Researching Vulnerable Groups: Ethical Issues and the Effective Conduct of Research in Local Authorities

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Researching Vulnerable Groups: Ethical Issues and the Effective Conduct of Research in Local Authorities

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Summary

T e Da a P. ec Ac 1998 a d *Research Governance Framework for Health and Social Care* (De a e f He , 2003a) a e b g c de a f e ca e e c d c f e ea c a e f c . T a e, ba ed a a e a ' e e ce f c d c g e ea c c d e ee d a d c e f e ab e c d e , e a e e ac e e c a ge a e ad e e ea c ce . T e d ff c e e ce b e ea c e ga g acce e ea c a c a de de e e de ce-ba ed c a d ac ce a e e ed. F a , e a e - e e ac e a ca be a e fac a e e effec e c d c f e ea c .

Keywords: Da a P. ec Ac 1998, e c , acce , effec e e ea c

Introduction

The purpose of much social care research is to provide evidence that can be utilized to inform policy and practice and enhance the well-being of vulnerable

children and families. However, as policy makers themselves recognize, 'research can involve an element of risk, both in terms of return on investment, and sometimes for the safety and well-being of the research participants' (Department of Health, 2003a, p. 3). These issues have been brought into sharper focus since the implementation of the Data Protection Act 1998 and the *Research Governance Framework for Health and Social Care* (Department of Health, 2003a); it is increasingly evident that careful governance is required to minimize these risks and promote the effective conduct of research. This paper draws on the authors' experiences as active researchers conducting externally funded research on children and families, and examines the impact a more transparent legal and ethical framework has had on local authorities and researchers, given their different roles and responsibilities within the research process and in respect of dealing with vulnerable groups. The difficulties experienced by researchers in gaining access to research participants in order to develop evidence-based policy and practice are also explored.

Whilst based primarily on the authors' experiences of conducting research on children in need and outcomes for vulnerable children, this paper also incorporates other researchers' accounts of the research process in different settings, including the NHS. Although the paper focuses upon research involving children, many of the issues raised are also likely to apply in relation to adult services research.

The role of research in local authorities

Social care, and child welfare in particular, is an intensely emotive field, and there is always a danger that legislation and policy will be influenced more by ideology and political pragmatism than by objective evidence (see Ward, 2000). This makes it all the more important that policy development should be underpinned by a strong evidence base. Since the 1980s, such a base has gradually been constructed through a series of government-funded research programmes (see, for example, Department of Health 1991, 1995, 1999a). Utting suggests that the lessons learnt from these studies have 'helped to redefine the relationship between the courts, personal social services, and families and children in need' (cited in, Department of Health, 1991, p. vi); in so doing, they have been instrumental in both the development of policy initiatives, such as Refocussing Services and Quality Protects, and in the construction of key pieces of legislation such as the Children Act 1989, the Children (Leaving Care) Act 2000, and the Adoption and Children Act 2002. The close link between social care research, policy and practice continues, with the government investing considerable sums in studies to evaluate current policy, inform decision-making and form the basis for future policy development. Shaw (2003) suggests that:

> Social work practice and services have gained in three broad ways from research. Research may shed light on the processes and outcomes of practice, thus assisting in building knowledge and skills for practice. Social work

> has also gained from the wider range of knowledge-questioning research that seeks to describe or explain social problems encountered by human services practitioners. Practice and research may mutually benefit from considering how far the perspectives and methods of one provide a template for the other. (Shaw, 2003, p. 111)

This is not to say, however, that such research is without its critics, for the validity of evidence-based practice in social work has frequently been questioned. Webb (2001) suggests that the increased emphasis upon and use of evidence-based policy has 'developed without critical commentary' (p. 59) and criticizes the separation of ' "facts" and "values" implicit in evidence-

Different perspectives

Policy makers require research evidence to respond to ministerial questions on key issues on the policy agenda and to develop and/or reform legislation, policy and practice. For instance, the research initiative on the costs and effectiveness of services for children in need was introduced partly in response to growing concerns that costs of providing care and accommodation appeared to be spiralling although the number of children looked after was diminishing. One aim of the research brief was to identify how the costs and effectiveness of different services could be compared more accurately. The need for the 13 research teams to complete their studies became more pressing when it became apparent that their findings would be of particular value to the policy initiative on Choice Protects, the purpose of which is to 'improve the outcomes for children looked after through developing better commissioning and service provision' (http:www.doh.gov.uk/choiceprotects/values.htm). As this example demonstrates, policy makers are under pressure to provide the government with clear answers to priority issues on the policy agenda, so as to facilitate social policy development and effective service delivery, and to promote positive outcomes for service users.

(Department of Health, 2002) acknowledges that when young people are consulted 'services become more responsive and better used by children and young people' (p. 59). The participation of local authorities in research studies can be a means of facilitating consultation, as well as providing findings that are essential to the evaluation and improvement of services (see Skuse and Ward, 2003). However, at times, research may be seen as an unnecessary intrusion that detracts from the social work role of protecting vulnerable children and working with families.

Although, ultimately, all involved are united by a common desire to promote positive outcomes for children and young people in need, it is nevertheless evident that each of the parties that contribute to research experience different pressures as they fulfil their roles and responsibilities. These differences, which can lead to conflicting perspectives, have been thrown into sharper relief since the implementation of the Data Protection Act 1998. This framework is examined below and is followed by discussion of its implications for the effective conduct of research. Following this, strategies to facilitate the research process in the current context are examined, with reference to the different needs and expectations of those involved.

Legislative framework

In 2000, two pieces of influential legislation concerning information handling, confidentiality and human rights came into force. The Data Protection Act 1998 goes further than preceding legislation in introducing provisions to protect the confidentiality and privacy of personal information whether held on paper, electronically or in other formats. In addition, an ethical framework has been set out by the Human Rights Act 1998, which incorporates the UN Convention of Human Rights into domestic law and specifies core rights that are protected, including the 'right to respect for private and family life' (Human Rights Act 1998, Article 8). The provisions of the Human Rights Act widen the scope for individuals to challenge decisions made by local authorities which could be considered as having contravened this right (see for discussion, Williams, 2001).

This newly implemented ethical and legislative framework is important to ensure that all individuals are afforded protection from unwarranted intrusion into private matters. Personal data on vulnerable children and families, held by child welfare and other agencies, are particularly sensitive, as they relate to the private sphere of family life. Yet, access to such data is necessary to researchers who are commissioned to evaluate services and analyse findings that can be used to develop policy and practice to protect and promote the well-being of children and young people.

It is noteworthy that the Data Protection Act 1998 acknowledges certain exemptions when personal data are processed for research purposes. Providing that:

difficulties within children and families social work, with particularly high vacancy rates in London and the South East and difficulties concerning the retention of staff (Social and Health Care Workforce Group, 2000, p. 1). In certain localities, there are simply not enough staff available to facilitate the proposed work.

However, concerns about contravening the 1998 Data Protection Act are also apparent. Local authorities hold different understandings of the circumstances under which information can be made available to research teams or where additional permission from service users is required. Although provisions are in place to ensure that ethical and legal duties are met, legal challenges are costly, and some authorities prefer to decline invitations to participate in research which appears to lay too great a burden on their staff, or too great a risk of contravening the privacy of service users. Negotiation and recruitment of those local authorities that do participate also become increasingly complex; lengthy delays are not uncommon, as it can take several months to reach a decision. Such delays are costly to the research programme, as the commencement date of research may have to be postponed after staff have been appointed; where there are long gaps between the recruitment of a group of authorities, the comparability of data may be affected. Inconsistencies in the way data are stored, collected and formatted also make comparisons between local authorities difficult. Before being commissioned, Department of Health-funded projects are rigorously vetted by a Research Liaison Group whose membership includes policy makers, academics and representatives from the ADSS. However, some local authorities also request additional ADSS approval, a process that leads to further delays.

These issues are not confined to research in local authorities. Stalker and colleagues (2004) also identified a range of difficulties in gaining access to children in hospital for social care research interviews. Ethical approval from the Multi-

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threatens the conduct of any retrospective studies. Moreover, there are no routine arrangements to ensure that such data will be accessible in the future, for currently service users are rarely asked whether they would agree to the possibility of confidential information being used for research purposes at a later date. Theoretically, therefore, all studies should begin with participating agencies tracing all potential research subjects to gain their permission to be included. Where data were collected several years ago and subjects are likely to have moved frequently in the intervening period, agencies are unlikely to be willing or able to undertake such a time-consuming procedure in which the research team cannot, *de facto* participate. Such considerations can and do seriously compromise research projects.

Difficulties in practice

Thoughtful consideration of potential concerns at the outset can minimize the chance that the research will have unforeseen consequences for local authorities and research participants. However, certain issues only become evident during the course of research projects. Researchers have a moral and ethical responsibility to discuss such issues with local authorities and to negotiate an appropriate course of action. Whilst this has always been the case, different interpretations of the legislative framework make it increasingly difficult to anticipate how local authorities will respond to requests for access to specific data items, some of which can only be identified after a project has begun.

For instance, one follow-up study of long looked after children had collected data from legal documents held on case files for over a year before de

both parties. Some general debate and agreement as to which circumstances require additional permission, and which do not, would be valued.

Practical difficulties

In addition to the legal and ethical concerns that discourage some local authorities from participating in research, there are also practical difficulties. Researchers need to be aware that project requirements can impose considerable additional work on social services staff. It takes time to locate files, to answer queries and to clarify case material, all of which may be needed in addition to the hour or so allocated for a formal research interview. Experience indicates that despite these impositions, social services staff are generally cooperative, supportive and committed when they are involved in research. However, organizational structure and resource issues can cause difficulties.

Staff retention and shortages continue to have an impact upon research projects, even once authorities have been recruited. In the early stages, it is advisable to identify a liaison person in the authority, who will assist in facilitating the study by acting as a conduit between researchers, practitioners and managers. Difficulties are then encountered if this person either takes long-term sick leave or leaves the employment of the authority. Without a facilitator, research teams can antagonize social services staff as they may fail to appreciate other work pressures and make apparently unreasonable demands, approaching them, for instance, at inappropriate times, suJ-olaxo(o)mvese ol

too much administrative time. Consequently, the research timetable was delayed by several weeks (see Ward *et al*., 2003).

During the course of research projects, many local authorities experience organizational change. As *Safeguarding Children* (Department of Health, 2002) identifies, the scale of change during reorganization means that relationships have to be 're-formed and open communication and trust established' (p. 42). Staff morale is often very low at such a time, as a result of job uncertainty. These issues can exacerbate many of the difficulties noted above. Moreover, the process of locating case files takes longer at such times as there are often delays before new information concerning case allocation is updated on the management information system (Ward *et al*., 2004).

The delays encountered as a result of these difficulties may make it necessary to employ additional contract researchers to ensure that research projects are completed within agreed time frames. However, additional time must then be spent familiarizing them with the aims of the study, interview schedules and/or databases. Furthermore, employing additional researchers reduces the consistency in database and/or interview data.

Practical difficulties may also arise when seeking to contact individuals for interview. For instance, researchers undertaking a retrospective study of looked after children found that addresses held by local authorities were often out of date. On one occasion, a researcher arrived at an address to find the building had recently been demolished. Even when addresses are correct, this does not guarantee that the interviewee will have remembered the researcher is coming. Such problems increase the time it takes to complete interviews and therefore the costs incurred. Despite these difficulties, there is evidence that children like being interviewed (see Skuse and Ward, 2003). Research investigating the views of young people with a chronic illness or disability who were involved in NHS service development projects revealed that none of the young people disliked the experience. Furthermore, some identified clear benefits, including personal development and 'improved confidence and self-esteem and . . . feeling valued and respected' (Lightfoot and Sloper, 2003, p. 283).

Some authorities have raised concerns that vulnerable children are sometimes being approached for interview for more than one study. Attempts to prevent this happening have been made, with different research teams working in the same authority checking the proposed samples prior to the young people being contacted. Although this is a beneficial process, it is also time consuming and requires agreement from the local authority for data to be shared between research teams.

Access to children for interview

Both the Children Act 1989 [section 1(3)] and Article 12 of the UN Convention on the Rights of the Child acknowledge a child's right to participate in decision-making processes that may be relevant to their lives. Morgan and

colleagues (2002) suggest that this legal framework has focused attention on research designed to ascertain children's views. Recently, the Department of Health has taken steps to 'increase the involvement of children and young people in policy making' (Department of Health, 2003c, p. iii). The Social Services Inspectorate (2003) also identified effective consultation with service users as a contributory factor to a council's performance in social care.

Ethical issues in research with children tend to receive particular attention, given the status of childhood and the perceived vulnerability of this group (Morrow and Richards, 1996; Thomas and O'Kane, 1998); these issues have implications for the research process. A number of research studies have attempted to include the views of children and their experiences of being looked after. However, practical difficulties have been encountered in doing so.

Local authorities have differing perspectives on a preferred methodology for seeking informed consent; with regards to the merits of adopting either an opt-in methodology (where subjects agree to participate by formally responding to a letter) or an opt-out approach (where subjects are deemed to have given consent if they do not refuse to participate within a given timescale). The opt-in approach has ethical advantages because consent is actively given by the child/young person, following consent from a range of adult gate-keepers (see below), and is often preferred by policy makers and social service managers. However, it is problematic for researchers because it leaves them more reliant on the efforts of local authority personnel to facilitate access to data subjects. Given time constraints and personnel shortages, this tends to result in a smaller sample. In one study, the completion rate for interviews in local authorities that agreed to an opt-in methodology was 25 per cent compared with 61 per cent in those adopting an opt-out approach (Ward *et al*., 2004). Other evidence suggests that many children and young people welcome the opportunity of being involved in research, and that failure to respond to an opt-out approach is often due to their not getting around to returning a reply slip rather than an indication of a genuine reluctance to participate (Skuse and Ward, 2003).

Deciding whether or not it is appropriate for a child or young person to be approached for interview tends to involve a number of gate-keeping procedures. Hepinstall (2000) suggests that seeking access to looked after children is particularly problematic since 'the process requires contacts with social services managers on different levels, social workers, birth parents and foster carers' (p. 868). While from an adult-centred perspective this process may be deemed to be in the child's interests, it may exclude children who would have valued the opportunity to participate. A number of respondents in a recent study of care leavers said they enjoyed taking part because they valued being listened to (Skuse and Ward, 2003). Their involvement in the research provided them with an opportunity to express their views:

> They don't really know do they, how I've been feeling because they have not been to ask me but then they seem to think they know everything. It wouldn't be so bad if they'd said 'Now what's been happening to you'... What they do is act as if they do know (Eliza. Age at entry: 12 years. Age left: 13 years) (Skuse and Ward, 2003, p. 112).

This quotation offers one young person's reflections on the failure of adults to include her in the decision-making process whilst she was looked after. There is a danger that young people's right to be consulted as part of the research process may be similarly constrained. In another recent study (Ward *et al.*, 2004), the research team found that adults often declined the invitation to participate on behalf of children with disabilities because they felt that these young people would not react positively to a stranger or would have difficulties with communication, and/or with a change in their routine (cf. Lightfoot and Sloper, 2003). Our concern that gate-keepers may sometimes unnecessarily deny children the opportunity to decide for themselves whether or not they want to be involved in research echoes that of others (see, for example, Thomas and O'Kane, 1998; Hepinstall, 2000). There is also evidence that these issues are not confined to looked after children. Stalker and colleagues (2004) encountered difficulties in gaining access to children in hospital for social care research. They suggest that ethical monitoring be done in a way which 'enables the *children*, wherever possible, to choose whether or not to participate' (Stalker *et al.*, 2004, p. 382).

A number of 'child-friendly' research methods can be adopted to address adult concerns about children's involvement in research and in order to reflect their different competencies. For example, Marchant and colleagues (1999) used a range of methods in consulting disabled children and young people. Children's views were communicated in a range of ways, including 'speech, sign, symbols . . . drawing' (p. 5). Punch (2002) suggests that a combination of traditional research methods used with adults, alongside 'child-friendly' techniques may be appropriate (p. 330). The techniques adopted should be critically considered in the context of specific research projects. However:

> No abstract and universal prescriptive ethical rules can unthinkingly be followed in empirical social research with children, only guidelines for thoughtful considerations within and about the specific context (Edwards and Alldred, 1999, p. 266).

Facilitating the effective conduct of research

Evidently, different interpretations of legislation since the implementation of the Data Protection Act 1998 have raised new challenges for local authorities and researchers and have influenced the conduct of research. The Department of Health Research Governance Framework and the development of Caldicott Standards in Social Care offer welcome guidance on these issues (Department of Health 2001, 2003a). The responsibilities of researchers to ensufidentiality, to promote the well-being of participants and to act ethically are now clearly spelled out. It is anticipated th

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Researchers need to 'demonstrate to the agencies with which they work that they will respect the rights of service users' (Ward, 2004, p. 348). They need to ensure that the well-being of children takes centre stage throughout the research process. However, they also need to be sure that participating agencies will be fully committed to the research programme and will do what they can to facilitate its successful completion.

At the outset of a research project, it is helpful to draw up formal letters of agreement to clarify the roles and responsibilities of the research team and participating agencies. The responsibilities of agencies will include specific arrangements for approaching potential subjects to seek permission to allow the research team access to confidential data, agreements about the part to be played by agency personnel in locating case files and organizing interviews—and any payments to be made for additional administrative work—and the practical arrangements for accommodating researchers who have to spend time in agency offices. The responsibilities of researchers will include specific arrangements for recording, storing and managing confidential data, as well as protocols to be followed in the appointment and management of staff and the conduct of the research programme, and the extent to which the data may be used in other research projects in which the team are involved.

One major function of a formal letter of agreement is to improve the transparency of the research process. It is, for instance, at present by no means clear to most participating agencies how research staff are appointed and what checks are in place to ensure that they hold the interests of children as paramount. Given current concerns, it is surprising that it is not yet universal practice to make a satisfactory Criminal Records Bureau (CRB) check a condition of any research appointment that may involve access to children. The agreement should also set out arrangements for discussing any concerns regarding convictions for minor offences that do not involve children, in confidence, with a representative from social services who can advise as to whether they are of sufficient severity to render the researcher unacceptable to the agencies in which research is undertaken.

In addition to drawing up a formal agreement, it is also important to ensure that a project liaison officer from each participating agency is identified at the outset. This person should be the first point of contact within the authority. Their role will be to act as a conduit between the agency and the research team. They will contact the research team if the agency is experiencing difficulties in the conduct of the research; they should also be contacted if the researchers encounter any concerns during the course of the study, for example, if a young person discloses or makes allegations of abuse.

Disclosures are occasionally made in the course of interviews. It is therefore vital that a clear explanation of the limitations of the principle of confidentiality

are outlined to participants and the authority before fieldwork begins, both in the letter of agreement and in the preamble to interviews. Disclosures can be discussed, in confidence, with the liaison person to decide upon the most appropriate course of action.

The project liaison officer also plays a valuable role in disseminating information about both the content and the quality of data collected. Researchers should feed back study findings, not only to managers but also to social work practitioners, so as to inform training and practice. This is usually done through seminars organized by the project liaison officer. In addition, a number of anomalies such as disparities in data held on management information systems and case files are often found incidentally in the course of data collection. Agencies often appreciate being alerted to such issues, which are regarded as a valuable side-product of research involvement.

Conclusion

Prior to the implementation of the Data Protection Act 1998, ethical issues in the conduct of social research were often considered and addressed informally by researchers and managers within social services departments, neither of whom were working to formal guidelines. Concerns regarding the exploitation of vulnerable subjects and at times a lack of respect for confidentiality have resulted in a new legislative framework and guidelines, resulting in changes in the way social care research is carried out. nt and 17 Tw[(the)-5.83edare guTJ and at timechi

running of research projects, but also promote moral and ethical research designed to ensure that

Morrow, V. and Richards, M. (1996) 'The ethics of social research with children: an overview', *Children and Society*, **10**, pp. 90–105.

Punch, S. (2002) 'Research with children. The same or different from research with adults?', *Childhood*, **9** (3), pp. 321–41.

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