Nind, Melanie. "Inclusive research as an evolving set of practices." *What is inclusive research?*. London: Bloomsbury Academic, 2014. 15–32. *Bloomsbury Collections*. Web. 26 Apr. 2023. <<http://dx.doi.org/10.5040/9781849668149.ch-002>>.

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2 Inclusive research as an evolving set of practices

In this second chapter I present inclusive research as an evolving set of practices. I start with the influences that led to researchers explicitly conceptualizing earlier examples of inclusive research as emancipatory, participatory or user-led or user-involved. In this way I put the current diversity in inclusive research into the context of a small number of origins and show the thinking that informed how the diversity developed. Thereby the diversification and application of ideas can be considered in relation to the drivers for researchers to conceptualize, design, conduct and disseminate their research in ways that are more inclusive of the communities their research concerns. This reflects the importance of the context in considering 'what is inclusive research' and it also allows the language of inclusive research, with terms such as 'co-researchers' (Cahill, 2007), 'peer researchers' (Coad and Evans, 2008) and 'children as active researchers'/'child-led research' (Kellett, 2005a), to emerge in those contexts.

The academic context

The context influencing the emergence of inclusive research approaches includes the academic and the wider societal context. I start with the academic and two broad, interrelated spheres of influence within this: the development of qualitative research and the sociology of the 1970s. Some commentators see participatory approaches as developing from qualitative research methodologies highlighting – and problematizing – the hierarchical relationships between researchers and participants and the need to give participants greater voice. French and Swain (1997), for example, reflect on how, with qualitative researchers concerned with listening to and documenting people's voices and experiences, research was extending more and more into seeing things from participants' perspectives. For some, a logical next step was utilizing those perspectives (and people) in the design and conduct of the research. Thus, participatory research is

seen as embedded in the qualitative research tradition and linked with the view that 'all knowledge is socially constructed' (p. 26) in contexts which underpin it. In *What is Qualitative Research?*, Hammersley (2013) reminds us of this concern to explore how people understand, experience, interpret, voice and produce their social worlds and the essential role of subjectivity within this. This is nowhere more clearly evident than in collaborative ethnography, an application of ethnography in which researchers and 'subjects' collaborate to produce ethnographic texts (Lassiter, 2005) or in feminist research that seeks to ground research in the actual experiences of women through methods that access these (DuBois, 1983, cited by Lassiter, 2005).

As qualitative research has gained momentum, so too has interest in seeing the world through the eyes of those the research concerns. Indeed, Lassiter (2005) argues that collaborating with the researched has a well-established tradition in applied anthropology where activist roots are evident. Such tendencies in qualitative research to consider 'responsibility to publics outside the academy' (Lassiter, 2005, p. 84), however, have not meant the prescription of a unique set of methods, nor is there consensus that this has been pervasive. While qualitative research has influenced inclusive research, not all inclusive research is qualitative and not all qualitative research has participatory or emancipatory dimensions (Bennett, 2004, cited by Frankham, 2009). Qualitative research, however, has brought with it a concept of research as 'cooperative experiential enquiry' (Reason, 1988; Kiernan, 1999) going beyond the priorities of researchers to those of the ordinarily researched.

If participatory research has roots in qualitative research then emancipatory research, argue French and Swain (1997), has roots in the social model of disability; this social model of disability, in turn, has its roots in the interface of sociology and the voices of disabled people. According to the social model, people are disabled not by their actual impairments but by physical and social barriers in the environment; the research agenda becomes focused on people's experience of those physical and social barriers, thereby challenging them. Thus, emancipatory research may be seen as less of a methodology and more as a 'part of the struggle of disabled [and other marginalized] people to control the decision-making processes that shape their lives' (p. 27). (Readers particularly interested in this field will be interested to note that French and Swain went on to develop their own, alternative, 'affirmative model'.) The essence of the social model has more

recently been applied to socially excluded groups, older people and users of mental health services (Warren and Boxall, 2009), people with learning difficulties (Bjornsdottir and Svensdottir, 2008) and those involved with alcohol misuse and its treatment (Staddon, 2012), each seeking to reframe their understanding of their situations. To various degrees, these groups have developed a commitment to mutual support and empowering themselves individually and collectively including through their involvement in research (Frankham, 2009). In this way, much inclusive research has been motivated by a drive to redress wrongs, both past and present; for academics this means responding to the 'call to discard our colonizing ways, drop the jargon, reject "rejecting research" and put ourselves and our skills at the disposal of people with learning difficulties [and others] so that they might take their rightful place in charge of the research agenda' (Walmsley, 2004, p. 66). Here inclusive research has developed as the antidote to the bulk of the research *done to* people which is experienced as oppressive – research being 'one of the dirtiest words in the indigenous world's vocabulary' (Smith, 2012, p. xi). 'People who have pioneered the work have done so because they want to change things, to show that in the small world of research we can do things differently, and better' (Walmsley, 2004, p. 69).

While sociologists of disability challenged the ways in which disabled people were conceptualized, with repercussions for how disability research was conceptualized, this pattern is also evident in the field of childhood. A changing model of childhood emerged in the 1990s and, with echoes of what happened in relation to disability, this led to 'a shift from a focus on the child as *object of* to a focus on the child as *subject* (and actor) in research' (Mason and Danby, 2011, p. 185). The new social studies and discourse of childhood connected with a rights discourse to bring about a 'participatory rights perspective' (Dockett and Perry, 2011, p. 232), which fostered a significant rise in participatory research with children. More recently this extended into pushes for research led *by* children (Kellett, 2005a). The theoretical conceptualization of children as active meaning makers capable of co-constructing knowledge has been influential in this context.

While children were not calling for more control over research practices in the way that disabled people were, this 'insistent voice' has been strongly heard among feminist and critical race theorists (Frankham, 2009, p. 2). Bowles and Duelli Klein (1983), for example, saw the need for dialogic research accounts that would better represent women's diverse

experiences; the vehicle would be the academic researcher and the woman researched taking their versions of reality to each other in a transactional process. Reinharz (1992, p. 181) describes feminist participatory research as adopting 'an approach of openness, reciprocity, mutual disclosure, and shared risk'. Indeed feminist research, premised on 'the personal is political', has been influential in supporting notions of research being linked to the struggle of oppressed groups to gain 'full citizenship' (French and Swain, 1997, p. 31) and to the core idea that 'research should contribute to women's liberation' (Acker et al., 1991, p. 131, cited by Danieli and Woodhams, 2005). It is perhaps here, more than in any other field, that the arguments for the abandonment of the role of researcher as expert in relation to the researched have raged and led to change (Reinharz, 1983; Danieli and Woodhams, 2005).

Not all the academic drivers for inclusive research are as principled or conceptually and theoretically oriented as the ones I have discussed here. There may be more pragmatic reasons for the increased interest in participatory methods, as ways of getting data from children or disabled people, for example, when other methods are inadequate. Edwards and Alexander (2011, p. 272) discuss the functional, instrumental benefits that community researchers offer to academic researchers with their 'privileged access' to networks and knowledge. Crow (2010) similarly postulates about the pragmatic considerations at work for researchers who need the participation of social groups and whose participation in research is otherwise difficult to secure. Interest in democratizing research, he argues, may also have been piqued by the increased value in academic circles placed on making impact outside of academic life. Technological advances, too, have played their part in making it possible to generate affordable, high-impact material such as video and disseminate it via the internet. Although this may have flourished in recent years, participatory video practices remain relatively understudied and evaluated (White, 2003; High, 2010).

The wider context influencing the emergence of inclusive research approaches

Inevitably academic debates are situated in wider contexts, and beyond the boundaries of academe other developments have made the rise of inclusive research timely. There is a strong history of social movements influencing inclusive research approaches (see Chevalier and Buckles'

(2013) chapter on action research history for an overview). Globally action research and PAR, for example, have influenced political activists as well as professional researchers, providing an underpinning social justice perspective. What people may now see as largely methodological has been, and in some circles continues to be, more strongly positioned as political (Carr and Kemmis, 2009) and as practical philosophy (Elliott, 2009) concerned with action or social justice (Griffiths, 2009). Concerns with social reform and community development have driven the more critical action research and emancipatory research. Grass roots organizations have been major drivers informing the development of ideas about collaborative, co-produced knowledge for change.

The interest in the democratization of research 'can be seen as part of what some commentators regard as a wider turn to democracy in society' (Edwards and Alexander, 2011, p. 271). In the global arena there has been an increased emphasis on a formal policy process for protecting people's rights reflected in, for example, the United Nations Convention on the Rights of the Child (1989) and the United Nations Convention on the Rights of Persons with Disabilities (2006). The emphasis on 'full inclusion and participation in the community' (United Nations Convention on the Rights of Persons with Disabilities, 2006, Article 19) has been translated into a drive towards the involvement of users of social care and similar services in the management of their services.

Often there has been a logical progression from more participation in service training and service evaluation to people's involvement in other kinds of research (Frankham, 2009). Personal histories of a lack of such involvement and of poor experiences of services helped to drive this forward (Beresford and Carr, 2012), in keeping with moves to use participatory appraisal approaches in international development to give voice to local communities. Moreover, increasingly 'research is grounded in and generated from the complex, entangled situations that comprise the actual challenges confronting communities and policy-makers' and 'emanates not from within the confines of academic disciplines, but rather from the lived experiences of community members and from the policy knots that bind legislative and executive responses' (CCREC, n.d.). In the United Kingdom, amid a climate of growing self-advocacy and growing understanding of the complexity of social problems, the Joseph Rowntree Foundation has led the way by beginning to take on a commitment to funding research in which lay people have had an increasing

say in defining research priorities and in the detail and conduct of the research itself.

It is easy to see how this mix of influences, each often adding weight to another, has underpinned the rationale of a multitude of inclusive research projects. Neoliberal new managerialism has provided a context for user-centred research to develop from user involvement in services, whereas disability rights campaigns have provided a context for a differently conceived approach. Holland et al. (2008, pp. 3–4) pin down three dominant lines of argument from analysis of the literature about participatory research and its context. They cleverly define these as: ‘rights’ (i.e. rights agendas producing a political and legal environment encouraging more participatory approaches), ‘right on’ (i.e. an implied ethical and moral superiority associated with research that reflects this environment) and the ‘right thing to do’ (related to methodological arguments about producing ‘better’ data and research products).

Core ideas in evolving inclusive research practices

Disrupting the hierarchy

I now discuss the core ideas coming from the contextual influences set out earlier and their impact on the development of inclusive research practices. The idea and practice of disrupting the perceived hierarchy of the powerful researcher and the powerless researched is important within and beyond the academy, both with methodologists and politicized emancipatory researchers. This language of disruption was used by Smith (2012, p. x):

I wrote *Decolonizing Methodologies* primarily to disrupt relationships between researchers (mostly non indigenous) and researched (indigenous), between a colonizing institution of knowledge and colonized peoples whose own knowledge was subjugated.

Reinharz (1992, p. 181) similarly refers to feminist participatory research seeking to achieve ‘an egalitarian relation’. One example of this is Lykes’ (1989) positioning of her research with Guatemalan women as communal rather than hierarchical. Todd (2012, p. 95) discusses how ‘researching with children involves “queer(ing) the relationship between the researcher and the researched” (McClelland and Fine, 2008) in order to “rupture . . . the ordinary” (Leitch et al. 2007).’ Warren and Boxall (2009, p. 293) reflect on

their desire to open up the academy with its hierarchical structures and self-interests to disrupt the dichotomy between 'those who teach and research v. those who are taught and researched'. This focus on who holds the power is sometimes travelling in new directions and developing new epistemological positions. It can be about democratization and mild discomfort with the traditional assignment of roles and privilege. Equally, it can be about anger and revulsion at the ways in which researchers have used their power over the researched to label and reject them (Townson et al., 2004), medicalize and pathologize them (Beresford and Wallcraft, 1997), or colonize them (hooks, 1990).

This concern with the power dynamic is, as one would expect, mobilized into action differently across the range of inclusive research. There can be a notion of handing power over to children, service users, and so on, as if power were a commodity that can be passed around. Thus, in participatory approaches there is a discourse about children and service users being given the power to conduct the interviews or to choose their preferred method(s). Alternatively, there can be a sense of sharing power, as in PAR in which the different communities involved seek sufficient openness to listening to each other to work towards a common purpose, or there can be a sense of seizing power by seizing control of the agenda for the research, as some groups of disabled people and mental health service survivors have done. Foucault (1989), however, maintains that power is exercised rather than possessed and the detailed examples in Chapter 3 illustrate this exercising of power at work in various research projects.

Maximizing participation and competence

Somewhat different to the focus on the power dynamic between researcher and researched is the focus on participation at a more basic level, this being intrinsic to inclusion in social, political and civic life: 'The need for meaningful involvement of disabled people and other commonly marginalised groups is increasingly accepted across policy, service planning and delivery, and research' (Sin and Fong, 2010, p. 13). This core idea is particularly important in opening up research to all and translates into developing more inclusive methods. As Booth and Booth (1996, p. 67) argue, 'too often the potential problems of interviewing inarticulate subjects are seen in terms of their deficits rather than the limitations of our methods' and therefore 'serves to legitimate' their exclusion from research. Their use of photovoice with people with learning difficulties to enable them to

share their experiences of being parents is an example of addressing this barrier to participation.

Porter et al. (2012, p. 131) reflect on the developments following the UN rights conventions, with young people's proactive participation in research promoted and fostered by child-focused non-governmental organizations (NGOs) and academics. This has translated into young people working in collaboration with organizations like Save the Children and supported by, for example, the Children's Research Centre at the Open University in England, planning and conducting their own research. Children and young people are increasingly involved in policy evaluation with the idea that this benefits the policy process and the young people as citizens (Fisher and Robinson, 2010). This may seem very tame, civilizing as much as empowering, but it reflects a significant shift from a position of people being seen as barely fit subjects for study to that of making a worthwhile contribution.

The debate about the competence of lay people, particularly children and people with learning disabilities, to do research has shifted as real projects have extended people's expectations. Thomas and O'Kane (1998, p. 346) argue that, 'rather than reinforce views of children's incompetence by portraying them as victims, we have to develop methods which allow us to explore children's capacities, needs and interests from their own point of view.' Inclusive research at its most basic, then, is about demonstrating people's competence to hold and give their perspectives and their growing status as social actors who do not need to be dealt with by proxies. The skill of researchers to 'tune in' and 'adjust our listening' (Clark, 2001, p. 333) has shown the ability of even very young children to contribute to research. In inclusive research, which 'is no longer the exclusive province of the "expert"', 'expertise and skills are shared collaboratively' (Johnson, 2009, p. 252).

Kellett (2005a, p. 7) puts less emphasis on traditional researchers enhancing their skills as facilitators in the research process, or on collaborative skill-sharing, and more emphasis on teaching children the skills of academic research. From her early action research to explore the potential of such training she became 'extremely positive about the ability of children as young as ten to undertake rigorous, empirical research and the impact of such participation on child self-development'. She has developed and widely promoted four models of training for children to become researchers, and (echoing the social model of disability) she argues that it is scepticism about children's competence as researchers that has been

the main barrier. She also maintains that child researchers are now seen as different to, rather than lesser than, adult researchers (Kellett, 2011, p. 207). A similar argument is made by Lou Townson, an experienced researcher with learning disabilities, about the barrier of low expectations faced by, and challenged by, the research groups she has been involved with (Nind and Vinha, 2012). Proponents of inclusive research such as Warren and Boxall (2009) see the failure of professionals and academics to recognize the competence of, for example, older people and their capability for full, equal partnership as presenting an ongoing problem.

Jones et al. (2012, p. 1) describe their desire to work with underrepresented voices in educational inquiry and to seek 'an inclusive lens'. They see their book on the Accessible Research Cycle (ARC) as offering 'a way to support teachers to generate and complete research about their own practice; thereby becoming the initiators and owners of the research' (p. 3). Focused more on teachers than learners, they discuss the tension of their being both users and generators of research evidence and the importance of viewing themselves as 'capable inquirers into their own practice' (p. 4). As with Kellett's (2005b) book on teaching research methods to children, they attempt a codification of process, in this case scaffolding the research process for practitioners and seeking to make it jargon-free to bring research closer to practice. Not all attempts to bring research skills to lay people are so prescriptive, however, and implicit rather than explicit approaches to building research expertise are in use (Nind, 2011).

The rise of inclusive research is inextricably linked with the rise of concerns about people having a voice and making a difference. The involvement of lay people in health research 'reflects the policy drive for greater accountability . . . and is based on the assumption that it will lead to services which are of better quality and more relevant to the needs of patients' (Ross et al., 2005, p. 269). Inclusive research practices therefore encompass a range of work enhancing, sharing and teaching research skills, including the skills related to managing the diverse voices involved. Walmsley, writing with Central England People First (in press), reflects on how self-advocate Simone Aspis (2000) used the powerful maxim of 'Nothing about us without us' 'to challenge the right of non disabled people to have any say in the history of learning disabilities'. Until the pioneering inclusive research of the social history of learning disabilities group at the Open University, this had largely been the province of non-disabled academics. The 'nothing about us without us' message reached Anne

McGuire, then Minister for Disabled People in England, who has stressed talking to and involving disabled people (Sin and Fong, 2010). Similarly Kellett (2010, p. 32), referring to Thorne (2002), argues that 'children and young people have been silenced historically in the accounts of sociologists, historians and anthropologists all of whom claim to speak with their voice'. The field of inclusive research therefore has been fraught with arguments about who can speak for whom, and often a resistance to the idea that the voices of those traditionally researched by others being mediated by others (e.g. Kellett, 2010).

The question of participation and the purpose it serves is addressed by Lassiter (2005, p. 84) in his discussion of collaborative ethnography/anthropology. Here participation is about working 'side-by-side' for mutual benefit. Participation in the research, he argues, is not just about 'giving back', but about 'give and take' in the sharing of expertise and 'fully dialogic exchange of knowledge'. In CBPR the 'ideological rationale [is] framed in terms of an explicit value position involving a commitment to sharing power . . . and to working for progressive social change' (Durham Community Research Team, 2011, p. 3); an emphasis placed on the research being 'more egalitarian and democratic, based on respect for and partnership with community members' (p. 6).

Enhancing authenticity

The democratization of research brings with it the democratization of knowledge and the questioning of what is authoritative knowledge and what is legitimate knowledge (Durham Community Research Team, 2011; Edwards and Alexander, 2011). Another core idea among proponents of inclusive research, then, is that it can, and does, produce more authentic knowledge (Grover, 2004; Reason and Bradbury, 2008). This is the idea that knowledge is more authentic, valid even, when grounded in the experiences and values of those concerned. This idea is strong in moves for child-led research and Kellett (2011, p. 211) explicitly states, 'the power of child-child research is that it can transcend inequalities in power dynamics and propagate authentic insider perspectives'. This reflects the notion that 'children are experts on their own lives', privileged as insiders to childhood, or when they are disabled or living in traveller communities, enjoying 'double' insider status (p. 212). The logic here is that one's identity brings with it a particular view of the world based in that identity, which in turn produces a particular kind of knowledge. Porter et al. (2012, p. 132) observe

that children are sought as co-investigators based on the premise that 'knowledge about children may best be produced by them'. For Thomas and O'Kane, (1998, p. 341), 'children's own understandings of their situation may be as valid as any other' but, for Kellett, children's own understandings are more valid because, 'with regard to childhood itself – in the sense of what it is like to be a child – it is children who have the expert knowledge' (Kellett, 2005a, p. 9). One view is that children's participation in the interpretation of data can enhance validity (Thomas and O'Kane, 1998) and the other view is that it is essential to validity. The underpinning assumptions here are fiercely critiqued, as I show in Chapter 4, with one counter-view being that people are not best placed to know themselves. The wider academic debates about insider/outsider research and the value of making the familiar strange are pertinent here.

Authenticity arguments can focus on who does the analysis and who authors the knowledge. For some the best knowledge comes from co-production or, as Lassiter (2005, p. 96) puts it, 'cointerpretation is what ultimately makes an ethnography collaborative'. For others co-production is inferior to community-controlled knowledge production (Durham Community Research Team, 2011). ICPHR (2013, p. 13) see participatory health research as characterized by producing knowledge which is 'local, collective, co-created, dialogical and diverse'. Arguments about inclusive research producing more authentic knowledge, however, rest not just on the importance of the involvement of children or other marginalized or oppressed people/participants in providing and analysing data, but on the importance of their involvement in shaping questions. Working collaboratively, for example, focused on the concerns of practitioners, can mean that the 'reality' gaps between them and academics are bridged (Fergusson, 2012, p. 125). For Torre and Fine (2006, cited by Cahill, 2007, p. 298) involving people usually marginal to setting the agenda is important because of the depth of their knowledge and, for Torre et al. (2001), because of its unique quality; 'insiders "simply know things that outsiders don't"'. Cahill (2007) suggests that these authors do not confuse deep, insider knowledge with 'the truth', but that they highlight the potential for new lines of vision. For Holland et al. (2008) and Fenge (2010) participatory approaches incorporating such multiple perspectives can create understandings that are more holistic, and for Burke and Kirton (2006, p. 2, cited by Jones et al., 2012, p. 1) involving insider, local perspectives can lead to more 'nuanced and complex understandings'.

A further argument about authenticity is based on what knowledge has previously been privileged and what neglected. Often experiential knowledge has been valued for its authenticity, but still allocated a lower status than other knowledge or evidence (Beresford and Carr, 2012). Thus, authenticity is enhanced when the approaches 'access and valorise previously neglected knowledges and provide more nuanced understandings of complex social phenomena' (Kesby, 2000, p. 423). There is seen to be a correspondence between democratizing knowledge production and increasing the validity of data (Kitchen, 2000). Many qualitative researchers are concerned with checking the validity of their data, through member checking, for example, allowing for misunderstandings to be identified and fixed and for constructs to be credible. Cho and Trent (2006), however, propose that an alternative to this transactional validity process is a transformational validity process involving more fundamentally changed relationships. As with Lather's 'catalytic validity', validity processes should empower and emancipate and 'the researcher should openly express how his or her own subjectivity has progressively been challenged and thus transformed as he or she collaboratively interacts with his or her participants' (Cho and Trent, 2006, p. 332). In this way it is not just participants'/co-researchers' capacity to perceive differently (and our need to learn from their firsthand, direct experience) that matters, but their capacity to make a difference to their worlds.

Empowerment

The idea of authenticity leads to the idea of empowerment. A central premise in inclusive research is that 'those who have in the past so often been the mere objects of investigation, themselves become the agents of their own transformation' (Fielding, 2004, p. 306). There is a good deal written about how 'the interests of children and young people, as a relatively powerless group, are served when they set their own agendas and lead their own research' (Kellett, 2005a, p. 6). The outcomes for children are said to be self-development, political agency, increased confidence and self-esteem, in turn leading to more active participation by children in other aspects affecting their lives' (p. 10). The evidence for this active citizenship happening in practice is sparse, as yet. In the field of learning disabilities it is those people who are already involved in organized self-advocacy who become researchers and so the nature of this relationship, if there is one, may be in the other direction. Cahill (2007) argues that

describing the engagement of young people in research as building their capacity for analysis and transformation may be a safer assertion than saying that they are actually analysing and becoming transformed. Indeed, involvement in the research process can be important for enhancing people's understanding of the barriers and enablers for their participation (Johnson, 2009), whatever they do with that understanding.

One of the key differences between children's involvement in the research process and the involvement of self-advocates/service users is that the former are likely to be involved as individuals and the latter as groups. This individual/group dynamic is important in that French and Swain (1997, p. 28) argue that 'emancipation of a group of people can further the empowerment of individuals just as empowerment of individuals can further the emancipation of a group'. The claim that participating in the conduct of research can be empowering and transformative beyond the realms of research reflects a particular view of participatory democracy as much as a reality. In the field of learning disabilities, for example, the engagement of learning disabled people in doing research has expanded the horizons of those individuals and enriched their lives, as well as sometimes changing things for other people with learning disabilities; nonetheless, structural barriers to their active citizenship and to careers in research remain immense (Nind and Vinha, 2012).

The debate about whether, and how, inclusive research empowers is for some people part of a wider debate about its impact in a wider sense. Staley (2009) has explored the impact of public involvement in health research in the United Kingdom for the organization INVOLVE, primarily because this development is founded on a rights argument about involvement, but raises the question of whether it actually makes a difference. In a tight economic climate, interest in evidence demonstrating the added value of an inclusive approach increases in importance. Staley notes the limited evidence available for judging impact and the difficulty in assessing it. Nonetheless, her literature review shows how researchers have been empowered to ask more relevant questions, design more accessible and meaningful studies and engage underrepresented groups. Moreover, the literature shows how the public have benefited from acquiring new knowledge and skills, developing personally, gaining in many ways, but also sometimes being emotionally burdened, overloaded, exposed or frustrated. Communities may gain credibility and recognition for their contribution and build important new alliances. Maximizing positive impact

(and perhaps empowerment and transformation) appears to depend on 'involvement throughout a research project, long-term involvement, training and support for the people involved, [and] linking involvement to decision-making' (Staley, 2009, p. 84).

Accessibility, authorship and readership

The core question of who the research is for relates not just to who benefits from it in the sense of positive impacts, but also to who can access it. Thus, evolving inclusive research processes centre on the audience for research knowledge as well as the producers of research knowledge. The principle of accessibility of the research question, research process and research products is a defining one for inclusive research, according to Walmsley and Johnson (2003). Similarly, Van Blerk and Ansell (2007, p. 314) argue that feedback to research participants and dissemination to wider policy and practice audiences both need to be 'active and participatory, where researchers engage with participants and practitioners', rather than 'passive, where the researchers take the lead'. Moreover, they argue that the discourse regarding participatory feedback and dissemination is underdeveloped and, with notable exceptions, passive approaches still dominate. This issue has though received particular attention in PRA and in research involving people with learning disabilities. Accessible products of research include plain English or 'easyread' reports and alternatives to the written word such as multimedia outputs including exhibitions, live drama productions and videos shared via the internet (Nind and Vinha, 2012).

For lay people involved in doing research, their relationships with the products of the research are important for a range of reasons. Writing research reports and papers may not have the same currency for career development outside of the academy, but not doing so can keep lay researchers on the outside. Authorship, or ownership, is an important way of people being credentialized through research (Warren and Boxall, 2009) and without it they can feel used or made inferior (McClimens, 2008). Yet, as Holland et al. (2008) warn, involving participants in dissemination can also lead to somewhat sanitized research stories being told because involving participants who know each other's identities precludes telling personal narratives about them. This whole area of authorship was a sensitive topic among the researchers in focus groups I have facilitated where learning disabled people were just breaking new ground in becoming peer-reviewers as well as editors of a journal special issue (see *British*

Journal of Learning Disabilities, 2012 special issue). Similarly, researchers working collaboratively with children have reflected on the challenge of getting published papers co-written with them (Nind et al., 2012). It may be that Lassiter's (2005) distinction between co-authoring and co-writing is helpful here, that is, participants or co-researchers can shape and influence a text without necessarily writing any of the words that appear in the final version of a research report, paper or ethnographic text. Lassiter recognizes the power issues here and also that not all collaborative research is equitable and good natured, which can make co-authorship difficult. In my experience, the terrain of who authors/writes and how in/accessible texts are made can be the battlegrounds of inclusive research.

Ethical considerations

As I alluded to when referring to Holland et al.'s (2008) reference to 'rights, right on and the right thing to do', one of the core arguments adopted by inclusive researchers is around ethics and an assumption of ethical superiority. This reflects the essential premise that inclusive research is respectful (Cornwall and Jewkes, 1995; Walmsley and Johnson, 2003). The Durham Community Research Team (2011, p. 2) acknowledge this claim to greater inherent ethics in CBPR compared with so-called traditional research, because it is 'more ethically-aware' and sensitive to issues of power, rights and responsibilities and 'more egalitarian and democratic' (p. 6). They set out to move beyond such assumptions to explore the distinctive ethical challenges and to draft ethical principles and guidelines for CBPR in the United Kingdom. They show how ethics is fundamental to inclusive researchers. Similarly, Zeni (2009) argues that the engaged nature of action research changes the ethics dimension so that it is the ethical standards of accountability, action for social justice, and caring and respect that become foregrounded and personal.

For Thomas and O'Kane (1998), a participatory approach in their research with children is important not just for its reliability and validity but for its ethical acceptability. They see giving children some control over the research process as an ethical course of action and part of addressing the disparities in power between children and adult researchers and the challenges associated with gatekeepers and overprotection. Smith (2012, pp. x–xi) writes of working to develop research approaches 'that addressed the stinging criticisms being made by my own communities about the unethical, individualistic practice of research that in their view

often rewarded researchers for telling half-truths or downright lies, that misrepresented our world, and that gave authority about us to academic researchers'.

Holland et al. (2008), however, learning from their own research involving young people, remind us of the complexities at work. They conclude that adopting a participatory approach is *a*, rather than *the*, right or helpful thing to do, not least because of the positive ethical framework in which it is embedded. Nonetheless, they also argue that it is not always ethical for children and young people to have power over each other or to analyse each other's data even if they are interested in doing so, which they may well not be. Acting ethically requires a critical reflexivity which may be challenging for some people who have not always been treated well themselves (Conolly, 2008), though Kellett (2005a) maintains that the child researchers she has trained have had no problems with ethical practice. Despite these uncertainties and differences in interpretation or detail, what is clear is that the drive for inclusive research is a drive for ethical research (Nind et al., 2012).

Ethics, then, have been at the forefront of people's concerns as inclusive research practices have evolved. The published ethics frameworks of research councils and learned societies are not always well suited to the more extreme changes associated with emancipatory/user-led research. We now see university ethics committees grappling not just with how to protect groups they see as vulnerable in the research process, but how to adjust to what it means when these people themselves occupy the status of researcher. The discourses around what is risky and safe are being challenged and, rather than understanding people to be either powerful or vulnerable, various competing interests need to be understood in a more fluid and nuanced way. Having the subjects/users of research redefine themselves as doers of research can be disconcerting, even challenging, and it can be tempting for these new researchers to test out what it feels like to be powerful. New marginal voices or groups can be created, or old ones re-created, in the power plays that transpire. The evolution of inclusive research practices can be ethical or perilous, or a mixture of the two!

Summary

There are core ideas that are important to researchers adopting more inclusive approaches. These ideas about power, participation, authenticity,

empowerment, accessibility and ethics represent common concerns. When it comes to the detail and practicalities, though, the core ideas are interpreted differently, influenced in part by disciplinary backgrounds, fields of knowledge, the nature of the participants/researchers and the socio-cultural contexts. Also influential is the limited time these developments have had to mature and to be subjected to ongoing scrutiny.