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Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges

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Abstract

This methodological paper reviews the research literature and discusses the issues that arise in conducting qualitative research with people for whom traditional methods of qualitative research might present challenges for researchers. The focus is on children and adults with learning difficulties, communication difficulties or other disabilities such as autism with associated complex challenges in communicating, understanding and taking part in qualitative research. The paper's structure follows the stages of conducting research and includes design, ethics, data collection, analysis and reporting. Both methodological challenges in common with researching other groups (including other so-called vulnerable groups, minority groups and hard to reach groups as well as mainstream participants) and those unique to research with this disabled group are addressed, culminating in guidance for researchers on methods, approaches and key issues. Recurrent themes 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 illuminates some of developments in what can be achieved in research with people with learning and communication difficulties and some of limitations in what has been managed to date. The review was commissioned by NCRM in 2008.

1. Introduction

This paper draws on a considerable quantity of literature identified both through systematic searching (using search terms to identify learning/communication difficulties, qualitative/participatory/emancipatory research, or specific techniques such as interview/focus group/narrative) in conjunction with hand-searching particular journals. *British Journal of Learning Disabilities* and *Disability and Society* proved key sources for both methodological papers and reports of studies that had addressed methodological challenges in interesting ways. In this way the review incorporates not just discursive literature about methodology but substantive literature describing the use of various methods. It does not have the transparency, replicability and claim to comprehensiveness of a systematic review; instead the emphasis is on providing an informed synthesis of the literature for practical purposes.

In terms of scope the review is limited to papers published in the English language with the majority being published in the UK. The history of qualitative research with people with learning/communication difficulties is relatively short and some of the early, seminal literature is included alongside very recent papers. The bulk of the literature concerns people with learning difficulties (many of whom also have communication difficulties). This reflects in part, where most of the material can be found, in part my own expertise, and in part a working premise that the specific nature of the impairment is often not of central importance. Like Gilbert (2004), I was able to find less literature on research with people with higher support needs. Indeed, the literature rarely addresses researching people with profound and multiple learning difficulties as qualitative research with this group is particularly rare and difficult. With regard to terminology, *learning difficulties* and *learning disabilities* are both used to reflect the choice of term used by various authors. This is likely to reflect subtle contextual nuances (e.g. difficulties is used more in education and disabilities more in health) or authors' preferences, but it does not distinguish differences in the participants themselves.

The review is based on some basic premises:

- the difficulties experienced by people with learning difficulties, communication difficulties, autistic spectrum disorders etc will be subtly different, but none of these groups are homogeneous and the impairment does not define the individual and their experience;

- 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;

- 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.

The review is primarily about providing a synthesis of the issues, the challenges and the ways these have been addressed. The goal is to take stock and to gather together methodological guidance to inform the continued development of qualitative research methods. This process begins with the values underpinning qualitative research with people with learning difficulties and how these determine how we think about our fundamental research approach.

2. Research Design: research for, with or on?

Kiernan (1999, p.43) very helpfully captures the political nature of qualitative research with people with learning difficulties:

> The goal of qualitative research is quite explicitly to 'ground' studies in the experience and views of respondents. Nonetheless, even in qualitative studies, it is the researcher (or, in externally funded research, the funding body) who determines the overall research questions, and the researcher who gathers, analyses and interprets the data and draws conclusions.

Thus, it is evident that while seeking to value the experiences of people with learning difficulties, traditional qualitative research is likely to encompass substantial barriers between the powerful researcher and the less powerful researched. While particular methods might be adopted to address these barriers, their existence has been challenged more fundamentally. This challenge, Kiernan argues, originally came from a 'new paradigm' of research originating

from sociology in early 1970s maintaining that research should be 'cooperative experiential inquiry' with research 'subjects' becoming co-researchers.

The challenge regarding who should own and direct research with disabled people is also echoed in the interface of disability politics and disability studies. Swain, Heyman & Gillman (1998) argue that research is essentially political; it has the potential to exploit vulnerable groups and further their disempowerment and oppression. For many disability theorists, including Barnes (1996), the researcher is either on the side of disabled people or one of the oppressors. Qualitative research can access the perspectives and experiences of oppressed groups lacking the power to make their voices heard through traditional academic discourse (the 'excluded voice thesis' (Booth, 1996)). How much voice is given and how this is done, may however still be in the gift of the academic researcher, whereas self-advocates such as Aspis (2000) and Townson *et al.* (2004) argue for a greater say in research done about them. This might take the form of working together in participatory research (as argued for by Cocks and Cockram (1995) and Chappell (2000)) or emancipatory research, which is under the control of disabled people and in their interests (as called for by Zarb (1992) and Oliver (1992)). Walmsley (2004) subsumes participatory and emancipatory research under the label of inclusive research and Kiernan (1999, p.45) maintains that 'the differences between participatory and emancipatory paradigms may be more a matter of emphasis than kind'.

The focus of this review is methodological – how can qualitative researchers conduct research with people with learning/communication difficulties – but the big philosophical or political questions have practical and methodological ramifications and so need addressing at the outset. One of the first methodological decisions to be made, for example, might be whether the research is *on* or *with* people with learning/communication difficulties. Kiernan (1999) argued in relation to people with learning disability, that participatory research was more practicable, en route towards emancipatory research. But researchers need to be aware of the limitations of partially giving voice. Townson *et al.* (2004, p.73) write of 'being partly included, *which also means partly rejected*, by someone else' (original italics). They, among other researchers with learning difficulties, have expanded our understanding of what can be achieved in research terms from just involving people with learning difficulties in academic studies to studies in which people with learning difficulties take the lead. Such possibilities are less realisable for people with more profound difficulties, who lack the intellectual skills to be in control at every, or any, stage of the research process, or for people with autism, who may lack the required communication and social skills and flexibility of thought, making active participation rare (Beresford *et al.*, 2004).

In this complex arena of inclusive or emancipatory research it can be extremely useful to begin with some of Barton's (1999) key questions: Who is this work for? What right do we have to undertake it? What responsibilities come with it? Tuffrey-Wijne, Bernal & Hollins' (2008) inclusive research with people with learning difficulties about their cancer illustrates this well. Their initial premise is 'We need to know how the illness is experienced, what helps, what hinders, how we can best support people'. This leads them to the position that, 'The question, therefore, is not *if* we should include people with learning difficulties in research, but *how* (p.186). In pursing their work on 'how' they found that people with learning difficulties could contribute to knowledge through participation in research, 'even when that involves very frightening topics like cancer, death and dying'. Moreover, they found that people with learning difficulties wanted to be involved because being listened to helped them and could help others.

3. Developing ethics protocols

In the early stages of conducting qualitative research, alongside fundamental design questions comes development of the ethics protocols. The political tensions discussed above are very pertinent to this and add extra weight to the usual tension in working ethically, that is, the 'need to protect vulnerable participant groups, while ensuring that demands placed on researchers are not so restrictive as to preclude valuable research' (Iacono & Murray, 2003, p.49). One key issue is the extent to which people with learning difficulties need protecting and who is best placed to do this. Does being more involved throughout the research make people with learning difficulties less vulnerable to harm from that research? They are certainly more likely to gain benefit from research chosen by people at the grass roots (such as closure of day centres) that they are passionate about, where participation will be high and their interests at the forefront (Abell *et al.*, 2007). Indeed Tuffrey-Wijne *et al.* (2008) argue that it

would be 'unethical to exclude people with more severe learning disabilities from studies that could provide insight into their experiences and help to shape sensitive care in the future' (p.188).

Traditionally, of course, people with learning difficulties have not been viewed as capable of discussing and understanding research ethics, leaving this part of the process safely in the hands of the academic 'expert'. With more examples of inclusive research in the public domain, however, we can see how people with learning difficulties have been engaging with ethics. For example, Abell *et al.* (2007) recount how the Burton Street Group of researchers used examples of real experiments to talk about ethics, choosing old examples with real, obvious ethical dilemmas to make the concepts accessible to the group.

3.1 The research relationship

A primary feature of ethics protocols in qualitative research is the quality of the relationship between researcher and participants. The terms of engagement (Walmsley, 2004) need to be negotiated between everyone involved and protocols need to focus on how rapport is established and boundaries maintained. Research with so-called vulnerable groups makes examination of this dimension paramount; rapport-building requires particular skill and needs to be monitored (Cameron & Murphy, 2007). People with learning difficulties lack social networks and these are made up more of professionals than friends (Pockney, 2006). Researchers going into people's homes to conduct research, Stalker (1998) argues, need to be particularly sensitive to this; researchers going into people's homes as self-invited guests could be perceived as being intrusive but are actually more likely to be misconstrued as being their friends.

Entering into a research relationship can potentially extend a person's social network and researchers need to consider what this means and feels like from the perspective of research participants with learning difficulties. Researchers can add to 'the succession of different faces drifting in and out of people's lives' not under their control (Stalker, 1998, p.10). In longer term studies researchers really can become like a friend and it can be hard to bring research relationships to an end as Atkinson (1993) found in her life history work with older people with learning disabilities and Swain *et al.* (1998) found in their ongoing interview study. Munford *et al.* (2008) use a 'bag of tools' to help with their research relationships. This bag, unpacked as part of the scene-setting routine in the field, includes physical objects or props that act as reminders that 'as we build rapport and develop relationships we are there as researchers' (p.337). The 'bag of tools' also refers to orientations to their work, such as joining in with household tasks as they talk to build some reciprocity into the research relationship, and to ongoing reflection on the quality of the relationships, the research process and the balance between researchers' and participants' evolving agendas.

3.2 Informed consent

Central to any ethics protocol and the start of any project is the need for informed consent. The policy context surrounding this has changed in recent years with the emphasis shifting from research being regarded as for the benefit of society with a corresponding obligation on individuals to participate, in favour of individuals' rights and their protection by regulation and legislation (Scott, Wishart & Bowyer, 2006). Thus getting informed consent to participate in research has become a legal requirement as well as a moral obligation. Scott *et al.* (2006) outline the three key issues in this: the person's competence to give consent, the extent to which the research is in the person's own best interests, and the balance with public interest.

With regard to competence to give consent, historically people with learning difficulties have been considered unable to make decisions for themselves. Attitudes to this have changed however, reflected in the legal changes marked in the Mental Capacity Act. In legal terms, a child is 'Gillick-competent' (referring back to the landmark Gillick case) not when a certain age is reached but when he or she 'achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed' and has 'sufficient discretion to enable him or her to make a wise choice in his or her own interests' (Morrow & Richards, 1996, p.96, cited by Scott *et al.*, 2006, p.277). This refers to capacity to make a decision and understand consequences of that decision and it is just one of the three major components of informed consent outlined by Curran & Hollins (1994, cited by Dunn *et al.*, 2006). In addition to capacity for decision-making the person must also possess sufficient information relevant to the decision to be made and be able to make the decision voluntarily and free from coercion,

but in research with people with communication difficulties and particularly learning difficulties and autism it is the capacity element that is often the focus for most attention.

Capacity to give informed consent may be impaired by cognitive difficulties, that is, with memory and problem-solving, and by difficulties in expressing views (Murphy & Clare, 1995, cited by Dunn *et al.*, 2006). Thus, some researchers seek to measure participants' ability to give informed consent, for example, Jones and Stenfert Kroese (2007) report using a procedure adapted from Arsott *et al.* (1999) for this. Arsott et al.'s original procedure involved presenting three vignettes (depicting a restraint, a psychiatric and a surgical intervention), with interviews to probe the person's ability to understand the problem, the nature of the intervention, alternatives, risks and benefits; their involvement in the decision-making process; and their ability to express a decision and rationale, resulting in a score of capable or not capable. There are dangers, though, in seeing capacity as fixed and difficulties with it as static or permanent impairments located within the individual. This neglects the fact that researchers can take positive action to increase capacity. For example, Wong *et al.* (2000, cited by Dunn *et al.*, 2006) found that capacity to consent increased as the decision-making task was simplified by presenting information as separate elements rather than in uninterrupted form. Dunn *et al.* (2006) similarly used simplification into key elements alongside delivering information in video format with illustrative scenes and voice-over summary, which 'may have helped participants to anchor knowledge into visual images recalled from the video' (p.218).

Harris (2003) helps us further with this when, writing about choice-making generally, he argues that while emphasis is usually put on intellectual capacity, social and environmental factors are also fundamentally important. He reminds us that people with learning difficulties often live in settings where choices are restricted, that they are often unaware of choices denied to them, and that with inadequate information and poor communication support they have little experience of choosing. Previous experience and availability and familiarity with choice-making obviously affect one's ability to make choices. Self-advocates who get involved in participatory or emancipatory research have already expanded, and continue to expand, this experience base. The accessibility of information also makes a difference to capacity. Access is multi-dimensional and is helped by multiple means (Nind & Seale, in press). Researchers therefore need to think beyond just re-presenting information in video format or simplifying information. Information may need to be absorbed over time with understanding reached in 'the doing' (Brooks & Davies, 2008, p.130).

With regard to making the decision to participate in research voluntarily and free from coercion the social context and personal histories of people with learning difficulties is again highly relevant. Harris (2003) notes that people can fear the consequences of choosing because they have learned the problems associated with making unpopular or inappropriate choices in social care contexts. Research participants who have taken an active part in self-advocacy groups may have learned to take risks with decision-making and dealt with the consequences and thus be better placed to give voluntary consent. Any kind of formalised consent neglects these social contextual dimensions and instead, Harris (2003) argues, is based on an idealized sequence of mental activities in which it is assumed the person: receives information; retains it; considers the options; considers the implications of each option; considers the implications of not deciding; makes a decision (mentally); and communicates that decision to other people. This sequence, he maintains, bears little resemblance to the real process and lacks empirical support. The emphasis in formal decision-making is on the individual psychological process (attention, memory, transfer etc) not on the individual's ability in interaction with others, whereas from a sociocultural perspective choice needs to be understood in relation to social practices and shared meanings.

Much of the research with people with learning difficulties addresses the problem of informed consent by carefully addressing the quality of the information, who it goes to and how, and the process of supporting participants to express views and not just acquiesce. Attention is paid to the language skills of participants (such as the number of information carrying words they can comprehend (Cameron & Murphy, 2007)) and the power dynamics at work between them and those who support them. (Quantifying the information carrying words is a simple test of the demands made by a sentence and involves counting the number of words that have to be understood for a sentence to be followed. Importantly, this should take into account contextual cues.) Cameron and Murphy (2007) used illustrated summary letters (constructed

using Mencap's accessible language principles), explained (using verbal and visual communication) to the potential participant in the presence of the carer who observed the interaction between them and confirmed willingness to participate. They used repeated explanations with time in between to process information and allowed time to inspect the information sheet. (See Appendix 1 for a list of sources of guidance on making information accessible.) Positive indicators of consent in this study were high level of engagement (eye contact, body language), relevant elaboration (verbal comments) and positive non-verbal responses (nodding). Low engagement and ambivalent nonverbal responses were seen as doubtful indicators, but importantly, responses were checked with carers. This fits with guidance from Walmsley (2004) who argues 'there is unlikely to be a substitute for working alongside people who know the individual well and can draw on the experience of what works with him or her' (p.60).

The need for consent is distinct from the need for assent (Scott *et al.*, 2006; Whitehurst, 2006) and often researchers will involve people who know the person in establishing both. Knox, Mok and Paramenter (2000) used a network of advocates and Kellett and Nind (2001), in addressing research on (not with) people with profound impairments, used a network of people round the participants – people who understood them, 'cared about them, knew when they were unhappy, distressed or uncomfortable' (p.53). It is often family members and advocates who can best advise on the individualised, sometimes idiosyncratic communication necessary to the interaction. This may be particularly true for children with autism, for whom an ongoing process of assent together with proxy consent may be needed (Beresford *et al.*, 2004). Proxy consent is rarely considered ideal, but rather a necessary compromise. Opinions vary on who is considered best to give proxy support; Stalker (1998) favoured hospital residents' psychiatrists over their parents in the desire to avoid positioning her research participants with profound impairments as eternal children, but others would see family members as stronger advocates than medical professionals.

This use of consent networks is one of many examples in which researchers establish a 'respectful relationship' as recommended in Department of Health (2001) guidance and by Morris (1998) who argues that consent should be inherent to the whole relationship. This helps 'decisional capacity' (Iacono & Murray, 2003, p.43) and communication capacity, but a power relationship could threaten the voluntary nature of any decision (Freedman 2001). Support/care workers can lack understanding of client choice and use gentle persuading and Cameron and Murphy (2007), alert to this danger, regard it as vital to collect and report non-participation data, thus showing that consent procedures are working and that there are not problems with compliance.

3.3 Anonymity

Protecting the anonymity of research participants is a fundamental ethical principle in qualitative research, but managing it is not always straightforward. Walford (2005) even questions whose interests this is in and whether researchers might be giving themselves permission to go further than they otherwise would when their participants are unnamed. A person with learning difficulties, like any other participant in research, may be proud of their contribution; they may want to own their story and to be named (e.g. Swain *et al.*, 1998). As Tuffrey-Wijne *et al.* (2005) recount though, a huge amount of care needs to go into this decision and still the consequences, for example, of in effect removing the anonymity of others around the person, cannot always be predicted.

3.4 Power of redress

Another important feature of qualitative research is the ethical principle of checking back with participants in a process of participant validation. In this way data are not included that the participant is later uncomfortable with or feels misrepresents them. This stage becomes more challenging with the complexity of the person's communication difficulties and may even get neglected or rejected altogether as too difficult. Stalker (1998) notes that participants with learning difficulties have less power of redress regarding the ways in which their words are used and analysed. This places even greater weight on the 'ethics of representation' (Booth, 1996) in which the researcher needs to be clear whose voice is being communicated in the study.

3.5 Steering or advisory groups

One way of gaining multiple perspectives on the ethical dimensions is to employ a steering or advisory group for the study. Indeed, this is now often required by funding bodies (Gilbert, 2004). Of course, who sits on this group can be an ethical dilemma in itself, with people with learning difficulties often being required to represent other people with learning difficulties or at least their interests. People may need training regarding the roles of advisory groups and the skills needed as these are likely to be outside of the experience of many (Stalker, 1998). Moreover, as Porter, Parsons & Robertson (2006) found, practical challenges like the availability of accessible transport and support staff, can make or break efforts to build and use inclusive advisory groups. They found benefit in having an advisory group comprising a small group of people with learning difficulties, who fed ideas into a larger steering group comprising a mixed constituency. For the advisory group, negotiating the terms of reference became an ongoing activity over 20 months, which greatly influenced the meaningfulness of the group's work.

4. Collecting data: methods and approaches

In this next section I discuss the various ways in which researchers have addressed the practical challenges of conducting empirical work. This includes specific data collection methods and broader research approaches. Inevitably many of the specific methods have been used in the context of case study or action research designs but I have not dwelt on design issues except where they provide particular challenges or affordances for research with people with learning and communication difficulties.

4.1 Gaining access

Gaining access to participants in order to collect data almost always involves going through gatekeepers or facilitators, and even through a hierarchy of gatekeepers (Hood *et al.*, 1996) or tiers of management (Lennox *et al.*, 2005). This means first approaching the senior figure in an organisation and working through to people with first hand contact with people with learning/communication difficulties. Using gatekeepers usually involves an additional stage of providing the gatekeeper with information about the study and asking them to suggest or contact potential volunteers to participate. This may also involve the building of rapport and trust with the gatekeeper before doing so with potential/actual participants, Before gatekeepers are likely to help they will need to be convinced of the benefits for the people who they will often regard as in need of their protection. Gatekeepers may actually block access (Stalker, 1998; Tuffrey-Wijne *et al.*, 2008). Carers, for example may be too busy and tired or too suspicious of the research to want to become involved (Lennox *et al.*, 2005). Self-advocacy organisations can become overwhelmed with too many opportunities to participate in research and reject approaches from some researchers. Gatekeepers may also facilitate access. Munford *et al.* (2008) reflect on their research relationships both with participants and with supporting organisations who facilitated safe access between them, bridging recruitment by allowing each to check the other out and providing information about each other. In their research with parents with learning difficulties, the gatekeeper organisation had a significant role in carefully explaining to participants how research is different from intervention with different purposes and timelines.

4.2 Communicating

Many of the communication challenges involved in gaining informed consent become evident again in the actual process of data collection. A common approach when communication is particularly challenging is for researchers, rather than engaging in direct communication with the participant themselves, using a person who knows the participant well to gather and interpret information (Whitehurst, 2006). Thus, as well as proxies for informed consent we see proxy research assistants. Proxies may be professionals such as speech therapists acting in an expert role, people with close relationships who know the person well, or someone else with learning difficulties. Emancipatory projects have illustrated some of the benefits here; Townson *et al.* (2004) for example argue:

> people who are not in the same boat as us don't understand what it is like to be us, they have not had our experiences. … Because of this people will want to talk to us. We know what they are talking about and understand them'. (, p.73)

Another communication strategy is to use augmentative and alternative communication (AAC). This may be informal and non-symbolic such as gesture, symbolic and low-tech such as sign language, symbol systems and photographs or symbolic and high-tech such as voice synthesisers, (see Appendix 2 for sources of further information on AAC). This necessitates finding out the AAC used by the participant ordinarily, whether this be a specific system or a combination of communication strategies as part of a total communication approach. Such individualized communication approaches are essential when participants do not communicate through speech but may also increase response/inclusion rates with those with some speech (Cambridge & Forrester-Jones, 2003, cited by Brewster, 2004).

4.3 Interview

Interviews are at the very heart of qualitative research. It is through interview that we elicit people's views and perspectives on the world and Lewis (2002; 2004) has focused on the methodological challenge of interviewing people with learning difficulties. There are, Lewis (2002) argues, three key principles in interviewing. First authenticity, requiring that views expressed are fair and representative and a need to check across strategies and contexts. Second, validity/credibility, requiring checks as to whether interpretations of views expressed are correct. Third, reliability/ trustworthiness, concerning whether responses are typical of what the person believes. Once again the social and historical context is part of the methodological challenge as 'individuals need to have self-esteem to believe that their views are valid and important […and] to believe that they will be listened to, responded to and understood' (Lewis & Porter, 2004, p.195). People with learning difficulties may have learned something quite different from this and may need the emotional support of a familiar, valued person involved in the interview process.

Clarke *et al.* (2005) in interviewing 27 people with learning difficulties faced the four areas of challenge identified by Booth & Booth (1996): inarticulateness (linked to low self-esteem, isolation and anxiety as well as language skill levels); unresponsiveness in open questioning; difficulty generalising from experience and thinking in abstract terms; and, conceptual difficulty around time, making it difficult for them to tell their story. Following Booth & Booth's (1996) advice they used direct questioning without abstract conceptual or time-oriented questions, working to develop a mutually trusting relationship, setting the agenda together, and seeking corroboration from family members where helpful.

Lewis (2004) found that question and answer formats may be more constraining than narratives or use of statements. The dilemma is that individuals with emotional, learning or communication difficulties may require highly structured support in giving their views, but such support may distort views through the nature and phrasing of questions (Lewis, Newton & Vials, 2008). One approach which has been developed to address this is Cue Cards used to facilitate eliciting views from a broad spectrum of children and providing 'a structure which, while scaffolding elicitation processes and responses, do not constrain or bias' (Lewis *et al.*, 2008, p.27). This is the kind of practical, visual complement to open-ended approaches which is seen as particularly useful for participants with autism. Originally used in child abuse interviews, Cue Cards can free the interview of verbal leads from researcher. The Cards usually have simple black and white symbols for key elements in a narrative: place, people, time, feeling, talk, action, end and consequence. Their meaning and use are systematically taught and practised and participants need time to handle the cards and become familiar with them, which leads to fuller, more fluently structured, uninterrupted narratives. Interviewers using the approach (like any skilled qualitative interviewers) need to keep their talk to a minimum, to get away from 'the rigid and limiting question-answer-response format of much adult-child talk' (Lewis *et al.*, 2008, p.27). Lewis (2001; Lewis *et al.* 2008) provides a full account of these issues for researchers wanting to find out more.

Grove *et al.* (1999) argue that authenticity, credibility and trustworthiness are all more important when AAC is used because the person with learning difficulties has to rely on someone else to select the vocabulary available to them. The necessity of access to the right vocabulary (Light & Binger, 1998) places considerable responsibility on the researcher or supporter to make judgments. Grove *et al.* (1999) recommend use of multiple informants and published vocabulary lists to avoid the problem of leading through vocabulary choice. Brewster (2004) highlights a potential danger of circularity in the process in that only vocabulary for topics the participant can already communicate about may be selected, which assumes that what the person talks about is want they want and need to talk about. Brewster

makes useful recommendations for addressing this danger: using peer informants to help to balance out the vocabulary, video recording interviews to monitor bias in the process and accessing views in an ongoing rather than one-off process, using different people producing and extending the vocabulary over time.

Brewster's (2004) recommendations relate in particular to one augmented approach, Talking Mats (Murphy, 1997), which is a facilitated conversation approach used to supplement interviews by moving graphic images around to make options more concrete (see http://www.talkingmats.com). This relies on pre-selected vocabulary but enhances the accessibility of the interview as a data gathering method. Bunning and Steel (2006) used Talking Mats to support the conversational flow and to provide a visual summary of the issues raised when interviewing people able to use and understand spoken language, because of the challenge of the abstract concepts concerned. The process involved placing a Mat on table in front of person and a single topic (e.g. Being Jewish) introduced by the researcher with a card representing this placed in the centre. Open-ended questions were asked and the participants chose symbols and placed them on the Mat as a record of their responses. If the symbol they wanted was missing they were encouraged to draw their own. The Mat was reviewed when the question sequence was completed. The topic card was then replaced with the participant's name card in the centre and the participant asked to place symbols in order of priority around the name card, enabling verification of the content. A digital photograph was taken as a record alongside the traditional transcript. Thus, Talking Mat photos could be used in the Accessible Summary of the research. This one detailed example illustrates some of the benefits of a supporting structure for interviewing. As Bunning and Steel (2006) sum up:

> As well as providing useful reference points during the course of the interview, it [Talking Mats] gave participants the opportunity to manipulate the content of the discussion. Visual symbols could be selected, newly generated, altered or moved according to the priority ascribed the concept by the individual. Each participant was able to check the display on the mat in a way that would not have been possible in an interview that relied on verbal exchange. Importantly, the pictorial representation of meanings allowed for participant verification of the data. (p.48)

For some people whose learning difficulties are more profound, no amount of visual or other structure will make the interview method possible. People with profound learning difficulties may be able, with support, to express some kind of preference for something in the here and now, but as Ware (2004) argues, this is not the same as being able to express views. Views are different from reactions, they are opinions, beliefs, standpoints, notions, ideas and they require the person to be an intentional communicator rather than at a pre-intentional stage in which communicative intent is inferred by others. With research participants who have profound learning difficulties, the whole process relies on other communication partners who are emotionally and communicatively involved. Any interpretations need to be kept under constant review (Porter *et al.*, 2001). Thus, the researcher is more likely to interview a proxy person about the person with learning difficulties and has to bear in mind, as Cummins (2002) notes, that proxies find it hard to divest themselves of own views. Clegg (2003) recommends that supporters are given space to express their views separately which helps to deal with this.

Finally, on the topic of interviewing people with learning difficulties, Goodley (1998) suggests that there are no safe formulae for this as interviewees with learning difficulties are not a homogenous group. He illustrates how sometimes trust may need to be built over prolonged periods, sometimes direct questions are helpful, and sometimes a natural style of interviewing, which includes probing/leading questions, can form the basis of shared narratives based on 'natural exchanges'. He reminds us that assumptions about people with learning difficulties requiring a particular interview style may be a more significant constraint on the interview than anything the interviewee brings to the situation.

4.4 Focus Groups

Focus groups are an alternative to interviews and questionnaires providing the advantages of a group dynamic that can help build confidence, safe environments that are not threatening or intimidating and peer support and validation, all enabling people with learning difficulties to contribute to research discussions (Cambridge & McCarthy, 2001). As Barr, McConkey & McConachie (2003) recount, focus groups have been used successfully in a number of studies with people with learning difficulties, but there can be problems. The mix of

behaviours, communication difficulties, sensory impairment and histories among a group of people with learning difficulties may not make for a productive dynamic. Nonetheless, Barr *et al.* (2003) overcame many of the obstacles to the use of focus groups to gather rich data about people's views of their accommodation. Using the places where people usually meet as the venues and the social education/resource centre managers as organisers helped with the practicalities of recruitment and getting started, but participation was limited to those who could engage in discussions and who had the expressive and receptive language abilities necessary. The potential difficulty with re-convening the groups for the process of 'member-checking' was avoided by doing this during the initial focus group meeting.

In Barr *et al.*'s (2003) study, established friendships, knowledge of each other's situations and readiness to word questions simply meant that participants encouraged and validated each other's contributions. They used verbal and non-verbal means of encouraging continued speaking and sought feedback more from each other than from the moderator. Similarly, Bollard (2008) found that with a skilled facilitator, focus group participants were able to take turns in contributing and that focus groups enabled participants to 'collectivize' their personal experiences of going to the doctor. Fraser and Fraser (2001) note that focus groups require both individual contributions and group dynamics; they found that with participants with communication difficulties groups smaller than the six-ten usually recommended were better and that the addition of an interpreter familiar with the participants' communication was important. Moreover, participants' ability to interact with others in a group was more important to success than various types of communication challenge: the ability to produce more than a few words, reliance on Makaton sign language, or even repetitive language. They conclude that 'focus groups are a very good method for some people with learning disabilities in some situations but not in others; it is important to be able to distinguish this before setting up the group' (Fraser & Fraser 2001 p.229).

4.5 Questionnaire and survey

Questionnaires for data collection in qualitative research with people with learning or communication difficulties appear relatively rarely in the research and methodological literature, which is unsurprising considering the obvious challenges related to literacy and comprehension. In some cases, such as McConkey & Mezza's (2001) survey of the employment aspirations of people with learning disabilities, questionnaires are completed by support workers who consult with the disabled person about their view. This has obvious limitations in terms of valid qualitative research. In contrast, the literature includes reference to people with learning difficulties contributing to the construction of questionnaires, their administration and collation of findings (Townsley, 1995). Questionnaires can be made very visual and tangible, as for example, in the inclusive Liverpool Heritage project (Rix, in press) in which the researchers with learning difficulties visiting various heritage sites completed basic visually supported post-tour questionnaires asking where was visited, what sense was used, what was enjoyed and so on. These incorporated the option to respond through text or imagery.

In contrast to the small questionnaire studies are larger surveys, the biggest example of which is the first national survey about the lives of adults with learning disabilities (Emerson, Malem, Davies & Spencer 2005) commissioned by the Department of Health following the Valuing People White Paper (DoH 2001). The survey was a joint effort between academic and professional researchers and a self advocacy organisation of people with learning disabilities and while large in scale focused on subjective experiences and feelings. Although the questions were devised using simple language with supporting pictures the survey was administered by interview. The full report, which is available online (see Appendix 3), includes details of the methods used. The focus of the questions were devised and piloted through discussion and workshops involving people with learning disabilities and supporters and drew on other national surveys. Great care was taken in preparation, piloting and training of interviewers. Interviewers used 'showcards' to illustrate the topic in open questions and the options for answering in closed questions. Nearly 3,000 interviews were conducted, a quarter of which were conducted just with a person with learning difficulties and three-quarters with a support person present, although in just under half the interviews it was the person with learning disabilities who answered most of the questions.

4.6 Visual methods

While some of the techniques discussed above have been adapted to build in some visual support, other methods of data collection are in themselves visual. Aldridge (2007) describes the use of participatory photographic research methods with people with learning disabilities to elicit the lived experiences of vulnerable people involved in a social and therapeutic horticulture project. The need for an alternative to semi-structured or open interviews arose because, with the participants with learning disabilities, letting them do more of the talking (a tenet of good social research) proved problematic. The photographs were intended to foster participation and elicitation, with respondents taking photos themselves of aspects of the project they particularly enjoyed and the researchers doing content analysis of the images generated. In the elicitation part, participants were asked to choose five favourite photos and to explain their choices. The approach, Aldridge argues, allowed a focus on the capacity rather than incapacity of the respondents, enabling them to show rather than tell of their experiences, with many of the photos speaking for themselves as much as needing to be interpreted.

Photographs have been used more widely and in a variety of ways, from using photo albums in open-ended interviewing (Swain *et al.*, 1998) to the more developed approach of photovoice adopted by Booth & Booth (2003). Photovoice (or photo novella) 'uses photography as a means of accessing other people's worlds and making those worlds accessible to others' (Booth & Booth, 2003, p.431) and has a history outside disability studies. Booth & Booth explain the rationale:

> Photovoice involves giving people cameras and using the pictures they take to amplify their place in the world. It puts people in charge of how they represent themselves and how they depict their situation. The process challenges the politics of representation by shifting control over the means for documenting lives from the powerful to the powerless, the expert to the lay-person, the professional to the client, the bureaucrat to the citizen, the observer to the observed. Photovoice is all about point-of-viewness: it sets out to capture and convey the point of view of the person behind the camera. Photovoice invites us to look at the world through the same lens as the photographer and to share the story the picture evokes for the person who has clicked the shutter. (p.432)

Thus we can see that this is more than a data collection method that gets around the problem of verbal and written communication, but an approach with a social and political agenda. This becomes more apparent when one understands that the method has a group dimension; while photographs may be taken by individuals, they may be selected by groups, are discussed in groups and collectively coded for themes and messages. There is therefore a reflective as well as an active element. Booth & Booth (2003) describe their use of the approach in a *Supported Learning Project* involving mothers with learning difficulties, in which photovoice was seen as a way of understanding the mothers' lives better, enabling the gaining of a sense of solidarity from seeing themselves through other people's photos and identifying priorities for group action. This was not without practical and ethical difficulties related to how long it all took, how to motivate the group discussion dimension, who owned the images, and how they could be shared more widely. Nonetheless, the photos were extremely revealing and powerful forms of data.

4.7 Life story/Narrative

Atkinson (2004) and colleagues have used oral and life history approaches with people with learning difficulties as a means of hearing their accounts – their 'lost voices' (Atkinson & Walmsley, 1999, p.204). This approach, they argue, can empower the person with learning difficulties by enhancing their knowledge and understanding of the world and their place in it. Life history work uses narrative methods to enable people with learning difficulties to recall, recount and review their lives, valuing them as expert witnesses rather than mere sources of data (Atkinson, 2004). This necessitates overcoming some of the communication barriers already identified, but as Atkinson (2004) notes, this has been achieved in the work of Bodgan and Taylor (1976), Edgerton and Bercovici (1976), Booth and Booth (1994, 1996, 1998), Goodley (1996), Rolph (1999) and Stuart (2002).

Atkinson herself has enhanced our understanding of oral/life history work with people with learning difficulties through projects like *Past Times* (Atkinson, 1993) and *Know Me As I Am* (Atkinson & Williams, 1990). The enabling factors for the people with learning difficulties are, Atkinson (2004) argues, time, space, support and practice, and including others with whom to share the experience and reflections. Thus enabled, her participants in the *Past Times* project told and used personal stories to make bigger points, challenge people and events in their lives, denounce practices and provide alternative social histories. This kind of qualitative research, through being particularly concerned with the person's unique identity and history, means they cannot be depersonalised; it enables participants to emerge as people not cases, to reclaim their lives as their own and to provide counter-narratives.

Meininger (2006) explains that the core activities in life story work are narrating, writing and reading. Narrating stories 'supposes mutuality and invites a dialogue' (p.184); it enables the person to find a thread running through their life and to give sense to it. In this way this qualitative research approach can be transformational through the new understanding of self gained (see e.g. Cooper, 1997). Writing stories involves re-shaping what has been heard, re-connecting parts so they can be read as a coherent whole. Lastly,

> [Reading life stories] puts us in the moral position of the main character and teaches us to look at our relationship to the main character in a new manner, that is to say, from the position of that central character. In this way the reader is forced into a critical confrontation with opinions, affinities, attitudes and behaviours other than their own. *In this confrontation with the other, the life story surpasses every method that attempts to chart the subjective aspirations of people with learning disabilities.* (Meininger, 2006, p.186) (my italics)

This research method then is a natural ally to (self-)advocacy. By encouraging story telling we bring together insight and empathy and affirm the subjective meanings of the story teller, enabling others in similar circumstances (or not) to make connections and take strength (Goodley 1996). Goodley's (1998) reflections on the narrative process illustrate how the practical challenges and political sensitivities are absolutely intertwined: The method involves practical ways of facilitating the recounting of experiences, such as through visual stimulus, or group discussion to elicit group memories, or interview skills that require continual reflection and refinement. It also involves an absolute commitment to listening, to interpreting the communications and the silences, and to supporting the process of reflection. It requires time and an honest approach to the contamination of the story by the researcher.

4.8 Ethnography/Observation

In-depth case studies have been common in the field of learning difficulties and some of these, such as Gleason's (1990; 1993) studies of people with profound disabilities, are ethnographic in nature or at least use ethnographic observation. In these studies, the nature of the communication challenge becomes even more about interpreting behaviour and interpreting people's subjective meanings. This does not remove the ethical dilemmas. As Tuffrey-Wijne *et al.*'s *Veronica* project found, in research with people with learning difficulties there are strong possibilities that one will observe practices that are 'sub-optimal' or even 'detrimental to the participant's well-being' (Tuffrey-Wijne *et al.*, 2005, p.189) and one needs a strong ethics protocol for supporting the participant observer in responding to this.

There are different challenges for the ethnographic researchers also. Davis *et al.* (2000) reflect on the temptation to rely on staff to interpret the cultural world of people with more profound difficulties, but also the dangers in this. Instead, they argue, ethnographers need to hold onto the concept of people (whatever their impairment) as competent social actors who may make decisions about whether to communicate and with whom, being 'the final gatekeepers to their worlds' (p.210). This message in reinforced by Pockney's (2006) ethnographic study of the friendships of people with learning disabilities using participant-observation, social diaries, photographs, life-mapping and discussion and by Nind, Flewitt and Payler's (2007) visual ethnography of young children with learning difficulties making sense of their different settings.

4.9 Other methods

While I have reviewed the issues and guidance related to individual data collection methods and approaches it is more common for researchers to combine a range of methods.

Goodman (1998) combined focus groups with drawings, role play, video and posters. Beresford *et al* (2004) combined observation, drawing and interviews in their Mosaic Approach (after Clark & Moss, 2001) with children with autism. In addressing the difficulties their participants had in dealing with new experiences they also used social stories (that is, personalised stories using a prescribed format (Gray, 1994)) supported by photos and illustrations to prepare children for a visit from the researcher - to inform and reassure them. Similarly, in addressing the participants' discomfort with direct, face-to-face interaction, they based the research session around a craft activity, looking at photos and making a poster, which was also beneficial for focusing the research on the here and the now.

5. Analysing data

Finding literature relevant to a review of data collection with children and adults with learning and communication difficulties is not difficult as the above synthesis shows. Much less is written about the process of data analysis implying that this stage is unproblematic or under-explored, yet there are two central challenges. Firstly, in relation to participatory approaches, the politics of participation does not stop at the research planning and data collection stages, leading to the question of how people with learning difficulties can be involved in the analysis stage. However, even checking with participants the validity of the data can pose practical challenges. Secondly, the data collected may not be in the traditional form of written transcripts; the very nature of the data may lead us to over-interpret and lose authenticity in a desire to draw out theoretical issues or practical recommendations. Often a narrative needs to be built from pictures, symbols and single words. Bunning and Steel (2006) used Emden's (1998) method of narrative analysis thereby deleting interviewer questions, identifying fragments of constituent themes and re-ordering themes for the coherence of a core story. They then used the story with most depth and breadth as their starting point. Brooks and Davies (2008) used thematic analysis for academic purposes combined with content analysis for expressive language in people's own words to retain authenticity.

Doubts about the possibility of people with learning difficulties being involved in data analysis and generation of theory have been widely expressed. Williams & Simons (2005) note that Stalker (1998), Minkes *et al.* (1995) and Lloyd (1996) all relate problems with this. Tuffrey-Wijne (2008) discuss the ethical tension when people with learning difficulties can understand and want to tell their story but not the process of theory building that may go on around it. Williams (1999) does not claim to have the solution to the challenge of involvement in data analysis, but she does recommend that data analysts with learning disabilities spend periods of concentrated time with the data on a frequent basis. Thematic analysis may then be possible, she argues, through using the research questions, through presenting a range of themes for co-researchers to explore, and by using the simpler concept of recording 'the bits they find interesting' and their reactions to these bits. We can debate whether this means involvement in theory building as such, but Williams (1999, p.51) argues that, 'if a theory is broadly taken to be a model that helps us to understand why things are as they are, then self advocates do engage in theory building incessantly'. Similarly, Joyce Kerhaw, a woman with learning difficulties working with Goodley, had much to say about analysis in Goodley's view (Goodley, 1998; Goodley & Lawthorn, 2005) in that she was able to reflect on what her life story said about the world.

6. Sharing the findings

The challenge of conducting responsible qualitative research with people with learning/communication difficulties continues into the stage of sharing the findings. If reports of research cannot be accessed by the participants problems arise with checking authenticity and the benefits of participation. Lewis and Porter (2004) are among many who argue the importance of reciprocity and that a minimum participants should expect for their participation is accessible feedback. One example of how this is achieved is Cameron and Murphy's (2007) interim brief, symbolized research update and 'Away Day' to explain the results. Further examples are discussed by Walmsley (in press), including, the Norah Fry Research Centre's Plain Facts, using audio recordings and printed illustrated summaries with bullet points of the key findings; the accessible abstracts approach adopted by the British Journal of Learning Disabilities in which authors of original papers are required to provide a plain language summary of their work; and, the University of Lancashire/Central England People First's commentaries by self-advocates on the important and interesting aspects of the work. Interestingly, the only version of the report of the national survey of the lives of adults with

learning disabilities (Emerson *et al.* 2005) is an accessible one (see Appendix 3 for website addresses to see this and other examples).

Writing up research has traditionally been the academic's domain with qualitative researchers in charge of giving voice to their research participants. Even with inclusive research the task of writing up has often remained in the domain of the academics because as Abell *et al.* (2007) note, it is the academics who have the access to computer facilities, conference information, the means to submit to journals and to understand referees' feedback. Increasingly though, the process of telling the story of the research is becoming a shared one, with many of the papers used in this review having been co-written by co-researchers with learning difficulties. This raises issues of how to acknowledge different types of authorship, so that readers can know what has been contributed by whom, something which can be hidden by a desire to deny difference influenced by normalisation (Walmsley, 2004). Transparency can be a preferable option as in Chapman and McNulty's (2004) discussion of the non-disabled researcher's role in helping people with learning disabilities prepare and practice their presentations and write journal articles.

7. Conclusion

Conducting qualitative research with people with learning/communication difficulties is challenging but achievable. This synthesis of research literature by academics and researchers with learning difficulties shows how shared knowledge in relation to addressing the challenges is developing. This is a rapidly developing field and a couple of decades ago the practical guidance contained in this review would not have been available. The synthesis shows how the practical, political and ethical challenges and sensitivities are interwoven with each other and across all stages of the research process. These challenges are being taken up now, not just by the pioneers in the field but by a whole raft of researchers in a range of disciplines who would no longer consider conducting research on people with learning and communication difficulties without, first and foremost, addressing them as human beings with something to say that is worth hearing.

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Appendix 1: Guidance on making information accessible

Mencap. Make it Clear: A guide to making information easy to read and understand.
Focused on people with learning difficulties, this resource is an example of communicating in an accessible style as well as providing guidance on doing so.
http://www.mencap.org.uk/document.asp?id=1579&audGroup=&subjectLevel2=&subjectId=&sorter=1&origin=searchPhrase&pageType=&pageno=1&searchPhrase=making%20myself%20clear

ChangePeople Accessible Information Guidelines
http://www.changepeople.co.uk/default.aspx?page=12855
Again a good example of being accessible for people with learning difficulties. ChangePeople also provide a service in making your information accessible for you, consulting with people with learning difficulties and adding illustrations. See:
http://www.changepeople.co.uk/default.aspx?page=14295

Dorset People First have a useful leaflet on **Making Things Easy to Read** and an accessible **Questionnaire about 'The Beeches' residential home** both available on their website:
http://www.dorsetpeoplefirst.co.uk/projects/tc.html

Easy-web-page.co.uk
For research incorporating websites there is information on making the internet easy for people with learning difficulties
http://www.easy-web-page.co.uk/AboutUs.aspx

Appendix 2: Augmentative and alternative communication

The primary source of information about AAC, both aided by technology and unaided, is **ISAAC, the International Society for AAC.**
http://www.isaac-online.org/en/home.shtml
The **UK chapter Communication Matters** provides courses on enabling individuals with complex communication difficulties to tell their stories, express their views etc
http://www.communicationmatters.org.uk/

The **Clear Communication People** provide a useful booklet on **Using Words, Photos and Symbols** which includes discussion about the processes of indicating preferences using symbolic and non-symbolic communication, the different types of symbols used and different ways of putting together communication packages.
http://communicationpeople.co.uk/Communication%20page.htm

For further information on the Talking Mats technique, see:
http://www.talkingmats.com

Symbol world and Widget both provide symbols that can be used in research:
http://www.symbolworld.org/
http://www.widgit.com/

Multimedia communication with people with profound learning difficulties is an emerging area:
http://www.pmldnetwork.org/resources/multi-media_profiling_factsheet.doc

The journal **Augmentative and Alternative Communication** contains useful research papers on this theme.

Appendix 3: Examples of Accessible Research Reports

The **National Survey of Adults with Learning Disabilities in England** (Emerson *et al.* 2005), can be found at:
http://www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/ListOfSurveySince1990/Generalsurveys/DH_4081207
The instructions for interviewers and showcards are also downloadable from this site.

The **Learning Disability Research Initiative** includes an accessible summary of the research related to the Valuing People strategy:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083079

For details and examples of **Plain Facts**, the accessible research summaries produced by the **Norah Fry Research Centre** see:
http://www.bristol.ac.uk/Depts/NorahFry/PlainFacts/index.html

The **Social History of Learning Disability Research Group** holds regular inclusive conferences with video and audio abstracts and papers in their website:
http://www.open.ac.uk/hsc/ldsite/research_grp.html