

Involving people with profound and multiple learning difficulties in research: barriers and possibilities

Kathy Boxall

kathy.boxall@sheffield.ac.uk

Disability Studies Conference, University of Lancaster, September 2010

ABSTRACT: Involving people with profound and multiple learning difficulties in research: barriers and possibilities

People with 'profound and multiple learning difficulties' (PMLD) have profound intellectual impairments and communication difficulties; they may also have physical or sensory impairments, mental health difficulties, or behaviours which challenge. Although a number of recent studies have involved people with mild and moderate learning difficulties in research, few studies have sought to involve people with profound and multiple learning difficulties, either as co-researchers or as respondents; this reflects a wider pattern of social exclusion in the lives of people with PMLD.

In qualitative research more generally, a range of innovative multi-media approaches have been developed to engage participants in research, explore data and present findings. These methods provide ways of involving research participants, which are potentially more accessible to people with PMLD than traditional talk- or text-based approaches. However, recent developments in research governance and ethical review in the UK, coupled with the increased complexity of ethical approval processes for people deemed to 'lack capacity' to consent, may be discouraging researchers from working in this area. Mental Capacity Act (MCA) guidance for social science researchers published on the Department of Health website acknowledges that this could be 'an unintended and unwelcome consequence of the MCA'. The same guidance also suggests that responses submitted on behalf of people 'without capacity' should be 'excluded' from any general surveys which do not have MCA approval.

This paper will explore attitudinal, practical and ethical barriers to the involvement of people with PMLD in research, and ways of overcoming such barriers. It will suggest that social model analysis offers useful pointers for the development of inclusive methodological approaches. Such approaches however raise questions about the nature of people with PMLD's participation or involvement in research and the validity of their responses. The paper will conclude by arguing that unless disability studies researchers strive to develop inclusive methodologies, the perspectives of people with PMLD will continue to be 'missing', since the pathologising methodologies of dominant individual/medical model approaches serve frequently to undermine even the possibility of such perspectives.

Involving people with profound and multiple learning difficulties in research: barriers and possibilities

- Terminology and definitions
- Existing research
- Social model understandings
- Barriers to inclusion in research
- Possibilities
 - Housing Preferences project
 - Photo Album project
- Conclusion

Terminology and definitions

- **‘Learning difficulties’** or **‘learning disabilities’**?
- International terminology moving towards **‘intellectual disabilities’**
- People with:
 - profound and multiple learning difficulties (PMLD); or
 - profound intellectual and multiple disabilities (PIMD); or
 - disabled people?
- Recent Department of Health publication uses the term **‘profound intellectual and multiple disabilities’** (Mansell 2010)

Why categorise and classify people?

- Social model doesn't distinguish between types of impairment;
- **BUT**, the needs of people with PMLD are seen as distinctive and marginalised;
- In order to raise the profile of this group, some sort of definition is required;
- But it is likely that any definition will be based on individual 'deficit'.

Jim Mansell (2010) offers the following definition:

‘People with profound intellectual and multiple disabilities are among the most disabled individuals in our community. They have a profound intellectual disability, which means that their intelligence quotient is estimated to be under 20 and therefore that they have severely limited understanding.

In addition, they have multiple disabilities, which may include impairments of vision, hearing and movement as well as other problems like epilepsy and autism. Most people in this group are unable to walk unaided and many people have complex health needs requiring extensive help.

People with profound intellectual and multiple disabilities have great difficulty communicating; they typically have very limited understanding and express themselves through non-verbal means, or at most through using a few words or symbols. They often show limited evidence of intention. Some people have, in addition, problems of challenging behaviour such as self-injury. ‘

See also videos at bottom of this webpage:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

Existing research

- Few studies have sought to elicit the perspectives of people with *profound and multiple* learning difficulties (PMLD);
- Melanie Nind's (2008, p16) methodological review of qualitative research concludes that research with people with PMLD is 'challenging, but achievable'.
- The Hearing from the Seldom Heard project (BILD 2009), explored ways of hearing the concerns and complaints of people with PMLD, though the project did not have a research focus.

Does the social model extend to people with profound and multiple learning difficulties?

- Dan Goodley calls for a view of (all) 'learning difficulties *impairment*' as socially and culturally produced. The alternative, he argues, is that:

... some elements of humanity are open to sociological investigation ('mild learning difficulties'), while some are left in the realms of static, irreversible, individualised biology ('severe learning difficulties') (Goodley 2001, p213).

- But whether or not people with profound and multiple learning difficulties' impairment is static, their experience of *disability* (socially imposed restriction) is not.
- The social model of disability diverts attention from away from individual impairment (*whether biologically based or not*) and focuses attention on barriers to inclusion in the mainstream. It can also be helpful in focusing attention on *barriers to inclusion in research*.

Barriers to inclusion in research

- People with profound and multiple learning difficulties are some of the most devalued people in our society and are still largely hidden in institutional settings (or in their own homes);
- Research funders and ethics committees lack understanding of the needs and experiences of this group;
- Ethics procedures present real (and imagined barriers) to people with PMLD's inclusion in research;
- Research with people with profound and multiple learning difficulties is likely to be very time-consuming, which leaves less time for the other demands of the academy (Research Excellence Framework etc);
- The research is also likely to be challenging methodologically in that it needs to adopt innovative creative approaches to including people with PMLD;
- If you do succeed in doing the research and write it up for publication, it may be difficult to get your message across to journal reviewers who may have never met someone with PMLD.

Ethical approval – a key barrier?

- Ethics procedures are designed to protect vulnerable research participants from harm. But in the UK, ethical approval processes required for people deemed to ‘lack capacity’ to consent to research appear to be discouraging researchers from working in this area.
- Mental Capacity Act (MCA) guidance (DH 2009, p8) acknowledges that this could be ‘a unintended and unwelcome consequence of the MCA’.
- Projects which propose the use of creative innovative methodologies with people who ‘lack capacity’ to consent to research seem to present particular challenges for ethics committees (Boxall and Ralph 2009).
- There is therefore a real risk that the perspectives of people with PMLD will continue to be missing from research.

Possibilities

- Housing Preferences project
- Photo Album project

Both of these projects were undertaken **before** recent changes to ethical review arrangements for social care research in the UK.

Housing Preferences project

- Explored the housing preferences of people with profound and multiple learning difficulties living in a hostel earmarked for closure.
- Despite my efforts to avoid a 'deficit-based approach', I found I remained focused on residents' 'shortcomings': their 'lack of communication skills' or 'lack of comprehension', their 'inability' to express a preference, or their 'behaviour problems'.
- I needed to refocus the 'problem' so that it was no longer located in the 'functional limitation' of individual residents with profound and multiple learning difficulties.

- In an attempt to reflect the social model of disability, I located the problems I experienced in ascertaining residents' housing preferences *in my data collection instrument*, rather than in the 'functional limitation' of individual residents.
- In conjunction with hostel staff and those residents who could speak for themselves, I designed a modified questionnaire – or '**form**'

The 'form'

The 'form' asked who the resident wanted to share with and, more importantly who they didn't want to share with:

If you want to share, are there any people you don't want to share with? If you know their names, please write them down.

Has the individual her/himself indicated clearly that s/he does not want to share with these people? YES / NO

If YES, how did they indicate this?

If NO, please state reasoning behind your identifying these people on behalf of the individual – what aspects of the individual's behaviour lead you to believe that these are the people they would choose not to share with?

'Speaking for' the residents

Where residents could not answer for themselves, I was always present when the form was being completed and I asked (repeatedly)

'Is that what you think, or is it what you think Fred would want?'

'How do you know that's what Fred would want?'

‘Fred wouldn’t want to share with Brian, because they don’t get on.’

‘Is that what **you think, or is it what you think **Fred** would want?’**

‘Well, Fred likes winding-up Brian, so I *suppose* he’d say he wants to share with him.’

Photo Album project

- The Photo Album project used photographic methods and challenged researchers and hostel staff to consider the 'point-of-view' of each of the individuals with profound and multiple learning disabilities living in a hostel.
- An unanticipated consequence of the project was staff interest in, and respect for, residents' capacity to engage with the research – and indeed their growing awareness of some residents' capacity for engagement and communication more generally.

Martha

Martha had lived at the hostel for many years. She was someone whose behaviour was viewed as 'challenging.'

Very occasionally, she would say one or two words but even the staff who knew her well did not find it easy to communicate with Martha.

It was difficult to engage Martha's interest in anything that was going on in the hostel and she rarely interacted with other residents and hostel staff.

Martha and the Photo Album project

- Martha was fascinated by the images on the researchers' laptop and appeared quickly to understand that there was a relationship between the camera and the images that appeared on the screen.
- Although we had been led to believe that Martha had a 'short attention span', she spent long periods of time with the researchers, engaging with the images generated during the project.
- Hostel staff expressed surprise at how Martha responded to the project, in particular the way in which the computer and images held her attention.

Manager

I was amazed at how Martha responded to [the project]. It's given her a chance to say what's important and what isn't important. Not just taking the photos, but using the photographs afterwards. [...]

Staff 1

One day she kept picking up the photo of her radio. I said do you want the radio turning on and it was like, 'No!' But when she pointed, she kept pointing to the photograph and pointing to her dressing table.

It took me a while to realise that she was actually saying: *'On the photograph of the radio there's a little [model] bus in the corner and the bus lives next to the radio and it's not there now!'*

So eventually I got the message – her bus was missing and then I could try and work out where it was.

[...]

Staff 2 I think there's still some further explanation needed here because what I'm not clear of exactly is what she sees in the photographs.

Staff 1 Like I saw the radio and she saw the bus?

Staff 2 Yeah, it may not be what you think is obvious. How we get to engage with that I don't know.

One of the staff summed up the importance of the project for Martha and the other residents:

Staff 2 I think anything that engages people and stimulates interest has got to be a good thing and this certainly has done that, and it's a key into some people where you wouldn't necessarily have a way in.

The engagement of the *staff* in the research and their renewed interest in Martha and the other residents' communication was also evident in the post-project interview.

Conclusion

- People with profound and multiple learning difficulties are among the most socially excluded people in our society. They are often placed in institutionalised settings with staff who have received little or no guidance on how to include people with PMLD in everyday life.
- People with PMLD are also frequently excluded from social research; research ethics procedures in the UK appear to be reinforcing such exclusion on the basis of perceived individual 'deficit'.
- Disability studies researchers have a responsibility to challenge the exclusive structures and methods of the academy and to develop creative, innovative approaches to including people with PMLD in research.
- In addition to uncovering the perspectives and experiences of people with PMLD, which have largely been missing, such approaches may also serve to engage staff working with people with PMLD and enable them to develop different (less deficit-based) understandings of the people with whom they work.

References

- BILD (2009) *Information and Resources to Support Complaints from People with Learning Disabilities and Complex Communication Needs*, Kidderminster, British Institute of Learning Disabilities, http://www.bild.org.uk/humanrights_seldomheard.htm
- Boxall, K. and Ralph, S. (2009) Research ethics and the use of visual images in research with people with intellectual disabilities, *Journal of Intellectual and Developmental Disability*, Volume 34, Issue 1, pp45-54.
- Boxall, K and Ralph, S. (2010 *Online Early View*) Research ethics committees and the benefits of involving people with profound and multiple learning disabilities in research, *British Journal of Learning Disabilities*.
- DH (2009) *Mental Capacity Act Factsheet for Social Scientists*, London, Department of Health, http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_106006.pdf
- Mansell, J. (2010) *Raising our sights: services for adults with profound intellectual and multiple disabilities*, London, Dept of Health - link to report and videos: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346
- Nind M. (2008) *Conducting Qualitative Research with People with Learning, Communication and Other Disabilities: Methodological Challenges.*, Southampton,, University of Southampton, National Centre for Research Methods, <http://eprints.ncrm.ac.uk/491/1/MethodsReviewPaperNCRM-012.pdf>