



## Understanding the ethical requirement for parental consent when engaging youth in research

Title	Understanding the ethical requirement for parental consent when engaging youth in research
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Publication Date	2015
Publisher	Sense Publishers

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## **UNDERSTANDING THE ETHICAL REQUIREMENT FOR PARENTAL CONSENT WHEN ENGAGING YOUTH IN RESEARCH**

### INTRODUCTION

The participation of youth in research is conditional on obtaining their informed consent. When research involves youth below the age of 18 it is a well-established ethical principle to also secure parental consent as part of the research process.<sup>1</sup> While the term ‘youth’ is a fluid concept, as explained in the introduction of this volume, the focus in this chapter is on youth aged between 15 to 18 years. There is unanimous agreement among the research community on the need for parental consent when research involves young children. However, whether parental consent should be required for youth is a subject of debate. While considered an important safeguard, the requirement to obtain parental consent can prohibit youth, particularly those on the margins, from participating in research when parental consent is not feasible or preferable due to the nature of the study. Moreover, its focus on protection can fail to respect the competence of youth. It is illustrative of the disconnect that is said to exist between current theoretical perspectives on childhood and ethical requirements (McCarry, 2012; Skelton, 2008). According to Graham and Fitzgerald (2010, p.139):

In an era that is increasingly recognizing the agency of children and their capacity to participate in research we are also witnessing an increasingly ‘nervous’ regulatory environment in relation to research ethics committees and children’s involvement in research processes.

Reflecting these debates, ethical guidance on the need for parental consent differs throughout the world. What is considered unethical by some is considered ethical by others and there is the view that different research contexts require different responses (France, 2004). To provide greater clarity on the matter, this chapter draws on the literature and ethical guidelines to review current practice in relation to the application of the parental consent requirement. To provide an overview of the broader legal context the ethical requirement is operating within, the chapter outlines examples of how international and national law addresses the issue of capacity to consent. This is followed by a critique of current ethical guidance on the issue of parental consent. The stringent to the more flexible approaches adopted in different countries are documented.

It is observed that uncertainty around ethical requirements can lead to overprotectiveness (Felzmann et al., 2012). Conversely, greater clarity and an understanding of what is considered ethically acceptable practice has the potential to facilitate the participation of even the most marginalized youth in research. To meet this objective, the chapter concludes with an overview of innovative, yet

ethically compliant, strategies employed by researchers to enable them to adhere to the parental consent requirement.

#### CHALLENGES POSED BY THE PARENTAL CONSENT REQUIREMENT

Working in partnership with parents should in general be viewed in a very positive light. It respects the role of parents to protect their children and to ensure they are not manipulated or harmed (Jones, 2004). When the child or youth is not capable of understanding the consequences of being involved in research, parents can play a particularly important role. If equipped with accessible information on the study, parents can assess, and support their child to assess, the value, authenticity and possible outcomes of the study. Their intimate relationship with the child often means they are best placed to make a decision on whether participation is in their best interests. During the research process parents can take on a supportive role and provide guidance to their child in helping them to formulate their views (Graham et al., 2013). Parents can also be a reassuring presence. As Beazley et al. (2011) remind us, researchers can overlook the fact that they are relative strangers to the research participants. It is said that a further benefit of obtaining parental consent is that it can promote parent-child discussion on sensitive issues and enhance the relationship between the researcher and the community (Moolchan and Mermelstein, 2002).

While there are many potential benefits to obtaining parental consent, a review of the literature brings to light that much has been written about the challenges parental involvement can pose. Some of the key challenges outlined in the literature are revisited here. This review of literature involved a search of the academic databases Scopus and Web of Science using key terms and phrases such as 'youth', 'participatory research', 'parental consent' and derivatives of them. The focus was on social science literature. An internet search was also conducted using google to identify relevant reports. Although broadly speaking the literature located by the author emanates from Western countries, a study led by The Childwatch International Research Network<sup>2</sup> underscores that obtaining consent and access to children and youth for the purpose of research is a challenge experienced by researchers globally (Powell et al., 2011). This study, involving 257 researchers across 46 low, middle and high income countries<sup>3</sup>, found that the ethical issues of most concern to the researchers overall were overly protective ethical review processes and consent, gatekeeper and access issues. However, while these issues were of concern to researchers across low, middle and high income countries, they were of greatest concern to those from high income countries. The greatest concerns for researchers from low to middle income countries included cultural beliefs about children's place or role in society, fear for the child's safety and concerns that a sensitive topic may cause distress for the child.

It is evident from the literature that gaining access to potential participants by obtaining parental consent can be complex when the research is of a sensitive or private nature. In this volume for instance, Flynn and Saunders outline the complexities in securing parental consent when conducting research with children

## PARENTAL CONSENT

of prisoners. Seeking parental consent has also been identified as a barrier when the research is focused on topics that are in the interests of youth to remain private, such as, studies focused on sexuality (Valentine et al., 2001) or tobacco, drug and alcohol use among adolescents (Moolchan and Mermelstein, 2002). It can also present a barrier for transient, including homeless youth who have limited contact with their parents (Abrams, 2010) or for youth who are in a situation where there is no parent or legal guardian able to give consent for the child to participate. This has been identified as an issue when researchers have sought to involve young carers in studies in sub-Saharan Africa, where the AIDS epidemic has left children and youth in child and youth-headed households (Graham et al., 2013)<sup>4</sup>. Participation may also be precluded when parents, not acting in the interests of their children, are unwilling to provide consent due to their fear of a disclosure and a child protection intervention as a result of their child participating in the study. This can arise in the situation where there is substance misuse on the part of the parent and they may not want to encourage outside interest in their family life or where some form of child abuse and neglect is occurring in the home (Kennan et al., 2012; Roth et al., 2013). Requiring parental consent when operating in these contexts can deny youth the opportunity to participate in research. This is of particular concern when it silences those already marginalized and most in need of being heard by the very nature of the circumstances they find themselves in.

From a research perspective, requiring parental consent introduces potential consequences for the integrity of the research. The need for parental consent can present difficulties in achieving a representative sample (Shaw et al., 2014). It may bias the sample towards parents who are easier to access and reach, youth who have a good relationship with their parents and have fewer behavioral problems (Moolchan and Mermelstein, 2002). A study in the United States, which synthesized the literature related to the use of parental consent in school-based research on adolescent risk behavior, found that students who secured the consent of their parents were more likely to be female, white, from intact homes with more educated parents and less likely to smoke (Tiggs, 2003).

A further challenge posed by the parental consent requirement is that it can unduly exert adult power and influence over a young person's decision to participate in research. Children and youth may feel constrained to comply with the decision of their parent to provide consent or not (Graham et al., 2013). For this reason, even when parents provide their consent, the importance of emphasizing to the young research participant that they can withdraw their consent has been highlighted as an important safeguard to ensuring voluntary consent (McCarry, 2012; Shaw et al., 2011).

## CAPACITY TO CONSENT AND THE LAW

The law and ethical guidance are generally closely interlinked. To understand the broader context ethical guidance is operating within it is useful to examine how the issue of capacity to consent is dealt with in law. It is apparent in law that as children mature their competence is recognized and parental control diminishes

(Masson, 2009). However, this is a complex area of law and there is no standardized approach across jurisdictions regarding when children are deemed competent to make decisions independent of their parents.

The UN Convention on the Rights of the Child (CRC), which enjoys almost universal ratification,<sup>5</sup> established in international law the principle that “as children acquire enhanced competencies, accordingly, there is a reduced need for direction and a greater capacity to take responsibility for decisions affecting their lives” (Lansdown, 2005, p. 3). This principle is embodied in Article 5 of the CRC, which acknowledges the role of parents in providing direction and guidance to their child in the exercise of their rights, while explicitly making provision for the “evolving capacities” of the child. The CRC defines a child as a person below the age of 18 years. However, neither the Convention nor the documentation of the UN Committee on the Rights of the Child prescribes an age below 18 when competence can be presumed to be achieved. It recognizes that children are not a homogenous group and their acquisition of competencies will vary according to individual circumstances, social and cultural contexts, levels of support and life experiences (UN Committee on the Rights of the Child, 2009). According to Lansdown (2005), children therefore require varying degrees of protection and opportunities for autonomous decision making across different contexts.

This established principle in international law is not necessarily reflected in domestic law. An overview of the situation in Ireland and the United Kingdom is illustrative of two differing approaches concerning the law and capacity to consent. For example, in Ireland fixed ages are provided in law regulating competence or capacity to consent. The age of majority in Ireland, or the transition from minority (childhood) to majority (adulthood), is 18 years of age and it is only on obtaining majority that youth are deemed competent to make decisions independently of their parents. Nevertheless, there are many exceptions to this rule. Under Irish law, the age of consent for sexual relations is 17 and at 16 years of age a young person can provide autonomous consent to surgical, medical or dental treatments.<sup>6</sup> In contrast, the United Kingdom provides a good example of domestic law firmly establishing that competence should not be equated to a certain age and an individual assessment of capacity to consent is required. It was the 1985 *Gillick v. West Norfolk and Wisbech Area Health Authority* House of Lords case that had profound implications for the law governing capacity to consent in the United Kingdom. The court found that a child, including those under the age of 16, who has “sufficient understanding and intelligence to enable him or her to understand fully what is proposed”, has the capacity to independently consent to medical treatment.

Returning to the issue of parental consent in the context of research, there is no law governing the need for parental consent in relation to the participation of youth in social research in either Ireland or the United Kingdom. The Irish courts did come close to pronouncing judgment on the issue. In 2007 the Office for the Ombudsman for Children engaged in an extensive consultation exercise with children from across the country. Children and young people below the age of 18 were asked to vote on the issues they perceived to be most relevant to their lives. Parental consent was not sought for the 74,000 children and young people balloted.

An application was made by an individual to the High Court for leave to seek an injunction to stop the consultation, on the grounds that the Ombudsman had exceeded her authority in consulting directly with children in the absence of parental involvement. The court held that the Ombudsman had not exceeded her mandate (Irish Ombudsman for Children, 2007). However, it did not directly address or pronounce judgment on the issue of parental consent.

In the United Kingdom, there is a view that the *Gillick* decision applies to all matters, unless otherwise prescribed in law, thereby governing the need for parental consent concerning a child's participation in social research (Masson, 2009). Researchers in the United Kingdom conducting research with young lesbian and gay people, some of whom were between the age of 16-18, relied on the *Gillick* judgment as a justification for not seeking parental consent (Valentine et al., 2001; Skelton, 2008). However, the view that the *Gillick* decision is applicable to social research is not a unanimous view. Others have expressed uncertainty as to whether the case law governing a child's capacity to consent to medical treatment can be translated to the need for parental consent for a child's involvement in social research (Hill, 2005). Furthermore, there is uncertainty around whether it could be relied on as a justification for not obtaining parental consent in other jurisdictions (Felzmann, 2010).

In contrast to the situation in Ireland and the United Kingdom, in South Africa the enactment, in 2012, of section 71 of the National Health Act, No 61, 2003, categorically provides in law that health research can only be conducted with a minor (persons below the age of 18) with the consent of a parent or guardian. Health research is defined broadly in the Act as all research contributing to knowledge of "the biological, clinical, psychological or social processes in human beings". It is said that this broad definition of health research could encompass and place the same demands on social science research (Zuch et al., 2012).

Before concluding this section it is worth mentioning the right of a child or youth to privacy. The right to privacy is a fundamental human right of all human beings, including children and youth and one that is recognized in law. Under international law the right of a child to be protected from arbitrary or unlawful interference with his or her privacy is explicitly protected in Article 16 of the CRC. It may be expected that the right to privacy is of relevance to a discussion on parental consent. However, in the literature reviewed, the right of youth to privacy is not an argument raised when debating the validity of the parental consent requirement. The focus is on the capacity of youth under 18 to consent as opposed to a right not to have their parents be aware of or interfere with their decision to partake in research. Similarly, the ruling in the *Gillick* case did not explicitly address the issue of privacy in terms of whether a confidential relationship should exist between a young person and a health professional, although it can be argued that this is implied in the judgment.

## ETHICAL GUIDANCE

While researchers must be aware of and heed the national law of the country they are operating within, when there are no laws governing the issue of parental consent ethical guidelines are the governing authority. Ethical guidance is not binding. However, adherence to ethical standards is generally deemed necessary to give credibility to the research and to satisfy university and funding authorities.

When children and youth below the age of 18 are involved in social research, ethically it is the norm that parental consent is actively obtained as part of the research process. This is an almost universal ethical requirement, with very little difference between low, middle and high income countries (Powell et al., 2011). An *International Charter for Ethical Research Involving Children* has been developed by leading academics in the field in collaboration with UNICEF and Childwatch International. It is intended to provide guidance to researchers worldwide irrespective of context and is a useful tool in the absence of national guidance. It states that, in all research involving children, children's informed consent must be obtained alongside parental consent (Graham et al., 2013).

In relation to a child's informed consent, there are some exceptions to the norm that a child's consent must be obtained. Some ethical guidelines require a researcher seeking to involve participants below the age of 18 to obtain their agreement or informed assent as opposed to informed consent. While a detailed discussion of this issue of a child's consent is beyond the scope of this paper it is worth noting that regarding the issue of assent, there is a growing movement away from solely securing a child's informed assent, as opposed to informed consent. Alderson and Morrow (2011, p.103) outline the following reasons for rejecting the use of the term assent: it fails to acknowledge that in law minors have been deemed competent to consent (for example the *Gillick* case); assent implies that children do not understand all the issues required for consent and it is questionable whether a partly informed decision can count as a decision at all; and it can mean "at least not refusing", which can mask a child's wish not to participate. Cocks (2006, p.249) reminds us that the process of seeking assent is a valuable method for securing the agreement of children who may not have the competence to consent, but acknowledges that it is not in itself sufficient and should be just one approach available to researchers operating within a "framework of ethical reflection".

The standard procedure for obtaining the informed consent of the young research participant and their parent comprises a number of steps. It requires the researcher to take the time to provide to the research participant and their parent adequate and accessible information on the study, to verify that they have understood the information provided, to ask the participant and their parent to voluntarily document their consent or refusal and to ensure that all parties are aware that consent can be renegotiated or withdrawn at any stage of the research process (Roth et al., 2013; Graham et al., 2013). These steps outline the process in obtaining active consent. While not generally the favored approach from an ethical perspective, as discussed later in this chapter, in some circumstances the parent's passive as opposed to active consent is deemed sufficient. It is also said that the consent of one parent is generally deemed sufficient, unless the research is of a

particularly sensitive nature, exceptionally burdensome or focuses on familial relationships (Shaw et al., 2011).

The question can be asked whose consent should be sought first, the parents or their child's. Guidelines for research with children and youth recommend obtaining parental consent first to avoid the scenario where a child agrees to participate and subsequently finds out the parent has not provided consent (Shaw et al., 2011). However, there is some evidence that this does not correlate with the views of children. A small scale consultation with children on the matter revealed that some of the young participants were of the view that a child's consent should precede parental consent (Felzmann et al., 2012). They noted that, in the context of researchers recruiting participants in the school setting, their consent is effectively obtained first as they act as gatekeepers choosing whether to pass on the consent forms to their parents or not.

Some ethical guidelines take into account the difference between young children and mature minors, in terms of competence to consent and the need for parental involvement. In certain circumstances exceptions to the norm of requiring parental consent up to the age of 18 will be permitted. However, on this issue, there is no definitive agreement. Ethical frameworks can vary greatly on the issue of whether parental consent is required for mature minors and in many countries there is no clear regulation of parental consent. A review of current ethical guidance reveals that there are a number of frameworks that ethical oversight bodies can operate within when seeking to maintain ethical standards in research involving minors. These can be broadly distilled as follows:

- Parental consent is required in all circumstances up to the age of 18;
- Provision of a fixed age below the age of 18, whereby parental consent is not required once a child reaches the prescribed age;
- General requirement of parental consent up to the age of 18, but provision is made for a waiver.

Each of these frameworks and illustrative examples of how they operate are set out and critiqued below.

#### *Requirement of Parental Consent in All Circumstances Up To the Age Of 18*

This approach embodies the most stringent application of the parental consent requirement. As set out above, it is evident in the legislative framework governing the need for parental consent in health research in South Africa. In terms of ethical guidelines, the situation in Ireland provides a good example of national guidance adopting this approach. In 2012, the Irish Government Department of Children and Youth Affairs published ethical guidance for social science research projects involving children. These guidelines were developed in part to encourage standardization in the approaches adopted by research ethics committees across Ireland (Felzmann et al., 2012). They state that parental and/or guardian consent is required for a child, defined as all persons below the age of 18, to participate in research. No provision is made for exceptions to this requirement. Of note, these guidelines are also an example of guidance that does not require a researcher to



secure a child's consent. However, according to the guidelines good practice requires the child's agreement (informed assent) to participate in the research.

On the one hand this approach is clear-cut. The same ethical rules apply to all research participants below the age of 18 and it relieves ethics committees of undertaking the onerous task of making an individual assessment of whether parental consent is required for the study under review. However, on the other hand, its emphasis on protectionism and its rigidity has the potential to exclude youth under 18 from participating in research. The approach is at odds with the broad recognition of the evolving capacities of youth to make decisions, when appropriate, independently of their parents.

#### *Provision of Prescribed Age Limits Below the Age of 18*

This approach makes the assumption that mature minors of a fixed age have the ability to consent to participate in research independently of their parents. Ethical guidance in New Zealand is illustrative of this approach. According to the national ethical guidelines for health and disability research, the consent of youth aged 16 and over to participate in research must be treated the same as if they were of full age. Their informed consent is sufficient and the consent of parents does not need to be obtained (National Ethics Advisory Committee, 2012). Similarly, in Sweden parental consent is not required for youth who have attained the age of 15 or in Poland for those over the age of 14.<sup>7</sup> The New Zealand framework referred to above also makes provision for children, below the age of 16, to demonstrate their ability to provide informed consent without the need for parental consent. Unlike youth over the age of 16, whose competence is presumed, this requires an individual assessment of the child's "competence to understand the nature, risks and consequences of the research".

Providing a fixed age below the age of 18, whereby parental consent is not required once a child reaches the prescribed age, is a more flexible approach to meeting the parental consent safeguard. It ensures consistency in approach to research involving youth of the prescribed age and removes the need for an individual assessment of competence for those within this age bracket. Arguably, not requiring parental consent for those above the prescribed age and below the age of 18 could expose them to the risk of harm. However, it recognizes their capacity to make their own assessment, independently of their parents, as to whether participating in research is in their best interests. In any case, it is to be expected that the ethical review process as a whole should act as an important safeguard to minimize the risk of any potential harm. Where the opportunity is provided for those aged under the prescribed age to demonstrate competence, such as in New Zealand, this makes allowance for current thinking that children acquire competence at different ages influenced by their personal experiences (UN Committee on the Rights of the Child, 2009; Lansdown, 2005; Hill, 2005). However, it places an onerous and challenging obligation on researchers to make an individual assessment of competence and to justify their analysis to ethical oversight bodies.

*Parental Consent Is Required Up To the Age of 18 but Allowance Is Made For a Waiver*

A review of current ethical guidelines brings to light that a more common approach to the parental consent safeguard is to require researchers to obtain the consent of parents when involving children and youth up to the age of 18, while making an allowance for a waiver in certain circumstances. Provision for a waiver is not focused on the competence of children and youth, but rather the research context. For example, in Denmark an exemption may be granted to the parental consent requirement when a minor has turned 15 years of age. A decision by a research ethics committee to grant an exemption must take into account the nature of the research and the level of risk (National Ethics Advisory Committee, 2012).

In the United Kingdom and the United States of America, ethical regulations also allow for a waiver of the parental consent requirement. However, the age at which a waiver may be acceptable is not prescribed in the ethical guidance reviewed here and neither is criteria established for when a waiver can be applied. In the United Kingdom, the leading organization for funding research on economic and social issues, the Economic and Social Research Council (ESRC), has developed a Framework for Research Ethics. It is mandatory for ESRC funded research to comply with the Framework, but it is also intended to establish “good practice for all social science research” (Economic and Social Research Council, 2012). The Framework allows for a waiver of the parental consent requirement but offers no further guidance than requiring that, where consent is not obtained, this should be justified to the research ethics committee and their approval obtained. Federal regulations governing the protection of human research subjects in the United States provide that, Institutional Review Boards (IRBs) may waive the parental consent requirement if, in light of the research conditions or the subject population, obtaining parental consent is not a reasonable requirement to protect the research participants (US Department of Health and Human Services, 2009).

While these Federal Regulations do not provide any detailed guidance on when a waiver can be applied, a study by American academics has shed some light on the practice of IRBs (Wagener et al., 2004). The study participants comprised 49 IRBs, primarily associated with university or academic institutions. Almost half of these IRBs granted waivers of parental consent for non-medical research. Among the research participants who indicated that their IRBs never granted waivers, some had not received such a request, however, the more common response was that parental consent was deemed essential or always required. The most common influencing factors, identified by those who had experience of IRBs granting a waiver, were: the research posed minimal risk; the subject matter; and the inability to carry out the research without parental permission. In the United Kingdom, the National Children’s Bureau, offers some guidance on when a waiver to the parental consent requirement may be appropriate. Their Guidelines for Research with Children and Young People suggest that parental consent should not be obtained for 16 and 17 year olds, unless the research is taking place within the family home, the participants are a particularly vulnerable population group or are in the care of

the state, in which case consent must be obtained from their social worker. If children are under 16 according to the guidelines, parental consent can be waived if seeking it would breach the child's confidentiality, such as they are using a service without their parents knowledge (Shaw et al., 2011, p. 30).

This type of ethical framework, whereby there is a general requirement of parental consent up to the age of 18 but provision is made for a waiver, offers an element of flexibility and is cognizant of the challenges the parental consent requirement can pose. Again its implementation can place an onerous task on ethical oversight bodies to assess whether a waiver of the parental consent requirement is justified and is in the interests of the research participants. However, the available guidance on when a waiver may be appropriate can aid the process and is less challenging and resource intensive than making an individual assessment of competence.

#### ETHICALLY COMPLIANT PRACTICE

When parental consent is required this generally involves obtaining the informed written consent of parents or legal guardians. Some alternative practices have emerged that are also considered ethically compliant. Passive consent is one such strategy that has been employed by researchers in meeting their obligation to obtain the consent of parents (Thomas and O'Kane, 1998; Heptinstall, 2000; Roth et al., 2013). Passive consent, or what is also known as the opt-out approach, is where parents receive information about the study and the researcher's intention to ask their child for their consent to participate. If no objections are raised by the parent they are deemed to have given their consent. Ethics committees in general are said to favor active or opt-in consent procedures (Graham and Fitzgerald, 2010). Evidence of this was found in the Wagener et al. (2004) study. Their research, conducted with IRBs in the United States, found that over half of the participating IRBs do not allow for passive consent. However, Shaw et al. (2011, p. 27) advocate an openness to using this approach and state that whether to adopt an opt-in or opt-out approach to consent should depend on the vulnerability of the young research participants, the nature of the research burden on the participants, the methodology employed and the sensitivity of the subject matter.

There is evidence that the procedures used for parental consent affect a studies participation rates. Tiggs's study in the United States (2003) found that, when passive parental consent is sought in school based research on adolescent risk behavior, parental permission is typically obtained for 30 percent to 60 percent of those sampled, compared to 93 percent to 100 percent when passive consent is relied on (Tiggs, 2003). Obtaining verbal consent over the phone, as opposed to written consent, is another approach which is considered ethically compliant and one which is effective in encouraging parents to be more responsive (Sime, 2008). It has been found that a key influential factor in the recruitment of hard to reach young people is taking the time to establish a relationship with gatekeepers and raising awareness about the importance of the study on a one to one basis (Kennan et al., 2012). The phone may facilitate one to one contact and initiation of a

relationship when it is not possible to meet with the individual parents to secure their written consent.

Other ethically compliant strategies adopted to satisfy the parental consent requirement can be conducive to including even the most marginalized youth in research. It is considered acceptable practice for a social worker's consent to replace that of parental consent, where children and youth are subject to a full care order or parental consent is not possible to obtain (Shaw et al., 2011; Heptinstall, 2000). Where parental consent or the consent of a legal guardian or social worker is not possible to obtain, an alternative approach adopted by researchers is to identify a trusted or responsible adult to give consent for the children to participate. In a study on young carers in sub-Saharan Africa, which was undertaken in the context of the AIDS epidemic leaving children and youth in child and youth-headed households, researchers asked the children to identify another "trusted adult", such as a teacher, aunt or grandparent to give their consent for the child to participate in the research (Graham et al., 2013). Similarly, a study in the United Kingdom with unaccompanied or separated asylum seeking children meant that parental consent was impossible to obtain. Obtaining the consent of their social worker was also not an option as many of the children did not know who their social worker was. In this case, when the child was under 16, the researcher sought the consent of a "responsible adult", such as a Children's Unit Manager or other adult working with the children in their place of accommodation (Hopkins, 2008).

It has been suggested that the use of online questionnaires may circumvent issues of consent and improve access to potential research participants (Curtis, 2004). However, this is not in keeping with ethical guidance that has provided direction on the issue. It is said that it is critically important for online research to obtain informed consent and to explore ways of ensuring the consent obtained is both genuine and informed (Graham et al., 2013). Shaw et al. (2011) provide two possible options. The first is an opt-in process, whereby the online survey commences by asking the respondent's age and, if the age signifies that parental consent must be obtained (this will depend on the ethical requirements the study is subject to), the software should be automatically programmed to ask for the parents contact details. The onus is then on the researcher to make contact with the parents and to obtain parental consent. The second is an opt-out procedure, whereby if the participant indicates in an opening question that they are of an age where parental consent is required, they will be asked to consult with their parents and indicate they have done so by, for example, ticking a box. In relation to either process, as there is no way of verifying the information supplied, Shaw et al. note that web-based surveys are generally not recommended for research with children and youth and certainly not for research of a potentially sensitive nature. Finally, educational settings have been identified as important access points for researchers seeking to engage children and youth in research (Kirby and Bryson, 2002; Sime, 2008). However, there is nothing in the literature to suggest that the access school authorities provide to researchers can circumvent the need for parental consent.

## CONCLUSION

In conclusion it is worth re-emphasizing that the requirement for parental consent is an important safeguard to protect children and youth from harm and one that should not be renounced lightly. This chapter has examined the dilemmas that can arise as a result of the parental consent requirement. The review of the literature and ethical frameworks is intended to go some way towards dispelling the ambiguity surrounding the parental consent requirement. While it is not the intention of the chapter to advocate one approach over another, what the review of the literature has brought to light is the importance of a flexible and tailored approach. Ethical guidelines offer a useful framework for researchers to operate within, but they should not close down any debate on how the appropriate balance between protecting children and youth from harm and enabling their participation in research can be achieved. It may be useful for researchers and ethical oversight bodies to keep in mind the words of Cree, Kay and Tisdall (2001, p. 48):

[C]odes of ethics and guidelines for research with children offers a helpful starting-point for building an ethical research study...[t]hey offer topics for consideration rather than ‘blue-prints’ for good practice, and this is important given the uniqueness of individual research projects.

We are often reminded that children and youth are not a homogenous group. As this chapter has outlined, understanding and assessing the local context, that is the immediate context in which the study is operating within, is crucial when determining how to observe the safeguard of parental consent. First and foremost it requires the researcher to be aware of the law and ethical guidelines in the country they are operating in. It may include factoring in the participant’s age, capacity, societal and cultural considerations, the nature of the research study and level of risk posed to the participants. While the local context must be taken into account, learning can also be drawn from the wider global context. Understanding what is considered ethically acceptable practice by looking to the law and ethical guidance offered in different jurisdiction across the world, as well as drawing on the lessons learnt from researchers grappling with the requirement of parental consent, can provide important guidance and learning for ethical oversight bodies, legislators and researchers. With this knowledge also comes the potential to challenge some of the more conservative approaches.

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<sup>1</sup> The use of the term parental consent in this chapter is intended to encompass the consent of a parent or a legal guardian.

<sup>2</sup> The Childwatch International Research Network is part of Childwatch International, a global, non-profit, non-governmental network of institutions that collaborate in child research for the purpose of promoting child rights and improving children’s wellbeing around the world.

<sup>3</sup> In the study the authors use the terms Majority and Minority world, equating countries with low and middle income economies with Majority world countries and countries with high income economies with Minority world countries. Here the author uses the terms low, middle and high income countries in keeping with the terms used in this book.

- <sup>4</sup> See Case Study 16: Caregiver consent for child participation in research: Reaching and protecting the most vulnerable. Contributed by Lucie Cluver, Franziska Meinck and Mark Boyes. Young Carers South Africa, University of Oxford. Available at: [http://childethics.com/wp-content/uploads/2013/11/ERIC\\_Compedium\\_Case-Studies\\_Informed-Consent\\_Lucie-Cluver-Franziska-Meinck-and-Mark-Boyes.pdf](http://childethics.com/wp-content/uploads/2013/11/ERIC_Compedium_Case-Studies_Informed-Consent_Lucie-Cluver-Franziska-Meinck-and-Mark-Boyes.pdf)
- <sup>5</sup> Three UN member states have not ratified the CRC. These are the United States of America, South Sudan and Somalia.
- <sup>6</sup> Irish Criminal Law Amendment Act 1935, Non-Fatal Offences Against the Persons Act, 1997 and the Health Care Act, 1947.
- <sup>7</sup> For further information on the ethical guidance governing the situation in Sweden and Poland, as well as other European countries, see the website of the European Union Agency for Fundamental Rights. Available at: <http://fra.europa.eu/en/theme/rights-child?page=child-participation-in-research>

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