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# Ethics in child research: rights, reason and responsibilities

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This paper explores the nature of the relationship between research ethics and children's rights by examining the historical origins of both concepts and then analysing several contemporary research ethics guidelines from a rights-based perspective. The analysis demonstrates that while many research ethics guidelines may contain references to human rights principles, implicit or otherwise, there is often a lack definition about what is meant by 'rights' and about the correlation between human rights principles and research ethics in practice. Within social sciences research, in particular, research ethics guidelines, including those guidelines specific to child research, noticeably lack direct reference to human rights principles such as those articulated within the UN Convention on the Rights of the Child (UNCRC). The paper argues that as child researchers do not stand apart from their obligations to protect and promote children's rights, research ethics guidelines relied upon by child researchers need to be informed by human rights principles and that those researchers may draw upon the UNCRC, in particular, to inform their consideration of inevitable ethical dilemmas arising within child research.

**Keywords:** children's rights; research ethics; guidelines; human rights principles

## Introduction

*We want a world fit for children, because a world fit for us is a world fit for everyone. (UN Special Session on Children 2002)*

Two delegates aged 13 and 17 years old delivered this message from the Children's Forum to the United Nations General Assembly Special Session on Children in May 2002. It was the first time in United Nations history that young people<sup>1</sup> addressed the General Assembly, making their presentation after a three-day session during which 404 young delegates discussed issues concerning the rights and well-being of children. The UN Special Session on Children, as it was known, focused world attention on societal need to respect the principles of children's human rights, including children's participatory rights in which children are actively involved in decision-making at all levels and in planning, implementing, monitoring and evaluating all matters affecting the rights of the child (UN Special Session on Children 2002).

Among its many objectives, child research<sup>2</sup> informs policy and practice in ways that are intended to improve the lives of children, such as those who want a 'world fit for children', and increasingly child research has endorsed participatory ways of ensuring children's views inform research outcomes. In conducting child research, social researchers have paid growing

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attention to research ethics but whether those same researchers have focused correspondingly upon the rights of children and their inherent relationship with research ethics is questionable. Mishna *et al.* (2004) argue that, surprisingly, the rights of children and ethical practice related to children have been ignored in the social sciences, professional practice, and research literature. In conducting my own child research, which has focused upon exploring the views of young people in residential schools, I relied upon a theoretical underpinning informed by a children's rights discourse and the inherent assumption that children have the right to express their views about matters important to them. As I began to explore the ethical issues arising within my research, however, I found myself wondering about what a rights-based approach to conducting child research entailed and about the relationship of children's rights with inevitable research ethical considerations. In my exploration of this topic, I discovered that it is not always apparent within research ethics guidelines whether such guidelines intend to reflect human rights principles and determined that, at best, there is often a demonstrated ambiguity about the relationship between children's rights and research ethics.

In exploring the relationship between research ethics and children's rights, this discussion paper briefly examines the emergence of human rights principles and research ethics in the latter twentieth century, explicating how their interconnected but sometimes obfuscated relationship exhibited shared principles in their earliest evolution. For purposes of this paper, 'research ethics' is defined as the application of fundamental research principles to child research, regardless of the research focus and whether the research includes participants or not. While research ethics committees exist within university and organisational communities, it is suggested that committee guidelines and requirements do not exonerate researchers from considering the full extent of research ethics arising within their research. Research ethics may exist that fall outside the parameters imposed by such committees, making it necessary for researchers to think about '*researcher ethics*' alongside '*research ethics*' and for the guidelines themselves to reflect their co-dependency.

History informs us that research ethics and human rights principles developed from societal concerns for the welfare of individuals who suffered horrendous injustices exemplified by the treatment of prisoners during World War II. In analysing various research ethics guidelines from the perspective of whether they refer to or reflect human rights principles, this paper illustrates the vast discrepancy among research ethics guidelines that may be relied upon by child researchers. In health-related research ethics guidelines, for example, human rights principles often inform the basic premise upon which the guidelines are based while within the social sciences' research ethics guidelines and, more particularly, guidelines specific to child research, there is a noticeable lack of reference to human rights principles and, in particular, the UN Convention on the Rights of the Child ('UNCRC'). As children's rights exist in the moment when research interests and children's everyday lives intersect, continuing throughout the research process and beyond, this paper argues that it is critical for research ethics guidelines to reflect human rights principles that also incorporate special considerations reflected within children's rights instruments such as the UNCRC.

This paper defines 'human rights' as those rights which cannot be waived or denied; impose obligations; are universal; and 'focus on the inherent dignity and equal worth of all human beings' (Office of the UN High Commission on Human Rights 2006, p. 8).

Human rights are universal legal guarantees protecting individuals and groups against actions and omissions that interfere with fundamental freedoms, entitlements and human dignity. (Office of the UN High Commission on Human Rights 2006, p. 8)

The definition of human rights is enhanced by Ignatieff's (2000, p. 2) argument, adopted for purposes of this paper, that, by working 'their way deep inside our psyches', human rights go beyond legal instruments to situate themselves as '... expressions of our moral identity as a

people'. In this paper, I argue that as an interdependent relationship exists between human rights (such as those reflected in the UNCRC) and research ethics, all research ethics guidelines need to reflect human rights principles in ways that ensure researchers adopt a general rights-based approach to their research and, more specifically, that human rights principles can be relied upon to inform research ethical dilemmas in child research. In making this argument, it is assumed that children have individual and collective rights, which they do not need to be given or to deserve, and that these rights include children's right to express their views about matters affecting their everyday lives – matters such as research topics and the research process itself. By examining the relationship between children's rights and research ethics, therefore, this paper hopes to promote consideration and debate about how the relationship between human rights and research ethics may be developed within child research to ensure that research processes *and* their outcomes are contributors to making 'a world fit for children'.

### **Human rights and research ethics: a historical perspective**

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in the spirit of brotherhood. (Universal Declaration of Human Rights 1948)

In the latter twentieth century, the Universal Declaration of Human Rights (1948) emerged as the pre-eminent international human rights instrument supported by such treaties as the European Convention on Human Rights and Fundamental Freedoms signed in 1950 by the European Council, which had convened in 1948 following the Second World War. Both of these instruments developed in response to the horrific experiences of individuals during the Second World War; these experiences raised ethical issues arising from research experiments conducted in concentration camps, whereby medical researchers, such as doctors, committed atrocities against prisoners of war, including children. United States judges, for example, convicted Nazi concentration-camp physicians of crimes against humanity, which sentencing led to the Nuremberg Code 1947 encapsulating ethical and legal principles, such as the principle of voluntary consent, intended to guide research involving participants. These principles, applying to children and adults, were reflected in subsequent enactments such as the Declaration of Helsinki in 1964.

Medical research is subject to ethical standards that promote respect for all human beings and protect their health and rights. Some research populations are vulnerable and need special protection . . . Special attention is also required for those who cannot give or refuse consent for themselves, for those who may be subject to giving consent under duress, for those who will not benefit personally from the research and for those whom research is combined with care. (The Declaration of Helsinki 1964, Section A.8)

This Declaration illustrates an ongoing commitment, in 1964, to the protection and promotion of human rights through the implementation of research ethics recognising, as well, that special considerations may arise in relation to vulnerable populations, such as children. While the Declaration of Helsinki appears to relate specifically to the medical sciences approach to research, research ethics guidelines were also formulated within disciplines such as anthropology and psychology as early as the 1940s and 1950s. Since that time, research ethics in many disciplines has continued to evolve as a 'modern research ethics', which arose predominantly in the mid 1960s once again influenced by medical research misconduct. As a continuing influence, the Declaration of Helsinki, revised in 1989 and 1996, now refers to children specifically in reference to informed consent and it remains a guide that is applied universally to child and adult participants in research.

### **Children's rights**

At the same time that research ethics became increasingly incorporated into the research agenda advanced by child researchers (see Thomas and O'Kane 1998, Lindsay 2000, Bostock 2002),

international and national human rights instruments continued to develop with worldwide endorsement. Children's rights, reflected in numerous international and domestic legal instruments, are rights that afford special consideration to children on the basis of their unique and vulnerable status. These rights, deemed necessary by the international community because children are often overlooked as 'rights bearers', gained momentum beginning with the UN Declaration of the Rights of the Child (1959) and evolving into a myriad of subsequently enacted instruments such as the UN Declaration on the Promotion among Youth of the Ideals of Peace, Mutual Respect and Understanding between Peoples (1965); the UN Convention on the Rights of the Child (1989); and the UN Declaration on the Survival, Protection and Development of Children (1990). In addition, the European Convention on the Exercise of Children's Rights was adopted by the Council of Europe in 1996 and makes reference to states obligations under the UNCRC.

Freeman (2000, pp. 277–278) places the UNCRC articles within several key areas: general rights (including the right to express one's views and information); protective rights; civil rights; development and welfare rights; and 'special circumstances' rights. Endorsing Freeman's argument that the right of children to express their views in all matters affecting their lives (UNCRC Article 12) is 'perhaps the most important provision in the Convention' (Freeman 2000, p. 288) has notable implications for child research. As researchers increasingly engage children as active research participants in research (see Hopkins and Hill 2006, Ross and Hill 2006), one implication is that researchers acquire an ethical duty to ensure that children have the right to express their views about the research process itself.

Children do have rights. They have the right not just to be sheltered and cared for and protected from abuse, but also to be treated as moral agents in their own right, with intentions, purposes, and visions of the world that we should not presume are identical to our own. (Ignatieff 2000, p. 108)

As children's rights exist in the moment when research interests and children's everyday lives intersect, continuing throughout the research process and beyond, to treat children as 'moral agents in their own right' requires researchers to recognise that children as research participants and as persons affected by research arrive with rights and retain their rights at all times. Researchers, like all adults, must not presume that children share their view of the world or that children pursue a common agenda. The UNCRC intends to ensure that children have participatory involvement in all matters affecting their lives, including research. What remains less obvious is how to ensure that these rights are recognised. Overtly acknowledging the correlation between human rights and research ethics by embedding human rights principles in research ethics guidelines is one way to foster a rights-based approach to child research.

### **Human rights and research ethics: shared principles**

An analysis of earlier developments in human rights and research ethics reveals that certain 'shared principles' exist in key human rights instruments and various statements on research ethics. Some of the key principles that appear within both contexts are: respect for human dignity; informed consent; individual autonomy; equality; privacy and confidentiality; freedom of expression; access to information; and justice. While each principle applies equally to children and adults, it is essential to recognise that principles such as 'freedom of expression' and 'access to information' are also fundamental rights expressed within the UNCRC.

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 child, the views of the child being given due weight in accordance with the age and maturity of the child (UNCRC, Article 12(1)).

The child shall have the right to freedom of expression; this right shall include the 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 (UNCRC, Article 13(1)).

From this standpoint, therefore, it is possible to conclude that current day research ethics guidelines must reflect human rights principles, including those principles articulated in the UNCRC which, as the most widely ratified international human rights instrument, recognizes that children as a vulnerable population must be accorded special consideration. In addressing ethical issues relating to special considerations arising for any vulnerable population, research ethics guidelines can draw from the UNCRC and other human rights instruments to inform their development. It is an essential connection to make in order to ensure that child research protects and promotes children's rights prior, during and beyond the research process. It is questionable, however, whether current day research ethics guidelines and, in particular, those guidelines that child researchers rely upon, adequately reflect human rights principles.

### Current child research context

Throughout the years many academic disciplines – geography, sociology, political science, anthropology, psychology – alongside specialist and multi-disciplinary organizations have formulated their own research ethics guidelines commensurate with the growth in child and adult participation in research. In many jurisdictions, as well, developments in domestic human rights law, arising from international human rights treaty obligations, has evolved – raising awareness about researchers' human rights obligations to all research participants and making litigation concerns a possible factor in developing and improving research ethics guidelines. In addition, the recent years' growth in research participant involvement has paralleled a cross-sector policy agenda to consult with 'service users', which has included involving children in consultation processes designed to inform practice and policy initiatives. In 2006, for example, the Scottish Commissioner for Children and Young People consulted with young people throughout Scotland on their policy priorities for the Commissioner (see <http://www.sccyp.org.uk>).

Multi-disciplinary and multi-sector research ethics guidelines continue to evolve alongside an increasing emphasis on human rights issues and the growing awareness of cultural and socio-economic factors impacting child participation in research processes. It is apparent, however, that there are varied approaches represented within research ethics guidelines as exemplified by the straightforward titling of such guidelines which may be called 'Statement of Ethical Research Practice'; 'Guidelines for Research'; 'Ethical Guidelines for Social Science Research' and so on. The plethora of diverse research ethics guidelines available to child researchers, therefore, requires them to ensure that the guidelines they rely upon for direction adequately protect the human rights of all children directly or indirectly affected by research.

Ethics involving children in general is a complex, ideological, and political process – a factor that may be frequently ignored by research ethics boards, guided by national policies on human research ethics that adhere to a 'one size fits all model' of ethical approval. (Van Hoonard *et al.* 2004 in Maguire 2004)

While it is acknowledged that human rights principles may be reflected within research ethics guidelines, it is suggested that these guidelines must clearly define 'rights' and facilitate a rights-based approach to child research by making specific references to the connection between rights and the consideration of ethical issues arising within the research context. In his close examination of ethical issues arising within child research, Hill (2005) argues that '[a] small number of key principles underpin an ethical approach . . . these principles can be developed and expressed as a set of rights: to self-determination, privacy, dignity, anonymity, confidentiality, fair treatment and protection from discomfort or harm'. It is a specific example of how human rights principles can be incorporated into research ethics guidelines

in ways that are designed to protect and promote children's rights throughout the research process.

In exploring whether rights-based principles are reflected in current day research ethics guidelines, the following sections draw upon examples of British research ethics guidelines, such as those guidelines designed for researchers working within health and social sciences disciplines, and extends to examining research ethics guidelines developed specifically for child research. These sections also examine research ethics guidelines designed for multi-disciplinary contexts that are child and non-child specific and located within an international context.

### **Medical research**

The relationship between human rights and research ethics has its origins in medical research evidenced by the term 'medical ethics', which is sometimes used interchangeably to reflect both concepts. Within recent medical research, researchers in South Africa, for example, faced numerous ethical issues relating to the provision of medical treatment to research participants who became HIV-infected during vaccine trials. The American Association for the Advancement of Science and Physicians for Human Rights (1998), at the request of the South Africa Truth and Reconciliation Commission, published a report illustrating how during apartheid, 'the leadership of the health sector in South Africa subordinated *ethical and human rights obligations* [italics added] to racist practices and political repression of the state' (<http://shr.aas.org/loa/index.htm>). A subsequent report highlights how persons working within a professional context may have a 'dual loyalties', such as their obligation to a patient and their perceived, or real, obligation to third party interests, such as those interests held by a state institution which can, in turn, compromise the protection of patients' human rights (International Dual Loyalty Working Group 2002). While these concerns arose within a medical research context, whereby patients were also research participants, it is possible to draw analogies between the observations made and a social sciences research context in which a researcher, acting in a professional work capacity, also has dual loyalties to the research participants *and* obligations to the organisation employing them, such as a university or children's charity. In the process of honouring their obligations to the organisation, researchers sometimes risk violating the human rights of research participants unless governing research ethics guidelines make clear what human rights obligations exist for researchers and to whom those obligations must be directed.

Morrow and Richards (1996) contend that while medical research guidelines have taken account of medical and behavioural research with children, the everyday tendency of adults to ignore children's views suggests that these challenges may arise in developing research approaches that are fair and respectful toward children. Since 1996, however, there has been an emphasis in child research toward recognising children as competent social actors (see Alderson and Morrow 2004, Hill 2005) and research ethics guidelines within health research are attempting to reflect this shift. In guidelines for the ethical conduct of medical research involving children, McIntosh (2000, p. 177), for example, states that the guidelines are '... written for everyone involved in the planning, review, and conduct of research with children'. Two of the six principles informing the guidelines recognise children as possessing the same entitlements as adult research participants while also highlighting the uniqueness of children that may warrant special consideration.

- (1) Research involving children is important for the benefit of all children and should be supported, encouraged and conducted in an ethical manner.
- (2) Children are not small adults; they have an additional, unique set of interests (McIntosh 2000, p. 177).

While it is possible to interpret these statements as ensuring children's rights, including their participatory rights, are acknowledged, there is no clear statement of entitlement making the relationship between rights and ethics somewhat ambiguous. In a subsequent reference the guidelines state that research with children '... should accord with the *Declaration of Helsinki* in that concern for the interests of the subject must always prevail over those of science and society' (McIntosh 2000, p. 178), a reminder to researchers that medical research is subject to ethical standards that promote respect for all human beings by protecting and promoting the rights of research participants (although the word 'should' risks implying that ethical research with children is discretionary rather than mandatory). For specific guidance relating to the conduct of child research that incorporates direct references to children's rights, however, the researcher must look to other sources such as the UNCRC when considering the second principle that describes children as people with 'an additional, unique set of interests'.

### Social sciences research

Within Britain, established social sciences research ethics guidelines provide direction for research with all research participants although the guidelines may, or may not, contain specific references to children. The Economic and Social Research Council Research Ethics Framework (2005), a guide designed to promote sound ethical practice within social science research, for example, associates child participants with 'vulnerable groups', stipulating that when children are involved in research 'every effort should be made to secure their informed consent' (Section 12.2). The Social Research Association Ethical Guidelines (2003) also refers to children when identifying 'vulnerable populations' although contemporary child researchers who see children as moral agents in their own right may argue that all references to 'subjects' or 'research participants' applies to children, as well, who may be participating in and/or affected by research. While the Statement of Ethical Practice for the British Sociological Association (2002) states that research involving children requires 'special care' it, too, can be interpreted as an overall guideline for conducting ethical research involving all children. If these guidelines are relied upon by child researchers working within a multi-dimensional research arena, however, do these generic guidelines adequately promote and protect of children's rights during the research process?

The relationship between human rights principles, as reflected in international human rights instruments such as the UNCRC, and research ethics guidelines is not always apparent or clearly stated within social science research ethics guidelines. While there is increasing recognition given to the relationship, it is sometimes difficult to determine how 'rights' are defined when the word is used and what theoretical concept informs its use. The Economic and Social Research Council Research Ethics Framework, for example, identifies six key principles of ethical research which include, as a first principle, that '[r]esearch should be designed, reviewed and undertaken to ensure integrity and quality'. In a particular reference to research subjects, the Economic and Social Research Council Research Ethics Framework states that they must be fully informed about the research and possible risks; confidentiality and anonymity must be respected; participation must be voluntary; and harm to research participants must be avoided. The word 'rights' appears under the heading 'Research Ethics Committee'.

Research Ethics Committee is defined as a multidisciplinary, independent, body charged with reviewing research involving human participants to ensure that their dignity, *rights* [emphasis added] and welfare are protected (Economic and Social Research Council Research Ethics Framework, 2003, Section 1).

Research participants have the ... *right* [emphasis added] to refuse to participate or withdraw from the investigation whenever and for whatever reason they wish. (Economic and Social Research Council Research Ethics Framework 2003, Section 3.2.4)



These two statements swing from the general ('to ensure that their . . . rights . . . are protected') to the specific ('. . . right to refuse to participate or withdraw from the investigation') while focusing on participant rights. The general reference to rights, however, is undefined while the specific reference to rights narrows the consideration. So while the guideline recognises research participant rights, those rights are undefined in their broadest sense and, secondly, the implication exists that rights may only apply to research participants. On this basis, it may be extremely difficult for researchers to interpret and implement this section in a manner that respects the rights of *all* persons potentially affected by the research. The placement of the word 'rights' in this section, as well, suggests ambiguity in its interpretation and uncertainty about how to embed 'rights' within the broader research ethics framework.

The Social Research Association Ethical Guidelines (2003) are more explicit in their use of the word 'rights', stating that ethical considerations have become more prominent within research, partly due to legislative changes in human rights and data protection and partly due to growing public concern about the limits of research across all sectors – police, health, social care, business, and so on.

Concern for *individual rights* needs to be *balanced* against the *benefits to society* [emphasis added] that may accrue from research activity. Such ethical conflicts are inevitable. Above all, however, researchers should not automatically assume that their priorities are shared by society in general. (Social Research Association Ethical Guidelines 2003, Level B 1)

Human rights discourse and instruments such as the *Declaration of Helsinki* suggest that the ethical test is not about balancing 'individual rights against benefits to society' as this sentence suggests but rather that concern for the individual participant must always exceed societal concerns. The Social Research Association Ethical Guidelines (2003) approach permits researchers to conclude that their research has such significance to society that their research agenda overrides individual rights, including the rights of children. This paper argues that there is no human rights entitlement to conduct research involving participants, including child subjects, but rather that the research process demands that researchers address and meet the ethical challenge of protecting the human rights of all research participants regardless of the research's perceived, and possible, future benefit to society. Within the Social Research Association Ethical Guidelines (2003), however, there is a heading entitled 'protecting the interests of subjects', which refers to the need to protect research participants from harm (although it omits any reference to non-participants who may also be harmed by research). Within this section, there is a reference to the Human Rights Act 1998.

The [Human Rights] Act [1998] incorporates into UK law rights and freedoms guaranteed by the European Convention on Human Rights. Strictly it applies to action by 'public authorities' so it should not directly affect research conducted by private and independent research organizations – unless such work is being carried out on behalf of a Government department. . . However, in e-mail communication the Human Rights Unit has suggested that the full implications of the Act for social research are as yet unclear and untested. . . (2003, Level B 4.4)

This statement implies a reluctance to embrace the application of human rights principles to research, suggesting that individual human rights exist solely under the Human Rights Act 1998 and that researchers do not have an extended duty to ensure compliance with all human rights principles, including those principles reflected in the UNCRC. It is a statement that may mislead researchers into a false understanding about their duties under international as well as domestic law. Certain domestic law, in particular, may reflect human rights principles in references to the protection of children and minority groups or the prohibition of discriminatory practices – which law is an adjunct to the Human Rights Act 1998. It is incumbent upon child researchers, therefore, to ensure a familiarity with all domestic legislation and international human rights instruments that may apply to a research context and to participant involvement.

The Statement of Ethical Practice for the British Sociological Association (2002) makes clear and explicit statements about 'rights' under the principle heading 'Relations with and Responsibilities towards Research Participants'.

Although sociologists, like other researchers are committed to the advancement of knowledge, that goal does not, of itself, provide an entitlement to override the *rights* [emphasis added] of others. (Statement of Ethical Practice for the British Sociological Association 2002, Section 11)

Sociologists have a responsibility to ensure that the physical, social and psychological well-being of research participants is not adversely affected by the research. They should strive to protect the *rights* [emphasis added] of those they study, their interests, sensitivities and privacy, while recognising the difficulty of balancing potentially conflicting interests. (Statement of Ethical Practice for the British Sociological Association 2002, Section 13)

Research participants should be made aware of their *right* [emphasis added] to refuse participation whenever and for whatever reason they wish. (Statement of Ethical Practice for the British Sociological Association 2002, Section 17)

In contrast to the Social Research Association Ethical Guidelines (2003), the Statement of Ethical Practice for the British Sociological Association (2002)'s Statement of Ethical Practice recognises that the research agenda cannot override individual rights although, again, there is no clear statement about what 'rights' are referred to or what principles underpin, or inform, the use of the word 'rights'. There is a subsequent statement acknowledging that research participants have '... rights in data, recordings and publications' (Statement of Ethical Practice for the British Sociological Association, 2002, Section 4) and that the '... interviewer should inform the interviewee of their rights under any copyright or data protection laws' (Statement of Ethical Practice for the British Sociological Association 2002, Section 4). These references to rights could be enhanced, however, to clarify other rights any persons impacted by research may possess. By stating that researchers 'should' strive to protect research participant rights, as well, the word 'should' falsely implies that protecting rights is discretionary – an oversight that could be rectified by stipulating that researchers 'must' strive to protect human rights. And, as this is a statement of ethical practice to guide researchers conducting child research, it could also include a reference to the UNCRC.

### Children's organisations

Within the United Kingdom, child research is occurring outside the boundaries of the academic community and within larger children's organisations focused upon improving children's lives and contributing to their overall well-being. While many children's organisations have expressed a commitment to UNCRC principles, it appears that larger children's organisations conducting research have not made explicit that commitment in their research ethics guidelines or, alternatively, they have relied upon generic ethical guidelines that do not specifically refer to children's rights. The public information available for one children's organisation, Children's 1st (2005), states that the organisation's overall work is underpinned by the UNCRC and that they have developed a particular set of 'research/consultation guidelines' to supplement the Social Research Association's Ethical Guidelines (2003) adopted by the organisation (<http://www.children1st.org.uk/>). As mentioned earlier, however, the Social Research Association's Ethical Guidelines (2003), which do not specifically mention the UNCRC, state that individual rights must be 'balanced' against societal benefits, which, if adopted as an 'ethical' approach to child research, may result in infringements of children's rights and the researcher's ethical obligations to children. Children 1st's own research guidelines do not specifically refer to children's rights or the UNCRC although some of the UNCRC principles are embedded within the guidelines.

Another children's organisation, Barnardos (2005), undertakes child research and, while it makes no reference on its website to children's rights informing its work, it quotes UNCRC Article 12 and

arguably adopts rights language to describe its work which, in turn, correlate with an ethical approach to child research (<http://www.barnardos.org.uk/>). In its 'statement of ethical research practice', there is no mention of the UNCRC or rights although there is the statement that 'research participants should be made aware of their right to refuse participation whenever and for whatever reason they wish' (<http://www.barnardos.org.uk/>). In contrast to Barnardos and Children 1st, a third children's organisation, National Children's Bureau (2005), endorses the BSA's Statement of Ethical Practice (see above). While the language used by the National Children's Bureau to describe its work also reflects human rights and ethical principles, the organisation's particular reference to rights is stated within its child protection policy, associated with its research guidelines, which policy states that it has adopted and works within the UNCRC (<http://www.nch.org.uk>). In a particular reference to its approach to child research, the National Children's Bureau states that it relies upon the Economic and Social Data Service guidelines on 'legal and ethical issues in interviewing children' and the organisation's research guidelines refer to UNCRC Article 12 (listening to children's views), the Nuremberg Trials and the Declaration of Helsinki (<http://www.ncb.org.uk/>). While there is an overall declaration and apparent intent to adopt a rights approach to its work, the National Children's Bureau research guidelines lack a clear, explicit statement about the relationship between research ethics and children's rights. Such a statement could supplement broader references to rights contained within the Statement of Ethical Practice for the British Sociological Association (2002), research guidelines relied upon by the National Children's Bureau, by making clear what human rights principles might inform ethical considerations arising within child research.

### **Alternative international approaches**

In a response to the growing multi- and inter-disciplinary nature of research, there are examples within the international community of research ethics guidelines that recognise the importance of embedding human rights principles within such guidelines. The examples below examine research ethics guidelines from the United States and Canada that have been developed for the increasing proliferation of multidisciplinary approaches to research, including child research. Once again, it is evident that while the guidelines acknowledge certain human rights, they share common weaknesses in their lack of rights definitions and in neglecting to correlate ethical practice with adherence to human right principles.

#### ***United States: joint medical and social sciences research***

Researchers have been engaged in joint medical and social sciences research that may also fall under the umbrella term 'child research' as it is research impacting the everyday lives of children, such as those affected by HIV and AIDS. The document 'Ethical Approaches to Gathering Information from Children and Adolescents in International Settings: Guidelines and Resources' (Schenk and Williamson 2005), for example, aims to provide practical guidance that will assist researchers, and others, to uphold ethical standards during research with children and to promote discussion of ethical issues when working with diverse populations. It draws parallels between the shared principles of medical ethics and human rights, particularly in relation to children.

Children and adolescents may suffer harm because they have less power and access to resources than adults. Thus, strategies used to gather information among adults cannot typically be used among children and adolescents without additional safeguards. This publication draws attention to commonly accepted principles of medical ethics and human rights as applied to the special needs of young people, and suggest measures that an adult working with children and adolescents must implement to prevent unintentional harm. (Schenk and Williamson 2005, p. iv)

In subsequent statements, this guidance identifies basic ethical principles, which it states are informed by fundamental principles of medical research although it is also clear that they are

principles reflected in human rights instruments such as the UNCRC. Interestingly, however, there is no reference in the document to specific human rights instruments, such as the UNCRC, despite language that parallels key UNCRC principles reflected in Article 3 and Article 12.

... the most important principle is to *always put the best interests of the child first* [emphasis added] by promoting and protecting their well-being ... Another important principle... is the value of *children's participation*... [emphasis added]. They have a right to express their views about decisions affecting their own lives and those of their families or communities. (Schenk and Williamson 2005, p. 2)

The second section in the guidance is entitled 'Children's participation' which appears, in particular, to adopt language from the UNCRC's Article 12 together with UNCRC principles from other key articles.

The principle of children's participation affirms that children and adolescents have the right to express their views in all matters affecting them. It requires that their views be heard and given due weight according to their age and maturity, in accordance with human rights conventions. . .

And:

Giving children and adolescents the maximum opportunity to express their views must be balanced with protecting their best interests and safeguarding them from potential harm by minimizing intrusion. Children and adolescents must have the opportunity to express their opinions without compromising their safety and wellbeing. (Schenk and Williamson 2005, p. 6)

This guidance reflects a strong endorsement of key UNCRC principles relating to children's best interests, protection and participation. The language used is very similar to UNCRC Article 12 and reflects the content of other articles such as UNCRC Article 3. Furthermore, while there is no particular reference to human rights instruments, the document states that investigators, or researchers, must meet legal and ethical standards, which presumably encompasses human rights law and ethical standards incorporating human rights principles. As a guideline intending to reflect the significance of adhering to human principles when conducting child research, it might be clearer to researchers if the guideline made explicit reference to the UNCRC and the more generalised role it can play in informing ethical issues arising within child research.

Another example of a joint medical and social science research ethics code, which does not refer specifically to children, states clearly that an essential underlying principle guiding research is that 'researchers need to respect and protect human rights of all the participants of research' (Jesani and Barai 2005). These guidelines articulate an ethical framework based on four moral, or normative, principles and 10 principles relevant to ethical considerations in social science and health research in India.

Fundamental to understanding and applying ethical principles and guidelines is the concern for and protection of the *human rights* [emphasis added] of the participants. Further, the guidelines formulate *rights* [emphasis added] and responsibilities of the four major actors in research endeavour; the researchers, the institutions, the sponsors and funders, and the gatekeepers. (Jesani and Barai 2005, Introduction)

While it is a guideline that apportions responsibilities and extends rights recognition beyond the research participants to other persons and institutions potentially involved in the research process, naming the four 'major actors' places parameters around whom, or what institutions, may be affected by research when it is not always possible to make those determinations prior to engaging in the research process. Interestingly, this guideline also makes very strong statements about how researchers 'should' view research participants.

Participants should be seen as indispensable and worthy partners in research. Researchers should recognise and ensure that respect, protection and promotion of the rights of participants are made intrinsic to every stage and level of research undertaken by them. (Jesani and Barai 2005, Section IV)

Arguably, this statement could be relevant to any person potentially affected by the research, including those children not directly participating in child research but who may be affected by the research outcome.

While there is no particular reference to children in these guidelines, they are guidelines that offer insight into how research ethics guidelines might employ language that emphasises the relationship between human rights and research ethics with the qualifier that these guidelines, like others, lack a rights definition necessary for informing researchers about how such an approach may have a practical application within everyday research practices. Researchers relying upon these guidelines, as well, must understand that their ethical obligations to individuals may extend beyond the research participants to other persons potentially affected by the research from its inception and beyond. Notably, however, these guidelines do draw attention to the concept of ‘rights and responsibilities’ as held by four major actors, broadening the ethical considerations and recognition of rights that must be into account when conducting research.

### ***Canada: multi-disciplinary research***

In recent years, approaches to research ethics initiatives within Canada have demonstrated a growing awareness of the significant relationship between research ethics and human rights. In Canada, the Medical Research Council of Canada; the Natural Sciences and Engineering Research Council of Canada; and the Social Sciences and Humanities Research Council of Canada joined together to create a ‘Tri-Council Policy Statement’ entitled ‘Ethical Conduct for Research Involving Humans’ (1998). The Tri-Council Policy Statement is based upon the assumption that fundamental ethical principles and issues in research involving participants transcend all disciplines, including the medical and social sciences.

[Ethical norms] reflect shared fundamental values that are expressed in the duties, *rights* [emphasis added], and norms of those involved in research. Research subjects can reasonably expect that their *rights* [emphasis added] shall be equally recognized and respected, regardless of the researcher’s discipline. (Tri-Council Policy Statement, 1998, Section B.2)

Although this statement clearly links human rights and research ethics while appearing to take a broad view of rights, it, too, lacks a clear definition of rights and the human rights principles relied upon. The statement does, however, refer to ‘respect for human dignity’, a fundamental human rights principle, as a moral imperative and identifies it as a guiding ethical principle. In advocating for a subject-centred perspective, the Tri-Council Policy Statement (1998) requires researchers to ensure that the individual participant’s welfare and integrity remain paramount in the conduct of research. The Tri-Council Policy Statement comments that human rights *law* has informed the development of guiding ethical principles within the framework (such as respecting human dignity and vulnerable persons) although it qualifies this observation by noting that while ‘the law tends to compel obedience to behavioural norms . . . [e]thics aim to promote high standards of behaviour through an awareness of values’ (Tri-Council Policy Statement, 1998, Section F), a statement which suggests that ‘*researcher ethics*’ is an adjunct to ‘*research ethics*’.

While the Tri-Council Policy Statement (1998) applies to all children affected by research, it makes a specific reference to children within the guiding ethical principle entitled ‘respect for vulnerable persons’.

Children, institutionalized persons or others who are vulnerable are entitled, on grounds of human dignity, caring, solidarity and fairness, to special protection against abuse, exploitation or discrimination. Ethical obligations to vulnerable individuals in the research enterprise will often translate into special procedures to protect their interests. (Tri-Council Policy Statement, 1998, Section C)

This statement, which reflects certain fundamental human rights principles inherent in the UNCRC and other human rights instruments, emphasises researchers' particular obligations to protect children although it can be argued that it neglects to emphasise the participatory and provision rights of children – rights that also impose obligations on researchers. Overall, however, the Tri-Council Policy Statement (1998) advances awareness about the relationship between human rights and research ethics while also demonstrating how research ethics guidelines can be developed in ways that emphasise that relationship. The guidelines are also an example of how such guidelines can be written for multi-disciplinary approaches to child research designed to take account of the multi-dimensional aspects of children's everyday lives.

## Conclusion

Current literature suggests there is a growing interest in working *with* children in research as active participants '... rather than as faceless objects and voiceless vulnerable victims of research' (Maguire 2004) with researchers increasingly listening to and respecting the contributions that children make to research (see Hopkins and Hill 2006, Ross and Hill 2006). While evidence suggests that current research ethics guidelines relied upon by child researchers are beginning to make reference to children's rights, such as their participatory and protection rights, these references often lack definition and are seldom correlated within the guidelines with ethical research practice. It is perhaps a reflection of how researchers, at times, may see themselves as standing apart from the obligations to respect human rights that are placed upon society at large. Researchers, as possessors of rights, need to see themselves as persons standing alongside *all* individuals within society who must incorporate respect for human rights within their everyday lives. Hill (2005) offers a practical way forward by suggesting that ethical child research can be guided by four commonly identified types of rights embedded in the UNCRC: welfare; protection; provision; and choice and participation. These UNCRC principles, it is suggested, need to be implemented within research processes, guided by research ethics guidelines that reflect essential human rights principles.

The relationship between human rights and research ethics may be developed within child research, therefore, by embedding human rights principles within research ethics guidelines, which, in turn, will promote and encourage a rights-based approach to child research. While it is possible to draw from a range of international human rights principles when contemplating research ethics, the principles reflected in the UNCRC, in particular, is a place to begin in the development of research ethics guidelines and as a way to assist child researchers when determining and contemplating ethical considerations arising in child research. When that approach is taken, we will make certain that researchers and research itself are contributors to making 'a world fit for children'.

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## Notes

1. For purposes of this article, the UN Convention on the Rights of the Child's definition of a 'child' as any person under 18 years of age is adopted. For that reason, 'child', 'children' and 'young people' are terms that may be used interchangeably.
2. Child research is defined as child-centred research that focuses primarily upon improving the well-being of children.

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