

Participatory data analysis: a step too far?

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Qualitative Research

11(4) 349–363

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DOI: 10.1177/1468794111404310

qrj.sagepub.com



Abstract

Interest in participatory research methods has grown considerably in the spheres of research with children and young people and research with people with learning disabilities. This growth is rooted in different but related paradigm shifts in childhood and disability. I argue that despite developments in participatory approaches, participatory data analysis has been attempted less than participation in other aspects of research with either children or people with learning disabilities, and that the challenges involved in this are particularly under-explored and important with the latter where we need to investigate what is possible. I discuss why participation in analysis is often neglected before reviewing different responses to the challenge including examples of informal and formal, unstructured and structured, trained and untrained, explicit and implicit approaches. Finally, I make the case for authentic reciprocal learning in exploring the potential benefits of participatory analysis to people and to research.

Keywords

data analysis, emancipatory research, inclusion, learning difficulties, participatory methods

Introduction

I focus in this article on participatory research with children and young people and participatory research with people with learning disabilities. This dual focus reflects my experience working in both fields and my stance that bringing together separate but related marginalized groups can be enriching and empowering (Nind, 2002). Thus, I begin by discussing issues in common across children and young people and people with learning disabilities participating in research. I then distinguish different but related arguments pertaining to each, before reconnecting the two groups in looking to the future. I use the terms *disability* and *disabled people* to refer to broad social constructs that encompass a range of impairments and the term *people with learning disabilities* to refer to a specific group within this (known also in policy and research as *people with learning difficulties*). People with learning disabilities are disabled people in the generic sense, yet many of the

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voices in disability research are those of people with physical impairments and not always inclusive of people with intellectual or complex impairments.

While not new, concern with participatory research has grown in recent decades in accordance with the largely separate but similar paradigm shifts that have led to childhood/children and disability/disabled people being reconceptualized and reframed. Thereby, in the social study of childhood children are now viewed as diverse social actors worthy of being taken seriously, competent to make decisions and contribute to constructions of their lives and childhoods (Greene and Hill, 2005; James et al., 1998). Participatory research is 'an integral part' of this reconceptualization and recognition of 'child cultures' (Veale, 2005: 253). Similarly, in a new valuing of disabled people (in a general sense) as holders of opinions and worthwhile insider insights, researchers have been challenged to work with disabled people, directed by their agendas, on research that will make their lives better (e.g. Barton, 1996; Oliver, 1996). In the social model of disability, disabled people have become understood as disabled not by personal tragedies but by social and material barriers residing in a disabling environment; researchers never neutral, they are either on the side of disabled people or one of the oppressors (Barnes, 1996).

Far from developing in a vacuum (Veale, 2005; Walmsley and Johnson, 2003), participatory approaches reflect not just these paradigm shifts but global concerns with rights and voice, community development perspectives, and developments in qualitative inquiry. Participatory research has grown up around people who have historically lacked voice and so people in poverty, users of mental health services, and others experiencing social exclusion as well as the two groups discussed in this article. Kiernan (1999: 44) connects the development of participatory research with people with learning disabilities with the sociology of the early 1970s, which maintained that research should be 'cooperative experiential inquiry' with research 'subjects' becoming co-researchers.

In children's research there is a sense of a continuum of approaches from adult-centred, adult-led to youth-centred, youth-led research (Freeman and Mathison, 2009). In the disability field, there are clear agendas for participation and for emancipation. Emancipatory research, which is under the control of disabled people and in their interests (as called for by Oliver, 1996; Zarb, 1992), goes beyond mere participation in the research. For some, such as Kiernan (1999: 45) emancipatory research could be said to be at one end of the continuum, the difference compared with participatory research being 'more a matter of emphasis than kind', for others, such as Zarb (1992), the distinction is more central.

Researchers have embarked on research using participatory approaches or methods with various groups for different reasons. Participation may be about listening, accessing perspectives, understanding experience, consulting, involving participants in decision-making, or working together to make something happen (Greene, 2009). Participatory methods may offer a pragmatic solution to engaging children through child-friendly methods (e.g. Conolly, 2008) or people with learning disabilities through accessible methods. They may be chosen as principled research, or they may represent for the researcher a political commitment to an inclusive agenda. These different motivations, moreover, are not mutually exclusive (Greene, 2009), especially in research with participants who are marginalized or so-called 'difficult to reach' where practical

and political challenges interconnect. Different motivations for adopting participatory approaches mean that there are ‘no strict rules for what constitutes PR [participatory research]’ or even clarity about the ‘essential ingredient’ (Bourke, 2009: 458). Nonetheless Bourke (2009: 458) offers an operational 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’.

Some scholars question the burgeoning of participatory research methods in research with children, asking if the priority is the quality of the participation or the quality of the research (Freeman and Mathison, 2009; Greene, 2009) and whether participatory research methods are necessary (Gallacher and Gallagher, 2008). One critique is of the assumption of superiority for participatory research as explained by Holland et al. (2008: 1): ‘we join with others in critiquing the notion that research which aims to be participative is necessarily more enabling for participants, is ethically or morally superior to other types of research or produces “better” research.’ In this case participatory methods may be a good option rather than the only option as they explain: ‘Nonetheless, we argue that participatory research *can* make a central contribution, in providing an ethical, epistemological and political framework and in the potential for rich findings’ (p. 1).

In research with children some critiques of participatory approaches have focused on the issue of how much participation – that participation is tokenistic if the research is not initiated and led by the child (Kellett, 2005) – a discourse that Gallacher and Gallagher (2008) refer to as tyrannous. Participation is regarded as more or less genuine and concerns are expressed that children are sometimes being exploited (Alderson, 2000). Some activities are regarded as meaningfully shared, while ‘some jobs are for adults’ (Greene, 2009). In disability research, an equivalent argument that some jobs are for non-disabled academics is often too controversial to be aired, yet academics clearly do retain some roles without always being explicit about this (Walmsley and Johnson, 2003). There are also equivalent concerns that ‘people with learning difficulties are being used as puppets’ (Aspis, 2000: 3).

Other critiques have focused on the privileging of some (already privileged) voices for participation over others. In children’s research this includes those who are white and middle class (see Holland et al., 2008) but also those who are emotionally literate over those who are less amenable (Davis, 2007). In the field of learning disabilities it includes those who are ‘tame’ over those who are politically challenging (Aspis, 2000: 2) and individuals with stronger communication abilities who are included more often and more readily than those with profound impairments (Nind, 2008; Walmsley and Johnson, 2003).

In working on what it means to be participatory, researchers have asked which aspects of the process matter most. Haw and Hadfield (2009) raise questions in relation to participatory video about the stage at which the participant needs to be actively participating: is it the planning, filming, interviewing, editing and so on. In the process of preparing a methodological review of qualitative research with people with learning, communication and other disabilities (Nind, 2008) I became acutely aware of the attention given to the stages of conceiving the problem, gathering the data, or disseminating the findings, and to the relative neglect of participation in data analysis. Thus, the purposes of this

article are to critically examine why participation in data analysis matters, why this is under-developed, ways forward and what can be achieved, how and to what ends.

Participatory research with children and young people

I now address participatory research with children beginning with why participation per se matters. Holland et al. (2008) sum this up:

we detect three lines of argument that we have identified as ‘rights’, ‘right on’ and the ‘right thing to do’. ‘Rights’ refers to where children’s and citizen’s rights agendas have produced a political and legal environment that encourages more participative approaches, ‘Right on’ suggests a hint of ethical and moral superiority that can perhaps create an environment that makes it difficult to critically examine participative approaches in social research. ‘The right thing to do’ refers to a question over whether participatory research can claim to be methodologically superior by producing ‘better’ data or research outputs and research engagements. (pp. 1–2)

Gallacher and Gallagher (2008: 501) question this kind of ‘ethical allure’ of ‘empowerment’, ‘agency’ and ‘self-determination’. They point to the limited methodological reflection on this and to the ways in which children have agency and power regardless of whether adults give it to them as a kind of commodity.

Another argument for participation in data analysis is that this enhances validity and insight into ‘children’s ways of seeing and relating to their world’ (Thomas and O’Kane, 1998: 337), producing more ‘authentic’ knowledge (Grover, 2004). Thus Jones (2004: 126), reflecting on children’s involvement in research on child labour argues, ‘children can reflect on what the findings mean to *them* and their perceptions are important in planning corrective measures’. Kellett (2005) argues that including the potentially highly valid perspectives of children and their development as researchers has suffered from the considerable obstacle of low expectations of children’s capabilities.

Data analysis has been recognized as a missing dimension of participatory research with children (Holland et al., 2008), acknowledged as an area where ‘children’s contributions are easily marginalised’ (Jones, 2004: 125). Byrne et al. (2009), reflecting on their research with socially excluded, socio-economically disadvantaged teenagers, acknowledge that establishing participatory research relationships is ‘easier said than done’ (p. 67) and that there few examples of participatory interpretation and analysis of data. Conolly (2008) argues that as the girls in her study with ‘fragmented and transitory’ lives (p. 206) lacked necessary commitment, confidentiality and sensitivity she managed only participatory data collection not analysis.

Nonetheless, there are examples of approaches to participatory analysis with children and young people which indicate potential ways forward. One approach is overtly training child researchers in this as in other research processes. Kellett et al. (2004: 332), for example, argue that ‘a barrier to empowering children as researchers is not their lack of adult status but their lack of research skills. So why not teach them?’ Kellett (2005) proposes supporting children with reducing data into manageable forms and children working with adults in models of Vygotskian scaffolding. There are problems though with this approach in that developing skills requires experience, time and opportunity

which children may not have. Learning skills is not the same as re-examining one's preconceptions. This is an area of tension found by Bourke (2009) in participatory work with aboriginal adults, and while children and young people may have fewer preconceptions they are not naïve and without assumptions gained from immersion in their contexts. Moreover, gaining skills is necessary, but not sufficient for becoming a (co-) researcher.

Byrne et al. (2009) also approach participatory data analysis through training. In their *Researching Our Lives* project with early school leavers in Ireland they adopted the Voice-centred Relational Method for collaboratively analysing interview transcripts, requiring them all to learn 'to listen attentively to the voice relating the story' (p. 68), confront difference and identify and make the conventions of interpretation explicit. A core concern was whether the teenagers would 'be able to move from talking to sociological interpretation, learning from personal accounts to making general statements' (p. 72). Yet, working on the transcripts in teams and pairs, the teenagers corrected inaccuracies, filled gaps, added to the narrative, and 'persisted in the task of data analysis though the work was difficult, tedious and time consuming' (p. 74). Ironically, Byrne et al. (2009) note they erred by focusing on the teenagers' disadvantaged stories and neglected their privileged ones, forgetting their own role as narrators and researched. Thus, while 'the teenagers had demonstrated that they could be researchers; the academics on the other hand found it difficult to become the researched and step out of the role of expert researcher' (p. 75).

This example illustrates my contention that difficulties do not belong to people as much as to the interactive spaces between them. In probing why these teenagers could do data analysis it is unclear what part was played by the training and structure, and how this interacted with the teenagers' high commitment to the project focus and with the enabling, mediating role played by the artist involved. In probing why these academics resisted losing their role as expert, I am reminded of the power and status associated with doing analysis compared to giving data.

In contrast to the trained approach, Holland et al. (2008) argue that in their *Extraordinary Lives* project with young people in care, formally training participants in qualitative analysis was not an option as this would conflict with their intention to enable them to 'develop their own ways of exploring their lives' and with their experience of the participants' frequent resistance to formalized interactions. Instead they 'experimented with both analysis as process and analysis as discrete activity ... tailored to these particular young people's own cultures of participation' (p. 16). In analysis as process the academics informally fed back, in brief interactions, to the young people their thoughts on the themes that were emerging, thereby involving them in their thinking in an ongoing way. More overt analysis as discrete activity happened towards the project end in one-to-one meetings in which participants were shown, in bespoke modality, the themes from the academics' initial analysis of data specific to them, to which responses were variable from high engagement to passive assent. Holland et al. (2008) question whether this discrete activity deepened the researchers' understanding of the young people's lives, which happened much more from on-going, recurrent discussion which had 'the advantage of responding to the young people's cultural forms of communication (informally and in short bursts)' (p. 16).

Thomas and O’Kane (1998), also conducting qualitative research with looked after children, are unusual in writing explicitly about creating ‘opportunities for children to participate in the interpretation and analysis of research data’ (p. 345). Their participatory approach focused on giving the children plenty of control and opportunities for choice of topics and instruments. They offered ‘vivid, graphic and concrete’ activities thus enabling the children ‘to talk about complex and abstract issues and to interpret the social structures and relationships that affect their lives’ (p. 342) and avoiding relying on just adult interpretation. The children, they argue, were able to contribute to the sense-making because the activities were ‘serious fun’ (p. 344), did not rely heavily on literacy abilities, broke down power imbalances and encouraged joint analysis. Children could review and refine their input by returning to them more than once and using spaces for collective re/interpretation in group processes. Thomas and O’Kane (1998: 345) conclude that while it is difficult to disentangle the contributions of adults and children, ‘there is no doubt that the course followed by the research, and the final conclusions, were very different as a result of the children’s own interpretations of the data’.

Participatory research with people with learning disabilities

Participatory research matters in somewhat different ways for people with learning disabilities and disabled people generally because of the history of exclusion and dehumanization. Participation in research is more centrally about the politics of inclusion and ‘nothing about us without us’ (Charlton, 2000). From here the logic is that nothing about us without us must include data analysis. Danieli and Woodhams (2005) observe how fiercely emancipatory research is promoted among social model of disability proponents as without it researchers are seen ‘as responsible for producing knowledge which perpetuates the oppression of disabled people’ (p. 283). Accordingly, as data analysis is central to knowledge construction, if there is to be participation or collaboration anywhere then for emancipation it must be here: it is through active participation in understanding the world through research that participants benefit from a transformative experience.

Danieli and Woodhams (2005: 290) critique a key premise in the emancipation argument and propose instead the solution of many feminists ‘to the dilemmas posed by emancipatory research’, that is, ‘the de-coupling of participation and emancipation’. Knowledge used for emancipating lives, they argue, ‘does not always require a particular methodological approach to achieve political objectives’. Yet, I argue, if participation in data analysis can be transformative and emancipatory, and if emancipation can come through other routes also, it is when the political objective of research is emancipation and inclusion that the argument for participation in data analysis becomes stronger. As Walmsley and Johnson (2003) reflect, one of the important questions in evaluating whether research has been inclusive and empowering is, ‘who analyses the data and how?’ (p. 72).

The argument pertaining to research with children that participatory research produces more valid data is applied to people with learning disabilities too. Kitchen (2000: 40) makes the case for inclusion of disabled people at every stage for ‘more valid data and

useful interpretations', that is, for increased validity via 'democratisation of knowledge production'. Without this academics can, as Simone Aspis has argued, 'appropriate people's stories and weave academic arguments around them' (Walmsley and Johnson, 2003: 98).

In participatory research with people with learning disabilities participation in analysis matters, I argue, primarily because inclusive politics matter. Inherently, therefore, it also matters that we explore what is possible in terms of people with learning disabilities as researchers and analysts of data. In recent history much has been achieved by, for, and with people with learning disabilities through challenging the discourse of incompetence and attempting what was previously unthinkable. In continuously maintaining the challenge to discourses of incompetence it is not enough to say that people with learning disabilities can define research problems (Aspis, 2000), understand ethics protocols (Abell et al., 2007), give informed consent (Cameron and Murphy, 2007), gather data through interview (Clarke et al., 2005; Lewis, 2004), focus group (Barr et al., 2003) and visual methods (Aldridge, 2007; Booth and Booth, 2003), and contribute to accessible reports of research findings (Walmsley, 2009). We need to push on to say that people with learning disabilities can do data analysis too, not in the sense of romantic idealism or positive spin, rather of finding out what can be achieved by exploring ever-more sensitively supportive approaches to breaking down barriers, opening up possibilities and achieving access (see Nind and Seale, 2009).

One challenge in explicating what is known about this already is that while researchers tend not to explicitly exclude analysis from discussion of participatory approaches, they tend not to explicitly include it either. Most often readers are left to infer that participation in analysis has or has not happened. However, review of over a hundred papers pertaining to research with people with learning and communication disabilities (Nind, 2008) showed developments across research design, data collection and dissemination, but much less written about the process of data analysis or even basic participant validation (member checking). Williams and Simons (2005) note that Lloyd et al. (1996), Minkes et al. (1995) and Stalker (1998) all relate problems with participants with learning disabilities being involved in data analysis or generation of theory.

Among the examples of approaches to data analysis in participatory research with people with learning disabilities there are not the overtly trained approaches to data analysis that can be found in research with children, though some researchers take a structured approach. For example, Booth and Booth's (2003) Supported Learning Project involved a structured photovoice approach with mothers with learning disabilities, where they put 'people in charge of how they represent themselves and how they depict their situation ... shifting control over the means for documenting lives from the powerful to the powerless' (p. 432). Despite the structure, Booth and Booth reflect that the group dimension of selecting and discussing photos as part of a process of collectively coding for themes and messages, which was intended to aid in understanding the participants' lives better and in enabling participants to gain a sense of solidarity from seeing themselves through other people's photos, was difficult to motivate.

A less structured, more fluid example is my own recent research with Jane Seale (Nind and Seale, 2009; Seale and Nind, 2009), which was both participatory and theoretical from the outset. The project involved bringing together academics, practitioners

and people with learning disabilities to explore and develop conceptual understanding of access. The vehicle was a series of seminars structured around a set of pre-defined and emerging questions. As with Holland et al.'s research with non-disabled young people, rich data were generated in an evolving process of interaction. Recurring meetings enabled a pattern of re-convening in the same interactive space in which relationships, familiar ground, and common assumptions could be built. Analysis of the ideas was what we did together in an informal and progressive way as we assimilated new seminar inputs with evolving concepts. This happened in conversation and in directed activities, including visual mapping on flip-charts, whole/small group and round table discussions, and roaming microphone-video interviews. The nature of the questions, which at the outset were, 'What do we mean by access? How do people with learning disabilities experience access? What is worth accessing? [and] What kinds of access do people with learning disabilities want and how can we make access happen?' (Nind and Seale, 2009: 275), enabled us to maintain a frequent interchange between the concrete and the abstract. Every shared story was a vehicle for thinking about the concept itself. Thus, the processes of data generation and analysis were concurrent and largely without hierarchical boundaries.

This concurrent approach to data collection and analysis is true also of life story work with participants with learning disabilities in which, once again, they are expert witnesses rather than mere sources of data as they recall, recount and review their lives and reclaim them as their own (Atkinson, 2004). Atkinson and Walmsley (1999) are acutely aware of the ways in which narrative methods are empowering, enhancing the person's knowledge and understanding of the world and their place in it. In our access project described above this was readily apparent in that to make the core ideas accessible people told stories – of events, lives, research projects and so on – 'None of these were told in the abstract, each had a narrator and central actors, and through this we could relate to the ideas' (Nind and Seale, 2009: 276). Life story and narrative, I argue, is participatory data analysis at its most informal, implicit and emancipatory, but the question remains of what it is that enables people with learning disabilities doing life story work to be active in analysis.

For Atkinson (2004) the enabling factors are time, space, support and practice, as well as including others with whom to share the experience and reflections. This combination enabled her participants in the Past Times project to tell and use personal stories to make bigger points, challenge people and events in their lives, denounce practices, provide alternative social histories and generate counter-narratives. For Meininger (2006) the core activities in life story work (narrating, writing and reading) bring an inherent structure. Narrating stories 'supposes mutuality and invites a dialogue' (p. 184), which enables the person to find a thread running through their life and to give sense to it. Writing stories enables re-shaping and re-connecting parts of the story so they can be read as a coherent whole. And reading stories forces readers 'into a critical confrontation with opinions, affinities, attitudes and behaviours other than their own' (p. 186).

Again, returning to my own example of participatory data analysis in the access project, participants engaged in writing chapters for an edited book. Those with learning disabilities were supported in the process by skilled enablers (as were some practitioner contributors), and they largely wrote about their life experiences. Writing one's ideas is

a means of getting to know them better, and this exercise was in some ways an exercise in analysis. Nonetheless it was my colleague and I who ultimately developed a multi-dimensional model of access, based on a synthesis of the data and analyses from the journey. In this example, it was the academics that had the (time, motivational and intellectual) resources to do this, but this does not mean that the analysis was ours alone.

Learning from and about participation in data analysis

I now turn to what we can learn from the debates and examples above and particularly by considering participatory research with children and young people alongside participatory research with people with learning difficulties. One question to emerge is about whose data participants can and should analyse. This goes beyond the usual debate of whether academic researchers can achieve the insider perspective that participants who are 'other' can offer. For Holland et al. (2008) and Conolly (2008) asking the young people to examine lives beyond their own was too problematic as the ethical sensitivities surrounding private material were too great. For Atkinson (2004) in comparison, the focus on the self was enabling, but it was making sense of this with and alongside others doing the same that was empowering. The ethical sensitivity of picking over someone else's life/data may be less immediate for people with learning disabilities whose stories have so often been owned by staff. Yet the idea of private troubles as public issues (Mills, 1959) could apply equally to both troubled youngsters and disabled people. 'Collaborative "sensemaking"', which Nicholls (2009) identifies as a reflexive process that is 'a theoretically consistent tool within participatory methodology' (p. 124) links with debates about who can know whom, whether we are 'transparently knowable' to ourselves (Gallacher and Gallagher, 2008: 502) and to others like us.

Less contentious is the theme of the role played by time and space with the data – of returning and re-visiting – which echoes throughout the practices of researchers co-researching with disabled and non-disabled young people. This is also emphasized by Williams (1999), who while not claiming to have the solution to the challenge of involvement in data analysis, recommends from experience that data analysts with learning disabilities need to spend periods of concentrated time with the data on a frequent basis.

Also arising from the examples is the question of conceptual understanding: what do we mean by participation in data analysis and what do we envisage as possible? Both children and people with learning disabilities may be regarded as having limitations when it comes to playing an active role in data analysis. Some of these may come from their inexperience and lack of training and some may come from their immaturity or intellectual impairment. There are whole spheres of analysis which may not be accessible to all, such as structural equation modelling and using all the features of computer-assisted qualitative data analysis software packages. Yet as I, too, find these difficult the issue may be one of degree of difference rather than kind. It may be that the field of participatory data analysis, in terms of explicit technique, argument and example as I am developing in this article, is generally held back by notions of what it means to do data analysis. It is, therefore, productive to consciously open up these notions. It is helpful to remember just how diverse approaches to data analysis are, even within, for example, narrative analysis, as well as across qualitative research more broadly.

Williams (1999) argues that thematic analysis by people with learning disabilities may be feasible if there is support in the form of presenting a range of themes for co-researchers to explore, and if the process is understood using the simpler concept of recording 'the bits they find interesting' and their reactions to these bits. This has good fit with the assertion of Outhwaite (1985, cited by Elliott, 2005: 37) that: 'understanding is not a matter of trained, methodical, unprejudiced technique, but an encounter ... a confrontation with something radically different from ourselves'. Elliott though, in discussing narrative approaches to analysing qualitative data, also argues that to go beyond lay understandings requires basic tools.

One can debate whether a 'best bits' approach means involvement in theory building as such, but Williams (1999: 51) argues that, 'if a theory is broadly taken to be a model that helps us to understand why things are as they are' then this is something people with learning disabilities frequently do. This is one of many interpretations of theory discussed by Thomas (2007) in his problematization of the concept for education, and a potentially inclusive one, making theoretical work more attractive to participants and not just the domain of academic researchers and allies. In my example of our participatory work on the concept of access, the academics' multi-dimensional model of access may be explanatory and even predictive on one level, but there was layer upon layer of other analysis also.

For Walmsley and Johnson (2003) there is an element of theorizing that involves connecting data to the wider world of ideas, which they argue in the field of learning disability is a challenge rarely met and which can lessen the impact of participatory/inclusive research. Here, there is the inevitable reality that children and young people and people with learning disabilities will be less well-read than their academic co-researchers, not schooled in particular theories or immersed in disciplinary fields. It is unrealistic to think of this imbalance being equalized, but the world of ideas can be opened for engagement and reflection. In the project on the concept of access the seminars provided an effective means by which speakers communicated core content that was provocative of wider thinking and that enabled participants to make connections across all kinds of boundaries.

Holland et al. (2008: 15) reflect on the theme of what it means to do participatory analysis:

It is often claimed that participatory research rarely involves participants beyond the data generation stage and that participants' involvement in analysis is minimal. This perhaps reflects a conceptualisation of analysis as a separate, formal stage of the research process, yet in qualitative research analysis is more often conceived of as beginning with the development of research questions and occurring throughout data generation and beyond ...

In this model, participation in analysis can be embedded and boundary-less – part of a broader approach to participation and to acting responsibly. It is about a process of dialogue, seeking input and feedback rather than sitting down together to a task or a 'mechanical application of a 'technique' or method' (Thomas and O'Kane, 1998: 346), or handing over control of something.

The danger of a feedback approach is that only the analysis and themes that fit with those of the academic researcher may make their way forward into discussion. Yet if the research has been designed as participatory or social action research there will already be a sense of a mixed community working with multiple truths that reflect complex, contextual social realities. Moreover, the diverse inputs into data analysis are not discrete voices: 'Children are not separate from the worlds they inhabit' (Jones, 2004: 116). The voice of the young person 'is neither neutral nor "authentic", but is produced by/within dominant discourses' (Thomson and Gunter, 2006: 852). Therefore data analysis by children or people with learning disabilities will not be immune to outside influences; there is not an option to have data analysis that is in some way pure or unsullied.

The option is likely to be more one of how much participation is enabled or allowed, and the challenge one of how much critical self-reflection can academic and participant researchers do together and alone. As Veale (2005) argues, 'a core principle of participatory research is the generation of knowledge (rather than its 'extraction') through a merging of academic with local knowledge to provide oppressed people with tools for analysing their life condition' (p. 253). Analysis of one's situation, I argue, need not be a once and for all thing, but emerges from repeated engagements in reciprocal learning through thinking about data and the 'best bits' or most important messages.

Going forward

I have shown that approaches to participatory data analysis can be informal and formal, unstructured and structured, trained and untrained, explicit and implicit. I do not translate this into participants being more or less active or passive (as critiqued by Gallacher and Gallagher, 2008). The examples all show a role for the participant as a sense-maker of data, and a role for the academic/adult researcher, but this variously incorporates trainer, coach, 'scaffolder', mentor, partner in dialogue, co-learner, reciprocal learner and practical facilitator.

Examples of conflict in the process of analysis tend not to be shared when research is disseminated, whereas the benefits of sharing this task are either emphasized or assumed. While critical debate about participatory methods may be live, critical debate about participatory data analysis more specifically is rare, meaning that more needs to be done before the arguments can develop. Nonetheless, Gallacher and Gallagher's (2008) core argument that we are all immature, developing, learning beings and researchers is a helpful one; it is very pertinent to where we are with participatory analysis and it recognizes the vulnerability and potential of us all as we take risky steps forward. There may be limits for what is possible in participatory analysis, but just as Hart et al. (2004) argue in relation to learning, placing pre-defined conceptual limits on the ability or potential of particular groups of people is limiting in itself. Being prepared to trust and to take risks in seeking transformation are integral to both learning without limits and to participatory research. In this process, sufficiently authentic reciprocal relationships in which we genuinely believe that we can learn from becoming involved in the process together are, I argue, central.

Academics need to adopt a competence discourse in which competence rather than incompetence on the part of participants/co-researchers is the starting assumption, but to

keep this balanced with a learning discourse in which no one is expert. Our prospects for learning are better if, as a community of researchers, we share philosophical and practical thinking across disciplines and across participant groups. Children and young people and people with learning disabilities may share issues in common as participants in data analysis and some issues may be unique (though we must not lose sight of the fact many of the people with learning disabilities whose research contributions are discussed in this article are also young people). Understanding the issues for the two groups alongside each other is particularly helpful in that things that seem acceptable or pertinent for or about children as co-researchers may seem less so for and about people with learning disabilities and vice versa. Unlike children, more politicized people with learning disabilities are demanding that research is with them and not on them. Crucially, the two groups serve to challenge our thinking.

Conclusion

For some children and people with learning disabilities their life experiences or impairment situation will preclude their involvement in data analysis, but this should not render them invisible to qualitative researchers or to emancipatory agendas. For other children and people with learning disabilities the process of analysis can be made accessible enough for them to understand what is involved and to contribute, but there is much to be learned here. Participatory research may not be the best way of bringing about better understanding and change in the interests of all marginalized groups; it is certainly not the only way. Yet in the absence of supporting empirical evidence the question of whether or not participatory approaches to data analysis are a 'good thing' remains one of political choice and the ethical allure endures. There is insufficient work to date to know what can be achieved in participatory analysis or what this means for the quality of the research, leaving researchers grappling with whether participation in analysis is an end in itself or a means to an end.

Current trends favouring participatory methods indicate that a methodological review repeated a decade on would include more that could be authoritatively said about participation in data analysis. The interesting question then would be what we could conclude, helped by new studies collaboratively exploring what is possible in analysis, about the benefits from this to children, to people with learning disabilities and to research. Meanwhile, researchers claiming participatory approaches need to grasp the nettle of participatory data analysis.

Funding

The author wishes to acknowledge ESRC National Centre for Research Methods who funded a methodological review leading to this research.

Acknowledgements

The author wishes to thank Jane Seale and Hilra Vinha, University of Southampton, for their helpful comments on an earlier version of this article.

References

- Abell S et al. (2007) Including everyone in research: the Burton Street Group. *British Journal of Learning Disabilities* 35: 121–124.
- Alderson P (2000) *Young Children's Rights: Exploring Beliefs, Attitudes, Principles and Practice*. London: Jessica Kingsley.
- Aldridge J (2007) Picture this: the use of participatory photographic research methods with people with learning disabilities. *Disability & Society* 22(1): 1–17.
- Aspis S (2000) Researching our own history: who is in charge? In: Brigham L, Atkinson D, Jackson M, Rolph S and Walmsley J (eds) *Crossing Boundaries: Change and Continuity in the History of Learning Disabilities*. Kidderminster: BILD Publications, 1–6.
- Atkinson D (2004) Research and empowerment: involving people with learning difficulties in oral and life history research. *Disability & Society* 19(7): 961–702.
- Atkinson D and Walmsley J (1999) Using autobiographical approaches with people with learning difficulties. *Disability & Society* 14(2): 203–216.
- Barnes C (1996) Disability and the myth of the independent researcher. *Disability & Society* 11(1): 107–110.
- Barr O, McConkey R and McConaghie J (2003) Views of people with learning difficulties about current and future accommodation: the use of focus groups to promote discussion. *Disability & Society* 18(5): 577–597.
- Barton L (ed.) (1996) *Disability and Society: Emerging Issues and Insights*. Harlow: Addison Wesley Longman.
- Booth T and Booth W (2003) In the frame: photovoice and mothers with learning difficulties. *Disability & Society* 18(4): 431–442.
- Bourke L (2009) Reflections on doing participatory research in health: participation, method and power. *International Journal of Social Research Methodology* 12(5): 457–474.
- Byrne A, Canavan J and Millar M (2009) Participatory research and the voice-centred relational method of data analysis: is it worth it? *International Journal of Social Research Methodology* 12(1): 67–77.
- Cameron L and Murphy J (2007) Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities* 35(2): 113–120.
- Charlton JI (2000) *Nothing About Us Without Us: Disability Oppression and Empowerment*. Berkeley & Los Angeles, CA: University of California Press.
- Clarke CL, Lhussier M, Minto C, Gibb CE and Perini T (2005) Paradoxes, locations and the need for social coherence: A qualitative study of living with a learning difficulties. *Disability & Society* 20(4): 405–19.
- Conolly A (2008) Challenges of generating qualitative data with socially excluded young people. *International Journal of Social Research Methodology* 11(3): 201–214.
- Danieli A and Woodhams C (2005) Emancipatory research methodology and disability: a critique. *International Journal of Social Research Methodology* 8(4): 281–296.
- Davis JM (2007) Analysing participation and social exclusion with children and young people: lessons from practice. *International Journal of Children's Rights* 15(1): 121–146.
- Elliott J (2005) *Using Narrative in Social Research: Qualitative and Quantitative Approaches*. London: Sage.
- Freeman M and Mathison S (2009) *Researching Children's Experience*. New York: Guilford Press.
- Gallacher L and Gallagher M (2008) Methodological immaturity in childhood research? Thinking through 'participatory methods'. *Childhood* 15(4): 499–516.

- Greene S (2009) Accessing children's perspectives and experience: some impediments. Advancing Participatory Research Methods with Children and Young People. NCRM/Child Well-Being Research Centre. London, 23 February 2009.
- Greene S and Hill M (2005) Researching children's experience: methods and methodological issues. In: Greene S and Hogan D (eds) *Researching Children's Experience: Approaches and Methods*. London: Sage, 1–21.
- Grover S (2004) 'Why won't they listen to us?' On giving power and voice to children participating in social research. *Childhood* 11(1): 81–93.
- Hart S, Dixon A, Drummond MJ and McIntyre D (2004) *Learning Without Limits*. Maidenhead: Open University Press.
- Haw K and Hadfield M (2009) Voice, video and the involvement of young people in participatory research. Seminar 1, Differing Notions of Participatory Video. 12 November 2009, London.
- Holland S, Renold E, Ross N and Hillman A (2008) Rights, 'right on' or the right thing to do? a critical exploration of young people's engagement in participative social work research. NCRM Working Paper Series 07/08. Available at: <http://eprints.ncrm.ac.uk/460/>
- James A, Jenks C and Prout A (1998) *Theorizing Childhood*. Cambridge: Polity.
- Jones A (2004) Involving children and young people as researchers. In: Fraser S et al. (eds) *Doing Research with Children and Young People*. London: Sage, 113–130.
- Kellett M (2005) NCRM Methods Review Papers, NCRM/003. Children as active researchers: a new research paradigm for the 21st century? Available at: <http://eprints.ncrm.ac.uk/87/>
- Kellett M, Forrest R, Dent N and Ward S (2004) 'Just teach us the skills please, we'll do the rest': empowering ten-year-olds as active researchers. *Children and Society* 18(5): 329–343.
- Kiernan C (1999) Participation in research by people with learning disabilities: origins and issues. *British Journal of Learning Disabilities* 27(2): 43–47.
- Kitchen R (2000) The researched opinions on research: disabled people and disability research. *Disability & Society* 15: 25–47.
- Lewis A (2004) 'And when did you last see your father?' Exploring the views of children with learning difficulties/disabilities. *British Journal of Special Education* 31: 3–9.
- Lloyd M, Preston-Shoot M, Temple B and Wu R (1996) Whose project is it anyway? Sharing and shaping the research and development agenda. *Disability & Society* 11(3): 310–315.
- Meininger HP (2006) Narrating, writing, reading: life story work as an aid to (self) advocacy. *British Journal of Learning Disabilities* 34(3): 181–188.
- Mills CW (1959) *The Sociological Imagination*. New York: Oxford University Press.
- Minkes J, Townsley R, Weston C and Williams C (1995) Having a voice: involving people with learning difficulties in research. *British Journal of Learning Disabilities* 23: 94–97.
- Nicholls R (2009) Research and indigenous participation: critical reflexive methods. *International Journal of Social Research Methodology* 12(2): 117–126.
- Nind M (2002) Some neglected common ground? Early childhood education and special needs education. *Westminster Studies in Education* 25(1): 77–90.
- Nind M (2008) Conducting qualitative research with people with learning, communication and other disabilities: methodological Challenges. *ESRC National Centre for Research Methods, Methods Review Paper*. Available at: <http://eprints.ncrm.ac.uk/491/>
- Nind M and Seale J (2009) Concepts of access for people with learning difficulties: towards a shared understanding. *Disability & Society* 24(3): 273–287.
- Oliver M (1996) *Understanding Disability: From Theory to Practice*. Basingstoke: Macmillan.
- Seale J and Nind M (2009) (eds) *Understanding and Promoting Access for People with Learning Difficulties: Seeing the Opportunities and Challenges of Risk*. London: Routledge.
- Stalker (1998) Some ethical and methodological issues in research with people with learning difficulties. *Disability & Society* 13: 5–19.

- Thomas G (2007) *Education and Theory: Strangers in Paradigms*. Maidenhead: Open University Press.
- Thomas N and O’Kane C (1998) The ethics of participatory research with children. *Children and Society* 12: 336–348.
- Thomson P and Gunter H (2006) From ‘consulting pupils’ to ‘pupils as researchers’: a situated case narrative. *British Educational Research Journal* 32(6): 839–856.
- Townson L et al. (2004) We are all in the same boat: doing ‘people-led research’. *British Journal of Learning Disabilities* 32: 72–76.
- Veale A (2005) Creative methodologies in participatory research with children. In: Greene S and Hogan D (eds) *Researching Children’s Experience: Methods and Approaches*. London: Sage, 253–272.
- Walmsley J (2009) Access in mind: a review of approaches to accessible information for people with learning disabilities. In: Seale J and Nind M (eds) *Understanding and Promoting Access for People with Learning Difficulties*. London: Routledge, 23–42.
- Walmsley J and Johnson K (2003) *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*. London: Jessica Kingsley.
- Williams V (1999) Researching together. *British Journal of Learning Disabilities* 27: 48–51.
- Williams V and Simons K (2005) More researching together: the role of non-disabled researchers in working with people first members. *British Journal of Learning Disabilities* 33: 6–14.
- Zarb G (1992) On the road to Damascus: first steps towards changing the relations of disability research production. *Disability & Society* 7: 125–138.

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