Judging quality in inclusive research: urgent challenges and diverse voices

Melanie Nind, University of Southampton

Paper presented at invited seminar -

Sharing experiences of researching with young people:
A European perspective

University of Barcelona, 16 March 2012

Sharing experiences of researching with young people: A European perspective

Seminar aims

Placing emphasis on doing research *with* young people implies an epistemological, methodological and political stance. Our goal is to question the dominant position in social research, where a majority of studies speak for, or about, young people. This seminar will serve as an opportunity for discussing what it means when young people become part of the research process, a collaboration that is conceived of as an exercise in emancipation and empowerment.

Judging quality in inclusive research: urgent challenges and diverse voices

Project aims

In this seminar I discuss a study currently underway in the UK and funded by the Economic & Social Research Council (RES-000-22-4423). This study is a response to the need to reflect on the development of inclusive research involving people with learning disabilities as active researchers of their own lives in light of policy being ahead of good scientific knowledge regarding what constitutes quality in such research.

The study began 1st April 2011 with the aim of building knowledge and capacity in inclusive research with people with learning disabilities. The objectives are to:

i. Take stock of the knowledge base regarding the participation of people with learning disabilities in research about them;
ii. Produce guidance on the issues and challenges in inclusive research that are faced by researchers with and without learning disabilities working collaboratively and separately;
iii. Develop materials and case studies based on the identification of practices in inclusive research that are breaking down barriers, making advances and challenging orthodoxies;
iv. Produce criteria for quality in inclusive research.

It will be completed by 31st May 2012.

I am acutely aware that the final objective will be the hardest to meet. Nonetheless, meeting the objectives will lead to products that are of immediate use and long term benefit to researchers and commissioners of research; the products will help trainers of professionals and be accessible to those with learning disabilities.

Inclusive research

In this paper, and throughout the research project, I use the term 'inclusive research'. It does not match entirely with the seminar focus on 'doing research with', but there are strong overlaps. Walmsley & Johnson (2003) define inclusive research as based on the principles that research:

- 'must address issues which really matter to people with learning disabilities, and which ultimately leads to improved lives for them',
- 'must access and represent their views and experiences', and
- reflect 'that people with learning disabilities need to be treated with respect by the research community' (p.16)

This definition, they argue, allows for the continuity and reciprocity between participatory research - actively involving people with learning disabilities in decision-making and conduct of research - and emancipatory research - which is under the full control of people with learning disabilities and in their interests. The research I am discussing here is about inclusive research – I leave it for our discussion later to tease out whether it is, in itself, inclusive research. You will see that my research approach of focus groups respectfully elicits the views of people with learning disabilities (among others), but the judgement (in Walmsley & Johnson's terms) must also rest on whether we judge the progression of inclusive research to matter to people with learning disabilities and the extent to which it improves their lives.

The problem

The research began from an identification of a problem, but not one identified by people with learning disabilities in any direct sense. I had enjoyed a year's study leave in which I had the reflective space to look back on the research I had done (some but not all of it *with* people with learning disabilities) and to look forward to where I wanted to go next. I had become intensely interested in research methodology and I wrote a paper on data analysis in participatory research – focusing on children and young people and people with learning disabilities – questioning the extent to which the analysis stage was done inclusively and raising the importance of this (see Nind, 2011). In reading around the topic three key sources illuminated for me an urgent research problem that I would want to tackle in my next research project.

Walmsley & Johnson (2003) made the argument that we need to take stock of inclusive research with people with learning disabilities, and to problematise it. They made a convincing case that we often avoid the most thorny issues and that the only way to make progress was through 'frank and open debate' (p.16). Holland and colleagues (2008:1) similarly asked bold questions about whether participatory research is 'ethically or morally superior' or 'more enabling'. With these important contributions we were moving away from simplistic notions of voice and involvement as straightforwardly important and reachable, into the realities of what participatory/inclusive research means and the nuances of realising political and methodological goals. Lastly, Grant & Ramcharan (2007: 12), reflecting on the state of the art of inclusive research, concluded that it had ended an initial phase such that we have achieved practical knowledge of how to do this; now what is needed, they argued, is a 'second phase', which is 'concerned with outcomes – what kinds of knowledge are attributable to inclusive research and how the knowledge claims of inclusive research can be assessed and authenticated'. This was convincing and appealing. In my role as co-director of the National Centre for Research Methods I was immersed in debates about research quality and methodological innovation and in the project of building capacity in both. By responding to what I saw as a well-articulated problem I could pursue something of intrinsic interest and value to others.

The funding council shared my view that the problem was worthy of investigation and the project was funded to address the research questions:

i. What does working in partnership with people with learning disabilities as researchers really mean?
ii. What kinds of knowledge are attributable to inclusive research?
iii. How can inclusive research and the outcomes of inclusive research be assessed and authenticated?
iv. What are the benefits of inclusive research to people with learning disabilities and other stakeholders?
v. Where do the problems lie?
vi. How might good science and good inclusive research practice come together?
vii. What can be added, from sharing and interrogating practice, to current understanding of what inclusive research is?

An inclusive research design?

As I explain the approach to problem you might like to consider if this is research *on, with*, or *for* people with learning disabilities and reflect on your own approaches to researching with young people. I was certainly challenged by some participants about whether the approach could be justified because I did not have a co-researcher with learning disabilities working alongside me throughout the study, I had no steering group of people with learning disabilities, and so my design did not fit within the tight confines of inclusive research that some people have come to expect. However, I had deliberately attempted to broaden the imagination about all this and, in seeking a small grant, to do something on a lower budget than could be realistic with greater involvement of people with learning disabilities at all stages.

My stance throughout has been that the challenges in this politically sensitive area cannot be addressed without: (i) creating vibrant interactive spaces in which best use can be made of constructive friction within the field; (ii) reframing the debate such that the research process is central and with researchers engaging in transformative dialogue (Gergen 2009); and (iii) researchers working ‘not only in the task of unveiling that reality [of inclusive research], and thereby coming to know it critically, but in the task of re-creating that knowledge’ (Freire 1970: 51). I was greatly influenced by Friere and by the use of his ideas by my research student and now research fellow on this project, Hilra Vinha. Thus, the research has been designed to be dialogical - listening to and engaging with a range of researcher voices, reflective - embracing the praxis of ‘naming the world’ (Freire 1970: 69) collaboratively, and transformative – re-locating authority away from the individual researcher or researched and instead embedding it in the interactive space between them. I wanted to get away from the idea of researchers doing research on or with participants, because this was about people involved in blurring these boundaries. Freire (1970: 61) proposes that ‘through dialogue, the teacher-of-the-students and the students-of-the-teacher cease to exist’, replaced by ‘teacher-student’ and ‘student-teacher’. In an equivalent process the participants and researchers in this project were conceived as ‘researcher-participants’ and ‘participant-researchers’ (after Vinha 2010). In this way I was attempting to do what Fine (1994) refers to as working the hyphen and thereby avoid othering.

© Melanie Nind, for permission to cite contact M.A.Nind@soton.ac.uk

What this looks like in practice is a rolling series of encounters in focus groups with a stable membership of inclusive researchers who are relatively homogenous in their relationship to research:

- Focus group 1 comprises researchers with learning disabilities who lead and conduct their own emancipatory research, often using the services of academic researchers and supporters working with them in an enabling role (in fact there are two of these groups in different locations, one with more experienced researchers and closer ties with universities than the other);
- Focus group 2 are a mixed, collaborative group of researchers with and without learning disabilities who work together as co-researchers;
- Focus group 3 comprises academic researchers with experience of gathering data from or with people with learning disabilities in which the latter are variously active participants.

The design involved each of the above focus groups meeting three times in what was to be safe, non-judgmental group interviews comprising of people with a common interest but without needing to reach consensus (see Krueger & Casey 2009). Additionally:

- Focus group 4 was to comprise policy-makers and commissioners of research, meet once, and engage with the emergent data and whole agenda from their perspective.
- A final focus group was to bring everyone together to debate the key messages and the media for communicating them.

Findings

At the time of this paper we are twelve months through the fourteen month project and only the final, plenary focus group is yet to take place. The other focus groups have taken place and been recorded and transcribed. I am immersed in ongoing analysis concerning (i) the issues involved in inclusive research, (ii) the process and lived experience of conducting inclusive research, and (iii) recognising quality in inclusive research. I suggest that in this seminar we can dwell on which ever of my initial research questions interests you most – I will present something on each and leave time for us to purse some of them.

1. What does working in partnership with people with learning disabilities as researchers really mean?

There is a mass of rich data emerging on this theme. One of the codes I am using most frequently on the transcripts is ‘Ways of working together’ and within this my most used code is ‘Talking about it’. This endorses the importance of dialogue at the heart of the whole project. I am also seeing that working in partnership is dynamic, with participant-researchers describing, for example, different ways of working together before and after winning funding and at the stages of doing the research and writing about it. I am beginning to get an idea of different models of working together which at the moment I am calling: interdependency, support, consensus/negotiation, formalised, and improvisation.

The participant researchers have talked a lot about learning along the way, learning through mistakes, and learning from each other. I am learning much more about the ways in which researchers with learning disabilities and those who do research with them, or who support them, work together on data analysis. One researcher with a learning disability from Focus Group 2 explained:

> What we did with analysis was, we used to transcribe all the tapes I actually did some of that. But then we realised that people can't simply think, some people in our research group can't read so what's the use of transcript in word form when you could just listen to them as tapes. So we went through the tapes using flipcharts around the room and people would pick themes that came up. It was not one of those like right we've analysed it that's it, we kept adding to it. So we did copies of tapes for people so they could bring home and listen to it at their leisure.

2. What kinds of knowledge are attributable to inclusive research?

The analysis of the dataset is indicating that the answer to this question is much more about pluralities of knowledge rather than hierarchies of knowledge. What dominates in terms of knowledge production from inclusive research appears to be knowledge that is experiential, authentic, grounded, and embodied. It is usually knowledge about the lives of people with learning disabilities and more often of the kind that is useful for changing people's lives. It is not the case that the inclusive participant-researchers are creating the kinds of knowledge that academics can produce alone; there is a difference and this is valued by those involved and apparently, those who fund their research.

3. How can inclusive research and the outcomes of inclusive research be assessed and authenticated?

There is no real consensus emerging about the criteria for judging the quality of inclusive research. On this topic there are most clearly different voices. For many participant-researchers, the central involvement of people with learning disabilities at all stages of the researcher is a marker of its defining quality as inclusive but it is unclear whether this equates with its defining quality as good social science. According to different perspectives, to be good the research needs to be of interest to people with learning disabilities, or to be accessible, or to represent meaningful collaboration, or to involve taking risks, or to be inclusive in the moment, or to be individualised…

As a result of the different views on this topic, therefore, I argue that it is unwise to measure against a fixed picture – some reified version of inclusive research as there are different models of doing it and different qualities valued within it. Indeed, a strong theme to emerge from analysis of the focus group transcripts is that we ask a lot of inclusive research – we want it to create knowledge, to build networks, to train people in new skills, to empower, to usefully occupy, to build self-advocacy and so on. Therefore we may need to be very explicit about the primary and multiple purposes and which of these the research will be measured against – whether the assessment should be targeted or reflect a more holistic agenda. Certainly whether the research is going on inside or outside academy makes a different to whether conventional, academic quality criteria are those that matter most, and even within this there are disciplinary differences in the way rigour, for example, is constructed.

4. What are the benefits of inclusive research to people with learning disabilities and other stakeholders? Where do the problems lie?

The benefits of inclusive research have been very apparent in the dialogue to date. We can think of these as material (e.g. paid work & funding for organisations), social (e.g. networks, friendship, fun), and pertaining to impact on people's lives. The impact relates both to those doing the research and to others who may benefit from the knowledge generated or from their

© Melanie Nind, for permission to cite contact M.A.Nind@soton.ac.uk

involvement as participants in the more traditional sense. The benefits of inclusive research are often talked about as inherently connected with the campaigning, advocacy and training agendas of the organizations of the people with learning disabilities.

The problem points have been less frequently discussed but there is clearly a debate about the power dynamics and matters of who does what (e.g. initiate, lead, choose the question, make decisions, write the report, claim the credit) carry considerable significance. There has been some acknowledgement of the limitations to what inclusive research can do (despite the huge amount asked of it), and some recognition that other kinds of research may be needed to sit alongside and do different things. Again the role of the academy raises its head in discussion of problems as there are reports of falsely raised expectations of people with learning disabilities building research careers and the rules of the academy working against this.

5. How might good science and good inclusive research practice come together?

This question is about what matters to both research councils and inclusive researchers, academics and people with learning disabilities. It is about where the common ground is rather than where they might conflict or compete. The answers that are emerging centre on the potential of inclusive research to:

- Answer questions could not be answered otherwise answer, but that are important
- Get access in ways we otherwise could not and need to do, thereby generating richer data
- Use insider, cultural knowledge to bring authenticity to research
- Generate impact

6. What can be added, from sharing and interrogating practice, to current understanding of what inclusive research is?

In answer to this question the dataset tells of something about the extent to which inclusive research has become mainstreamed: the limited range of funders, the restriction of research focus to researching the lives of people with learning disabilities; the limited routes in to research. The process of sharing and interrogating the experiences of inclusive researchers, in the whole in the way this project has done, tells us something about the challenges of sustainability of inclusive research. We can see how much more can be achieved by inclusive researchers as they build experience through involvement in a variety of projects, but we also see how hard it is for them to keep going when funding is so precarious. We see the value of inclusive researchers training others, but just how ad hoc this process can be. We see the integral relationship between inclusive research and self-advocacy groups, which raises questions about what will happen in terms of producing the next generation of inclusive researchers as these groups lose funding or momentum.

We have added, furthermore, to understandings of things we have no time to discuss here: the nature of support; differences between academics and researchers with learning disabilities; power dynamics; identities; processes; outcomes; barriers; how problems are solved (or not); favoured topics, funders and methods; the importance of accessibility; the rules of ‘game’ of research; ongoing challenges; and the contribution inclusive research makes.

© Melanie Nind, for permission to cite contact M.A.Nind@soton.ac.uk

Concluding thoughts

I will not attempt to sum up as much as leave you with some thoughts that currently interest me as I immerse myself in data from this project. It may be that building capacity in the 'system' is as important as building capacity among individuals. It may be that we ask too much of inclusive research – can it really do everything we ask of it – or at least do all of those things equally well. It seems that interdependency in inclusive research is under-explored and possibly under-valued. Co-analysis is evidently possible, but participant-researchers have different relationships with theory. The knowledge generated by inclusive research tends to be experiential, grounded in people's lives. The knowledge generated by this research is grounded in people's experiences of doing research together. It goes without saying that I still need more diaologic space and more reflective space to make sense of it all and that I am greatly indebted to everyone who is taking part.

References

Fine, M. (1994) Working the hyphen: reinventing self and other in qualitative research, in N.K. Denzin & Y.S. Lincoln (eds) *Handbook of Qualitative Research* (pp.70-82). Thousand Oaks, CA: Sage.

Freire, P. (1970) *Pedagogy of the Oppressed.* New York: Continuum.

Gergen, K.L. (2009) An Invitation to Social Construction. London: Sage.

Grant, G. & Ramcharan, P. (2007) Valuing People and Research: The Learning Disability Research Initiative. Overview Report. DoH.

Holland, S., Renold, E., Ross, N. & 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*. http://eprints.ncrm.ac.uk/460/

Krueger, R.A. & Casey, M.A. (2009) *Focus Groups: A Practical Guide for Applied Research*. Thousand Oaks, CA: Sage.

Nind, M. (2011) Participatory data analysis: A step too far? *Qualitative Research*, 11(4), pp.349-63.

Vinha, M. (2010) Learners' perspectives of identity and difference: a narrative study on visual and verbal representation of self and other, PhD thesis, University of Southampton.

Walmsley, J. & Johnson, K. (2003). *Inclusive Research with People with Learning Disabilities: Past, present and futures*. London: Jessica Kingsley.

© Melanie Nind, for permission to cite contact M.A.Nind@soton.ac.uk