**Inclusive research: A site for lifelong learning for people with learning disabilities?**

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**Introduction and background**

In Europe, in the absence of other opportunities for adult learning for people with learning difficulties, self-advocacy has an important role as a site for learning (Fernandez *et al.* 2002). In the UK, increasingly self-advocates are learning not just skills in speaking up, active citizenship and self-determination (as promoted in the government white paper *Valuing People,* DH 2001); many of those in organized self-advocacy groups are also learning research skills through their involvement with research. This is not merely involvement as participants, but as co-researchers, researchers in their own right, authors, reviewers and commissioners of research. This phenomenon is also evident in Australia and parts of Europe where debates and action are growing. The adoption of these new roles by people who may otherwise be seen as subjects or even objects of research is characteristic of inclusive research (Walmsley and Johnson 2003), inclusive research being an umbrella term encompassing what is also known as participatory, emancipatory, community-based, participatory action, partnership and user-led (Nind 2014). Such research is increasingly valued by funders for its power to ask the right questions and have impact (Involve 2004; Nind & Vinha 2012). It is valued by self-advocates for its potential bringing funds to organisations and for making a difference to people’s lives, for building networks, gaining employment, and learning new skills (Nind & Vinha 2014). This conference paper summarises an exploration of this last element and the educational lifelong learning resource that inclusive research is and can be.

I have argued previously that lifelong learning for people with (profound) learning disabilities ideally needs to be ‘“owned” by the individual’, ‘meaningful to them’, enhancing ‘their feeling of self-worth and personal power’; it needs to be ‘active and interactive’ and ‘set within the context of warm and nurturing relationships and rich communications’ (Nind 2007: 111). This is in stark contrast to what Wright (2006) argues is often the limited and limiting provision in further education colleges. But is it a good description of the learning that takes place in the context of inclusive research? Biesta (2006) depicts a multi-dimensional model of lifelong learning spanning the economic, personal and democratic. The economic dimension concerns ‘acquisition of new skills and knowledge … important both for one’s own employability and financial well-being and for the well-being of the economy as a whole’ (173). The personal dimension concerns ‘developing one’s potential and talents’, ‘finding meaning in life and even living a better life. And the democratic dimension is about ‘the empowerment and emancipation of individuals so that they become able to live their lives with others in more democratic, just and inclusive ways’ (173).

People with learning disabilities have certainly made strong arguments about the importance of their involvement in research if it is to be meaningful and useful for them (e.g. Townson 2004; The Learning Disability Research Team 2006). Much has been written about their gains in confidence and self-esteem (e.g. Chapman & McNulty 2004). Huge skills and role advances have been made – echoing Mittler’s (2000) observation of the unpredictability of the pace and extent of change – recent generations would not have anticipated that people with learning disabilities could learn to analyse research data. This paper uses the dataset from the author’s recent study (on inclusive research involving people with learning disabilities) to interrogate what it can tell us about inclusive research as a site for lifelong learning.

**Methods**

The research was designed to build knowledge and capacity in inclusive research with people with learning disabilities. The objectives were to take stock of the knowledge base regarding the participation of people with learning disabilities in research about them, produce guidance on the issues and challenges, develop materials and case studies based on the identification of practices in inclusive research that are breaking down barriers, making advances and challenging orthodoxies, and to produce criteria for quality in inclusive research. The approach taken was intended to create vibrant interactive spaces in which to make best use of the constructive friction within the field and to engage researchers in transformative dialogue (Gergen 2009). The inclusive researchers’ involvement in dialogic methods meant they were invited to work ‘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). Hence, this work was educational for everyone involved in discussing what it means to do research, do it inclusively and do it well. This was achieved through a rolling series of encounters in focus groups, interspersing dialogic spaces with reflective spaces. Two focus groups comprised researchers with learning disabilities who lead/conduct their own research; one comprised researchers with and without learning disabilities who work together as co-researchers; one comprised academic researchers with experience of including people with learning disabilities using participatory methods or design. These focus group each met up to three times and discussed ideas from each other’s as well as their own group. A small focus group of funders of inclusive research met once and a plenary session brought everyone altogether to inform the final analysis. This research design was hoped to produce data not achievable through individual interviews and ‘powerful interpretive insights’ that could reveal previously ‘unarticulated norms’ (Kamberelis & Dimitriadis 2005: 903).

In the interpretation of the dataset informing this paper the agenda shifted from the methodological to the educational. Transcripts of the focus group discussions, plus fieldnotes, reflective diaries, memos to self and the materials produced throughout the process were all re-analysed to elicit themes and narratives about the learning involved in inclusive research. This was related back to the wider literature to explore inclusive learning as a site of lifelong learning.

**Findings**

The data indicate what was learned in the context of inclusive research. For the participant-researchers this encompassed:

* overlapping skills-based learning related to research (know-how) and methodological knowledge about the nature of (inclusive) research (know-what);
* the rules of the inclusive research game (what it means to be an inclusive researcher);
* interpersonal learning (often related to new roles); and
* problem-solving.

The dataset also includes narratives of learning journeys, usually enjoyable ones for the researchers with learning disabilities, but for the academic researchers and support workers, often journeys encompassing struggle.

In terms of learning research skills, learning disabled participant-researchers in particular learned much about data collection, especially conducting interviews. For example, Malcolm described the interview and his accumulation of know-how:

It's face-to-face, you know what the other person is saying. When you are interviewing you got to look in the eyes, the mouth, the lips and the eye contact as well. I've been doing it for so long now, and got to be careful on how it's been done. ... I like being an interviewer … It's quite a lot of work doing interview. They say it's very hard but it's not, when you get used to it, it's not that hard.

People learned from good experiences, such as Ian’s experience doing a national survey in partnership with a university and market research company, which was ‘probably the most successful research project we have taken on board’. But there was less positive experience of survey work too, Becca learning the lesson of poor response rate faced my many novice researchers.

In terms of data analysis, Lou, an experienced researcher from the research cooperative described learning various roles in the analytic process:

What we did with analysis was, we used to transcribe all the tapes I actually did some of that. But then we realised that … 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. … People would say things like funding, and we [would] see that as a theme.

Some of the description of the learning process for co-analysis was reconstructed through the process of dialogue between self-advocates and support workers discussing things like using different coloured pens for different themes and other visual strategies. Craig described a process of talking and ‘looking at stories’ and Becca of ‘looking at meaning’.

The participant-researchers volunteered a lot about their learning experiences related to the skill of disseminating research findings:

I ended up going to Helsinki - my first international research … conference of over 1000 researchers … that was quite a daunting experience. (Ian)

We did a report afterwards – how to make it accessible and to make people read the report – how we did the research and how we put it on the internet (Craig)

We made this video about what we do, then I uploaded to YouTube, so if someone goes to our website they can see it on YouTube (Michael)

Dance is good for that (Sharon); Drama works (Becca)

Some of this learning will have resonance for any researcher, and some is more specific to inclusive research where there are accessibility challenges.

Participant-researchers talked about *how* they learned, such as ‘I just I started asking loads and loads of questions’ (Lou), ‘working quite hard’ (Ian), learning ‘on the job’ (Rose) and through experience (Kerrie):

I learned about doing it through working with Lisa one day. We were sent off with Val, I think it was, to do a research project in York. We took up a consent form and they didn't understand it. So we thought, I don’t know if Lisa can remember that. So we thought how can we make the consent forms better? We should use pictures? We should actually bother to go around and see what form of communication people use, what method? Do they talk? Do they sign? Do they use pictures?’

There was evidence of learning that research is a kind of game with rules. Lou talked about their group having transcribed interviews ‘for the sake of it’, not because they needed this for analysis but because they felt funders expected it. They were playing the game of participation validation too, sending out transcripts to participants - who were unable to read them - because they felt they should. The learning continued into the focus group itself as another experienced researcher pointed out that the participants might, nonetheless, value having the record of the interview. The more experienced learning disabled researchers knew about how to work with their funders while some aspects of the funding world, such as why they didn’t give feedback on unfunded projects, was a mystery to some (as it is for many academics!)

Inclusive research was a site for interpersonal learning for academics and support workers as well as for the participant-researchers with learning disabilities. There was talk of having to learn new approaches and roles of researcher, co-researcher, and co-worker and also reference to ‘co-learning’. People appointed to work as supporters were pushed to learn about research as in the self-advocacy groups this was a source of funding. As expertise grew, so the learning of new roles expanded; Lou explained: ‘My skills have moved from researcher to researcher support.’ Ian explained how, in the national survey, people with learning disabilities trained professionals on handling interviews with people with learning disabilities, producing accessible information and consent forms, and also using their expertise to make an input into the report. Two of the learning disabled researchers had moved into doing some university lecturing, including ‘teaching people about how to do research’ (Kerrie). Their expertise led to one group taking on the role of managing research tenders from others and another into editing a journal special issue including doing the peer reviews.

The data include several narratives of learning journeys. Gordon (academic), for example, reflected on having ‘stumbled into more inclusive forms of research by making mistakes’. For the people with learning disabilities though, the initiation was into research and not just inclusive research. Lou recounted:

I got into to doing research [when] I was looking into the local day service closing down and what people thought of it. Back then I didn’t even know that was what we were doing, I thought research was just what the professionals did and the reports just got left and nobody ever looked at them or read them or anything like that. … Once I started learning about research I just I started asking loads and loads of questions. Why did they do that this way … Basically just asking questions. Later on my skills have developed so much that I started to move into the research support role … I think it’s just from asking questions that I got into research

Most of the steep learning curve narratives from the self-advocates were also life-affirming narratives. One group of people with learning disabilities mostly leading their own research discussed the ‘enjoyment’ (Gareth) and satisfaction they got out of doing research. Gareth explained, ‘You say to yourself, look what I did weren't I good? You say to yourself I am good at that’ (Gareth); Rose added ‘and show how you've achieved that by helping others in the group’. Several spoke of gaining ‘confidence’, Kerrie, echoed by David, spoke of her ‘sense of worth’, and Nigel of gaining ‘experience’. As well as communicating a sense of social inclusion and worth, such comments were indicative of the many levels on which inclusive research was working for them. More experienced self-advocate researchers also recognised some of the tedium and difficulty in learning to be a researcher, yet it was some of the supporting staff who presented narratives of graft. For some, inclusive research was a site of struggle as well as of enjoyment and learning.

**Discussion**

For the participant researchers, inclusive research was a site for learning in all four of Biesta’s (2006) dimensions: personal, economic and democratic. For the self-advocates this was in some ways *learning to be*, a somewhat natural extension of their self-advocacy. The sense of individual self-fulfilment is evident in the data, alongside a sense of continuous and conscious learning in adapting to new roles and challenging situations. There are echoes of Billett’s (2010) lifelong learning as a socio-personal process mediated by a new situation demanding new knowledge and skills. In the economic dimension there are echoes of *learning to be productive and employable* too (Coffield, 1999), learning to operate in a market place necessitating competing for research money. Inclusive research is a site where people with learning disabilities are needed and valued for their insider cultural knowledge or ‘expertise by experience’ of what it is to be learning disabled. The self-advocate inclusive researchers were not so much gaining power as consumers (Crowther, 2004) but as people with valued human capital. This provided an opportunity to gain paid work (in addition to enjoying the social experience of doing research). The participant-researchers were learning the rules of this game including the inherent structural inequalities also. Participants’ motivation for being inclusive researchers was a mix of intrinsic interest and concern for the survival of the self-advocacy group and the well-being of people with learning disabilities. The learning was largely self-directed, if sometimes of economic necessity. In terms of the democratic dimension people were learning new roles for a common good. Learning to be an inclusive researcher was not an individual responsibility but a group responsibility, the learning being with each other and for each other and for the long term.

**Conclusion**

Using evidence from analysis of the dialogue with a range of inclusive researchers I have argued that inclusive research can be understood as a site of lifelong learning. This holds true for the different partners involved in inclusive research collaborations, but it is particularly pertinent for the people with learning disabilities whose opportunities for such learning often emerge from, and then extend beyond, their involvement with self-advocacy organizations. Crowther (2004) argues: ‘Instead of more lifelong learning, people need to acquire a clear sense of how education can help them make sense of their world and change it for the better’. The informal learning involved in inclusive research it seems can do just that. Informal, lifelong learning happens particularly when our lives and roles change (Billet, 2010) and involvement in inclusive research has particular value for self-advocates in this respect.

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**Further details:** Further information about this project can be found at [www.doingresearchinclusively.org](http://www.doingresearchinclusively.org)A fuller version of this paper is under review, if you are interested in receiving it in due course please email M.A.Nind@soton.ac.uk

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