

Exploring the barriers and facilitators to health research with children and young people who are looked after.

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Introduction

Service provision for children and young people who are looked after should be evidence based, as far as possible, in order to improve their health and wellbeing. This evidence base comes from literature and research. Yet research with young people who are looked after is scarce despite their poor outcomes (For example, Dale and Watson, 2010). This paper provides some reflections on the research process of a health needs assessment in Fife, in which the experience and views of young people was critical (Dale, 2009). It will explore some of the barriers and facilitators in research relevant to health, and makes a plea for a more facilitative approach, within the existing regulatory systems.

Barriers to conducting research with looked-after young people

Procedural barriers

Our research project relating to the sensitive topic of sexual health of looked-after young people had senior support from NHS, social work, and experienced academic input. Nonetheless, it took approximately five months for ethical approval to be granted and several months to recruit just ten looked-after young people. It is correct that research should be open to scrutiny particularly to ensure that vulnerable people will not be harmed; however it has been discussed more generally in health that the need to seek ethical approval may discourage investigators from researching certain groups, in part due to the lengthy procedures (Hedgecoe, 2008; Schnitzbauer et al., 2009). Further justification and procedures may also be legitimately needed when researching vulnerable groups; this may mean fewer researchers and practitioners will carry out research with young people in the care system for fear of rejection by ethical committees, avoidance of lengthy ethical approval processes and poor projected sample sizes.

Gatekeeper barriers

Due to the complexity of the organisations involved with looked-after young people and their legal status, there is a strong dependence on gatekeepers to approach them about a research project. Gatekeepers for this group are most likely to be social work staff or residential child care practitioners. Ethical procedures usually stipulate that young people may not have direct contact with the researcher prior to expressing interest in the research. Therefore, a huge reliance is placed on these staff members to be enthusiastic about the research, understand the value of it, and have the motivation and time to discuss it with their young people.

There are a number of reasons why staff who are gatekeepers for young people may not see research as a priority. Contextual issues which impacted on recruitment in our study included that social work were preparing for a child protection inspection, undergoing re-organisation and had other service demands. Our research was also met with a certain amount of scepticism when approaching gatekeepers, despite senior social work support for the project. This included the belief of some staff members that though the research may inform interventions to improve the health of their young people in the longer term, there would be no tangible benefit to their young people. Some scepticism could have been a reflection of the topic area; sexual health may be either too sensitive, or there may be reluctance to accept this as a key area for looked-after young people. Many staff stated that there were no young people with whom they worked who were suitable to take part in interviews. This is perhaps linked to the concern by some that consulting directly with young people about aspects of their health and care may be indirectly harmful. In addition, previous consultations with looked-after young people several years previously had led to no service improvement or benefit for participating young people. After this experience, staff were protective of the young people with whom they worked, and less likely to inform them of future research. Unfortunately, this took away the choice of the young people about whether or not to participate. In addition, it is known that in research with children and young people, gatekeepers may 'select' participants they think may be suitable, which can skew research findings (Heath et al., 2007).

Interestingly, the barriers appeared less prevalent when attempting to recruit from private and voluntary settings. Half of the young people recruited for our research were recruited through the private or voluntary sector, and the process took weeks rather than the months it had taken to recruit young people from the statutory sector. Whilst there was a great deal of support from the statutory sector for the research, and assistance given by many staff members, they were clearly very busy and did not always have time to learn about the research, disseminate it to other staff members or discuss it with young people. Further, private and voluntary agencies are sometimes not able to access certain

health projects due to funding being targeted at those in statutory care therefore they may be more open to any input around health, even if it is research-based.

Barriers relating to young people

Once gatekeepers did identify young people suitable to take part, further issues affected recruitment their recruitment. For example there had to be at least 24 hours between a young person hearing about the research and actually taking part. On several occasions young people wished to take part at the time of hearing about it, but ethical protocols stated they could not. This proved difficult to explain to young people, and acted as a limitation to the establishment of necessary rapport. Once returning to conduct the interview, young people were sometimes unable to take part due to tiredness, personal issues arising since the first meeting, or simply not being available at the arranged time. This highlights the fact that the complex lifestyles that looked-after young people often have needs to be taken into consideration when designing research with this group. Even though this was a procedure laid down by the ethics committee, for some client groups questions arise about how 'ethical' it actually is (Pickersgill, 2009). Many young people clearly wanted to take part at the first meeting time, not 24 hours later. Hence it could be construed as being less ethical to always adhere to such procedures, as long as allowances are made if young people subsequently change their mind and wish their data to be withdrawn. The procedure also raises questions about the capacity of young people to make their own decisions. In one way, this is yet another life decision that is not under the control of the young people themselves.

Young people were also put off by the long information sheet (two-pages) and the consent form stipulated as part of the ethical approval procedure. Sometimes they were unwilling to read the information sheet since they said they knew enough about the project. This in particular introduced a formal air to the situation that did little to put participants at ease; a barrier previously highlighted in interview-based studies (Pickersgill, 2009). Information sheets should therefore be as attractive and user-friendly as possible for looked-after young people.

A further barrier resulted from concerns about privacy; one young person did not wish to take part due to the conversation being recorded. Some young people, especially in residential settings were concerned about being overheard or were unable to find a quiet space to talk to me, and were not willing to meet in another location. While these concerns were understandable, it shows the difficulties that can arise purely due to the environment. It is another area which must be carefully considered when designing research in this area.

Our research project was about sexual health. Sexual health is perceived as a sensitive topic, and young people may have inhibitions about discussing such

matters due to stigma (Mitchell & Wellings, 1998; UNICEF, 2009). A history of sexual abuse may be a factor for some young people who are looked after. Achieving healthy behaviours may be a particular challenge for these young people.

In order to ensure ethical research when investigating hard-to-reach groups, ethics committees should be encouraged to permit a degree of flexibility in the study protocol. This should not be there to exempt researchers from ethical conduct; rather, it would encourage reflective work that strives, at all times, to maintain a high standard of ethics and science.

Facilitators to research with looked-after young people

The first step to carrying out research with looked-after young people is to secure a group of gatekeepers who are enthusiastic about the research and have the time to disseminate invitations to participate. Therefore, requesting face-to-face meetings with staff and carers is very important. Identifying a research 'champion' within a team can assist in dissemination of information and promotion of the research among other staff members. An emphasis on the potential benefits of the research may be needed in order to convince staff of the value of the research, and should form a large part of any written information provided to gatekeepers. Since staff working with looked-after children and young people are very busy and work in environments which can be highly stressful, patience and persistence may be needed by researchers. This persistence will likely help relationships to develop between researchers and practitioners and may lead to an increase in the numbers of gatekeepers informing young people of the research.

Due to the scarcity of research with looked-after young people - particularly around sexual health - and their generally poorer health outcomes, the research process should be flexible and informal where possible. For example, the research could be carried out by or alongside suitably trained staff members already known to potential study participants. This may result in a greater uptake, dependent upon a good relationship between the staff member and young person. Issues of inadvertent coercion – and ways of deflecting this – must, however, always remain at the forefront of both the researchers' and the practitioners' minds.

In Scotland, although it may be good practice, it is not a requirement to obtain consent from a parent or guardian for those under 16 years old (Children (Scotland) Act, 1995; Medical Research Council, 2004). For this group in particular, direct invitations to participate would enable young people, especially those living away from home, to choose for themselves whether or not to take part. Literacy and trust issues may impede this approach, so such invitations should be designed with these challenges in mind. Researchers should strive

to write short, informal information sheets of less than one page to assist in reducing the formality, whilst still making every effort to make sure that young people understand the nature of the study and what their participation will involve, in order to ensure informed consent. In any case, researchers should remember that consent is a dynamic process that is constantly being navigated from study initiation to completion – it is not an ‘event’ that can be taken care of solely by a ‘one-off’ signature on a form (Kuczewski & Marshall, 2002). Finally, given the vulnerable nature of this group, researchers considering this approach must keep in mind at all time issues of power, and actively strive to avoid coercion.

Several of these points may represent barriers to a research proposal being passed by an ethical committee, and researchers may feel disempowered to challenge recommendations due to the authority that ethics committees hold (Dixon-Woods et al., 2007). However, if adequate justification is given to certain procedures, ethical committees may, perhaps, look favourably on an application and see that more flexible and informal research with looked-after young people may improve the quality and depth of research. Certainly, it behoves the research community to engage more directly with ethical committees on points that they feel will significantly compromise the study without tangible ethical gain, particularly when these committees require investigators to introduce procedures which may unnecessarily be a deterrent to the success of a project with a ‘hard to reach’ group.

Conclusion

This paper has provided a commentary on the issues faced by researchers when they are trying to engage with a hard-to-reach and vulnerable community such as young people who are looked after. Research is vitally important if we are to gain the evidence base needed for effective interventions with young people. At senior level, organisations need to see the value in legitimate research with appropriate partnership arrangements, senior oversight and governance, to improve the long-term health and wellbeing of this group of young people. Ethics committees may need to take a more flexible approach with these groups. Staff and carers where possible, should be encouraged to assist such researchers in recruiting young people since more research with this group is vital, in order to improve outcomes for them through further improvements to service provision. It is the responsibility of researchers to design studies which take into account the unique circumstances of looked-after young people. Equally, it is the responsibility of practitioners working with looked after children and young people to understand the potential value of research and to join researchers in a partnership that may lead ultimately to more positive outcomes for young people in care.

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