Research unpacked

Building an inclusive research community: the challenges and benefits

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A recently completed study illustrated what happens when research communities become inclusive of people with learning disabilities.

While there is a lot of research undertaken about people with learning disabilities, not all of it is research that learning disabled people would condone or find helpful. The Valuing People strategy (DH, 2001) helped to shift the culture around this with its emphasis on people with learning disabilities as active citizens enjoying rights, independence, choice and inclusion. This paved the way for Government investment into research concerned with things that really matter to people with learning disabilities.

By the time Valuing People was published various self-advocacy organisations were already involved in conducting research projects and the Norah Fry Research Centre at the University of Bristol, learning disability campaigning charity Values into Action and others were beginning to change the dynamic so that people with learning disabilities were being researchers and not just researched. A language emerged about research *done with* and not *on* people with learning disabilities when collaborations and partnership are involved.

The Learning Difficulties Research Team (2006), a group of people with learning disabilities and their supporters working together as equals, refer to research *done by* them rather than *done to* them. They reviewed the level of involvement of people with learning disabilities in 12 projects of the £2 million Department of Health Learning Disability Research Initiative and found that even when there is an expectation from the funders that people with learning disabilities will be involved, that involvement can be quite limited. This had echoes of Simone Aspis (2002: 4) earlier imploring; “How many times have we heard that we are working in partnership with people with learning disabilities? We need to think about what that really means.”

Regarding research

So what happens when the research community becomes inclusive of people with learning disabilities? There are new roles available to people as researchers, advisors, writers and even reviewers, editors and commissioners of research. Questions, though, emerge about how this research is regarded, how much it changes things and how sustainable the developments are.

Walmsley & Johnson (2003) argued that sometimes the debate about the challenges of inclusive research was stifled and that the difficult things simply weren’t talked about enough. Meanwhile, Grant and Ramcharan (2007) maintained that we had worked out how to do inclusive research, and that now we needed to explore what kinds of knowledge inclusive research can produce, how we know it can be trusted, and how good science and good inclusive research can come together.

Inspired by these arguments and a realisation that funding bodies may lack clear ideas about how to evaluate inclusive research, the idea for this research was born. It was a response to the need to bring people together to talk about how we do research inclusively, how we know when we do it well, and what we can learn from talking and reflecting together. A stronger future for inclusive research would be aided by better understandings of it – so we needed to research research.

Our approach

The aim of our research, which took place over 14 months spanning 2011-12, was to build capacity for inclusive research among individuals and systems. We set out to produce guidance on the issues and challenges faced by researchers with and without learning disabilities working together and separately, to develop materials and case studies to show how barriers are being broken down, and to produce criteria to help judge quality in inclusive research.

The grant for the study came from the Economic and Social Research Council to an academic institution rather than an inclusive research group. We therefore developed another model of working together, suited to research that was about the research process rather than about people's lives. The study was designed around facilitating the kind dialogue that could be transformative (Gergen, 2009).

We did not see ourselves as doing research *to* or *on* people, but rather working *with* fellow researchers in a process of co-constructing knowledge. The idea, adapted from Freire (2007), was to have 'dialogic (talking) phases' interspersed with 'reflective (thinking) phases' in small communities. We were actively involved in this as researcher-participants in dialogue with participant-researchers. We tried to avoid the tyranny of who was the real expert and instead position everyone as knowers and learners.

The research involved a series of focus groups, each lasting about two hours. We wanted the focus groups to be safe spaces to talk so we had:

- One group of participant-researchers with learning disabilities who led and conducted their own research with their supporters
- One group of participant-researchers with and without learning disabilities who worked together as co-researchers
- One group of academic participant-researchers with experience of gathering data from or with people with learning disabilities.

These groups each met three times to allow rapport to flow and ideas to flow between them. In addition there was:

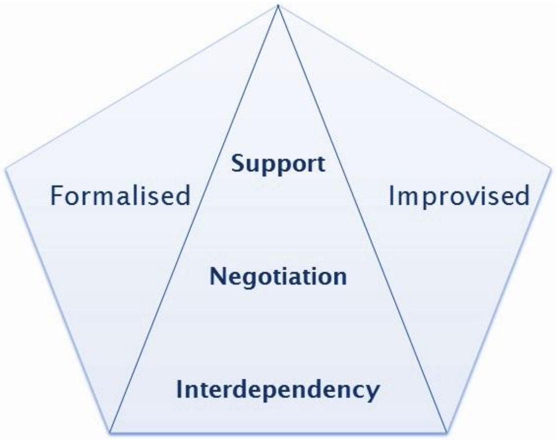
- One group of participant-researchers with learning disabilities who met twice
- One focus group of policy-makers and commissioners of research who met once to discuss the emerging ideas and add their perspective regarding what is important in inclusive research.

The meetings of the focus groups were recorded and transcribed and then analysed for key themes. In a final event everyone came together and worked in mixed focus groups to talk about the key findings and how they might be best communicated. This gave an important opportunity for the analysis to be checked and the reporting to be influenced.

What we learned – what working in research partnership really means

While some of the findings are of most interest to researchers, there is much that has wider relevance including understanding about the meaning of partnership and community in research. Despite the progress of the past decade, when people with and without learning disabilities worked together on research, issues of power dynamics and accessibility were often still live and raw.

We were able to build a model (shown below) of different ways of working together based on where the greatest emphasis lay: on support, negotiation or interdependence.



- When support is emphasised, people become categorised, in terms of decisions and actions, as *in charge* or *in support*. There may be some fluidity in roles but people in support are often insecure about their right to voice their own views
- When negotiation is emphasised, considerable effort goes into agreeing how to proceed, who has what powers and what practices are acceptable. This may lead to rule-bound practices or to the negotiation of power being as important as the research itself
- When interdependence is emphasised, there is a strong sense of teamwork and community. The high levels of trust mean that tasks can be shared or allocated to the people with the skills that fit best. Mutual respect is such that no one is regarded more expert than any other to the extent that they do not need or highly value the other.

There were participant-researchers involved whose way of doing research epitomised each of these models and there were people who moved between them depending on the project and situation.

In addition, there were ways of working that were formalised and others that were more improvised. Formalising involved steering groups, training and pre-planned processes, whereas improvising involved responding flexibly *in situ* to challenges. The model is not definitive but it can be helpful for reflecting on practices of working together.

What we learned – the hope and potential of inclusive research

Bringing together people involved in inclusive research in dialogue illustrated just how much people using, funding and doing inclusive research ask of it. We want it to:

- Create knowledge (the research goal)
- Give voice and build self-advocacy (the political goal)
- Bring funding to organisations (the pragmatic, sustainability goal)
- Provide training, skills, jobs, networks and friendships (the wider agenda).

Wanting a lot from inclusive research reflects the multiple benefits already being experienced by those involved.

Participant-researchers spoke of what they got from their involvement with research, which included new skills, networks of communities (“making lots of friends and all that”) and sense of confidence and self-esteem (“we feel valued and they learn something about us”). They spoke of finding out about things that mattered to them such as helping to show the experiences people with learning disabilities who are parents have with social workers, or the history of a place or group.

This helps to illustrate that for many people involved in inclusive research there are huge overlaps between research, (self-)advocacy, training and campaigning. People doing inclusive research, like the majority of researchers, want to make a difference: they are concerned with improving lives and changing services and practices. People funding inclusive research also want more from it than just knowledge, for them there is a social inclusion agenda too.

What we learned – is inclusive research quality research?

There are many reasons, then, why opening up the research community to become more inclusive is worthwhile. Not all of these are about the research itself, but about the other things it can do for people. The dialogue though did pursue what distinct benefits inclusive research may have over other kinds of research. Features identified include: the empathy and connection between researchers and research participants and the relevance and accessibility of the research questions and methods. These could lead, it was argued, to richer, more credible data.

We were able to establish that there is a strong case that inclusive research becomes quality research when it:

- Answers questions other research cannot answer (or answer so well) but that are important, such as questions of how people experience things or feel about them
- Accesses participants, communities and knowledge in ways that other research cannot
- Involves the reflexive use of the insider, cultural knowledge of researchers with learning disabilities (about such things as day centres, long stay institutions, and social workers)
- Is authentic, genuinely benefitting from the researchers and participants
- Has social or other impact on the lives of people with learning disabilities.

The future

So, while there has been a cultural shift supporting inclusive research those involved in it are also acutely aware that its sustainability is threatened by a lack of funding, lack of capacity in the system, and lack of support for People First groups. In addition, there are attitudinal, social and material barriers that make it challenging. Funders, publishers and universities can be inflexible in their systems and create closed communities.

But our collective process of holding a mirror up to ourselves, and engagement in dialogue, has expanded our own capacity somewhat and shown how much there is to gain from continuing to invest in, and learn about, doing research inclusively.

References

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Further information

Information about the Doing Research Inclusively, Doing Research Well? study is available at www.doingresearchinclusively.org