

# Ethical Principles, Dilemmas and Risks in Collecting Data on Violence against Children

A review of available literature

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Technical Working Group on Data Collection on Violence against Children  
Child Protection Monitoring and Evaluation Reference Group

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This joint report reflects the activities of individual agencies around an issue of common concern. The principles and policies of each agency are governed by the relevant decisions of its governing body. Each agency implements the interventions described in this document in accordance with these principles and policies and within the scope of its mandate.

The text has not been edited to official publication standards.

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The global Child Protection Monitoring and Evaluation Reference Group (CP MERG) was established in 2010 in response to gaps and challenges in child protection monitoring, evaluation and research. Given the general lack of data on violence against children and the momentum created by the United Nations *Study on Violence against Children* (2006), the CP MERG created a Technical Working Group (TWG) to specifically address this area. The aim of the TWG is to produce outputs that will guide and support reliable, useful and ethical data collection on violence against children.

Membership of the TWG currently consists of the following institutions and individuals: ChildFund (Martin Hayes); European Agency for Fundamental Rights (Ioannis Dimitrakopoulos and Astrid Podsiadlowski); ICF Macro (Sunita Kishor); International Labour Organisation (Federico Blanco); Plan International (Elsebeth Elo); Population Council (Katie Schenk); Save the Children (Denise Stuckenbruck); and UNICEF (Claudia Cappa, Chair).

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The report contributes to the broader work on the development of the International Ethics Charter and Guidelines for Involving Children in Research, led by UNICEF's Office of Research at the Innocenti Research Centre (IRC), Florence in collaboration with the Childwatch International Research Network.

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# ACRONYMS

CIOMS	Council for International Organizations of Medical Sciences
CP MERG	Child Protection Monitoring and Evaluation Reference Group
ESOMAR	European Society for Opinion and Market Research
ICC	International Chamber of Commerce
ILO	International Labour Organization
IMPACT	Implementing AIDS Prevention and Care Project
IOM	International Organization for Migration
IPEC	International Programme for the Elimination of Child Labour
NGO	Non-governmental organization
NSPCC	National Society for the Prevention of Cruelty to Children (UK)
OPRR	Office for Protection from Research Risks (US)
RWG-CL	Regional Working Group on Child Labour in Asia
TWG	Technical Working Group on Data Collection on Violence against Children
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNCRC	United Nations Convention on the Rights of the Child
UNICEF	United Nations Children's Fund
VAC	Violence against Children
WHO	World Health Organization

# 1

## EXECUTIVE SUMMARY

**E**thical guidelines are crucial when carrying out research on violence against children (VAC). Such guidelines help to minimize the risk of potential harm resulting from the data collection process to participants, researchers and others, and ensure that any remaining risks are outweighed by the potential benefits. Research ethics and methodologies are closely linked, with ethically sound research protocols and tools adding to the value of the research.

Recent years have seen growing efforts to collect data on VAC and close gaps on child protection monitoring, evaluation and research. However, there are, as yet, no internationally recommended or agreed upon ethical guidelines for VAC research.

This literature review is a contribution to the foundations for the development of such ethical guidelines. It aims to capture current thinking around ethical issues and provide empirical support to guide recommendations for ethical research practice and decision-making in collecting data on VAC. The review was prepared on behalf of the Technical Working Group on Data Collection on Violence against Children (part of the Child Protection Monitoring and Evaluation Reference Group). A sister project that has been carried out simultaneously to this research provides a more detailed inventory and assessment of existing tools and methods to collect data on VAC.

This review examines documentation, including both published and 'grey' literature that is of specific relevance to research ethics in collecting data on VAC. It includes ethics guidelines, codes, protocols and practice-related documentation, as well as research-based publications. An Internet-based search was used to identify and locate documentation for review.

The review has six main sections:

1. An introduction to the review and its aims.
2. A discussion of the scope and methodology of the review.
3. A review of ethics documentation, such as guidelines, codes and standards, focusing on aspects relevant to VAC. This starts with an overview of ethical principles and frameworks to provide a philosophical context for the paper, followed by a review of the documentation used to guide the implementation of ethics in research with children, and ethical policy and codes.
4. A review of publications relevant to ethics in research on VAC.
5. A discussion of the ethical challenges and dilemmas that emerged during the review process and possible recommendations from the literature.
6. Concluding comments.



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## REVIEW OF ETHICS DOCUMENTATION: GUIDELINES AND CODES

The main ethical frameworks that underpin ethical guidelines for research are based on duties (deontological), best outcomes (consequentialist) rights, and virtues. Guidelines relevant to research with children draw on many principles and dimensions from across the entire range of ethical approaches.

### *Ethical guidelines*

The review provides an overview of documentation on ethical guidance relevant to research on VAC and violence against youth. The sectors in which ethical guidelines address research with children most specifically are child protection, health and social welfare, clinical health, and monitoring and evaluation. The largest number of documents is found in the child protection sector, including VAC, child labour, trafficking, and children living in contexts of armed conflict and humanitarian emergencies.

The key ethical issues that appear throughout the ethical guidelines and documentation have particular resonance or present specific challenges when collecting data on VAC in certain contexts. The context has a major impact on the nature of these ethical issues and the means by which to address them. The issues that were emphasised most in guidelines related to VAC include privacy and confidentiality, child protection, dissemination of findings, and the training and welfare of researchers. Other cross-sectoral issues that affect research on VAC include local context, community consultation, risks to children, researcher responsibility, child protection, researcher training, and payment and remuneration.

### *Ethical codes*

The ethical codes of countries and professional bodies were reviewed. The extent to which these referred to children and young people varied, with some codes making no mention of them, some including sections of documentation dedicated to ethical guidelines for research with child participants and most falling somewhere between these two poles. Overall, country/national codes demonstrate considerable gaps and inconsistencies, with the documentation showing a lack of consistency and a tendency to focus on consent/assent policies and risk-benefit ratios. Specific references to children in professional ethical codes were related (in descending order of importance) to issues of consent, confidentiality, protecting children from distress or risk, and one mention of incentives. There was, in general, a paucity of attention to ethical constraints in research with children and young people.

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## REVIEW OF PUBLISHED LITERATURE

The key ethical issues emerging from the review of published literature include consent, protection from harm, privacy and confidentiality, and payment of research participants. While these are key issues for any research with children, they each have particular resonance in relation to research on VAC. Discussions relating to the topic of consent include obtaining informed consent from children and parents, passive versus active procedures for obtaining parental consent, and the various merits of consent and assent.

The protection of children is particularly relevant, and includes a range of issues. The issue of privacy, for example, encompasses the trade-offs between confidentiality and child safety and the need to maintain confidentiality in the dissemination of research findings. Ethical decision-making about payment is particularly complex in contexts such as developing countries, where children contribute to the economic well-being of their families, and where participation in research takes them away from work.

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## ETHICAL CHALLENGES AND DILEMMAS

**C**onflicting ethical issues in VAC research are evident within the literature, and there is a lack of clear standards to balance these conflicts. This section outlines each ethical dilemma and the relevant research used to discuss the issues, and makes recommendations. The dilemmas include the possible impacts on children of participation in research on VAC, particularly the risk of discomfort, distress, or trauma and the risk that others will learn of their involvement in the research. Challenges also include those related to the provision of information, including how much information to provide to children and how much to provide to parents; children's consent to participate in research; and confidentiality in relation to child protection.

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## CONCLUSION

**T**his paper has reviewed a significant body of literature, including ethics documentation and research-based publications, to contribute to the foundations for the development of ethical guidelines relevant to collecting data on VAC. Its findings identify existing gaps in documentation and research, and point to the need for further research to gain an understanding of the ethical issues involved. In addition, the review highlights areas of potential risk to children who participate in research and the existing debates on these within the literature.

The findings point to the need to develop a strong framework for ethical research practice on violence against children, which provides clear direction while supporting reflexivity, given the multiple contexts in which the research takes place. Key ethical principles can provide guidance to support this development, in conjunction with a children's rights-based approach to research on violence, underpinned by the United Nations Convention on the Rights of the Child. The literature review points to the need for ongoing investment in continued discussion and the extension of knowledge through research.



# 2

## INTRODUCTION

**E**thical guidelines help to minimize any risk of potential harm resulting from the data collection process, to participants, researchers and others, and assist in ensuring that any risks are outweighed by potential benefits. Research ethics and methodologies are intertwined, with ethically sound research protocols and tools adding to the value of the research.

Over the past five years there has been a proliferation of data collection efforts that aim to address existing gaps in child protection monitoring, evaluation and research.

It is a matter of concern that, as data collection efforts increase, there are no internationally recommended or agreed-upon ethical guidelines for research on violence against children (VAC). This is particularly worrying, given the increase in participatory research activities with children, and the emphasis placed on their participation by the *UN Study on Violence against Children*, which recommended that the development and implementation of systematic national data collection and research should include interview studies with children and parents, with a particular focus on children who are vulnerable.<sup>1</sup>

This literature review, focusing on research ethics in collecting data on VAC, contributes to laying the foundation for the development of ethical guidelines.<sup>2</sup> The review scopes the existing ethical guidelines and appraises the relevant literature, identifying and examining the ethical principles, issues, challenges and dilemmas that emerge. The ultimate aims of the review are to elucidate current thinking around ethical issues and to provide empirical support to guide recommendations for ethical research practice and decision-making in collecting data on VAC.

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### 2.1 SCOPE AND METHODOLOGY OF THE REVIEW

**T**he scope of the review is documentation that is relevant to ethical research in data collection on VAC. This encompasses institutional documentation, such as ethics guidelines, standards and codes, and research publications that are relevant to ethical issues, challenges and dilemmas in collecting data on VAC. The review has three key objectives.

<sup>1</sup> *UN Study on Violence against Children (A/61/299 August 2006, p. 27).*

<sup>2</sup> A sister project that has been carried out simultaneously to this literature review provides a more detailed inventory and assessment of the quantitative studies on VAC (CP MERG, 2012).

1. Review and critique existing ethics guidelines and documentation, written by and/or in use by UN partner agencies, research institutions, NGOs, etc.
2. Review published research literature relevant to research ethics on VAC.
3. Review literature relevant to ethical challenges and dilemmas in data collection on VAC, sourced from child research ethics and clinical research publications, to provide an evidence-based context for ethical research practice and decision-making.

For the purposes of the selection criteria used in the searches and the ongoing analysis in the review, the definitions of the terms ‘child[ren]’ and ‘violence’ are drawn from the United Nations Convention on the Rights of the Child (UNCRC).

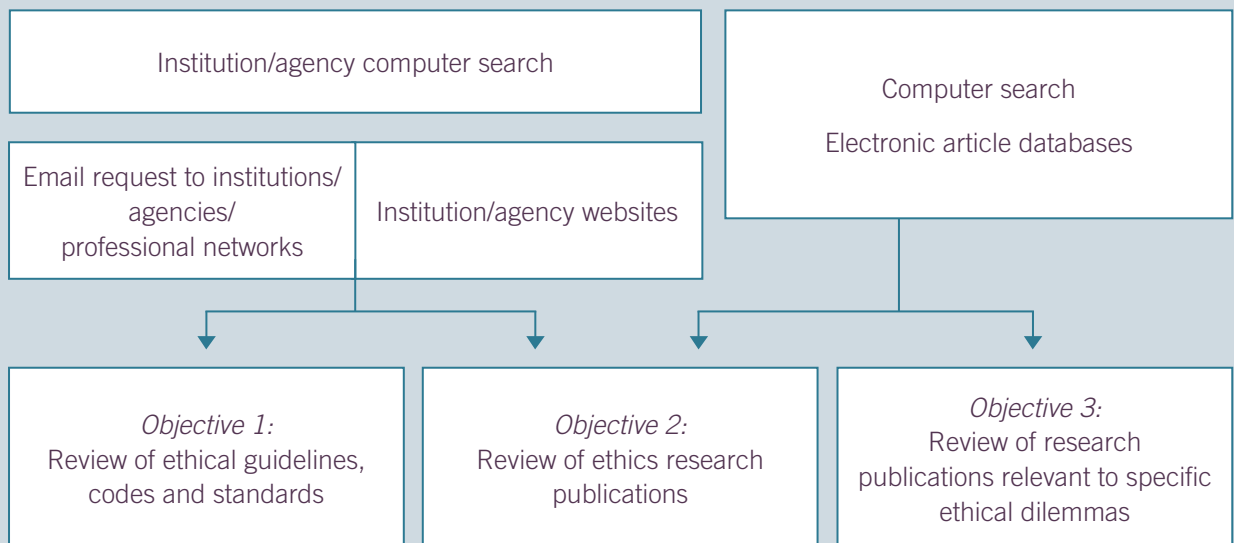
A child is defined in Article 1 of the Convention as *“every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier.”*

Violence is defined in accordance with Article 19 of the Convention as: *“all forms of physical or mental violence, injury and abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse [...]”*

The interpretation of violence draws further on the World Health Organization (WHO) definition in the *World report on violence and health* (2002), as used by the TWG on Data Collection on Violence against Children: *“the intentional use of physical force or power, threatened or actual, against oneself, another person or against a group or community, that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation”* (Krug et al., 2002, p. 5).

The methodology uses an analytical framework that incorporates structured, Internet-based searches of the literature to address the three objectives. This included searches of websites, professional/institutional networks and electronic article databases, as demonstrated in Figure 1.

**Figure 1: Methodology for literature review of research ethics in collecting data on violence against children**



Ethics documentation and published literature were included in the review if they met the following criteria:

- They applied to ethical issues in research with children, or referred to ethical aspects that are of direct relevance to research with children.
- They applied to data collection on any form of VAC, or on aspects directly pertinent to VAC.

These selection criteria were deliberately broad in order to increase the likelihood of accessing a large range of relevant documentation and literature.

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## OBJECTIVE ONE: REVIEW OF ETHICAL GUIDELINES AND CODES

Addressing the first objective involved a review of existing ethics guidelines, standards and codes, and any other relevant documentation. There was a particular emphasis on reviewing the ‘grey literature’ used by organizations and institutions to guide data collection on VAC.

An Internet-based search was conducted of agency/institution websites, using website menus and internal search engines to identify and locate documentation. Menu references to guidelines, handbooks, tools, etc. were also searched. A matrix of keyword terms was used with search engines, interchanging ‘youth research’, ‘child research’, ‘research ethics’ and ‘ethical guidelines’.

The professional network search was undertaken by sending a direct email request to organizations, agencies and networks. The email outlined the review being undertaken and asked recipients to send any documentation or references they were aware of that were relevant to ethics in research with children, with a particular focus on VAC. The request was sent to members of the Child Protection Monitoring and Evaluation Reference Group’s Technical Working Group (CP MERG TWG) on Data Collection on VAC, and known contacts both within and beyond UNICEF. It was also distributed through email lists to members of the Childwatch International Research Network, International Child and Youth Research Network, the Child Participation Network, and the Child Poverty Network.

The response to the email request resulted in a total of 71 people sending documentation, references and suggestions. Most responses included several documents or references, and a number of people sent material on more than one occasion. All emails were responded to, and ongoing correspondence developed with some respondents.

A total of 168 documents were secured from website and network searches for review to meet the first objective: reviewing ethical guidelines, codes and documentation. These documents were subject to a preliminary review, using the selection criteria to ascertain their suitability for inclusion in the more detailed review. While many of the documents were interesting reading and useful for contextualizing ethics in collecting data on VAC, the vast majority were culled from the review when the selection criteria were applied. Following this initial review process, 83 documents were retained for review and were coded into four categories<sup>3</sup> (see Appendix 1 for an annotated bibliography of each category) as follows:

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<sup>3</sup> Two additional categories of documentation received were not considered to be specifically relevant to this review, and were not therefore included: documents related to ethics review mechanisms and governance; and documents relevant to children’s participation (but not specifically about ethics, research or VAC).



SOMALIA *Fatima [name changed], 16, holds her newborn, in a shelter for girls and women who have endured sexual and gender-based violence in Mogadishu, the capital. Fatima became pregnant with her infant after a group of men raped her. In addition to safe accommodation, girls and women at the shelter run by the Elman Peace and Human Rights Centre with UNICEF support also receive educational and psychosocial assistance.*

1. Documentation used as a tool/guide in implementation of research procedures/practice in research with children: 21 documents secured; 8 documents pertaining specifically to VAC<sup>4</sup> (Appendix 1, Table 1).
2. Documentation relevant to ethical issues in research with children: 12 documents secured; 3 documents pertaining specifically to VAC (Appendix 1, Table 2).
3. Documentation related to research ethics (not specifically with children): 8 documents secured; 7 documents pertaining specifically to research about violence (Appendix 1, Table 3).
4. Ethical codes, protocols, pro formas: 37 documents secured; none specific to VAC (Appendix 2).

<sup>4</sup> One of these is specific to violence against women but includes a section on children: World Health Organization (2007), *Ethical and safety recommendations for researching, documenting and monitoring sexual violence in emergencies*. World Health Organization, Geneva.

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## OBJECTIVE TWO: REVIEW OF ETHICS RESEARCH PUBLICATIONS

Meeting the second objective involved a structured review process, primarily a search of electronic article databases to review published research articles that were relevant to ethical data collection on VAC.

The electronic databases considered the most likely to yield results, based on previous searches completed, were: ProQuest, Academic Search Complete (EBSCO), PsychINFO (via Ovid) and Medline. These databases were searched using keyword search terms, adopting a Boolean procedure that uses various combinations of terms. These were based on child research ethics terms in relation to different forms of violence; using individual keywords; 'violence', 'sexual abuse', 'psychological abuse', 'verbal abuse', 'maltreatment', 'exploitation' and 'neglect'. The keyword structure used was: (keyword) AND (child OR children) AND research AND ethic\*.<sup>5</sup> The search was open to all fields and was used to search literature from the past 15 years. A total of 79 articles were identified from this search process as suitable for inclusion in the review (see *Appendix 3*).<sup>6</sup>

Additional sources of literature included in the review were articles supplied in response to the email request for ethics documentation and literature sourced for a previous child research ethics literature review (Powell et al., 2012). In addition, a form of 'snowballing' occurred as relevant references in articles were identified, secured and reviewed for inclusion.

First, the title and abstract of the identified articles were reviewed to ascertain if the inclusion criteria were met. Articles were then selected for further review based on the content of the entire article. The review involved summarizing the article, thematic analysis, and identification of strengths and limitations.

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## OBJECTIVE THREE: REVIEW OF RESEARCH PUBLICATIONS RELEVANT TO SPECIFIC ETHICAL DILEMMAS

Research publications were the primary source of literature to meet the third objective, sourced in the electronic article database search. Ethical challenges and dilemmas, with a particular focus on data collection on VAC, were identified, followed by further literature searches to identify and secure research-based literature relevant to specific issues.

The remainder of this paper is structured into three sub-sections, corresponding with the three objectives of the review. The discussion within each sub-section centres on the documentation identified, secured and reviewed for that specific area. It is, however, further informed by the literature reviewed in the other sub-sections.

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<sup>5</sup> The exception to this was ProQuest, where the search structure was refined to: (Keyword) AND (child OR children) AND 'research ethic\*'

<sup>6</sup> A total of 104 articles were identified using the keyword searches, as indicated in Appendix 3; however this total included the repetition of a number of articles across keyword categories. The actual number of articles identified and secured, once repetitions were taken into account, was 79.





# 3

## ETHICS DOCUMENTATION REVIEW: GUIDELINES AND CODES

The search methodologies described in the previous section resulted in the collection of a significant body of literature with potential relevance to ethics and research activities with children. At first, this appeared to bode well for ethical research with children. However, a thorough examination of the documentation revealed that much of it was broad in application and not of direct relevance to providing ethical guidance or promoting ethical practice in child-associated research activities, and that very little related specifically to violence against children. Consequently, one key finding of the literature review is that there is very little guidance of direct relevance to ethics in research and the collection of data on VAC.

The relevant ethics documentation, which was coded into four groups (as discussed earlier), falls into two main categories:

1. Documents intended to guide ethical practice.
2. Institutional or organisation policy documents, such as ethical codes, protocols and pro forma.

This chapter is divided into three sub-sections. First, a brief overview of the ethical principles and frameworks that underpin ethical guidelines and codes, to provide the context for the chapter.

The following sub-section addresses the first category of documentation specified above: documents to guide ethical practice. The documentation reviewed includes: documents relevant to research ethics in the wider population (in particular, research on violence related topics); documents relevant to ethical issues in research with children; and guidelines for implementation of ethical research procedures/practice in research with children. The latter documentation – ethical guidelines – is of greatest relevance and is the primary focus of this sub-section. Key ethical issues within the documents, and their relative strengths and weaknesses, are identified and discussed.

The third sub-section addresses the second category: policy and protocol documents, such as institutional ethical codes. It examines the extent to which these address ethics in research with children, and specifically research on VAC. Key ethical issues and significant gaps that are relevant to collecting data on VAC are identified and discussed.

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### 3.1 ETHICAL PRINCIPLES AND FRAMEWORKS

Underlying ethical guidelines and codes are ethics principles and frameworks that are based on centuries of philosophical debate about duty, harm-benefit and rights (Alderson & Morrow, 2011), as well as wisdom drawn

from sound research practice. The importance of ethical principles in research was acknowledged formally for the first time with the development of the Nuremberg Code (1947) in response to wartime experimental atrocities (Farrell, 2005). The Nuremberg Code was based on Anglo-American law, and focused on respect for personal integrity in experimental research (Alderson & Morrow, 2011). Subsequent ethical guidelines and codes were developed for medical research, aimed primarily at biomedical clinical studies. The first international code of ethics was the Declaration of Helsinki (adopted by the World Medical Association (WMA) in 1964, with successive amendments, most recently in 2008) which was written for medical research and provided a basis for later ethical codes for other branches of research, including social research.

Alderson (2005) describes three main ethical frameworks that reflect ethical philosophies and that help determine the action to be taken: duties, best outcomes (harm-benefit) and rights. These are used in medical ethics and apply to social research with children. Another common philosophical approach to ethical considerations is a virtue-based approach (Gallagher, 2009). Such philosophical approaches, usually identified as 'ethics', are promoted and enforced through tools including codes of conduct and ethical guidelines and regulatory mechanisms such as ethics review committees. These four main ethical approaches are now discussed to provide a philosophical context for the ethical research documentation reviewed in this paper.

### 3.1.1 A DUTY-BASED FRAMEWORK

The duty-based (deontological) approach is the most widely established framework underpinning many ethical guidelines and codes. It takes the underlying ethical position that *"right actions are those that treat people as ends, never as means to an end"* (Gallagher, 2009, p.12), and is based on the idea that there are certain universal duties that should be carried out that incorporate the principles of autonomy, beneficence and non-maleficence, and justice. These are often referred to as the basic or fundamental ethical principles,<sup>7</sup> transcending geographic, cultural, economic, legal and political boundaries (Schenk & Williamson, 2005).

In an unpublished review of guidelines for ethical social policy research practice with children and young people, these three principles were deemed to *"determine the structure and content of most current theoretical discussions, empirical studies and professional guidelines on research ethics"* (Corlyon et al., 2006, p.12). They are operationalized in international ethical guidelines, for example, Council for International Organizations of Medical Sciences (CIOMS) and World Health Organization (WHO) biomedical and epidemiological studies guidelines (2002, 2008) and the Belmont Report (1978) which, in turn, are often cited by national guidelines that influence the provision of professional or legal guidance. Duty-based principles are manifest in terms of voluntary consent, freedom to retract consent, and avoidance of unnecessary pain or harm (Hill, 2005).

*Autonomy* refers to the individual's capability and right to make reasoned decisions about issues that affect them (Richter et al., 2007), including the right to privacy (Corlyon et al., 2006). 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 (King & Churchill, 2000). Richter and colleagues (2007) divide autonomy into five components:

---

<sup>7</sup> Usually referred to as three ethical principles, some documents articulate them as four, counting beneficence and non-maleficence separately.

1. Disclosure: provision of accurate, comprehensive information to potential participants.
2. Understanding: participants need to understand relevant information, appreciate the situation and its consequences, and make choices.
3. Competence: participants, including vulnerable populations, must have sufficient cognitive abilities, experience and competence to understand the information.
4. Voluntariness: acting freely, without coercion, with consideration given to the influence of power dynamics, particularly on vulnerable populations.
5. Consent: provision of informed, freely given, valid consent, with the option to withdraw at any time without consequence.

*Beneficence* and *non-maleficence* mean, respectively, 'to do good' and 'to do no harm'. In research contexts, the concept of beneficence is "*broadly interpreted as maximizing the benefits or good outcomes associated with research participation for both individuals and society*" (Corlyon et al., 2006, p. 9). Non-maleficence is expressed in researchers' obligation to assess the potential harms from research and work assiduously to minimize or eliminate them (Richter et al., 2007).

*Justice* denotes fairness and equity, requiring equality of inclusion alongside the non-discriminatory selection of participants, fair treatment of participants during the research process and in relation to the consequences of the project, and the collection of disaggregated data as a means to ensure equity in research. It can be divided into distributive justice and procedural justice (Richter et al., 2007). Distributive justice refers to the just distribution of the goods and benefits from research, and also means that no harm or unfair burden should be inflicted on any particular segment of the population. Procedural justice means that an ethics review board, or similar mechanism, should review the proposed research.

These ethical principles provide a philosophical basis for research and a structure to underlie ethical decision-making. They improve research with children and young people by:

- avoiding intuitive and ad hoc procedures in decision-making, thereby maintaining consistency;
- providing a clear way to justify decisions and explain why one act is morally superior to, or chosen over, another;
- avoiding narrow or biased approaches, based on uncritical habit and self-serving rationalisations (King & Churchill, 2000; NSW Commission for Children and Young People, 2005).

One criticism of this approach, however, is that definitions of these ethical principles often provide researchers with only abstract notions of the requirements of ethical research practice, and "*typically fail to offer more than vague or largely theoretical insights into the implementation of these principles in a variety of research settings*" (Corlyon et al., 2006, p.12). Corlyon and colleagues argue that these principles are often called on and uniformly defined, regardless of the type of research being conducted, which contributes to making it difficult to translate them into practice and restricts their capacity to protect research participants.

Difficulties can also occur when duties conflict with each other, or with other rights. For example, respect for a child's autonomy to decide about their participation in a study about parental alcohol abuse may conflict with their parents' right

to privacy (Gallagher, 2009). Some researchers lend more weight to particular duty-based principles: King and Churchill (2000) argue that non-maleficence is of more importance to research with children than beneficence, as children are in a position of compromised autonomy and personal benefits are a side effect of research, not its primary aim.

### 3.1.2 A BEST OUTCOMES FRAMEWORK

**T**he best outcomes approach involves strategies to reduce harm and costs, and promote benefits. It is a form of consequentialist ethics, in which the rightness or wrongness of the actions depends on the nature of their consequences (Gallagher, 2009). Within this context, actions that are ‘right’ are those that result in the greatest overall good for the greatest number of people.

One limitation of the harm and benefit approach in research with children is that the focus on ‘the greatest good for the greatest number’ outcome can be less beneficial for individual children. Gallagher (2009) gives the example of a disruptive child who is excluded from a focus group being considered a right action as it benefits a study that will have positive effects for children in general, even though it is potentially damaging to the excluded child. Guidance offered by the Declaration of Helsinki on the possible tensions around beneficence says that benefits should be prioritized so that *“concern for the interests of the subject must always prevail over the interests of science and society”* (King & Churchill, 2000, p. 716). This is in line with a children’s rights-based approach, discussed later in this chapter.

Weighing the risks of harm and potential benefits in child abuse or maltreatment research can be extremely difficult and controversial:

Because direct benefits to subjects are not the primary intention of research, and because the collateral benefits of counselling and reporting may involve additional harm for both children and their parents, it is important that non-maleficence be recognized as the chief principle guiding the obligations of researchers to subjects. This requires researchers to focus on minimizing any risks of harm that participation in the research may pose rather than on attempting to provide countervailing benefits (King & Churchill, 2000, p. 715).

A further limitation is the extent to which benefits and harms can be predicted, compared and measured. Alderson and Morrow (2011) point out that *“harm is often invisible and elusive, complicated by different estimations, different viewpoints – researchers’, children’s or carers’ – and differences between short – and longer-term outcomes”* (p. 23). Definitions of risk vary according to the specific characteristics of the group of children being researched (Corlyon et al., 2006). Likewise, different kinds of benefits cannot always be compared, against each other, or at the level of the individual child as opposed to the group level.

### 3.1.3 A RIGHTS FRAMEWORK

**A** rights-based approach involves recognition and promotion of children’s provision, protection, promotion and participation rights, as expressed in the UNCRC. In particular, three of the four ‘General Principles’, identified by the Committee on the Rights of the Child as providing a framework for the interpretation and implementation of all the rights contained in the UNCRC are relevant to research policy and practice:

- The best interests of the child (Article 3.1) states that the best interests of the child must be a primary consideration in all actions concerning children and
- Non-discrimination (Article 2) requires the application of all the rights in the Convention to all children at all times and identification of children who may require special measures for the full implementation of their rights and
- The right to be heard (Article 12) states that children's opinions must be sought in matters that affect them, and that their views must be given due weight.

It is critically important that the best interests of the child (Article 3.1) are prioritized in ethical guidelines. However, although the best interests appear in different aspects of ethics documentation, they are not, in general, actually stated as such. There are some exceptions to this, for example, the WHO (2011b) draft document on ethical and safety guidelines for sexual and reproductive health research specifically cites Article 3.1; the UNICEF (2002) research, monitoring and evaluation technical note for managers states that the best interests of the child must be a major factor; and the UNICEF (2006) guidelines on protection of child victims of trafficking also state that the best interests of the child are the primary consideration.

The prioritizing of the best interests of the child is apparent in a number of guidelines through the emphasis given to particular ethical principles. For example, guidelines produced by Save the Children focus on the principle of 'do no harm', exhorting researchers to ensure that children are not harmed through their participation in research, and clearly stating that confidentiality does not override the duty of the researcher to protect children (Laws & Mann, 2004; Feinstein & O'Kane, 2008).

The "*right to be properly researched*"<sup>8</sup>, in accordance with the international rights-based framework provided by the UNCRC, underpins a large number of the ethical guidelines, (see, for example, Boyden & Ennew, 1997; WHO, 2011b; Edmonds, 2005; Ennew & Plateau, 2004; ILO & UNICEF, 2005; Laws & Mann, 2004; Shaw et al., 2011). While the right to be properly researched is not a specific provision of the UNCRC, it is derived from a combination of provisions from four articles (Ennew & Plateau, 2004, p. 29).

Article 3.3: "*States Parties shall ensure that the institutions, services and facilities responsible for the care of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, the numbers and suitability of their staff, as well as competent supervision.*"

Article 12.1: "*States 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 children, the views of the child being given due weight in accordance with the age and maturity of the child.*"

Article 13.1: "*The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.*"

Article 36: "*Protects children against all ... forms of exploitation prejudicial to any aspects of the child's welfare.*"

<sup>8</sup> A phrase coined by Judith Ennew and discussed in a number of publications, see for example, Beazley, Bessell, Ennew and Waterson, 2009, p. 365.

Ennew and Plateau (2004) interpret these articles to mean that research must conform to the highest possible scientific standards and researchers must be carefully recruited and supervised (Article 3.3). Children's perspectives and opinions must be integral to the research (Article 12.1) and methods need to be found, and used, to help children to express their perspectives freely in research (Article 13.1). In addition, Article 36 requires that children must not be harmed through their participation in research. Therefore, Ennew and Plateau (2004) argue, children's rights have two practical consequences for child research: *"Children must be protected during research by an ethical strategy; and research methods must be found that enable them to describe their experiences and express their views"* (p. 35). Aitken and Herman (2009) suggest that relations between the UNCRC and research practice are dynamic because, rather than statically *"drawing a bright line between ethical and unethical research practices with regard to children, the UNCRC locates axes along which a child's rights are defined and urges researchers, among others, to account for the impacts of their own choices"* (p.19). They consider that researchers are required to assess the balance of protection/nurture and participation/self-determination in each research setting and then manage the research process to maintain that balance. As such, the UNCRC provides a useful framework for deliberations and therefore has an influence in creating more ethical research practices.

One key benefit in the use of a children's rights-based approach to research ethics is that the UNCRC is an international human rights instrument that provides a framework of common, universally agreed-upon standards. As such, application of the principles of the UNCRC to ethical dilemmas prioritizes the well-being of the individual child who participates in the research, as well as children as a social group (Reading et al., 2009).

#### 3.1.4 A VIRTUE-BASED APPROACH

**A** virtue-based approach is concerned with people possessing, and acting on, good character traits (virtues) rather than bad ones (vices) (Gallagher, 2009). The focus is on *"being rather than doing, on the qualities of moral agency rather than on choices or actions per se"* (King & Churchill, 2000, p. 711). Virtues include characteristics such as honesty/truthfulness, justice, courage, fidelity and kindness, as opposed to vices such as deceit, injustice and cowardice. While ethical guidelines are not framed in terms of virtues and vices, the terminology associated with such characteristics is often included.

The limitations of the virtue-based approach include the lack of universal agreement on what constitutes virtues (Gallagher, 2009). Definitions of virtues differ among and even within societies. Gallagher offers the example that *"some would argue that a good researcher is someone who strives to be objective and unbiased; others would claim that a good researcher is someone compassionate, caring and empathic"* (p. 12), although it could be argued that these are not mutually exclusive characteristics.

One merit of a virtue-based approach is that it allows for reflection on ethical dilemmas, without reducing ethical discussion or research practice to a set of rules based on codified principles. Researchers are able to recognize the characteristics from their own personal lives and experiences, and understand their importance, which assists in thinking through potential ethical challenges and solutions.

#### 3.1.5 ADDITIONAL COMMENTS ON ETHICAL FRAMEWORKS

**A**lderson and Morrow (2011) point out that, *"there is often disagreement within and between the frameworks, and debate about which framework is best"* (p. 19). Each of the ethical frameworks presented has, as we have seen, advantages and limitations in guiding ethical research practice with children. Ess (2002, cited in Dench, Iphofen





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*PHILIPPINES Several girls who have been abused participate in an interview for UN Radio, in Roxas City. They are being interviewed by Cora Buala, 19, who was herself abused by her alcoholic father. With the help of the international NGO Christian Children's Fund (CCF), she was able to attend school. Today, she is a university student and also works for the Katin-Aran Children's Center, a local CCF affiliate that supports education and child rights.*

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& Huws, 2004) suggests that European countries are more likely to adopt a duty-based approach, whereas a best outcomes approach is more often used in the US. However, Dench and colleagues (2004) also cited other researchers looking at various ethical guidelines and concluded that most guidelines take a range of perspectives. In the review of ethical documentation that follows, it is clear that the guidelines that have been developed with relevance to research with children draw on a range of ethical principles. Sets of guidelines tend to incorporate principles and dimensions from across the range of ethical approaches, rather than drawing exclusively on one.

King and Churchill (2000) suggest that recognizing regulations as elaborations of ethical principles makes it easier to apply them to research by broadening the understanding of researchers and regulators about their relevance and meaning. It is important to acknowledge that, as well as ethical principles drawn from across the range of philosophical approaches that inform researchers' understanding, wisdom acquired from sound research practice also contributes to the development of ethical guidelines. These guidelines form a link between abstract ethical principles and sound research practice, and are informed by both. In turn, reflection on ethical dilemmas and the implementation of ethics in research informs the development of legitimate and useful guidelines.



One area of keen interest and critical importance is the applicability of ethical guidelines and standards across different cultures. Some researchers point to a cultural bias in the ethical principles that underpin international ethical guidelines. This is highlighted, for example, in the different emphases placed on individualism and collectivism in different cultural contexts. In general, 'Western' cultures tend to favour autonomy over beneficence, while other cultures, including but not limited to those in developing countries, often prioritize concern for distributive justice. Here, the risk that the research poses to the community is a higher priority than the risk posed to the individual (Seedat et al., 2004).

Fontes (2004) argues that ethical principles, such as autonomy and beneficence, focus on the individual, and that this Western bias towards individualism shapes most discussions of research ethics. This argument tends to highlight the focus on the ethical considerations for individual research participants during the research process, rather than the collective benefits of the research outcomes. However, there is increasing exploration of research ethics questions by researchers in developing countries (see, for example, *Children's Geographies*, 7 (4), November 2009), and this is reflected in some of the more recent guidelines reviewed for this paper.

Some researchers also argue that while there are clear cultural variations on ethical considerations, the underlying ethical principles remain the same and should be respected regardless of the context. For example, Lukes (2008, cited in Alderson & Morrow, 2011) argues that "*among all the many varied values there are constant principles and rights that matter in every society: justice, respect, solidarity and honesty*" (p. 20), although people vary in how and why they express and experience these.

The ethical approaches described above contribute to the development of sound ethical approaches to research. In conjunction with the accumulated wisdom derived from research practice, ethical principles drawn from a range of approaches underpin guidelines that encourage reflection on ethical issues and consideration of the minimization and management of ethical dilemmas.

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## 3.2 DOCUMENTATION USED TO GUIDE THE IMPLEMENTATION OF ETHICS IN RESEARCH PROCEDURES/PRACTICE

**M**any ethical guidelines have been developed by organizations across a range of sectors to address ethics in research that involves humans. However, the body of documentation intended to provide specific ethical guidelines for research with and on children is fairly small (see Appendix 1, Table 1). It consists of guidelines that focus on ethical issues in research, and handbooks, toolkits and manuals that incorporate ethical and methodological issues in research with and on children. In addition, there are some relevant sector-specific ethical guidelines for research (for example, on violence against women) that include a section focusing on research with children.

The ethical guidelines reviewed include sector-specific and cross-sector guidelines. The sector-specific guidelines address research with and on children in relation to child protection, humanitarian emergencies, health and social welfare, and clinical health. These areas are not discrete and there are overlaps between them in the documentation. In addition to these, there are also a number of documents that are not sector-specific, but are methodologically united, focusing on participatory research with children. Some of these cross-sector, participatory research guidelines have been developed from specific sectors in response to consultation and collaborative processes (for example, child labour in development contexts) and draw on examples from these areas, but are aimed at, or relevant to, a broader cross-sector audience. The documentation reviewed in this section has been limited to international and regional (multi-country) guidelines.

### 3.2.1 CHILD PROTECTION ETHICAL GUIDELINES

Not surprisingly, the child protection sector has documentation on ethical issues in relation to collecting data on VAC. This sector has more documents focusing on ethical issues in research with and on children than any other sector. This probably reflects the increase in research with and on children in response to the UN Study and the recommendation for more research. Several areas have been the focus of recent research publications in this sector: VAC (in relation to both the UN Study and violence against women studies); child labour, including the worst forms of child labour<sup>9</sup>; child trafficking; and children living in situations of armed conflict and humanitarian emergencies.

#### ***Violence against children***

The UN Study has provided significant momentum resulting in increased research activities with children to collect data on VAC. The emphasis placed on including interview studies with children and parents in the UN Study recommendation on developing and implementing systematic national data collection and research has led to a proliferation of research in this field and a significant trend toward participatory research. Participatory and child-centred research methodologies lend themselves to research with vulnerable children (as will be discussed later in this paper) and the recommendation from the UN Study suggests, in particular, that vulnerable children should be included in interview studies.

Save the Children has made a significant contribution with a series of toolkits produced for the UN Study to encourage meaningful and ethical participation by children in research related to violence against children. This includes toolkits to support children's involvement in research, *So you want to involve children in research?* (Laws & Mann, 2004), and to guide consultation with children, *So you want to consult with children?* (Save the Children Child Participation Working Group, 2003).

The toolkit supporting research is particularly relevant to this review, with a chapter dedicated to ethical issues in children's participatory research. It emphasises that in all ethical issues, a key factor is the inherent imbalance of power between the adult researcher and the child participant. The ethical issues discussed include: avoiding harm to participants; child protection; informed consent; confidentiality; an inclusive approach; fair return for participation (noting that any financial dealings alter relationships); welfare of the research staff; and wider accountability to the participants, community and stakeholders. Examples are given throughout the document to illustrate the issues and a checklist of key ethical considerations is included. In addition, the Save the Children Child Protection Policy is incorporated into the document, and examples of consent forms are included.

Another useful Save the Children publication, "How to research the physical and emotional punishment of children" (Ennew & Plateau, 2004) includes ethical guidelines that are inspired in part by the UN Study and also by the *UN Decade for a Culture of Peace and Non Violence for Children of the World (2001-2010: UN Resolution 53/245)*. This publication focuses on research with children on the difficult and sensitive topic of physical punishment and is a handbook providing a 12-step approach to research on this topic in the context of the South East, East Asia and Pacific Region, drawing on examples from this area. It describes in detail what the authors see as eight essential ethical rules that focus on: voluntary research participation; protection from harm; safety of researchers; respect for cultural traditions, knowledge and customs; creating equality; avoiding raising unrealistic expectations; respecting

<sup>9</sup> According to ILO Convention 182 (1999), the worst forms of child labour include unconditional worst forms of child labour (e.g. slavery, slavery-like practices, trafficking of children, debt bondage, prostitution, pornography) and hazardous forms of child labour, that is "work which, by its nature or the circumstances in which it is carried out, is likely to harm the health, safety, or morals of children" (Article 3(d)).

privacy; and ensuring confidentiality and anonymity. In accordance with the topic, one section is dedicated to the special ethical challenges of research on the physical punishment of children. The handbook strongly advocates that all research should have a written ethical strategy in the research protocol, based on these rules, which researchers agree to abide by at all times. An appendix explores elements of the protocol in depth, including ways to seek consent with examples of consent forms that have been used in research projects in three different countries.

Two WHO documents that focus on research on violence against women have relevance and areas of overlap with VAC, as well as an obvious resonance for adolescent girls who have experienced violence. For example, *Putting women first: Ethical and safety recommendations for research on domestic violence against women* (WHO, 2001) lists ethical and safety considerations for domestic violence research that are relevant to research with children, including: the paramount safety of respondents and researchers, protecting confidentiality, specialised training and ongoing support for research team members, reducing stress to participants caused by research, having referral services and sources of support to offer, and ensuring that findings are properly interpreted.

Similarly, the WHO and PATH document *Researching violence against women* (Elsberg & Heise, 2005) contains a chapter that addresses ethical considerations for researching violence against women. This chapter discusses issues in the context of the ethical principles of biomedical research that involve human subjects, citing the Council for International Organizations of Medical Sciences (CIOMS) (1991) “International guidelines for ethical review of epidemiological studies”. These principles are drawn from a duty-based approach to ethical research, namely, respect for persons (autonomy), beneficence, non-maleficence and justice.

### ***Emergency and armed conflict contexts***

As a consequence of a two-year evaluation process of work on children’s participation in situations of armed conflict, post conflict and peace building, Save the Children Norway developed “Ethical guidelines for ethical, meaningful and inclusive children’s participation practice” (Feinstein & O’Kane, 2008). These guidelines present some general ethical principles that are intended to be universally applicable, although adaptable to the specific context in which the research is occurring. These include: avoiding harm to participants; child protection; informed consent; confidentiality; an ethical approach (recognizing the power imbalance between children and adults and developing strategies to address this); an inclusive approach (with equal opportunities for all children); timing of the research; motivation for the research (maintaining a transparent approach); and wider accountability (to children, communities and stakeholders). It is a thorough document that includes a checklist of key considerations and scenarios that are encountered when dealing with ethical challenges in research. As well as general ethical principles for research with children, the guidelines discuss issues specific to research in situations of armed conflict. Here, the authors draw on a working paper from the Oxford Refugee Studies Centre (Hart & Tyrer, 2006) that focuses on concepts, ethics and methods of research with children in situations of armed conflict.

Hart and Tyrer (2006) argue that participatory approaches are particularly valuable in emergency contexts. In relation to ethics, they consider that existing ethical guidelines and codes of conduct, which are commonly organized by academic discipline, are too broad and do not capture the specific issues related to research in settings of extreme violence and instability. These include: the need to take into account the practicalities that can make research difficult; the necessary preparation in unstable situations; adult-child and child-child power relations; rewards; gender dimensions; and immediate consequences of participating in the research, as well as issues around dissemination.

Another document with a specific focus is the WHO *Ethical and safety recommendations for researching and monitoring*

*sexual violence in emergencies* (2007). This includes an ethical recommendation that addresses the specific and additional safeguards that must be put in place when researching with children. These include seeking advice from experts about involving children; designing consent procedures with children's specific needs, age and level of understanding in mind; anticipating and planning for all possible consequences (including responding to disclosure of danger and referral to at least basic care and support services); and using only those interviewers who have had specialized training.

### ***Child labour in development contexts***

Documentation on ethical research with children in the area of child labour includes an International Labour Organization (ILO), International Programme for the Elimination of Child Labour (IPEC) publication: "Ethical considerations when conducting research on children in the worst forms of child labour in Nepal" (Edmonds, 2005). While this document draws on research undertaken in Nepal and uses this to provide examples, it also draws on ILO research experiences in 19 countries and one border area, and is relevant to other country contexts. Edmonds (2005) emphasizes training and awareness of researchers in research ethics. His practical guidance considers ethical issues in three contexts: pre-research (research risks, informed consent, the right to say no); during research (language and logic, trust, successful listening, misinformation as a coping strategy, pay and promises); and post research (privacy and anonymity, sharing research). Checklists are included at each stage.

The emphasis on researcher training is also apparent in the ILO and UNICEF *Manual on child labour rapid assessment methodology* (2005). This includes a cautionary note, stating that researchers must be trained to cope with sensitive situations, a psychologically skilled counsellor should be available, and contingency plans must be made before the research starts for responding if a child reveals themselves to be at risk of harm. This manual has appended the ILO-IPEC ethical guidelines (Edmonds, 2005) almost entirely.

A collaboration of international organizations, the Regional Working Group on Child Labour in Asia (RWG-CL), produced a *Handbook for action-oriented research on the worst forms of child labour including trafficking in children* (2002), which includes significant reference to ethical considerations. It draws heavily on the Save the Children publications *Children in focus: A manual for participatory research* (Boyden & Ennew, 1997) and the previously discussed handbook for researching the physical and emotional punishment of children (Ennew & Plateau, 2004), including the "eight essential ethical rules".

### ***Trafficking***

Three documents were identified that have a specific focus on interviewing and research in the context of trafficking. One of these is specific to research with children: "Guidelines on the protection of child victims of trafficking" (UNICEF Technical Notes, 2006). This document discusses the key ethical principles to take into consideration when doing research on child trafficking, including researchers' responsibility to do no harm, provide health and safety information, avoid raising unrealistic expectations, and assess the potential risks for the child participant. It suggests that 'informed consent' would be better termed 'informed dissent' to emphasize the child's right to refuse or withdraw participation.

The International Organization for Migration (IOM) produced a comprehensive set of guidelines to standardize data collection on trafficking and promote its exchange between the European Union Member States: "Guidelines for the collection of data on trafficking in human beings, including comparable indicators" (2009). Although not specific to the collection of data from children, it offers useful guidance on data protection and compliance with relevant European regulations and international standards (Guideline 8), and ethical standards for processing data (Guideline 9). This

includes discussion of using data only for pre-defined purposes, with the consent of the trafficked person and/or guardian; de-personalizing data for further use, regulated according to national legislation and the EU data protection laws; and having mechanisms that allow victims access to their personal data to modify, update or withdraw it at any time.

The WHO *Ethical and safety recommendations for interviewing trafficked women* (Zimmerman and Watts, 2003) has relevance to research with children and particular resonance for adolescent girls. It discusses ten guiding principles for research in this area. These are: do no harm; know your subject and assess the risks; prepare referral information; adequately select and prepare interpreters and co-workers; ensure anonymity and confidentiality; get informed consent; respect each woman's assessment of her situation and risks to her safety; do not re-traumatize a woman; be prepared for emergency intervention; and put information collected to good use.

### ***Reflection on ethical research considerations***

Alongside these documents that aim to provide ethical guidelines across different aspects of the child protection sector, there are several useful documents that reflect ethical aspects of experiences of children's participation in research. These make a valuable contribution to guiding research. Two such documents are Save the Children publications on children's participation in research – first, on the care and protection of separated children in the context of emergencies (Mann & Tolfree, 2003) and second, in relation to the *UN Study on Violence against Children* (Feinstein, Karkara & Laws, 2004). Both documents reflect on different aspects of research practice.

Mann and Tolfree (2003) focus on considerations related specifically to the difficult context of research in emergencies, including discussion of informed consent, the balance between distress and empowerment, and important local community considerations. These include cultural considerations regarding children, not raising false expectations of change and power dynamics. Feinstein, Karkara and Laws (2004) focus more on key ethical issues such as avoiding harm, child protection, informed consent, confidentiality, being inclusive, the welfare of researchers and wider accountability to the community. This document also recommends that researchers adhere to the Save the Children "Practice standards in children's participation" (2005).

Similarly, two publications from the Young Lives Research Project reflect on experiences researching child poverty in four developing countries: Ethiopia, India (Andhra Pradesh), Peru and Viet Nam. These have focused on the ethics of social research (Morrow, 2009) and, in the case of Viet Nam, the ethics of research reciprocity in the context of research with children in poverty reduction policy (Lan & Jones, 2005). A key aspect of their usefulness lies in their application of ethical principles to actual research situations. In particular, Morrow (2009) outlines the approach taken in the Young Lives project to a range of ethical issues across the four countries, emphasizing the importance of understanding local contexts. Discussion includes informed consent, compensation or rewards, child protection, reciprocity and managing data.

## ***3.2.2 ETHICAL GUIDELINES FROM OTHER SECTORS***

### ***Health and social welfare ethical guidelines***

**A** very useful document is the "Ethical approaches to gathering information from children and adolescents in international settings: guidelines and resources" (Schenk & Williamson, 2005). This document is often cited by other guidelines, and was one of the two ethical guidelines documents cited most frequently as helpful by researchers in a recent international survey (Powell et al., 2011). This publication was developed by the Population Council's Horizons Programme and IMPACT (Implementing AIDS Prevention and Care Project), a collaboration of health organizations.

Initial development focused on the need for health research in the context of children and adolescents affected by HIV and AIDS. However, this document also applies in broader health and welfare contexts. It is a comprehensive guide to ethical considerations in research and information gathering with children and adolescents, including research design, consultation, anticipating adverse consequences, being sensitive to children's specific needs, and ensuring that stakeholders understand the limits to the research activity. The document tends to focus on ethics at the point of data collection, and emphasis is placed on the need for careful advance planning (including the anticipation of adverse consequences), local community consultation and ensuring that services are in place to address possible eventualities. In addition to the guidelines provided, the document also lists current accessible resources.

A more recent WHO draft document provides *Ethical and safety guidance for sexual and reproductive health research and data collection with adolescents* (WHO, 2011b). This document addresses adolescence as a unique period, characterized by rapid biological, cognitive, emotional and social development, and highlights the importance of identifying vulnerabilities and effective interventions for younger and older adolescents. It draws on various key texts, including the Population Council document outlined above, the CIOMS guidelines outlined below, Save the Children's *So you want to consult with children*, and the UNCRC. Recommendations focus on risks and benefits, confidentiality, adolescent informed consent, parental/guardian informed consent, community consent, adolescent-friendly research, and health risks and safety.

### ***Clinical/biomedical ethical guidelines***

A recent publication by the Centre of Genomics and Policy, McGill University, and the Canadian Institutes of Health Research, provides guidelines on the *Best practices for health research involving children and adolescents: Genetic, pharmaceutical, longitudinal studies and palliative care research* (Avard et al., 2011). These guidelines are based on the review and comparison of eight international and two Canadian health guidelines. The document reflects on the current situation, identifying issues and providing an overview of international and Canadian ethical norms, and suggests 10 guidelines to assist best practice. These cover the inclusion of children in research, consent to research, assent of the child, dissent of the child, departures from consent, evaluation of risks and benefits, privacy and confidentiality, return of research results, payment in research, and composition of research ethics boards.

Two documents produced by the Council for International Organizations of Medical Sciences (CIOMS) and WHO are often cited in ethics documentation, particularly ethical codes for medical and health research. These are the *International ethical guidelines for biomedical research involving human subjects* (2002) and *International ethical guidelines for epidemiological studies* (2008). Both of these international guidelines include a specific guideline on research with children (Guideline 14). Guideline 14 states that *"before undertaking research involving children, the investigator must ensure that:*

- *the research might not equally as well be carried out with adults;*
- *the purpose of the research is to obtain knowledge relevant to the health needs of children;*
- *a parent or legal representative of each child has given permission;*
- *the agreement (assent) of each child has been obtained to the extent of the child's capabilities; and,*
- *a child's refusal to participate or continue in the research will be respected"* (CIOMS & WHO, 2008, p. 54).

Additional commentary in the CIOMS guidelines elaborates on these points.





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PAKISTAN (all names changed) *Eleven-year-old Kamran who is a sex worker, rests his hands on his jeans, in a poor neighbourhood of the city of Karachi. Kamran had his first sexual experience at age eight and was raped soon after, by a man who then paid him. He has never been to school. Kamran recently moved, with his mother, into the apartment of an 'uncle', Amjad, who was himself raped as a child and became a sex worker at age 12. Amjad and another man run a massage business which is a front for soliciting sexual customers for themselves and the 4-5 children, including Kamran, who work for them.*

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A document focusing on *Ethical considerations for clinical trials on medicinal products conducted on the paediatric population* has been produced for the Europe region, to contribute to the development of guidelines for good clinical practice (European Medicines Agency (EMA), 2008). While the CIOMS guidelines state that children *should* be included in research studies, the EMA document emphasizes that trials are *necessary* on children, although (as with the CIOMS guidelines) preference should be given to the inclusion of older children, as they are considered less vulnerable and more able to indicate assent or dissent. The document advises that the same ethical principles apply in research with children as with adults, and that ethics committees should have paediatric expertise.

The UNAIDS document *Ethical considerations in biomedical HIV prevention trials* (2007) contains a guidance point on research with children and adolescents. The focus is on the importance of including children and adolescents in clinical trials in order to verify safety and efficacy from their standpoint, as they could be future recipients of biomedical HIV preventive interventions. While making reference to addressing the particular safety, ethical and legal considerations related to children and adolescents, the focus is on beneficence for science and society.

### **Monitoring and evaluation ethical guidelines**

While programme monitoring and evaluation activities (M&E) are seldom bound by the same strict requirements of ethical review as other research activities, Schenk and Williamson (2005) argue that the programme manager has a responsibility to ensure that the same high standards of ethical supervision are upheld. Similarly, UNICEF documentation, *Children participating in research, monitoring and evaluation: Ethics and your responsibility as a manager* (2002), states that managers are considered to be just as responsible for ensuring that ethical issues are identified and resolved in methodology design as researchers and evaluators. Key considerations for managers in these activities include accountability, protection of children's best interests, informed consent, equity and non-discrimination, respect of children and their views, and methodological limitations. The UNICEF document includes 10 questions for managers adapted from Alderson's (1995) ten topics in ethical research.

The Save the Children 2011 Standard Operating Procedure (SOP) for ethical standards in monitoring and evaluation states that “*all data collection processes (baseline, monitoring, evaluation, research) adhere to recognised ethical standards and the best interest of the child*” (p.1). The SOP advises that an ethical assessment should be carried out by the Country Office before undertaking any M&E activity, and by in-country and institutional ethical review boards as appropriate.

### **3.2.3 CROSS-SECTOR ETHICAL GUIDELINES FOR PARTICIPATORY RESEARCH PROCESSES**

**M**ost of the ethical guidelines referred to so far, excluding those in the clinical/biomedical sector, focus on participatory research with children. In addition to the sector-specific guidelines outlined above, guidelines, manuals and toolkits have been developed to address ethical and methodological considerations in undertaking participatory research with children and young people (Boyden & Ennew, 1997; ChildFund, 2010; Shaw, Brady & Davey, 2011).

One manual that is often cited is the Save the Children *Children in focus: A manual for participatory research with children* (Boyden & Ennew, 1997). This is a comprehensive training manual for NGOs and research institutions, covering participatory research with children in a range of contexts. The focus is on training, with exercises throughout the manual. Boyden and Ennew (1997) link children's rights with participatory research and state that “*thinking about the power relationships involved in this kind of research has led to new considerations about ethical issues in the research process*” (p. 42).

Similarly, the UK National Children's Bureau (NCB) document *Guidelines for research with children and young people* (Shaw et al., 2011) contextualizes participatory research with children within a children's rights framework. The focus of the ethical discussion is on issues relating to consent, confidentiality, protecting children and safeguarding. Consent is discussed in some detail across a range of contexts, including both 'opt in' and 'opt out' strategies (discussed later in this paper) and with checklists suggesting issues of which researchers should be aware. Similarly, the ChildFund International *Child- and youth-friendly participatory action research toolkit* (2010), which appends ethical guidelines, focuses on informed consent, confidentiality and child protection.

There are also guidelines that focus on research with children as co-researchers, which include ethical considerations. For example, the INVOLVE document *A guide to actively involving young people in research: For researchers, research commissioners and managers* (Kirby, 2004) looks at methodological and ethical issues and has specific sections on the power issues of involving young researchers, supporting their involvement, and ensuring young people's



health, safety and well-being. Similarly, *Funky Dragon, Children as researchers: Resource pack*, which is primarily a methodological guide, includes a checklist of ethical considerations (Children and Young People's Assembly for Wales, 2011). While both of these documents are aimed at the UK context, they have been included here as an example of the documentation in this area.

### 3.2.4 KEY ETHICAL ISSUES IN THE ETHICAL GUIDELINES

There are some key ethical issues that recur throughout most of the ethical guidelines and documentation reviewed, across all the sectors. Those mentioned most frequently are obtaining the informed consent or assent of children, avoiding harm to children, and issues related to privacy and confidentiality.

#### ***Research on violence against children***

Contextual issues: While ethical issues are apparent throughout the guidelines across sectors, they have particular resonance or specific challenges associated with them in specific contexts when collecting data on VAC. The context in which the research is being conducted has a significant impact on the nature of the ethical issues and the means by which to address them. For example, in research with children living in situations of armed conflict, guidelines emphasize the importance of taking proper account of the conflict and the impact it has on everyday practicalities and, consequently, ethical challenges (Feinstein & O'Kane, 2008; Hart & Tyrer, 2006). Consenting to participate in research may place children at risk from authority or community figures.

In another consent example, undertaking research in the context of humanitarian emergencies may mean working with displaced persons and unaccompanied and orphaned children, challenging the usual ethical requirement for parental consent. Guidelines prepared by the Human Sciences Research Council of South Africa, *Informed consent guidelines re minors (including orphans and vulnerable children (OVC)) and parental substitutes* (2010), provide guidance for managing the ethical requirement for parental consent in this difficult situation. The guidelines stipulate a descending order of people from whom consent should be sought, namely:

- the child
- the parent
- if no parent, then the guardian (court or parent appointed)
- if no guardian, then the foster parent (court appointed)
- if no foster parent, then caregiver
- if the child is a caregiver then a 'responsible person' or trusted adult nominated by the child (for example, community worker or teacher)

When researching sensitive subjects, the researcher can request a waiver of parental (or substitute) permission by prior negotiation with the communities concerned. The complexity of this guideline highlights the difficulty in obtaining parental consent in particular contexts and the need for researchers to be resourceful and ethics committees to be flexible, without compromising the protection of research participants.

The ethical issue of minimizing harm by referral to support services may also be difficult or impossible in certain contexts, such as countries where there is conflict or that are resource poor. There may be only minimal services

available, if any at all, to provide support to individuals, leading to a significant dilemma in research on topics such as sexual violence in emergencies, in which the availability of referral services is considered “*an ethical imperative*” (WHO, 2007). Preparation and advance planning is vital to assess the nature of the research setting, and the potential risks and adverse consequences, in order to develop strategies to minimize these.

The specificity of these guidelines to, for example, situations of armed conflict and humanitarian emergencies may also indicate the lack of practical, detailed guidance in existing child research ethics literature. There is little practical guidance about how to operationalize the ethical principles and ensure the safety of children, which may account for the need for these specific guidelines within areas of the child protection sector, which require the management of research in very complex situations.

Some ethical issues were emphasized more in the guidelines related to VAC than in guidelines relevant to other sectors. These include issues related to privacy and confidentiality, child protection, disseminating information, and findings following the completion of the research project training, and welfare of members of the research team.

Privacy and confidentiality: These are essential in research on VAC. In some instances participants may be at personal risk for disclosing information relating to violence and maltreatment (WHO 2001, 2007). It is important, therefore, that practical measures are taken to ensure that privacy and confidentiality are maintained during and after research participation. Care should be taken that research activities take place in private spaces where participants will not be overheard and that their identity is protected. The protection of their identity includes consideration of data storage. For example, it may be inappropriate to use tape recordings as it can be difficult to be certain of their security (Edmonds, 2005). It also includes ensuring anonymity in the dissemination of research findings, such as research reports and presentations, so that participants, families and communities cannot be identified (Edmonds, 2005; WHO, 2011b).

Child protection: The limits to confidentiality are often raised in the guidelines relevant to research on VAC, with most documents recommending the development of a contingency plan before the project starts for providing support or referral to appropriate services for children who reveal themselves to be at risk of harm (for example, Feinstein & O’Kane, 2008; ILO & UNICEF, 2005; UNICEF, 2002). Boyden and Ennew (1997) argue that it is the responsibility of the researcher to protect a child from putting themselves at risk and to decide whether, or when, to intervene when a child is indeed at risk.

Some ethical guidelines also refer to a specific child protection policy and/or a code of conduct for researchers, either including or appending extracts from existing protocols, for example Save the Children (Laws & Mann, 2004). The Save the Children toolkit for involving children in research includes a specific extract that spells out a code of conduct for staff behaviour. The principle underlying the code “*is that staff should avoid actions or behaviour which may be construed as poor practice or potentially abusive*” (Laws & Mann, 2004, p. 31).

Dissemination of findings: The guidelines that emphasize issues related to the dissemination of findings are those developed in relation to research on aspects of violence in development contexts. The emphasis is on ensuring that findings are disseminated to those who are able to use them effectively to promote positive action (Ennew & Plateau, 2004) and taking special care to ensure that sharing the research findings does not place child participants at risk (ILO-IPEC, 2005). Some guidelines stress the importance of not revealing participants’ identities at the time of publication or sharing reports.

Training of researchers: Research guidelines that focus primarily on violence against women tend to place a great deal of emphasis on ensuring that researchers have the necessary skills and expertise (WHO 2001, 2007; Zimmerman & Watts, 2003). This includes the ability to assess the situation and any risks to the participant or the research staff, to ensure that participants are not re-traumatized by the research process, and to be able to make emergency interventions if necessary. The WHO (2007) document on researching and monitoring sexual violence in emergencies comments on the unique set of challenges posed in this extremely sensitive area of information gathering, and recommends that only people with appropriate training should engage in this work.

Welfare of researchers: A research team that is collecting data on VAC may be exposed to a degree of risk. Save the Children documents stress that the safety of the researcher needs to be placed above completion of the research tasks at all times (Laws & Mann, 2004). In addition, the emotional well-being of research staff is an issue, as they are exposed to distressing information and may need opportunities to discuss upsetting experiences or access professional support.

### ***Cross-sector ethical issues***

Local context: The importance of the local context in which the research is taking place is emphasized in the documentation. For example, research focusing on child poverty (Morrow, 2009), with children in the context of armed conflict, post-conflict and peace-building (Feinstein & O’Kane, 2008), and sexual reproduction and health (WHO, 2011b). This requires efforts to understand the local context and, accordingly, take a reflexive approach to the research process. *“Every research setting poses its own ethical challenges requiring sensitivity, reflexivity, and a strong sense of social responsibility on the part of the researchers”* (Hart & Tyrer, 2006, p.18).

The Young Lives project provides an example of reflexivity across four different countries, adapting processes to the local context (Morrow, 2009). For example, the issue of compensation or rewards is dealt with in ways that are locally specific, reflecting cultural contexts about the value of people’s time, the willingness to undertake research and the reality of poverty. Researchers’ understanding of cultural considerations is also important to avoid imposing secondary distress on children, by encouraging behaviour or responses that are not culturally acceptable (Mann & Tolfree, 2003).

Community consultation: The importance of consultation with local groups is emphasized across sectors, both in the planning of the research and during the research process. In situations of armed conflict, for example, consultation with civil or military authorities prior to the implementation of the research project is vital (Hart & Tyrer, 2006). International ethical guidelines highlight that decision-making in some contexts is collective, rather than individual, and that consent needs to be sought from the wider community for the participation of children and young people in research (WHO, 2011b). As well as assisting in preparation, local consultation demonstrates transparency to the community stakeholders, who may be curious about the research (ChildFund International, 2010) or who need to be involved in consenting to the project. Schenk and Williamson (2005) advocate consulting with an independent local community stakeholder group throughout the research project.

Power dynamics have an impact on children’s involvement in research in differing ways in different cultures. Mann and Tolfree (2003) note that *“in many cultural contexts, children do not take readily to the role of genuine informant and participant, and it is important for the researcher to know from the outset about cultural practices concerning how adults and children communicate”* (p. 23).

Risks to children: Balancing the risks and benefits to participants is an essential issue in research with children

across the sectors, and is referred to throughout the guidelines. However, it is not always clear, for example, in clinical/biomedical guidelines, how a risk-benefit ratio is to be conducted, and how this would be specific to child participants (Bero, 2010). This specific example highlights the lack of more practical guidance on ethics practice in research activities. Schenk and Williamson (2005) advocate local consultation in assessing risks and benefits, and ensuring children's protection.

The inclusion of children in health research reflects an important shift in norms relating to research involving children (Avard et al., 2011). Following what Avard and colleagues refer to as *"unfortunate scandals in research involving children, for example, the Willowbrook case in the 1950s ... [in which] ... researchers intentionally infected them [healthy institutionalized children] with hepatitis in order to understand the disease and to develop a vaccine"* (p. 22), children were effectively excluded from research in an attempt to protect them. The unintended consequence of this exclusion, according to Avard and colleagues, was a lack of data and appropriate medical treatments for children in general, until the Declaration of Helsinki laid out clear inclusion criteria for children. There is consensus evident in the documentation on the need to include children while offering them appropriate protection, but how often and which children should be included is less clear.

Some biomedical/health ethics documentation tends to stress the potential benefits to science and society, essentially arguing for children's participation in trials (for example, UNAIDS, 2007). There is variation in this documentation on whether studies should include healthy children. A few guidelines allow inclusion of healthy children if the risks are negligible, or comparable to the level of risk a child would be exposed to ordinarily in everyday life or routine medical care.

There is, however, literature on clinical trials on children in developing countries that belies this, and Alderson and Morrow (2011) argue that *"despite bioethics safeguards, harmful and fraudulent medical research and practices continue to be reported ... such as the use of dangerous experimental drugs on African children"* (p. 107). Some guidelines allow the inclusion of children if the least vulnerable (older) children are considered first. Other guidelines state that slightly more than minimal risk is acceptable if the research has prospects for major or vital medical significance. The analyses of risks and benefits are therefore variably assessed in accordance with varying levels of risk and against individual, and wider, benefit.

Researcher responsibility: This is stressed in the context of balancing the risks and benefits of children's participation in research. This has an added dimension, with additional considerations required, when the children involved are unaccompanied, orphaned or separated from their family (Schenk & Williamson, 2005) as a consequence of adverse conditions such as humanitarian emergencies, forced migration, HIV/AIDS, or living away from parents for work or educational reasons. Some documentation emphasizes that unaccompanied children in contexts such as emergencies should only participate in research if it is of direct benefit to them (WHO, 2007). For example, a Save the Children document about research with children separated from their families in emergencies states that *"researchers who seek information from children have an inalienable responsibility towards them, especially when the subject matter of the research concerns their private lives and potentially difficult and emotional issues"* (Mann & Tolfree, 2003, p. 21). It is essential that children are not left feeling exposed or vulnerable without follow-up support, and that researchers are able to deal appropriately with any distress that is expressed.

Child protection: The limits of confidentiality in child protection are not always made explicit in ethical guidelines. However, there is a tendency within most recent documentation to state that a duty to ensure the safety of children

and young people overrides the responsibility of researchers to guarantee confidentiality. The second recommendation in the WHO (2011b) draft safety and ethical guidance for sexual and reproductive health research, concerning confidentiality, is one example, stating that *“confidentiality of adolescent participants must be protected, except where there is risk of significant harm to the participants or others”* (p. 9). A number of guidelines include a separate child protection policy or protocol. Most notably, the Save the Children (2003) child protection policy is referred to or appended to some guidelines.

Researcher training: A recurring theme in the documentation is the need for preparation and advanced planning before the conduct of research with children. In addition to this, some of the guidelines reviewed emphasize that *“ethical guidelines for research activities cannot replace contingent ethics: decisions that are made in specific contexts, in the unplanned and creative spaces of gender relations and social interaction”* (Edmonds, 2005, p. 2). Given the need for researchers to make on-the-spot decisions in the field, training and awareness are of the utmost importance.

Payment and remuneration: Payment related to participation in research can be divided into four categories: reimbursement, compensation, appreciation and incentive (Wendler et al., cited in Alderson & Morrow, 2011; Avarid et al., 2011), and ethical guidelines attend to particular aspects of these. In general, guidelines warn against incentives or inducements to participate in research, as these may constitute persuasion or pressure on participants and, therefore, contravene the Nuremberg standards (Alderson & Morrow, 2011). Any financial dealings alter relationships and may have the effect of bribing or coercing people to take part, potentially creating a sense of obligation, raising expectations or becoming a form of control (Laws & Mann, 2004).

Key reasons for offering payment include recognizing and recompensing the participation of children and young people, with guidelines emphasizing that this should be in line with local living standards, cultural and socio-cultural factors, and the contribution made (Laws & Mann, 2004; Schenk & Williamson, 2005; Shaw et al., 2011; WHO, 2011b). This is particularly important when researchers are faced with acute poverty and/or when children's involvement in research has a negative impact on the income of children and their families (Edmonds, 2005).

Schenk & Williamson (2005) stress that the nature of payment and compensation should be determined by local consultation, while Edmonds (2005) argues for national-level deliberation with selected stakeholders. The Young Lives study dealt with the issue of compensation or paying research participants in ways that were locally specific, with country teams offering different forms of payment to reflect cultural contexts about the value of people's time, their willingness to undertake research activities and the reality of poverty – with people lacking the capacity to miss a day's work to talk to researchers (Morrow, 2009). Morrow comments that the question of remuneration is becoming increasingly important as economies become more marketized and people are becoming more aware of the financial value of their time.

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### 3.3. ETHICAL POLICY, CODES AND PROTOCOLS

The search methodologies produced ethical codes and policies relevant to research with children and young people from several sources (see Appendix 2). These included country/national codes and professional body ethical codes. While these are not an exhaustive list, and represent primarily those ethical codes that were easily accessible, they provide a glimpse of the key ethical issues and guidance available to researchers. This is illustrated by the use of a range of these ethical codes in a recent large scale study by the National Society for Prevention of Cruelty to



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HAITI *A girl victim of domestic violence attends an interview conducted by members of the Children Protection Brigade at the new Transit Center for minors in Port au Prince. The new center is designed for interviews of children in conflict with the law or victims of violence and was built by UNICEF in collaboration with the French Embassy in Haiti.*

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Children (NSPCC) on child abuse and neglect in the UK (with over 6,000 participants) (Radford et al., 2011). The NSPCC study developed an approach informed by professional guidance on research ethics from guidelines produced by the British Sociological Association (2004), the Social Research Association (2003), Medical Research Council (2005), National Children's Bureau (2003), the Society for Research on Child Development, and the Economic and Social Research Council (2010).

### 3.3.1 COUNTRY/NATIONAL CODES

The vast majority of the country/national ethical codes reviewed (18 of the 24 reviewed, or 75 per cent) related specifically to health and/or biomedical research. The remainder covered other research aspects with human participants but were also relevant to health research. Only two of the country/national ethical codes reviewed focused specifically on research ethics with children and these were from very diverse countries: one from South Africa and one from New Zealand. These two codes had different foci, reflecting the ethical considerations relative to each country, with the code from South Africa providing informed consent guidelines for minors, including orphans and vulnerable children



and parental substitutes (South African Human Sciences Research Council, 2011), and the New Zealand document providing guidelines for health research with children (New Zealand Health Research Council (HRC), 2007).

The New Zealand document made reference to consent being required from a child's parent or guardian, whereas the South African document went into detail about the descending chain of parental substitutes who may give consent, highlighting the differing realities for researchers seeking parental consent for children to participate in research in the two countries. The New Zealand HRC document was the only health-related ethical code accessed that was specific to children, rather than the general population. It is probable that other national/country documentation exists to specifically address ethics in health/clinical research with children. However, it is unlikely to be in any great measure, given the rigour of the documentation search and the voracity of the response to the email request.

Four of the country ethical codes accessed make no reference to children at all, and all four codes have a medical/health focus. The remainder of the country/national codes reviewed have varying degrees of reference to children and young people, with attention focused in almost every case on gaining the consent of parents (or an authorized adult) for children's involvement in research (16 codes) and children's assent or consent (15 codes). However, despite the reference to consent issues and the conditions under which it is necessary, there is little detail about procedures for obtaining children's consent or assent. Similarly, some ethical codes make reference to respecting children's refusal to participate, but do not offer guidelines about how this could be manifest.

The other key area of attention in health and medical research ethical codes related to children is an analysis of risks and benefits, included in ten of the codes reviewed. This analysis is complicated by risks involved in the inclusion of healthy children and exclusion of children who may potentially benefit from the trial, and benefits to the individual child and/or the greater community. Consequently, ethics codes tend to list the possible options.

For example, the Uganda National Council for Science and Technology National guidelines for research involving humans as research participants (2007) state that if there is greater than minimal risk and the study entails no prospect of direct benefit to the individual child participant, it may not be conducted unless:

- the risk is only a minor increase over minimal risk;
- the intervention or procedure presents experiences that are commensurate with those inherent in their actual or expected medical, dental, psychological, social, or educational situations;
- the intervention or procedure is likely to yield generalizable knowledge about the child's disorder or condition that is of vital importance for the understanding or amelioration of that disorder or condition; and
- adequate provisions have been made for the solicitation of the child's assent and their parents'/guardians' permission (p. 33).

In addition, some guidelines (for example, EMA) define direct benefit to include prevention (that is, vaccine testing), while others consider only therapeutic benefit as a direct benefit (Bero, 2010).

Overall, reviewing country specific guidelines demonstrates considerable gaps and inconsistencies in the guidelines. These gaps are related largely to social research, with medical and health research codes dominating the ethical landscape. However, within this body of documentation there is a lack of consistency and a tendency to focus on consent/assent policies and risk-benefit ratios.

### 3.3.2 PROFESSIONAL ASSOCIATION CODES

Ethical codes from 12 professional associations have been reviewed. Two of these associations were not specifically research-related bodies (National Association of Social Workers (NASW) and the British Psychological Society (BPS)). They were included in the review as they had been referred to in other relevant research ethics documentation and in email correspondence with researchers. In addition, the inclusion of these codes is a recognition that some professional codes governing work with children and young people are relevant to research activities. These can provide useful guidance, even though researchers are not formally bound by them (Schenk & Williamson, 2005). Whilst NASW did not refer to research, BPS considered research to be part of the role of psychologists and, therefore, the code of ethics and conduct pertains to members' research activities.

The review found that the reference to children in the codes varied considerably from no reference at all to sections of documentation dedicated to ethical guidelines for research with child participants, with most institutions falling somewhere in between these two poles. The specific ethical issues relating to research with children addressed in the documentation reviewed included consent, protection of child participants, information, confidentiality and anonymity, and financial inducements. The variation in documentation was considerable, with obtaining consent to participate the dominant issue. The findings of this review are consistent with an earlier nationwide review of ethical codes in New Zealand (Powell & Smith, 2006).

Most of the codes (eight) made reference to children and/or young people (or minors). There were two exceptions: the American Anthropological Association and the Association of Social Anthropologists of UK and the Commonwealth, neither of which made direct reference to children or young people. However, they were sent by respondents to the email request, perhaps because they both contain useful guidance for research in countries other than the researchers' country of origin.

The primary focus of the codes that referred to children was issues of consent to participate in research, with eight of the codes referring to obtaining parental consent. Six codes made reference to obtaining children's consent. Only one of these, the BPS code, did not identify the need for parental consent for children specifically, although it is implied in stating that psychologists "*need to remain alert to the possibility that those people for whom ... research participation are contemplated may lack legal capacity for informed consent*" (BPS, 2009, p.12).

One-third of the codes (four) included reference to issues of confidentiality that relate specifically to children during research. Three of these (BPS, CRAE and ESRC) were concerned with breaching confidentiality when there were issues relating to danger and safety. The fourth (Market Research Standards), referred to respecting the participant's confidentiality.

Four codes made reference to protecting children from distress or ensuring that the risks of research were weighed against the potential benefits. Specific reference to child protection was made in the ESRC ethical framework, in an appended ethical protocol of the Young Lives study. This protocol specifically recommends use of the Save the Children (2003) child protection policy. The guidelines from the British Educational Research Association (BERA) specify that researchers must comply with child protection clearance procedures.

Only one code referred to issues of incentives. The Market Research Standards, Draft (2010) outlined the need for incentives to be appropriate, to not be client's goods or services, and for parents to be informed.



In summary, references in professional ethical codes specific to children and young people were related (in descending order of importance) to issues of consent, confidentiality, protecting children from distress or risk, and one mention of incentives. There was considerable variation between the codes and an overall paucity of attention to ethical constraints in research with children and young people.

# 4

## ETHICS LITERATURE REVIEW: PUBLICATIONS

### 4.1 KEY ETHICAL ISSUES

Recent years have seen a significant growth in interest in child research ethics, in response to developments in both child research and ethics (Alderson & Morrow, 2011; Hill, 2005; Farrell, 2005) and an accompanying burgeoning of literature. 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). Instead, researchers conducting research with children emphasize the ongoing nature of ethical considerations and the need to consider ethical issues 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 (Powell et al., 2012), which we will now look at more closely.

#### 4.1.1 CONSENT

The ethical issue of consent has probably generated the most debate on research with children (Alderson & Morrow, 2004; Cocks, 2006; Morrow & Richards, 1996). The literature includes debates about such issues as: who should be required to provide consent to children's participation in research, how that consent should be obtained, considerations of children's competence to give consent, and the nature of fully-informed, freely-given consent.

Informed consent rests on four core principles:

1. Consent involves an explicit act, such as 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 (Gallagher, 2009).

#### ***The explicit act of consent***

Informed consent has been described as *"the invisible act of evaluating information and making a decision, and the visible act of signifying the decision"* (Alderson & Morrow, 2011, p.101). Despite the emphasis that tends to be placed in ethics review committee guidelines on written consent, *"informed consent is not a consent form or a legal document; it is a communication and decision process"* (Sieber, 1994, p. 5). Informed consent always involves

a two-way exchange of information between researcher and potential participants; however there are additional ethical complexities in research with children. Consent dynamics necessarily include consideration of parents and/or authorized adults, thus creating a dynamic triad with multiple relationships (Trussell, 2008).

Professional and legal requirements on parental consent are not consistent internationally. For example, while researchers are generally required to obtain parental consent under Federal regulations in the US, there is uncertainty about its necessity in the UK (Kendrick et al., 2008). In the UK, one law provides the framework throughout the country (Bogolub & Thomas, 2005), but the law and practice are complex, and related to the notion of competence (Cashmore, 2006). The standard, often referred to as 'Gillick competence', is that children under the age of 16 years are not presumed to be legally competent, but if they can be judged to understand what participation in research will involve, then parental consent is not necessary. This standard, based on legalities relating historically to consent in a case involving medical care, is important as it highlights that it is not simply chronological age that determines competence (Morrow & Richards, 1996). There are difficulties with the concept of Gillick competence, however, as assessing competence is not straightforward and the question arises of who should make the assessment (Cashmore, 2006).

The US has a more cautious interpretation of legal competence in the Federal regulations governing research with human subjects, and more stringent requirements on parental consent. The regulations allow for waiving the requirement for parental consent in research with children and young people, if parental consent is not a reasonable requirement under the circumstances and if safeguards are in place in the research project to protect children from harm (45CFR46.408). Children who have been abused or neglected are mentioned specifically in the regulations as the only example of a population for whom parental consent may not be a reasonable request (King & Churchill, 2000). While parental consent requirements can be waived under these specific conditions, Cashmore (2006) states that studies indicate that waivers are not easily obtained or consistently applied.

An important consideration in research on VAC is whether parental consent is appropriate or in children's best interests. It may not be possible to get parental consent for some groups of children, for logistical and practical reasons. For example, in many countries, there can be difficulties gaining parental consent regardless of the legalities that are linked to lack of parental mobility, problems establishing who the child's guardian is, low rates of literacy and scepticism about signing documents (Abebe, 2009; Clacherty & Donald, 2007; Hutz & Koller, 1999).

In addition, it may not be appropriate or possible to seek parental consent when children are 'runaways' and homeless (Meade & Slesnick, 2002), living on the streets (Richter et al., 2007; Vakaoti, 2009), or emancipated minors (King & Kramer, 2008). Researchers in a South African study with street children reported many obstacles when seeking someone to take legal responsibility for the participants and provide consent for their participation in the research (Richter et al., 2007). They argued that the experiences these children had, in terms of difficult lives, gave them greater life wisdom and, in fact, an earlier capacity to give informed consent. In this particular study, the participants were eventually granted mature minor status for its duration.

Research studies in which the potential participants are children and young people in care can also encounter difficulties in gaining parental consent. Children are often in care as a consequence of abuse or family breakdown, which makes the practicalities of gaining informed consent difficult and time-consuming (Kendrick et al., 2008).

In addition to difficulties with practical issues, parental consent may be difficult to obtain if parents' interests conflict with their ability to make decisions in the best interests of their children (King & Churchill, 2000). The assumption



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*BRAZIL Sonia [name changed], 17, covers her face with her hands, in a room with dolls lined up on a shelf behind her at CEDECA, the Centre for the Defense of Children and Adolescents, in a major city in Brazil. From age 11 to age 15, Sonia was sexually abused by an older male cousin. At 15, she became pregnant and had an abortion, but while the abortion was reported to the police, the abuse was ignored. When Sonia first came to CEDECA 18 months ago, she was angry and barely spoke — now she is recovering. She would like to eventually work in legal services to help other children.*

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that parents will always act in their children's best interests, inherent within usual parental consent procedures, cannot be assumed in child maltreatment research (Knight et al., 2000). 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 the disclosure of problems (Cashmore, 2006; Øverlien, 2010).

An ongoing debate in the literature, salient to research on violence against children, concerns the use of passive or active consent procedures. Passive consent procedures inform parents about the research and they are 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 and informed consent can be compromised by parents' failure to receive, read or understand the form (Cashmore, 2006), it is taken to be an affirmative response. 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 children whose parents have given their formal consent are allowed to participate in the research.

Passive consent procedures allow researchers to bypass the usual gatekeepers and allow children to participate and contribute their knowledge to research about topics that are considered sensitive, such as their experience of violence (Carroll-Lind et al., 2006). This has the advantage of higher participation rates and, therefore, increased representativeness of the sample. In a review of six child abuse research projects, the adoption of passive or active consent processes was considered to be the decisive factor affecting the participation rate and ultimate sample size (Lynch et al., 1999). The review led Lynch and colleagues (1999) to suggest that *“the adoption of a rigorous ethical stance at each stage of the recruitment process may have a cumulative effect on the ultimate sample size”* (p. 72), with factors including how explicit the researchers were about the nature of the research in provision of information, the use of intermediaries to recruit participants, and the type of consent procedure used.

A large New Zealand survey (with a representative sample of 2,077 children), which asked children directly about their experiences of violence, attributed the relatively high participation rate to the use of consent procedures that incorporated parental passive consent and children deciding for themselves about participation (Carroll-Lind et al., 2006). Researchers in this study held the view that protecting children’s right to participate was more important than parental rights to privacy about abuse in the home (Carroll-Lind et al., 2006). They cited Perry (1997), saying: *“violence and abuse are not private issues: they are social issues”* (p. 984).

While some researchers argue for passive parental consent to bypass the need for parental consent, Mudaly and Goddard (2009) counter this. They argue that it is inappropriate to bypass parental gatekeeping in research with children who have been abused, as children have a right to protection and support during and after the research process, which parents are usually best-placed to offer. This is an important argument as parents are, usually, a source of support for children. However, it is worth noting that Mudaly and Goddard’s research was undertaken in the organizational context of a therapeutic agency for children in which parents were also engaged and familiar with acting in a supportive capacity toward their children on abuse-related issues.

Cultural context is an important consideration in discussion of passive and active consent procedures. Some cultures, such as the Pasifika culture, do not favour passive parental consent (Powell & Smith, 2009).<sup>10</sup> The right to consent and pass on knowledge is a collective issue for the Pasifika and many other cultures, and one that involves the wider family and community, which sits uneasily with the Western individualistic, ethical framework that seeks consent from individual participants (Suaalii and Mavoa, 2001).

Similarly, in the cultural contexts of some developing countries, like those in which the Young Lives child poverty research is taking place (Ethiopia, India, Peru and Viet Nam), the primacy of the individual in the concept of consent can seem inappropriate or meaningless (Morrow, 2009). Here, research teams first approached community leaders to gain consent, before approaching individual parents and children. This approach would be necessary in many other developing countries. In some respects this parallels the experiences of researchers in wealthier countries who seek consent from a hierarchy of gatekeepers before consulting children.

Another issue debated in the literature on the explicit act of consent is the relative merits of ‘consent’ or ‘assent’ in child research (Alderson and Morrow, 2011; 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 et al., 2004). A child’s

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<sup>10</sup> The term ‘Pasifika’ is used to refer to the New Zealand population who are Pacific Island people and their descendants.

assent is given less power within the consent process than the consent of other representatives (Goodenough et al., 2003). If a parent refuses consent, this outweighs a child's assent. However, 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). Alderson and Morrow (2011) consider the use of assent to be disempowering to children and prefer consent for three reasons. First, assent is not needed when children are legally able to consent (as in the UK). 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 at all, 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.

### ***Informed consent***

To give their consent, potential participants must know and understand the purpose of the research (Cree et al., 2002). Their ability to give informed consent is, therefore, dependent on the quality of the explanation given (Bogolub & Thomas, 2005). Typically, consent procedures involve the provision of information describing the purpose of the research, the research procedures, expected risks or benefits to the participants, identification of the researchers and of any sponsoring or funding agencies, the right to refuse participation, and the willingness of the researchers to answer any questions (Esbensen et al., 1996).

An explicit example of this in the US, and cited in different publications (for example, King & Kramer, 2008; Sieber, 1994), is the Federal regulation requirement that research with human subjects must include eight basic elements in research consent documents (45CFR46.116).<sup>11</sup> These eight elements have particular application in research on VAC, discussed by Sieber (1994):

1. An explanation of the purpose of the research, the expected duration and a description of the process. Details of the design that may affect participants' responses, and thereby jeopardize the validity of the research, do not need to be included. For example, inclusion of reference to child maltreatment or abuse is something of a dilemma, as it may lead to participants omitting information or declining to participate [see section on ethical dilemmas later in this paper].
2. A description of any foreseeable risk or discomfort. In research on VAC this may include "*distress and anxiety, embarrassment and loss of self-esteem*" (Alderson & Morrow, 2011, p. 27), and the risk of revealing information that could lead to child abuse being suspected and subsequently reported.
3. A description of any benefits to the subject that can be expected. Alongside the risks, the opportunity to discuss the abuse or neglect that has occurred in one's life can have helpful or useful consequences, including being referred to services that may help (for example, Carroll-Lind et al.'s (2006) study, in which children were informed before the study began that writing their name on the survey form would be taken by researchers as a request to access follow-up support).
4. A description of alternatives to participation that may be advantageous to the subject. For example, those who have sought clinical treatment and are offered an experimental treatment must be offered the standard treatment as an alternative.
5. A description of how confidentiality and anonymity will be assured and any limits to such assurances. This could include those imposed by mandatory reporting laws or protocols on suspected child maltreatment or abuse, see section on ethical dilemmas later in this paper.

<sup>11</sup> Sub-part D of these Regulations is "Additional protections for children involved as subjects in research"; however the eight basic elements related to consent outlined above are aimed at all human subjects and are not specific to children.

6. For research involving more than minimal risk, a statement of whether compensation or treatment for harm or injury is available. While this is more relevant to biomedical research in which physical harm is a possibility, harm such as emotional upset and disturbance is possible in social research on VAC, and immediate counselling or provision of contact with appropriate services should be available.
7. Contact information for answers to questions about the research, the rights of the subject, and research-related injury to the subject.
8. Indication that (a) participation is voluntary, (b) refusal to participate will involve no penalty or loss of benefits to which the subject would otherwise be entitled, and (c) the subject may discontinue participation at any time.

There is an inherent tension for researchers between wanting to ensure that research participants are fully informed, with consent freely given, and wishing to maximize participation in their research (Hill, 2005). One core ethical issue is, therefore, the nature of the information given to potential participants and their parents or guardians, and the extent to which it is permissible to hide or disguise part of the purpose of the research.

Covert research during which children are watched or questioned without their own permission or that of their parents is still accepted by some researchers (Alderson, 2005). However, Hill (2005) notes *“covert or semi-covert research is often seen as unethical because it goes against the principle of informed consent”* (p. 69). The continuation of research that is covert or involves deception raises an ethical dilemma that is clearly relevant to research on VAC.

Some researchers in child maltreatment studies have decided to avoid the use of terms such as ‘child abuse’, ‘child maltreatment’ and ‘child neglect’ in the information provided to potential participants, on the grounds that their use would decrease the likelihood of people participating in the study, or allowing their children to do so (Kotch, 2000). However, lack of full disclosure challenges the ethical principles of honesty and autonomy, which underpin the requirement for informed consent.

Another aspect is the consideration of the issue of terminology in a broader socio-political context. There is an argument that avoiding terms such as child abuse contributes to the ‘textual abuse’ of children by *“using language that effectively reframes and minimizes the seriousness of offences committed against children”* (Saunders & Goddard, 2001, p. 446). Child abuse and maltreatment tends to occur in secret and the argument can be made that being explicit about it helps to expose harmful practices and advocate for children.

Developmental factors may have an impact on children’s capacity to participate in consent or assent procedures and to weigh up the risks and benefits of participation (Seedat et al., 2004). A Canadian study looking at children’s assent in clinical trials found that the quality of assent in children under the age of nine years was very poor, suggesting that children of this age could not consent or assent to participation in a meaningful way (Ondrusek et al., 1998). The size of the sample in this study was very small, covering just 18 children, aged 5 to 18 years. While the results are valid, it would be interesting to measure the quality of children’s assent with a larger sample.

### ***Voluntary consent***

Given the nature of power relations between adults and children, it can be difficult to ascertain whether 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 suggests

that, at times, children and young people may be pressured to participate by their parents (Seedat et al., 2004). In one study, researchers discovered that parents had neglected to consult children about their participation in the research (Dyregov et al., 2000).

The issue of ensuring that children and young people's consent for participation in research is freely given is particularly relevant in research on VAC. Adults hold a powerful position in relation to children (Sime, 2008) and children may feel an obligation to comply (Robinson & Kellett, 2004; Valentine, 1999). The multiple contexts of VAC, including the dynamics of child abuse, amplify the power dynamics and can leave children feeling disempowered, as well as compelled to comply. In a study with children and young people who had experienced domestic violence, for example, Baker (2005) was concerned that participants would feel they had to comply for fear of sanctions if they did not.

Researchers also note, however, that participants who have experienced domestic violence have asserted themselves through subtle methods of objecting and withdrawing consent, such as using silence and disruptive behaviour (Baker, 2005), avoidance of eye contact, fidgeting and a rigid posture (Kerig & Federowicz, 1999). This observation highlights the need for researchers to have sufficient training and/or experience to be able to read the non-verbal and potentially subtle signs of dissent.

Parents can have a significant impact on whether children and young people consent to participate in research. In health research children can be more likely to agree if both the professionals 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 given independently. It is arguable whether parental support could be perceived as supportive or compelling. It may in fact have the opposite effect, making it difficult for children to refuse participation (Miller, 2000).

Another study suggests that young people have more autonomy around consent if they are alone at the time of deciding. Adolescents approached to participate in a hospital-based study following emergency department admissions after violent incidents and who were alone in a room were more likely to report that they chose freely to participate than those who had parents or family members with them at the time (Cohn et al., 2005). Similarly, some Bosnian refugee children in a Norwegian study wanted to be informed about the study separately from their parents and the majority (two thirds) would have preferred to be asked directly by letter (Dyregov et al., 2000).

The concept of informed, voluntary consent is further complicated in some developing-world contexts by the expectations of potential research participants of short- and long-term benefits and advantages, as a consequence of research projects by NGOs and others in this area (Ahsan, 2009; Nyambedha, 2008). For example, Ebrahim (2010) states that in South Africa research is perceived traditionally as a potential way to secure resources and open up opportunities in disadvantaged communities.

### ***Re-negotiable consent***

While great importance tends to be placed on gaining written confirmation of consent, this is not always appropriate, and the recent literature emphasises the ongoing nature of consent (Alderson & Morrow, 2004; Cashmore, 2006; Cree et al., 2002; Gorin et al., 2008; Hill et al., 2004; Hood et al., 1996; Miller, 2000; Mudaly & Goddard, 2009).

Some researchers advocate '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 as the most



ethical course of action (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 carries the risk of participants withdrawing from the study, and subsequent logistical difficulties and validity concerns.

#### 4.1.2 PROTECTION OF CHILDREN

A key ethical issue discussed in the literature, and of particular relevance to VAC, is the protection of children who participate in research. Underlying this are the principles of beneficence and non-maleficence, emphasizing the desire to protect children from the potential harm of research while allowing them to benefit from the results. However, identifying benefits and harm to children participating in research is not always straightforward.

Until fairly recently most of the ethics literature relating to children came from medical and psychological research, and it was concerned mainly with the risks to which children were exposed in clinical studies (Edwards & Alldred, 1999). The debates within clinical sciences have focused on protection of children from risk or direct harm, and the key dilemma is the *“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).

Ethical debates from social science disciplines have tended to focus on children’s exclusion from research and argue for the inclusion of children as a means to protect them through participation, addressing power imbalances and giving children a voice (Powell et al., 2012). Issues of harm and risk are not, however, as clear-cut in social research. While the potential for physical damage is less likely to apply (Hill, 2005), social research can also be intrusive and cause great distress to participants (Alderson & Morrow, 2011).

*“‘Harm’ is often invisible and elusive, complicated by different estimations, different viewpoints – researchers’, children’s or carers’ – and the difference between short- and longer-term outcomes”* (Alderson & Morrow, 2011, p. 23). Likewise, 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. The benefits can be to individual participants or to the wider community. However, some researchers argue that in violence-related research, the welfare of the individual child must be a higher priority than the needs of science or society (Øverlien, 2010) and ultimately, the guiding principle should be one of beneficence (Seedat et al., 2004).

There are unique issues in research about VAC relating to the protection of children. These include the risks, identified in a critique of a national study of VAC in India, of emotional harm to children from the emotionally-charged nature of first time disclosures, and potential physical risks to participants following disclosure from those who have perpetrated the violence (Veena & Chandra, 2007). In addition, researchers are privy to intimate information and observations, and can be recipients of unwanted information, while participants can be caught off guard and reveal more than they intended (Duncan et al., 2009).

Ethical issues in research with children on topics considered sensitive, such as child abuse or family violence, include: difficulties gaining parental consent (Cashmore, 2006), concerns about re-traumatization of children (Øverlien, 2010), and increased scrutiny from a hierarchy of gatekeepers (Hood et al., 1996). Parents may be concerned that participation in research may be painful for children, and withhold consent as a result (Lynch et al., 1999). Baker

(2005) notes that time needs to be taken to ensure that gatekeepers and parents understand the safeguards put in place by researchers, in order to fulfil their duty of protection to the children and young people in their care. In addition to ensuring that parents understand safeguards, it also seems particularly pertinent in research activities related to VAC to engage parents in supporting children during their participation in research activities, assuming the parent is not the perpetrator of the violence.

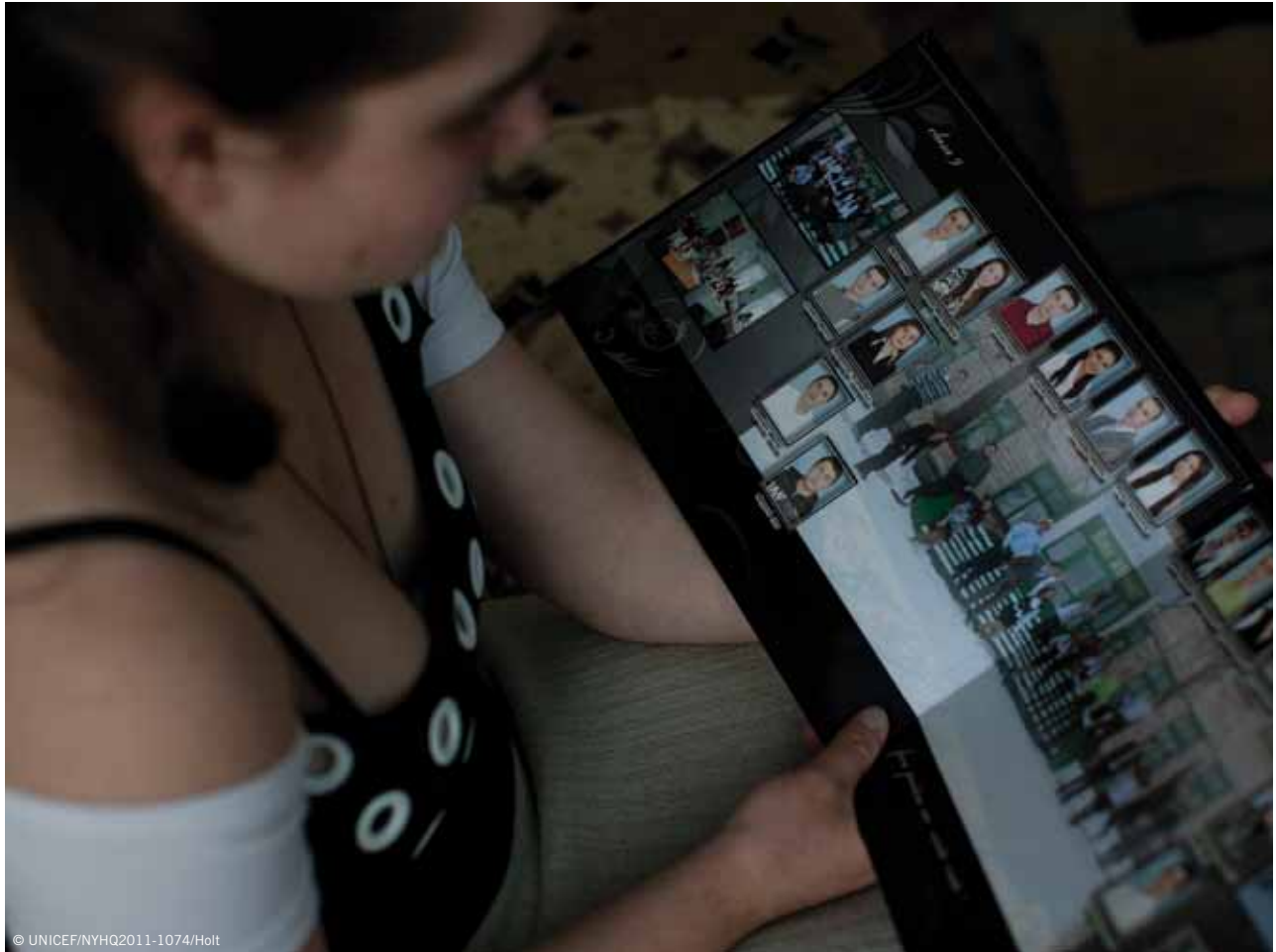
A key concern for parents, gatekeepers and researchers in research with children who have been abused or maltreated is whether they will be re-traumatized by the research process. A distinction can be made between re-traumatization and interview-engendered distress (Amaya-Jackson et al., 2000), but even the latter can leave researchers feeling uncomfortable and questioning their ethical choices (Mudaly & Goddard, 2009; Robson, 2001).

Researchers in the child protection sector have designed and implemented specific measures to ensure children's protection and care, and to minimize discomfort, which can be integrated into the research design (Black & Ponirakis, 2000; Knight et al., 2000; Mudaly & Goddard, 2009; Seedat et al., 2004; Ybarra et al., 2009). These include debriefing procedures, going at the child's pace, being aware of non-verbal signs of discomfort, practising means of indicating dissent and using computer-administered interviews, which increase children's privacy and allow them to skip questions easily.

Protection of children may involve making decisions about referral to child protection services, which researchers can experience as *"complex, fraught with ethical dilemmas and ... a process of balancing risks and benefits of actions"* (Gorin et al., 2008, p. 284). There is, however, little discussion in the literature on the development of referral protocols. Guidance is offered in the form of recommendations that researchers work in partnership with experienced researchers and local child protection experts (Duncan et al., 2009; Gorin et al., 2008) and have specific training in this area (Fisher, 2009; Gorin et al., 2008). However, an additional dilemma that is not well addressed arises in some contexts where referral to services is simply not possible as these do not exist, for example, in rural areas in developing countries (Clacherty & Donald, 2007).

A hierarchy of gatekeeping, which functions to protect children from harm, can increase the 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). Gatekeeping can seem excessive as a consequence of protectionist discourses about children and concerns about the risk of harm associated with research into sensitive topics, such as VAC. Gatekeeping is an important 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, but, in a New Zealand survey of researchers, some argued that 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).

The requirements for the protection of children are especially pertinent for children who are considered particularly vulnerable, such as 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). 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 services"* (p. 29) and a logistical nightmare can unfold as researchers are required to track down and engage multiple parties to give consent. Children in care are often denied the opportunity to participate in research, precisely because of their perceived vulnerability (Berrick et al., 2000).



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REPUBLIC OF MOLDOVA [name changed] Paulina, 16, looks at photographs of her school, at the Centre for the Placement and Rehabilitation of Children in Chisinau, the capital. After living in an institution between ages six and 11, she moved in with her grandmother and an uncle who repeatedly raped her. "He would come home late at night, drunk, and come into my room and rape me. I didn't really understand what he was doing. He did this regularly," she said. "When I turned 15, he also started to beat me and threaten me, saying that if I told anyone what he did to me he would kill me." Paulina became pregnant and gave birth to a boy.

Some studies indicate that parents of children who are recruited to take part in research on sensitive topics declined consent for a number of protective reasons including: not wanting the child to be labelled or distressed, concerns about reviving past problems, or not wishing to impose on children who were having a difficult time (Cree et al., 2002; Sandbaek, 1999). While these studies do not relate specifically to VAC, the issues resonate with the child population.

One argument in support of asking research participants about child abuse is that the decision *not* to ask about abuse plays directly into the hands of the forces that perpetuate such abuse (Becker-Blease & Freyd, 2006; Black & Black, 2007). "From a public health perspective, the question is not whether to ask but how to ask about participants' experience with violence and abuse" (Black & Black, 2007, p. 329).

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 development contexts. He states that researchers can cause

harm if no action is taken to address the high expectations participants may have for some form of assistance. Researchers need to be wary that research does not raise false hopes. For example, in a study researching violence with young people in South Africa, Parkes (2008) had concerns that the participants' increased perception of self-efficacy and reflexive agency through the research process may have raised false hopes, been potentially disappointing for participants and increased actual risks to children's safety if they challenged existing social relations.

#### 4.1.3 PRIVACY: CONFIDENTIALITY AND ANONYMITY

**P**rivacy is a key ethical issue raised in the literature that has specific relevance to research on VAC. 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 confidentiality. Most often, the setting in which research with children takes place is at school or at home, and confidentiality can be compromised in both of these locations through difficulties in finding a private space (Valentine, 1999; Sime, 2008) and parents' curiosity and concern for the child (Fargas-Malet et al., 2010). In some contexts, seeking to find a private setting may in fact have the opposite effect and result in increased attention and the presence of family members and friends (Clacherty & Donald, 2007). During data collection in Ethiopia, Abebe (2009) found that greater privacy ensued if children were interviewed in crowded settings, such as community market spaces and tea houses where children worked, drawing less interest from others.

Researchers argue that studies with young people on sensitive research topics require confidentiality and privacy for the protection of the participant, for example, in studies about sexuality (Valentine et al., 2001) or drug use (Langhinrichsen-Rohling et al., 2006). Similarly, confidentiality and privacy are imperative in research with children who have experienced abuse and violence, in order to protect children from potential stigma and/or reprisals from an abusive parent or adult (Baker, 2005).

Researchers have to consider multiple requests, pressures and potential lapses that might breach confidentiality across a range of contexts. These include: parents wanting to know what the child has said; research professionals feeling the need to discuss data as a result of the emotional impact; shared datasets in projects, which increases the risk of privacy violations; individuals involved in legal proceedings who want to access information for their legal cases; and researchers feeling legally or ethically obligated to report information disclosed in the study related to suspected child maltreatment (Socolar et al., 1995).

One particularly 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. There are divergent opinions and practice about breaching confidentiality to report suspected child abuse (Cashmore, 2006). Some researchers would breach confidentiality even if the child did not agree to further disclosure, and specify this clearly before the interview (Lynch et al., 1999). Others believe that disclosure of abuse should not occur until the child consents, following a discussion (Hill, 2006).

There are many considerations in breaching confidentiality, including the legal and ethical requirements, and the damage caused to the research by the loss of participants at the stage of recruitment and attrition during the project itself (Fisher, 2009). Choosing to breach confidentiality could damage the trust between child and researcher irrevocably (which may have an impact on other situations of trust for the child) (Campbell, 2008).

Williamson and colleagues (2005) highlight the dilemma in UK and US legal contexts. Researchers in the UK are not required by law to report suspicions of child abuse. However, certain professions such as health professionals have a

clearly defined duty to report such suspicions, and ethical guidance from professional bodies (contained in ethical codes) is provided to teachers, psychologists and social researchers. Therefore, while there is no legal mandate in the UK, practitioner guidelines and good practice indicate that professionals who have concerns about child abuse have a duty to disclose this to a third party.

In the US, the underlying premise is that there is a potential conflict between scientific research and a duty to report (Williamson et al., 2005). The legal mandate to report suspicions of child abuse varies between states and, in some situations, specific trainings or professions exempt some professional groups from a requirement to report. In some situations researchers may be required to report in another professional or personal capacity. For example, two states (Wyoming and New Jersey) maintain that any individual who suspects abuse must report it (Fisher, 2009). However, other than that, researchers are not specifically mandated to report.

The issue is further complicated in the US by the issue of liability on false accusations of abuse. As researchers are not mandated reporters of child abuse or maltreatment, they may expose themselves to a lawsuit for malicious reporting (Kotch, 2000) if they breach confidentiality. However, Kotch also notes that direct observation is not deemed confidential (unlike data) and suspicions based on this can be reported.

Opinions and practice about breaching confidentiality to report suspected child abuse can diverge even within the same major project, such as the LongSCAN project in the US (Runyan, 2000). This project covered five sites in different states, and variations existed between these sites on the explicitness of instruction related to reporting maltreatment (Amaya-Jackson et al., 2000) and on the interviewers' position as mandated reporters as a result of state law or employment by state agencies (Knight et al., 2000). Some researchers prioritized participant autonomy and preservation of the confidentiality of the data, while others saw reporting to Child Protection Services, based on data collected, to be mandated legally and ethically by the principle of beneficence (Knight et al., 2000).

Confidentiality in research with children about maltreatment can be assured by using anonymity of the data and avoiding researchers' knowledge of individual disclosure of abuse or concern. This can be achieved by ensuring that the survey responses children provide are not linked to their consent forms and that they are not, therefore, 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 any legal or ethical obligation to report any disclosures of abuse or harm (King & Churchill, 2000). Researchers have, therefore, designed and implemented research methodologies that keep children's individual data confidential but allow children who want help to indicate this (Carroll-Lind et al., 2006).

In weighing the dilemmas involved, Kotch (2000) concluded that maintaining the confidentiality of data is superior in ethical terms to reporting suspected maltreatment. This decision guided the research ethically, and the research design included: avoiding using terms such as 'child abuse'; reliance on non-project workers for recruitment; development of an elaborate strategy to protect confidentiality, including blinding interviewers to participants' responses; and obtaining a Certificate of Confidentiality.

Each of the sites in the US LongSCAN project obtained a federal Certificate of Confidentiality to protect data confidentiality. These certificates are provided on application by the Office for Protection from Research Risks (OPRR) for funded and unfunded research when there is a reason to fear that data may be subpoenaed, and automatically for research funded by the National Institute of Justice (Sieber, 1994). As such, the Certificate is not intended to protect researchers from divulging suspected child abuse and there is some debate as to whether it would do so successfully.

Researchers argue that the Certificate ensures that records cannot be subpoenaed but does not absolve researchers from their obligation to report suspected child maltreatment (Black & Ponirakis, 2000; Knight et al., 2006).

The dissemination of research findings and their return to the participants can be difficult in studies of VAC. It is imperative that confidentiality is maintained and that children are not identifiable through any revealing details in the information disseminated. For example, families who have experienced family violence may be highly transient and require secrecy to avoid being located (Baker, 2005).

An issue raised in developing countries, in particular, is ensuring that individual children are not subject to negative personal repercussions on the basis of identifying details that are revealed when reporting the research findings (Angucia et al., 2010; Clacherty & Donald, 2007; Young & Barrett, 2001). It is at the stage of dissemination that Young and Barrett (2001) see the greatest potential for harm in research with vulnerable populations such as children who live or work on the streets. For example, identification of the spaces frequented by such children in Uganda by government departments or NGOs *“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).

#### 4.1.4 PAYMENT

There is no clear consensus in the published literature on whether children should be paid for participation in research (Kellett & Ding, 2004) or what kind of payment or rewards are appropriate (Gallagher, 2009). Some researchers view payment negatively as bribery or inducement, and others consider it fair recompense (Hill, 2005) or acknowledgement of a participant's contribution to research (Fargas-Malet et al., 2010).

Researchers sometimes choose to provide payment or a gift after the interview, without the participants having prior knowledge of this. They consider that this nullifies the impact payment would have had on the interview had the interviewee been notified beforehand and, therefore, induced to participate on that basis (Baker, 2005). Some researchers choose to give tokens that are particularly relevant to the population being researched. For example, in their South African study, Richter and colleagues (2007) offered children living or working on the street children a meal following participation. Conversely, researchers conducting a study with street children in Brazil considered it ethically inappropriate to give children incentives, as monetary gifts might be used to buy drugs or perceived as coercive.

Cultural context influences perceptions of research payment and incentives. The issue of remuneration or payment is more complex in developing-country contexts where children participate in the economic well-being of the family, and participation in research takes them away from work. Payment for research participation is seen by some researchers as necessary compensation for the time during which participants would otherwise have been earning money (Vakaoti, 2009; Porter et al., 2010; Robson et al., 2009).

Ethical concerns about payment are accentuated in contexts in which children and families live in poverty, as potential participants are especially vulnerable to coercion, bribery and exploitation. Participants may place themselves at greater than usual risk because they need the goods and services offered for involvement in the research activity (Rice & Broome, 2004). Payment could also fuel tension and resentment from others in the community against participants who gain some material benefit from their research involvement (Clacherty & Donald, 2007; Hart & Tyrer, 2006).

Issues associated with payment highlight the relationship between the researcher and the participant. Some



researchers argue that in certain circumstances, such as poverty, it is ethical and humane to help participants out with small cash payments (Abebe, 2009; Vakaoti, 2009). Similarly, in an emergency context, researching the re-integration of war affected children in Uganda, Angucia and colleagues (2010) perceived the decision to give tokens to participants as exercising humanity in a difficult conflict situation. However, payment can also accentuate power imbalances between researchers and participants.

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## 4.2 POWER ISSUES, METHODOLOGY AND ETHICS

**M**ethodology and ethics are integrally linked (Powell et al., 2012). Alderson (1995) suggests that “*bad science is bad ethics*” – the implication being that ethical assessment needs to consider whether the research questions are worth asking and if the methods used are an effective way to answer them. Power is a major issue in considering the links between methodology and ethics. Power imbalances have been widely recognized as being the biggest ethical obstacle and challenge to researchers who include children in research (Alderson, 1995; Mayall, 2000; Morrow & Richards, 1996; Thomas and O’Kane, 1998) and addressing these is a recurring theme in the methodological and ethical guidelines reviewed earlier in this paper.

Participatory methods are perceived as a means to reduce the power imbalances. 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).

A growing trend in participatory research is research *by* children and young people, with children as co-researchers or primary researchers (Kellett, 2010). However, the research with children is still mediated by adults, so this does not resolve issues of power entirely (Clavering & McLaughlin, 2010; Kellett, 2010). It is important to consider the impact on the child interviewers, particularly in relation to VAC, if the questions ask participants to describe specific and violent personal experiences. A recent large scale study by the NSPCC study on child abuse in the UK, with over 6,000 participants, saw the participation of children and young people in consultation and decision-making processes throughout the research design and implementation as a critical factor in the overall success of the project (Radford et al., 2011).



# 5

## ETHICAL CHALLENGES AND DILEMMAS

An understanding that ethical dilemmas are inevitable, situational and require the ability to respond to unanticipated events is inherent in the recent literature, including research publications, ethical guidelines and grey literature. The key approach taken is that *“ethics is about how to deal with conflict, disagreement and ambivalence rather than attempting to eliminate it”* (Edwards & Mauthner, 2002, cited in Gorin et al., 2008, p. 278).

It is also evident within the literature that there are conflicting ethical issues in research on VAC, and a lack of clear standards to balance these conflicting issues (Mudaly & Goddard, 2009). This chapter addresses the key ethical dilemmas that have emerged from the literature during the review process. Each ethical dilemma is outlined and relevant research is used to discuss the issues involved. Although the body of research is growing in this area, there is still only limited empirical evidence to help inform the design and implementation of research studies with or on children who have experienced trauma or violence (Chu et al., 2008). There is, however, an emerging tendency to report on how ethical dilemmas encountered in research are addressed (Mudaly & Goddard, 2009; Matthews, 2001; Horton, 2008). These provide insights, and many also offer suggestions, for ways to resolve or manage some of the ethical dilemmas.

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### 5.1 IMPACT ON CHILDREN OF PARTICIPATION IN RESEARCH ON VAC

A key concern for all involved with research on VAC, including researchers, parents, gatekeepers and others, is the impact that participation in research will have on the children involved. Mudaly and Goddard (2009) outline some of the key questions:

- Does involvement in child abuse research conflict with ethical principles of beneficence and non-maleficence?
- Is it justifiable to include children in abuse research classified as non-therapeutic that has limited, indirect or minor benefits for children?
- What are the possible long-term consequences?

To be ethical, research must be of sufficient importance, and the benefits must outweigh the risks (King & Churchill, 2000). Foremost among the inherent risks is that participation might cause the child participant distress or trauma (Knight et al., 2000). This may be by way of emotional distress from participation in the research, or harm caused to the child by other people as a consequence of their participation in the research.

### 5.1.1 THE RISK OF DISCOMFORT, DISTRESS OR TRAUMA TO CHILD RESEARCH PARTICIPANTS

In the case of children who have been abused or experienced violence, the underlying and often stated concern is whether involvement in research will cause discomfort, distress or even re-traumatization of children, perhaps in the form of memories or flashbacks. For children who do not have a known history of experiencing violence, the concern is related more to the potential harm to children of being exposed unnecessarily to potentially distressing issues that are beyond their experience or knowledge.

In order to minimize harm to participants it is important to establish the extent to which children and young people are affected by research on sensitive topics such as VAC. Minimal research has been done on the effect of questions about violence on research participants. However, a recent US national survey has been carried out with 1,588 participants (aged 10-15 years) to address this issue (Ybarra et al., 2009), which ended with questions about how they experienced the violence-specific questions. The findings indicated that approximately one-quarter (23 per cent) of the participants reported being upset by questions about violence, with younger participants being far more likely to be upset than older participants. The survey was administered by computer and younger children were also more likely to report that other people were in the room while they did the survey, which led the researchers to reflect that the lack of privacy may have affected their responses. Another important finding was that children who had experienced victimization were just as likely as those who had not been victimized to *not* be upset by the violence-related questions.

Similarly, another US study that gathered information from multiple samples of young people about the degree to which they reported being upset while completing a self-report survey about sensitive events, found that 30 per cent reported some level of feeling upset (Langinrichensen-Rohling et al., 2006). The highest rates were found among younger, middle school children and a truancy sample within a juvenile justice setting. Interestingly, the middle school sample also reported the highest frequency of interest in the study, highlighting the importance of assessing both the risks and benefits to participants. Unlike the study by Ybarra and colleagues (2009), young people in this study who reported a history of suicidal thoughts, drug use, or physical or sexual abuse also reported more frequent feelings of upset than adolescents without those experiences.

Both of these two studies indicate a need for consideration and caution in planning research on sensitive topics, particularly with younger participants and those with a history of experiences that may increase their vulnerability. However, the researchers argue that the findings also point to a need for further investigation to ascertain the magnitude, duration and nature of upset feelings, as well as any positive benefits reported from participation.

Interestingly, the recent UK NSPCC study on child abuse and neglect had very low levels of participants who sought follow-up contact for support or help, suggesting that the risk of distress may be less than expected (Radford et al., 2011). Of a total sample of more than 6,000 participants, only 35 young people (0.6 per cent) sought such help. This low rate may reflect methodological choices made by Radford and colleagues, which included piloting the interview process and questionnaire to ensure that young people understood the questions, and having young people involved in consultation and research implementation. Children's level of discomfort or distress does not appear to have been measured beyond the indication gained by those seeking help. Presumably, other children may have been affected to differing degrees and decided not to ask for help. This low rate of help-seeking may also indicate other factors, such as low expectations of the care and support available, concerns about safety/confidentiality, or lack of rapport with the research team.

Some studies report that children are positive about their participation in research and its potential to benefit others, including studies in which children's experiences may have been expected to increase their vulnerability. For example, a US study by Chu and colleagues (2008), looking at the perceptions of 181 children aged 7-12 on their research participation, found that their appraisals were generally positive and that their perceptions did not differ significantly whether they had a history of trauma exposure or not. Nor did they vary in terms of the number of traumatic events they had experienced.

A study with Bosnian refugee children and parents living in Norway also found that the children experienced participation in the research as positive (Dyregrov et al., 2000). It is worth noting, however, that this study had a relatively small sample and children were interviewed by the same interviewer for follow-up questions on their participation experiences, which may have influenced their reporting by making it difficult to report negative feelings.

A US study with children hospitalized following a traumatic injury (one sample on traffic-related injury, and one on traumatic injury, excluding child abuse) reported that children were willing to answer questions about research participation honestly, including both negative and positive reactions (Kassam-Adams & Newman, 2002), and that over three-quarters (77 per cent) felt good about the possibility that their participation might help others (Kassam-Adams & Newman, 2005).

Taken collectively, these studies suggest that a history of trauma does not prevent children from participating in research and that the benefits of participation, for most children, include a positive feeling, even when the topic is serious and/or the child has had traumatic experiences. It is important to note, however, that these studies did not have a focus on violence-related trauma, and that traumatic injuries differ markedly from violence against children, especially sexual violence.

Other studies, referred to by Kerig and Federowicz (1999), suggest that talking to a supportive adult about traumatizing experiences causes relief rather than distress for children. This resonates with the argument that one potential benefit of participation in research is the sense of relief and being heard that is associated with disclosure of abuse. For example, a study with adults who have experienced violent trauma (domestic violence, rape and physical assault) suggests that sharing experiences of trauma in research was not experienced as distressing, but viewed as valuable and a relief by most participants (Griffin, Resick & Waldrop, 2003, cited in Seedat et al., 2004). However, the purpose of research is not therapy, and researchers themselves are not trained therapists. While talking about traumatizing experiences may bring relief for some, there is a risk that researchers who are not trained may, in fact, exacerbate a child's distress.

A critical issue for dilemmas about the impact on children of asking about violence and/or abuse is the response of the researcher to any disclosure (Becker-Blease & Freyd, 2006; Ullman, 2007). Although not citing empirical evidence in support of this notion directly, Ullman (2007) claims that in research (as well as in the 'real world') it is the negative responses received by people who disclose abuse that results in harm, rather than the disclosure *per se*, and that any benefits of talking about the trauma can be diluted by those harmful effects.

The findings of the studies cited above on children's perceptions of research participation tally with studies related to the perceptions of adult participants about taking part in trauma-related research. Seedat and colleagues (2004) cite research studies that suggest individual personality and health characteristics may play a role in different participation experiences in trauma research studies. Of particular interest is the suggestion that some negative reactions may be

associated with underlying psychological vulnerabilities. However, the extent to which such empirical observations are relevant or transferable to research populations of children who have been traumatized is unknown.

Little is known about the effects of participation in research about trauma on children and young people (Seedat et al., 2004) and more direct empirical research appraising child participants' experience is clearly needed. Learning more about children's perspectives of their upset, regret and benefit will provide a more accurate estimate of distress and satisfaction, which could then be used to inform the decision-making of researchers and ethics review committees (Seedat et al., 2004).

Becker-Blease and Freyd (2006) suggest that risk and benefit decisions on asking about child abuse have been made largely on the basis of individuals' beliefs about the prevalence, importance and effects of child abuse on individuals and society. Arguing in favour of asking children about abuse, they claim that most ethics discussions focus on risks to participants and assume there are no benefits to them. They cite findings from research conducted with adult participants on child abuse and trauma, and a study interviewing children about mental illness, family conflict and parents' alcohol use, that indicate participants had enjoyed their research experience, learned about themselves and gained something positive from it. They further argue that not all negative reactions are dangers from which research participants require protection, and may in fact be transitory negative states. However, it is difficult to determine causality, and no literature was located in this review that provided evidence to support the argument that there are positive benefits for children participating in research specifically on VAC. Again, this points to the need for further empirical study of the short and/or long term impact of asking research participants about violence and abuse.

## RECOMMENDATIONS FROM THE LITERATURE

One key recommendation is the call for further research to help understand the potential risks to children and young people from participating in research on VAC, and efforts to ameliorate those risks. In particular, further research is needed on the nature, duration and magnitude of research-engendered distress, for both children with a history of violent experiences and those without. There is also a need for further research on the role of different factors such as age, gender and other individual differences. Chu and colleagues (2008) also encourage continued systematic assessment of research participants' perceptions of research that is embedded in research project design.

Until there is further empirical evidence to extend understanding of the potential risks to children and young people, the relatively high number of children reporting upset (between one-quarter and one-third of participants in some studies) suggests the need for caution and for careful consideration of methodological choices to help ameliorate distress.

Suggested methods and strategies to minimize harm and reduce the risk of distress include: debriefing at the end of the interview or research process (Black & Ponirakis, 2000; Carroll-Lind et al., 2006); informing children of avenues of support, such as toll-free telephone numbers of counsellors (Carroll-Lind et al., 2006); the use of computer-assisted self-interviewing methods (Knight, 2000; Radford et al., 2011); and a child-centred approach that allows the process to proceed at the child's pace and under the child's control (Mudaly & Goddard, 2009).

Recommendations for debriefing include post-interview informal group discussion of positive experiences (Carroll-Lind et al., 2006) and debriefing by experienced interviewers who are trained to look for signs that may indicate a need for clinical intervention, acknowledging to the child that there have been some sensitive questions and providing information about obtaining professional assistance (Black & Ponirakis, 2000).

Some of these suggestions to minimize harm, such as telephone and computer-based methods, are clearly less appropriate to resource-poor countries where children may not have access to information and communication technology, highlighting one of the difficulties of conducting research on aspects of VAC in these countries.

Researchers can also spend time ensuring that children are informed about, and understand, the concept of

dissent and their right to withdraw from participation in the research and they can also actively encourage children to practice stopping the interview (Gorin et al., 2008). They should also 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). Finally, researchers should have sufficient training, skills, knowledge and supervisory support to be able to recognize and respond appropriately to children's distress.

### 5.1.2 THE RISK TO CHILD PARTICIPANTS FROM OTHERS LEARNING OF THEIR RESEARCH INVOLVEMENT

The ethical guidelines for research in the child protection sector and on VAC contain frequent reference to the risk of retribution towards research participants from perpetrators of abuse and violence (for example, WHO 2001, 2003, 2007). The importance of ensuring confidentiality in minimizing this risk is stressed in the ethics documentation and research publications. This includes confidentiality at all stages of the research process, including data collection and dissemination of the findings (as previously discussed).

## RECOMMENDATIONS FROM THE LITERATURE

Recommendations on maintaining confidentiality throughout the research process include finding private settings in which to conduct the research, or settings in which researchers and participants are less likely to be disturbed. The ethics documentation discusses being discreet about the topic of the research to avoid drawing negative attention to the participant. There is the potential for this to conflict with recommendations from the literature on the provision of information to participants and communities (as discussed previously and later in this paper).

The means to minimize the risk of harm from others toward the research participant include consideration of the data collection mode. Methods that involve little or no direct face-to-face contact can help to maintain confidentiality, such as computer-assisted self-interviewing, online Internet-based surveys and telephone and postal surveys, although these all rely on children being literate and and/or having access to the necessary resources. They do not cater, therefore, for non-literate and/or resource-poor populations.

## 5.2 PROVISION OF INFORMATION

Gaining the consent of research participants is an integral requirement in ethical guidelines or standards (as discussed elsewhere in this paper) and by ethics review boards. In order for consent to be valid, participants must be provided with sufficient information about the research project to weigh up the risks and benefits and make an informed decision about taking part. However, some researchers argue that providing too much explicit information may affect recruitment, resulting in a diminished and non-representative sample and, therefore, affecting the validity of the study. In certain contexts explicit information about the nature of the research topic can result in stigmatization or safety risks to participants. Some ethical guidelines recommend that researchers avoid giving children and young people written documents to keep if this could place them at risk (WHO, 2011b).

### 5.2.1 HOW MUCH INFORMATION TO PROVIDE TO CHILDREN

The dilemma of how much information to provide to children about research is particularly relevant to research about VAC. Too much information may alarm the child and result in them feeling labelled; too little may make it difficult for them to evaluate the research project accurately and make a decision about participation (Mudaly & Goddard, 2009).

Lynch and colleagues (1998) consider that the dilemma about providing information to children revolves around refraining from total honesty, in case it engenders distress, and ensuring complete honesty to avoid recreating the dynamics of powerlessness and betrayal inherent in abuse. In their UK study of children who had been sexually abused and their carers, Lynch and colleagues decided in favour of clear, honest information. However, although there were other factors (and parental consent procedure was identified as the most decisive), it is possible that the explicit information may have contributed to their difficulties with recruitment and the relatively small sample size (35 children were interviewed out of a potential sample of 202 children, following geographical broadening of the initial recruitment area).

Conversely, the explicit title of a New Zealand research study – “Children’s experience of violence” was used in a national, randomized study that drew a relatively large sample of over 2,000 children (Carroll-Lind et al., 2006). A key factor in this study (as discussed earlier) was the use of passive parental consent, whereby parents responded only if they did not want their child to participate. As noted above, passive consent procedures were found to be the decisive factor associated with recruitment of larger samples (Lynch et al., 1998).

How much information children actually want about the research study is another issue to consider. In a UK study with children in care, despite the requirements of ethics review boards and dictates of current thinking around ethical practice, researchers found that many young people seemed disinterested and impatient with the process of informed consent and were keen to “*just get on with the interview*” (Kendrick et al., 2008, p. 89). For the researchers in this study, this highlighted a tension between adult values and requirements, and respect for the level of interest among children and young people.

The principle that consent can only be given if the participant has been fully informed is problematic in practice. The information provided about a project may not be welcome, go unread or may be misunderstood, with different understandings between the researcher and the participants, and also among participants (Gallagher et al., 2010). Children are likely to interpret information in the light of understandings they already have (David et al., 2001), which can lead to misunderstandings. Such “*mismatches of understanding can be difficult if not impossible to detect*” (Gallagher et al., 2010, p. 478).

### 5.2.2 HOW MUCH INFORMATION TO PROVIDE TO PARENTS

How parents assess potential research risks to their children and, therefore, how much information to provide, may differ according to the population from which the sample is being drawn. Recruitment and gaining consent for children to participate are more difficult with children who are considered particularly vulnerable (Powell & Smith, 2009). This may indicate that seeking to recruit children who have a history that includes experiences of violence may engender a protective response as a result of fears of further re-traumatization or threats to privacy, while recruiting from the general population may be easier without this specific concern.

An issue emerging from the literature is whether it is necessary to inform parents about any protocol on the reporting of child abuse disclosures. Newman (2007) queries whether providing details to participants about mandatory reporting of disclosures of child maltreatment has an impact on the participation rate. People who have a history of abuse, concerns about the topic or fear of being reported may choose not to participate. From a methodological perspective, if those most likely to have been involved in maltreatment refuse to participate because they are made aware of sensitive questions, the findings will be biased (Black & Ponirakis, 2000). However, there is a lack of empirical knowledge about this and there are, therefore, no clear guidelines for researchers (Newman, 2007).

Socolar and colleagues (1995) claim that *“much research is conducted by giving accurate but incomplete information about the study”* (p. 579). They argue that full disclosure of the purpose of child abuse research would limit the strength and scope of the study, with only those who have already disclosed abuse and those with no involvement in it considering participation. The assumption that parents have the best interests of the child at heart cannot be assumed in child maltreatment research, as the consenting parent may be abusive or have conflicting allegiances between the child and another abusive adult (Knight et al., 2000).

## RECOMMENDATIONS FROM THE LITERATURE

**C**learly, further research is needed in this specific area, given the lack of current knowledge about the relationship between the provision of information to parents and children and participation rates in research on VAC. This includes research on how parents weigh the risks and benefits of participation in VAC research.

The requirement for honesty and transparency about the nature of the research is problematic in research on this subject. As discussed earlier, participants may be vulnerable to further abuse or retribution as a consequence of participating in the research, and it may not be in the best interests of participants to be explicit about the nature of the research. The terminology used in the information provided may also have an impact on the comfort and anxiety levels of participants, with some descriptors being perceived as highly charged or stigmatizing.

It would seem that different provisions are appropriate in different contexts, and that, therefore, careful reflection and consideration is needed. Studies seeking to recruit a representative sample may have fewer concerns about the potential risks

to participants, but may need to factor in the impact of explicit information on the participation rates. However, studies that aim to recruit a sample with histories that include experiences of violence may need to balance the requirement to fully inform participants with the potential for risk involved in the topic being made public.

A further recommendation from the literature concerns children’s comprehension of the information given to them about the research project. Alderson and Morrow (2011) suggest that it is important for researchers to spend time explaining the research to potential participants verbally to overcome any difficulties with understanding.

The suggestion from the literature that children may be less interested in being informed about research than to the extent required by rigorous research ethics practice emphasizes the need for researchers to be reflexive in their practice. ‘Ethics’ often occurs in the moment and cannot be anticipated. Researchers need to be attentive to children and young people’s rights and responses, and attuned to their expression of these.



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## 5.3 CHILDREN'S CONSENT

**A** key issue in children's consent to participation in research is the extent to which they comprehend the nature of the research and the implications of their consent. Studies cited earlier of research with children with and without histories of trauma (Chu et al., 2008) and hospitalized for treatment following traffic accidents (Kassam-Adams & Newman, 2005) have shown that children understand the nature of voluntary participation and are able to participate in the informed consent/assent procedure. Another study on children's comprehension of an informed consent procedure, with children aged 5-12, found that children generally understood that they could choose to participate in research and could stop their participation, but that younger children were not sure how to actually do this (Abramovitch et al., 1991). There may be a range of reasons that make it difficult for children to withdraw consent to participation, such as not knowing the practicalities of how to withdraw, viewing the researcher as an authority figure, or being concerned about negative consequences (Ondrusek et al., 1998).

Understanding, however, does not always equate to believing. The study by Abramovitch and colleagues (1991) also found that many children thought that there would be negative consequences if they did not comply, and felt under pressure to agree to participate if their parents had given consent. A US study, with children aged 8-12 found that children understood their research rights, but were unconvinced about confidentiality (Hurley and Underwood, 2002). Kerig and Federowicz (1999) also question children's comprehension about limits to confidentiality. They cite Kalter and colleagues (1988), who argued that young children often misunderstand confidentiality as meaning they must keep secret from their parents what they say to the interviewer.

The impact of parental presence on the giving of children's consent is a debatable point. 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, 2010; Dorn et al., 1995). Participants in one health study thought the researcher would be unhappy if they withdrew from the study (Ondrusek et al., 1998).

However, the belief expressed by some ethics committees, that parental presence may lessen children's powerlessness, could 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', that is, 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 given independently. 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 et al., 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.

Another consideration in children's participation in research about VAC is the process and timing of gaining their consent. In an evaluation of children's experiences of a sexual abuse therapeutic service, Hutchfield and Coren (2011) point out that it is important that children and young people retain the decision about participation, given the powerlessness and coercion associated with abuse. Their study endeavoured to give children and young people the opportunity to reflect on the research and whether or not they wanted to participate, making it a two-week process. Other researchers have documented the importance of allowing time for participants to consider their participation in research. For example, researchers in the Young Lives study, researching child poverty in Ethiopia, India, Peru and Viet Nam, give participants 24 hours to consider participation (Morrow, 2009).

## RECOMMENDATIONS FROM THE LITERATURE

The literature considered in the previous section offers recommendations about assisting children to be fully informed that are relevant to gaining children's consent, including verbal discussion of the research project. Potential participants should be allowed sufficient time to decide about their participation, and researchers should endeavour to ensure that children and young people fully

understand what is involved in their participation, encouraging questions and clarification. The considerations for researchers include using consent quizzes to assess children's understanding of consent/assent (Chu et al., 2008), asking children questions one-to-one or asking them to summarize what they have been told (Ennew & Plateau, 2004; Laws & Mann, 2004; WHO, 2011b).

### 5.4 CONFIDENTIALITY AND CHILD PROTECTION

The limits to confidentiality and the issue of whether or not researchers should be required to report suspected child maltreatment to the child protection services has been the subject of considerable debate in Western literature, particularly from North America, Canada and the UK. There is a great deal of controversy over how best to resolve this dilemma (Amaya-Jackson et al., 2000; King & Churchill, 2000; Runyan, 2000), as discussed earlier in this paper. Aspects of this ethical dilemma include the following key issues.

#### ***Whether child abuse should even be asked about in research at all***

On occasion, researchers have chosen not to undertake research with children about maltreatment because of the ethical dilemmas involved, particularly around confidentiality in relation to child abuse disclosure (Ghate & Spencer, 1995, cited in Radford et al., 2011). However, others argue that avoiding research that will increase understanding of child abuse is an unethical position to take (Becker-Blease & Freyd, 2006; Priebe et al., 2010). In the US, particularly, the underlying premise is that there is a potential conflict between scientific research and a duty to report (Williamson et al., 2005).

#### ***Whether reporting suspected child abuse is mandated by the principle of beneficence***

While some researchers prioritize autonomy and preservation of confidentiality of research data, others see reporting to child protection services as ethically mandated by the principle of beneficence (King & Churchill, 2000). In this case, the beneficence is not related to the benefits of participating in the study, but based in part on the belief that reporting will decrease risk to the child (Knight et al., 2000).

Kotch (2000) argues that the benefits must outweigh the risks to justify a breach in confidentiality. He perceives the risks in reporting maltreatment to include: harm to a child from an angry parent, lack of substantiation resulting in participants being exposed to unnecessary humiliation and stigma without any follow-up services, and intervention by the Child Protection Services that is not necessarily successful and that may, in fact, have a negative impact on the child. He argues that research shows that nearly 70 per cent of reported cases are, in fact, unsubstantiated. On the other hand, 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).

Arguments that present the benefits to balance against the risk of harm include: that the research is contributing to solving a social problem; that individual participants may find it beneficial to talk; and that the research involves provision of knowledge.

### ***Whether researchers should be legally mandated to report suspected child abuse***

As discussed previously in this paper, in the UK there is no legal mandate for researchers to report suspected child abuse, although practitioner guidelines and professional ethical codes and standards of practice make this a requirement for some researchers (Williamson et al., 2005). In the US the law varies between states, but at the Federal level there is no mandate at present for researchers to report suspected abuse.

Allen (2009) presents a succinct yet thorough précis of the arguments for and against mandatory reporting of suspected child abuse by researchers.

#### **Arguments for** researchers' mandatory reporting of suspected child maltreatment:

1. The primary goal of mandated reporting is to protect children.
2. Some research suggests that vulnerable populations may expect researchers to provide aid on disclosure (discussed further below).
3. Not reporting maltreatment ultimately weakens professional codes of ethics.

#### **Arguments against** researchers' mandatory reporting of suspected child maltreatment:

1. Researchers may lack adequate training in the detection of maltreatment.
2. Reporting requirements cause inconvenience to researchers, in terms of considerable time and effort, damage to rapport, and interference with research efforts.
3. Including researchers as mandated reporters may lead to over-reporting.
4. Over-reporting of invalid cases will increase stress and hardship for some families.
5. Suggestions that it may be preferable to encourage and support maltreating families to self-report to child protection and mental health services.
6. Reporting threatens the integrity of research and may result in difficulties advancing science and knowledge:
  - sampling methodology damaged due to potential participants' refusal to take part for fear of being reported (falsely or otherwise);
  - difficulty recruiting and retaining participants if reporting is discussed during the consent process or confidentiality broken during the course of the research project;
  - problem of consistency over multisite studies;
  - possibility of participants not providing accurate data for fear of being reported to child protection services.

Uttal (2003) argues that requiring researchers to act as mandated reporters could have a 'chilling effect' on research that is beneficial to children. However, Urquiza (2003) argues that, in most cases, it is against the law not to report child abuse and that the moral and ethical obligations are clear. Knight and colleagues (2006) state that there has been very little research on how often the need to report actually arises or how it may affect the participation. Their study on the retention rates of participants who were reported by the LongSCAN project found a very low rate of reporting (15 children from 1,354 participants) and a high retention rate, suggesting that asking about child abuse is less risky than may be thought.



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THAILAND A 16-year-old girl attends a counselling session with a state social worker at her home in the town of Lanta Pier, Lanta District, in tsunami-affected Krabi Province. She was raped the year before, became pregnant and was moved to an emergency shelter where she gave birth. She gave the baby up for adoption. Her rapist was eventually arrested and imprisoned.

### ***Whether researchers should use methodologies that avoid reporting***

Socolar and colleagues (1995) suggest that researchers have sought ways to avoid reporting and its potential negative consequences, including limiting response options and warning subjects not to tell. However, these strategies, while resolving the dilemma of reporting, create the new methodological dilemma of not allowing for the collection of valid information about child maltreatment. Other options to avoid reporting include masking the data so that the interviewer is 'blinded' to the responses of individual participants, thereby allowing people to make full disclosures with no fear of subsequent reporting to child protection services.

### ***Whether children want researchers to maintain confidentiality and anonymity***

The requirement for anonymity in reporting the research is not always welcomed by the child participants. Studies indicate that it is not unusual for children and young people to want to be named in reports and presentations, including studies with children in care (Kendrick et al., 2008). However, some researchers assert that the adult view of the children's best interests must prevail over the expressed wishes of some children (Hill, 2005; Kendrick et al., 2008).

One study found that children thought researchers should follow up on concerns about abuse by facilitating self-referral to child protection services or informing parents or concerned adults (Fisher et al., 1996), thereby indicating that disclosure of concern in a research context may be a way to seek help and should lead to further support. Some studies have used methods that allow for anonymity of data, but allow for children to self-identify if they would like follow-up referral for support (Carroll-Lind et al., 2006).

### ***Cultural considerations in child protection***

Research reports highlight cultural contexts and considerations in child protection dilemmas for researchers. In some countries there are no government-sponsored child protection services to report to and limited availability of social services to which children and families can be referred. For example, as discussed previously, referring children and families to services is very difficult in India (Veena & Chandra, 2007). Similarly, in other research projects with children in developing countries who are living on the streets or otherwise disadvantaged, referral sources may be in short supply and children may mistrust social services (Abebe, 2009; Hutz & Koller, 1999).

It may not always be in the child's best interests to report abuse. Reporting child abuse or maltreatment may increase the child's vulnerability to further maltreatment. For example, in Young and Barrett's (2001) research with children living or working on the streets in Kampala, Uganda, the children were at risk from those who are supposed to be society's protectors.

## **RECOMMENDATIONS FROM THE LITERATURE**

**R**ecommendations on the dilemma of breaching confidentiality, following disclosures of child maltreatment in the US context, include ensuring that ethics review committees and institutional review boards have a standard requirement for mandated reporting of maltreatment (Allen, 2009) and that researchers are designated specifically as mandated reporters to ensure more uniform reporting practices in research settings (Steinberg et al., 1999). These authors argue that if reporting was mandatory it would provide clear guidelines to a thorny ethical dilemma, prioritize child protection and ensure uniform research practice. Similarly, having a clear child protection policy in the research protocol, such as the Save the Children child protection policy, provides clear guidelines for managing disclosures of concern and suspected maltreatment (Baker, 2005).

To better manage issues of child protection when collecting data on VAC, researchers could benefit from working in partnership with experienced researchers and child protection experts; further training in this area; increased resources; additional time for

reflection and to discuss concerns when children are identified as at risk; and regular debriefing sessions (Gorin et al., 2008).

Ethical guidelines that have explicit processes in the case of suspected maltreatment also tend to advocate that the confidentiality protocol must be explained clearly to participants during the consent process and throughout the research (for example, WHO, 2011b).

In relation to the difficult issue of cultural context and lack of resources in reporting suspected child maltreatment, the WHO (2011b) draft ethical and safety guidelines recommend that national laws should provide direction when considering confidentiality protocols. However, first and foremost, they state that disclosure should only occur where it will benefit the adolescent. It is suggested that national laws should be the primary source for direction when considering confidentiality protocols, unless such laws contradict human rights principles.

# 6

## CONCLUDING COMMENTS

This paper has reviewed a significant body of literature, including ethics documentation and research-based publications, to contribute toward laying the foundations for the development of ethical guidelines on collecting data on violence against children (VAC). It has provided a thorough review, identifying and exploring key issues and challenges, and highlighting gaps in the literature.

Ongoing, high-quality research about violence against children is essential and can lead to important benefits for society, including a wide range of health outcomes (Becker-Blease & Freyd, 2006; Black & Black, 2007; Edwards et al., 2007; Gleaves et al., 2007). However, it is critical that such research is undertaken ethically.

### *Key findings of the literature review*

**1. There is limited documentation that relates specifically to the ethical guidance for research on VAC.** The literature that guides ethical research practice directly – the ethical codes and guidelines – does not provide clear, explicit directions for research with children. The ethical codes reviewed often contained little or no reference to children. There is considerable variation between the codes and an overall paucity of attention to ethical issues in research with children and young people, particularly in relation to social research. Any reference to children is dominated by issues of consent and protection of children.

The ethical guidelines do not tend to provide concrete guidance for research on VAC. While general ethical guidance is offered, guidelines are less specific about how to operationalize ethical principles. This finding is consistent with that of Corlyon and colleagues (2006) that ethical principles are often called on and uniformly defined, regardless of the type of research being conducted, and offer little more than vague or largely theoretical insights into the implementation of these principles. There are a few exceptions to this in guidelines that focus very specifically on particular sectors and situations, but, for the most part, the interpretation of ethical principles in the guidelines is left to the researcher. One example is the requirement for parental consent in complex situations where children are unaccompanied, orphaned or separated from parents. Some ethical guidelines mention such difficulties and additional considerations, but few go on to specify what steps researchers could (or should) take in this situation. There are limited guidelines for developing protocols essential to research processes, such as consent procedures, provision of age-appropriate, child-friendly information, referral to services and so forth.

**2. The lack of concise ethical guidance and the subsequent need for researchers to interpret and operationalize the, at times, vague guidelines highlights the central role of the researcher in responding to ethical considerations.** One key theme in the literature is the use of ethics to promote the exploration and examination of dilemmas, rather than purely as a basis for the rules of research conduct (Hill, 2005; Tisdall et al., 2009; Alderson & Morrow, 2011). Engagement



with ethics and reflexive thinking is emerging as a keystone of ethical research practice (Aitken & Herman, 2009; Davis, 1998; Gallagher et al., 2010; Hill, 2006), with individual researchers having a responsibility to take an ethical approach to their research practice. It is important, therefore, that researchers have suitable training, support and supervision. Specialized skills and training in specific areas of research on VAC is mentioned in some ethical guidance documentation, such as research on sexual violence in emergencies (WHO, 2007). However, there is little guidance on what type of training exists or what particular skill sets researchers should have (beyond saying that it should be specialized).

**3. The ethics documentation lacks sufficient depth to guide research across the range of activities related to VAC satisfactorily.** Ethical guidelines need to take into account the range of contexts in which research can occur, and encourage both consideration of these and the measures to address them. These include, for example, the following issues:

- Children's history of victimization. Research may be undertaken with children who have been victimized and also with children who have not. There is a tendency for the literature to focus on children who have experienced victimization, but, while it is clear that this is of critical importance for some research activities, researchers are ethically responsible for *all* children. Ethical considerations therefore have to take into account the different experiences children have had and the subsequent differing areas of sensitivity and concern.
- The relationship between the child and the perpetrator of the violence. Parents usually have a key role to play in supporting and protecting their children, although this is distorted and negated when parents are perpetrators of violence against their children. Ethical guidelines are, at times, strongly influenced by the possibility or assumption that the parent may be the perpetrator, which has a negative impact on the potentially protective role parents can play. This affects ethical decision-making about the consent process, the information provided and the strategies planned for child protection. Family violence is, however, only one aspect of VAC. Parental support can be a welcome consideration when other aspects are researched.

**4. A significant gap identified in the ethical guidelines is what to do if no services are available for the referral of children to psychosocial support or child protection services.** There is frequent reference in the guidelines to referral of children to appropriate services as required, but little attention is given to how to proceed if no services are available. Some documentation advises strongly against proceeding if there are no referral services available, while other guidelines advise finding an alternative, such as services that have been developed in response to violence against women. Clearly, the advice has important ramifications for the advancement of knowledge through research and for the well-being of the individual children participating in research.

**5. Another gap identified in the review is the relationship between the age of the children participating in data collection activities and the ethical considerations.** Most ethical guidelines are aimed at research with children and, when definitions are used, these tend to follow the UNCRC definition of those under 18 years of age. The exceptions are the WHO (2011b) draft ethical guidelines that focus on sexual health and reproduction research with adolescents, and the Population Council and IMPACT guidelines for gathering information from children and adolescents (Schenk & Williamson, 2005). More attention is required for ethical considerations related to different age groups of children and young people.



**6. There are few research-based publications that provide evidence about the risks for children associated with participating in research on VAC.** Gaps have been identified, with further research needed to focus on: the emotional impact on children of participating in research on VAC for all children; the nature, duration and magnitude of research-engendered distress for both children who have a history of violent experiences and those who do not; the role of different factors, such as age, gender and other individual differences on children's response to participating in research on VAC; the relationship between the provision of information to parents and children and participation rates in research on VAC; and how parents weigh up risks and benefits of participation in research. With such gaps in the research it is difficult, at present, to derive any full understanding of these issues. Further research in these areas is critical, especially as research and data collection continue despite the lack of any evidence base to support current methodology, raising the pivotal question of whether this research is in the best interests of the children participating.

**7. There are common and universal ethical issues across international contexts, but cultural, social, political and economic factors interact to pose particular challenges related to these issues in different contexts.** One dominant theme in recent literature is the importance of context, and the difficulties and challenges inherent in applying ethics developed in a 'Western' context to research in resource-poor settings. Ethical issues such as informed consent, confidentiality and payment are entirely relevant in such settings, but are further complicated by particular practical challenges, particularly in relation to VAC. The sheer diversity of childhood requires different approaches to ethical issues in research (Young & Barrett, 2001), and diverse contexts require a flexible and responsive stance. The UNCRC outlines useful general principles and standards that underlie an ethical approach to research based on children's rights that applies across international contexts, despite very relevant cultural differences.

#### *Implications of the literature review findings*

The findings of the literature review identify existing gaps in the documentation and research, and point to the need for further research to gain an understanding of the ethical issues involved in research on violence against children. In addition, the review highlights areas of potential risk to children who participate in research and existing debates about these areas within the literature. This raises the critical question of how to proceed, given these areas of ethical uncertainty.

The findings point to the need to develop a strong framework for ethical research practice on VAC that provides clear direction while supporting reflexivity, given the multiple contexts in which research is occurring.

Ethical guidelines form a link between ethical principles and research practice. Key ethical principles, in conjunction with a children's rights-based approach to research on VAC, may provide guidance to underpin the development of an ethical framework. The UNCRC is a recognized international instrument of children's rights that lends itself to conceptualizing ethical research practice and provides a sound basis for prioritizing the best interests of the child in research.

Ongoing critical and robust discussion and debate, incorporating the multiple contexts in which research on VAC is taking place, and the knowledge gained from research practice and underlying ethical principles, are all essential to the development of a strong framework for ethical research practice. The literature points to the need for ongoing investment in continuing discussion and the extension of knowledge on this critical issue through research.

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## APPENDIX 1 Documentation on ethics research publications

**TABLE 1: DOCUMENTATION USED AS A TOOL/GUIDE IN IMPLEMENTATION OF RESEARCH PROCEDURES/PRACTICE IN RESEARCH WITH CHILDREN**

VAC	SOURCE	REFERENCE	NOTES
✓	World Health Organization (2007)	Ethical and safety recommendations for researching, documenting and monitoring sexual violence in emergencies	<p><b><i>Child protection – sexual violence; Emergencies</i></b></p> <p>Ethical guidelines specific to researching sexual violence in emergencies, to complement existing ethical guidelines.</p> <p>Stress only those with appropriate training should engage in such information gathering.</p> <p>Ethics defined (p. 7).</p> <p>Eight safety and ethical recommendations including: Children – additional safeguards must be put in place if children are subject of information gathering (p. 27-29).</p> <p>Very useful document. Recommendations include one specifically for children. Emphasizes seeking advice and consulting with experts and local community; gaining consent; protecting children; expertise of staff.</p> <p>Selection of good references.</p>
✓	Save the Children (2004a)  <i>Southeast, East Asia and Pacific Region</i>	How to research the physical and emotional punishment of children	<p><b><i>Child protection – punishment</i></b></p> <p>Resource book for ethical research with children with focus on physical and emotional punishment.</p> <p>Aimed at programme managers and researchers.</p> <p>Asks, “Is it ethical to ask children about painful experiences?”</p> <p>Ethics and methods of rights-based research (p. 35); eight essential ethical rules (p. 37-41); special ethical challenges in researching punishment (p. 42-43); ethical strategy (p. 111); consent protocol (p. 180-191).</p> <p>Detailed account of how to approach research in specific area.</p> <p>Social research.</p> <p>Children’s rights-based approach.</p> <p>Outlines eight (essential) ethical rules.</p> <p>Advocates each research project having a detailed, written ethical strategy based on these rules, included in research protocol.</p> <p>Includes special ethical challenges of research on physical punishment.</p> <p>Describes 12-step research process – Ethics are important in protocol design (step 6), data collection (step 7), report writing (step 11) and disseminating information (step 12).</p> <p>Draws heavily on Regional Working Group on Child Labour in Asia (2002) and Save the Children (2004b, see p. xii).</p>
✓	Save the Children (2004b)	So you want to involve children in research? A toolkit supporting children’s meaningful and ethical participation in research relating to violence against children	<p><b><i>Child protection – VAC</i></b></p> <p>Toolkit providing guidance on children participating in research related to violence.</p> <p>Includes ethical issues and techniques of participatory research.</p> <p>Children’s rights-based.</p> <p>Highlights importance of planning for ethical issues at the outset.</p> <p>Chapter on ethical issues in children’s participation in research (p. 27-41), covering avoiding harm, child protection, informed consent, confidentiality, inclusive approach, fair return, welfare of research staff, wider accountability – includes checklist.</p>



VAC	SOURCE	REFERENCE	NOTES
✓	Save the Children (2008)	Ethical guidelines: For ethical, meaningful and inclusive children's participation practice	<p><b><i>Child protection; Emergency – armed conflict, post conflict and peace building</i></b></p> <p>Guidelines to ensure ethical, meaningful and inclusive child participation practice in research, consultation, etc.</p> <p>Developed during two-year thematic evaluation of STC Norway's work on children's participation in armed conflict, post conflict and peace building.</p> <p>Underpinned by Child Protection Policy of STC (in Appendix of Feinstein &amp; O'Kane, 2008) and STC Practice Standards in Children's Participation (see 1.7).</p> <p>Covers general ethical principles (p. 7-9); ethical issues specifically involved in research with children in armed conflict situations (p. 9-10) (cross-reference Hart &amp; Tyrer, 2007); child protection (p. 11); diversity (p. 11); power relations (p. 12); discrimination (p. 12); communication (p. 13).</p> <p>Includes checklist of key considerations; and scenarios from workshops and country experiences that highlight consideration of ethical guidelines in local, socio-cultural, political contexts.</p>
✓	Regional Working Group on Child Labour in Asia (2002)	Handbook for action-oriented research on the worst forms of child labour including trafficking in children	<p><b><i>Child protection – worst forms of child labour including trafficking</i></b></p> <p>Handbook for researchers.</p> <p>Covers 12 steps to planning and implementing action-oriented research.</p> <p>Includes toolkit of research methods.</p> <p>Ethical considerations integrated throughout handbook.</p> <p>Eight ethical rules (p. 21-24); ethical strategy (p. 68); research team and ethics (p. 78-81); ethics throughout data collection phase; dissemination (p. 108); informed consent (p. 115-118).</p> <p>Handbook for action-oriented participatory research on worst forms of child labour including trafficking.</p> <p>Covers same issues as Save the Children (2004a).</p> <p>Outlines eight (essential) ethical rules.</p> <p>Advocates each research project has a detailed, written ethical strategy based on these rules, included in research protocol.</p> <p>Includes special ethical challenges of research on physical punishment.</p> <p>Describes 12-step research process – Ethics is important in protocol design (step 5), data collection (step 7), and disseminating information (step 12).</p>
✓	ILO & UNICEF (2005)	Manual on child labour rapid assessment methodology	<p><b><i>Child protection – child labour</i></b></p> <p>Comprehensive, practical guide for designing and implementing rapid assessment investigations of child labour, including hard-to-reach children and the worst forms of child labour.</p> <p>Brief ethical considerations (p. 34); cautionary notes regarding interviewing (p. 52, 54); ethical considerations integrated throughout section on hard to reach children; Annex 3 Module on ethical considerations (p. 167-178) (see below, originally published 2003).</p>

**TABLE 1: DOCUMENTATION USED AS A TOOL/GUIDE *cont.***

VAC	SOURCE	REFERENCE	NOTES
✓	IPEC – ILO (2005)	Ethical considerations when conducting research on children in the worst forms of child labour in Nepal	<p><b><i>Child protection – worst forms of child labour</i></b></p> <p>Explores ethical dilemmas in research with children in worst forms of child labour (applicable to other contexts). Looks at issues: pre-research (risks; informed consent; right to say no), during research (language/logic; trust; listening; misinformation as coping strategy; pay and promises), post-research (privacy; sharing research). Includes checklists designed to counteract and preempt children's rights violations. English/French/Spanish.</p> <p>Specifically research ethics-focussed.</p>
✓	Refugee Studies Centre, University of Oxford (2006)	Research with children living in situations of armed conflict: Concept, ethics & methods	<p><b><i>Emergency; Child protection – children living in situations of armed conflict</i></b></p> <p>Explores conceptual, ethical and methodological issues in participatory research with children living in situations of armed conflict.</p> <p>Very good ethics section (p. 18-25) covers taking account of conflict situation, preparation, power relations (adult-child and child-child), gender, informed consent, rewards, confidentiality, anonymity, consequences and dissemination.</p> <p>Focus on specific ethical challenges in conflict setting. Discusses issues to be considered by researcher.</p>
	Save the Children (1997)	Children in focus: A manual for participatory research with children	<p><b><i>Participatory research</i></b></p> <p>Training manual for NGOs and research institutions about participatory research with children.</p> <p>Exercises throughout the manual to aid in teaching.</p> <p>A section on ethics (p. 42) recognizing children's rights, fulfilling adult responsibilities.</p>
	Population Council (2005)	Ethical approaches to gathering information from children and adolescents in international settings: Guidelines and resources	<p><b><i>Information gathering, participatory research</i></b></p> <p>Provides practical guidance to help researchers to understand and uphold ethical standards in planning and implementing information gathering activities with children and young adolescents. Promotes discussion of ethical issues.</p> <p>Key ethical issues: key principles (p. 3); participation (p. 5); legal/prof requirements (incl. ethical supervision and IRB/ERCs) (p. 7); culture and gender (p. 11); especially vulnerable children (p. 12).</p> <p>Practical guidelines high ethical standards (p. 15-56), presented as questions and responses.</p> <p>Absolute requirements (p. 57).</p> <p>Excellent resource list in appendices.</p>
	UNICEF (2002)	Children participating in research, monitoring and evaluation (M&E) – Ethics and your responsibilities as a manager [ <i>Evaluation Technical Notes</i> ]	<p><b><i>Participatory research; Monitoring and evaluation</i></b></p> <p>Evaluation technical notes aimed at managers commissioning research. Emphasizes that managers' responsibilities are the same as researchers'.</p> <p>Includes key ethical considerations in children's participation (p. 4-5); checklist of questions for managers to consider in any monitoring, evaluation and research (p. 6-10), adopted from Alderson (1995).</p>

VAC	SOURCE	REFERENCE	NOTES
	National Children's Bureau (NCB) (2011)	Guidelines for research with children and young people	<p><b>Participatory research</b></p> <p>Practical guidelines for research with children and young people.</p> <p>Includes a section on research ethics with child participants, focusing on consent (p. 27-33); confidentiality, child protection and safeguarding (p. 33-34).</p> <p>Section on involving children, (p. 43).</p> <p>NCB uses Social Research Association ethical guidelines.</p>
	ChildFund International (2010)	Child- and youth-friendly participatory action research toolkit	<p><b>Participatory research</b></p> <p>This toolkit focuses on methods to use in participatory action research.</p> <p>A one-page appendix has ethical guidelines (p. 40).</p>
	European Medicines Agency (EMA) (2008)	Ethical considerations for clinical trials on medicinal products conducted with the paediatric population	<p><b>Clinical trials</b></p> <p>Recommendations on various ethical aspects of clinical trials performed on children.</p> <p>Covers consent/assent, RCTS, placebos, pain control, risk benefit ratio, healthy children and neonates, inducements.</p>
	Council for International Organizations of Medical Sciences (CIOMS) and WHO (2008)	International ethical guidelines for epidemiological studies [Provisional text]	<p><b>Epidemiological research</b></p> <p>Ethical guidelines for epidemiological studies.</p> <p>Based on guidelines in CIOMS and WHO 2002. Includes general ethical principles and ethical guidelines.</p> <p>Guideline 14: Research involving children (see also Guidelines 8, 9 and 13).</p>
	Council for International Organizations of Medical Sciences (CIOMS) and WHO (2002)	International ethical guidelines for biomedical research involving human subjects	<p><b>Biomedical research</b></p> <p>Ethical guidelines for biomedical research. Considerable overlap with CIOMS &amp; WHO 2008 which was based on these guidelines.</p> <p>Includes general ethical principles and ethical guidelines.</p> <p>Guideline 14: Research involving children (see also Guidelines 8, 9 and 13).</p>
	Ministry of Education, New Zealand (2010)	Involving children and young people in research in educational settings	<p><b>Education – national (NZ) context</b></p> <p>Document examining theory, practice and ethical considerations when including children and young people in research – intended to inform MOH and researchers.</p> <p>Inclusion of exemplars relating to the debates.</p> <p>Introductory chapter discusses issues related to consent (p. 4-9).</p> <p>Following chapters each address children in specific research context: Early Childhood Education, Maori, primary school, secondary school, disabilities, with each chapter having a section on ethical issues. Therefore ethical considerations throughout document.</p>
	The Children and Young People's Assembly for Wales (2011)	Funky Dragon – Children as researchers: Resource pack	<p><b>Child researchers</b></p> <p>Resource pack for participative working with children as researchers.</p> <p>Includes ethical considerations checklist as Appendix 1 (p. 66), with links to Children and Young People's Participation Standards for Wales (Appendix 3, p. 70).</p>

**TABLE 1: DOCUMENTATION USED AS A TOOL/GUIDE *cont.***

VAC	SOURCE	REFERENCE	NOTES
	INVOLVE (2004)	A guide to actively involving young people in research: For researchers, research commissioners, and managers	<b><i>Participatory research</i></b> Guide to involving young people as researchers and partners in the research process. Aimed at young people and parents. Chapter on power issues (p. 13). Chapter on ensuring young people's health, safety and well-being (p. 23).
	World Health Organization (2011)	Ethical and safety guidelines for sexual and reproductive health research and data collection with adolescents DRAFT	Recent draft making recommendations for ethical research with adolescents. Includes risks and benefits, confidentiality, adolescent informed consent, parent/guardian informed consent, community consent, adolescent-friendly research, and health risks and safety.
	Save the Children (2002)	Children and participation: Research, monitoring and evaluation with children and young people	Outlines ethics and methods in participatory information gathering with children. Guide to further resources – references and links. Section on ethics (p. 8-15) fairly generalised but includes child protection and diversity.

**TABLE 2: DOCUMENTATION RELEVANT TO ETHICAL ISSUES IN RESEARCH WITH CHILDREN**

VAC	SOURCE	REFERENCE	NOTES
✓	Save the Children (2003)	Children's participation in research (CPSC): Reflections from the care and protection of separated children in emergencies project	Review of experience of children's involvement in CPSC research, including section on ethical considerations (p. 21-23). Issues covered include consent, distress, expectations and power dynamics.
✓	Save the Children (2004)	A workshop report on child participation in the UN study on violence against children	STC workshop report reflecting on experiences of children's participation in UN Study on VAC. Ethical issues in children's participation (p. 9-11). Ethical issues and practice standards (p. 20-23).
	Young Lives Research Project (2009)	The ethics of social research with children and families in Young Lives: Practical experiences [Working paper 53]	Describes the approach taken to ethics in Young Lives project and some of the practical difficulties encountered. Emphasizes the importance of local context in research with children and young people. Appendix: Memo of understanding for Young Lives field researchers.
	Young Lives Research Project (2005)	The ethics of research reciprocity: Making children's voices heard in poverty reduction policy making in Vietnam [Working paper 25]	Discusses 'reciprocity' as a proactive (and unexplored) approach to research ethics, using the Young Lives project as a practical example.
	Save the Children (2011)	Ethical standards in monitoring and evaluation. Standard Operating Procedure	Standard operating procedure for ethics standards in monitoring and evaluation. Procedures to be adhered to by STC Country Offices.

VAC	SOURCE	REFERENCE	NOTES
	Save the Children (2003)	So you want to consult with children? A toolkit of good practice	Toolkit offering advice, ideas and guidance for involving children in consultations at national, regional and international levels. Includes focus on meaningful participation.
✓	ChildONEurope (2009)  European Network of National Observatories of Childhood	Guidelines on data collection and monitoring systems on child abuse	Focus on data collection and monitoring in relation to child abuse. Aim to support development of systems and instruments. Aimed primarily at policy-makers and planners. Ethical dimension (p. 9); principles underlying data collection (p. 63); mandatory reporting (p. 71-73); data security (p. 87).
	McGill University and Canadian Institutes of Health Research (2011)	Best practices for health research involving children and adolescents	Reviews eight international and two Canadian ethical guidelines for health research and makes ten recommendations.
	Childwatch International Research Network (2011)	Building capacity for ethical research with children and young people	Research report discussing researchers' experiences in relation to ethics and research activities with children and young people. Includes researchers' concerns and ethical issues restricting children's participation. Highlights international/local contexts.
	Communities and Families Clearinghouse Australia (CAFCA) (2011)	Collecting data from parents and children for the purpose of evaluation: Issues for child and family services in disadvantaged communities	Practice sheet outlining challenges in data collection for evaluation of child and family services. Four key methodological (and ethical) considerations: culturally competent evaluation; consent, privacy and confidentiality issues; data collection techniques with children; involvement of children and parents in the process.
	World Health Organization and ISPCAN (2006)	Preventing child maltreatment: A guide to taking action and generating evidence.	Guide providing technical advice for setting up policies and programmes for child maltreatment prevention and services, taking evidence into account and generating expansion of evidence base. Chapter 2 makes suggestions about how to gather info that can be used in preventing child maltreatment, with 1 page about ethical considerations (p. 26).
	UNICEF (2006)	Guidelines on the protection of child victims of trafficking [Technical notes]	Guidelines to standards for good practice in protection of and assistance to trafficked children. Section on research and data collection. Ethical principles (p. 36). Ethical questions (p. 37).

**TABLE 3: DOCUMENTATION RELATED TO RESEARCH ETHICS (NOT SPECIFICALLY WITH CHILDREN)**

VAC*	SOURCE	REFERENCE	NOTES
✓	World Health Organization (2001)	Putting women first: Ethical and safety recommendations for research on domestic violence against women	Ethical recommendations for research with women relating to domestic violence. Useful overlap with research with children.
✓	World Health Organization, PATH (2005)	Researching violence against women: A practical guide for researchers and activists	Manual outlining methodological and ethical challenges in conducting research on violence against women; describes a range of techniques. Chapter on ethical considerations for researching violence against women covers respect for persons throughout research process, minimizing harm, maximizing benefits (beneficence), balancing risks and benefits (justice) (p. 34-47). Useful overlap with research with children.
✓	World Health Organization (2003)	Ethical and safety recommendations for interviewing trafficked women	Discusses ten guiding principles for interviewing trafficked women. Focus on ensuring ongoing safety.
✓	World Health Organization, UNFPA, & UNICEF (2008)	Sexual violence in conflict: Data and data collection methodologies	Report from meeting looking at data collection methodologies in sexual violence in conflict. Raises some ethical questions.
✓	International Organization for Migration (IOM) (2009)	Guidelines for the collection of data on trafficking in human beings, including comparable indicators	Section on protection mechanisms and ethics (p. 87).
✓	InterAction Protection Working Group	Data collection in humanitarian response: A guide for incorporating protection	Toolkit for incorporating protection considerations into data collection.
	United Nations Inter-Agency Project on Human Trafficking (2008)	Guide to ethics and human rights in counter-trafficking	Guiding ethical principles in counter-trafficking research. Not specific to children, but has relevance.
	Office of the First Minister and Deputy First Minister Ireland (2003)	Ethical principles for researching vulnerable groups	Guidelines for use of research undertaken on behalf of the OFMDFM, Ireland. Ethical issues for children integrated throughout document. Three key ethical principles: professional integrity of the researcher; respect for the rights and dignity of participants; well-being of all involved.

\* In Table 3 the VAC column refers to documentation relevant to violence in general, as it is primarily regarding violence against women, or trafficking in human beings.

## APPENDIX 2 Ethical codes

### *Country/national ethical codes*

Australian National Health and Medical Research Council – Australian code for the responsible conduct of research (2007)

Australian Government – National statement on ethical conduct in human research (2007)

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada – Tri-Council policy statement: Ethical conduct for research involving humans (2010)

Council for Children of Bosnia and Herzegovina and Save the Children Norway – Code of ethical conduct for research involving children (2006) – in translation

Council of Children, Government of Republic of Croatia – Code of Ethics Research with Children – in translation

Ethiopian Science and Technology Commission, National Health Science and Technology Council, Health Department – National health research ethics review guideline (2005)

European Commission – National regulations on ethics and research in Bulgaria (2003)

European Commission – National regulations on ethics and research in Hungary (2003)

European Commission – National regulations on ethics and research in Latvia (2003)

European Commission – National regulations on ethics and research in Lithuania (2003)

European Commission – National regulations on ethics and research in Malta (2003)

European Commission – National regulations on ethics and research in Poland (2003)

European Commission – National regulations on ethics and research in Romania (2003)

European Commission – National regulations on ethics and research in Slovenia (2003)

Human Sciences Research Council (HSRC) (South Africa) – Informed consent guidelines regarding minors (including orphans and particularly vulnerable children (OVC)) and parental substitutes (2010)

Indian Council of Medical Research – Ethical guidelines for biomedical research on human participants (2000)

Medical Research Council of Zimbabwe – Guidelines for researchers and ethics review of committees in Zimbabwe (2004)



National Committees for Research Ethics in Norway – Guidelines for research ethics in the social sciences, law and the humanities (2006)

National Health Research Ethics Committee of Nigeria – National Code of health research ethics (2007)

Nepal Health Research Council – National ethical guidelines for health research in Nepal

New Zealand Health Research Council – Guidelines for health research with children

Organic Law of Protection of Children and Adolescents (LOPNA) Venezuela – in translation

South African Medical Research Council – Guidelines on ethics for medical research (2002)

Taiwan (No. 0960223088) – Human research ethics policy guidelines (2007)

Uganda National Council for Science and Technology – National guidelines for research involving humans as research participants (2007)

USA Department of Health and Human Services – Federal regulation 45.46 (“Common Rule”) Sub-part D (1983)

### ***Ethical codes of professional associations***

American Anthropological Association – Code of ethics of the American Anthropological Association (1998)

Association of Social Anthropologists of UK and the Commonwealth – Ethical guidelines for good research practice (1999)

British Educational Research Association (BERA) – Ethical guidelines for educational research (2011)

British Psychological Society – Code of ethics and conduct (2009)

Children’s Rights Alliance for England (CRAE) – CRAE’s research ethics statement (undated)

Economic and Social Research Council (ESRC) – Framework for research ethics (2010)

ESOMAR World Research Codes and Guidelines – Interviewing children and young people (1999)

ICC/ESOMAR International code on market and social research (2008)

International Statistical Institute – ISI Declaration on professional ethics (2010)

Market Research Standards (MRS) – Guidelines for research with children and young people – Draft (2010)

National Association of Social Workers (USA) – Standards for the practice of social work with adolescents (2003)

Social Research Association – Ethical guidelines (2002)

## APPENDIX 3 Documentation on ethics research publication

### DOCUMENTATION SECURED TO ACHIEVE OBJECTIVE NO. 2 – REVIEW OF ETHICS RESEARCH PUBLICATIONS – USING ELECTRONIC ARTICLE SEARCHES

ARTICLES IDENTIFIED USING KEYWORD SEARCH									
ARTICLES IDENTIFIED					ARTICLES INCLUDED FOR REVIEW				
KEYWORD	Academic Search Complete (EBSCO)	Psych-Info (via Ovid)	Med-line (via Ovid)	Pro-quest*	Academic Search Complete (EBSCO)	Psych-Info (via Ovid)	Med-line (via Ovid)	Pro-quest**	Total articles included following further review
Violence	95	35	38	220	18	13	18	23	32
Sexual abuse	38	35	22	89	12	9	8	17	22
Psychological abuse	2	0	1	17	2	0	0	2	4
Verbal abuse	0	0	1	9	0	0	0	0	0
Maltreatment	35	29	14	62	21	13	8	11	24
Exploitation	23	13	9	353	12	5	5	4	11
Neglect	39	19	19	406	13	6	2	9	11

\* Search structure was refined using Proquest to: (keyword) AND (child OR children) AND “research ethic\*”

\*\* Categories with over 200 articles were not searched exhaustively, searching ceased when titles were repeated.



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*COVER PHOTO: SOMALIA A girl stands, her mother's arm wrapped around her, in a shelter for girls and women who have endured sexual and gender-based violence, in Mogadishu, the capital. The girl was raped while living in a camp for displaced people. In addition to safe accommodation, girls and women at the shelter run by the Elman Peace and Human Rights Centre with UNICEF support also receive educational and psychosocial assistance.*