



<http://www.diva-portal.org>

This is the published version of a paper published in *SAGE Open*.

Citation for the original published paper (version of record):

Harcourt, D., Quennerstedt, A. (2014)

Ethical Guardrails When Children Participate in Research: Risk and Practice in Sweden and Australia.

SAGE Open, 4(3): 1-8

<http://dx.doi.org/10.1177/2158244014543782>

Access to the published version may require subscription.

N.B. When citing this work, cite the original published paper.

Permanent link to this version:

<http://urn.kb.se/resolve?urn=urn:nbn:se:oru:diva-35863>

Ethical Guardrails When Children Participate in Research: Risk and Practice in Sweden and Australia

Deborah Harcourt and Ann Quennerstedt

SAGE Open 2014 4:

DOI: 10.1177/2158244014543782

The online version of this article can be found at:
<http://classic.sgo.sagepub.com/content/4/3/2158244014543782>

Published by:



<http://www.sagepublications.com>



Additional services and information for *SAGE Open* can be found at:

Email Alerts: <http://classic.sgo.sagepub.com/cgi/alerts>

Subscriptions: <http://classic.sgo.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Ethical Guardrails When Children Participate in Research: Risk and Practice in Sweden and Australia

SAGE Open
 July-September 2014: 1–8
 © The Author(s) 2014
 DOI: 10.1177/2158244014543782
 sgo.sagepub.com


Deborah Harcourt¹ and Ann Quennerstedt²

Abstract

This article investigates interpretations of sound research ethics in social science research involving children as framed through regulation. Coinciding with an emergent significance being given to research that involves children, debate has developed regarding whether particular ethical considerations are warranted in this type of research. We overlay the examination of regulation documents in Sweden and Australia with an interpretative lens drawn from these regulations that has the potential to position children as competent social actors in the research process. We then argue that there is possibility for ethical procedures to be viewed not only as risk management but also as beneficial research practice to stimulate continuing debate about how to work ethically in social science research when children are participants.

Keywords

research ethics, research with children

Introduction

With changing views on children's role and status in research in the last decade, there has been intense activity and discussion within social science settings about what constitutes sound research ethics. A fundamental question in this ethical debate is whether special consideration is warranted when children are included in research and, if so, to what extent and in what way. It has been argued that research ethics have been conceived mainly as a question of *risk management* (Graham & Fitzgerald, 2010). A range of authors have claimed that with a reconceptualization of what research ethics might mean when children are viewed in a new way, the risk management view is an overly narrow approach to ethical issues in research involving children (Harcourt & Conroy, 2011; Harcourt & Einarsdottir, 2011; Moss, 2006; Sargeant & Harcourt, 2012; Smith, 2011). A complementary understanding of research ethics as *research practice* has been brought forward in the debate as necessary. The backcloth to this shift in thinking, about research ethics in relation to children, can largely be traced to two academic fields: childhood sociology (James & James, 2004; Mayall, 2000, 2003) and children's rights (Freeman, 1998; Quennerstedt, 2010). Drawing on these fields, an influential contemporary image of the child as a knowledgeable agent in the present with full human dignity has led to a repositioning of the child within many areas of our societies (see Mayall, 2000, 2003; Quennerstedt & Quennerstedt, 2014; Rinaldi, 2001, 2006; Smith, 2002, 2011).

A question, however, is whether this decade-old ethics debate in social science settings with an interest in children has influenced the general conception of research ethics: for example, how children's participation in research is approached in the regulation of research ethics. The formal regulation that exists in most countries¹ is argued in the literature as aiming primarily at minimizing the risks of research (Graham & Fitzgerald, 2010). In particular, the ethical considerations that are highlighted in formal regulation often focus on curtailing the use, and associated risk, of ethically unsound activities such as exposing research subjects to exploitative, harmful, or offensive investigations. However, the formal regulation of research ethics in many countries is also seen as an essential monitoring point for researchers as they formulate their own ethical approach and, as Sargeant and Harcourt (2012) suggest, should be considered a support and resource for researchers. Ethics regulation is intended as an instrument to protect society and the people involved from unethical research, and thus also act as a thoughtful restriction to the researcher's freedom. Besides the formal regulation, there can also be a body of less formal regulation affecting the researcher's thinking and actions.

¹Australian Catholic University, Brisbane Australia

²Örebro University, Örebro, Sweden

Corresponding Author:

Deborah Harcourt, Australian Catholic University, Nudgee Road, Nudgee, Brisbane, Australia
 Email: deborah.harcourt@acu.edu.au



This may take the form of national guiding documents embodying an idea of professional ethics of the researcher. Such guiding documents may not have the status of law, but nevertheless be considered as main instruments and support to researchers. Formal and informal regulation of what constitutes sound ethical conduct in research is, from our point of view, essential to how research ethics is understood by researchers.

With this article, we wish to contribute to the conversation about research ethics in child-related research within the social sciences by providing an *exploration of the meanings and consequences of the national formations of research ethics in formal and informal regulation of research ethics*. By means of a comparative text analysis of laws and other authoritative texts in two nations—Australia and Sweden—we seek to identify what meaning is given to research ethics as offered in the respective regulation. The identified meanings will be related to the two approaches to research ethics described above: ethics as risk management and ethics as research practice. We will also discuss possible consequences of interpretations of research ethics in child-related research when taken from the regulation.

Design of the Study and Analyzed Material

The research was undertaken by text analysis of the central formal regulation documents and other authoritative guiding texts in Sweden and Australia. As the authors of this article are based in the respective nations, in-depth knowledge about each context formed the base for the selection of documents. For Sweden, the following documents were analyzed:

- Act on Ethical Review of Research Involving Humans (SFS 2003:460).²
- *Sound Research Conduct* (Vetenskapsrådet [The Swedish Research Council], 2011).³

For Australia, the following documents were analyzed:

- *Australian Code for the Responsible Conduct of Research* (Australian Government, 2007a).
- *National Statement on Ethical Conduct in Human Research* (Australian Government, 2007b).

The selected documents were first screened for any mention of children. The following analytical readings of the selected parts of the text were guided by the questions,

- How is children's participation in research seen to affect ethical considerations?
- How are the anticipated risks due to children's involvement to be dealt with?
- How does children's participation in research affect ethical review procedures?

- Which ethical aspects outside the “risk management”-approach are discernible?

The documents from each nation were analyzed separately, and the meanings of research ethics in relation to children were clarified for each nation. Thereafter, the regulations and identified meanings of both nations were compared, and consequences were drawn from the comparative analysis.

Historical Contextualization and Meaning of Research Ethics

Research ethics is a broad term that can include a number of aspects. The Swedish Research Council (SRC; Vetenskapsrådet, 2011) claims that

Research ethics is not a well-defined area, although it is clear that it includes questions about the relationship between science and ethics, the ethical demands on the researcher and ethical requirements for research direction and undertaking.⁴ (p. 16)

Hopkins and Bell (2008) suggest the meaning of research ethics as “(1) the selection and achievement of morally acceptable ends and (2) the morally acceptable means to those ends” (p. 2). Hopkins and Bell thus highlight that the aim of the research must start from an ethically acceptable position and maintained from an ethical viewpoint. Morrow (2008) states that “ethics” can be defined as a set of moral principles and rules of behavior, which infers/implies that research ethics is the application of such a system of moral principles in research.

The historical origins of current ethical principles for conducting research with children arises from the Nuremberg trials, which took place after the Second World War, and the Nuremberg Code (1947), which emerged from these trials. The Code sets out statements around certain moral, legal, and ethical principles relating to research involving human subjects. The first, and most elaborated principle, is the absolute necessity that humans who are involved/participate in research must have given their voluntary consent to be part of the research: what is now commonly referred to as informed consent. A basic condition of this principle is that research can only be sanctioned if it can be undertaken with respect for human dignity. This first articulation of research ethics was also closely related in time to the emerging formulation of human rights (Bell, 2008).

In the decades after the Nuremberg trials, a number of ethical codes in different disciplines began to emerge. One of the most important of these was the Declaration of Helsinki (1964/2013) that, through continuous revision, remains one of the most widespread and influential codes of ethical conduct. This Declaration primarily addresses medical research, but its high status has come to give a broader significance and has consequently been applied across other disciplines and fields (Vetenskapsrådet, 2011). Like the Nuremberg Code, the Declaration of Helsinki also proposes some basic

ethical principles. One of these is that, in research where humans are involved, participant well-being must always take precedence over other interests; therefore, the researcher must never give preference to knowledge at the expense of the research subjects. The researcher's ethical responsibility toward "vulnerable populations" is emphasized. In addition to the internationally applicable ethical codes, many nations produce national ethics documents, sometimes compelling and sometimes of a guideline nature. Both Australia and Sweden have established codes for the responsible conduct of research (Australian Government, 2007a; Vetenskapsrådet, 2011).

The Swedish debate on research ethics has tended to divide ethical considerations into two parts, which has been described as a different pair of concepts; for example, the research requirements and individual protection requirement, researcher and research ethics, and internal and external research ethics (Gustafsson et al., 2005; Korsell, 2010; Vetenskapsrådet, 2011). The first term in each of these pairs relate to ethics in connection with the researcher's responsibility toward the (scientific) community to produce research of good quality and knowledge that promote the community. The second term refers to ethical considerations for those involved in the research. No corresponding explicit distinction can be observed in the Australian context.

Findings

Sweden

In Sweden, the regulation of research ethics is constructed around two key components: (a) Act on Ethical Review of Research Involving Humans (SFS 2003:460; hereinafter the Ethical Review Act or the Act) and the ethical review boards that have been established to review research covered by the Act; and (b) the individual researcher's professional ethics. The formal, and thereby strongest, regulation is the Act. Professional ethics are a more informal "code" because they do not have the status of legal authority. Nonetheless, the researcher's professional ethical responsibilities are stated in authoritative forums as being crucial.

The purpose of the Ethical Review Act is specified as the protection of the individual and the respect for human dignity in research. The Act stipulates when the law is applicable to research, and the grounds relevant for the social sciences are when the research

- involves the processing of sensitive personal data (racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, health, sex life) or data involving crime or criminal convictions;
- includes physical intervention on a research person, or is performed by a method that aims to affect the subject physically or mentally, or poses a clear risk of

harming the person physically or mentally (§ 3-4 Ethical Review Act).

Only research that falls under the Act should be subjected to formal ethical review, by review boards. However, it is not entirely clear which research that is—for example, it is not easy to grasp what constitutes "sensitive personal data" and what is meant by "affecting" and "obvious risk of injury." As a result, the application of the law has had to be made clear in practice through the decisions of ethical review boards. Generally speaking, for educational research, many projects submitted to review in Sweden have been sent back without being reviewed (Korsell, 2010). Decisions from ethical review boards have often been that a review is deemed unnecessary because the data are not considered sensitive and the risk of impact or damage to the participant is not seen as evidenced. The fact that children are included in a study is not articulated either in the law or by the review boards as a reason to direct the research to formal review.

The only statement in the Ethical Review Act specifically referring to children's participation can be found in the clarification of what kind of information should be given to research persons and the preconditions of consent. The Act specifies the rules that apply for information and consent from research persons who are younger than 18 years. § 18 states that "If the research person is aged 15 or over, but under 18 years, and can realize what the research means for his or her part, he or she is to be informed about and consent to the research." This has been interpreted in Sweden to mean that children from the age of 15 years, generally, have the legal right (and perhaps the perceived competence) to give their consent to participation in research and that parental consent may not be required. Furthermore, the law is interpreted as stating that if the child is younger than 15 years, parental consent is always required, regardless of whether the child can understand what the research entails (again, the issue of perceived competence arises).

However, there is another important indication in § 18, namely, "Despite the guardians consent, the research may not be performed on a research person who is under 15 years who realise what it means for his or her part, and who opposes to taking part in the research." The Act here enunciates that it is not enough to only have parental approval to include children younger than 15 years in the research. The researcher must, in addition to parental informed consent, also conclude whether the child can understand what the research entails. In this case, the researcher is obliged to ask the child if he or she wants to participate in research through an informed consent process, and is also obliged to respect the child's wishes.

The ethical aspects particularly connected to children's participation in research pointed out in the Swedish Ethical Review Act relate to risks surrounding consent. Two assumptions of consent risks may be discerned: (a) There is a risk that children younger than a certain age cannot interpret

information about research well enough and that children therefore may consent to harmful or exploitive research, and (b) if only parents'/guardians' consent is required, there is a risk that researchers will ignore seeking children's consent. To deal with these risks, the law in the first case requires consent from a responsible adult, and in the second case that the researchers examine the child's ability to understand what is at stake and to give consent. Even though this second view could be viewed as an expression of risk (rather than research practice), an influence from the changing conception of the child as a competent rights-holding actor is visible. In that way, an interpretive possibility to researchers to engage with the competent child in their ethical approach opens up.

As the only ethical guidance given in the formal regulation for research involving children concerns the matter of consent, it would appear that for research conducted in Sweden ethical reflection needs to find encouragement in a less regulated arena: professional ethics. As part of maintaining his or her own sound professional ethics, it remains primarily the researcher's responsibility to formulate his or her own ethical approach. The SRC (Vetenskapsrådet, 2011) writes,

Researchers should follow good research practice. Therefore, one cannot argue that the Ethical Review Act replaces ethical codes as the Declaration of Helsinki, or renders the own moral judgement meaningless. The researcher's own reflections on his or her project must instead be based on both knowledge about the law and the content of codexes and on his or her own moral judgement. (p. 25)

It may then be asked, "Do the ethical codes or other guideline documents provide any specific support for Swedish researchers whose studies involve children?" The SRC's guidance document *Good Research Conduct* is the principal ethics text of the main funding body in Sweden. The document discusses a range of ethical issues such as formal review, the managing of research material, ethical aspects of research cooperation, ethical difficulties in relation to publication, the various roles of the researcher, and misconduct in research. Very little attention is given in the guiding document to ethical aspects of involving human participants in research. Moreover, it does not include any other special ethical considerations for children than the requirements for parental approval if the child is younger than 15 years. Accordingly, nothing further than what is already said in the Act is added in the guidance text. To sum up the Swedish regulation, little is said at all about special ethical concerns when children participate in research, both in law and in other guide texts. The few aspects that are raised are all in reference to informed consent issues.

Australia

The foundation document in Australia for research ethics is the *Australian Code for the Responsible Conduct of Research*

(Australian Government, 2007a). This national code has the characteristics of a guidance document, but does not have the status of law. In addition to stating basic principles, the code gives attention to a range of matters such as how research data should be managed, the supervision of research trainees, presentation of research results, authorship and peer review, management of conflict of interest, the ethical aspects of research collaborations, and misconduct in research. A research-ethical perspective on human participation in research is thus quite invisible in the national code and is found mainly in the initial values and principles section. This is detailed instead in a supplementary national document: *National Statement on Ethical Conduct in Human Research* (the Statement; Australian Government, 2007b). The Statement has a stronger position than the code because research funded or undertaken within one of the authoring institutions is required to follow the specifications in design, ethical review, and conduct of research. The Statement thus functions both as regulation and guidance for the researcher, and as a framework for ethical review bodies.

Respect for human dignity is the fundamental value principle that, according to the Statement, should characterize research that includes people. This includes respect for human self-determination and care and protection of vulnerable people. From this basis, the Statement pronounces four themes of ethical considerations in research involving humans:

- That research should be of value and implemented with merit and integrity
- That research should be just; just selection of research subjects and fair recruitment processes, fair distribution of risks and benefits to those who are part of the research
- That potential risks of harm or discomfort to the research subjects must be justified by the potential benefits of the research, and such risks must be minimized
- That research must respect human welfare and safety, personal beliefs, culture, privacy, and abilities.

Ethical aspects of particular importance in research involving children and young people are dealt with in a separate section. A first special consideration that researchers need to give is related to children's capacity to understand what the research entails and, based on that, whether consent from the children themselves is sufficient for their participation. In decisions about consent to children's and young people's participation in research, the Statement emphasizes that researchers must respect the continuing development of the child's ability to participate. The wording used here paraphrases the United Nations Convention on the Rights of the Child (United Nations, 1989) and indicates a clear influence from children's rights thinking and the idea of the competent child is therefore visible in the document. Researchers are

asked to assess the child's maturity and capacity to give consent; no age levels are given, instead the content of research and other factors will form the basis for the assessment. Researchers must further be able to describe how children's capacity to consent will be assessed and how children will be informed of the research's purpose and effects. We see then, like Sweden, the Australian regulation offers a "double view." Children's lack of capacity brings about risks, but simultaneously a risk is posed if children's consent is not sought in a way that respects the child's abilities.

The Statement points out two other risks that need to be dealt with by the researcher: that children may be subjected to coercion or influence from adults and peers to participate in research against their will, and that there may be conflicts of value or interest between parents and children.

Several of the themes for ethical consideration in research involving humans are generally considered to apply specifically to children and young people's participation in research. In relation to research merit and integrity, it is pointed out that research methods should be suitable for children. The term "suitable" may here be interpreted as meaning that there are research methods that risk harming children more than adult research participants and therefore should be avoided to decrease risk. But it may also be interpreted as suggesting that certain research methods are more suited to meet the child as competent agent, which would place this ethical aspect in Australian regulation more in the *ethics as research practice* thinking.

Regarding aspects of justice, it is noted that the participation of children who do not have sufficient maturity to be able to consent themselves can only be justified if their participation is indispensable to the research, or if the research will advance knowledge about issues that are important for children and young people. This is an important utterance in the Statement, which signals that the risks of involving children in research are seen as significantly higher than with adult participants and that these high risks can only be warranted in certain cases.

In the nationally validated Statement, there is significant information about necessary ethical considerations in research involving humans and, further, special attention is devoted to ethical issues when children are involved in research. Apart from the general high risk discussed above, some specific risks are pointed out: the double risk surrounding consent, the risk that children are coerced into research, and the risks in employing unsuitable research methods. There is, however, also clear indication that a changing view of the child as a competent rights holder has influenced the document: the reference to the continuing development of the child's capacity and the alternative interpretation of the section on research methods as an expression for a view of ethics as research practice.

Child-related researchers in Australia can find considerable support for ethical reflection in the formal statement. Universities in Australia are responsible for ensuring research

conducted under the auspices of their institution comply with current requirements. This is achieved through a Human Research Ethics Committee (HREC). Projects where people are included but are deemed as negligible risk will go through an expedited review process. However, if the research involves children younger than 18 years, all projects, without exception, will undergo a full review. For this reason, even in the simplest project, the process from the initial ethics application to when the research can begin can take many months. Moreover, the review process is rigorous and projects are often thoroughly questioned and revision is required (Allen, 2005; Harcourt & Sargeant, 2009).

A Comparative Discussion of the Regulation and Its Consequences

The following section compares how ethical issues in research involving children are described in the regulation in Australia and Sweden, and points out some similarities and differences between the two countries.

A first important difference is whether children's participation *in itself* is considered a risk or not. In Sweden, there are few signs that including children in the research is seen to automatically raise the risk level (maybe with the exception in the mention that children are a vulnerable group). In Australia, it is assumed that research that involves children always constitutes more than low-risk research, regardless of the topic/methodology (Harcourt & Sargeant, 2009). These two differing positions are manifested both in the nations' respective formal regulatory documents, and in the consequent review procedures. In Australia, the basic standpoint that children in research *per se* raises the risk level is expressed in the constraint that children should only participate in research if there is no other means of producing the knowledge. In Sweden, nothing in the documents indicates this position. In the practices of formal ethical review, Australian researchers face a rigorous level of ethics review when children participate in the research, whereas in Sweden, including children in research does not obligate ethical review.

An evident similarity between the two nations is the attention given in formal regulation to various complications surrounding informing children and gaining children's consent to participate in research. What is particularly interesting here, and which is noticeable in both countries, is that the perceived risk is ambivalent. The child is both positioned to lack the required capacity to understand and make decisions, *and* is seen to be in possession of such abilities. The child is to be protected from his or her inability to understand yet juxtaposed with being respected as someone who indeed understands. This is where the most evident influence from a changing perception of the child can be found.

Australia and Sweden have chosen different ways to handle the ambivalence around consent. Sweden sets an age

limit, which works to define the age of formal consent (15 years), albeit with the additional statement that also younger children should be asked for consent if they can understand what the research is about. This positioning of children younger than 15 years could well offer Swedish researchers the opportunity to embrace the interpretation of the competent/agentive child cited earlier by academics such as Mayall (2000, 2001), Smith (2002, 2011), and Rinaldi (2001, 2006). Australia instead defines levels of maturity, which in turn sets the conditions for information and consent through the assessment lens of the researcher. This, however, clearly links to the responsibilities of Australia as a signatory to the United Nations Convention on the Rights of the Child. Cock (2006) warns, however, that little discussion has examined how child's competence is measured and assessed by a researcher.

There is also a difference concerning where the main responsibility is placed for ensuring that ethical aspects are dealt with. In Sweden, it is the responsibility of the individual researcher to acquire knowledge about research ethics, to evaluate the risks in his or her own research and to identify when research requires formal ethical review. In Australia, the researcher is also responsible for the ethical sustainability of the research, but as the authorizing body, the researcher's University holds primary responsibility. When these factors are combined, the following picture emerges:

Sweden:	Australia:
- Individual researcher holds main responsibility	- Universities hold main responsibility
- Insufficient support for ethical considerations in formal documents	- Relatively good support for ethical considerations in formal documents
- Low formal review requirements	- High formal review requirements

It is important to discuss the implications of these different situations. For Sweden's part, it could be argued that the lack of a nationally validated ethics document offering guidelines for research (when people are included in the research) is problematic. This is even more so in the absence of guidance directed specifically toward children's participation in research. In combination with the relatively low demands for ethical review of research in Sweden, there is a real danger that ethical awareness among Swedish (child focused) researchers may be low.

When ethical "input" for child research cannot be found in guiding or regulatory documents, and when researchers are not often required to present their reasoning, the ethical considerations made by the researcher may end up with the conclusion that the project is not subject to the Ethics Act and that further ethical reflection therefore is not needed. However, the situation in Sweden may also accommodate some potential. When formal ethical review and management of risks in research does not consume the entire space for ethical reflection, room might be created where ethical considerations include wider moral and ethical aspects (Mortari & Harcourt, 2012).

In Australia, the combination of stronger guidance and comprehensive ethical review works in favor of a heightened ethical awareness and competence of Australian researchers. But the danger is that this awareness and competence can be so strongly directed toward clearing requirements and rules that the possible space and energy for wider reflections of moral and ethical character is consumed. The notion of ethics in the Australian context has been significantly appropriated by a mind-set that adhering to the legal obligations of the research process constitutes ethical behavior. Another very troublesome consequence of the situation in Australia is that the difficulties of gaining ethical approval for research involving children means that research on sensitive issues may not be done (Balen et al., 2006). To avoid lengthy review processes, it is not uncommon for researchers to simplify or alter their initial project ideas, and in some cases where the ethical review process is expected to be too difficult to pass, the project is simply dropped. The apparent anxiety of university ethics committees when children are involved, and thereby the substantial risk of rejection of the ethics application, is therefore problematic. Because of the perceived barriers, important research ideas may be sidelined. For example, if research about children in vulnerable/priority circumstances is constantly rejected, or takes an inordinate amount of time to review, the knowledge about children's lives and situations will be poorer, and society is deprived of knowledge that might be decisive in improving the lives of these children (Sargeant & Harcourt, 2012). In addition, this means that some children are excluded from research and denied space in the production of knowledge.

However, maybe the combination of the high level of ethical awareness and an understanding of the negative consequences of the situation in Australia is a breeding ground for a broader discussion of the meaning of ethical conduct in research. Australian researchers are well represented in the international debate about how research ethics should be reinterpreted in the sense of research practice.

Conclusion

In this article, we have offered an insight into the formal regulation and less formal guidelines that support social science researchers when working with children in our respective countries. While acknowledging there are similar, and divergent, approaches being undertaken across the scientific world, the guardrails that we have discussed pertaining to Australia and Sweden are intended to bring additional clarity to the notion of ethics as research practice, not just as a risk management framing, which we believe could be applied more broadly. As social scientists engage in work *with* children through more innovative and original research projects, there appears potential for positioning children as competent/agentive actors in both formal and informal ethical processes. It is through this possibility that researchers could develop reflexivity and reciprocity when interpreting the

guardrails to ensure ethical integrity is seen as integral and critical across the entire research enterprise.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research and/or authorship of this article.

Notes

1. It is important to notice here that regulation of research ethics may be significantly less present or formalized in some nations.
2. Swedish name of act translated by author.
3. Swedish name of publication translated by author.
4. The quotes from the Swedish Research Council's guidance text (Vetenskapsrådet, 2011) are translated from Swedish by one of the authors of this article.

References

- Allen, G. (2005). Research ethics in a culture of risk. In A. Farrell (Ed.), *Ethical research with children* (pp. 15-26). Maidenhead, UK: Open University Press.
- Australian Government. (2007a). *Australian code for the responsible conduct of research* <https://www.nhmrc.gov.au/guidelines/publications/r39> Retrieved 8 July 2014.
- Australian Government. (2007b). *National statement on ethical conduct in human research* <https://www.nhmrc.gov.au/guidelines/publications/e72> Retrieved 8 July 2014.
- Balen, R., Blyth, E., Calabretto, H., Fraser, C., Horrocks, C., & Manby, M. (2006). Involving children in health and social research: "Human becomings" or active beings? *Childhood, 13*, 29-48.
- Bell, N. (2008). Ethics in child research: Rights, reason and responsibilities. *Children's Geographies, 6*, 7-20.
- Cocks, A. (2006) The ethical maze: Finding an inclusive path towards gaining children's agreement to research participation. *Childhood, 13*(2), 247-266.
- Declaration of Helsinki. (1964/2013). *World Medical Association, latest amendment at the 64th WMA General Assembly*, Fortaleza, Brazil, October 2013.
- Freeman, M. (1998). The sociology of childhood and children's rights. *The International Journal of Children's Rights, 6*, 433-444.
- Graham, A., & Fitzgerald, R. (2010). Children's participation in research: Some possibilities and constraints in the current Australian research environment. *Journal of Sociology, 46*, 133-147.
- Gustafsson, B., Hermerén, G., & Petersson, B. (2005). *Vad är god forskningssed? Synpunkter, riktlinjer och exempel*. Vetenskapsrådets rapportserie.
- Harcourt, D., & Conroy, H. (2011). Informed consent: Processes and procedures seeking research partnerships with young children. In D. Harcourt, B. Perry, & T. Waller (Eds.), *Researching young children's perspectives* (pp. 38-51). Oxon, UK: Routledge.
- Harcourt, D., & Einarsdóttir, J. (2011). Introducing children's perspectives and participation in research. *European Early Childhood Education Research Journal, 19*, 301-307.
- Harcourt, D., & Sargeant, J. (2009). Literature review: Ethical and consent issues in involving children and young people in research. Involving children and young people in research: A compendium of papers and reflections from a Think Tank co-hosted by the Australian Research Alliance for Children and Young People on 11 November 2008 (pp.186-197). Woden: Australian Research Alliance for Children & Youth (ARACY) and the NSW Commission for Children and Young People..
- Hopkins, P., & Bell, N. (2008). Interdisciplinary perspectives: Ethical issues and child research. *Children's Geographies, 6*, 1-6.
- James, A., & James, A. (2004). *Constructing childhood: Theory, policy and social practice*. Hampshire, UK: Palgrave Macmillan.
- Korsell, I. (2010) Etik i utbildningsvetenskap och didaktik – i spänningsfältet mellan barnkockböcker, utbildningspolitik och musikfans. [Ethics in educational research and didactics] <http://www.oru.se/Utbildning/Utbildning-paforskarniva/Forskarskolor1/Forskarskolor/UVD—Utbildningsvetenskap-med-inriktning-mot-didaktik1/Publikationer/> Retrieved 2012-01-03.
- Mayall, B. (2000). The sociology of childhood in relation to children's rights. *The International Journal of Children's Rights, 8*, 243-259.
- Mayall B (2001) The sociology of childhood in relation to children's rights. *International Journal of Children's Rights 8* (3): 243-259.
- Morrow, V. (2008). Ethical dilemmas in research with children and young people about their social environments. *Children's Geographies, 6*, 49-61.
- Mortari, L., & Harcourt, D. (2012). "Living" ethical dilemmas for researchers when researching with children. *International Journal of Early Years Education, 20*, 234-243.
- Moss, P. (2006). Listening to young children: Beyond rights to ethics in Learning and Teaching Scotland. In *Let's talk about listening to children: Towards a shared understanding for early years education in Scotland* Vol. 2, Edinburgh; Learning and Teaching Scotland http://www.ltscotland.org.uk/Images/listeningtochildren_tcm4-324433.pdf Retrieved 8 July 2014).
- Nuremberg Code. (1947) Retrieved from https://www.princeton.edu/~achaney/tmve/wiki100k/docs/Nuremberg_Code.html retrieved 8 July 2014).
- Quennerstedt, A. (2010). Children, but not really humans? Critical reflections on the hampering effect of the "3 p's." *The International Journal of Children's Rights, 18*, 619-635.
- Quennerstedt, A., & Quennerstedt, M. (2014). Researching children's rights in education: Sociology of childhood encountering educational theory. *British Journal of Sociology of Education, 35*, 115-132.
- Rinaldi, C. (2001). A pedagogy of listening: A perspective of listening from Reggio Emilia. *Children in Europe, September, 1*, 2-5.
- Rinaldi, C. (2006). *In dialogue with Reggio Emilia*. London, England: Routledge.
- Sargeant, J., & Harcourt, D. (2012). *Doing ethical research with children*. Maidenhead, UK: Open University Press.
- SFS 2003:460. *Etikprövningslagen* [Ethics Review Act].
- Smith, A. B. (2002). Interpreting and supporting participation rights: Contributions from sociocultural theory. *The International Journal of Children's Rights, 15*, 147-164.
- Smith, A. B. (2011). Respecting children's rights and agency: Theoretical insights into ethical research procedures. In D.

Harcourt, B. Perry, & T. Waller (Eds.), *Researching young children's perspectives* (pp. 11-25). Oxon, UK: Routledge.

United Nations. (1989). *The United Nations convention on the rights of the child*. New York, NY: UNICEF.

Vetenskapsrådet [Swedish Research Council]. (2011). *God Forskningsled* [Sound Research Conduct]. Retrieved from http://www.cm.se/webbshop_vr/pdf/2011_01.pdf

Author Biographies

Deborah Harcourt is Professor of Early Childhood Faculty of Education and Arts at the Australian Catholic University and Visiting Professor at Karlstad University, Sweden.

Ann Quennerstedt is Associate Professor in Education School of Humanities, Education and Social Sciences Örebro University, Sweden