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1 Inclusive research defined

Introduction

This book introduces readers to inclusive research including how to recognize it, understand it, conduct it and know when it is done well. I have a developing – rather than fully developed – stance on inclusive research myself. As I discuss further in Chapter 5, I have adopted a more inclusive approach at some times than at others and I have recently engaged in a study of what quality means in inclusive research. The quality study (Nind and Vinha, 2012) involved focus group dialogue with over 60 inclusive researchers/supporters and funders of inclusive research to co-create knowledge about this way of approaching research and supporting social inclusion. I am convinced by the argument (e.g. Walmsley and Johnson, 2003) that inclusive research requires critical scrutiny and I engage in this throughout the book.

Inclusive research encompasses a range of approaches and methods and these may be variously referred to in the literature as participatory, emancipatory, partnership and user-led research – even peer research, community research, activist scholarship, decolonizing or indigenous research – the list goes on. By way of illustration, the International Collaboration for Participatory Health Research (ICPHR, 2013) add to the list of research traditions in this camp: Participatory Rural Appraisal (PRA), Liberationist Research approaches, Action Research, Human/Cooperative/Appreciative Inquiry, Community-Based Participatory Research (CBPR), Constructivist Research, Feminist Research, Empowerment Evaluation and Democratic Dialogue. Many of these terms are in more frequent usage than the term ‘inclusive research’ that I have opted to use for this book. I use inclusive research deliberately as the most generic term, however, to embrace this whole family of approaches, all of which reflect a particular turn towards democratization of the research process.

It is worth noting at this juncture that alongside common threads and distinctive features among research approaches that might be considered

inclusive, there is variation in terms and meanings that relate to international variations. I write from the United Kingdom where inclusive research is emerging as a term. It is used differently here from action research where the ideas of Kurt Lewin, Lawrence Stenhouse and John Elliott have been influential in a concept evolving to stress the personal, professional and political in educational action research in particular (Noffke, 2009). In the United States, collaborative research is a similar umbrella term, more commonly used to embrace research that actively engages communities and policy makers in conducting research, including framing the research problem and interpreting and acting on the findings. Minkler and Wallerstein (2008) regard CBPR also as an 'overarching' term: for action research, participatory action research (PAR), mutual inquiry and feminist action research, all of which stem from a reaction to a dominant research tradition and bring a new 'orientation' based on mutual respect and co-learning. They note the difference between the way that action research is understood in the United Kingdom and Australia compared to the United States, and the different geographical roots of PAR in work with oppressed peoples in Asia, Africa and Latin America. Wallerstein and Duran (2008) similarly note Northern and Southern traditions and variations. The Durham Community Research Team (2011) observes that while the concept of CBPR is most used in US health research it is used in the United Kingdom also.

In this first chapter some of these nuances are acknowledged and some, by necessity, are set aside as inclusive, collaborative, participatory, emancipatory, participatory action, and partnership/user-led/child-led research are defined and explained in relation to each other and to the fields and arguments from which they have evolved. Within each of the research approaches defined in this chapter there are elements of consensus, elements where there are differences of emphasis, and matters of greater contention. This includes discussion of the ways in which they overlap and what makes them distinctive. In later chapters the rationale for inclusive research in different fields and disciplines is explained (Chapter 2), different models of inclusive research are presented through illustrative examples (Chapter 3), the challenges and criticisms – together with responses to these – are discussed (Chapter 4), and the quality, status and future of inclusive research is explored (Chapter 5).

Inclusive research is a growing field and one in which researchers can be passionate, often arguing that inclusive research (or their particular variety

of it) is superior in some way. Contested matters include who gets to participate in research (Cornwall and Jewkes, 1995; Holland et al., 2008), what constitutes active participation (Gallacher and Gallagher, 2008), whether it is the quality of the participation or the quality of the research that matters more (Freeman and Mathison, 2009; Greene, 2009), whether inclusive or participatory research is necessarily 'ethically or morally superior' or 'more enabling' (Holland et al., 2008; Frankham, 2009) and whether participation and emancipation can be decoupled (Danieli and Woodhams, 2005). There are also debates about the individuals, groups and topics for whom inclusive research is helpful or necessary, and about what is driving the push to make the research inclusive. To enter such debates it is first necessary to look at the various ways in which these kinds of research are conceptualized.

Defining inclusive research

The term inclusive research can be found prominently in the field of learning disability¹ research and in the work of Walmsley and Johnson (2003). They use the term to embrace 'a range of research approaches that traditionally have been termed "participatory", "action" or "emancipatory"' (p. 10). Importantly, they pinpoint the commonality between these: 'Such research involves people who may otherwise be seen as subjects for the research as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users' (p. 10). In answer to why yet another term is needed for this kind of research, Walmsley and Johnson are clear: inclusive research as a term allows for the blurred and shifting boundaries between, for example, feminist, participatory and emancipatory research and it 'has the advantage of being less cumbersome and more readily explained to people unfamiliar with the nuances of academic debate' (p. 10). It is a term that can be used across fields and disciplines.

Inclusive research can be usefully thought of as research that changes the dynamic between research/researchers and the people who are usually researched: it is conceived as research *with*, *by* or sometimes *for* them (see Griffiths, 1998), and in contrast to research *on* them. Inclusive

¹ In this book, the term learning disability (and people with learning disabilities) is used to refer to people with intellectual impairment; this is interchangeable with learning difficulties in the United Kingdom, but not in the United States.

research shares common ground with qualitative research more widely, particularly the concern with grounding research in the experiences and views of respondents (Kiernan, 1999). Most qualitative research, though, retains the status quo of the researcher being the person who defines the questions, handles and controls the interpretation of the data, and makes and communicates the conclusions; it is this that is unsettled in inclusive research. Kiernan (1999) regarded such a turn as a new paradigm but with variations in how it was understood and enacted by traditional and new 'co-researchers'. Fenge (2010) in the title of her paper about PAR with older lesbians and gay men, 'Striving towards Inclusive Research', reminds us that journeying towards being inclusive is at the heart of what the shift in paradigm is about.

Predictably, inclusive research cannot be translated into one particular way of doing things; the options or permutations for this are extensive (Walmsley, 2004). Nonetheless, it is possible to pinpoint the characteristics and principles underpinning inclusive research. Walmsley and Johnson (2003, p. 64) do this in relation to people with learning disabilities:

- The research problem must be one that is owned (not necessarily initiated) by disabled people.
- It should further the interests of disabled people; non-disabled researchers should be on the side of people with learning disabilities.
- It should be collaborative – people with learning disabilities should be involved in the process of doing the research.
- People with learning disabilities should be able to exert some control over process and outcomes.
- The research question, process and reports must be accessible to people with learning disabilities.

An alternative umbrella term to inclusive research might be CBPR, as discussed earlier, or collaborative research, as used for example by the University of California Center for Collaborative Research for an Equitable California (CCREC). They describe collaborative research as 'engaged scholarship in action, in which university researchers, community members, and policy makers respect the knowledge that each partner brings to the discussion so that together they might know better how to understand the complex problems facing our communities and how to design and implement research-based responses to those problems' (CCREC, n.d.). They also recognize the plethora of similar labels attached to such

research, including community-based research, CBPR, engaged scholarship and PAR. The overlap with inclusive research is clear to see. While throughout this book I use inclusive research as my umbrella term, I acknowledge that collaborative research as a term might work equally well if it were not also used to refer to all kinds of collaborations, for example, between parties of equal status or between universities and business partners, which reflect a completely different agenda. Similarly action research terms are problematic in that not all action research has a participatory element and CBPR carries with it the concept of community that does not travel well across cultures and languages (Springett et al., 2011). While the nature of this book series and book theme necessitates using an overarching term, I also, at times, adapt choice of language to reflect political and other contexts as Springett et al. (2011) argue is necessary.

Defining participatory research

To see how the term inclusive research also allows for the overlap and reciprocity between participatory and emancipatory research these too need to be defined. Cancian (1989) sees participatory research as involving democratic relationships to produce knowledge which incorporates participants' everyday knowledge, and to solve problems. Bourke (2009, p. 458) offers a definition of participatory research as 'a research process which involves those being researched in the decision-making and conduct of the research, including project planning, research design, data collection and analysis, and/or the distribution and application of research findings'. This definition indicates that it is the people being researched who are participating and that the participation is comprehensively across the multiple stages of the research. It stresses involvement in the process of doing the research rather merely providing data for it, which is echoed by many. As with inclusive research, many writing specifically about participatory research tend to resist further delineation of what this involves in practice.

Byrne et al. (2009, pp. 67–8) address the inherent motivation for participatory research: 'participatory researchers seek to engage in meaningful partnerships with the researched seeking meaningful data for social transformation.' Thus, participatory research has an element of doing things in a more participatory way for a reason – to bring about change (Durham Community Research Team, 2011; ICPHR, 2013). At this point

there are different emphases among the various advocates of this kind of research. The change might be about how knowledge is produced, including 'a de-privileging of "researcher-only" expertise' (Byrne et al., 2009, p. 68; ICPHR, 2013), or about what the knowledge is used for. For Fenge (2010, p. 880) this is about 'lay researchers . . . setting the agenda for the research to be undertaken', and for Browne et al. (2012) it is about influencing the agendas of those with power while empowering those without. The social change associated with participatory research is partly achieved by making research more of a dialogue; a crucial element is academic and lay researchers² working closely together to benefit from each other's perspectives.

In participatory research the contention is mostly about whether participatory research is a set of techniques or a political philosophy (Cleaver, 1999). Methods can be important. Dyslexic doctoral researcher Spires has explained to me the importance of her video methods in doing research with university students with dyslexia: providing alternatives to producing and reading written text, for all their benefit. Similarly, Ayrton (2012) sought fitting methods for her research with mothers in Southern Sudan where literacy is limited. By stringing beads on to a leather thong to make bracelets, she supported the women to tell their life stories without employing artefacts associated with education and literacy. This also provided them with a valued product of the reflections. Nonetheless, many would argue that methods are not the essence of participatory research.

ICPHR (2013) stress that participatory research, or participatory health research which is their particular concern, is a research paradigm rather than a research method. This means that it is the underlying assumptions that matter most, or as Cook (2012) argues, such research 'inhabits different spaces and offers different ways of seeing'. Fals-Borda and Rahman (1991) even refer to participatory research approaches as a range of epistemological principles or paradigms. Cooke and Kothari (2001), Punch (2002), Kesby (2007) and Clark (2010) have all argued for participatory design rather than for participatory methods. Participatory methods for research with children are often devised and referred to as child friendly, but Todd (2012, p. 193) explains that 'the adoption of methods as seemingly

² I use the term lay researcher, adopted by INVOLVE, as it offers a distinction from professional researchers and can be inclusive of people of any age or identity (see Ross et al., 2005).

more “child friendly” misses the complexities of the research situation, as a contested and constructed site.’ Thomson (2007, p. 209) is also explicit about this, arguing that ‘participation is not inherent to the research methods themselves as some accounts of participatory methods seem to imply.’ She has an alternative concept of participatory research as ‘spatial practice’. Spaces for life experiences to be discussed may be ‘closed’ (or ‘invited’) spaces, directed by the researcher, or ‘claimed/created space’, in which participants can create new power and possibilities. Cornwall and Jewkes (1995, p. 667) similarly argue that ‘what is distinctive about participatory research is not the methods, but the methodological contexts of their application’ – the researchers’ attitudes on the various research problems leading them to adapt ordinary methods for use by and with ordinary people. Also contentious, they argue, is whether participatory research is ‘a universal panacea for the problems besetting conventional practice’ or ‘biased, impressionistic and unreliable’. This panacea question is discussed further in Chapter 4.

Defining emancipatory research

Emancipatory research is usually defined in more overtly political terms than participatory research. It ‘has been widely taken to mean only that sort of research which is controlled by those who are implicated by it, with the aim of the empowerment of those participants through the research process and outcomes’ (Frankham, 2009, p. 3, after Barnes, 2003). Oliver (1992, p. 110), a major proponent of emancipatory research for disabled people, describes it as being about confronting social oppression. This for him necessitates a fundamental change in ‘the social relations of research production’ such that researchers have to ‘learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose’ (p. 111). Oliver’s criteria for emancipatory research include the following: it is disabled people who gain; the research combats social oppression; disabled people are in control of the resources (otherwise it is more like participatory research); and the research process is politicized. Disabled people’s groups offer guidance on this, thereby making clear, and in some ways policing, what is seen as acceptable. For Oliver, emancipatory research is the ideal and participatory or action research is what people settle for when this cannot be achieved; moreover, settling for less involves a ‘limited vision of the possible’ (1997, p. 26) and

a reinforcement of the status quo in terms of power. A useful metaphor he uses to help make the distinction is that participatory/action research approaches 'allow previously excluded groups to be included in the (research) game as it is, whereas emancipatory strategies are concerned about both conceptualising and creating a different game, where no one is excluded in the first place' (p. 26).

Oliver is not alone in attempting to distinguish emancipatory research from other forms. Zarb (1992) similarly emphasizes the requirement for change in the social and material relations of research production. Chappell (2000) argues that the distinction between participatory and emancipatory research is that the latter is accountable to disabled people and their organizations. Walmsley (2004, p. 66) distinguishes them by noting that, in participatory research, non-disabled people have an enduring role in a way that is not true of emancipatory research. McLarty and Gibson (2000, p. 138), referring to emancipatory research by practitioners rather than disabled people, stress their ownership of the research problem. They draw on Heron (1996, p. 28) to delineate two levels of empowerment, one involving productive use of 'informants' and one 'when informants are empowered by being initiated in, and by collaborating in, the research design itself and the values embodied in it'. Thus the empowerment is important alongside the ownership. Similarly, coming back to disabled people again, French and Swain (1997) combine these two core features. They note the insistence within emancipatory research 'that disabled people should be in control (rather than merely participate in) the entire research process' (p. 27). They define it also as 'a form of education and political action', 'towards the achievement of their liberation' (p. 28). Some people take the position that research about disabled people should be done only by disabled people, and so on. Emancipatory researchers, therefore, may also be regarded as activists (Kiernan, 1999), and as change agents to a far greater extent than participatory researchers.

Defining participatory action research

Participatory research and emancipatory research clearly have common and distinct features, but these are muddled somewhat in another member of the family of inclusive research approaches – PAR. This is a form of action research that has been written about extensively and therefore I do not dwell on it in this book. Rather I refer you to the PAR toolkit from

Pain et al. (n.d.) and to Fals-Borda's (1991) ingredients of PAR: education, research and socio-political action, bringing different agents to work together for social transformation. Nonetheless, it is noteworthy that research in which ordinary people participate or take control is often conceptualized as PAR. We might think of this as a cousin of participatory or emancipatory research, sharing a 'commitment to break away from traditional research conventions by involving the "researched" in some or all stages of the research process (Pain, 2004)' (Cahill, 2007, p. 298), or even as 'architects' (Torre and Fine, 2006, cited by Cahill, 2007, p. 298) of it. McTaggart (1997, p. 28) refers to their agency in producing knowledge and improving practice – their 'authentic participation'. Thus, also shared is the concern with the research making things better for the people involved and affected, while removing knowledge production from the elite (Rahman, 1991). In PAR there is perhaps greater emphasis on process and on seeing people as change agents (Cahill, 2007). PAR has emerged from grassroots (feminist, antiracist) movements and is very much a 'bottom up' approach (Cahill, 2007, p. 308). Other cousins are activist participatory research and PRA (Chambers, 1992; Narayanasamy, 2009) where the concern is with underprivileged peoples and political action with outsiders acting as facilitators or catalysts. In PRA, local people 'share, enhance and analyse their knowledge of life . . . to plan and to act' (Chambers, 1992). The key premise in PAR, though, is the notion of exchanging expertise and working together in a process in which action and research are simultaneous and inseparable.

Defining partnership, user-led or child-led research

Not everyone favours the language of participation and emancipation and for some the term 'user-led' research reflects that the crucial issue might just be who works together on, or who leads, the research. Service users are often involved in research about services when there is a desire to incorporate, first hand, their direct experience of the service (Frankham, 2009). Thus, in such 'partnership research', the particular 'way of knowing' (p. 17) of service users (or consumers, patients, pupils) is used to inform the planning and conduct of the research, empowering them along the way and generating useful, authentic knowledge. There has been significant growth in use of the partnership research where control of the research process is shared between service users and academic allies (Frankham,

2009) and also some growth in user-controlled research (Boxall et al., 2007), which most closely parallels emancipatory research.

Kellett (2005a, 2011) has done much to promote the idea of child-led research including research led by young children and specifically those in middle childhood. Here again the issue is ownership and control, but this case is different from emancipatory research. It is often adults/academic researchers who argue that children should be in the controlling seat, rather than children claiming this as their rightful position in research production of knowledge about them.

Returning to inclusive research

Returning to inclusive research as a useful term to embrace a range of related approaches it can be helpful to visualize their relationship as a Venn diagram, as shown in Figure 1.1, imagining inclusive research as encircling them all. This image is in keeping with the stance of Walmsley and Johnson (2003) and French and Swain (1997) that participatory and emancipatory research share certain characteristics, despite their different social and historical roots. While the overlap may not be great, these are at least complementary approaches to achieving meaningful social change through research. The problem – and potential – of this visual model is that it raises questions about whether it should include three equally sized

Figure 1.1 A family of overlapping approaches.

circles with equally proportioned overlaps or whether PAR is more of a subset of participatory research or of emancipatory research, and so on. The point is that people see the overlaps differently and that the conceptual boundaries between these different approaches are inevitably blurred. An alternative visual model might be that shown in Figure 1.2, which represents the idea of a continuum in which power is more shared or less shared. This is the model that Freeman and Mathison (2009) envisage when they describe a continuum of adult-led, adult-centred research through to youth-centred, youth-led research. It is also the model of participatory research described by Holland et al. (2008, p. 4) involving a range of approaches from simply inviting children and young people as participants in research, through data collected through 'child-centred' methods, to training children and young people as researchers to study their own topics and ultimately giving them control over the research process itself. The continuum proposed by Cornwall (2008) goes from (tokenistic) co-option through compliance, consultation, co-operation and co-learning to collective action. Coad and Evans (2008) similarly use the idea of a continuum of involvement in, specifically data analysis, from adults doing it and children helping to verify adults' understanding of the data, to children and young people undertaking the analysis, with a middle position of adults facilitating and working alongside children and young people. Kiernan (1999, p. 45) holds a similar position when discussing research involving people with learning disabilities, arguing that 'the difference between participatory and emancipatory paradigms may be more a matter of emphasis than kind', with participatory research a 'step toward emancipatory research' that is 'more practicable'. Kellett (2005a), in contrast, would not support the common ground suggested by this continuum model. She argues that 'research *by* children is fundamentally different from adult research *about* children and we cannot use the same norms of reference nor the

Figure 1.2 A continuum of overlapping approaches.

same terms of measurement and assessment' (p. 30). She does not present child-led research as sitting alongside child-participatory research as equal. For her (after Oliver), the pinnacle is research that is led by children, with 'every decision, every action, every word in every sentence . . . sourced, discussed and approved by the young people to ensure their own voice [is] neither diluted nor distorted' (Kellett, 2010, p. 42). For some, once 'the researched', whether child or adult, is in control of the research it becomes distinct from everything else on the continuum (see also Beresford, 2002; Frankham, 2009).

Moving on from definitions

I have defined in this chapter what I and others mean by inclusive research and related research approaches. By way of introducing the rest of the book I also need to say a little about their varied uptake and importance. In the field of disability research the debate about doing research on, with, for or by disabled people has been sufficiently prominent in sociological, geographical, health and social work arenas to mean that the question of participation of disabled people would almost always be asked. The opposite is the case in the field of psychology, where participatory research would still often be seen as radically new. The depth as well as breadth of reach is patchy. People with learning disabilities have moved from being objects of research to becoming interviewers involved in service evaluation, self-advocates having established their desire and ability to be involved in planning and conducting research, disseminating it, even commissioning and reviewing it (*British Journal of Learning Disabilities*, 2012 special issue; Nind and Vinha, 2012). The trend towards participatory and emancipatory research has been evident in some studies of poverty, in gender studies and in aspects of educational research (Frankham, 2009). In the field of children and young people there has been increased involvement, especially of older children/teenagers as co-researchers. Techniques seeking children's engagement in research have 'generated widespread interdisciplinary and global interest' (Coad and Evans, 2008, p. 41). In children's geography and childhood studies a participatory approach is 'almost universally lauded' (Gallacher and Gallagher, 2008). Some educationalists and childhood researchers are involving younger children and supporting children to lead their own research (Kellett et al., 2004).

Wherever there are socially excluded groups there are moves towards inclusive research. Walmsley (2004, p. 69) helpfully reminds us that 'only the excluded need inclusive research', although I would argue that others also benefit from it. Politically active groups of socially excluded people have often driven the move towards inclusive research (Frankham, 2009), though not every individual wants it. Where there is a culture of service provision, such as with older people, this is more likely to take the form of service evaluation, user-led or user-involved research, or PAR. Users, survivors or resisters of mental health service provision may perceive a need for a radically different approach from conventional research done on them. Similarly, feminist and lesbian, gay, bisexual and transgender (LGBT) groups often want to start from a different conceptual place altogether. Participation has been fundamental in international development and collaboration has underpinned a wealth of PRA, CBPR and PAR (Ackermann et al., 2003; Frankham, 2009).

As Walmsley (2004, p. 69) argues, 'inclusion can, quite appropriately, take different forms' and there is 'no one right way to approach inclusive research'. There is, then, no uniformity to the involvement of lay researchers or those traditionally the subject of other people's research in the research process. They are more likely to be co-researchers in some fields than others. They are more likely to be involved in data collection than in the interpretation and analysis of data (Byrne et al., 2009; Nind, 2011). They are more likely to be funded by some funding bodies than others and published in only a handful of journals (Nind and Vinha, 2012). As Sin and Fong (2010, p. 10) observe, there is a great deal of 'mundane messiness' in research decisions when the terrain, value systems and drivers are complex. While there is no uniformity, however, there is a trend. There is more inclusive research now than a decade ago and more in that decade than the previous. The sustainability and desirability of this trend is explored further in the book, together with what is driving this trend. My intention is to bring to this text, which introduces inclusive research to those who are interested but not expert, a sense of the debates associated with it as well as the practicalities and challenges that have been insufficiently debated in a methodological development still in its relative infancy (Walmsley and Johnson, 2003; Frankham, 2009).