



ETHICAL RESEARCH INVOLVING CHILDREN

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NEW ZEALAND

INFORMED CONSENT

Addressing issues of consent and participation in research with young people

Background context:

The research project involved the exploration and mapping of the social capital of 50 young people aged between 14 and 18 years from a Shire in south-west of Sydney, Australia. This project was undertaken in partnership with a Community Links program. A key question addressed by the study was 'What is youth social capital?'

A literature review revealed that previous research on youth social capital was relatively scarce. Of those studies which have been conducted, much research has been criticised for the lack of appropriate attention paid to ethical details. Issues of concern raised by youth researchers have centred on several issues including lack of adequate consent, representation and participation by young people within these studies. Consequently, one of the aims of the research was to explore ways in which youth consent, representation and participation can be adequately ensured within the context of youth social capital research. An unexpected challenge faced in attempting to ensure adequate consent, representation and participation was the lack of avenues for youths under the age of 16 to 'spontaneously' partake in the research process.

The ethical challenge:

Adequate consent, representation and participation are a vital consideration of any ethical research project. These considerations can produce tensions between ethics committees' requirements, the practicalities of obtaining informed parental consent and young people's ability to spontaneously participate in research, which then has implications for the overall representation of young people, particularly those that are most marginalised. In my own study, this tension was often the case. Institution ethics approval required parental consent to be obtained for young people under the age of 16 years. This process involved informing parents of the purpose, risks and benefits of their child participating in the study. Gaining parental consent took extra time, and sometimes the young people appeared frustrated at needing to go through this process, when they were clearly desiring to participate in focus groups immediately. For these young people, participation was at the discretion and availability of their parent/guardian rather than their own desire to participate. While many parents did give consent, many others could not be contacted in time to participate in the focus group process, or parental consent was not given, thus negating the young person's agency. Hence, a significant challenge I faced in the evolution of the youth social capital research project was how to allow for young people, both over and under the age of 16, to participate in a spontaneous manner.

Choices made:

Clearly, the experience of negotiating consent in this study of youth social capital underlines the need to carefully consider the impact of consent requirements on young participants' representation and participation in research. It highlights the issues raised by parental consent requirements and the importance of obtaining young people's consent or dissent, independent of parental consent, as all young people, regardless of their age, should have a chance to evaluate and choose whether to participate in research of their own free will.

For youth under 16 years, self-referral was almost impossible. These young people could not, as their older counterparts often did, walk in off the street to join a focus group, or be invited by friends to participate at short notice. In order to allow these young people to participate, it was necessary to implement unexpected and on-the-spot processes to obtain parental consent. This often meant the need for a youth worker or the researcher to telephone the young person's parent to explain not only the project but also the necessity for the parent to come to the venue to sign the parent/guardian consent form - a sometimes time consuming and laborious enterprise.

On more than one occasion, I was faced with young people so eager to participate in the research project that they attempted to contact their parents to obtain signatures just minutes before the start of focus groups. At other times, at the insistence of the young people and with the backing of the group, it was necessary to delay starting the focus group by 15 minutes to allow the young person to rush home and obtain a parent's consent to participate. Thus, our methods and time allocation were necessarily adapted to allow for the consent process.

Reflexive questions/considerations:

Having examined these experiences, it is clear that we as researchers need to balance ethics committees' requirements, the need to obtain informed consent from parents and young people, with the right of the young people to choose to participate spontaneously. While only a finite amount of time can be given for research and processes such as adult consent are in place in order to protect a young person's welfare, researchers need to consider how young people can participate in research.

Some questions for reflection are:

- How can we as researchers ensure the participation of young people in research?
- How can the research process allow the time required for negotiation and parameters to assist gaining consent for young people under the age of 16 years to participate as spontaneously as possible?
- How can we balance the potential harm that a lack of parental consent may cause in low risk research against the potential benefits of spontaneous participation?
- What processes, such as parents being able to give consent for participation over the phone, can be incorporated into research methods in order to simplify the process for those under 16?

- And finally, what parameters, if any, can be used as best practice by researchers to determine a young person's ability to consent?

References

Billett, P. (2011). 'Youth social capital: getting on and getting ahead in life', PhD thesis, University of Wollongong.

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