

Inclusion in Research?

People with intellectual disabilities and the academy

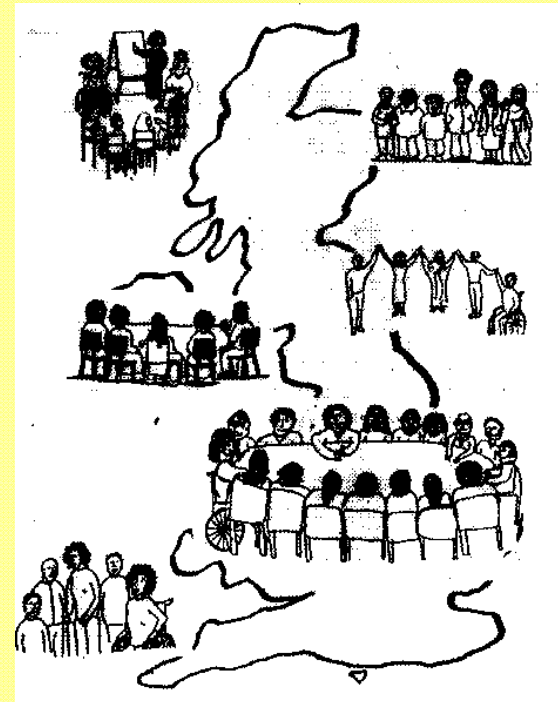


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Inclusion in research?

People with intellectual disabilities and the academy

In the United Kingdom government has a clear commitment to service user involvement in research, policy, practice and also in social work education (see Boxall et al 2007).



Inclusion in research?

People with intellectual disabilities and the academy

- The social model of disability
- Disability studies
- Standpoint epistemologies
- Applying these ideas to research with people with intellectual disabilities
- Working within the academy
- People with 'profound and multiple' intellectual disabilities

The social model of disability

- Rather than being concerned with what's 'wrong' with individual disabled people, the social model of disability (Oliver 1990; 2009) is concerned with what's 'wrong' with the environment or society;
- The social model of disability has close connections to the UK disabled people's movement – a grassroots network of organisations controlled by disabled people.

Disability Studies

- My work is situated in the UK discipline of **disability studies**, where disability is understood as barriers to full inclusion in the mainstream of society, **not** individual (perceived) deficit or difference;
- This is a sometimes contentious discipline area with disabled and non-disabled activists and academics holding strong views on the relevance and utility – *or otherwise* – of the social model (see Shakespeare 2006 and Sheldon et al 2007);
- I wanted to see if it would be possible to work with a social model understanding of intellectual disability when involving people with intellectual disabilities in research.

Standpoint epistemologies

- Collective ways of knowing or understanding the world from particular perspectives or points of view;
- Concerned particularly with issues of power;
- Based on the idea that less powerful people have access to both their own understanding of their situation as well as dominant group understandings of the situation of 'people like them';
- And that less powerful groups' understandings provide a better starting point for research than dominant group understandings (see Harding 2004).

- Standpoint epistemologists appear to reject postmodernism 'on the grounds that it obviates the possibility of the systemic knowledge that is necessary for social change' (Hekman 1997, p350);
- Patricia Hill Collins (1997) for example argues for knowledge produced on the basis of 'shared group-based experiences.'

Feminist standpoints

Feminist standpoint theorists argue that the academy's disciplines often support the agendas of public institutions.

Standpoint researchers on the other hand try to:

'... avoid taking their research problems, concepts, hypotheses, and background assumptions from the conceptual frameworks of the disciplines or of the social institutions that they serve (the legal, welfare, health, education, economic, military and other institutions)' (Harding 2004, p6).

And instead 'study up'- that is:

'... start off thought from women's experiences, lives and activities (or labor)' (Harding 2004, p6).

- I also wanted to ‘study up’ **from the lives and experiences of people with intellectual disabilities**
- But how could I do this from within an academy which asserts their inferiority?
- I also had my own standpoint – *commitment to the social model of disability* – which provided a starting point for my research.
- How could I avoid imposing **my** standpoint on the people with intellectual disabilities with whom I worked?

Research

My PhD involved three projects to explore these ideas in practice; I have continued to work on a range of projects in this area.

- PROJECT A – *Parents with Learning Difficulties*
- PROJECT C – *Writing Together*

PROJECT A

- Worked with a couple with intellectual disabilities – ‘Shaun’ and ‘Michaela’ – to document from their ‘point of view’ the experience of having their two children removed by Social Services;
- I had previously been their advocate and had ‘translated’ and shared with them research findings about parents with intellectual disabilities (Booth and Booth 1994) ;
- During the time we were working on Project A together, Shaun and Michaela found out they were expecting another baby.

Social Services don't know yet that we're expecting this baby.
[...]

We'll have to go to court in the end. People like us always have to go to court when they have a baby. You know that, I know that. Wendy Booth's book says that.
[...]

A newborn baby's very vulnerable isn't it? It can easily be sucked out of your hands by Social Services, even if you're not doing anything wrong. *Even if we're looking after it properly, they can still do that can't they?*

[Shaun in Boxall et al 2002)

Key learning from PROJECT A

- Shaun and Michaela already had an understanding of their experience which fitted with social model ideas, though they didn't use this language – lottery example;
- I needed to think more about standpoints as shared **group based** experiences (Collins 1997)
- My presumption/conviction of people with intellectual disabilities' incompetence;
- The illusion of joint authorship (some of our work was published as Boxall et al 2002);
- Shaun and Michaela's own words **were inherently accessible to them** – they had little interest in my words

PROJECT C – *Writing Together*

- Built on my learning from Project A about Shaun and Michaela's own words being inherently accessible to them;
- I worked with a group of seven people with intellectual disabilities to write, in their own words, a journal article for publication in a peer reviewed academic journal;
- Supported by two research assistants.

Peer review

'Peer review is when people double check an article to see if it's good enough. We don't think university people should double check this article. No disrespect to university people, but they don't know what it's like to be learning disabled, they don't have the knowledge. If you get university people double checking this article, they won't be able to say if it's good enough or if it's not good enough. We think our article should be double checked by another group of learning disabled people. And they would get the opportunity to know what we are doing too. The more learning disabled people who get involved in this article the better' (Docherty et al *forthcoming 2010*).

Two parts?

The university researchers were going to write a separate part of the article.

We had a meeting with the learning disabled researchers to talk through the university researchers' part. I had written:

'Anne Louise Chappell (1998) argues that learning disabled people are marginalised within the social model of disability and their perspectives and experiences are missing from discussion.'

The learning disabled researchers were very unhappy about there being two parts to the article

They were also unhappy about social model literature being inaccessible to them.

Our discussion, like all of our meetings, was taped.

I later transcribed what had been said by the learning disabled researchers and this section of the article now reads:

Anne Louise Chappell (1998) says that learning disabled people are left out of the social model of disability. The social model of disability is in writing so that professionals can look at it. It's not accessible to learning disabled people. We might want to study the social model ourselves but we can't because it isn't accessible. It should be in pictures and large print.

Discussion about the two parts is also included within the article:

Them and Us?

This article has been written by all of us. Some of us know what it is like to be learning disabled; others are university researchers who don't know what it is like. [...]

We talked about whether we would have two parts to our article; one part for the learning disabled writers and a 'professional side' for the university researchers. In the end we decided that if we did two separate sections we wouldn't learn from each other; it would be like 'them' and 'us'. It's better all in one together with everybody helping and learning from each other, so the two groups have worked in partnership writing this article together. But really there haven't been two groups because all of us are researchers and we have supported each other in writing the article. The university researchers, who don't know what it is like to be learning disabled, have supported the learning disabled researchers to write the article and they have learnt from the knowledge of the learning disabled researchers (Docherty et al *forthcoming 2010*).

Reviewer 1

Thank you for asking me to review this paper. I think this is an important paper that challenges 'academic publishing' in a number of important ways. It certainly questions the established ways that we do peer reviews. The authors argue that their paper should be reviewed by another group of learning disabled people rather than university people. In a way I agree with the authors and hope that the paper will also be reviewed by a group of learning disabled people. But I am a 'university person' so how can I review the paper?

I think my job as a reviewer must be different from the usual reviewer's job. I think my job must be to say whether I think this paper should or should not be published as it stands. This can only be a personal judgement based on what the paper says and what I know about publishing papers.

My answer is yes – The paper should be published as it stands. [...]

Reviewer 2

- This is a wonderful paper. Publish it.

Reviewer 3

(transcribed from handwritten notes)

[...] I think researchers should understand people with learning disabilities.

Yes this is a good way of showing. Big print with pictures, accessible for people with learning disabilities and it is a lot easier for people to follow this.

I think that is something said very good. Yes that is wonderful thing to say, to learn from others.

The researchers should know that people are learning disabled. The knowledge of people with learning disability and how they think. What is going on in the brain and being supported. Why are disabled researchers writing this article and being independence and disciplined as well. [...]

Key learning from PROJECT C

- The learning disabled researchers had an implicit understanding of the social model and readily applied this to their own lives.
- An inclusive social model would not only need to take account of the experiences of people with intellectual disabilities, but would also need to be accessible to them.
- It was possible to support people with intellectual disabilities to write a full length paper from their point of view and to get positive reviews - but the journal didn't publish it!!
- Became a chapter in a book published by an obscure publisher - about to be re-published by Routledge in a major disability reader (Docherty et al *forthcoming* 2010)

Working within the academy

- With notable exceptions, I've found the academy surprisingly accepting of my work and the work of the people with intellectual disabilities I've supported
- We've received funding for several projects and have been invited to present at the Economic and Social Research Council's Research Methods Festival at the University of Oxford
- Recently, I've found it more difficult to obtain funding – several recent funding reviews have suggested that this kind of work is 'not scientific' or is 'partisan' and shouldn't be funded
- I now work as a Lecturer in Social Work and am increasingly being pulled towards the agendas of academic and professional social work – more difficult to remain focussed on the standpoints of people with intellectual disabilities

Supporting intellectually disabled researchers from within the academy

Dick Pels is critical of standpoint epistemologies, arguing that 'it is not so much the contradictory or marginal location of women as such, but precisely that of the female feminist *thinker* that is deemed to offer epistemological advantages' (Pels 2004, pp280-1).

Other authors (Atkinson et al 2000, Walmsley and Johnson 2003) argue for a similar role in relation to the work of people with intellectual disabilities

But Simone Aspis (2000a & b) who describes herself as an experienced researcher 'labelled as having learning difficulties' is unhappy about her work being introduced by academic researchers

A role for academic researchers?

- My view is that there is a 'spokesperson' or 'thinker' role (Pels 2004) for 'university researchers' who support the development of people with intellectual disabilities' knowledges from within the academy and that standpoint epistemologies offer a very helpful way of thinking about our role.
- Like the early social model writers (eg Barnes 1992) standpoint theorists argue that it is not necessary have *lived experience* of oppression in order to achieve a standpoint (Pels 2004).
- The standpoint of an oppressed group may be achieved through a process of consciousness raising and self-education, supporting and working alongside people with intellectual disabilities in their everyday struggles in a disablist world.

People with 'profound and multiple' intellectual disabilities

- These ideas can also be applied to people with 'profound and multiple' intellectual disabilities
- Standpoint epistemologies and the social model challenge researchers to:
 - Spend more time *alongside* people with profound intellectual disabilities learning more about their everyday lives (Barnes 1992; Harding 2004)
 - Find new ways of doing research which do not locate problems in the individuals but rather in the environments and communities in which they live **and also in the researchers' methods and data collection instruments**

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