INTRODUCTION

There are many reasons for involving children and young people in the process of research (Kirby, Lanyon, Kronin, & Sinclair, 2003). We may for example believe that the research will be better or more meaningful, and have greater validity in revealing children’s views and experiences. Additionally we may believe in the importance of democratic participation, and that children should contribute to the decision-making process in the development of aspects of their lives that particularly concern them. We may also as educators recognize that contributing to the research process provides an important vehicle for personal development. There is therefore a growing body of interest in developing research that might be described as participatory, whether this involves ensuring that the voices of all children are included, extends to the active engagement of children in the research process, or (as in emancipatory research traditions) involves children explicitly leading the research process.

A key theme in this chapter will be what we term ‘flexing the boundaries’ – that is, exploring where the limits to engagement of pupil voice come and how those limits ebb and flow both with different methodological perspectives and in the course of evolving methods. This has clear implications for the very way in which research is understood in two ways; first, in relation to researchers’ different epistemological and ontological stances and, second, to questions about whether research is uncritically ‘a good thing’. A continuing challenge for researchers is to work in a critical and self-reflective way including testing the boundaries. Research in the field of disability has been both innovative and radical in its attempt to flex the boundaries of what is possible, drawing on the creativity of practitioners and researchers to develop their own skills as well as their co-researchers (Porter & Lacey, 2005). This has provided an important body of research that documents many of the challenges that are shared by those eliciting the voice of children and young people.

We start the chapter by recognizing the extensive influence of the rights agenda before exploring the assumptions underpinning different research positions. A number of
broad tensions are raised prior to looking at some of the ethical issues raised by participatory research. We look specifically at the challenge of developing research tools that meet the needs of children with limited communication skills and the ways in which researchers are pushing out the boundaries of conventional approaches and conclude by reviewing the implications of these practices for research and researchers.

BACKGROUND

The United Nations 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).

Following from this, there has been a torrent of initiatives worldwide involving hearing children’s views in matters that concern them. These range from formal procedures, often taking a rights emphasis (UNICEF, 2004), through the development of children as participant or co-researchers and their involvement in national and local evaluations of their provision (for example, NECF in the UK). All these are found worldwide and many have included hearing the views of children with learning difficulties and disabilities. The United Nations Children’s Fund (UNICEF, 2004) reported on the proliferation of one aspect – independent national institutions for children’s rights, such as a commissioner or ombudsman offices for children. However there is a danger that such mechanisms over-formalize the hearing of children’s views and interestingly UNICEF notes: ‘Now it (the movement towards having spokespersons for children) can only gain from rigorous evaluation – by children and young people among others – to inform the strengthening of existing institutions and the continuing development of new ones’ (UNICEF, 2004, p. 10).

EPISTEMOLOGICAL ISSUES – CONTRASTING STANCES

Interest in pupil voice is not only fuelled by the rights agenda. As researchers, a situation may be seen as not fully understood without representation of the views of all stakeholders. The validity of research must be immeasurably strengthened where not only have we collected information on the views of all our participant group, but we have also ensured that the topics we have addressed and the questions we have asked are meaningful. This is well illustrated with reference to the clinical interview. This approach (a long-established method in much cognitive and developmental work) places the power emphasis with the researcher, and even in this context there has been increasing recognition of the multidimensional child perspective. The viewpoint of the child is essential to investigating and therefore understanding a given context. So, for example, in post-/neo-Piagetian work the cluster of expectations engendered in the child by the interview situation have been recognized. As a result of the classic ‘naughty teddy’ studies (Donaldson, 1987), experimenters have had to reappraise young children’s apparent failure to conserve, and emphasize the importance of basing research around an assumed shared meaning.

A further point concerning work in this tradition is that it has tended typically to focus on developing children. It is important to involve a wide range of children in such developmental studies for several reasons. First, any theory of development needs to be based on a diverse group of children (covering variables of gender, age, social background and ability, and so on) if it is to be generally applicable. Second, evidence concerning children who are not typically developing can shed light on typical processes (see work by Lewis, 2004).

These points relate to the conclusions of such studies but there are also methodological reasons for including children who are not typically developing in such studies. Where disabled children have been the specific focus...
of interest (as in Theory of Mind and autism) the clinical interview has also prompted developments in method. Thus, contrary to what may at first appear to be the case, the clinical interview, like participatory research, can contribute to our understanding and methods for giving all children a voice.

We have, in this chapter, used the term participatory research to refer to approaches that are best characterized as research ‘with’ rather than ‘research on’ (such as the clinical interview). This distinction emphasizes the social relations between researcher and researched, a key aspect of emancipatory research. Although there is dispute about the use of the term ‘emancipatory’ (Oliver, 1997; Zarb, 1997; Barnes, 2002) there is an underlying recognition of the role of research in bringing about change that is empowering, that uncovers the barriers placed by society and reveals how lives are constrained by systems that are oppressive. Emancipatory research is explicitly underpinned by a social model of disability (French & Swain, 1997) although this may not be apparent in all participatory approaches (Chappell, 2000).

Collaborative research can involve a number of participatory practices, at a fundamental level it strives to ensure that the voice of all those with special educational needs (SEN) are represented, not simply those whose views are more readily captured. Further along the participatory continuum, it can include collaboration in all or some of the following: establishing the research agenda, applying for research funding, designing and carrying out the research including analysing the data, and disseminating the research findings.

CHALLENGING THE BOUNDARIES

Hearing children’s views in research and policy contexts presents us with several significant challenges. First, there are indications that commentators and professionals are beginning to express some disquiet about what is possible and reasonable in this context (Hart, 2002). Richard Dawkins has written that ‘with so many mindbytes to be downloaded, so many mental codons to be replicated, it is no wonder that child brains are gullible, open to almost any suggestion, vulnerable to subversion’ (cited in Mills & Keil, 2005). Felce (2002), with reference to people with learning disabilities, 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 (Ware, 2004, see below).

The UNCRC assumes, broadly, that there are no boundaries, that is, that (ultimately) pupil/children’s voice as users and as research participants is a reasonable goal for all children. The UNCRC does include, in passing, reference to recognition of the impact of developmental level. This point has not generally been taken up (but see Hart, 2002) as it has been obscured by the much stronger reference to, and interpretation of, the UNCRC as essentially a rights-based document. However, in contrast to this position, scepticism is still voiced about the feasibility of (any) children expressing ‘reliable’ views.

Second, there is a danger that the pressure arising from the welter of policy initiatives leads to an over-formalizing and/or an over-pressurizing of the process of hearing the views of children, perhaps particularly those with learning disabilities. The presence of assigned support workers, signers or translators may (despite good intentions) be, or be seen by the child, as making obligatory a response of some kind (see further below). The position of governments, as well as that of children’s charities and even the groups run by children themselves, invariably understates or ignores the possible choice by a child for silence, privacy and a non-response. Some children may genuinely and freely prefer silence to voicing their views. Silence is a very powerful statement if others, particularly those in authority, expect one’s voice to be loud. In line with this, the philosopher Roger
Homan (2001) has argued that children are particularly susceptible to intrusions of private space and so the urge to hear children’s views needs to be tempered with respect for their choices even (especially) if this is for silence. (See Lewis & Lindsay, 2000; Alderson & Morrow, 2004, Clegg, 2004 and Porter & Lewis, 2004, for reviews of ethics and consulting with children in a research context.)

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? For example, if physically able children make vociferous calls for better play areas and those calls are acted upon, do the resultant facilities reflect the views and needs of all children or only those of the physically able? This would represent a second-order representation of the views of disabled children, that is, obtained second hand through other children’s perceptions.

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); that is, creating a ‘radical collegiality’ (Fielding, 2004).

ETHICAL ISSUES

In this section we shall discuss three key aspects of ethical issues in this context. Given the potential breadth of this section we shall consider in particular:

- the impact on the child of being given a voice in the research context
- issues about adult response/actions to that voice in the research context
- a re-evaluation of child voice drawing on debates (see, for example, Fielding, 2004) about the ways in which adults may, perhaps unwittingly, subordinate the child’s voice in the research context.

Education has been slower to respond to ethical issues, in sharp contrast to the formal and often lengthy procedures for research approval characteristic of other disciplines. There has been a tacit assumption that the gatekeepers are the arbiters of the research, so that local education authority (LEA) or school-level agreement together with parental consent determine the inclusion of children in the research process. In this way children’s views can be collected without their explicit consent and often without a clear understanding of the purpose of the research. This highlights the power relations in much child-based research. As others have highlighted, consent should be seen as an ongoing process with children consulted at each step along the way rather than a single hurdle through which the researcher has to pass (Rodgers, 1999; Knox, Mok, & Permenter, 2000). Even when the child is unable to give informed consent, there should be opportunities for assent and dissent to ensure that their inclusion in the study is voluntary and not as a result of coercion. Tozer (2003) provided children with autistic spectrum disorder (ASD) in her study with a stop symbol with reminders that they could use it to control whether the interview continued. In our own research (Parsons, Daniels, Porter, & Robertson, 2004; Porter et al., 2005) participants with learning disabilities were given control over the video recorder thereby being able to terminate the interview at any point if they so wished. One of the outcomes of this shift in power is that some groups of pupils are more likely to actively dissent than others and we need to reflect on the implications of this both for the format and content of research.

As we shall see in the following section, research has focused more readily on examining linguistic and cognitive influences than on recognizing the emotional aspects of giving one’s views. There has to be an element of
self-belief on the part of the child; that their view is worth listening to and, moreover, that people will hear their voice and that it will make a difference. If the researcher does not actively gain the consent from the child then they are reinforcing a notion (often unwittingly) that the child does not have a voice or that only certain views are worth listening to.

Fielding (2004) poses a number of questions and dilemmas:

- Do we recognize the plurality of voices?
- Do we downplay the voices that seem too strident and foreground those that most readily make sense to us? Are we genuinely attentive to criticism?
- How does our professional and adult status frame our perspective?
- How confident can we be that our research does not perpetuate the status quo? Can we be sure that our data will not be ultimately used for the purposes of control?

He argues that what is needed is a transformation of roles – we need to rethink what it means to be a pupil and therefore our own professional position and responsibilities. We need to establish a dialogic process in which the research is collaborative at each of the key points and ‘avoid the equally mistaken polar opposites of, on the one hand, ignoring or excluding the speech of the marginalized group, and, on the other hand, treating its inclusion as unproblematically insightful and liberating’ (Fielding, 2004, p. 305). Walmsley, in a recent article on the role of the (non-disabled) researcher argues for the importance of ‘honest reflection’ in order to avoid being ‘trapped in a cycle of sentimental biography or individual anecdotes’ (2004, p. 65). We therefore need to be self-critical about the way that we collect children’s views and recognize how the methods we use can subordinate the child’s voice.

The difficulties inherent in this process are well illustrated in the following case study in which a facilitator acted as intermediary conveying the views of Lucy, a 9-year-old girl with profound hearing loss (from Lewis, Robertson, & Parsons, 2005). In this example, the facilitator interpreted Makaton signs for the researcher and also translated the child’s signing back to the researcher. However, the filter of the facilitator can distort the views held by the child in several ways. First, the facilitator may unwittingly introduce bias in the way a comment or question is phrased (as discussed further below). Second the signed language (for example, Makaton or British/American sign language) will have different nuances from spoken language (and from one another) and so shift emphasis or meaning and differences between what disabled, compared with non-disabled, children are being asked. Some expressions may be difficult to sign, as in the following extract in which sense of autonomy was the focus of discussion with Lucy. (Note: throughout the signer was signing and speaking, as given.)

**Interviewer** Can you tell me something where you have lots of choice in school.

**Signer** Lots of choices. Lots of things (.). Lots of things that you like to do or friends. You’ve got lots of friends.

**Interviewer** Where you decide.

**Signer** You decide. Lucy says. Lucy decides what. What do you decide?

**L** [signing]

**Signer** Decide. Idea. Lucy’s idea. When does Lucy have an idea?

**L** Idea.

**Signer** When? When do you have an idea. Outside? What?

**L** [signing]

**Signer** Do you have an idea when you’re playing? What do you choose?

**L** [signing]

**Signer** Skipping.

**Interviewer** You choose skipping.

**Signer** (?) 

**Interviewer** Choose skipping. So that’s lots of choice.

**Signer** That’s lots of things to choose and have your own ideas.
Interviewer: Now here. No choice. When does Lucy have no choice?
Signer: Lucy must do. Not Lucy’s idea but Lucy must do when? In school. Lucy must what?
L: School.
Interviewer: Yes. That’s right. Good. To come to school. No choice. What else?
Signer: What else do you choose?
L: [signing]
Signer: To play with ball.
Interviewer: Playing with a ball. Is that more or less choice?
Signer: I don’t think she really understands the concept.

Lucy was very able but her communication difficulties seem to have prevented her from, in this context, conveying her views about degree of autonomy and the choices she was able to exercise in various contexts. The signer, perhaps inevitably, gave leads and the interviewer was totally dependent on the signer to present and interpret to/from Lucy. Lucy’s deafness makes more transparent a process that may well be occurring with other children but is less noticeable there.

We turn now to consider in more detail the challenges in collecting and representing the views of children who are less articulate including those who do not communicate through speech.

**SPECIFIC CHALLENGES: COMMUNICATION SKILLS**

Much of the research methodology literature has focused on those who make verbal responses in interview situations and has, particularly, investigated different question forms. Three aspects of these have been highlighted: the vocabulary, the syntax and the pragmatic demands (Dockrell, 2004) in the search for reliable and valid methods. It can be difficult to distinguish between cognitive and linguistic aspects of communication. Studies that make a fine-grained analysis of typically developing children in addition to those with special educational needs, contribute to our understanding. Dockrell (2004) reviews research on studies of memory as well as language. As she points out, we are often specifically interested in children’s feelings and their emotional response to an event or situation. Research suggests, however, that their recall is tempered by how well they coped with the situation; with those who fared well later reported as having more intense emotional states than those who did not. She also highlights the impact of repeated questioning which can negatively impact on children’s recall of events.

Research with people with learning difficulties has highlighted the increased likelihood of acquiescence (or ‘yea-saying’) (Sigelman, Budd, Spanhel, & Schoenrock, 1981; Finlay & Lyons, 2002), and, as with young children, this tendency has often been seen to reflect increased suggestibility rather than being a product of the interview situation. We need to consider whether such agreement is an artefact of the interrogative force of a question, or one that involves an abstract concept or a judgement that is too difficult, or whether we are demanding an opinion about something that has never been considered in detail before. Lewis (2004) draws our attention to the importance of children feeling that they can ask for clarification or say simply that they do not know. Some interviewers use a device, such as a squeaky toy, which the child pushes to signal ‘don’t know’. Equally it is important that the setting does not suggest that the adult knows the answer or indeed that there is a right response. Research suggests that a yes/no answer format encourages those who do not know to respond. Dockrell (2004) suggests that we use open-ended and ‘wh’ questions and Lewis (2004) that we use statements rather than questions; however, both these recommendations suggest that the child has the vocabulary to respond to these.

If we turn now to consider children with only limited independent ability to use a formal linguistic code, we are likely to rely on others to make inferences about meaning and
to distinguish between intentional and non-intentional communicative acts. This group of children are not well placed to contradict an interpretation (Grove, Porter, Bunning, & Olsson, 1999). Clearly researchers who do not know the child are disadvantaged, not only in understanding the child, but when liaising with others and being certain about the ownership of the message. Research with adults with learning difficulties has debated the veracity of data collected through a third party (Hatton & Ager, 2002; Schalock et al., 2002; Schwartz & Rabinovitz, 2003) and has recognized that surrogates may consider the standpoint of the individual including their interests preferences, values and past experiences (Freedman, 2001) or make a response that reflects their own position. If facilitators or proxies are used then any report needs to acknowledge how views were collected so that the reader/listener can make a judgement about whether the conduit for views may have distorted the evidence. Rigorous and systematic checking of the data, including a search for contradictory evidence, are important parts of the validation process (Porter, 2003). There are also implications for work in schools when school-based facilitators, although well-meaning, may unwittingly lead a child or, if not well briefed, may be uncertain and possibly anxious about the degree to which they can do so.

Research on the use of advocates gives us some important further suggestions for the characteristics needed by someone who supports people with learning disabilities. These include being seen as independent and willing to put forward views that they do not share, having time for them and treating them with respect, and lastly someone who will give them confidence (Dalrymple, 2005). Facilitators who are well known to the child may be reassuring but may also inhibit the child from expressing negative views about, for example, experiences in school. Clearly, it is crucial that such facilitators liaise with researchers/interviewers beforehand about the purpose of the interview and how much to lead. They also need ample time before the interview to consider how best to sign a point/question so that it is more likely to be understood/interpreted appropriately by the child.

These potential difficulties may lead researchers or professionals to conclude that it is preferable to use indirect methods (such as observation of the child in particular contexts) in order to gauge children’s views, particularly of those with profound or multiple learning difficulties (Ware, 2004). The debate around such issues shows how far opinion has moved in formally recognizing the importance and feasibility of trying to ascertain the views of those children.

POSSIBLE METHODS – WAYS IN WHICH THE BOUNDARIES CAN BE PUSHED OUT

Materials about how to explore children’s views are widely available and encompass general guidelines, accounts of projects and specific materials (for example, Kirby, 1999; Clark and Moss, 2001; Kirby et al., 2003). These materials vary widely in how far they incorporate approaches applicable to children and young people with learning difficulties. Materials to use in exploring the views of children with learning difficulties have come from the larger children’s charities often working in collaboration with academic researchers. These materials include general accounts and guidelines (for example, Aitken & Millar, 2004); materials (for example, Marchant & Cross, 2002) and accounts of projects (for example, Whittles, 1998).

The range of potential methods varies on at least four dimensions:

1. Degree of support offered (for example, facilitator, puppet, information and communications technology (ICT)-linked, friend, peer group).
2. Mode of communication to and from the child (for example, varying degrees of reliance on linguistic, receptive and/or expressive, skills; pictorial; symbolic; dramatic; ICT-linked; enactive).
3. Use of concrete referents (for example, materials to manipulate)
Degree to which the child sets the agenda and/or pace (for example, those in which the child has a comparatively free rein such as using observation, mapping, photos, drawing; contrasted with those in which the child is primarily responsive to the interviewer/researcher such as prompted interviews). Note: children, including those with learning difficulties, have been involved as co-researchers and this has considerable potential, although such work should not place expectations on children that are not applied to adults in comparable situations.

Researchers from differing epistemological backgrounds will differ in what they regard as an appropriate method of data collection, whether, for example, they use a method which predetermines the outcomes (perhaps by the choice of available vocabulary or symbols) or whether a more open-ended approach is adopted that allows for the possibility of serendipity. Choices about methods will in turn prompt particular approaches to data analysis. It is beyond the scope of this chapter to explore methods of data analyses more fully. Whatever the epistemological position, implementing diverse methods effectively can be fostered by building on insights and findings derived from more formal, developmental approaches. This recognizes that exploring children’s views does need to take into account differing developmental levels.

Methods suited to exploring the views of children with learning difficulties include (outline typology based on Greene and Hogan, 2005):

- Observation. Naturalistic observations of children have a long tradition in this field, particularly with children with multiple or profound difficulties, and may supplement more child-derived approaches. The dangers in making unwarranted assumptions about the wishes of children through observation have been explored by Ware (2004). Observational approaches encompass various degrees of structure depending on the area of interest and the researcher’s epistemological stance (for example, structured observations of specific behaviours or more open, ethnographic, observations).
- Individual interviews (possibly supported through a facilitator or signer, see above, or supported through the structure for example, using cue card prompts; Lewis, 2004).
- Small group interviews (possibly supported, as for individual interviews).
- Creative methods (such as cameras, video, drawings, drama). These are a growing area of researcher interest in this context and have considerable potential to gain insights into a child’s construction of the world that does not rest on their facility with language (see Tozer, 2003; Brewster, 2004; Germain, 2004). Motor-assisted cameras can be used if children have difficulty winding on the film. Researchers will be aware that there are ethical issues in possibly photographing children in, for example, school contexts and fully informed consent from parents, teachers and children is needed first.
- Elicited and spontaneous narrative accounts (such as questionnaires, e-surveys, life stories).
- Prompted (via material or visual cues) approaches (for example, using mapping, puppets or photographs). For example, the PATH approach (Pearpoint, 2002) is being used in several areas for self- and project-evaluation. ‘Talking mats’ is used to elicit the views of people with learning difficulties (Cameron & Murphy, 2002).
- Projective techniques (for example, specific projective tests).

Some of these approaches can start to address qualms about researcher–researched power relationships but they raise issues about how best to interpret and analyse resultant data in ways which are convincing to research communities. It is usually necessary to validate the meaning through the collection of other data (Porter & Lacey, 2005). The recurrent message from workers in the field is of the importance of exploring children’s views flexibly, collaboratively and variously. Researchers may endeavour to present the child or young person with a portfolio of methods from which they choose, and so realize their preferences across these dimensions (Lewis et al., 2005). If children are given a choice of methods, including cameras, then all these permissions (and the materials) need to be obtained in advance.
CONCLUSION

One of the key drivers behind eliciting pupil voice has been the rights movement whereby children are seen to be vital contributors to decision-making around the provision of services. In the fields of SEN and disability this drive for more participatory forms of research is paralleled in the disability rights movement. Both are underpinned by the assumption that change will result from the collection of views. The channelling of much research to contribute to evidence-informed policy and practice suggests that children should have an expectation that their views will indeed contribute to the shape of provision. It is not, however, simply a process of acting on pupil views. Such power comes with responsibilities, and perhaps we need to be more honest with the child in our recognition of the tensions this raises.

If we accept the importance of pupil voice then it is vital that we include all children. Challenges have led to the innovation of new methods. There is a need to view methods of communication in flexible and imaginative ways in order to circumvent possible problems including memory, emotion, social skills, linguistic pragmatics, receptive language, expressive language. Using proxies is increasingly seen as inappropriate, so the emphasis has shifted to finding better ways of communicating directly. This may in itself lead to both more caution (because difficult) and more optimism (because with trial and error is likely to be found to be possible) about boundaries. New methods include technological solutions as well as creative ones – but we must be aware that the medium may distort the message. New methods need developing as research tools and evaluating. We need to recognize the choice of a child to be silent but also recognize that silence gives a message of its own that we should hear.

More than ever, we need to recognize that there are no universal solutions, nor a perfect methodology (Northway, 2000; Nind, Benjamin, Sheeny, Collins, & Hall, 2005) waiting out there to be discovered. As others have argued, there is a need for transparency around the difficulties and a fuller sharing of the methods used, including those which were not successful. This calls for a willingness to be flexible in using more innovative approaches and developing new skills, and to be thorough and systematic in validating our analysis. It is likely that such research will take longer and require a much greater level of commitment than that of a ‘hit and run’ researcher (Vincent & Warren, 2005).

Fielding has argued that we need to rethink what it means to be a pupil and the implications for our own role. This will mean that we rethink not only our role as researcher but the many assumptions that underpin our thinking about the nature of research.

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