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Methodological challenges and developments in qualitative research with people with learning, communication and other disabilities

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Background

Interest in research methods in inclusive education has increased with the paradigm shifts whereby childhood (James et al 1998) and disability (Oliver 1996) have been reconceptualised such that all children and young people are viewed as potentially active contributors to research. Together with greater concern regarding research governance and increased scrutiny of ethics protocols, a context has evolved in which new and diverse research approaches for with people with learning, communication and other disabilities are being chosen and better understood. This includes not just qualitative research, 'grounded' in the views and experience of respondents, but participatory or emancipatory research involving participants in 'cooperative experiential inquiry' or as co-researchers (Kiernan 1999) with the research conducted in their interests or under their control (Zarb 1992).

Research Questions

This methodological paper reviews the literature and identifies the issues that arise in conducting qualitative research with people with learning difficulties or who experience challenges in communicating, understanding and taking part in qualitative research. It provides echoes of the research by Tuffrey-Wijne et al. 2008) in its premise that 'The question ... is not if we should include people with learning difficulties in research, but how (p.186). It engages with Townson et al.'s (2004, p.73) warning of the danger of 'being partly included, *which also means partly rejected*, by someone else' (original italics). The review was commissioned by ESRC's National Centre for Research Methods and completed in 2009.

Methods

Literature was identified through systematic searching (using search terms to identify learning/communication difficulties; qualitative/ participatory/ emancipatory research; or specific techniques e.g. interview/focus group) in conjunction with hand-searching particular journals. The process was, by design, not as transparent, replicable or comprehensive as in systematic review, but it informed a substantial synthesis of over 100 publications. Literature on people with learning difficulties dominated whereas there was less qualitative research available with people with higher support needs (Gilbert 2004). Each research stage was considered. Regarding research design, the literature highlights the interaction of the practical and philosophical thinking which comprise methodological decision-making, such as whether the research is on or with people with learning/communication difficulties. Regarding writing ethics protocols, issues arise as to the extent to which people with learning difficulties need protecting and who is best placed to do this, particularly in light of earlier views of this group as incapable of discussing and understanding research ethics. Developments in the research relationship and approaches to gaining informed consent are discussed. Literature on data collection is particularly rich and addresses gaining access as well as particular, supportive techniques in interview, focus groups, survey, visual methods, life story and ethnography. Limited developments in data analysis are contrasted with the new ground in accessible reporting of research. Methodological challenges in common with researching other groups (including other so-called vulnerable groups or hard-to-reach groups) as well as those unique to this disabled group are addressed.

Frame

The analytical premises of the review, influenced by Thomas' (2004) social relational model of disability and Shakespeare's (2006) critical realist perspective are that: (i) difficulties experienced by people with different disabilities will be subtly different, but that people with particular impairments are not homogeneous; that impairment has effects but does not define the individual or their experience ; (ii) the challenges faced by qualitative researchers doing research with this group, like the challenges faced by the disabled individuals themselves, are as much as a product of the interactions between them and the wider context as of any inherent impairment; (iii) people with learning/communication difficulties have something to say that is worth hearing and experiences that are worth understanding, making it important to commit serious attention to the methodological challenges involved in researching them.

Research findings

Recurrent themes from the literature include: *techniques for communicating abstract ideas* to participants, *enabling participants to express their views* and tell of their experiences, ways of *acting responsibly* and ways of *acting inclusively*. The review indicates what can be achieved methodologically and the challenges, such as participatory data analysis, that remain relatively under-explored in a rapidly developing field. It shows how the practical, political and ethical challenges and sensitivities are interwoven with each other and across all stages of the research process. The paper draws particular attention to the relevance of core issues for educational research and inclusion.

References

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