**Interviewing children and young people with learning disabilities:
Guidelines for researchers and multi-professional practice**

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*Short title
Interview methods and children with learning disabilities

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Abstract

We argue that it is important for researchers and service providers to not only
recognize the rights of children and young people with learning disabilities to
have a 'voice', but also to work actively towards eliciting views from all. A set of
guidelines for critical self evaluation by those engaged in systematically collecting
the views of children and young people with learning disabilities is proposed. The
guidelines are based on a series of questions concerning: research aims and ethics
(encompassing access/gatekeepers; consent/assent; confidentiality/anonymity/secrecy,
recognition, feedback and ownership; and social responsibility) sampling, design and
communication.

Introduction

In this article we focus on eliciting young people's views. In many respects more attention has been paid in the past to methodologies for achieving this within adult services where issues of quality of life and decision-making have played a key role in developing provision. We therefore draw on this literature to inform our practice. A key aim of educational provision for children with severe learning difficulties has always been the development of communication skills. Long before the introduction of the National Curriculum it formed a core area of the curriculum resulting in a body of teachers who have always seen this area of knowledge as crucial to their professional expertise. In consequence we hope that bringing together these two aspects of the literature will be mutually supportive to those working across the life span to actively elicit the views of all people with learning disabilities. We start however by providing the context for those working with children and young people.

The 1989 UN Convention on the Rights of the Child (UNCRC) calls for State parties to: 'assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child' (Article 12). These rights are aspirational and conditional. In discussions, the UN noted the important proviso that these children's rights must respect the rights and reputations of others; rights could not be exercised in ways that would harm others.

In recognition of the UK's ratification of the UNCRC, there has been a recent torrent of initiatives from the UK government, particularly the Department of Health, involving hearing children's views in matters that concern them. This theme is evident too in recent policy proposals (DoH 2003, Audit Commission 2003, DFES 2003; Estyn (HMI Wales) 2003). The revised SEN Code of Practice (DFES 2001a) and associated SEN Toolkit (DFES 2001b) also stressed the importance of hearing the views of children with SEN and building a 'listening culture' in schools. The emphasis from the UK government has been on formally hearing views and, for many campaigners from the children's charities this is a very weak response. It stops short of empowering and involving children and young people as partners in developing their services. For example, Save the Children (2002) has argued that the UK response has been piecemeal, welfare- rather than rights- based, lacking support in law and failing to give all 'vulnerable' children the right to independent legal advice.

Context for these guidelines

The commitment to hearing and responding to children's views has increased across research and service contexts. This has been stimulated by both rights-based arguments and policy initiatives (Alderson and Morrow in press). However much of the resultant work has developed in isolation. In particular, in the context of working with children and young people with learning disabilities, the opportunities to learn from those working in adjacent fields has been missed.

Rectifying this position, underpinned the rationale for a recent series of workshops (see footnote) in which people working across a range of services (including Education, Psychology, Health, Legal and Social Services) met to develop

good practice in eliciting views, including those of people with limited verbal communication. This provided a unique forum for researchers working within different paradigms to collaborate with practitioners. The prime aim of the seminars was to develop innovative practice in robust and authentic ways.

The following questions were constructed to serve as guidance and support in critical self evaluation by those engaged in systematically collecting the views of children and young people with learning disabilities. Our guidelines fall into ten broad sections: research aims, ethics (encompassing access/gatekeepers; consent/ assent; confidentiality/anonymity/secrecy, recognition, feedback and ownership; and social responsibility) sampling, design and communication. We do not have sufficient space here to give a full and detailed discussion of all these issues; the questions are designed as prompts for further reflection.

The guidance questions and their rationale

Research aims

There is a growing expectation that research in the field of learning difficulties should be both inclusive and participatory in nature (Walmsley 2001; Chappell 2000; Porter and Lacey in press). The emphasis should lie in research *with* , rather than research o*n,* people with learning difficulties (Kiernan 1999). Participation can be viewed as a continuum with some writers espousing that people with disabilities should set the research agenda, collaborate on the design and development of strategies, collect some of the data, contribute to its analysis and share in the dissemination process (Zarb 1997, Ward 1996, 1998, Ward and Trigler 2001, Goodley and Moore 2000, Barnes 2002). These writers also note some of the possible difficulties in this strongly participatory and democratic approach. Other writers have argued that the cognitive and linguistic demands of such activity prevent the full involvement of *all* people with learning difficulties but that it is important that they participate by contributing their views (Kiernan 1999). Researchers and practitioners are continuing to push forward the boundaries of what is possible. Researchers are developing new skills and understanding in inducting novices into the research process. One example is the recent establishment of a Children's Research Centre at the Open University, based around empowering children to do their own research. As a very minimum, researchers should establish the value of their research to people with learning difficulties. In order to do this they need to be clear about the aims and purposes of the research.

1. How will the research be useful? How will it contribute to the lives of people with LD?
2. Will the research bring about change?
3. Have people with LD contributed to establishing the aims and purpose of the research? For example, Burke et al (2003) describe the role of a conference in enabling people with learning disabilities to contribute their ideas about the topic of the research.
4. Could research participants be harmed in any way through involvement?

Access/gatekeepers

Given inequalities in the relationship between the researcher and the researched it is

unsurprising that there are a number of critical ethical issues, which arise in the course of planning and carrying out research. Thus while safeguarding the dignity and well-being of participants, researchers must also reflect on the integrity of the research and their commitment to providing an accurate account (Pring 2003). One particular dilemma concerns who contributes to the decision-making as a third party is likely to be involved at some stage. They will have their own views about the value of research and who should, or could, contribute to it. The attitudes of these intermediaries are powerful in shaping what is researched and whose voices are heard and, as we shall see, potentially have a contribution to make at each stage of the research process. This is clearly manifest in the first issue for researchers, locating and gaining access to the sample, where others act as gatekeepers. Minkes et al (1994) describe how parents were more willing to be part of the research themselves than to let their children take part. Further, Morris (1998) describes how insistent she had to be to include those people in research who were not able to be interviewed in the usual way. Tensions may also be heightened where researchers are working with a range of agencies and sources of information and lines of communication are unclear.

2.1   Who will support location and access to participants?
2.2   What are the potential synergy, contrasts and conflicts when there is multi agency involvement?
2.3   What control is there over, and checks on, the actions of intermediaries?
2.4   Are facilitators or proxies in a position to represent participants' views?

Consent/assent

The actions of gatekeepers can mistakenly be taken as conclusive of the final sample. There needs to be explicit recognition of the rights of the individual to agree or disagree to their involvement in research. Individuals who agree to take part in the research should do so knowingly. This includes understanding about what this involvement entails, the purpose of the research and the outcomes, including the potential effects. The complexity of understanding these issues means that proxies may reach decisions in a variety of different ways. For example, some proxies may base decisions on whether they feel the research involvement is in the best interests of the individual; others may base their decision on a judgement about whether the individual would want to consent if they were able (Freedman 2001; Dye, Hare and Hendy 2003). Even where proxies are used it is still important to provide opportunities to assent or dissent from involvement. So the consent process has often been described as ongoing. That is, there are a series of decision points as the research process unfolds and at which participants should be given the opportunity to express their view about their continued involvement and whether they would like to opt out (Rodgers 1999; Knox et al. 2000).

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3.1   Does the research involve fully informed consent from participants?
3.2   To what extent is the participant able to give fully informed consent?
3.3   Is understanding of consent to what checked/tested?
3.4   Does the research involve assent from participants?
3.5   If others give consent, has the participant given assent?
3.6   Has an explicit distinction been made between assent and consent in relation to what is given?

3.7   Is consent/assent confirmed throughout the research?
3.8   Can potential participants opt out?
3.9   Have ways of checking for understanding of confidentiality/research purposes been explored?
3.10 Has a right to silence/privacy (informed dissent) been recognised?
3.11 Have participants, at appropriate intervals, been reminded of their right to withdraw?

Confidentiality/anonymity/secrecy

One of the challenges to the field results from ethical issues of ensuring anonymity. In some situations a number of factors may make it relatively easy to identify participants. Minority populations, which are heterogeneous in their characteristics, make it harder to make this promise. Moreover provision may be bespoke or individual to a region making individuals easier to locate. Innovative projects are, by their very nature, likely to be unique and consequently highly identifiable along with the particular individuals who are part of them. Confidentiality may also be an issue. Research indicates that children and young people with learning difficulties are more vulnerable to abuse (Morris 1998) thus increasing the likelihood that disclosures may be made which call for action. Researchers need to be aware of the possible outcomes that can arise both during the process of data collection and as a result of the dissemination process. Researchers need to provide considered responses to participants rather than blanket reassurances of confidentiality.

4.1   Is it clear to all involved what can/should be guaranteed with respect to confidentiality?
4.2   Has it been recognised that in some contexts (for example, a child with severe learning difficulties who is integrated or included in a mainstream school) it may not be possible to safeguard anonymity in some public accounts/ dissemination of the work?
4.3   Is confidentiality guaranteed? If so, can this be sustained?
4.4   Is anonymity guaranteed? If so, can this be sustained?

Recognition, feedback and ownership

A fundamental concern that underpins participatory research is to ensure reciprocity in the activity. As a minimum, participants should have the opportunity to receive feedback from researchers about the outcomes of the study. With children, feedback may be done through adults known to them. Increasingly there is recognition of the importance of disseminating the findings of the study in a format that is accessible to those who have taken part and to their peer group (Goodley and Moore 2000). The production of newsletters with accessible text using graphic or pictorial supports keep participants updated on the progress of the project as well as the final outcomes. This is well illustrated in a recent report from the Learning Disability Task Force (Mendonca 2004) which uses different kinds of graphic illustration and case study material to support a simplified text.

In much research, ownership of data is generally presumed to belong to the researcher (although data protection measures apply giving participants rights to access electronic data under certain conditions). Kellett and Nind, (2001) propose the

researcher as a banker, retaining data/information (eg video material or interview narrative) but giving others access to it. In the inclusion context, it might be argued that schools should have access to such information and the right to use it in certain contexts. This again has implications for promises of confidentiality.

5.1 Are participants given due recognition/reward for their involvement? If so, how?
5.2 Does the participant understand that involvement may not be linked with tangible and immediate personal reward?
5.3 Have appropriate levels and type of feedback been explored?
5.4 To whom is feedback to be given?
5.5 Is a check made on accuracy of feedback?
5.6 Are research accounts accessible to the user group(s)?
5.7 How is the end of the research relationships with participants managed?
5.8 Have ways whereby a host organisation eg school or centre acts as banker for data been explored?
1. Have possible sensitivities about 'returning' material including that it may be see as 'not good enough' been recognised?

Social responsibility

Embedded within the ethical issues raised by research are the potential moral dilemmas encountered in ensuring its integrity. Research can, for example, uncover some unpalatable facts, (for example, about the use and allocation of resources, the underlying ethos or culture of the provision) which if verified have unforeseen outcomes that sit uneasily with the values of researcher, participants or indeed funder. At a crude level this raises the dilemma of where the duty of the researcher lies. Is it with the truth? Or with their relationship to others whether participants or funders?

6.1 Have moral and social responsibilities to report evidence as understood, even when this may conflict with orthodoxies been recognised?
6.2 Has the legal context (for example, concerning statements of special educational needs) been recognised?
6.3 Has the use to which findings may be put (eg to foster/curtail inclusion) and sensitivities around this been recognised?

Sampling

People with learning disabilities are very diverse and there is a high incidence of additional disabilities including multiple impairments. For the researcher, there are few assumptions that can be made reliably about the nature of provision or about the characteristics of the population using that provision. This is well documented in relation to school provision (Male 1996a,b) . We know from statistical data that regionally there may be considerable disparity in the population who attend supposedly similar schools (eg schools for pupils with 'moderate learning difficutlies' (MLD)). Populations are also not static. There are changes in policy at national, regional and local levels resulting in shifting client groups. For example, in some LEAs MLD schools have been re-classified as provision for pupils with emotional and behavioural difficulties . As a result of these types of shift, researchers in the field of learning difficulties are often hard placed to establish the generalisability of their research findings. This difficulty however should not seduce researchers

into accessing only the views of those for whom conventional methods of data collection are appropriate. Similarly, researchers should not assume that the addition of alternative modes of communication (e.g. signs, symbols, photographs, technology aided) will be sufficient to make the experience meaningful to all potential participants.

7.1 Are children with learning disabilities routinely involved in all research projects?
7.2 Has the heterogeneity of children with learning disabilities in relation to the nature, complexity and extent of their additional needs been recognised?
7.3 Have sampling strategies been broadened to obtain a range of views of children with learning disabilities?
7.4 Have the repercussions of systematically including/excluding certain groups been considered?
1. Is there awareness of communication needs and their possible impact on researcher requirements/sampling eg re signing capabilities/ICT skills and access?
7.6 Is there awareness of participants' additional cognitive needs and their possible impact, including requirements of attention, memory and discrimination that the research task presents?
7.7 Is there awareness that in simplifying, structuring or contextualising the research presentation in order to access views, the focus or nature of the views collected may be subtly altered?

Design

Previously we raised the question of whether people with learning disabilities had contributed to the decision-making around the aims and purpose of the research project. Is the research a result of a shared agenda? Participation at the initial stage of research development may, for logistical reasons, have been restricted. Eliciting people's views rests on the assumption that the subject is one on which they have an opinion. Therefore responses are likely to be limited if questions are asked outside a meaningful context or if those questions are perceived as having no relevance or interest to the person themselves. In a recent project with college students a focus group was set up to discuss aspects of their learning. What was immediately clear to the researcher was that the interest of the students lay not with what happened in the classroom but with other activities, such as what happened in the refectory or car park; College life had a very different meaning or significance for the young people. In the field of learning disabilities a lack of response, or acquiescence, is more likely to be seen as a feature of the person rather than a reflection of the research design.

Although the emphasis has often been placed on the cognitive and linguistic demands placed by researchers, less attention has been given to the emotional demands (Freedman 2001). Individuals need to have the self-esteem to believe that their views are valid and important. Further, they genuinely need to believe that they will be listened to, responded to and understood (Sternfert Kroese, Gillot and Atkinson 1998; Harris 2003). This suggests that some participants will need the emotional support of a familiar and valued person, those who would also have a contribution if needed to act as proxies. Others may benefit from being in a group in which there is a role model who demonstrates how to respond. That person may also provide a stimulus by airing alternative views. Both of these features may reduce in respondents a

sense of anxiety and perceived risk. Such situations may also highlight the potential diversity of views and clarify, possibly unwarranted, expectations of change as a result of the research.

8.1   Are the research questions and motivation clear and meaningful?
8.2   Is continuing support to participants built in?
8.3   Are relationships with participants built up over time?
8.4   What are the benefits to participants vs. benefits to the general population?
8.5   Is the distinction between research and intervention (and repercussions) recognised?
8.6   Are user groups involved at the design stage?
8.7   Are groups used? If so:
8.8   Do individuals have the ability to participate?
8.9   Do participants know one another?
8.10 Do participants support one another to elicit views?

Communication

Arguably developing appropriate communication skills is one of the greatest challenges for the researcher, especially where they may be meeting an individual for the first time. The use of facilitators, who physically support the person in (for example) the selection of symbols, may be attractive to the novice researcher but many have questioned the authorship of a view elicited in this way (e.g. Grove et al 1999). Many have argued for the importance of establishing a relationship as a first step towards eliciting the views of people with learning difficulties (Aitken and Millar 2002; Rodgers 1999). Researchers have to establish the best medium through which communication takes place. They also have to conceptualise the message in a way that is meaningful to the recipient. Poor or limited communication skills lead to ambiguity in the interpretation of the response, and difficulty with clarifying the meaning conveyed. It is not enough to use simple language and offer different modes of communication. There is some dissent about the virtues of open or closed questions which no doubt reflects differences in the communication skills of both the participants and researcher. A growing body of evidence suggests that question and answer formats may be more constraining than narratives or the use of statements (Lewis 2002, 2004). A variety of supports have been suggested including the use of pictures, cue cards, Talking Mats, and one of the tasks for the researcher is to consider the extent to which these serve to constrain or pre-determine the responses available to the interviewee (see also Brewster this issue). There is likely to be increasing use made of a variety of technology-supported approaches including, for example, the use of Powerpoint, texting, and sign-supported internet-based questionnaires or interviews.

9.1   Is the style of questioning appropriate for the participants?
9.2   Is the interviewer skilled in the specific skills of interviewing people with learning disabilities?
1.   Is it recognised that multiple disabilities may involve difficulties associated with restricted communication channels eg deafness as well as learning disabilities?
2.   Are the implications for exploring views recognised ?
3.   Has consideration been given to utilising computer-mediated communication to access views?

4. Have narratives been preferred to question formats as much as possible?
5. Has consideration been given to using cue cards for facilitating uninterrupted narratives?
6. Have focused questions been preferred to either very specific or very general, questions?
7. Has consideration been given to using various motor activities (e.g. stepping onto a marker) to assess scale of responses?

Methods

Our previous discussion presupposes that the main method of eliciting views is through the use of language. Given the difficulties for many children and young people in expressing their views in this way, alternative methods have been sought. The use of visual or enactive methods through (for example) photographs, video, movement and drama are being given increasing attention in the literature. These methods have the potential for shifting control to the participant, as the potential range of responses can be wider, indeed limitless. Researchers however face the task of analysing the meaning or message behind the response. They are therefore called on to validate their interpretation. This is often best achieved through the use of additional methods which may serve to confirm or elucidate their analysis.

10.1 Are methods triangulated? If so, is the possibility recognised that different rather than confirmatory responses may be elicited?
10.2 Are pictures used as stimuli? If so, is the possibility recognised that these could constrain responses?
10.3 How is anomalous material dealt with?
10.4 Are there ways to shift the power relationships to greater equality eg using peers?
1. Have complementary methods been used in exploring views eg drawings, diaries, observation, role play, cameras, as well as video?
2. Have the researchers been imaginative and self critical in relation to innovative methods such as the use of PowerPoint?

Challenges and conclusion

In the longer term, hearing children's views presents us with several significant challenges (Lewis, 2004). First, there is a danger that the pressure arising from the welter of policy initiatives leads to an over-formalising of the process of hearing the views of children, perhaps particularly those with learning disabilities. Second, there are indications that commentators and professionals are beginning to express some disquiet about what is possible and reasonable in this context *(*Hart 2002). Felce (2002) has also raised concerns: *'Obtaining the views of people with learning difficulties – even those with severe or profound intellectual impairment – is becoming a ubiquitous imperative'*. We should, he suggested, be much more cautious than we usually are about assuming the validity of views passed on via proxies or facilitators (see also Ware, this special issue). Third, the emphasis in policy making has been on giving individual children a voice. How do we move from hearing individual children's views, to helping children to present a collective 'choir' which always, and routinely, includes those with disabilities and difficulties? Finally, how do we explain to all children (including those with difficulties or disabilities) how and

why, having heard their views, we are making (or not making) a particular response? This will test whether adults are serious about the process of not just hearing, but also responding to, children's views (which, as implied in the above UN comment about the balancing of rights, does not necessarily mean acting on them).

The questions raised here serve to highlight the complexity behind the rhetoric of giving voice. They remind us that if we are committed to this principle then the process requires careful planning, preparation and the apportioning of appropriate time. These are not procedures that can be rushed. If we are to avoid the risk of tokenism then we need to keep asking ourselves what trust we can place in our methods and check that we have not overly predetermined the views that we have encouraged to be heard.

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[1] We use the term learning disabilities as it has currency across a range of UK professional and service contexts. In educational terms we have in mind the group of children who might be described as having severe or profound learning difficulties.

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