



ETHICAL RESEARCH INVOLVING CHILDREN

Centre for Children
and Young People



Childwatch
INTERNATIONAL
RESEARCH NETWORK

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Te Whare Wānanga o Ōtago
NEW ZEALAND

REVIEW OF OTHER ETHICAL GUIDELINES

REVIEW OF GUIDELINES: HARMS AND BENEFITS

Guidelines on harms and benefits in research involving children include significant emphasis on researchers' responsibilities to justify the inclusion of children in research and protect them from harm, during and after the research, with additional emphasis on children who are particularly vulnerable.

- There should be clear and justifiable reasons why children are being included in the research, with researchers able to substantiate that the information is not readily available elsewhere (WHO, 2011). Children should be protected from both over-research and under-research (Alderson & Morrow, 2011).
- Researchers are responsible for protecting children from any physical, social or emotional harm that might arise from the research (Ennew & Plateau, 2004; Laws & Mann, 2004). Therefore, researchers should do everything possible to anticipate any adverse consequences and ensure that participation will not lead to harm (Alderson & Morrow, 2011; Schenk & Williamson, 2005), including developing strategies to minimise any possible distress and managing context-specific risks (Feinstein & O'Kane, 2008), and protecting children from putting themselves at risk (Ennew & Plateau, 2004).
- Care must be taken if the subject is contentious, disturbing or in any way in advance of what the child or young person may be expected to know or understand (Market Research Standards, 2010).
- Researcher responsibility is further emphasised when the children involved are particularly vulnerable, such as children who are unaccompanied, orphaned or separated from family (Schenk & Williamson, 2005). The research must be conducted in a manner that is sensitive to children in complex situations, such as children with disabilities; children affected/infected with HIV/AIDS; children orphaned or separated from families; as well as children who are distressed or known to have been abused (Mwaipopo, 2006).
- Unaccompanied children and those who have lost their families should participate only in research that will directly benefit them (WHO, 2011).
- Dissemination of findings should not pose risk or stigmatisation to children, young people or their families (WHO, 2011).

Guidance related specifically to research in the health/biomedical sector emphasises the importance of benefits to the participating child or others and the need for follow-up support if needed:

- The participation of a child in research should offer the possibility of direct benefit to his/her health. Where no direct benefit is likely, the results should benefit other children who are the same age or have the same disease, condition or disability, and the child should not be exposed to more than minimal risk (Avard, Amuel, Black, Griener & Knoppers, 2011).
- Research should be conducted in settings in which the child and parent can obtain adequate medical and psychological support (CIOMS & WHO, 2002, 2008).

Guidelines in sectors, other than health/biomedical, also address the need for referral processes if children or families require services as a consequence of their participation in the research process:

- All research should have planned protocols for addressing situations of concern and for making referrals for support or protection (WHO, 2011). Community consultation is important to ascertain organizations or agencies that may be able to offer support (Edmonds, 2005; Schenk & Williamson, 2005).
- Alternative services should be sought if there is an absence of child-focused services (Laws & Mann, 2004).

A number of ethical guidelines address researcher safety with reference to strategies, protocols and researcher training:

- Safety for research staff is essential (WHO, 2011) and should be placed above completion of the research tasks at all times (Laws & Mann, 2004). Researcher safety can be attended to with security plans, back up communication systems, secure transportation and team strategies (WHO, 2007).
- Training programmes should establish professional boundaries and self-care for researchers (WHO, 2011).

Ethical guidelines emphasise the responsibility and obligations of the researcher in protecting children and having intervention plans in place:

- Ensuring child protection is an integral part of planning and implementing the research (Feinstein & O’Kane, 2008; WHO, 2007, 2011). It is the researcher’s responsibility to protect children from putting themselves at risk and to intervene when a child is at risk (Ennew & Plateau, 2004; Mwaipopo, 2006).
- The duty of researchers to protect the safety of children overrides their responsibility to guarantee confidentiality (WHO, 2011).
- Talk carefully with the child before taking any action, be transparent about the steps that will be taken and if possible reach agreement with the child about these (Feinstein & O’Kane, 2008).

- The skill of researchers is paramount in dealing with situations that involve balancing risks and benefits of actions and the need for training is highlighted (WHO, 2007).
- The laws of the country in which the research is taking place should be consulted regarding the obligations for researchers to report to relevant services (WHO, 2011).

The ethical guidance literature also addresses the matter of protecting children from the abusive actions or poor practice of research staff. This includes recommendations to adopt child protection policies and staff conduct codes:

- Some ethical guidelines recommend adopting, or do adopt, a child protection policy and/or an ethical Code of Conduct for researchers (Laws & Mann, 2004). Child protection policies, such as the Save the Children Child Protection Policy (2003), provide clear guidelines for managing concerns about child protection, and conduct codes incorporate guidelines for recruitment, training and ongoing conduct of staff.
- Research staff should avoid actions or behaviour that may be construed as poor practice or potentially abusive (Laws & Mann, 2004).

REVIEW OF GUIDELINES: INFORMED CONSENT

Existing guidance clearly indicates that children should be required to give consent to participate in research:

- It is essential to have full agreement of children to their participation in research (Schenk & Williamson, 2005).
- Children must be made aware who else consent is being sought from (WHO, 2011). In group settings, individual consent must still be obtained (Shaw, Brady & Davis, 2011; WHO, 2011).
- Consent is usually signified by the written signature of the research participant, but in certain situations the full informed consent process may be carried out verbally by research staff (WHO, 2011).
- Covert research, in which children are not aware the research is taking place and have not given consent for their involvement, is not acceptable (Laws & Mann, 2004).
- Children and young people's consent must always be voluntary (Laws & Mann, 2004). Children should not be enticed, persuaded or intimidated into giving consent (Schenk & Williamson, 2005).

A key topic emphasised in the existing ethics documentation is that children should be provided with information about the research and that researchers should make efforts to ensure that children understand what is involved. This may involve using strategies to encourage and/or ensure understanding, including providing appropriate information, allowing the child time to consider participation and being clear about what the research will and will not provide.

- Consent procedures should be designed with consideration of the child or young person's developmental stage, personal experience and circumstances, and information tailored accordingly (Shaw et al., 2011; WHO, 2011).
- Children must be fully informed to be able to understand and consent to participation in research (Alderson & Morrow, 2011; Laws & Mann, 2004). Information must be child-friendly and age appropriate (WHO, 2007). Steps should be taken to ensure that children understand the research process and what they have consented to do, for example, by asking children questions one-to-one or asking them to summarise what they have been told (Ennew & Plateau, 2004; Laws & Mann, 2004; WHO, 2011).
- It is important that researchers spend time verbally explaining the research to potential participants (Alderson & Morrow, 2011), to help ensure that there are not mismatches in understanding.
- It will not always be appropriate to inform children about all items when seeking consent, as their age or cognitive ability may preclude this. Researchers may wish to seek advice from experts as to what information it is appropriate to impart and how best to do this for younger children or those with learning disabilities (Shaw et al., 2011).
- Children should have sufficient time to consider the information, reflect on their decision, talk to people about it and have any questions answered before giving their consent (Avard et al., 2011; Shaw et al., 2011).
- Special care must be taken in gaining consent to avoid any risks of 'therapeutic misconception' in which individuals do not understand that the defining purpose of clinical research is to produce generalizable knowledge, regardless of any potential benefit (WHO, 2011).

REVIEW OF GUIDELINES: PRIVACY AND CONFIDENTIALITY

Guidelines on privacy and confidentiality in research involving children emphasise the importance of maintaining confidentiality and protecting participants' identities. However, in some contexts privacy is challenged by other ethical concerns, such as child protection issues, and cultural and social circumstances preventing privacy in the process of collecting information. The tensions that may arise are evident in some of the existing ethical guidelines:

- Confidentiality must be maintained and participants' identities protected (Feinstein & O'Kane, 2008; Laws & Mann, 2004; WHO, 2011).
- Interviews should be conducted in privacy, to the extent that this is accepted in the local community (WHO, 2011).
- An important exception to keep in mind is the recommendation that parents should be given the opportunity to observe clinical/epidemiological research, so as to withdraw the child if the parent decides it is in the child's best interests to do so (CIOMS & WHO, 2002; 2008). [This has relevance with regard to ensuring that children are not harmed through their participation in research.]
- For the researcher's own protection, as well as that of the child, it is important never to be alone in a house or building with the child (Shaw et al., 2011).

- If it is a child's wish (not a parent's wish) that a parent or friend be present during research interviews the researcher should agree to this (Shaw et al., 2011; Laws & Mann, 2004).
- Recent ethical guidelines tend to recommend that confidentiality be breached if the researcher suspects child abuse, has concerns for the child or another person's safety (Schenk & Williamson, 2005; WHO, 2011), or has a communicable or sexually transmitted disease which is required by law to be notified (CIOMS & WHO, 2002, 2008). Researchers are advised to inform potential participants of this during the consent procedure, and have a planned strategy in place if needed (Schenk & Williamson, 2005; WHO, 2011).

Some ethical guidelines advocate developing protocols regarding aspects of confidentiality in data collection and storage processes:

- Confidentiality protocols should be made clear to all the research staff (Laws & Mann, 2004; WHO, 2011).
- Data should be securely stored and protected, especially when it is sensitive (Shaw et al., 2011). Data should be kept separate from identifying information (Laws & Mann, 2004). Personal data should be accessible only by those who need to use it, and sensitive data must be kept in a locked room with controlled access, or kept in a locked filing cabinet or a locked drawer, or in password protected computer files (Shaw et al., 2011). Consideration needs to be given to the transporting and storage of audio or videotapes (Laws & Mann, 2004). Direct identifiers should be removed or destroyed at the earliest possible opportunity (Avard et al., 2011).
- Safeguards adopted to ensure that privacy and confidentiality are maintained should adhere to local law (Avard et al., 2011).

Specific guidance relates to the privacy of the research participants so that they are not identifiable in the dissemination of findings:

- To achieve public confidentiality some researchers omit participants' names, use pseudonyms and remove or disguise identifying information from reports, including aspects of stories in qualitative data while maintaining integrity of the findings (Laws & Mann, 2004).
- As far as possible, researchers should share findings with participants before making them public and seek their consent to plans for distributing publications or communication information, especially photos and video recordings (Ennew & Plateau, 2004). Researchers are advised to discuss issues with children about maintaining confidentiality, especially in assessing the risk in using potentially identifying material in reports (Feinstein & O'Kane, 2008). It is important that researchers avoid giving children and young people written documents or other materials related to the research study to keep if this potentially places them at risk (WHO, 2011).

REVIEW OF GUIDELINES: PAYMENT AND COMPENSATION

Existing literature points to arguments both for and against the use of payment in research, depending on the form of payment and the context in which the research is occurring. Ethical guidelines tend to advise researchers

against giving incentive payments for participation in research:

- Offering incentives is best avoided, as it may influence participation (Schenk & Williamson, 2005), constitute persuasion or pressure on participants (Alderson & Morrow, 2011), potentially create a sense of obligation, raise expectations or become a form of control (Laws & Mann, 2004). Payment of children should be linked to their attendance and involvement in the research study and independent of their responses and behaviour during the process, including the decision to stop participation or not answer certain questions (Schenk & Williamson, 2005).
- Some organizations' guidelines generally advise against financial payment for research participation (mostly due to concerns regarding incentives) (Edmonds, 2005; Ennew & Plateau, 2004).
- Save the Children guidelines (Laws & Mann, 2004) outline the pros and cons of providing incentives for participation in research. Arguments in favour of incentives for respondents include that it can increase participation levels considerably, especially in poor communities; expedite recruitment and hence save time and resources; recognise the value of respondents' time and contribution; and prevent sample bias by helping to ensure poor people are not prevented from participating. Arguments against providing incentives to respondents include the cost involved; the possibility of compromising voluntary consent by creating a sense of obligation; the possibility of sample bias through encouraging those who want recompense to participate and possibly say what they think the researcher wants to hear; and it can create expectations of recompense for participation in research in the future.

Some ethical guidelines emphasize the importance of taking the local context into account in decision-making regarding payment of research participants. This includes recommending consultation with local and national stakeholders, payment to benefit communities (rather than payment to individual research participants) and consideration of people's livelihoods and local living standards in determining the payment, with a particular awareness of situations of poverty and disadvantage:

- The nature of payment and compensation should be determined by local consultation (Schenk & Williamson, 2005) or national-level deliberation with selected stakeholders (Edmonds, 2005).
- It may be appropriate to give payment to the community for the benefit of the children involved in the research, their families and the community (Schenk & Williamson, 2005). If so, this should be discussed with broad representation of community members and stakeholders to ensure fair distribution.
- Children's participation should be recognised and recompensed, in line with local living standards, cultural and socio-cultural factors, and their contribution (Laws & Mann, 2004; Schenk & Williamson, 2005; Shaw et al., 2011; WHO, 2011).
- Researchers are advised to be transparent about payment or remuneration to avoid fuelling community tensions, particularly in situations of acute poverty (Feinstein & O'Kane, 2008; Hart & Tyrer, 2006).
- The livelihoods of research participants should not be adversely affected by their participation in research (Ennew & Plateau, 2004; Feinstein & O'Kane, 2008)

Some ethical guidance suggests that payment should be addressed in the planning stages of the research, and considered by potential participants and ethics review boards:

- Any payment or compensation should be decided in advance, prior to recruiting participants (Ennew & Plateau, 2004) and discussed during the consent process (Avard et al., 2011). An ethics review board should review the proposed payment plan (Avard et al., 2011).

ORGANIZATIONS' DOCUMENTATION RELEVANT TO RESEARCH ETHICS

Avard, D., Black, L., Samuël, J., Griener, G., & Knoppers, B. M. (2012). Best practices for health research involving children and adolescents: Genetic, pharmaceutical, longitudinal studies and palliative care research.

Centre of Genomics and Policy, McGill University and Maternal Infant Child and Youth Research Network (MICYRN); with the collaboration of the Institute for Human Development, Child and Youth Health, Canadian Institutes of Health Research and Ethics Office, Canadian Institutes of Health Research. Available from: <http://www.pediagen.org/>

Description: These Best Practices provide an overview of international and Canadian ethical norms, reflecting the current situation in Canada regarding health research involving children and adolescents. For a more critical analysis of these norms, please refer to *Pediatric Research in Canada* (D. Avard, J. Samuël and B.M. Knoppers (eds), Les Éditions Thémis, 2009) and *La recherche clinique avec les enfants: à la croisée de l'éthique et du droit* -Belgique, France, Québec (ML Delfosse, MH Parizeau et JP Amann (éd.) PUL & Anthémis, 2009). These Best Practices do not provide specific guidance for research involving the First Nations, Inuit and Métis peoples of Canada. For research involving Aboriginal children and youth, the Best Practices should be used in conjunction with the Tri-Council Policy Statement, Chapter 9, "Research Involving the First Nations, Inuit and Métis Peoples of Canada" (<http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/>).

Council for International Organizations of Medical Sciences (CIOMS), & World Health Organization (WHO). (2002). International ethical guidelines for biomedical research involving human subjects. Geneva: CIOMS.

Available from: <http://www.cioms.ch/index.php/texts-of-guidelines>

Extract from introduction (p. 8): "This is the third in the series of international ethical guidelines for biomedical research involving human subjects issued by the Council for International Organizations of Medical Sciences since 1982. It consists of a statement of general ethical principles, a preamble and 21 guidelines, with an introduction and a brief account of earlier declarations and guidelines. Like the 1982 and 1993 Guidelines, the present publication is designed to be of use, particularly to low-resource countries, in defining national policies on the ethics of biomedical research, applying ethical standards in local circumstances, and establishing or redefining adequate mechanisms for ethical review of research involving human subjects."

Council for International Organizations of Medical Sciences (CIOMS), & World Health Organization (WHO). (2008). International ethical guidelines for epidemiological studies. Geneva: CIOMS.

Available from: <http://www.cioms.ch/index.php/texts-of-guidelines>

Extract from introduction (p. 6): "Epidemiology is the study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to control of health problems' (John Last, Dictionary of Epidemiology, 4th edition). This volume sets forth ethical guidance regarding the first part of this definition, namely, how epidemiologists – as well as those who sponsor, review, or participate in the studies they conduct – should identify and respond to the ethical issues that are raised by the process of producing this information."

Edmonds, C. (2005). Ethical considerations when conducting research on children in the worst forms of child labour in Nepal. Switzerland: International Labour Office (ILO), International Programme on the Elimination of Child Labour (IPEC).

Available from: http://www.ilo.org/ipec/Informationresources/WCMS_IPEC_PUB_1341/lang--en/index.htm

Extract from preface (p. v): "Although there is a body of knowledge, data, and documentation on child labour, there are also still considerable gaps in understanding the variety of forms and conditions in which children work. This is especially true of the worst forms of child labour, which by their very nature are often hidden from public view and scrutiny. ... The ILO has carried out 38 rapid assessments of the worst forms of child labour in 19 countries and one border area. The investigations have been made using a new rapid assessment methodology on child labour, elaborated jointly by the ILO and UNICEF. ... The investigations on the worst forms of child labour have explored very sensitive areas including illegal, criminal or immoral activities. ... I am convinced that the important ethical considerations when conducting research on children engaged in the worst forms of child labour contained in this document will contribute to a well-planned and meaningful research process."

Ennew, J., & Plateau, D. P. (2004). How to research the physical and emotional punishment of children. Bangkok: International Save the Children Alliance, Southeast, East Asia and Pacific Region.

Available from: <http://vac.wvasiapacific.org/further-reading/violence-against-children-in-the-home.html>

Extract from preface (p. x): "The important purpose of this Handbook is to encourage sensitive and ethical research on punishment of children, wherever possible directly involving children themselves. It provides an invaluable and practical resource kit for both programme managers and researchers. The aim is to reveal children's experiences and their views. The imperative for prohibiting and eliminating all corporal punishment and other humiliating treatment of children is human rights. The human rights standards are clear, but persuading states to honour their obligations and take the necessary actions – law reform, awareness-raising and public education – is not easy."

Feinstein, C., & O’Kane, C. (2008). Ethical guidelines: For ethical, meaningful and inclusive children’s participation practice. Oslo: Save the Children Norway.

Available from: <http://tn.reddbarna.no/default.asp?HMFILE=130232>

Extract from preface (p. 1): “These guidelines have been drawn up to ensure ethical, meaningful and inclusive child participation practice, both with and by children, young people and adults, during the Thematic Evaluation and Documentation process. They draw upon existing Save the Children policies, practice standards and good practice guidelines for involving children in research, consultations, advocacy and so on. ... In particular, these guidelines are underpinned by and should always be used in conjunction with the Child Protection Policy of the Save the Children or partner organization and the Save the Children Practice Standards in Children’s Participation (2005).”

Hart, J., & Tyrer, B. (2006). Research with children living in situations of armed conflict: Concepts, ethics & methods. Oxford: Refugee Studies Centre, University of Oxford.

Available from: http://www.rsc.ox.ac.uk/publications/working-papers-folder_contents/RSCworkingpaper30.pdf/view

Extract from introduction (p. 5): “Research about children’s lives conducted in the volatile setting of armed conflict places particular demands upon researchers. The suggestion that researchers should, whenever possible and appropriate, involve children as meaningful participants in that research may seem unreasonable or inappropriate. However, the production of this paper has been motivated by the conviction that participatory research is especially valuable because of the emergency context. Firstly, such an approach is likely to yield richer and more detailed data than a conventional, adult-led approach. These data can be invaluable to the design of interventions. Secondly, engagement in well-planned research activities can offer direct benefits for young participants by enhancing their skills and awareness. In settings of conflict where the young may be required to play an expanded role in their own protection and in the care of others, their personal development is especially important. Our aim here is to equip researchers to most safely and profitably pursue participatory research with children and, to that end, we explore the specific conceptual, ethical and methodological issues concerned.”

Laws, S., & Mann, G. (2004). So you want to involve children in research? A toolkit supporting children’s meaningful and ethical participation in research relating to violence against children. Stockholm: Save the Children Sweden.

Available from: <http://images.savethechildren.it/f/download/Policies/st/strumenti.pdf>

Extract from introduction (p. 7): “This research kit is one part of a series of toolkits produced by the International Save the Children Alliance. This part of the toolkit aims to encourage meaningful and ethical participation by children in research related to violence against children. It promotes research that sees children as active agents in their own lives, not passive victims or research ‘subjects’. There are many ways in which children can be more actively involved in research, both as respondents and as co-researchers. This kit aims to give guidance on ways of approaching this work, on ethical issues to be considered, and on techniques that can be used. Case studies from around the world draw on a rich field of participatory research with children that has developed in recent years.”

Lobe, B., Livingstone, S., Olafsson, K., & Simões, J. A. (2008). Best practice research guide: How to research children and online technologies in comparative perspective. London: EU Kids Online / London School of Economics.

Available from: <http://www2.lse.ac.uk/media@lse/research/EUKidsOnline/EU%20Kids%20Online%20reports.aspx>

Extract from Introduction (p. 5): "This Best Practice Guide has been compiled by drawing on the multi-disciplinary and multi-method expertise of the sixty plus researchers who comprise the EU Kids Online network. ... Its purpose is to distil the knowledge, experience and insights of those actively researching children's use of online technologies for the benefit of those entering this domain. It is intended to be useful to new researchers, to experienced researchers new to this domain, to those commissioning or evaluating research on children and online technologies, and to students and interested others. The Best Practice Guide is presented in the format of Frequently Asked Questions, since this how new researchers most commonly express their need for knowledge and guidance."

Market Research Standards (MRS). (2012). MRS Guidelines for research with children and young people. London: MRS.

Available from: <http://www.mrs.org.uk/standards/consultation.htm>

Extract from introduction (p. 4): "These Guidelines interpret the market research standards (MRS) Code of Conduct (UK) (revised 2010) and provide additional best practice advice. Unless otherwise stated, Guidelines are not binding. Rules B27 to B33 of the MRS Code of Conduct contain specific mandatory provisions relating to research with children. ... Under the Code, children are defined as those aged under 16 years. These Guidelines also provide additional best practice for research with young people aged 16 and 17 years. There is no recommended minimum age for research among children but it is expected that researchers will involve very young children directly in research only when this is necessary and appropriate to the particular project."

Morrow, V. (2009). The ethics of social research with children and families in young lives: practical experiences. Oxford: Young Lives Research Project.

Available from: www.younglives.org.uk

Abstract: A great deal of attention is now paid to the ethics of social research. Research governance has expanded, and a burgeoning literature is emerging that describes the processes, practices and questions that arise in social research with children, families and communities. This paper outlines the approach taken to research ethics within Young Lives, a long-term study of childhood poverty in four developing countries. It describes some of the practical difficulties that Young Lives faces, and emphasises the importance of understanding local contexts in undertaking research with children and families in environments that are dynamic and may change rapidly from one year to the next, economically, environmentally and politically. The paper aims to contribute to current debates about research practices, the ethics of longitudinal research with children and research with communities in majority world contexts, in the spirit of shared enquiry and learning.

Mwaipopo, R. (2006). Children participating in research. Dar es Salaam: Research on Poverty Alleviation.

Available from: <http://www.repoa.or.tz/index.php/publications/category/briefs/P30>

Extract from abstract: Research with children is important to reach out to a section of society disadvantaged by age in terms of their representation in societal issues. The traditional method of conducting research with children is to use adult researchers who adapt their mode of communication to suit the children as much as possible. The innovative way is to train young people to conduct the research, involving children in the research process as collaborators, not merely using them in data collection by assigning them roles as passive subjects of research.

National Children's Bureau. (2003). Appendix V: NCB research department data protection guidelines. UK: National Children's Bureau.

Available from: <http://www.ncb.org.uk/>

Appendix V of the National Children's Bureau's Guidelines for Research details the steps the research department takes to comply with the Data Protection Act 1998 (UK), which came into force in 2001.

National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research. (1979). The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research. U.S. Department of Health, Education and Welfare.

Available from: www.videocast.nih.gov/pdf/ohrp_appendix_belmont_report_vol_2.pdf

Summary: "On July 12, 1974, the National Research Act (Pub. L. 93-348) was signed into law, there-by creating the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. One of the charges to the Commission was to identify the basic ethical principles that should underlie the conduct of biomedical and behavioral research involving human subjects and to develop guidelines which should be followed to assure that such research is conducted in accordance with those principles. In carrying out the above, the Commission was directed to consider: (i) the boundaries between biomedical and behavioral research and the accepted and routine practice of medicine, (ii) the role of assessment of risk-benefit criteria in the determination of the appropriateness of research involving human subjects, (iii) appropriate guidelines for the selection of human subjects for participation in such research and (iv) the nature and definition of informed consent in various research settings" (summary retrieved from <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>).

National Disability Authority. (2009). Ethical guidance for research with people with disabilities. Dublin: National Disability Authority Ireland.

Available from: [http://www.nda.ie/cntmgmtnew.nsf/0/232F61AE5397A93D802576650052B3B9/\\$File/ethicsfootnotes.html](http://www.nda.ie/cntmgmtnew.nsf/0/232F61AE5397A93D802576650052B3B9/$File/ethicsfootnotes.html)

Extract from Introduction (p. 7): "Research is undertaken to expand knowledge, discover the truth and provide evidence for practitioners, policy-makers and legislators. [1] Research that involves people with disabilities is important in uncovering issues requiring attention; in informing policy; in evaluating programmes and services; and in tracking how social and economic change

affects people with disabilities. The importance of research and data related to disability has been underscored in the Report of the Commission on the Status of People with Disabilities (1996), and in the United Nation's Convention on the Rights of Persons with Disability (2006), adopted in December 2006. [2] Disability research ethics are located within the wider research ethics framework. Ethical principles require that any research involving human subjects is framed and conducted in a way that respects the human rights of the individuals concerned. The UN Convention sets out what recognised human rights principles mean in respect of people with disabilities. Central to the UN Convention's understanding of human rights are respect for the inherent dignity, individual autonomy — including the freedom to make one's own choices — and independence of persons."

Save the Children. (2003). Child Protection Policy. London: International Save the Children Alliance.

Available from: <http://resourcecentre.savethechildren.se/content/library/documents/save-children-child-protection-policy>

Extract from introduction (p. 1): "Members of the International Save the Children Alliance have a common commitment to the prevention of child abuse and protection of children. The Child Protection Policy sets out common values, principles and beliefs and describes the steps that will be taken for the Alliance commitment to protect children. The policy was adopted by the International Save the Children's Member's Meeting May 2003."

Schenk, K., & Williamson, J. (2005). Ethical approaches to gathering information from children and adolescents in international settings: Guidelines and resources. Washington DC: Population Council.

Available from: <http://www.popcouncil.org/what/ethics.asp#/jQueryUITabs1-2>

Extract from preface (p. iv): "This publication was developed in response to a growing need for practical guidance on collecting information from and about young people. The initial need for such recommendations was identified in the context of activities being conducted among children and adolescents affected by HIV and AIDS. However, they apply equally well to gathering information from young people to address other health and social welfare conditions and difficult circumstances, such as those who have experienced abuse, trafficking, or displacement."

Shaw, C., Brady, L.-M., & Davey, C. (2011). Guidelines for research with children and young people. London: National Children's Bureau (NCB) Research Centre.

Available from: <http://www.ncb.org.uk/>

Extract from introduction (p. 3): "These guidelines have been produced for researchers who are contemplating involving children and young people (CYP) in their research project – whether as participants or in a more active role. These guidelines set out the NCB Research Centre's general approach to research with CYP (Section 2); provide practical guidance for the researcher, through all stages of the research process from planning to dissemination: Section 3 focuses on research in which CYP are participants (that is, as sources of data); Section 4 considers other ways in which CYP can be involved in the research process. These guidelines are illustrated throughout with examples from the recent work of NCB's Research Centre."

Spriggs, M. (2010). Understanding consent in research involving children: The ethical issues. A handbook for human research ethics committees and researchers. Melbourne: Children's Bioethics Centre (Royal Children's Hospital Melbourne / University of Melbourne / Murdoch Children's Research Centre).

Available from: www.mcricri.edu.au/media/62539/handbook.pdf

Extract from 'Purpose of this document' (p. 3): "This handbook together with a project website is an educational resource developed for Human Research Ethics Committees (HRECs) and researchers. The questions in this handbook are based on actual issues of concern expressed in key informant interviews with members of HRECs who review research involving children and young people and researchers who conduct that research. The questions reflect ethical issues that are being encountered by researchers and HREC members and the concerns on which they seek further guidance."

World Health Organization (WHO). (2007). WHO Ethical and safety recommendations for researching, documenting and monitoring sexual violence in emergencies. Geneva: World Health Organization Press.

Available from: <http://www.who.int/gender/documents/violence/9789241595681/en/index.html>

Overview: Sexual violence in humanitarian emergencies, such as armed conflict and natural disasters, is a serious public health and human rights issue. Yet, the prevalence of sexual violence is under-reported almost everywhere in the world, and ethical and safety guidelines specific to the particular issues that arise during collection of information about sexual violence in emergencies are lacking. The ethical and safety guidelines (or recommendations) in this document are meant to complement existing internationally-agreed ethical guidelines for research and to inform ethics review processes. Failure to consider ethical and safety issues can result in harm to the physical, psychological and social well-being of those who participate and can even put lives at risk.

Zimmerman, C., & Watts, C. (2003). WHO ethical and safety recommendations for interviewing trafficked women. Geneva: World Health Organization.

Available from: <http://www.who.int/iris/handle/10665/42765>

Abstract: The recommendations should be used in conjunction with existing professional standards applicable to the work being conducted. These recommendations provide a set of ten basic standards for interviewing women who are in or have left a trafficking situation. The significance of each issue is explained and examples are offered of how, in practice, each can be addressed. The recommendations should not be taken as a comprehensive guide to working with women who have been trafficked.