusively and do it well.
A series of focus groups

- talking separately and together
- taking stock of what we had learned about doing inclusive research
- answering difficult questions

A change of name; A change of focus

- From ‘Quality & Capacity in Inclusive Research with People with Learning Disabilities’ to ‘Doing research inclusively, doing research well?’
- From the tyranny of experts by experience vs experts by training to we are all learners together
From dialogue to data

- Visual prompts, poems and the cake metaphor

Over to Michael:

http://www.doingresearchinclusively.org/

Bridges to a different world
Ways of working in partnership?

Questions rather than criteria

- Why are you working together on the research? What do you each understand inclusive research to be?

- What values guide the way you want to work together? How will you put those values into action?

- What terms will you use to describe yourselves?

- How will you talk about the research?

- Who is setting the agenda?

- Does everyone have equal right to speak? How will you make sure this happens in practice?
The quality questions

- Is the topic relevant ... could it become relevant?
- Does the research involve people with learning disabilities in a meaningful and active way?
- Are the participants in the research treated with respect?
- Is the research communicated in a way people with learning disabilities can understand and respond to?
- Is there honesty and transparency about everyone’s role and contribution?

- Were the ways of working carefully thought through ...?
- Does the research create worthwhile knowledge?
- Are there likely long-term wider benefits for those involved?
- And finally...
Inclusive research is quality when:

- The research answers questions we could not otherwise answer, but that are important.
- The research reaches participants, communities and knowledge, in ways that we could not otherwise access.
- The research involves using and reflecting on the insider, cultural knowledge of people with learning disabilities.
- The research is authentic.
- The research makes impact on the lives of people with learning disabilities.

But ...

- There is no one way of doing research inclusively and doing it well.
- If we think there is one right way then we will stifle debate and stifle action; we will replace one normative framework with another.
- Hence doing research inclusively (not doing inclusive research).
- We are all learning together.
ASK