Nind, Melanie. "Summary and where next? The pursuit of quality in inclusive research." *What is inclusive research?*. London: Bloomsbury Academic, 2014. 83–92. *Bloomsbury Collections*. Web. 26 Apr. 2023. <<http://dx.doi.org/10.5040/9781849668149.ch-005>>.

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5 Summary and where next?

The pursuit of quality in inclusive research

I began this book by showing that describing ‘what is inclusive research’ is not straightforward. Inclusive research encompasses a range of research practices conducted for a range of reasons, but with some fundamental principles and frustrations in common with other kinds of research. In Chapter 2, I have shown the diverse influences on the development of inclusive research as an overarching concept, the development of the specific concepts of emancipatory, participatory, participatory action and the development of partnership/user-led/child-led research. The various drivers at work were illustrated by the examples in Chapter 3 where I have tried to bring the diversity of inclusive research to life. I have then taken us through the various debates within the field, the criticisms waged at the concepts and practices and the defences offered. In this final chapter, I focus on where inclusive research has got to and how the future might unfold. This is no less controversial than the material that has gone before and no less dependent on one’s standpoint.

The state of the art of inclusive research

I do not wish to repeat the content of earlier chapters, but it is helpful at this juncture to list some of the achievements in the field of inclusive research alongside some of the challenges. This reflects my own analysis of where we are. This, in turn, is based on my own position as researcher with particular interests in social and educational inclusion, in methodology, and in the social and communication worlds of people with learning disabilities (stemming from earlier professional interest as a teacher). I am someone who does research *on*, *with* and *for* people with learning disabilities (and also other learners, educationalists and researchers). I have a strong interest in doing research inclusively, but I am not exclusively allied to it. (I deliberately use this phrase *doing research inclusively* with the active verb, preferring it to the apparently more fixed *inclusive*

research, as it implies greater flexibility.) I am not immune to the ethical or moral allure of inclusive research, but I think we need to come to know it critically, not superficially. The analysis in this chapter is also based on my extensive involvement with this field of research and on the recent completion of *Doing Research Inclusively, Doing Research Well?* (Nind and Vinha, 2012) in which I had the privilege of engaging in extended dialogue with experienced people conducting inclusive research in all kinds of ways. I am therefore fascinated by the intricacies and nuances of interpreting inclusive principles in action and, particularly as a result of the recent study, persuaded that inclusive research needs to remain vibrant, fluid and the subject of further dialogue (Nind and Vinha, 2013).

I set out some of the achievements and challenges in Table 5.1.

Dialogue in inclusive research

It is clear when we stand back and look at inclusive research that its full potential is yet to be realized. There are plenty more twists and turns to be travelled in its development. There is much to be gained from making constructive use of the frictions in the field to understand it better. There is plenty to be learned too from more engagement across the different conceptualizations of particular approaches under the umbrella of inclusive research, as researchers working with each of these are relatively unaware of each other's work. There are also potential benefits to be gained from dialogue across substantive areas so that, for example, researchers in community LGBT groups are talking to advocates of child-led research and to people with and without labels of learning disability who collaborate in research. Particularly important is 'frank and open debate ... untrammelled by unhelpful dogmatizing' (Walmsley and Johnson, 2003, p. 16). We went some way towards constructive dialogue with inclusive researchers in the learning disability field in the *Doing Research Inclusively, Doing Research Well?* focus groups. Here we used dialogue as Freire (1970) suggests 'as a means of understanding and transforming – reflecting and acting' (Nind and Vinha, 2013, p. 6). Nonetheless, while some participant-researchers embraced the opportunities for learning from and with each other, accepting that there is no right way to do inclusive research, others were more comfortable with their own sense of expertise and preferred to assert their views about what inclusive research *should* be like. This limited the extent

Table 5.1 State of the art of inclusive research

Achievements	Challenges
The need for inclusive research has become recognized in government policies that embrace service user involvement.	Such government policies lack a clear vision of what is meant by inclusive research.
The rhetoric about ordinary people in their diversity needing to enjoy rights, choices, inclusion, citizenship and involvement in services/decisions affecting them is well established.	The implications of this in research terms are underexplored.
The high profile of the importance of collaborations between academic researchers and those they research is influencing the choices made by pure and applied qualitative researchers.	The implications of this for our understanding of high-quality social science research are underexplored.
There is a growing interest in the impact of involving lay people in research related to them. Evidence of positive and negative impacts on the public, the lay people involved, the researchers and the research is beginning to be gathered and reviewed.	This is partly concerned with justifying the additional time and cost. The difficulties in evaluating impact and making comparisons are considerable.
The additional time and costs involved in doing research inclusively are increasingly recognized.	The economic and non-economic costs and benefits related to participation in research of service users/lay researchers are little understood.
Supporters of inclusive research have created a positive association between involvement in research and social inclusion more generally.	This is largely still at the level of claims making with supporting evidence beginning to emerge. Policy is ahead of good scientific knowledge in this respect.
Previously excluded or marginalized people are becoming recognized as social actors/change agents and gaining benefits from their new socially valued roles.	The long-term benefits are unknown and there are indications that new roles may be short-lived.
Inclusive research is being commissioned and funded by respected sources, indicating the acceptance by that this is valid research.	Only a minority of funding bodies and research programmes have ventured down this path; they are learning as they go along.

Continued

Table 5.1 Continued

Achievements	Challenges
<p>Users of services and people whose voices have traditionally not been heard, who have felt some anger or distrust of their treatment by services and research, have begun to take a role in the following: shaping research priorities; commissioning research; evaluating research tenders; advising on research; conducting research; publishing research; teaching research methods; peer-reviewing research.</p> <p>There have been huge advances in our practical knowledge about how to make the research process, and the products of research, more accessible to lay people.</p>	<p>These roles are largely limited to individuals who have already sought to have a voice through organized community action. Those individuals are grappling with huge social and material challenges.</p> <p>Participatory methods are less well developed and reported for data analysis compared with data collection. There may be most potential for participatory data analysis when the boundaries between data collection and data analysis are blurred and the process is organic.</p>
<p>Participation varies; there co-exists claims to genuine participation throughout the whole research process and accusations of tokenism.</p> <p>Rhetoric about researching in partnership is rife.</p>	<p>The extent of participation can become a preoccupation and a distraction from how participation is achieved and to what effect.</p> <p>Researchers, co-researchers, supporters and allies are actively negotiating what partnership actually means in their research contexts.</p>
<p>There is much variation in the terms used to describe people doing inclusive research including: co-researchers, lay researchers, learner researchers, participant-researchers, experts by experience.</p> <p>Different kinds of knowledge and ways of knowing are being valued, including the grounded knowledge that has historically been missed or dismissed.</p>	<p>The variation in terms reflects fluidity in concepts, diversity of backgrounds, political sensitivities, and a general lack of certainty in what is still a new field.</p> <p>The status of knowledge grounded in everyday experience is somewhat troubled, ranging from being reified as expert knowledge to being subjected to expert analysis by others.</p>
<p>There are many rich reports of inclusive research and some reflections on the inclusive research process.</p>	<p>Often reports lack detail on how participation was optimized and critical self-reflection and shared reflection are needed.</p>

Table 5.1 Continued

Achievements	Challenges
There is emerging guidance on managing ethics in inclusive research.	Developments like this in CBPR are not quickly or automatically known or applied by inclusive researchers working under a different label, e.g. child-led research or participatory health research.
Training on how to do inclusive research is emerging and some of this includes the pursuit of quality.	Spaces for reflexive thinking about inclusive research can be constrained by the political sensitivities. Fear and accusations about getting it wrong can limit engagement with theoretical and pragmatic criticisms.
There are celebratory narratives surrounding inclusive research and the added value it can bring.	We are only just beginning to understand how to assess quality in inclusive research and how to judge its worth in light of the multiple things asked of it.

to which, in some focus groups, people's assumptions were troubled. It may be that in other fields the ground is less sensitive and there is less wariness about causing conflict or offence. Even so, this communal process of reflection highlighted the many different ways in which people work together as inclusive researchers, making sensitive judgements and taking considered actions, committed to the principle that research should be done *by, with or for* people, but not simply *on* them. The intellectual and physical space to discuss this was welcomed and notions about what made our research inclusive and good gradually became more refined.

Quality in inclusive research

When I discussed the debates and controversies surrounding inclusive research in Chapter 4, I did not interrogate the question of what constitutes quality in inclusive research. This is because this is rarely discussed in any depth in the literature about any of the kinds of inclusive research approach. The starting point is often that it is better, has greater potential or meets a particular need (Minkler, 2005). Staley (2009), though, when interrogating the question of impact, recognizes the complexities of evaluating the impact made when research that breaks traditions and norms

to increase user involvement. This field has a hidden subtext in which in various studies the level of participation is said to be weak or superficial and these are assumed to be poor examples of inclusive research, but this is not quite the same as judging the research to be of poor quality; the converse is equally true. Yet there is also a sense in which the quality of the participation and the quality of the research sit in a kind of tension. Criteria for what makes research good quality from a traditional social science perspective are unlikely to be the first things that come to mind when service users/lay researchers talk about what makes research good from their perspective.

The CCREC (n.d.) recognize the knowledge and knowing dimension of collaborative/inclusive research as an ethical as well as quality issue. They include in their questions for interrogation in developing a code of ethics for collaborative research, 'How should the epistemic standing of research partners and participants be respected while also meeting established research norms that warrant findings?' Similarly, Edwards and Alexander (2011, p. 272) question assumptions about community involvement leading to better data, arguing instead that 'there may be "trade-offs" between research quality and empowerment' when community (lay) researchers are involved. They break the tradition of celebrating the special qualities of peer researchers as interviewers with examples of poor practice, lacking in rigour. This 'trade-off' idea is applied more generally to the matter of balancing what insider and outsider researchers bring to the process; Edwards and Alexander (2011) are explicit that insider, peer researchers can damage as well as enhance quality through their (over)familiarity with the research context or problem. Potential for such negative impact is endorsed in Staley's (2009) review, where other negative as well as positive impacts are discussed, though Staley reminds us that many of the former are avoidable with more support and training.

Lather (1986) reminds us of the need to disrupt normative criteria for quality in research and that validity equates with power. She reflects on how qualitative concepts of quality have evolved to be more fluid, blending rigour and ethics and she nominates face validity and catalytic validity as especially suited to new paradigm research and the concern with transformation through understanding for those involved. The quality question was one of the conundrums that we focused on in *Doing Research Inclusively, Doing Research Well?* (Nind and Vinha, 2012). Specifically, one of our research questions was about what makes a piece of research good

for people judging it for its research and for its inclusive qualities – when do good social science and good inclusive research come together? The dialogue about this was productive and ultimately, after time immersed in the focus group transcripts, we could see that collectively we could understand that quality is recognizable in research *and* inclusivity terms 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 (recognized by the people involved),
5. the research makes an impact on the lives of people with learning disabilities. (Nind and Vinha, 2012, pp. 43–4)

In this set of circumstances the research would be valued by funding councils and self-advocates alike. Matters of relevance, design and methods that are the best fit for purpose, reflexively considering different ways of knowing and making an impact come together to provide a framework through which we might judge quality in inclusive research. This does not equate with prescribing how it should be conducted. This was not the purpose of the study and it is not the purpose of this book. There are many useful texts that take the reader through *how to do* inclusive research and these are outlined in the section on further reading and resources. Understanding what inclusive research is and what quality means in inclusive research are more fundamental challenges. Cook (2012) cites the argument of Wright et al. (2010) that this is important if we are to avoid the situation in which each participatory research proposal needs to be argued and judged on its own terms. She sees value in establishing a uniting paradigm so that such ‘repeated individual justification’ (para 44) becomes unnecessary and argues:

The responsibility for ensuring that participatory research is judged according to its own merits, and that it finds appropriate and powerful spaces to make a difference to current practice, lies in two courts, those of participatory researchers and those who review participatory research. If the first step is to be more explicit about the nature, purpose and potential of the paradigm within which

we work, the ball is currently in our side of the court. Participatory research faces the challenge of establishing its credentials. (para 60)

Here I merely represent in Table 5.2 the guidance generated in *Doing Research Inclusively, Doing Research Well?* which to some extent operationalizes quality indicators without being prescriptive. As we clarify in the research report (Nind and Vinha, 2012) there is no formula for turning the answers to these questions into some kind of quality score – this is a trigger for reflection and discussion only – because, when it comes to understanding inclusive research, we are still learning. This viewpoint is endorsed by ICPHR in that they anticipate that any framework they produce for quality in participatory health research ‘would not be rigid, but rather serve as an aid to informed judgement’ (Springett et al., 2011, p. 1). It should be noted that, while these questions (Table 5.2) are worded in relation to research with people with learning disabilities as in their original form, they could apply to any group.

Table 5.2 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?

Other groups of researchers are beginning to tackle the matter of quality in inclusive research. ICPHR (2013, p. 20), looking at this in relation to participatory health research, follow Patti Lather in identifying the different concepts of validity (in the sense of achieving what one sets out to achieve) that might be usefully applied in an evaluative context:

- *Participatory Validity*. The extent to which all stakeholders are able to take an active part in the research process to the full extent possible.
- *Intersubjective Validity*. The extent to which the research is viewed as being credible and meaningful by the stakeholders from a variety of perspectives.
- *Contextual Validity*. The extent to which the research relates to the local situation.
- *Catalytic Validity*. The extent to which the research is useful in terms of presenting new possibilities for social action.
- *Ethical Validity*. The extent to which the research outcomes and the changes exerted on people by the research are sound and just.
- *Empathic Validity*. The extent to which the research has increased empathy among the participants.

Rahman (1991) stresses the need for people to select or create their own verification system to have control of the legitimacy of their knowledge. Nonetheless, the concepts listed here are all familiar and have been addressed in the book, albeit not always with these labels.

Cook (2012, para 11) sums up some of the core concepts when she discusses the qualities of quality in inclusive research as involving co-labouring, citing Sumara and Luce-Kapler's (1993, p. 393) description of this involving 'toil, distress, trouble'. For her, good participatory research builds communities of practice (Wenger, 1998), with working interactions that 'harness a dynamic interchange of knowledge and understanding' (para 11). She concludes, 'What is important in participatory research is not existing "hierarchies of credibility" (Winter, 1998, p. 57) but mutual learning and emergent knowledge' (para 11). All these concepts are most helpful in steering a reviewer to questions of whether the research meets the qualities desired of participatory or inclusive research, perhaps more so than in judging whether the research is good quality per se.

Conclusion

The key messages I choose to leave the reader to consider are as follows:

- Inclusive research means different things to different people. It is a useful term to embrace a range of research approaches that share some common aspirations.
- There is no single right way to do inclusive research. There is conceptual confusion and pluralism as well as a multitude of practices.
- There is a need for honesty, transparency, realism and detail when we report how we go about doing research inclusively; different contributions to research should be 'named and described and recognized for what they are, not for what we wish they could be' (Walmsley, 2004, p. 69).
- It is possible to move towards understanding how good social science and good inclusive research can co-exist. Achieving this is challenging but necessary, and may take time.
- 'Fear of doing it [inclusive research] badly should not prevent us from attempting it' (Sin and Fong, 2010, p. 21).

This book has been about what inclusive research is. I recognize and value inclusive research as a helpful term. As I alluded to briefly earlier in this chapter, my own preference, however, is to refer instead to doing research inclusively (Nind and Vinha, 2012, 2013). This moves us away somewhat from the categorical process of labelling an approach or family of approaches in research. Instead, it places the emphasis on the entity being dynamic and in evolution – renegotiated to fit each unique research situation. My own relationship with inclusive research is shifting and the less it is seen as static or prescribed the more comfortable with it I am.