PUBLIC RESEARCH, PRIVATE CONCERNS: RESEARCH INTO THE LIVES OF PEOPLE WITH LEARNING DIFFICULTIES

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Introduction

This paper is prompted by associated broad changes in research into the lives of people with learning difficulties. These changes are themselves, in part at least, a reflection of the changing social and historical context of the lives of people with learning difficulties from the 70s to present day. The growth of care in the community has been accompanied by a changing agenda of issues deemed worthy of research. A direct consequence has been the expansion of research into lifestyles and experiences of people moving from hospital into the community (Marková, Jahoda and Cattermole, 1988), focusing on questions relating, for instance, to networks of formal and informal support,

'independent living' and participation in the community.
There has been an allied change in focus from the abuse of
people with learning difficulties in large scale institutions
(HMSO, 1969), to the abuse, particularly sexual abuse,
faced within the community and smaller scale residential
settings (Turk and Brown, 1992). There has also been a
growth of research into issues thought to be associated with
living in the community rather than in large-scale long-stay
institutions: parents with learning difficulties (Booth and
Booth, 1994a); sexuality and sexual relationships (Craft,
1987); and risk-taking (Heyman and Huckle, 1993).

Associated with the changes in foci for research has been a
changing methodological orientation with the increasing use
of qualitative approaches. In their summary of these
developments Booth and Booth (1994b) state: *"In Britain and
abroad there has been an increasing acknowledgement of
the importance of listening to people with learning difficulties"*
(p 415). It is possible, too, to discern changes in the
dominant theoretical frameworks which underpin research,
and indeed conceptions of learning difficulties, from largely
medical and behavioural towards social constructionist and
interpretive approaches.

This 'paradigm shift' has not been universally welcomed. Though we can find no instances in the literature of criticism specifically by people with learning difficulties, fundamental critiques have been levelled by disabled people. Oliver (1992) states:

> *". . . while the interpretive paradigm has changed the rules, in reality it has not changed the game. Interpretive research still has a relatively small group of powerful experts doing work on a larger number of relatively powerless research subjects."*
> (p 106)

Oliver thus lays down the gauntlet to researchers. Research is not justifiable simply on the traditional grounds of furthering knowledge on the grounds that knowledge is intrinsically good. All research is political, and research processes can further the oppression of those who are the subjects of research. This challenge is particularly acute when the subjects of research have learning difficulties and research focuses on issues which might be deemed intimate and personal.

This paper focuses primarily on a single case within a much

larger research project at the University of Northumbria at Newcastle (UNN). In total 32 adults with learning difficulties have been interviewed using a variety of techniques, such as talking about research subjects' own photo albums, to help research subjects discuss topics which included home life, personal relationships and leisure activities. Four interviewers were involved in the whole project, with interviews being taped and fully transcribed. The analysis was carried out using a grounded theory approach (Strauss and Corbin, 1990).

The main subject of this case study is May, whose story, as a victim of abuse, seems particularly to highlight some impenetrable ethical dilemmas. May was approached through a self-advocacy organisation. The interviews, at May's request, took place in a university tutorial room and the interviewer was John Swain (JS). There were three interviews of between one and a half and two hours in length. Further methodological details are provided in the discussion below. Although the principal focus will be on this one case, links will be made to ethical issues arising from interviews with other research participants.

May's Story

May is thirty-one years old. She is one of eight children born to a family living in a housing estate which is renown for its high levels of social problems. She has a child of ten called Andrew who attends a school for pupils with learning difficulties. May and Andrew live with May's mother and father, with members of the extended family also living in the vicinity.

Three core themes emerged in May's story which have direct relevance to the discussion within this paper. May's story is first and foremost a narrative of sexual, physical and psychological abuse. She was subjected to sexual abuse first by her father and, as emerged later in the interviews, her father's friends and her brother.

"All my life, I mean I'd been abused by my Dad and, I mean, that's, I suppose that's why I just don't get on with him, you know. He started the whole thing off, you know, and it was just, right from the age of three years old, till I was about sixteen and went into [local hospital for people with learning difficulties]. *You know, it was horrible, it was just horrendous, and terrible. Me Mam just didn't know what to do with us. I was just always crying and you know what I mean. I was just a pain I suppose, you know, to me Mum, because she didn't know."*

At sixteen, following a number of attempted suicides, May spent six years within two hospitals for 'the mentally handicapped'. Her experiences in these institutions were such that she stated:

"I used to think, gosh, I'd be better off just getting that at home off my Dad, my brothers and all these different folk than this, you know."

These experiences included the following.

- **Denial of privacy**

"And like it was horrible in that hospital there. I mean, you were locked up. You were tret like a bairn. They used to come into the bathroom with you, stand at the toilet with you in case you done anything to yourself, you know."

- **Denial of personal possessions and clothing**

"I used to be wearing this woman's cardy and that woman's dress and somebody else's furry slippers and somebody else's tights. I used to think, gosh, only thing I ever wore of me own is me underthings, you know, which was really, oh god, you know, it was really horrendous."

- **Use of drugs as punishment to control May**

"I remember me getting an injection for something that Veronica did because I was crying and I was really scared, and I was really upset, so they give me summick to calm me down. And I was away with it for weeks. I was out of this world. I was just wondering round like a zombie, you know. Well they were on top of my drugs and stuff like, you know, they just done my head."

- **Denial of freedom**

  "I was taken to another ward and then I, they just

  strip you off and give you a needle and stick you in

  a robe. Like this room, padded thing it is, s'like a

  padded room. They're quite soft walls, but it doesn't

  look padded, if you get what I mean. They're quite

  hard to lie on, like you have to lie on a thing, you

  know, really uncomfortable.

May also spoke of pressures she faced, from formal carers,

to have an abortion and suggestions, from a particular

professional involved, that she was physically abusing

Andrew once he was born.

The second major theme in her story was the consequences

of abuse for May herself and key people in her life. For

herself, these consequences included fear and avoidance of

sexual relationships, suspicion of others and, perhaps above

all, fatalism (Heyman et al, in press).

  "I tried all sorts of things and saying things that

  might, would have helped but 'nah'. Just made it

  worse. It is easier just to be quiet whenever it

  happens I suppose. Horrible."

May also asserted:

> *"And nobody just could get out of me what was*
>
> *wrong, because every time I tried to tell somebody,*
>
> *they were saying don't be silly, you know. So it got*
>
> *to the stage where I thought it's just a waste of time*
>
> *telling anybody about this."*

The third major theme was May's establishment of her life as a single parent with her son, Andrew, and in particular her growing determination that others should not face the kinds of abuse she experienced.

> *"I mean I can actually stick up for myself sometimes.*
>
> *I mean it depends if, if somebody hurts Andrew,*
>
> *then I'm a different person. (. . .) I think it's*
>
> *because I've gone through so much. I just don't*
>
> *want him ever to go through what I've gone through.*
>
> *Never ever will he go through what I've gone*
>
> *through."*

Questions of Ethics

May's story is one of abuse. It is an intimate, emotional and revealing story told through self-disclosure and conveys the

meaning of experiences of abuse through the eyes of a victim. A central question is whether, and in what terms, the research process itself was abusive towards May or others involved. It is in this light that we turn to questions of ethics.

The ethics of social research, under different guises, have been the subject of lengthy and controversial debate over many years. It is the umbrella under which social scientists attempt to address the kinds of issues raised by Oliver (1992) from the viewpoint of disabled research subjects. It is a fraught arena of debate in which every standpoint in the literature seems to be countered by an alternative position. Even the importance of ethics in research is at times an issue. Sears (1994), for instance, argues that for a number of reasons, *"it is not only wrong but also dangerous to apply 'ethical' judgements to so many different areas of our work"* (p 237). Brickhouse (1992), on the other hand, takes a contrary position: *"Giving ethical considerations a position of primary importance requires us to be more critical of the research questions we ask and how we pursue answering them"* (p 101).

The central challenge to researchers is that the essentially

political act of research exploits vulnerable and powerless groups within society, furthering their disempowerment and contributing to their oppression. There can be few areas of research in which the challenge is so dramatically highlighted than research into the 'private concerns' in the lives of people with learning difficulties, particularly if these concerns involve sexual matters.

There are at least two orientations to analysing the ethics of research. The first takes questions of ethics as a set of issues arising within fieldwork, for example justification of research or informed consent (French, 1993). These are discussed below in relation to research into the lives of people with learning difficulties in general and May's story in particular. The second orientation is directed towards theoretical and philosophical stances taken in understanding and addressing ethical issues. This is the focus for the conclusion of this paper.

"Don't People Have The Right to Unexamined Lives?"

The first ethical dilemma was whether or not to undertake the research. How can qualitative research which examines private concerns in the lives of people with learning

difficulties be justified? In the literature such questions are

discussed under the guise of the ethical evaluation of

research content and "the principle of beneficence" (Lynch,

1994). In the research under discussion in this paper there

are four possible "beneficiaries". The first, and broadest, is

the general public and/or specific interest groups such as the

research community or service providers. The "public right

to know" is the dominant justification of conducting and

publishing social research (Homan, 1991). Research which

illuminates the detailed qualitative accounts of the feelings,

experiences and views of individual victims of abuse, for

instance, is arguably justifiable in terms of public interest on

the grounds that wider knowledge of the full personal

implications of abuse may lead to the instigation of

preventative and supportive measures.

Full justification of exposing 'private' concerns to public

scrutiny, however, can never be made solely on the grounds

of public interest for at least two reasons. First, there are

limits to which people's lives should be open to public

scrutiny, albeit they are difficult to define. "Don't people have

a right to unexamined lives?" (Ashworth, 1993) is the key

question here. Second, justifications in terms of public

interests are made either explicitly or implicitly against possible predicted harm to research subjects. Such predictions are hazardous in this type of research. The dangers of contravening the rights and endangering the safety (psychologically) of research subjects are paramount.

The second potential beneficiaries are the research subjects themselves. It is crucial here to distinguish between research being justified <u>by</u> rather than <u>for</u> people with learning difficulties. As Mittler (1991) states, people with learning difficulties *"are in greater danger of being victims of the good intentions of others than most other maginalised groups. It is precisely because of their intellectual limitations that others make decisions for them"* (p 22). Discussing her involvement in research, May stated,

> *"Cos I'm only doing it for the other people, you*
> *know, so that other people have a better life than*
> *what I've had anyway."*

For May, the justification for the research lay in the dissemination of her experiences. It was a type of "in the public interest" reasoning but, significantly, it was from May's viewpoint.

Though such justifications for the research are clearly essential, they are also problematic. Firstly, May was untypical, at least in relation to the other research subjects in the UNN project. They did not themselves give a clear rationale for participating in the research, and may have been motivated by personal factors, such as the desire for social contact. While such reasons may be personally valid for research subjects, people with few social outlets are vulnerable to exploitation. Secondly, the subjects' reasons for participating have implications for the evaluation of research. How far were May's aims realised within the whole research process? Thirdly, and perhaps crucially, the control of the research process remains at the discretion of the researcher not the research subjects.

The third potential beneficiary is people with learning difficulties generally. One crucial question is the orientation of the research in defining "learning difficulties". The traditional approach to learning difficulties has been individual or pathological, locating disability within the ostensible deficits of the individual, including lack of intellectual ability, lack of independence skills, inability to cope and so on. In contrast, a social model of disability has

been developed by disabled people themselves over at least the past twenty years. Within this model, disability, including learning difficulty, is socially determined within an oppressive social and physical environment. The general arguments are well documented elsewhere (Oliver, 1990). Here we are suggesting that the espousal of an orientation towards defining learning difficulties is an important component of the ethical decision making involved in conducting research. The crux of the argument is that a social model of disability can contribute to the emancipation of people with learning difficulties, while a pathological orientation maintains the status quo of oppression.

The fourth potential beneficiary of research is rarely mentioned in the context of justifying research, that is the researcher. Indeed, it could be argued that the whole process of justifying research is founded on establishing benefits for others against the personal interests of the researcher (see below).

Respect

Respect involves trust and acceptance in a relationship. It also involves communicating that the other person is a

worthwhile, unique and valued being (Swain, 1995). This principle seems unquestionable, but dilemmas and issues become apparent when research is seen as a process of intervening in the lives of others, particularly in relation to private concerns. Crucial questions here relate to the exercise of power in decision making throughout the research. In this light 'respect' is realised through the extent to which research subjects can exercise control over the processes of data collection, and reporting. It is problematic to the extent that the power relations and structures of research are hierarchical with the ultimate control remaining at the discretion of the researcher. Open-ended interviewing, for instance, at least in comparison to an interview conducted through a set of questions pre-determined by the interviewer, ostensibly allows for the data collection to be constructed between the interviewer and interviewee.

One major issue for debate in the literature generally has been the pros and cons of deception on the part of the researcher, usually under the more acceptable umbrella of 'covert versus overt' research. Whilst covert research with people with learning difficulties seems difficult to justify, the

only constraint on the possibilities of overt deception is the integrity of the researcher. It is easy to lie to research subjects by, for example, saying that they will own the data (tapes and transcripts).

The possibilities of unintentional deception are also manifest. 'Deception' is inherent in the method of open-ended interviewing. The researcher takes a contradictory position which on the one hand says to the research subjects that they are in control, and may disclose at their discretion, but on the other hand employs techniques of listening which are geared to enabling research subjects to talk freely and openly about the most private details. To give a specific example, the following statement was made by May whilst discussing her involvement in the research:

> *"I think with you being a nurse and you're trying to help people as well. You know what I mean, you're trying to do things right. It's best that you know these things, I mean, it's best you know so that you can help other people."*

Earlier in the interview JS had told May that he had been a nurse in a hospital for people with learning difficulties. This

had happened while May had been speaking about her experiences as a patient, and JS had hoped to encourage her by suggesting that he knew the type of situation she was talking about. The message May received, however, was obviously quite different. She believed that JS was still a nurse and in a position to directly influence others to prevent abuse to people with learning difficulties. Thus, while no deception was meant, JS had conveyed a false message.

Dilemmas can also be raised for the researcher in situations in which there is a conflict between respect expressed as acceptance and respect expressed as congruence or honesty by the researcher. Bob Heyman (BH) experienced such a situation with another research subject in the UNN project who described events, such as stealing cars, which BH believed to be false. Respect as acceptance put the onus on BH to pretend to believe the research subject. Respect as honesty could be expressed through challenging the subject. The dilemma was further complicated by the interests of the researcher both to explore the 'fantasy' and to foster openness in communication.

Problems concerning respect are possibly even greater in

other stages of research. This article is in itself an example

of a stage in the process of research which is controlled

solely by the researcher and has direct benefits for the

researcher rather than research subjects. The question of

respect becomes, in part, one of ownership of data,

particularly where it involves private concerns. The

involvement of research subjects with learning difficulties in

the writing of academic articles of this kind, however, seems

cosmetic. 'Respondent validity' and consent could be gained

from May in relation to the quotes used to express her

feelings and experiences, but the general ethical issues of

social research are beyond May's personal interests.

Informed Consent

Informed consent has probably received more attention in

the literature than any other principle of ethics in social

research. The principle is ostensibly straight-forward: the

research subjects' unquestionable right to make a voluntary

decision of whether or not to participate in the research. It

requires the decision to be "informed" by an understanding of

what the research entails and it requires the capacity to

"consent". The importance of participation through informed

consent is, arguably, a safeguard to protect the rights of research subjects, and also to protect researchers in fulfilling their responsibilities for the safety of research subjects.

A fairly substantial procedure was followed with May, which included several explanations of the research. However, though the procedure was lengthy, the whole process remained deeply problematic in relation to May's decision being informed and consent being voluntary. The former raised three major issues. Open-ended interviews are open-ended, and go down lines which neither the researcher nor research subjects may expect. There were indications in the interviews with May that she felt less comfortable with certain sections of the discussion, e.g. when talking about her relationship with her mother. It was not clear, however, whether this was due to a general anxiety, or discomfort about discussing such topics, or because the interview had gone down tracks May had not expected or had wanted to pursue. There were points too when topics were raised that JS had not expected and felt concerned that May was making unwanted disclosures, or disclosures she might regret later, e.g. concerning her sexual relationship with her present boyfriend. The point at issue here is that a full

exposition of the research was not possible at the outset. In this form of research, informed consent is not simply contracted at the outset, but is a continuous process to be re-affirmed as the research progresses.

Second, even within the limited scope of what could be explained, the information offered to May was limited. Homan (1992) has levelled criticisms against qualitative research generally along these lines. In hindsight, for instance, there was little in JS's explanation about the funding of the research or expectations in relation to publications.

The third difficulty with 'informing' was that the information might not have been understood. It was clear, for instance, that May believed that her story, as told to the researcher, would be widely disseminated. The difficulties and practicalities of publication may not have been beyond May's comprehension, but they were certainly outside of her experiences.

Fourth, this whole view of "informing" is simplistic. Informing was not a matter of information being passed from JS to May. As Walmsley (1993) states, *"explaining is an*

interactive process." Informing or explaining is a sharing of understandings or agendas (Bamberg and Budwig, 1992). With May, informing did involve sharing but not a meshing of views.

'Consent' was also problematic. Whereas the researcher seeks consent for the whole research process, the research subject has his or her own agenda. May consented to "telling her story to help others" and perhaps to talking with the researcher as a desirable experience in its own right, rather than consenting to the whole research process as conceived by the researcher, including possible publications.

Finally, the heart of informal consent needs to be seen as problematic. Is it a voluntary decision? Researchers put pressures on research subjects, sometimes overt and sometimes more manipulative and unintended. The above example of JS's self-disclosure that he had worked as a nurse can be seen as part of a manipulative "trust me" process. It is also possible that May felt a personal obligation to JS to agree to further interviews.

Privacy

Privacy, often viewed as a right, is a central concern in

debates on research ethics. As a principle in social research privacy is the right of research subjects to control the information communicated to others, that is to the researcher initially and in subsequent public documents of any kind. The central dilemma is again the rights of the individual to privacy as set against the public right to know.

The dangers of intrusion of privacy in qualitative research into the lives of people with learning difficulties are readily apparent. Yet May's story challenges simplistic interpretations of the 'right to privacy' in two ways. First, the issues are issues by virtue of the very fact that they are deemed 'private'. Privacy is the context for sexual abuse and for the lack of opportunity of the people to discuss sexuality. It is their concern. Privacy is not only a right, it is a context for oppression and abuse. Here is the crux of the ethical dilemma: to deem abuse and sexuality 'private' is to strengthen the very context in which they arise. Part of their construction as issues is the very fact they are deemed 'private'.

Second, qualitative research has a role to play in promoting the voice of people with learning difficulties. This is evident

in publications of prose, poetry and art by people with

learning difficulties (Atkinson and Williams, 1990), and is

particularly pertinent to people who have experienced abuse.

Indeed it could be said that May has a right to privacy, but

she also has a right to be heard: a 'right to voice'. This right

took on a particular significance in the research with May as

suppression and denial of voice are in themselves abusive

and crucial components of sexual and physical abuse. May

experienced both suppression of disclosure through threats

of further abuse if she 'told', and denial, in that her

disclosures were not believed. Research in such

circumstances offered May opportunities to tell her story and

express her feelings to a receptive audience of the

researcher in the first instance, and a wider audience

through publications.

Confidentiality and Anonymity

While widely recognised as ethically sound in principle

confidentiality and anonymity, again, can be problematic in

practice. First, anonymity cannot be guaranteed. The more

biographical details are made public, the greater the

possibility of recognition of May's real identity, particularly by

anyone who knows of May's involvement in a research project.

There are additional problems in relation to others involved in research subjects' lives. May's story names people who have subjected her to sexual abuse, and institutions in which she was physically and mentally abused. This is problematic not least because those named have no means of reply.

Another complicating factor was May's own ambivalence towards confidentiality and anonymity. Though the principle has been observed, and all names of people and places have been changed in any public documentation, this, if anything, has been against May's wishes. For May, this was her story, not an anonymous account. The adherence to confidentiality and anonymity was the researcher's rather than May's decision.

Finally, issues of confidentiality can arise from disclosures made to the researcher. The principle of confidentiality can conflict with principles of safety and respect. Dilemmas arise for the researcher in situations in which the subject discloses information which the researcher believes should be passed on in the best interests of the subject or others. Though

May, for instance, maintained that she was no longer being subjected to sexual abuse, elements of her story suggested to the researcher that she remained at risk. BH experienced a similar dilemma with a research subject who, he felt, was clinically depressed.

Safety

On the surface it would seem that safety is not an issue in qualitative research of the kind focused on here. It does not involve the administration of drugs or the use of physically dangerous procedures. Nevertheless, there are ethical problems in terms of safety. Fox (1976) identifies the foundations of risk:

> *"researchers often seem to ignore the fact that active participation in a research project, even on a purely verbal level, may arouse feelings, stir memories, or force perception which otherwise may not have occurred."*

In research of this nature, the researcher's only direct involvement in the lives of research subjects is one of collecting data. The ending of the relationship between the researcher and research subject is problematic in these

terms. Qualitative research can provide the opportunity for research subjects to make sense of traumatic experiences in what can be, in an informal sense, a counselling relationship. The dangers are that the research subject can become reliant on the relationship or that the relationship is terminated before the research subject feels that the process is complete. This did not prove to be a problem with May. As Wilde (1992) recognises, involvement in research can be an opportunity for research subjects to learn about and become interested in the research process itself. May continued to participate in the research project of which her story was a part, and even acted as interviewer with other people with learning difficulties.

The ending of the research relationship was, however, problematic for BH with two of the research subjects for whom participation in the research provided significant social contacts. To conduct research of this nature is to become involved in people's lives. The involvement may be peripheral as far as the researcher is concerned but may not be from the subject's viewpoint.

The dangers of open-ended interviews in relation to the

mental health of research subjects are equivalent to the use of drugs in relation to physical health. The research raises highly emotionally charged issues with the possibility that the researcher's responses might be unhelpful or even exacerbate the problem and not be able to provide adequate follow up. With May, too, there seemed to be possibilities of collusion. Encouragement could have taken May into expanding in increasing detail on the abusive experiences in her life, perhaps with elaborations and even exaggerations to present her story. This may provide "rich data" (albeit of questionable validity) but at the expense of the best interests of the research subject.

Safety, then, is in major part a responsibility for the researcher particularly in this arena in terms of the possibilities for the continued involvement of research subjects either in the research project itself or with the researcher beyond data collection.

Booth and Booth (1994b) suggest that emotional involvement can also be a issue for the researcher. They state:

"There is the strain of witnessing and sharing the

anguish of the informant, and the strain of coping

with the feelings they release in oneself. There is

also the worry of unleashing emotions that one may

not know how to deal with or that might cause

further pain to the informant." (p 422)

They also suggest that researchers can need support from

others who are bound by the rules of confidentiality. Such

support was available in an informal way in the research

project of which May's story was a part.

Exploitation

The final issue, and one which pervades all the issues

discussed above, is the question of the researcher exploiting

research subjects. The fundamental ethical question for

researchers is whether their own agendas and motivations

predominate over those of research subjects. Capturing this

Finch states:

"I have emerged from interviews with the feeling that

many interviewees need to know how to protect

*themselves from people like me." (*1984, p 80)

The pressures on researchers are for articles. As Homan states:

> *"A dominant motive among researchers is the development of a reputation fulfilled by keeping one's name in the clear view of one's colleagues."*
> (1991, p 4)

Again, this paper is itself an example. It is at the point of publication that research becomes 'public', and data is open to re-interpretation, formally or informally, by people other than the researcher, and to *"secondary analysis by less empathetic researchers"* (Homan, 1992, p 327).

Ethical actions, then, cannot be judged entirely on the principles by which research is planned and conducted, or on the treatment of research subjects, or on the final outcomes. Account must be taken of the whole social relations of the research, including the motivations of the researcher.

A Labyrinth of Dilemmas

It is a matter of convenience to categorise ethical issues under the above subheadings. The most complex and

intractable dilemmas encountered in the UNN research project, however, invoked questions that spoke to many issues and conflicting principles. An example, which was the subject of much debate by the research team, emanated from concerns about the safety of Andrew within a household in which there had already been sexual abuse. There were numerous factors within the situation, as described by May, which fuelled concern, including her devotion to Andrew, fear of him being placed in care, and her son's learning difficulties. Questions of ethics, then, related to the possible responsibilities of the researcher to intervene.

There were many complicating factors, not least being the fact that May had not herself specifically raised such concerns, and also that others who were not participating in the research were involved. The dilemmas were intensified too by the level of uncertainty in the situation and the impossibility of predicting the consequences of possible actions to be taken. The debates of the team covered such possibilities as approaching and consulting formal carers involved with the family. The general issue addressed was the specification of circumstances in which confidentiality should be breached. Another possible course of action was

to return to May to initiate further discussions, and perhaps counselling, in relation to Andrew's safety. The dangers of this, however, were also apparent and any alerting of May to risks might have exacerbated an already difficult situation. Furthermore such counselling had not been consented to by May. The dangers of taking no action were, of course, equally apparent.

This labyrinth of dilemmas was eased by our knowledge, gained without breaking confidentiality, that May had spoken to formal carers about the sexual abuse she had experienced and, indeed, seemed to generally talk openly about it. Furthermore the family was receiving formal help of various kinds. Also the team was able to approach external consultants in relation to these issues, again without breaching confidentiality. Nevertheless, though in this particular instance questions of 'researcher responsibility' were somewhat alleviated by circumstances, ethical soundness remained a minefield. General principles provide a foundation for negotiating questions of ethics, but their realisation in practice is fundamentally problematic.

Conclusion

The ethical principles and issues discussed above are dimensions of the whole process of research, and pertain to decisions which shape and direct the research throughout. The ethics of social research can also be considered in terms of the theory and philosophy through which these principles and issues are understood and addressed in the practice of research. Four general approaches are discernible within the literature, and each played a part in researching May's story.

In the first and dominant orientation, ethical questions are translated into principles which balance the public right to know, and the utility of knowledge, against the rights research subjects. Ethical research, according to this approach, is planning in accordance with a set of principles. Thus Codes of Ethics, as issued, for instance, by the British Psychological Society (Robson, 1993), are specified to limit the possible harm to subjects while being founded on the potential or assumed benefits of research for society generally and specific groups, including service providers. A Code was, for instance, drawn up in the planning phase in

the research in which May was a participant. As is typical in such research projects it was used as part of the access process to establish the rights of research subjects.

There are a number of interrelated limitations to an approach based solely on a Code of Ethics. As evident in the above analysis, the research process is inherently fraught with ethical dilemmas that cannot be predicted at the outset. For instance, the principle of informed consent is rightly a major feature in any Code. However, questions which arise in practice are specific to: the particular context, including the substantive focus of the research, the expectations and understandings of both the researcher and the research subjects, and the nature of the research process. There is the danger that researchers see their responsibilities as fulfilled within an *a priori* approach (Homan, 1992).

The second orientation to ethics is through an evaluation of how research was conducted, including explanations to subjects, subjects' objections to aspects of research and so on (Wax, 1977). Such a review was conducted informally with May as in the following extract from the manuscript:

JS: *How have you felt talking? Did you, do you feel*

> *all right talking to me or do you feel . . ?*

May: *Well, I've never ever spoke to a man before,*

really. But it's like when I met you the last time, I

just says to the lady I felt really safe. There's

something about you. Dunno what it is, but there

is something about you.

Notwithstanding the importance of this approach to

addressing questions of ethics, the limitations are again

clearly evident. The most fundamental question concerns

the meaning that can be attached to such statements by

May. Ashworth (1993) writes:

> *". . . human science research is essentially an*
>
> *interpersonal process, and . . . therefore research*
>
> *activities cannot avoid such Goffmanesque features*
>
> *of self-presentation as resistance to being*
>
> *understood and eager acceptance of understanding,*
>
> *which are both pervasive possibilities of all social*
>
> *interaction. Thus, the research participant's*
>
> *agreement or disagreement cannot be taken as*
>
> *evidence as to the adequacy of a qualitative*
>
> *research description or interpretation."* (p 3)

Ashworth's argument is that research subjects' agreement with qualitative research findings does not constitute evidence of validity. The same objections can be levelled at the acceptance of May's statements as evidence that the research was ethically sound. May was indeed eager to accept understanding, and eager too to show that she felt that she was being understood, a stance which was consistently encouraged by the researcher. Thus, May's evaluation can be understood in terms of her self-presentation in the interviews and in her relationship with JS, rather than in terms of questions of ethics.

A third general approach to questions of ethics takes a specific standpoint in relation to respecting the rights of research subjects. The argument is that the greater the control by research subjects at every decision point in the research process, the less likely it is that the research will infringe their rights. For instance, May's control over which sexual matters were disclosed, and which not, was crucial to questions of informed consent, safety and privacy. From this viewpoint, questions of ethics are constructed and confronted throughout processes of interaction. This approach, then, is the most direct in addressing Oliver's

(1992) challenge (see introduction). Though the production of research still lies in the hands of researchers, there is an attempt to shift some control to research subjects in the social relations of research.

Again, there are limitations to this approach. First, Oliver is correct. The control of the research rests in the hands of the researcher and is only shared at the discretion of the researcher. Furthermore, there are a number of aspects of the social context which can further the controlling power of the researcher. Obvious factors in the research of May's story are: the researcher was in his late forties, May in her early thirties; the researcher was male, May female; and the researcher had a higher social status than May. The most obvious factor in the research under discussion is the possible significance of learning difficulties. From the standpoint of this paper, it is a fundamental axiom that the learning difficulties of research subjects is irrelevant to ethical principles and the rights of subjects in social research. There are two caveats to this. First, as Brickhouse (1992) states, *"principles and obligations do not address the diversity in . . . individual human needs."* Ethical principles and obligations are interpreted and take particular

manifestations within particular contexts and between the

particular people involved. Any implications of learning

difficulties are, then, constructed in the interaction and

relationship between the researcher and the research

subject. Second, people with learning difficulties can be

particularly vulnerable to manipulation and ethical

maltreatment by researchers. This is recognised by Booth

and Booth (1994b) in their research with parents with

learning difficulties:

> *"we decided to be guided by the fundamental tenet*
>
> *of the citizen advocacy movement which requires*
>
> *that the advocate (in our case, the researcher)*
>
> *treats the interests of their partner (here the*
>
> *research subject) as if they were their own."* (p 416)

The obvious problem here is that the roles of advocate and

researcher are not separated, and researchers have their

own vested interests. This takes the discussion onto the

final orientation towards questions of ethics.

Our analysis of ethical issues has questioned any exclusive

reliance on Codes, retrospective evaluations or the control

ethical decision making by research subjects. As bases for

understanding and addressing questions, these approaches

fulfil the researcher's obligations in principle while leaving the

practice of field work open to manipulation and the pursuit of

the researcher's vested interests. Ethical questions pervade

the whole research process with dilemmas and decisions

from the initial proposal to the final publication. Furthermore,

ethical questions need to be understood and addressed

within the particular context of the particular research and

constructed in field relations between the researcher and the

research subject. This orientation towards ethics thus puts

the onus clearly on researcher' integrity. Homan (1992)

summarises the position as follows:

> *"What sociologists need if their profession is to be*
>
> *respected by its public is not a code which liberates*
>
> *practitioners to exploit the research situation but*
>
> *formulations which emphasize moral precepts in*
>
> *place of procedures."* (p 331)

This standpoint is similar to a relational approach to ethics:

"A relational ethic remains tightly tied to experience because all its deliberations focus on the human beings involved in the situation under consideration and their relations to each other" (Noddings, 1988, p 218)

The specific context and the individuals involved provide the particular forum in which ethical principles are critically interpreted in practice through a commitment to human caring (Brickhouse, 1992).

Open-ended qualitative research with people with learning difficulties highlights the need for relational ethics. This type of research is not abusive by the very nature of the social relations of production, but it is inherently potentially abusive. The possibilities for exploitation, invasion of privacy, manipulation, deceit and abuse of power are ubiquitous. Indeed, it could be argued that the dangers are such that it is the perpetrators of abuse who should be the subjects of research rather than the victims. As May's story demonstrates, however, this would deny the 'right to voice' of people with learning difficulties. The integrity of the individual researcher may be a dubious and ephemeral

foundation for ethical soundness, but such is the fraught

nature of public research into private concerns, and indeed

professional integrity is the ultimate basis for ethical decision

making in all professional intervention.

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