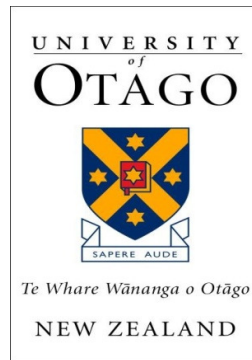


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INTERNATIONAL LITERATURE REVIEW: ETHICAL ISSUES IN UNDERTAKING RESEARCH WITH CHILDREN AND YOUNG PEOPLE

CHILDWATCH INTERNATIONAL THEMATIC STUDY GROUP: BUILDING
CAPACITY FOR ETHICAL RESEARCH WITH CHILDREN AND YOUNG PEOPLE

Childwatch
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EXECUTIVE SUMMARY

This paper reviews recent literature regarding ethical issues in research with children and young people. This is a topic that has seen a significant growth in interest over recent years, in response to developments in both child research and ethics (Alderson & Morrow, 2011; Hill, 2005; Farrell, 2005). Whilst acknowledging the clear importance of the issues related to medical and psychological research studies *on* children, they are beyond the scope of this review which is focused on ethical issues related to research *with* children, who are actively participating and expressing their views and opinions.

Child research ethics

Research ethics is a complex construct, essentially concerned with the principles of right and wrong conduct (Gallagher, 2009), that reflect various epistemological paradigms and methodological practices within particular social and cultural contexts (Trussell, 2008). Over the last two decades developments within childhood studies have led to increased recognition of the importance of listening to children's voices and experiences, and emphasis on their rights to participation and expression of their views is recognised in the United Nations Convention on the Rights of the Child (UNCRC). Some researchers argue that these rights need to be translated into workable ethics (Bell, 2008; Robson, Porter, Hampshire & Bourdillon, 2009).

Increasingly, researchers question the assumptions that ethics can be reduced to codified sets of principles, and that following these systematically will make research more ethically sound (Gallagher, 2009). Consequently, a key theme in the literature is using ethics to promote exploration and examination of dilemmas, rather than purely as a basis for rules of research conduct (Hill, 2005; Tisdall, Davis & Gallagher, 2009; Alderson & Morrow, 2011). Researchers conducting research with children emphasise the ongoing nature of ethical considerations and that ethical issues need to be considered throughout the entire research process (Alderson, 1995; Alderson & Morrow, 2011; Hill, 2005; Lindsay, 2000; Morrow & Richards, 1996). The key ethical issues discussed in the literature are informed consent, protection of children, anonymity and confidentiality, and payment of research participants.

Key ethical issues

The ethical issue of consent has probably generated the most debate in regard to research with children (Alderson & Morrow, 2004; Cocks, 2006; Morrow & Richards, 1996). In the literature informed consent rests on four core principles: consent involves an explicit act, for example, verbal or written agreement; consent can only be given if the participants are informed about and have an understanding of the research; consent must be given voluntarily without coercion; and consent must be renegotiable so that children may withdraw at any stage of the research process (Gallagher, 2009). Ongoing debates in the literature regarding consent include the use of passive or active consent procedures (Cashmore, 2006; Ebensen et al., 1996; Langhinrichsen-Rohling, Arata, O'Brien, Bowers & Klibert, 2006) and the relative

merits of consent or assent with in child research (Alderson and Morrow, 2011; Balen et al., 2006; Cocks, 2006).

Underlying the ethical issue of protecting children from harm are the principles of beneficence and non-maleficence. These emphasise the importance of researchers balancing the desire to protect children from the potential harms of research, while allowing them to benefit from the results. Identifying benefits and harms to children participating in research is not always straightforward (Spriggs, 2007), particularly in social research where harm and risk is not as clear cut as in clinical studies. A hierarchy of gatekeeping, which functions to protect children from harm, increases barriers to children's participation in research (Hill, Davis, Prout & Tisdall, 2004; Hood, Kelley & Mayall, 1996; Masson, 2004; Miller, 2000; Morrow & Richards, 1996; Powell & Smith, 2009). Gatekeeping is particularly an issue when the children involved are considered especially vulnerable, which is then equated with requiring extra protection, or when the research topic is considered sensitive. Protecting children from harm, is a genuine concern (Butler & Williamson, 1994), but a strong protectionist discourse can deny children the right to express their views on matters of concern to them (Powell & Smith, 2009) and children may be gate-kept out of research on the basis of potential risk (Graham & Fitzgerald, 2010).

Significant ethical dilemmas related to confidentiality are raised in the literature. Privacy considerations in research include both the need to have a safe, private physical location in which the research can take place, and ensuring participants' privacy through anonymity and confidentiality. Most often, the setting in which research with children takes place is at school or home and in both of these locations confidentiality can be compromised, through difficulties finding private space and parents' curiosity and concern for the child. A contentious issue in the literature is the dilemma around the limits of confidentiality in the light of a child participant's disclosure of abuse or risk of harm. Fargas-Malet, McSherry, Larkin and Robinson (2010) consider that it is common practice for researchers to encourage the child to talk to appropriate adults, if they disclose abuse, or agree to the researcher doing so. However, opinions and practice about breaching confidentiality to report suspected child abuse are divergent (Cashmore, 2006).

There is no clear consensus in the literature on whether children should be paid for participation in research (Kellett & Ding, 2004) or what kind of rewards are appropriate (Gallagher, 2009). Some researchers view payment negatively as bribery or inducement, and others seeing it as fair recompense (Hill, 2005). Cultural context influences perceptions of research payment and incentives. In Majority world countries payment considerations include the fact that children participate in the economic wellbeing of the family and participation in research takes them away from reproductive or productive work.

Majority world contexts

There are common and universal ethical issues across world contexts, such as consent, protection from harm, confidentiality, payment, power disparities and authenticity in representation of children's views (Clacherty & Donald, 2007; Porter et al., 2010; Young &

Barrett, 2001). However, cultural, social, political and economic factors interact to pose particular challenges with regard to these issues in different contexts. The dominant theme in the recent literature about ethics in research *with* children in Majority world countries is the importance of context, and the difficulties and challenges inherent in applying ethics from Minority world contexts (Abebe, 2009; Ahsan, 2009; Nyambedha, 2008; Vakaoti, 2009; Young & Barrett, 2001). For example, the issues around informed consent are entirely relevant in Majority world contexts, but they are further complicated by particular practical challenges (Clacherty & Donald, 2007).

In many Majority world countries research *with* children participating (rather than research *on* children) is relatively new. There is a lack of regulatory mechanisms and monitoring of research projects (Leach, 2006) and a greater need to ensure that children are protected and respected (Vakaoti, 2009). Difficulties in ensuring confidentiality are compounded by the conceptualisation of childhood, and the inferior social status of children (Abebe, 2009). The issue of remuneration or payment is more complex in Majority world contexts, such as African countries, where children's lives vary greatly from those in Minority world countries on account of the economic imperatives driving households which require children to provide labour and other support within their extended families (Porter et al., 2010). Payment is seen as necessary compensation for the time in which participants would otherwise have been earning money (Vakaoti, 2009; Porter et al., 2010; Robson et al., 2009). The ethical issues in the literature regarding research in the Majority world context clearly have significant ramifications for cross cultural research. Ethical issues have different resonances in different world contexts, and research planned and undertaken in Majority world countries challenges assumptions underlying Minority world ethical guidelines.

Methodology and ethics

Methodology and ethics are integrally linked; ethically sound techniques are perceived as adding to the value of research and, conversely, methodological soundness can improve ethics (Thomas & O'Kane, 1998). Researchers have suggested that 'bad science is bad ethics' with the implication being that ethical assessment needs to include consideration of whether the research questions are worth asking and if the methods used are an effective way of answering them (Alderson, 1995; Thomas and O'Kane, 1998). Power is not the only issue, but it is a major one in considering the links between methodology and ethics. Power imbalances have been widely recognised as being the biggest ethical obstacle and challenge to researchers including children in research (Alderson, 1995; Mayall, 2000; Morrow & Richards, 1996; Thomas and O'Kane, 1998). Power has tended to be viewed as something that adults have more of than children. However, conceptualising the research relationship in this way is overly simplistic and researchers' experiences in the field, in both Majority and Minority world contexts, give rise to questioning the oppositional model of power (Ahsan, 2009; Barker & Smith, 2001; Gallagher, 2008).

Critical reflection on issues of children's voice and representation in research is an emerging theme in the literature (James, 2007; Komulainen, 2007; Lewis, 2010; Spyrou, 2011). Suggestions to redress power imbalances and facilitate understanding and representation of

children's views include using participatory methods, adopting different researcher roles, reflexivity and involving children throughout the research process (Ahsan, 2009; Gallagher, 2009; Hunleth, 2011; Kirk, 2007). James (2007) argues that the predicaments of representation are inescapable and therefore researchers have to find a way of engaging with it. Issues include acknowledging the situated character and context of children's voices (Spyrou, 2011) and the extent to which 'children's voice' can obscure the heterogeneity of childhood and the power disparities (Hunleth, 2011; James, 2007).

A growing trend in participatory research is research *by* children and young people, with children as co-researchers or primary researchers. Research by children provides a means of managing some of the dilemmas about children's representation, but not resolving it (James, 2007), as all research with children is mediated by adults and that processes of power remain (Clavering & McLaughlin, 2010; Kellett, 2010).

A strong trend emerging from the literature is researchers advocating the use of critical reflexivity (for example, Barker & Smith, 2001; Horton, 2001, 2008; Matthews, 2001a, 2001b; Morris-Roberts, 2001). Reflexivity is a means of managing the gap between adult researchers and child participants by encouraging self-awareness on the part of the researcher regarding assumptions about childhood and how this may influence the research process (Davis, 1998) and also on the choice and implementation of research methods (Punch, 2002).

Ethics mechanisms

Ethics mechanisms, including ethical codes and guidelines, and research ethics committees are means of trying to ensure that ethical standards are met and maintained in research. Researchers conducting research with children emphasise the ongoing nature of ethical considerations, however, most ethical codes place disproportionate emphasis on only certain features of the research process (Lindsay, 2000). An interesting debate in the literature concerns whether existing Minority world codes can be valid in other cultures (Skelton, 2008), with some researchers problematising the notion of universal ethics and advocating situational ethics (Ahsan, 2009; Ebrahim, 2010).

It is now a standard requirement that researchers in Minority world countries obtain approval from their institutional ethics committees and boards before commencing research projects (Bessant, 2006). Research ethics committees play a vital role in raising awareness of ethical issues and monitoring research standards (Alderson & Morrow, 2004). However, some researchers argue that current guidelines and protocols within universities and institutions are problematic, as they evolved from medical, rather than social sciences perspectives, and tend not to be child-centric (Skelton, 2008). There is a danger that after gaining approval from an ethics committee a project may be regarded as ethical in its entirety, and certain issues may given precedence by ethics committees, such as consent and protection (Morrow & Richards, 1996; Powell & Smith, 2006), but less attention be given to ethics as an ongoing social practice (Christensen & Prout, 2002). As well as protecting research participants, ethics committees also exist to protect researchers and manage risks to their institutions and universities (Graham & Fitzgerald, 2010; Morrow & Richards, 1996). A number of

recommendations and suggestions to improve the role and capacity of ethics committees have emerged from the literature, including means of increasing the expertise of ethics committees regarding children and directly including children and young people in their processes (Campbell, 2008; Carter, 2009; Coyne, 2010; Powell & Smith, 2006; Stalker, Carpenter, Connors & Phillips, 2004).

A gap has been identified in the literature regarding ethics related training of researchers. Beyond occasional references to the need for training to encompass particular aspects, and several publications which act as reference material or guides for students, novice and experienced researchers (for example, Alderson & Morrow, 2004; 2011; Matthews et al., 1998), there appears to be a dearth of literature addressing this issue.

Conclusion

Overall, there is a significant body of literature concerning ethical issues in undertaking research with children and young people. It covers a broad range of ethical issues, concerning both the nature and underlying principles of ethical research and the mechanisms which are in place to facilitate this. As interest in research with children and young people continues to grow, developments and understandings about methodologies and ethics increase too. A key focus of the literature is critical reflection on ethics in research practice, with clear demand from researchers for further development in this area. An area identified in the review which requires further exploration is the potential use of the UNCRC in progressing ethical research with children and fostering dialogue regarding research ethics in Majority and Minority world contexts.

1. INTRODUCTION

This paper reviews the current literature regarding ethical issues in research with children and young people. Child research ethics is a topic that has seen a significant growth in interest over recent years, in response to developments in both child research and ethics (Alderson & Morrow, 2011; Hill, 2005; Farrell, 2005), and consequently there is a large body of literature related to this. The burgeoning interest is clearly apparent in a preliminary search of the literature using the key words children, research and ethics, which revealed between 1,900 and 11,000 journal articles in four article database search engines.¹

The focus of this review is ethical issues in relation to undertaking research *with* children and young people. Clavering and McLaughlin's (2010) recent comprehensive literature review examined the ways in which children have been engaged in health-related research practices, and found that the three approaches used were best summarised as research *on* children, *with* children and *by* children.

There is a significant body of literature relating to research undertaken *on* children, mainly in relation to ethical issues concerning the involvement of children in clinical, non-therapeutic biomedical and psychological studies, including participating in Randomised Control Trials. These clinical research studies are at the more scientific end of the spectrum, underpinned by positivist epistemologies (Tisdall, Davis & Gallagher, 2009). This body of work raises significant ethical issues, particularly in a context of children's exposure to risk of harm, without the assurance of individual benefit to be gained. Exploration of these issues is increasingly important as there has been a move from medical and science research communities in the United States, since the mid 1990s, to increase access to healthy children to take part in trials that involve risk and harm (Coleman, 2007).

However, whilst acknowledging the clear importance of the issues related to medical and psychological research studies *on* children, they are beyond the scope of this review which is focused on ethical issues related to research *with* children, who are actively participating and expressing their views and opinions. This body of literature has grown exponentially in conjunction with the literature that signalled and accompanied the emergence of sociological studies of childhood, over recent decades. Childhood studies views children as competent social actors, who actively participate in the construction of their own childhoods, and have the right to express their opinions in matters that affect them, including research (Prout & James, 1990). The emergence of this new paradigm necessitated new methodologies in research (James & Prout, 1990; Pufall & Unsworth, 2004). Correspondingly, this has required critical reflection on the ethical issues, which is apparent in an increasing number of publications (see, for example, *Children's Geographies*, 6(2); *Ethics, Place and Environment*, 4(2); Alderson & Morrow, 2004, 2011; Greene & Hogan, 2005; Tisdall et al., 2009, as well as numerous other texts reviewed in this paper).

¹ The four article databases used were: Proquest; Academic Search Complete; PsychInfo (via Ovid) and CINAHL (via EBSCO).

Consequently, the literature reviewed in this paper excludes focusing on clinical biomedical and psychological research with children. The search was also refined to include peer reviewed, scholarly publications, in the English language.²

This paper has seven main chapters. Following this introductory chapter, the second chapter primarily focuses on literature defining and providing an overview of ethics in the context of research with children. Following this, the third chapter discusses the key ethical issues emerging from the literature. There are four sub-sections covering the issues of informed consent; protection of research participants; confidentiality and anonymity; and payment of research participants.

The fourth chapter focuses on the key ethical issues in different global contexts, namely Minority and Majority world contexts. The Majority and Minority world distinction is used to broadly delineate two different world areas. Majority world refers to the economically, poorer countries in which most of the world's population live, sometimes referred to as the 'developing world', namely Africa, Asia and Latin America. Minority world refers to the economically more privileged countries, such as Europe, United States, Australia and New Zealand. Clearly not all countries fit neatly into one area. However, distinguishing between the two is useful to enable reflection on "the unequal relations between these two world areas previously referred to with negative connotations (Third/First World) or with geographical inaccuracy (North/South, or East/West)" (Punch, 2001, p. 819). Ethical issues in Minority world contexts dominate the literature, however a number of recent publications have focused on research in Majority world locations. These have relevance for research in those areas, cross cultural research and also have aspects that are applicable in other contexts. Reference is made throughout the paper to both Minority and Majority world studies, however chapter four provides a more specific focus on the issues emerging from the literature.

The fifth chapter takes up the critical issues concerning the interplay between ethical and methodological choices. There is a significant body of literature exploring the ways in which methodology and methods can be responsive to, and integrated with, ethical research practice.

The sixth chapter considers the literature relating to ethical guidelines and regulatory standards, and the role of ethics boards and committees. It then addresses the issue of training researchers in ethics. The final chapter of this paper provides a conclusion to the review.

² The language exclusion criterion is an unfortunate limitation given the significant contribution to sociological studies of childhood from Nordic countries.

2. CHILD RESEARCH ETHICS

Research ethics

The “notion of ‘ethics’ is a complex construct, imbued with particular values and beliefs that influence how we approach research” (Graham & Fitzgerald, 2010, p. 134). Research ethics are, at their simplest, “principles of right and wrong conduct” (Gallagher, 2009, p. 11). They can be conceived of as “a set of moral principles and rules of conduct” (Morrow & Richards, 1996, p. 90), with ethical questions “woven through every aspect of research, shaping the methods and the findings” (Alderson & Morrow, 2011, p. 5).

The term ‘research ethics’ can be used to refer to ethical philosophies and also the mechanisms used to promote and enforce these, including the “bureaucratic systems of regulation, management and governance” (Gallagher, 2009, p. 13). These mechanisms and systems include ethical codes and guidelines, which are generally endorsed by ethics review boards and committees who monitor compliance of research proposals. The literature considered here refers to the first meaning, whilst literature pertaining to the mechanisms is reviewed in chapter six.

The major, well established and accepted principles of ethics in research include: autonomy, beneficence and non-maleficence, and justice (King & Churchill, 2000). Respect for autonomy gives potential research participants the freedom to choose and act without being constrained by others, including informed choice about participation in research. Beneficence and non-maleficence means that researchers have an obligation to assess the potential harms from research and work assiduously to minimise or eliminate them. Justice requires that all research participants are treated fairly.

These principles underlie ethical guidelines developed since World War II, mostly in response to wartime experimental atrocities (Farrell, 2005). The first of these, the Nuremberg Code (1947), applied particularly to experimental research, although it had wider relevance, and included the key ethical principles, operationalised in terms of voluntary consent, freedom to retract consent, and avoidance of unnecessary pain or harm (Hill, 2005). Initially, these ethical guidelines were primarily concerned with medical research, however, they were subsequently used as a basis for guidelines for social research.

Child research ethics

Understandings of ethics in research with children are embedded within particular contextualised understandings of children and childhood (Farrell, 2005). Ontological and epistemological assumptions held by researchers determine the methodological position taken in research (Dew, 2007) and influence the ethical position. Trussell (2008) points out that “ethical issues in research are constantly evolving, reflecting the various epistemological paradigms and methodological practices within a particular socio-historical context” (p. 164). Hence, the understandings and images of childhood that researchers hold will influence and

inform their methodological and ethical choices (Christensen & Prout, 2002; Mayall, 2000; Punch, 2002).

Discussion and debates surrounding children's involvement in research are "nested within broader discourses about the nature and status of childhood" (Munford & Sanders, 2004). Over the last two decades developments within childhood studies have led to increased recognition of children as competent, social actors and emphasised the importance of listening to children's views. Consequently, values and beliefs associated with this paradigm have impacted on research practice, leading to the growth of research *with*, rather than *on*, children (Claverling & MacLaughlin, 2010).

However, the social context in which research occurs, in the Minority world, has historically framed children and childhood in discourses of incompetency and vulnerability. The increased attention given to hearing the views and voices of children and young people, is in contrast to earlier (mostly medical and psychological) research, dominated by the positivist paradigm, with an emphasis on measurement, abstraction and statistical relationships (Hill, 2005). There are ongoing tensions between historical, dominant discourses and those more recent ones, drawing on childhood studies, of children's competence and agency. In addition, the current socio-political climate is one which is risk averse, and research ethics are under increasing surveillance and regulation (Farrell, 2005; Graham & Fitzgerald, 2010). The tensions inherent in undertaking research with children and young people, within the current socio-historical context, are reflected in the ongoing debates about ethical issues throughout this paper.

Alderson (2005) describes three main ethical frameworks, drawn on in medical ethics and applicable in social research with children. One of these is a *principles* framework based on the major, accepted principles outlined earlier of respect, justice and doing no harm. The other two frameworks are: a best *outcomes* framework, involving strategies for reducing harms and costs and promoting benefits; and a *rights* framework, involving children's provision, protection, promotion and participation rights. Alderson (2005) suggests that ethical questions are resolved by thinking about principles, outcomes and rights, and argues that these frameworks offer such broad guidance that researchers have to work out how best to apply them in any given research context.

Whilst there are some established ethical guidelines based on the major ethical principles,³ increasingly, child researchers question the assumptions that ethics can be reduced to codified sets of principles, and that following these systematically will make research more ethically sound (Gallagher, 2009). Instead there is the suggestion "that ethical process might be seen as an ongoing process of questioning, acting and reflecting, rather than straightforward application of general rules of conduct" (Gallagher, 2009, p. 26).

Subsequently, a key theme in the literature is the use of ethics to promote exploration and examination of dilemmas, rather than purely as a basis for rules of research conduct (Hill,

³ And will be discussed further in Chapter 6.

2005; Tisdall et al., 2009; Alderson & Morrow, 2011). For example, Alderson (2005) states that, “ethics is about helping researchers to become aware of hidden problems and questions in research, and ways of dealing with these, though it does not provide simple answers” (p. 29).

Inherent in the literature is the understanding that ethical dilemmas are going to exist, and are situational, requiring the ability to respond to unanticipated events (Birbeck & Drummond, 2005). “Ethics is about *how* to deal with conflict, disagreement and ambivalence rather than attempting to eliminate it” (Edwards & Mauthner, 2002, cited in Gorin, Hooper, Dyson & Cabral, 2008, p. 278).

An increasing number of child research publications reflect on research practice and demonstrate the “problematic, messy and contested nature of ethical dilemmas” (Gallagher, 2009, p.11). Discussion of research ethics includes acknowledgement that research does not exist in a vacuum, that surprises happen, and that researchers and participants are vulnerable, emotional, embodied beings in bodily proximity and contact with other beings (Horton, 2008). Some researchers report a sense of ‘failure’ as a function of the mismatch when putting ethical ideals into practice in the unpredictable, messy, real world (Horton, 2008; Robson, Porter, Hampshire & Bourdillon, 2009).

Approaching ethical practice as an ongoing process, rather than a codified set of principles, is consistent with the framework developed by Alderson (1995). This framework identifies ten ethical topics, around which Alderson formulated eighty questions for debate. The ten topics are: the purpose of the research; the costs and hoped for benefits; privacy and confidentiality; selection, inclusion and exclusion; funding; review and revision of the research aims and methods; information for children, parents and other carers; consent; dissemination; and the impact on children. These ten topics have been further revised and elaborated on to provide guidelines in Alderson and Morrow’s (2004, 2011) practical handbook for research with children and young people.

Alderson’s ten topics can be grouped in four categories (Hill, 2005, p. 65), as follows:

1. Involvement of children in the research
2. Consent and choice
3. Possible harm or distress
4. Privacy and confidentiality

Research ethics and children’s rights

The literature elucidates a relationship between the major principles underlying research ethics and human rights. Hill (2005) maintains that the small number of well established and accepted principles underpinning an ethical approach (autonomy/respect for persons, beneficence and non-maleficence, and justice/equity/non-discrimination), can be “developed and expressed as a set of rights: to self determination, privacy, dignity, anonymity, confidentiality, fair treatment and protection from discomfort or harm” (p. 65). Similarly, Bell (2008) identified values held in common by key human rights documents and various

research ethics statements, namely: respect for human dignity; informed consent; individual autonomy; equality; privacy and confidentiality; freedom of expression; access to information; and justice.

Children's involvement in research is underscored by increasing recognition of the citizenship and status of children, which has been universally recognised in the United Nations Convention on the Rights of the Child (UNCRC). The UNCRC has implications for researchers, both as an international charter of children's rights and as a framework for interpretation and application of children's rights in the context of research ethics.

Some researchers advocate incorporating a children's right perspective into child research ethics (Alderson, 2005; Hill, 2005). However, in exploring the relationship between children's rights and ethical considerations in research Bell (2008) determined an ambiguous relationship between them. She suggests that "Hill (2005) offers a practical way forward by suggesting that ethical child research can be guided by four commonly identified types of rights embedded in the UNCRC: welfare; protection; provision; and choice and participation" (p. 19), as follows:

1. Welfare – the purpose of research should contribute to children's well being, either directly or indirectly;
2. Protection – methods should be designed to avoid distress and contingency arrangements available in case of upset or situations of risk or harm;
3. Provision – children should feel good about having contributed to research as a service informing society, individuals, policy and practice;
4. Choice and participation – children should make informed choices about all aspects of participation, including consent, opting out, determining boundaries of confidentiality and contributing ideas to the research agendas and processes.

(Hill, 2005, p. 81)

Some researchers believe the rights of children and young people, as enshrined in the UNCRC, need to be translated into workable ethics (Bell, 2008; Robson et al., 2009). Bell (2008) maintains that it is not always apparent how children's rights are recognised in research ethics and considers that overtly acknowledging the correlation between them is one way to foster a rights based approach to research; "the principles reflected in the UNCRC, in particular, is a place to begin in the development of research ethics guidelines and as a way to assist child researchers when determining and contemplating ethical considerations arising in child research" (p. 19).

Recognition of children's voice is a key aspect of progressing children's citizenship, with an increasing acknowledgment of children's right to express their views (Alderson & Morrow, 2011; Lewis & Lindsay, 2000). Article 12 of the UNCRC,⁴ recognising children's right to

⁴ Article 12: State parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

express their opinions and have these taken into account in any matters that affect them, protects and promotes children's rights to participation and expression of their views. However, a New Zealand study indicates that is not easy for children to exercise their participation rights in research (Powell & Smith, 2009). Furthermore, despite the significant body of literature relating to progressing children's participation rights generally, there is little published about children's participation rights in research specifically.

The principles of the UNCRC have "created a research space and a culture that emphasizes children's and youth's competencies, and the importance in providing them with the opportunity to give voice to their own experiences, meanings and interactions" (Trussell, 2008, p. 166). The UNCRC, as a universal framework of children's rights, has the potential to provide the basis of a framework for a universal child research ethics charter.⁵

Whilst ethics have a moral imperative, and ratification of the UNCRC imposes upon the state "international legal obligations to accord children their rights under the Convention" (Tapp & Henaghan, 2000, p. 95), Gallagher (2009) cautions researchers against assuming that their ethical position will coincide with the law. Masson (2004) states, there is "a close relationship between law and ethics, but not everything that is legal is ethical" (p. 43). She describes ethical practice as having "higher aspirations" (p. 43) than law, which frequently only sets minimum standards to prevent bad practice (Alderson & Morrow, 2011). For example, there is currently no legal requirement in the United Kingdom for children's informed consent for research participation, but the ethical standards of professional bodies or funding organisations may have higher requirements of this (Masson, 2004).

There is clearly a link that can be made between children's participation in research, children's rights as recognised in the UNCRC, and ethical research with children. However, these links have not been fully explored in the literature. There is, therefore, huge potential for progressing ethical research by articulating and examining these links, and the concomitant meanings they have for children and researchers.

⁵ UNCRC has been ratified by all but two UN countries (Somalia and the United States of America).

3. KEY ETHICAL ISSUES

Researchers conducting research with children emphasise the ongoing nature of ethical considerations and that ethical issues need to be considered throughout the entire research process (Alderson, 1995; Alderson & Morrow, 2011; Hill, 2005; Lindsay, 2000; Morrow & Richards, 1996). The key ethical issues discussed in the literature are informed consent, protection of children, anonymity and confidentiality, and payment of research participants.

Informed consent

The ethical issue of consent has probably generated the most debate in regard to research with children (Alderson & Morrow, 2004; Cocks, 2006; Morrow & Richards, 1996) and a large body of literature is dedicated to discussions of consent. Although, Alderson (2005) notes that, despite this substantial body of literature, covert research in which children are watched or questioned without their own or their parents' permission is still widely accepted.

Informed consent is a process of three interactions: provision of information by the researcher; the potential participant understanding the information; and then making a response to it (Cocks, 2006). The interactive nature of this process makes it “a two way exchange of information, with the central feature present in all decision making of digesting information, weighing it up in light of personal values, and making and standing by a decision” (Alderson, 2002). Alderson and Morrow (2011) thus aptly describe informed consent as “the invisible act of evaluating information and making a decision, and the visible act of signifying the decision” (p. 101).

Gallagher (2009) considers that in the literature informed consent rests on four core principles:

1. Consent involves an explicit act, for example, verbal or written agreement.
2. Consent can only be given if the participants are informed about and have an understanding of the research.
3. Consent must be given voluntarily without coercion.
4. Consent must be renegotiable so that children may withdraw at any stage of the research process.

However, Gallagher goes on to note that “putting these principles into action is often challenging” (p. 16). Each of these principles will now be considered in turn, in light of the challenges involved.

First, consent involves an explicit act

A contentious and challenging aspect of consent in research with children is the issue of who provides the consent for the child's participation. Alderson (2004) maintains there are three levels of involving children in research, as: *unknowing objects of research* who are not asked for consent and may be unaware that they are being researched; *aware subjects* who are asked for their informed, willing consent within fairly rigid projects, for example questionnaire

surveys; and *active participants* who willingly take part in research that has flexible methods (p. 100). Each of these levels reflects power differentials in the research relationship (Trussell, 2008).

Children's involvement in research almost invariably requires agreement from significant adults in the child's life, most notably their parents. Trussell (2008) considers that the research with young people has unique, ethical complexities "as the research relationship often becomes a dynamic triad with multiple relationships formed between the research, the youth, and the youth's parent(s) or guardian(s)" (p. 167). These relationships require careful negotiation, particularly when the research takes place in the participant's home.

Researchers are in the position of balancing two imperatives: ensuring that children and young people can freely choose to participate (respecting their autonomy) and acknowledging parental responsibility to ensure children's safety and wellbeing (Munford & Sanders, 2004). The requirement for parental consent may be seen as a well intentioned, but restrictive safeguard, which impacts on children and young people's right to be self determining in participation.

In the United States there is an assumption of a fiduciary relationship in requirements for parental consent, and researchers may be more constrained by the law, which varies between states, than the United Kingdom, where one law provides the framework throughout the country (Bogolub & Thomas, 2005). The law and practice in the UK is complex, relating to the notion of competence, however in the US context there is a more cautious interpretation of legal competence and more stringent requirements for parental or third party consent (Cashmore, 2006). In the US ethics review boards can waive the requirement for parental consent, but this is not easily obtained or consistently applied. Research undertaken in Majority world countries by Minority world researchers adds another dimension to the debates about legal requirements related to consent, given the practical challenges that can be related to obtaining parents' consent. For example, challenges in African countries can include difficulties identifying and/or accessing the child's parent or caregiver, as a consequence of parental mobility related to employment, orphaned children due to HIV/AIDS, and caregiver illiteracy (Clacherty & Donald, 2007).

Whilst there appear to be no formal legal requirements around informed consent for children's participation in research in most countries, generally, researchers cite the legalities relating to consent to medical and health treatment as having resonance in the social research context (Alderson & Morrow, 2011; Hill, 2005). A core issue in the United Kingdom is perceptions of children's competence to make informed decisions about their involvement in research. Historically, it was assumed that children lacked the cognitive maturity and/or moral development to make these decisions (Coyne, 2010), but these assumptions have been, and continue to be, disputed and challenged by researchers and practitioners working with children (Alderson, 1995; Cocks, 2006; Danby & Farrell, 2004).

The notion of ‘Gillick competence’ is frequently raised in the literature. This relates to English law, and consequently has relevance in Commonwealth countries (Alderson & Morrow, 2011).

The legal distinction of ‘Gillick-competence’, which stipulates that a competent child is one who ‘achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed’ and further that the competent child has ‘sufficient discretion to enable him or her to make a wise choice in his or her own interests’, is important, because it highlights the fact that it is not simply chronological age which determines competence. (Morrow & Richards, 1996, p. 95)

Whilst ‘Gillick-competence’ was specifically related to medical care, it is referred to in many other areas, and provides a means of framing children’s competence in contrast to age based definitions.

The focus on individual capacity to consent implies that some children who may be considered incapable of giving consent, for example, very young or severely disabled children, cannot be active participants in research (Gallagher, Haywood, Jones & Milne, 2010). However, a recent study demonstrated obtaining consent from children with moderate or severe learning difficulties, paying particular attention to avoiding coercion (Lewis, 2010). Similarly, studies in early childhood contexts have demonstrated that even very young children are able to give informed consent if approached ethically (Bone, 2005; Hedges, 2002; Smith, Duncan & Marshall, 2005). Coyne (2010b) maintains that studies demonstrating young children’s competency abilities support the argument that, irrespective of age, children who can demonstrate understanding of the research and their rights should be allowed to consent or dissent to participation, without their parent’s consent being a foregone requirement.

Coyne (2010b) points out that some assumptions about children that are used to support the argument for parental consent, apply equally to adults. In response to the argument that children are unable to understand the risks, benefit and purpose of research Coyne cites reports that suggest “parents often find it difficult to comprehend and absorb the implications of the research for their child” (2010b, p. 231). She also notes that adults, as well as children, may agree to research in order to please researchers.

Hood, Mayall and Oliver (1999) note that, “researchers generally have to accept the status quo, that adults control children’s lives, and so they collude with adult permission-giving” (p. 18). However, Coyne (2010b) argues that “if we accept the view of children as ‘beings’ capable of understanding and participating on different levels in the decision making process, then the parental consent requirement is questionable” (p. 228).

Active and passive consent Parental consent may be obtained in several different ways. Using passive consent procedures parents are informed of the research and required to respond only if they do not want their child to participate (Ebensen et al., 1996). Although the meaning of a

non-response is fairly ambiguous, it is taken to be an affirmative response. A ‘tricky’ issue in using passive consent is ensuring that parents are actually informed (Cashmore, 2006). Informed passive consent can be compromised by parents not receiving the information, not being able to read or understand the information, or by children failing to inform the researchers that participation has been refused by the parents (Langhinrichsen-Rohling, Arata, O’Brien, Bowers & Klibert, 2006).

Active consent requires parents to give consent if they want their child to participate. A non-response is assumed to be a refusal of consent, and only those whose parents have formally consented are allowed to participate in the research. Using an active consent process allows researchers to feel confident that children and their parents have intentionally chosen to participate (Barron Ausbrooks, Barrett & Martinez-Cosio, 2009). However, it is not unusual in active consent procedures for parents to forget or fail to return the form despite having no objections to the research, thus denying children the right to decide for themselves whether or not they wish to participate (Carrol-Lind, Chapman, Gregory & Maxwell, 2006).

Researchers tend to prefer passive parental consent procedures to active consent procedures (Ebensen et al., 1996). This method means that inclusion in the research sample can be dependent on the child’s active agreement, and passive agreement of the caregivers (Thomas & O’Kane, 1998). The assumption that a non-response is an affirmative response increases sample size (Ebensen et al., 1996) and also privileges children’s decision making and participation rights (Carrol-Lind et al., 2006; Thomas & O’Kane, 1998).

Ongoing debates have ensued about whether active or passive consent procedures are most ethical when undertaking research on sensitive topics. Passive consent procedures allow researchers to bypass the usual gatekeepers and children to participate and contribute their knowledge in research about topics that are considered sensitive, such as children’s experience of violence (Carrol-Lind et al., 2006). Langhinrichsen-Rohling et al. (2006) argue that determining which consent approach to use “requires each researcher to conduct a cost-benefit analysis of his or her own research” (p. 428), with a lack of consensus amongst researchers with regard to determining minimum harm.

Ethics committees tend to favour active consent, or ‘opt in’ consent procedures (Alderson, 1995). It serves the purpose of respecting people’s privacy and allowing for freedom of choice (Alderson, 2004). However, it also has the effect of silencing many people, including children, who are dependent for the most part on someone else being sufficiently motivated to give consent for them to participate (Alderson, 1995).

Cultural and social context Ethical decisions are of course made in a cultural context, including whom consent is required from (Bogolub & Thomas, 2005). Passive parental consent, for example, is not favoured in Pasifika culture (Powell & Smith, 2009).⁶ The right to consent and pass on knowledge is a collective issue in Maori and Pacific cultures, involving

⁶ The term ‘Pasifika’ is used to refer to the New Zealand population who are Pacific Island people and their descendants.

the wider family and community, which is incongruent with the Minority world individualistic, ethical framework (Suaalii and Mavoa, 2001).

In some Majority world countries gaining active parental consent is not possible, due to difficulties identifying and locating parents or guardians, low rates of literacy and scepticism about signing documents (Abebe, 2009; Clacherty & Donald, 2007; Hutz & Koller, 1999). Issues regarding consent in relation to Majority/Minority world cultural contexts are discussed in some depth further on in the fourth chapter of this paper.

In some research studies, researchers argue that in some situations it may not be appropriate to ask for parental consent. These include studies with young people regarding sensitive research topics that require confidentiality and privacy for the protection of the participant, for example; sexuality (Valentine, Butler & Skelton, 2001) or drug use (Langhinrichsen-Rohling et al., 2006). It may also not be appropriate or possible to seek parental consent when children are 'runaways' and homeless (Meade & Slesnick, 2002), living on the streets (Vakaoti, 2009), or emancipated minors (King & Kramer, 2008).

Assent and consent Some researchers advocate the use of assent, rather than consent, in gaining children's agreement in certain situations (Balen et al., 2006; Cocks, 2006). Assent carries less weight than informed consent, but provides the alternative of an affirmative agreement of a child to participate in the research (Balen et al., 2006) and a forum through which their willingness to participate can be respected (Mishna, Antle & Regehr, 2004). For assent to be valid "the child must show evidence of understanding the purpose of the research, what he or she is to expect, and what will be expected" (Lee, 1991, as cited in Ireland & Holloway, 1996, p. 160), rather than merely failing to object.

Cocks (2008) explored and developed the use of assent in a project with children with learning impairments, and concluded that it is applicable for research in a variety of contexts. "In reducing reliance on 'competence', which in many ways prioritizes language and definable methods of understanding between the researcher and the researched, 'assent' increases the accessibility to research for children for whom these measures are difficult to achieve." (Cocks, 2008, p. 263).

A child's assent is given less power within the consent process than other representatives' consent (Goodenough, Williamson, Kent & Ashcroft, 2003). If a parent refuses consent, this outweighs a child's assent. However, conversely, assent enables the child to give or refuse their agreement to participate, in situations where parental consent has been given (Danby & Farrell, 2004; Balen et al., 2006).

However, Alderson and Morrow (2004, 2011) prefer to use the term consent, rather than assent for three reasons. First, assent is not needed when children are legally able to consent (as is the situation in the United Kingdom). Second, they question if a partly informed decision, made by assenting children who do not understand all the issues required for consent, can count as a decision and perceive it as having a "spurious quasi-legal status"

(Alderson and Morrow, 2011, p. 103). Third, they suggest that assent can be used to mislead and cover up children's refusal to consent.

Second, consent can only be given if the participants are informed about and have an understanding of the research

Informed consent involves children knowing and understanding the purpose of the research (Cree, Kay & Tisdall, 2002), with the ability to give informed consent depending on the quality of the explanation given (Bogolub & Thomas, 2005).

As defined by numerous professional standards, informed consent involves providing potential study participants information describing research procedures, including the research design and purpose, expected risks or benefits to the participants, expectations placed on participants, identification of the researchers and of any sponsoring or funding agencies, the right to refuse participation partially or entirely, and the willingness of the researchers to answer any questions concerning procedures. (Esbensen et al., 1996, p. 738)

Studies have shown that children understand the nature of voluntary participation and are able to participate in the informed consent/assent procedure (Chu, DePrince & Weinzierl, 2008; Kassam-Adams & Newman, 2005). However, the principle that consent can only be given if the participant has been fully informed is problematic in practice.

Informing participants about the research is often attended to by the preparation of a leaflet that is designed to appeal to children (Alderson & Morrow, 2011; Gallagher, 2009). The information provided about a project may not be read or may be misunderstood, with different understandings between the researcher and the participants, and also between participants (Gallagher et al., 2010). Children are likely to interpret information in the light of understandings they already have (David, Edwards & Alldred, 2001), which can lead to misunderstandings. Such "mismatches of understanding can be difficult if not impossible to detect" (Gallagher et al., 2010, p. 478). Therefore, it is important that researchers spend time orally explaining the research to potential participants (Alderson and Morrow, 2011).

Anticipating the outcomes of a research project, or what may occur during it, is not always possible. Particularly in qualitative research, which tends to be unstructured in nature, participants rarely know exactly what will happen (Cree et al., 2002) and children (and parents) may have difficulty assessing the range of potential risks (Mishna et al., 2004).

In addition, there is an inherent tension for researchers between wanting to ensure that research participants are fully informed, with consent freely given, and wishing to maximise participation in their research (Hill, 2005). A core ethical issue therefore is the extent to which it is permissible to hide or disguise part of the purpose of the research. Hill (2005) notes "covert or semi-covert research is often seen as unethical because it goes against the principle of informed consent" (p.69), but that some researchers in some situations see it as justified, believing that full disclosure of information will consequently limit the number of people

choosing participate. For example, an ethical dilemma in child maltreatment research exists around some researchers' decision to avoid the use of terms such as 'child abuse', 'child maltreatment' and 'child neglect' in the information provided to potential participants (Kotch 2000). Using these terms would increase the likelihood that less people would participate in the study, or allow their children to. However, not using these terms challenges the principle of full disclosure. It also contributes to what Saunders and Goddard (2001) term the textual abuse of children by "using language that effectively reframes and minimises the seriousness of offences committed against children" (p. 446)

Third, consent must be given voluntarily without coercion.

Given the nature of power relations between adults and children, it can be difficult to ascertain that children's consent or assent is given freely. Indeed, "children's consent must be seen in the context of constraints, obligations and expectations over which researchers have little control" (Gallagher et al., 2010, p. 479).

The literature includes exploration of the nature of children's decision making and consent in a range of different contexts. There has been criticism that consent from children is sought in contexts unfamiliar to them in medical research (Alderson, 2002) and in other research fields (Danby & Farrell, 2004). Research in the health field has found that when children have access to information and experience it increases their awareness of relevant issues, and presumably their competence, in decision making (Ireland & Holloway, 1996). In a study with hospitalised children, all of the children felt their consent was sufficient (as did their parents) and questioned the need for parents to sign consent forms (Coyne, 1998).

Health research studies have found that parents and clinician researchers influence children's understanding of the research and decision making processes (Broome & Richards, 2003; Coyne, 2010a; Dorn, Susman & Fletcher, 1995). The requirement of some ethics committees for parents to be present when children's consent is sought is perceived to lessen children's powerlessness. However, it may in fact have the opposite effect making it difficult for children to refuse participation (Miller, 2000). Children can be more likely to agree if both the professional and parents are supportive of the research (Cree et al., 2002). The 'sponsorship of trust', the way in which trust is passed on from one individual to another, makes it impossible to be certain that consent or assent has been independently given. One health study found that children wanted some parental input into decision making about research participation, but thought that the final decision should be theirs (Geller, Tambor, Bernhardt, Fraser & Wissow, 2003). Both parents and children in this study stressed the importance of children not being forced to participate in non-therapeutic research if they did not want to.

Participants in another health study thought the researcher would be unhappy if they withdrew from the study (Ondrusek, Abramovitch, Pencharz & Koren, 1998). The researchers in this study noted that there may be a range of reasons that make it difficult for children to withdraw participation, such as not knowing the practicalities of how to withdraw, by viewing the researcher as an authority figure, and being concerned that there may be negative consequences.

Case studies in which the researcher is the child's teacher or therapist illustrate how difficult it can be for children to refuse to participate when the researcher is also a practitioner (Tisdall et al., 2009). Adults hold a powerful position in relation to children in the school context (Kellett, Forrest, Dent & Ward, 2004; Sime, 2008) and children may feel an obligation to comply (Robinson & Kellett, 2004; Valentine, 1999). Research with children in schools is "framed by children's attitudes to adults within the school setting" (Goodenough et al., 2003, p. 116). These include: the possibility of children interpreting the research project as schoolwork (Kellett & Ding, 2004); perceiving the researcher as being in a teacher role (Goodenough et al., 2003; Hill, 2006); and feeling pressured to give the correct answer to research questions (Punch, 2002). In addition, there can be inclusion of children with 'desirable' attributes and the exclusion of others (Ireland & Holloway, 1996; Robinson & Kellett, 2004; Valentine, 1999).

In the school context, participation could verge on coercion (David et al., 2001) as the school culture is such that children's conformity and compliance with adult/authority requests and requirements is usually compulsory. Children are used to following rules in this setting and may feel under obligation or pressure to comply from adult authority figures or peers (Alderson, 1995; Ireland & Holloway, 1996; Morris-Roberts, 2001; Valentine, 1999). High pupil response rates in school based research may be attributed to the hidden pressure (Fargas-Malet, McSherry, Larkin & Robinson, 2010), as "the school context is inscribed by differential power relations" (David et al., 2001, p. 352), making it difficult for children to opt out of participation. It is not clear in most studies the extent to which children and young people feel able to refuse or to withdraw from participation, and how this can be done in school settings without being conspicuous or breaching privacy (Cashmore, 2006).

Fourth, consent must be renegotiable so that children may withdraw at any stage.

Consent is something that occurs prior to the research process of gathering data, but it is also an ongoing process that takes place during it (Alderson & Morrow, 2004; Cashmore, 2006; Cree et al., 2002; Gorin et al., 2008; Hill, Davis, Prout & Tisdall, 2004; Hood, Kelley & Mayall, 1996; Miller, 2000; Mudaly & Goddard, 2009). Several authors note the importance of reviewing the decision to participate throughout the research process (Alderson, 1995; Danby & Farrell, 2004). For example, with very young children consent can be considered provisional, with frequent revisiting during the research process (Flewitt, 2005).

Some researchers consider that the most ethical course of action is 'process consent', whereby consent is gained for each research tool, or at each stage of the research process, rather than an all encompassing agreement to the whole project at the outset (Sime, 2008; Vakaoti, 2009). They argue that this method of gaining ongoing consent gives the participant full control at all stages of the project. It can also reduce anxiety related to research participation (Dorn et al., 1995). However, Sime (2008) cautions that using process consent the researcher must be prepared to face the logistical difficulties of participants withdrawing from the study.

Informed dissent is a concept that allows children to refuse participation once the project is underway (Edwards & Alldred, 1999). This can be important in contexts where children do

not have much control over their choice of voluntary participation initially, for example, societies where children are subordinate to adult gatekeepers insistence that they participate (Ahsan, 2009), or school based projects.

Informed dissent can include using strategies which offer children something else to do while the research is taking place in preference to participating in it (Edwards & Alldred, 1999) as well as provision of opportunities and further choice for informed dissent throughout the research project. Researchers can actively encourage children to practice stopping the interview in order to exercise their dissent (Gorin et al., 2008). Although Lewis (2010) contends it is unusual to read published accounts in which the processes for children's withdrawal were reported and discussed reflexively, and concludes that wider discussion of withdrawal strategies is warranted.

Even with an active dissent process some children may feel the pressure to continue, because of various incentives or they were chosen by more powerful adults (Ahsan, 2009; Lewis, 2010; Sime, 2008). Researchers advocate the need to be vigilant in attending to children's visual, verbal and non-verbal cues to monitor unspoken expressions of unease or dissent (Ahsan, 2009; Cree et al., 2002).

Some researchers assert that by withdrawing their consent and support for research that it is children themselves who are the final gatekeepers in research with children (Barker & Smith, 2001; Davis, Watson & Cunningham-Burley, 2000; France et al., 2000).

Protection from harm - Issues of risk, harm and benefit

The ethical principles of beneficence and non-maleficence emphasise the importance of researchers balancing the desire to protect children from the potential harms of research, while allowing them to benefit from the results. Dixon-Woods, Young and Ross (2006) maintain that ethical debates from disciplines such as sociology of childhood have tended to focus on children's exclusion from research, based on assumptions of lacking competence, and argued for inclusion of children as a means of addressing power imbalances and giving children a voice. On the other hand, debates within the clinical sciences have focused on protection of children from risk or direct harm, and the key dilemma "is that there is a desire for children to benefit from the progress that scientific research can bring, but at the same time avoid placing any individual children at risk of being harmed by such research" (Dixon-Woods et al., 2006, p. 166). These contrasting debates highlight the existing tension between respecting children's autonomy and protecting children. This tension is derived, in part, from the underlying conceptualisations of children in Minority world contexts. Conceptualising children as immature and incompetent "invites the presumption that they are at risk and vulnerable to exploitation in the research process and therefore in need of protection" (Graham & Fitzgerald, 2010, p. 141); a presumption which can then dominate research ethics mechanisms.

Identifying benefits and harms to children participating in research is not always straightforward (Spriggs, 2007). Calculating harm using a risk-benefit assessment is not a simple process. “‘Harm’ is often invisible and elusive, complicated by different estimations, different viewpoints – researchers’, children’s or carers’ – and difference between short- and longer-term outcomes” (Alderson & Morrow, 2011, p. 23). Benefits can be hard to define and assess, and causality difficult to determine with some benefits not being known until long after the research has happened. Further, focusing on a risks benefit analysis can be at the expense of focusing on the ongoing nature of ethical dilemmas, which may arise at any time (Graham & Fitzgerald, 2010).

In some United States regulations the term ‘minimal risk’ is used to indicate the acceptable level of risk, and defined as that which is encountered in daily life, or during the performance of routine physical or psychological examinations or tests (Spriggs, 2007). Spriggs argues that risks in research and risks people take in their daily life are not equivalent, and what is important is how people judge the risk and whether or not they are prepared to take that on for themselves or on behalf of their children.

Until fairly recently most of the ethics literature relating to children was from medical and psychological research, and it was mainly concerned with risks that children were exposed to in clinical studies (Edwards & Alldred, 1999). The issues raised about risks and benefits appear more clear cut in these areas than in others, and the potential for physical damage is not likely to apply in social research (Hill, 2005). However, social research can also be intrusive and cause great distress to participants (Alderson & Morrow, 2011).

Risks in social research are more likely to include “distress and anxiety, embarrassment and loss of self esteem” (Alderson & Morrow, 2011, p. 27) than physical harm. Ethical dilemmas can arise when there is a conflict of interest between using “methodologies based on axioms of non-interference in opposition to the higher duty of care incumbent on researchers and demanded by society when working with children” (Birbeck & Drummond, 2005, p. 585).

Researchers are privy to intimate information and observations, and can be recipients of unwanted information, while participants can be caught off guard, particularly young people (Duncan, Drew, Hodgson & Sawyer, 2009). Concerns about these kinds of risks are particularly highlighted in relation to the specific topic being researched and the children or young people being recruited. If the research topic is considered sensitive and/or if the children are considered particularly vulnerable the research is more likely to engender concern from adult gatekeepers (Powell & Smith, 2009).

Ethical issues in research with children around ‘sensitive’ topics, such as child abuse or family violence include: difficulties gaining parental consent (Cashmore, 2006), concerns about re-traumatisation of children, and increased scrutiny from a hierarchy of gatekeepers (Hood et al., 1996). Parents may refuse consent for children to participate in research about family violence or child abuse, acting either in the children’s best interests or to protect the privacy of the family and prevent disclosure of problems (Cashmore, 2006).

An important consideration in research with children is “might an adult with abusive intentions use research as a means of access to children” (Hill, 2005, p. 72). The literature provides examples of bona fide researchers’ sense of unease being in situations which invoke suspicion (for example, being alone and unobserved with children) particularly for male researchers (Barker & Smith, 2001; Horton, 2001). Matthews, Limb and Taylor (1998) caution, that researchers should not “underestimate the scale and extent of public anxieties and moral panics” (p. 316) in relation to children’s safety. There is the risk of potential accusations of harm when interviewing a child alone and out of view (Sime, 2008). To protect both researchers and children, Barker and Smith (2001, citing Cameron et al., 1999) recommend using ‘cautionary practice’ – following ethical guidelines, and ensuring that fieldwork can be observed, while not necessarily overheard, to make sure that actions were not misinterpreted.

A key concern in research with children who have been abused or maltreated is if they will be re-traumatised by the research process. The risk of further harm or trauma needs to be a fundamental consideration in this kind of research and specific measures to ensure children’s protection and care must be integrated into the research design (Mudaly & Goddard, 2009). For example, even with computer administered interviews about maltreatment, researchers recommend being prepared to deal with children’s emotional response to sensitive questions and including a debriefing procedure at the end of every interview to assess possible trauma (Black & Ponirakis, 2000). Whilst authors distinguish between re-traumatisation and interview engendered distress (Amaya-Jackson, Socolar, Hunter, Runyan & Colindres, 2000), the latter can leave researchers feeling uncomfortable and closely questioning their ethical choices (Mudaly & Goddard, 2009; Robson, 2001).

Barron Ausbrooks et al. (2009), in their study with young people who had survived Hurricane Katrina, highlight a dilemma for researchers in stating:

The primary role of researchers is to collect data. Researchers are neither judges nor therapists. Neither are they made of stone and devoid of emotional response to human issues, including great suffering and pain that may unfold during research activities. (Barron Ausbrooks et al., 2009, p. 103)

They argue it is important to be able to refer research participants to appropriate resources and services if problems arise during the study.

Graham and Fitzgerald (2010) draw attention to the ‘ethics of risk’ and current emphasis on risk assessment, which has increased surveillance and regulation of research ethics involving children. Whilst being mindful of the importance of attending to children’s wellbeing, they caution against “gate-keeping children out of research purely on the basis of potential risk to them” (p. 141). They point to “a growing body of theoretical and empirical research which signals some important links between children’s participation and their wellbeing” (Graham & Fitzgerald, 2010, p. 136), and argue that children’s participation in research contexts is crucial to inform policy debates. Some studies report children are positive about their

participation in research and the potential for that to benefit others, including children with and without trauma histories (Chu et al., 2008), refugee children from Bosnia (Dyregrov, Dyregrov & Raundalen, 2000) and children hurt in traffic accidents (Kassam-Adams & Newman, 2005).

Gatekeepers

Researchers are, at times, compelled to seek consent from a range of adults in children's lives and negotiate "a hierarchy of gatekeeping" (Hood et al., 1996, p. 120) before children are allowed to be approached about participating in research. Indeed, Hood et al. (1996) note that children cannot be approached directly, "their sociopolitical positioning means that adults must give permission" (p. 126). Three levels of gatekeeping include research ethics committees, professionals asked to assist in recruitment of children, and parents (Campbell, 2008). These three layers can involve many people, for example, gaining access to children in hospital often requires negotiation with multiple layers of gatekeepers, at different stages of the research process (Coyne, 2010a). This hierarchy of gatekeeping increases barriers to children's participation in research (Hill et al., 2004; Hood et al., 1996; Masson, 2004; Miller, 2000; Morrow & Richards, 1996; Powell & Smith, 2009). It can also potentially affect the representativeness of the sample that is recruited and therefore the validity of the findings (Cashmore, 2006).

Whilst gatekeepers have a positive function in protecting children from potential harm, they can "use their power to censor young people" (Masson, 2004, p. 46). Some researchers question the entitlement of teachers, health professionals and others to prevent access to children, who may themselves be willing to assist (Hill, 2005). "Gatekeepers may in some instances deny children the opportunities to express their views, or cause extensive delays, less children accessed and abandoned projects" (Coyne, 2010a, p. 452). Researchers have reported difficulties in recruiting children through professional organisations (Campbell, 2008; Cree et al., 2002; Gilbertson & Barber, 2002; Punch, 2002). They often feel powerless because they are "completely dependent on the goodwill of agencies to access respondents" (Aldgate & Bradley, 2004, p. 91).

Gatekeepers can play a helpful role, assisting in recruitment and avoiding any researcher coercion (Coyne, 2010a; Cree et al., 2002). However, Coyne (2010a) also argues that this 'screening' is dependent on the professional's personal idiosyncrasies and views, some of whom resent the time demands involved or the responsibility of gatekeeping tasks, and that researchers may in fact have the necessary expertise to recruit participants directly.

Gatekeeping is particularly an issue when the children involved are considered especially vulnerable, which is then equated with requiring extra protection, for example, children in care. In both the UK and US foster-care systems access for researchers is carefully governed and cooperation from gatekeeping caseworkers is essential (Bogolub & Thomas, 2005). Children in care are often denied the opportunity to participate in research because of their perceived vulnerability (Berrick, Frasch & Fox, 2000). Davies and Wright (2008) note that the "concept of the 'state as parent' poses significant problems for locating responsibility

within bureaucratic organisations such as child service” (p. 29) and consequently a logistical nightmare can unfold as researchers are required to track down and engage multiple parties to give consent. The critical political and media scrutiny that children’s care services are under, and the time involved for overstressed staff may contribute to a reluctance to further expose the service and professionals working in it (Butler & Williamson, 1994; Heptinstall, 2000).

Some studies indicate that parents of children being recruited to take part in research with sensitive topics declined consent for a number of protective reasons including: not wanting the child to be labelled, or distressed, or to revive problems that had gone, or to impose on children who were currently having a difficult time (Cree et al., 2002; Sandbaek, 1999).

Protecting children from harm, and any possible adverse consequences of participation in research, is a genuine concern (Butler & Williamson, 1994). However, a strong protectionist discourse denies children the right to express their views on matters of concern to them (Powell & Smith, 2009) and children may be gate-kept out of research on the basis of potential risk (Graham & Fitzgerald, 2010). Whilst the protectionist discourse is most salient in relation to sensitive topics, it is also evident in other research, with a general perception of children as vulnerable implying a need for adult protection (Miller, 2000).

The literature emphasises the importance of the researcher establishing sound relationships with adults in a gatekeeping position (Berrick et al., 2000; Butler & Williamson, 1994; Powell & Smith, 2009; Thomas & O’Kane, 1996). Successful negotiation of access with gatekeepers often depends on the researchers’ skills and their ability to convince the gatekeeper that the research is worthwhile, with one researcher describing “a sense of trying to market the project to key adults” (Sime, 2008, p. 68).

Privacy – anonymity and confidentiality

Hill (2005) identifies three elements to confidentiality in research with children. These are:

1. Public confidentiality – not identifying research participants in research reports, presentations and so forth;
2. Social network confidentiality – not passing on information to family members, friends or others known to the child;
3. Third party breach of privacy – where a group or household member reveals something personal about another.

(Hill, 2005, p. 75)

Significant ethical dilemmas related to confidentiality are raised in the literature. Public confidentiality essentially equates with anonymity, “the principle of which is that participants should not be identifiable in research outputs” (Gallagher, 2009, p. 19). To achieve this researchers omit participants’ names, using pseudonyms instead, and remove identifying information from the reports. A dilemma arises when children do not share the researchers’ concerns about privacy and wish to have their own name used. Whilst allowing children to select their own pseudonym is a way of resolving this, one unforeseen drawback occurring in

Dwyer's research project (reported in Tisdall et al., 2009) was children's use of non-gender-specific pseudonyms, which resulted in 16 per cent of the sample not being analysable in terms of gender (Gallagher, 2009).

Privacy considerations in research include both the need to have a safe, private physical location in which the research can take place, and ensuring participants' privacy through anonymity and confidentiality. For example, both these privacy aspects are highlighted in a UK study with lesbian and gay participants who were vulnerable, due to stigmatised identities (Valentine et al., 2001). In this study, as in others, it was essential to have a safe research space in which participants could speak privately and freely, and also to protect their anonymity and confidentiality so that they were not identifiable in reporting the findings.

A difficulty in research with children is negotiating a location that allows for privacy (Mauthner, 1997) and maintains confidentiality (Barker & Weller, 2003). The need for privacy is also perhaps complicated by concerns in the wider societal context over children's safety from harm by adults, particularly strangers (Barker & Smith, 2001; Matthews et al., 1998).

Most often, the setting in which research with children takes place is at school or home. In both of these locations space may be at a premium and it can be difficult to find a 'private niche' where it is possible to talk without being overheard or interrupted (Valentine, 1999).

School as a setting for collecting data may be more cost effective than children's home (Fargas-Malet et al., 2010; Goodenough et al., 2003) and recruiting children to participate is considerably less demanding and time consuming (Morgan, Gibbs, Maxwell & Britten, 2002). However, there are considerable problems with the school setting as a location for research (Fargas-Malet et al., 2010), including difficulties encountered in finding a private space (Kellett & Ding, 2004).

Undertaking research with children in their homes can be more costly and time consuming (Scott, 2000) and gives rise to significant ethical issues. A crucial issue in eliciting children's views is the requirement for flexibility (Bushin, 2007; Gollop, 2000) and this is maximised by interviewing children in their homes. However, interviewing at home means that every interview setting is different, and they cannot all be managed the same way (Bushin, 2007). Sime (2008) suggests that "homes need to be considered as complex, unpredictable settings that are likely to configure the nature of the research relationships and of the data collected in every single encounter" (p. 76).

Children may be more used to having voice at home, and be more comfortable there (Bushin, 2007), however confidentiality may be difficult to ensure. Challenges in home interviewing include the nature of the environment and multiple interruptions which are part of the complex social reality of people's lives (MacDonald & Greggans, 2008). There can be problems finding a quiet private space, without parents/carers or siblings (Mahon, Glendinning, Clarke & Craig, 1996; Mauthner, 1997; Sime, 2008). This can be particularly

acute in some situations, for example, when families living in poverty sleep and live in the same room (Gorin et al., 2008).

Confidentiality can be difficult as a consequence of parents' curiosity and concern for the child (Fargas-Malet, 2010). Parents may ask about the content of interviews, which can put stress on the child (Masson, 2004) and on the researcher (Bushin, 2007). The researcher needs to negotiate their position as a guest in the child and parent's home (Alderson & Morrow, 2011; Mayall, 2000; Sime, 2008) and there can be an uncomfortable conflict between being a good guest and being a good interviewer (MacDonald & Greggans, 2008).

Parents may want to be, or even insist on being, present at interviews with children, which may influence a child's responses (Kellett & Ding, 2004; Scott, 2000). There is the possibility that interviewing family members together can lead to spontaneous discussion with richer, more detailed accounts however, it can also serve to silence children (Valentine, 1999). Parents can take over the role of interviewer and reinterpret the questions for children (Hood et al., 1996). Bushin (2007) suggests a range of covert and overt techniques to minimise parental involvement, for example, limiting eye contact with the parent, specifically using the child's name when asking a question, raising issues it was more likely only the child would know about, reiterating the importance of ascertaining the child's opinions.

A contentious issue in the literature is the dilemma around the limits of confidentiality in the light of a child participant's disclosure of abuse or risk of harm. Fargas-Malet et al. (2010) consider that it is common practice for researchers to encourage the child to talk to appropriate adults, if they disclose abuse, or agree to the researcher doing so. However, this is clearly not universally accepted practice. Some researchers would breach confidentiality if the child did not agree to further disclosure, and clearly specify this prior to the interview (Lynch, Glaser, Prior & Inwood, 1999). Others believe that disclosure of abuse should not occur until the child consents, following discussion (Hill, 2006). Breaching confidentiality can be seen to irrevocably damage the trust between child and research, and potentially impact on other trust situations for the child (Campbell, 2008). Attrition and lack of participation are two other fears related to breaching confidentiality (Fisher, 2009).

Williamson, Goodenough, Kent and Ashcroft (2005) highlights the dilemma in UK and US legal contexts. In the UK context researchers are not required by law to report suspicions of child abuse. However, there is a clearly defined duty of health professionals to report, and guidance provided to teachers, psychologists and social researchers. Thus, whilst there is no legal mandate in the UK, practitioner guidelines and good practice consider that professionals who have concerns about child abuse have a duty to disclose this to a third party. In the US context the underlying premise is that there is a potential conflict between scientific research and a duty to report. The legal mandate to report suspicions of child abuse varies between states and in some situations specific training makes some professional groups exempt from

requirement to report. In some situations researchers are exempt as researchers, but may be required to report in another professional or personal capacity.⁷

The issue is further complicated in the US by the issue of liability with regard to false accusations of abuse. As researchers are not mandated reporters of child abuse or maltreatment, in breaching confidentiality they may be exposing themselves to suit for malicious reporting (Kotch, 2000). However, Kotch also notes that the information obtained in interviews is confidential, but direct observation is not and suspicions based on this can be reported.

Opinions and practice about breaching confidentiality to report suspected child abuse are divergent even within the same major project, for example, the LongSCAN project in the United States (Cashmore, 2006). This project covered five sites in different states, each of which obtained a federal ‘certificate of confidentiality’ to protect data confidentiality. There were variations between the sites with regard to the explicitness of instruction related to reporting maltreatment (Amaya-Jackson et al., 2000) and with regard to the interviewers position as mandated reporters, on account of state law or employment at state agencies (Knight et al., 2000). Some researchers prioritised participant autonomy and preservation of the confidentiality of the data, whereas others saw reporting to Child Protection Services, based on data collected, to be legally and ethically mandated by the principle of beneficence (Knight et al., 2000). This beneficence is based in part on the belief that reporting will decrease risk to the child, rather than the potential benefit of participating in the study. However, Kotch (2000) argues that to justify a breach in confidentiality the benefits must outweigh the risks, and that in reporting maltreatment the risks include: harm to a child from an angry parent, lack of substantiation (as happens in nearly 70% of cases) means participants are exposed to humiliation and stigma without any follow up services, and that intervention by the Child Protection Services is not necessarily successful and may have a negative impact on the child.

Fisher (2009) argues that the moral obligation to protect children supersedes any cost-benefit analysis. “Simply put, reporting suspected abuse and neglect is the just thing to do” (Fisher, 2009, p. 25).

Confidentiality in research with children about maltreatment can be assured by using anonymity, for example, ensuring that children’s survey responses are not linked to their consent forms and thus children are not identifiable (Amaya-Jackson et al, 2000; Carroll-Lind et al., 2006; Kotch, 2000). However, this approach has been challenged as it means that researchers avoid their obligation to report any disclosures of abuse or harm (King & Churchill, 2000). Carroll-Lind et al. (2006) addressed this issue in a New Zealand study about children’s understanding and experiences of violence by informing children about the

⁷ For example, two states (Wyoming and New Jersey) maintain that **any** individual who suspects abuse must report it (Fisher, 2009). Other than that, researchers are not specifically mandated to report.

anonymity and confidentiality of their responses, but also advising them that if they wanted help that they could write their name on the survey and this would be attended to.

However, the extent to which children understand and believe the concept of confidentiality in the research context remains unclear (Cashmore, 2006; Knight et al., 2000; Lewis, 2010; Williamson et al., 2005). For example, in a US study looking at children's understandings of their research rights Hurley and Underwood (2002) found that children understood, but were unconvinced about confidentiality. This leads to discussion about whether, or how, to tell children about limits to confidentiality. Williamson et al. (2005) note that children are not ordinarily informed of the limitations of confidentiality in everyday interactions with adults, and that it is important to understand the meanings children ascribe to the terms used. For example, Gorin et al. (2008) in an English study with hard to reach families, decided to explain the limits of confidentiality to children and parents, and used terms like 'being safe' rather than abuse or harm, which seemed to be familiar and acceptable to the children.

In studies with runaway and homeless young people, researchers anticipate a high rate of abuse and risky behaviour reporting (Meade & Slesnick, 2002). Consequently, Meade and Slesnick recommend informing participants explicitly of the limits of confidentiality, the actions that will follow any discovery of abuse or intent to harm, and providing specific examples of situations in which reporting is required and which organisations will be involved.

Gorin et al.'s (2008) experiences of dealing with concerns about harm and risk, and making decisions about referrals, was "complex, fraught with ethical dilemmas and throughout was a process of balancing risks and benefits of actions" (p. 284), and put considerable strain on the researchers. They advise:

- Working in partnership with experienced researchers and child protection experts to ensure rigorous approach;
- The skill of individual researchers was paramount in dealing with situations;
- Need for more training in this area is highlighted.

The need for training is also endorsed by Fisher (2009) who argues that lack of training could lead to numerous false reports and family disruptions as well as inadvertently putting participants in potentially harmful situations.

The dilemma of breaching or maintaining confidentiality is not solely related to disclosures of abuse. As a consequence of a young person telling a researcher of a health concern during their Australian project, Duncan et al. (2009) draw on the literature to offer the following "key pieces of advice for minimising and managing ethical dilemmas concerning confidentiality" (p. 1698):

1. Information clarifying limits to confidentiality should be included in consent forms for young people and their parents

2. Issues should be dealt with promptly, including documentation of concerns and actions taken
3. Hire staff with the right balance of research, community and clinical experience
4. It is vital to have a supportive project team, with opportunities for debriefing

Payment and gifts

There is no clear consensus in the literature on whether children should be paid for participation in research (Kellett & Ding, 2004) or what kind of rewards are appropriate (Gallagher, 2009). Opinions vary as to whether children should be given payment or gifts for participating in research, with some researchers viewing it negatively as bribery or inducement, and others seeing it as fair recompense (Hill, 2005). It may place pressure on participants to take part and to say what the researcher wants to hear, or it may be perceived as an acknowledgement of the participant's contribution (Fargas-Malet, 2010).

Rice and Broome (2004) consider the purpose of incentives is to maximise participation and minimise attrition and note three different models guiding researchers' choice of incentives:

1. Market model – in which participants are specifically required and given an incentive to take part; based on supply and demand.
 2. Wage payment model – participation requires time and effort from the child and is sometimes a burden, payment is made for services; based on minimum wage.
 3. Reimbursement model – participation requires some financial outlay for the child or family, and their expenses are reimbursed; based on expenses.
- (Rice & Broome, 2004, p. 165)

Some researchers give a gift or payment after the research has taken place, but do not let the participant know in advance so that it is not perceived as an incentive to participate or likely to affect consent (Bushin, 2007; Mahon et al., 1996; Alderson & Morrow, 2011). Sime (2008) gave participants gift vouchers after each stage of the research process, without warning at the initial stage. However, she noted that this may have made participants feel obliged to continue participating in the following stages.

Cultural context influences perceptions of research payment and incentives. For example, studies with low income participants use remuneration options that are sensitive to the practical needs of the participating group (Mosavel & Oakar, 2009; Sime 2008). In another example, researchers undertaking a post hurricane survivor study gave store gift cards to help young people obtain necessities that may have been lost (Barron Ausbrooks et al., 2009).

In Majority world countries payment considerations include the fact that children participate in the economic wellbeing of the family and participation in research takes them away from reproductive or productive work.⁸ As a consequence of having done research in Africa, Robson (cited in Gallagher, 2009) states that if children would otherwise be working that they

⁸ This is discussed in greater detail in the fourth chapter of this paper.

should be compensated financially for loss of income: “This is not child labour or exploitation, but a moral imperative – after all adults get paid for doing research, why not children?” (p. 23).

An issue that has only recently been addressed in the literature is that of payment for child researchers (Porter et al., 2010). The authors suggest that the gap in the literature is probably because adult and child collaboration in research is rare, particularly in low income countries, such as Malawi, Ghana and South Africa, where their research took place. A problem faced in this study was involving children as researchers who were below the minimum age of employment. The authors concluded that whilst they offered children a range of other benefits, for children to participate without pay would be economic exploitation. “It is insulting and denigrating to children and their contributions to suggest that they, unlike adults, can be adequately compensated for their work by receiving training, experience, acknowledgment in publications and token gifts” (Porter et al., 2010, p. 224). This is particularly pertinent when the research is competing with significant income generating work of children.

“Yet any payments, however fair, may still bribe or coerce people into taking part” (Alderson & Morrow, 2011, p. 68). An ethical concern related to incentives is that participants can place themselves at greater than usual risk, either because they are unable to weigh the risk involved, or because they need the goods or services offered by the researcher (Rice & Broome, 2004). Rice and Broome (2004) note the increasingly common practice of giving relatively large cash payments to parents for children’s participation in industry sponsored trials.

These key ethical issues; informed consent, protection of participants, confidentiality and anonymity, and payment of participants, dominate the child research ethics literature. They are influenced by the epistemological understandings of researchers, as well as the context in which the research is occurring. Methodological choices contribute to ameliorating and moderating the effects of these issues, and it is clear that there are no ‘one size fits all’ methods to ensure ethical research practice. Rather, ethical dilemmas arise throughout the research process, and can be responded to in a multitude of ways, with the literature highlighting possibilities for consideration and reflection. The following chapter addresses the key ethical issues in the context of research based in Majority world countries.

4. MAJORITY WORLD CONTEXTS

Some researchers argue that there is an acceptance of the importance and validity of children's voice in Minority world countries, even beyond the research community, but contend this is far from the case in some Majority world contexts, for example southern African countries (Clacherty & Donald, 2007). Whilst there are common and universal ethical challenges across world contexts (Clacherty & Donald, 2007; Porter et al., 2010; Young & Barrett, 2001) the dominant theme in the recent literature about ethics in research *with* children in Majority world countries is the importance of context, and the difficulties and challenges inherent in applying ethics from Minority world contexts (Abebe, 2009; Ahsan, 2009; Nyambedha, 2008; Vakaoti, 2009; Young & Barrett, 2001). The major principles of respect for autonomy, beneficence and justice provide a universal framework and underpin ethical issues, however, the ethical and moral dilemmas that arise during the research process are shaped by the context in which the research occurs.

Clacherty and Donald (2007) consider unequivocally that the key ethical principles in research are universal. "However, the interpretation and application of ethical principles with different groups of children in different social contexts must take varying factors into account. This requires flexibility and often complex decision-making." (Clacherty & Donald, 2007, p. 147) Despite this recognition, of the importance of context in interpreting and applying ethical principles, there appears to be a gap in the literature as to how this could be attended to. The success of the UNCRC as an internationally agreed charter of children's rights suggests the potential for a universal framework that incorporates situated context and universally accepted principles.

Informed consent

The issues around informed consent are entirely relevant in Majority world contexts, but they are further complicated by particular practical challenges (Clacherty & Donald, 2007). The debates in Minority world literature about who should be required to give consent, and whether parental consent should be passive or active are silenced to a large degree in countries where accessing parents is a major challenge.

In African contexts children may be living separately from parents as a consequence of HIV/AIDS or parents living elsewhere in order to have work (Abebe, 2009). In rural areas guardians may be working in the fields far from the home. It can be difficult to establish who the guardian of the child is. The literacy rates in some areas mean that some parents are unable to read the information supplied. In addition, people can be sceptical about signing documents (Abebe, 2009).

Finding the parents of children who live on the streets can be difficult (Hutz & Koller, 1999; Vakaoti, 2009), with the added dilemma of how ethical it is to insist on parental consent in this context. For example, Vakaoti (2009) decided it would be unethical to exclude a 17-year-

old boy (on the grounds of not having parental consent) who had been living on the street in Fiji, independently of his parents for five years.

A further challenge in gaining children's consent or assent to participate in research is the social context of obedience to adults. The dilemma of ascertaining that children's consent is freely given is apparent in Minority world literature, and it is thrown into sharper relief in Majority world contexts in which the power disparities are such that children are most often subordinate to adults and there is an emphasis on obedience to and respect for adults (Clacherty & Donald, 2007). Children may consent to participate because they want to show respect to adult caretakers (Nyambedha, 2008), or are constrained by power relations in the community (Ahsan, 2009).

The concept of informed, voluntary consent is further complicated by expectations that potential research participants may have as a consequence of non-government organisations (NGOs) and other research projects in the area (Ahsan, 2009; Nyambedha, 2008). There may be an expectation of short and long term benefits and advantages to participation that influence parents' and children's consent and participation. The understandings around the purpose of research or role of researchers may vary across contexts. Ebrahim (2010) argues that in South Africa research is traditionally perceived as a potential way to secure resources and open up opportunities in disadvantaged communities. In a project with children and women affected by HIV/AIDS in Kenya, Nyambedha (2008) found that the people in the area did not differentiate between activities of non-government organisations (NGOs), other researchers and his own study. Consequently, there were raised expectations that participation in the research could lead to interventions that would assist participants.

Similarly, Ahsan (2009) found, in a study exploring children's participation in decision making in Bangladesh, that being a national in a privileged position, who had previously worked for a funding organisation, led to an expectation from participants that she would quickly fix existing problems.

Protection from harm

Nyambedha (2008) argues that the definition of harm needs to be broadened to address the ethical challenges of social science research with vulnerable populations, in which researchers can cause harm if no action is taken to address the high expectations participants may have, for assistance in some form. He further points out that frequently the participants' understanding is that the researchers will benefit from the study by gaining higher degrees, which arguably leads to better employment opportunities and higher incomes for the student/researcher, while the lives of the community under study remain the same.

Assessing beneficence is a challenge in some Majority world contexts. Potential benefits of research include helping children learn to express their thoughts and opinions and listen to and respect others. Whilst this has resonance in Minority world contexts also, the concept of empowerment is especially important in certain contexts, for example southern African "where children are coping with such marginalising issues as HIV stigma, orphanhood,

extreme poverty, and dominant social values wherein children's opinions are generally not heard" (Clacherty & Donald, 2007, p. 153). Another benefit is the potential for action and social democratisation through the outcomes of the research, although children need to know that this can take a long time and is not guaranteed (Clacherty & Donald, 2007).

Protection of children can look different in different world contexts, and assessing risks in Majority world contexts is dependent on researchers' sensitivity and social awareness (Clacherty & Donald, 2007). Referral for professional help is often not possible in Majority world countries, especially rural areas (Clacherty & Donald, 2007). Although researchers sometimes try to conduct studies adjacent to schools or organisations that may be of some assistance to participants.

Young and Barrett (2001) note the numerous guidelines in the UK aimed at protecting children, who are engaged in research, on account of their age, social status and powerlessness. However, they found these 'suggested' rules inappropriate or impractical in their research exploring the lifeworlds of street children in Uganda. They were confronted with unique and difficult ethical and moral dilemmas, around sensitive topics such as children's drug use and sexual abuse on the streets. Within this specific context Young and Barrett maintain that children have very good reasons to use drugs, but suggest that understanding the children's unique lifestyle and survival strategies is necessary as researchers grapple with the ethical issues and their moral obligation to children.

In many Majority world countries research *with* children participating (rather than research *on* children) is relatively new. There is a lack of regulatory mechanisms and monitoring of research projects (Leach, 2006) and a greater need to ensure that children are protected and respected (Vakaoti, 2009). The lack of regulatory mechanisms in some Majority world contexts, places the onus on researchers and the institutions to which they belong (Leach, 2006). Leach argues it is important that national authorities and research sponsors put clear ethical codes in place, and transparent and rigorous system of approving research proposals, in order to meet research challenges, particularly in the area of research on sexual and gender violence in schools.

Privacy and confidentiality

A difficulty in ensuring confidentiality in Minority world countries relates to finding a physical, private place in which to conduct interviews (Bushin, 2007; Valentine, 1999). However, in Majority world countries this is compounded by the conceptualisation of childhood, and the inferior social status of children (Abebe, 2009). Researchers find that parents, relatives and other children just come and join in the interview (Abebe, 2009), with adults commonly believing that they should participate in children's interviews in order to provide 'correct' answers (Clacherty & Donald, 2007).

Whilst children may value the researcher's assurance of confidentiality and find it important that the research setting offer privacy, in practicality that can be difficult to maintain (Ahsan, 2009). Abebe (2009) managed the difficulty with confidentiality and other people joining

interviews by converting them into less private events and conducting them in public spaces, for example, the community market space and tea houses in which children worked. The public setting drew less interest and involvement from others than an attempt at privacy.

Privacy is particularly important when the research study is exploring children's issues related to HIV/AIDS because of the social stigmatisation and secrecy attached to it (Clacherty & Donald, 2007; Hunleth, 2011; Nyambedha, 2008).

Young and Barrett (2001) note that disseminating research outcomes and 'giving back' to the participants is a common theme in participatory research. However, they caution that this is the stage at which the potential to do most harm exists. This is both in terms of participants having to decide what to do with tangible items, and with ensuring that the information being given to powerful groups, such as government departments and NGOs, does not in any way compromise the individuals involved.

Payment

Whilst compensation is an area of ethical contention in Minority world contexts, especially the use of cash (Sime, 2008), for some researchers in the Majority world it is seen as necessary compensation for the time in which participants would otherwise have been earning money (Vakaoti, 2009; Porter et al., 2010; Robson et al., 2009). The issue of remuneration or payment is more complex in Majority world contexts, such as African countries, where children's lives vary greatly from those in Minority world countries on account of the economic imperatives driving households which require children to provide labour and other support within their extended families (Porter et al., 2010).

Some researchers argue it is more ethical when faced with participant's poverty to help out with small amounts of cash for basic necessities (Abebe, 2009; Vakaoti, 2009). Vakaoti (2009) argues that this can help strengthen the rapport, without compromising the research relationship.

In a research study with formerly abducted children in Northern Uganda, Angucia, Zeelen and de Jong (2010) considered it more ethical to "go with the heart and give tokens to the participants; this was not considered to be 'buying' information (after all this was always done after the discussions) but to share with them in the moment of need" (p. 228). They go on to say "Thus, to the researchers, ethics was about sharing ... or is it celebrating our common humanity in a conflict situation?" (p. 229).

Conversely, Hutz and Koller (1999) advised against offering inducements or rewards in their study with street children in Brazil, on the grounds that children will attempt to be interviewed several times by different researchers to gain the inducement each time, and that in a context of hunger and drug use that inducements constitute a form of coercion. However, this advice appeared to be more in the context of research using structured interviews and questionnaires, rather than methods encouraging more active participation and did not appear

to consider the positionality of the researcher and adoption of more flexible friendship-type roles as other, more recent researchers have done (Abebe, 2009; Ahsan, 2009; Vakaoti, 2009).

A further consideration in the giving of gifts or payments is the problem that occurs in some contexts of extreme poverty where there can be resentment against children who participate in research and gain any material benefit (Clacherty & Donald, 2007).

Cross cultural research

The ethical issues in the literature regarding research in the Majority world context clearly have significant ramifications for cross cultural research, with researchers from the Minority world undertaking research in Majority world countries. Cross cultural interactions further complicate the power relations in the research (Porter et al., 2010). Some Minority world researchers have attempted to minimise cross cultural issues by having research teams composed of country nationals doing the fieldwork (Porter et al., 2010).

Ethical issues have different resonances in different world contexts, and research planned and undertaken in Majority world countries challenges assumptions underlying Minority world ethical guidelines. In contemplating research in the Caribbean, UK researcher Skelton (2008) outlined the profound social and cultural differences in family and household formation that challenged the University ethical requirements and assumptions, particularly around the consent process. She questions whether ethical frameworks developed in Western universities can be valid for research in other cultures, and notes “ethical research guidelines could be yet another western construct that create a global discourse of ‘our way’ is the ‘right way’ to do things” (p. 29).

In Leach’s (2006) call for regulatory ethics mechanisms in African countries she highlights the issue that much research is carried out in developing countries by researchers from other countries. In addition to decrying the lack of internal ethics regulation she maintains that the authorities know nothing about much of the research being done. “It is well known in Africa, for example, which countries are accommodating toward outside researchers and which are not” (Leach, 2006, p. 1144).

Collaboration between adult and child researchers in Majority world contexts raises issues that are applicable across other cultural contexts (Bray & Gooskens, 2006; Porter et al., 2010). A recent study in three sub-Saharan African countries, Ghana, Malawi and South Africa, looking at child mobility and associated transport issues, involved a collaboration of adult and child researchers and the researchers note common challenges across different cultural contexts including: protecting children from harm, remuneration of child researchers, and management of children’s expectations (Porter et al., 2010). They argue that the “very complex and thorny ethical dilemmas” (p. 215) raised in their collaborative research project, have applicability and relevance beyond the specific African context.

The activities labelled ‘research’ “are embedded within pre-existing relationships that have their own ebbs and flows” (Bray & Gooskens, 2006, p. 54). Bray and Gooskens argue that

research takes place for children within the broad spectrum of other forms of social interaction, and that whilst protection and guidance is important, the experiences that young researchers had of interactions with the adult research team and with the young people participating carried greater weight than their intellectual understandings of how to conduct ethical research. The research process was experienced as an on-going dialogue rooted in everyday social interactions and particular relationships that developed during the study.

5. METHODOLOGY AND ETHICS

Methodology and ethics are integrally linked; simply put, “ethics has methodologies and methodologies have ethics” (Jones, 2001, p. 177). Ethically sound techniques are perceived as adding to the value of research and, conversely, methodological soundness can improve ethics (Thomas & O’Kane, 1998). Researchers have suggested that ‘bad science is bad ethics’ with the implication being that ethical assessment needs to include consideration of whether the research questions are worth asking and if the methods used are an effective way of answering them (Alderson, 1995; Thomas and O’Kane, 1998). This section considers some of the areas where ethics and methods interact.

Participatory methods

To access and understand children’s views Morrow (2005) argues that methodologically, researchers need to consider the standpoint from which they research children. The standpoint taken has ethical implications (Morrow & Richards, 1996) as it critically influences research methods and interpretations of data. Taking a child standpoint, acknowledging and trying to understand the different ways children have of viewing the world, paves the way for conversations and developing a research dialogue with those children participating. Mayall (2002) argues that the unequal power evident in the generational divide need not be an obstacle, and that the standpoint of children is essential in gaining an understanding of society and social life, in relation to adult standpoints. A key issue here is acknowledgement. By acknowledging, rather than avoiding or masking the different standpoints, the question then becomes what sort of dialogue adult researchers can have with children. Having a child standpoint facilitates the development of the research process as a collaborative one. Integral to this standpoint, respect for children’s competencies “needs to become a methodological technique in itself” (Morrow, 2005, p. 154).

Historically, research with children has been dominated by observational methodologies and laboratory based study, usually in the context of medical and psychological research. Research designs at times neglected what are considered core ethical issues, in the current research context, such as informed consent, right to withdraw, confidentiality, and deception about the researcher’s intentions (Woodhead & Faulkner, 2000). Children have been deceived, upset and sometimes harmed (Alderson, 2003).

Some researchers argue that the use of participatory methods, with children playing a more active role, can enhance the ethical acceptability of research with children and young people and its validity (Sime, 2008). Ontologically, this kind of qualitative research “begins from a view of children as social agents, beings in their own right and experts in their own lives, whose ‘voices’ are nonetheless routinely ignored or misrepresented by adults” (Gallagher, 2009, p. 70). Influences on children’s increasing participation in research include: the inclusion of participation rights in the UNCRC, the impact of the Gillick ruling in the UK determining that competent children under the age of 16 years can give valid consent, new

approaches in the sociology of childhood and increased awareness of children's competencies in many areas of life (Alderson, 2001).

Gallacher and Gallagher (2008) argue that "participatory methods are no less problematic, or ethically ambiguous, than any other research method" (p. 514), and that critical examination and reflection of participation and participatory methods is necessary. Gallagher (2009) argues that the rationale for participatory methods rests on claims about their epistemological validity and their ethical merits, both of which are based on a problematic, oppositional model of power that obscures the actual complex multivalency of it.

One challenge faced by researchers is how they can authentically access children's views; "find ways into children's visions of life" (Clavering & McLaughlin, 2010, p. 607). Another challenge is how they give representation to children's voices (James, 2007). This is particularly pertinent with the recognition that research with children is framed by the concerns of the adult researchers (Christensen, 2004).

Suggestions to facilitate ways of understanding and representing the child's point of view include "adopting different researcher roles, reflexivity and involving children at all stages of the research process" (Kirk, 2007, p. 1255). Reflexivity in the researcher role provides opportunities for building rapport and establishing the participants as the experts regarding the research focus (Sime, 2008). Researchers have suggested and debated various researcher roles such as non-authoritarian adult, friend, least adult, and observer, in facilitating children's authentic participation (Davis, 1998). Christensen (2004) is critical of the 'friend' approach as it does not acknowledge or address the complexities of the differences and similarities between children and adults, including those of power imbalances. Mayall (2000) argues that adults can never be children and prefers to position herself as an adult who lacks knowledge about children and wants to learn from them. Ebrahim (2010) accepted Mayall's (2000) argument and adopted a stance of an "acceptable incompetent" (p. 294); a non-threatening person who asks ignorant questions. Birbeck and Drummond (2005) advocate the role of participant adult, stating this is a familiar adult role to children.

The researcher role appears more flexible in Majority world contexts as researchers grapple with the ethical dilemmas raised. This takes place in a context in which the established ethical guidelines from Minority world contexts do not sit easily and there are no established research 'rules' or shared understandings amongst people about the nature of research (Vakaoti, 2009). This contributes to researcher positionality being more fluid, as demonstrated with two research examples – Abebe (2009) and Vakaoti (2009). For Abebe (2009), researching with disadvantaged children in Ethiopia, this involved working toward developing a bond of friendship. Vakaoti (2009), researching with street frequenting young people in Fiji, alternated between the roles of researcher, friend, elder brother and facilitator to ensure that the participants felt at ease. Reflexivity demanded constant repositioning of his role in light of the realities of field work. Being reflexive and assuming a flexible position minimised the authoritative connotations often associated with adult researchers. Abebe (2009) highlights

the importance of the researcher and the researched “co-creating and managing ethical spaces within a given socio-cultural context” (p. 462).

Children’s participation in research that included hearing their voices represented “a radical epistemological break, not only with developmentalism but also with traditional assumptions about children’s incompetence and inarticulateness” (James, 2007, p. 265). However, Lewis (2010) suggests that there is currently such a strong ‘pro voice’ climate “that the promotion of child voice has become a moral crusade” (p. 15).

Critical reflection on issues of children’s voice and representation in research is an emerging theme in the literature. Spyrou (2011) argues that:

... a critical, reflexive approach to child voice research needs to take into account the actual research contexts in which children’s voices are produced and the power imbalances that shape them. However, instead of detracting from the value of voice research, acknowledging and reflecting on the situated character of children’s voices and their limits can, potentially, contribute to new, more productive ways of producing and representing children’s voices. (Spyrou, 2011, p. 152)

Spyrou (2011) contends that, apart from a few recent exceptions (for example, James, 2007; Komulainen, 2007), the preoccupation with children’s voices, accessing these in research and presenting them to the world, has mostly failed to attend critically to the issues of representation. James (2007) argues that there is “no way of escaping the predicaments of representation” (p. 269), and therefore researchers have to find a way of engaging with it:

This means that ‘children’s perspectives’, ‘the child’s point of view’, ‘hearing children’s voices,’ and ‘listening to children’ have to be regarded as standpoints, places from which the analysis sets out, rather than the definitive descriptions of empirical phenomena embodied in the words that children speak. (James, 2007, p. 269)

The conceptualising of children’s voice “can uncritically clump children together as members of a category” (James, 2007). Calling research methods which attempt to access children’s voices ‘child-oriented’ or ‘child-led’ obscures underlying issues such as the heterogeneity of childhood and power disparities in the adult-child research relationship (Hunleth, 2011). The use of these terms serves to circumvent critical analysis of the issues. For example, Hunleth (2011) concludes that the participatory methods she used, in a project with children caring for sick parents and guardians in Zambia (drawing and tape recording), were as much for herself as for the child and argues that without critical reflection these methods can reinforce adult expectations and restrict understandings of children’s experiences and knowledge. “There is an emerging discontent in the social studies of children with the unreflexive use of participatory methods and also their dominance as methods in research with children’ (Hunleth, 2011, p. 82). However, she also points out that children have their own reasons for

participating in research, and can use the methods to air their own concerns and gain information, which in turn is informative.

Children may not wish to participate or express their views, and silence may hold meaning that researchers need to acknowledge and respect (Lewis, 2009). Lewis (2010) argues that interpretation of silence is an integral part of analysis, and that listening reflectively to the silences “could contribute to the development of methodologies of silence alongside methodologies of voice” (p. 20). She advocates researchers include in their work “an explicit account of why and how children’s silences were recognised, noted, responded to and interpreted” (p. 19).

There has been a recent trend in research approaches toward using visual methods in an attempt to overcome problems associated with actualising children’s voices (Spyrou, 2011). However, these do not resolve problems of representation and give rise to other ethical concerns. For example, there are concerns regarding privacy with participants using cameras, including intrusion on others and whether consent is necessary when capturing images of other non-participant people (Sime, 2008; Vakaoti, 2009). Capturing non-participant children on film can lead to further negotiation of consent or editing of potentially valuable data (Robson, 2011).

A growing trend in participatory research is research *by* children and young people, with children as co-researchers or primary researchers. In these approaches children may be included at any point across the research process, and in some cases children initiate and direct the research, and thereby setting the research agenda (Alderson, 2001). Kellet (2010), a key advocate for empowering children as researchers, argues that “child-led research generates valuable knowledge about children’s lived experiences otherwise inaccessible to adults” (p. 202), as children “observe with different eyes, ask different questions and communicate in fundamentally different ways” (p. 195).

Research by children provides a means of managing some of the dilemmas about children’s representation, but not resolving it (James, 2007). Clavering and McLaughlin (2010) contend that all research with children is mediated by adults and that processes of power and questions of representation remain issues in research by children, just as they are in other ways of working with children. In addition, more articulate groups of children can ‘hijack’ research agendas (Kellett, 2010).

Issues of representation and power imbalances are particularly apparent in relation to interpreting and disseminating research findings (Trussell, 2008; Valentine, 1999). Some researchers attempt to include children and young people in the data analysis and interpretation phase as a means of addressing this issue (Alderson & Morrow, 2011). Others suggest sending the data interpretation to young people for their input (Morrow, 2005). Researchers also emphasise the importance of ensuring that research participants are provided with a research report, specifically designed for children and young people, at the completion of the project (Alderson, 1995; Valentine, 1999).

Dissemination of research findings can be fraught with ethical issues that potentially impact on children, both as a group in society and as individuals or specific groups of children. One issue for researchers is ensuring that the research does not contribute to discrimination, stigmatisation or negative outcomes for children and young people through mass media hype around sensitive child and youth issues or media misrepresentation (Alderson & Morrow, 2011; Morrow, 2008). Another issue, particularly raised in the literature regarding Majority world contexts, is ensuring that individual children are not subject to negative personal repercussions on the basis of identifying details inadvertently revealed in wider reporting of the research findings (Angucia et al., 2010; Clacherty & Donald, 2007; Young & Barrett, 2001). For example, identification of spaces frequented by Ugandan street children to government departments or non-governmental organisations “could result in direct harm to the children as, at best, the children might be moved on or, at worst, arrested and harassed” (Young & Barrett, 2001, p. 134).

Power relations

The literature regarding research with children in Majority world contexts throws the issue of power relations, between adult researchers and child participants, into sharp relief. There is a considerable body of literature addressing this issue in Minority world contexts. The majority of it focuses on disparities in power between adults and children, which are perceived to permeate children’s everyday lives, and are “heightened and reinforced by dominant cultural ideologies of power and control” (Trussell, 2008). Power imbalances have been widely recognised as being the biggest ethical obstacle and challenge to researchers including children in research (Alderson, 1995; Mayall, 2000; Morrow & Richards, 1996). According to Thomas and O’Kane (1998) the most critical ethical challenge in research with children is the disparity in power and status between adults and children.

Child researchers have tended to see power as something that adults have more of than children. However, conceptualising the research relationship as one in which adults are ‘all powerful’ is overly simplistic (Barker & Smith, 2001; Gallagher, 2009). Researchers’ experiences in the field, in both Majority and Minority world contexts, give rise to questioning the oppositional model of power, as children and young people resist researchers’ attempts to engage them in particular ways, appropriate participatory tools and exert power over the researcher (Ahsan, 2009; Barker & Smith, 2001; Gallagher, 2008). The distribution of power between adults and children in the field is “fluid, constantly renegotiated and prone to slippage” (Barker & Smith, 2001, p. 144).

Gallagher (2008) suggests that a revised model of power needs to account for the fact that on one hand, adults appear to be more powerful than children, and on the other hand recognise that “this generalised domination does not preclude multiple points of resistance and confrontation at which children are able to exercise power over adults” (p. 144). He argues that power is best viewed as “a form of action, carried out through multivalent strategies and tactics, rather than a commodity or a capacity” (p. 147). Similarly, Holland, Renold, Ross and Hillman (2010) shift away from a dichotomous view of power, to conceptualise it as, “dynamic and relational” (p. 363).

Discussion of power in the literature, either from a dichotomous perspective in which the researcher embodies ‘power’ and the participant embodies ‘powerlessness’ (Holland et al., 2010) or as an action involving domination and resistance (Gallagher, 2008), segues into discussion of the methods and means of addressing this. Some researchers critically exploring power relations argue for the need to redress power imbalances, with many suggesting that participatory methods and reflexivity can be a helpful way to do this (Ahsan, 2009; Gallagher, 2009; Hunleth, 2011). Participation “has become both an *aim* and a *tool* in an ethical quest towards “empowering” children” (Gallacher & Gallagher, 2008, p. 501).

Reflexivity

A strong trend emerging from the literature is researchers advocating the use of critical reflexivity, based on their experiences in the field (for example, Barker & Smith, 2001; Horton, 2001, 2008; Matthews, 2001a, 2001b; Morris-Roberts, 2001; Skelton, 2001). Matthews (2001) introduces ten short essays examining some of the ethical dilemmas posed in a range of different research contexts, in an issue of the journal *Ethics, Place and Environment*, from which he comments “emerges an overwhelming sense of the need for critical reflexivity” (p. 118). Some researchers consider that reflexive thinking is the real hallmark of ethical practice (Davis, 1998; Gallagher et al., 2010).

Reflexivity is a means of managing the gap between adult researchers and child participants by encouraging self-awareness on the part of the researcher regarding assumptions about childhood and how this may influence the research process. This includes awareness of: childhood experiences and engagement with children as an adult (David, Tonkin, Powell & Anderson, 2005); personal biases and how these impact on the study (Lobe, Livingstone & Haddon, 2007); and the influence of academic paradigms and non-academic life-based experiences (Davis, 1998). David et al., (2005) suggest researchers need to “critically reflect upon their own assumptions, values and aims, the impact of each in shaping the research process, and the potential effect on those who are recruited as participants” (p. 127). An implication of this is that an integral part of researcher training should be reflection on what researchers themselves bring to the research encounter and relationship, alongside consideration of methods and ethical issues, in how to do ethical research.

Reflexivity can play a central role in the research process enabling reflection on assumptions and roles (Davis, 1998) and also on the choice and implementation of research methods (Punch, 2002). There is debate as to whether research with children requires the same methods as, or different from, those used with adults (Christenson & Prout, 2002; Punch, 2002).

Recently researchers have argued for approaches to research ethics that take the social and cultural context into account, and foreground flexibility and reflexivity as key aspects of ethical research. These approaches allow for flexibility across cultural contexts. Thomson (2007) argues that participation is not inherent to the research methods themselves, but “is embedded within the social-spatial interaction between participants, which includes the

researcher and rests on how researchers invite participants into a research arena and facilitate their exploration and sharing of views on a topic” (Thomson, 2007, p. 209).

“Participatory ethics involves acknowledging that ethical concepts and issues are socio-culturally and contextually specific so may not be shared by researcher and researched” (Pain, 2008, p. 105). Similarly, Ebrahim (2010) argues that ‘situated ethics’ creates space for a flexible approach to research that allows researchers to engage with the children participating, the childhood contexts and the many situational factors that shape the research process. From these perspectives the researcher has to take into account the ethical perspectives of young people and negotiate ethical practice with them. Ethical codes need to be iterative and responsive, which does not fit the standard format of knowing in advance what will happen and how it will be managed, as is generally required by ethics committees.

6. ETHICS MECHANISMS

Ethics mechanisms, including ethical codes and guidelines, and research ethics committees are means of trying to ensure that ethical standards are met and maintained in research. Ethical dilemmas are unavoidable in the research process and “sometimes they can be pre-empted, sometimes they emerge spontaneously” (Duncan et al., 2009, p. 1691).

Ethics codes and regulations

The first international code of ethics (the Nuremberg Code, 1947) was developed in response to the extreme harm caused to human subjects by wartime medical experimentation (Farrell, 2005; Gallagher 2009). Since then health and medical researchers have continued to develop ethical codes and systems of healthcare ethics are now well established in many countries (Alderson & Morrow, 2011). Ethical guidelines for medical research were used as the basis for social research ethical guidelines (Farrell, 2005).

“On the whole, codes produced by academic and professional disciplines do not single out children for special consideration” (Hill, 2005, p.78). This is clearly apparent in different international contexts, for example: Lindsay’s (2000) review of ethics documentation from professional psychologist bodies in the UK, Europe and the US; and Powell and Smith’s (2006) review of academic and professional ethics documentation in New Zealand. Both reviews conclude that scant attention was paid to children in ethical codes of conduct, and that what reference there was lacked specificity and consistency.

As discussed previously, researchers conducting research with children emphasise the ongoing nature of ethical considerations (Alderson, 1995; Alderson & Morrow, 2011; Hill, 2005; Morrow & Richards, 1996). However, most ethical codes place disproportionate emphasis on only certain features of the research process (Lindsay, 2000). For example, the review of New Zealand ethics documentation revealed the ethical issues in descending order of dominance were: consent, protection, information, confidentiality, anonymity, and financial inducement (Powell & Smith, 2006).

The literature clearly highlights the usefulness of ethical codes, but also emphasises that ‘the map is not the territory’. It is not possible to know in advance what will happen in the research process, or to be prepared for every eventuality (Horton, 2001, 2008). Alderson (2004) notes that formal ethical guidelines “can prove useful checklists”, but they have gaps, and are more valuable if they are used “to ask heard searching questions about all aspects of research” (p. 102).

Cree et al. (2002) argue that ethical codes can never be more than a starting point because there will always be ambiguities and complexities in research (Cree et al., 2002, p. 54). Similarly, Lindsay (2000) concludes that “research on ethical dilemmas has indicated that practice cannot be made to fit written codes, however well they are devised” (p. 18).

Horton (2008) suggests “there is a temptation to figure research ethics guidelines a ready-made solution to uncertainties and complexities in/of research practice, and thereby as a means, ironically, of deferring thoroughgoing consideration of ethically-loaded uncertainties and complexities” (p. 365). He argues that social science researchers are obliged to critically and reflexively query the relationship between the ethics guidelines and the research ethics in the context of “the ‘hurly burly’ and ‘forever imperfect realities’ of research practice” (Horton, 2008, p. 369). To this end his paper outlines a series of unexpected ‘banal’ and everyday happenings and situations that occurred over the course of a research project and needed to be attended to ethically, despite the project being subject to and shaped by guidelines prescribing good ethical practice.

Bray and Gooskens (2006) note that most ethical codes focus on protection of participants and “fail to mention, or merely gloss over, principles that support children’s positive engagement in social interaction (which includes research) and thereby acknowledge their competence to do so” (p. 54).

An interesting debate in the literature is about the viability of universal ethical codes. As noted earlier, ethical issues have different resonances in different world contexts, and research planned and undertaken in Majority world countries challenges assumptions underlying Minority world ethical guidelines. Skelton (2008) questions whether ethical frameworks developed in Western universities can be valid for research in other cultures, and notes “ethical research guidelines could be yet another western construct that create a global discourse of ‘our way’ is the ‘right way’ to do things” (p. 29).

Situational ethics problematises the notion of universal ethics, by arguing that although there are general ethical principles, these must be examined in practice with sensitivity to the socio-political and cultural contexts in which the research takes place (Ebrahim, 2010). This requires researchers to adopt fair practices and take a reflexive stance. Ahsan (2009) similarly supports the idea of ethics as situational and responsive, which is “specific to the socio-cultural setting and the context of the moment” (p. 396).

Ethics committees

A line of increasing bureaucratisation of research ethics can be traced from the Nuremberg Code of 1947, through ... the US government’s legislative requirements for Institutional Review Boards, to the creation of Research Ethics Committees (RECs) in Europe over the last 20 years or so. (Gallagher et al., 2010, p. 472)

It is now a standard requirement that researchers in Western countries obtain approval from their institutional ethics committees and boards before commencing research projects (Bessant, 2006). Some researchers are critical of the increasing formal, bureaucratic regulation, seeing it as ‘rule fetishism’ that does not help develop understanding of ethical decision making in specific contexts (Gallagher et al., 2010). Other researchers argue that the increase in formal ethics mechanisms and subsequent scrutiny of research studies and

researchers results in better protection for children (Alderson & Morrow, 2004; Balen et al., 2006).

Research ethics committees play a vital role in raising awareness of ethical issues and monitoring research standards (Alderson & Morrow, 2004). They “can help prevent poor research, safeguard research participants and be a protective barrier between potential participants and researchers” (Alderson & Morrow, 2011, p. 74). They play a pivotal role in scrutinising research proposals and evaluating the adequacy of the research (Balen et al., 2006).

However, some researchers argue that current guidelines and protocols within universities and institutions are problematic, as they evolved from medical, rather than social sciences perspectives, and tend not to be child-centric (Skelton, 2008). Ethics committees, and their subsequent decisions, are contextualised within a discourse of children’s vulnerability, in conjunction with an increasingly risk averse wider context (Graham & Fitzgerald, 2010). Carter (2009) suggests that the historical framing of children, within a discourse of vulnerability, is the default setting in many countries (for example, the UK, USA and Australia), and that research with children is perceived as inherently risky, thus positioning children, researchers and ethics committees in a particular way. Researchers are positioned as ‘barbarians’ and reviewers as ‘champions’ of vulnerable children. This perspective “inevitably positions researchers as (potentially) dangerous and requires reviewers to adopt a (super-) cautious approach to any research proposal involving children’s participation” (Carter, 2009, p. 858). Carter does not argue that children are invulnerable, but finds such positioning problematic, especially when it ‘trumps’ all other issues, such as children’s participation and involvement.

There is a danger that after gaining approval from an ethics committee a project may be regarded as ethical in its entirety. Approval from an ethics committee does not guarantee that the research project itself will be ethical and there is a danger that researchers may abdicate responsibility to ethics committees (Powell & Smith, 2006). Research “committee guidelines and requirements do not exonerate researchers from considering the full extent of research ethics arising within their research” (Bell, 2008, p. 8).

The issues given precedence by ethics committees, such as consent and protection (Morrow & Richards, 1996; Powell & Smith, 2006), and a focus on specific ethical issues such as gaining access to participants, recruitment, anonymity and confidentiality, may mean that these requirements are in order, but less attention is given to ethics as an ongoing social practice (Christensen & Prout, 2002).

Gaining ethics approval can be a lengthy process, with research committees taking months to decide about approval, which unintentionally blocks or delays the research project (Coyne, 2010a). In a recent Australian study, about children’s involvement in decision making following parental separation, the response rate from the University ethics committee was much longer than three service organisations (Campbell, 2008). The delayed response can

cause problems with funders and project deadlines (Stalker, Carpenter, Connors & Phillips, 2004). It results in some projects never being realised and abandoned completely (Skelton, 2008), or significantly modified in approach (Campbell, 2008). Anecdotal evidence suggests that “many researchers decide against research about or with under-18-year-olds because the ethics requirements create too much work’ (Bessant, 2006, p. 54).

As well as protecting research participants, ethics committees also exist to protect researchers and manage risks to their institutions and universities (Graham & Fitzgerald, 2010; Morrow & Richards, 1996). Discussion of researchers’ experiences during two conference sessions in America and England (2006)⁹ suggested that ethics committees priorities “are not ethical in the way that we as researchers understand the term, and favour protecting Universities against litigation over genuinely forefronting the fair and respectful treatment of young people as research subjects” (Pain, 2008, p. 105).

Ethics committees can vary widely regarding safeguards for research participants, access protocols and the required wording for consent and information forms (Coyne, 2010), and the level of expertise and knowledge fluctuates within and between ethics committees (Powell & Smith, 2006).

A hypervigilant approach in health research can see researchers avoiding studies with children who may be regarded as particularly vulnerable, leading to under-representation of those children (Coyne, 2010). Graham and Fitzgerald (2010) point out a paradox that, “in an era that is increasingly recognising the agency of children and their capacity to participate in research we are also witnessing an increasingly ‘nervous’ regulatory environment in relation to ethics committees and children’s involvement in research processes” (p. 139). They argue the escalating regulation of research involving children, means that the ethical frameworks that facilitate children’s involvement in research provide fewer opportunities for them to do so.

Recommendations and suggestions to improve the role and capacity of ethics committees that emerged from the literature include:

- Inclusion of children, young people and parents on ethics committees and/or involved in screening research projects (Carter, 2009; Coyne, 2010). Although, Carter (2009) cautions care would be needed to ensure that children’s roles were not tokenistic and that the heterogeneity of children was represented.
- Developing specialist research ethics committees, specifically for consultation regarding research with children and young people (Powell & Smith, 2006; Stalker et al., 2004)
- Co-opting individuals who have expertise in the area of research with children onto ethics committees (Coyne, 2010)

⁹ The Association of American Geographers in Chicago and the Royal Geographical Society/Institute of British Geographers in London (Pain, 2008)

- Ensuring ethics committee members are required to update themselves regarding current understanding of children and their levels of competence (Campbell, 2008; Coyne, 2010)
- Using independent agencies to review research proposals (Gilbertson & Barber, 2002)
- University ethics committees redesigning their systems of approval to ensure that: supervisors have an understanding of the risks involved and will monitor student researchers effectively; student researchers have adequate experience and/or training for working with children's issues; and children participating in research are fully informed (Campbell, 2008). These issues resonate with those argued to be fundamental to ethical requirements in a wider than university context: that children should always be required to give consent, information should always be provided to them, and researchers should have sufficient knowledge to reflexively consider children's responses as the research process unfolds (Powell & Smith, 2006).

Researcher training

Answering difficult ethical questions is an issue for both novice and experienced researchers (Duncan et al., 2009). MacDonald and Greggins (2008) reflect that it is naïve to assume that prior experiences are sufficient to anticipate and plan for all potential factors.

However, there is a gap in the literature regarding ethics related training of researchers, perhaps reflecting the gap in practice. Hill (2005) argues that training in the area of ethical issues in non-medical research is usually minimal. Some researchers argue that training in research ethics does not, and perhaps can not, "fully prescribe or legislate for the peculiarities of research practice" (Horton, 2008, p. 370). However, the emphasis in the literature on the need for critical, reflexive practice and the increase in publications discussing problematic ethical issues indicate a keen interest in discussing and extending knowledge in these areas.

Some researchers advocate training with regard to specific issues, for example, with regard to issues of suspected child abuse and neglect (Fisher, 2009; Gorin et al., 2008). Fisher (2009) argues that without such training researchers may base their judgement solely on what they view as normative for their own cultural and social groups. Kellett (2010) acknowledges that promoting child led research requires comprehensive training programmes that may not be readily available.

However, beyond occasional references to the need for training to encompass particular aspects, and several publications which act as reference material or guides for students, novice and experienced researchers (for example, Alderson & Morrow, 2004; 2011; Matthews et al., 1998), there appears to be a dearth of literature addressing this issue.

7. CONCLUSION

This paper has reviewed the current literature pertaining to ethical issues in research *with* children and young people. It is by no means an exhaustive review; the body of literature whilst relatively recent is of significant size and continuing to grow, as theoretical and practical aspects of working with the ethical issues and challenges are further explored. However, it provides an overview, with reference to topic and recent issues. In addition, it has identified gaps in the literature which could be usefully attended to.

One area identified in the review, which could benefit from further exploration is the potential use of the UNCRC in progressing ethical research with children. It raises the question of whether the UNCRC could be used for conceptualising ethical research conduct with children and young people. Further questions relate to whether there are fundamental principles of ethics that can and/or should guide our research with children, and if it is possible to develop internationally agreed upon guidelines, or a charter, for undertaking research with children. If so, how can the UNCRC be used in this?

Literature has been discussed regarding the extent to which ethical issues are universal, and difficulties in applying principles evolved in Minority world research settings to Majority world contexts. An important question is: how do we take what we know and build capacity and understanding in and between majority and minority world contexts? Can the knowledge and experience of Majority world researchers (which is often directly addressing dilemmas identified in Minority world research settings) be used better to inform research in Minority World contexts? The use of the UNCRC in fostering dialogue between researchers from Majority and Minority work contexts is another area to be explored. Such exploration and use of critical reflexivity may help in understanding better the dissonance that currently characterises the application of Minority world ethics in Majority world contexts.

The key ethical issues that dominate the literature have been discussed in some depth. These include informed consent, protection of participants, confidentiality anonymity, and payment. The interplay between research ethics and methodology was considered. Particular attention was paid to discussion in the literature around participatory methods and reflexivity in relation to ethical research practice. These have been explored in the literature with particular regard to addressing power disparities in hearing children's voices and issues of representation of children, in interpretation, understanding and dissemination of research data. Literature relevant to the role of ethics mechanisms in attending to ethical issues and challenges was also discussed. Whilst the important role these mechanisms play is acknowledged, there are concerns about aspects of their function.

There is plenty of scope for further elaboration in these areas. This review presents a broad overview, referencing the established and emerging trends in the literature about ethical issues in research *with* children and young people. The burgeoning interest in child research ethics is

evident in the sheer volume of literature available and the range of ethical issues covered and it bodes well for the ongoing development of ethical research with children.

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