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### **Introduction**

A special issue of *Children's Geographies* (2009, 7, 4) examined 'the right to be properly researched' and published examples of social researchers' commendable growing concern with rights and ethics in research with children. The issue included an editorial on 'the right to be properly researched: research with children in a messy, real world' (Beazley et al. 2009), which drew on the UN (1989) Convention on the Rights of the Child (UNCRC). This Viewpoints piece reviews how children's rights in research are also grounded in national laws and other international human rights treaties besides the UNCRC, as well as on agreed research ethics guidelines. I will end by suggesting an alternative approach to children's rights in research.

### **Human rights and rights in research**

Rights are practical remedies for wrongs. They are specific, carefully worded, legal statements that are ultimately enforceable in the courts. Children therefore do not have a right to love or to health, because these goods cannot be willed or enforced. Children and adults have demonstrable rights, such as to 'the highest attainable standard of health' (UN 1989, Article 24), or to protection from violence, injury or abuse (UN 1989, Article 19). Paradoxically, rights are most valuable and necessary if they are violated, because they are claims to precious entitlements and tools for change.

Rights are the most powerful agreed statements, and trump all other claims. English landowners fought for basic freedoms during feudal times to protect themselves, their family and property from arbitrary assault, theft or imprisonment by the monarch (Woodiwiss 2005, Clapham 2007). Enlightenment philosophers expanded physical freedoms into first generation intellectual ones: rights to freedom of information and expression, thought, conscience and religion, association and peaceful assembly and, most of all, rights to privacy and non-interference in the life and affairs of rational autonomous 'Man'. Rights centre on respect for the worth, dignity and integrity of the human body and mind.

These are freedoms and also protections for which oppressed groups have struggled through succeeding centuries. Today they are endorsed for 'everyone' as universal principles open to local interpretations (United Nations 1948; Council of Europe 1950). These treaties were agreed largely in reaction to the 'messy, real world' of the atrocities during the Second World War, and so too was the first international code on research ethics (Nuremberg, 1948), which begins: '1. The voluntary consent of the human subject is absolutely essential', as a crucial protection from harmful and even lethal research (Proctor 1988).

Although the international treaties speak of 'everyone', they include rights to vote, to work and to found a family, which are denied to many children. So does that mean children are anyone or no one? The UNCRC (UN 1989) has benefited children by insisting on their many human rights in 42 articles. However, unfortunate side effects or misuse of the UNCRC have included: to separate concepts of children's rights from human rights; to support child rights advocacy that is largely divorced from men's and women's legal rights; to dilute the foundational autonomy rights into so-called 'participation rights'; and to emphasise provision and protection rights over first generation autonomy rights. Klug (2000) reviews the history of developing rights that has recognised subsequent socio-economic rights in order that basic freedoms can be realised. Alderson (2008) examines how the whole UNCRC applies to 'all members of the human family' (UN 1989, Preamble) from birth. Yet many adults who work and research with children seem to be unaware of how they tend to collapse supposed 'participation' projects into provision and protection processes, while they regard adults as benign agents and children as dependent recipients (Alderson 2010).

Like human rights, the rights of subjects/participants in medical research were mainly originally advanced by lawyers and philosophers, who insisted that medical researchers must be accountable to their subjects and to society. From the 1970s, review by medical research ethics committees slowly and unevenly spread around the world (WMA 1964/2008, US 1977, RCPCH 2000, MRC 2004, Nuffield 2005, WHO n.d.). Medical researchers' original opposition gradually turned into acceptance that ethical standards help to protect not only research subjects, and researchers (from complaint and litigation), but also the good name and credibility of research, and the public support and funding on which research depends. Harmful and lethal research with children, however, still occurs (Sharav 2003, Baughman 2007; Howden 2009).

Having been involved in medical and social research ethics for over 30 years, I have observed how social researchers have clung on to complacent faith in their beneficence for years after most healthcare researchers have acknowledged that research can harm, wrong and mislead people, and requires independent review. However, the past decade has seen rapid progress in the minority world towards routine ethics review of social research. This has been largely initiated by research funders and councils (for example, MRC 2004, Boddy 2010). Three editions of a book on the ethics of social research with children (Alderson 1995, Alderson and Morrow 2004, 2011) have reviewed the extensive literature and traced the gradual transfer of high medical ethics standards into social research, besides noting contributions to ethics from social research. These include: promotion of the active involvement of participants, concern about psychological wrongs and risks of research, and attention to ethics at every stage of research from first plans to final dissemination instead of concentrating mainly on the central data collection stage as healthcare ethics tends to do.

Research ethics is based on recognition that research cannot do good directly although, in future, the findings might benefit others, in the fairly rare event that they are published and implemented. Potential future benefits of research include contributing to knowledge and raising awareness, improving services, policies and practices, and closing or changing services that have been shown to be inadequate.

Numerous reported studies with children have encouraged new respect for children's views, experiences and competencies. During research projects, the data collection stage involves the benefits (data mean given things) being conferred by altruistic donors/participants on to researchers. Although participants might enjoy and gain from taking part in research, this cannot be guaranteed and is not the purpose of research. We do not know how many children feel misunderstood or misrepresented by researchers, embarrassed and intruded upon, or disappointed and angry that promised benefits never appeared, just as we do not know how many children wanted to take part in research but have been prevented by gatekeepers or by lack of opportunity. Informed and freely given consent involves understanding the risks and realities of research, in order to weigh any likely costs or harms to the participant against the hoped-for future benefits of the implemented findings to other children (WMA 2000, discussed in Freeman 2006, Alderson 2007). Benefits may possibly accrue only after young participants are no longer children themselves.

In summary, rights are clear, agreed, specific legal statements; they respect the worth, dignity and integrity of human minds and bodies; they can be powerful protections from harm, and remedies for wrongs.

### **'The right to be properly researched'**

This idea expresses researchers' high aims and ideals. However, the idea raises certain problems. First, the compelling positive phrase 'the right to' misleadingly implies that all children should be able to take part in research, as if it is a basic right, a need like clean water or primary education, of which no child should be deprived. Second, the idea implies that to take part in 'proper' research is always a direct good and benefit to participants, an assumption that is questioned by the evidence reviewed above. Third, the word 'right' implies a clear, specific, agreed, legal claim, whereas the word 'properly' is unclear and neither specific nor agreed, and so could be open to interminable disputes among lawyers and researchers. Fourth, in such disputes, the courts and the mass media invite the advice of expert witnesses - who would be social researchers. So, paradoxically, if 'the right to be properly researched' were taken seriously, the final arbiters would be researchers, and this would transfer power further from children on to researchers. Children are unlikely to be called to define 'properly', whereas ethics codes and human rights treaties provide standards for research, and hold researchers accountable to research participants and society, while avoiding vague terms such as 'properly'.

The recent editorial (Beazley et al. 2009: 372-3) refers to outdated claims from 1996 that researchers' real dilemmas 'sometimes make nonsense of university checklists' and that 'over-formal rules' of the medical model of ethics miss 'ethical dilemmas thrown up by the real and messy world'. This does still happen today though less frequently, and the editorial could refer to the literature since 1996 and the great changes made by ethics committees, funders and sponsors of research, professional associations and researchers themselves over the past 15 years, including standards for international research sponsored from the minority world (from numerous examples, WMA 1964/2000, MRC 2004, Nuffield 2005, WHO n.d).

Beazley et al. (2009: 370) while noting that 'the right to be properly researched' is not in the UNCRC, identify this 'right' mainly with four UNCRC articles, which they loosely paraphrase as: 'the right to provide opinions' (12), freedom of expression

(13); protection from exploitation (36); and ‘the highest possible standards being used in work with children’ (3). The authors do not explain why they have selected these four from 42 Articles and they overlook the extensive literature on related complications.

For example among the complications, Article 12 omits the basic human right to make decisions; children can only influence these. However, UNCRC article 41 respects national laws that exceed the Convention, and in English common law, influential in the 54 British (ex-colonial) Commonwealth countries, including several countries reported in the special issue of *Children’s Geographies*, the Gillick case [1985] does this. Gillick respects the valid consent of legal minors aged under 16 years provided they understand what is involved and have the discretion to make a wise choice in their best interests. Gillick deals with consent to medical treatment, not to research, where the guidance emphasises still greater respect for young children’s refusal (US 1977; RCPCH 2000). English case law on consent to research on children is unclear; there has not been a specific case in court for judges to rule on. Researchers are therefore advised to be cautious and to respect the consent or refusal of both children and their parents (see Alderson and Morrow 2011, Alderson 2007, in press 2012b for a review). The law and ethics of minors’ consent to research have been debated in England from Nicholson (1986) through to the lawyer Hazel Biggs (2009). Biggs is deeply concerned that new European and English statute law (EC 2001/2004) override children’s informed consent to medical research, reducing it into the meaningless concept of ‘assent’. This law now applies to clinical trials research on children throughout Europe and, in Britain, to all kinds of research with children that is reviewed by the healthcare research ethics committees (NRES 2009). The age at which minors can give legally valid consent to research varies between different countries, so that researchers need to check their national standards. However, the law is meant to prevent poor practice, whereas ethics is about aiming for high standards. Researchers can respect the views of children at any age, but they may have to involve parents too as a legal safeguard. Article 13 is not only about children giving information (to researchers) as the editorial discusses. It includes children’s ‘freedom to seek, receive and impart information’, in other words to be informed by the researchers before consent is considered, which is not mentioned in that part of the editorial.

Article 3’s actual wording is ‘standards established by competent authorities’ and this could include research-based evidence, which would support research with children. Article 3 connects to Articles 24, 26-29, 31. However the key right in article 3 (omitted in the editorial) is that ‘the best interests of the child shall be a primary consideration’. This has led to long debates (since Nuremberg 1948, US President’s Commission 1977; Nicholson 1985, RCPCH 2000, onwards) as to whether research must not be conducted with children because it can never be *in* the child participant’s best interests, or research is permissible because it is not necessarily *against* the interests of the child.

Article 36, which vetoes exploitation, is important, but so too are other articles in the indivisible UNCRC: non-discrimination (2); parental guidance and children’s evolving capacities (5, 18); autonomy rights (14-17) especially the central right to privacy and to protection from interference and unlawful attacks on the child’s honour and reputation (16), a serious risk in some social research; also children’s rights of

access to a diversity of national and international sources through the mass media (17). This connects with information given to participants before, during and after each project and also to respectful publication of the research findings and recommendations in the professional and mass media. Then there is protection from abuse and neglect (19), extra respect and protection for specific groups (20-23, 25, 30,32-36, 38-40), including those in the juvenile justice system, which links to the extensive literature on the abuse of prisoners in research. Lawyers believe that freedom from torture or other cruel, inhuman or degrading treatment is the most essential right (37), and one that is vital for researchers to remember given the history of research noted above.

The editorial is limited by its concentration on the UNCRC. Although it enshrines many central rights in research, the Convention does not mention research or the key human right in ethical research: freedom to give or withhold consent. The editorial overlooks the extensive literature on consent in child- and adult-related law, philosophy, ethics, politics, sociology, psychology, medicine, nursing, social work and policy, besides the changing professional, national and international guidance, which could be cited to strengthen and clarify the authors' arguments.

The editorial stretches Article 12, rather beyond its meaning, into advocating rights to participatory research, conducted at every stage by children. Methods of participatory research with children (for example, Boyden and Ennew 1997) have immensely increased international research with children, which has brought new understanding of their impressive range of views and experiences, values and competencies. Participatory research does, however, raise questions, which have been extensively although not completely discussed and resolved, for example in *Children's Geographies*. Despite important, respectful, emancipatory research with disadvantaged groups, is it possible to involve all groups in such research? Do they all have the capacity, time, resources and inclination to join in? Are those who do not, then unfairly at risk of further disadvantage? How can matters be agreed about time, payment, extra costs, training and status within research teams that include untrained children or adults? Given the choice, would disadvantaged children prefer to spend the funds on other matters than research? If anyone can do research with similar competence, what is the point of studying for years to become a postdoctoral researcher? Are child-centred researchers too keen to set all processes at a level that young people aged from 12 or 10 or 8 years can understand and perform? If so, are researchers subtracting vital matters from their work, for example, the abilities to develop deeper new insights through sustained theoretical analysis, to synthesise systematic reviews, or to conduct statistical analyses, beyond collating data and describing events?

Informed consent is defined towards the end of the editorial, in terms of explaining to potential participants: the purpose, methods, research agents, 'how the information will be used and by whom. They need to be assured that the information will be confidential and that it will not be possible for people unconnected with the research to identify them' (Beazley at al. 2009:373). However, research data are collected to be published, not to be confidential, and although anonymity can be carefully respected, it is often vital to conceal identities from people *connected* with the research (parents, friends, teachers) as well as those who are *unconnected* with it. Rights to refuse and to withdraw are mentioned, but details about risks and harms,

which crucially inform potential participants' consent or refusal, are omitted. Teachers and caretakers are described as giving consent, although they can only control access and have no legal power to consent to research on other people's children. Risks of stigma are mentioned, when researchers select disadvantaged groups. These risks can partly be resolved ethically and scientifically by more inclusive research that involves 'normal' children as comparisons to establish realistic local norms, as the authors recommend. The authors propose that research outside academic institutions is 'usually orientated towards children's rights' although most research with children is conducted by commercial companies, concerned with marketing rather than with rights. The editorial concludes: 'the real questions for fulfilling children's rights in research concern how you ask the questions (and whose questions), how well you collect the data, and how well you do the analysis' (Beazley et al. 2009:376). However, these are all questions about researchers' agency and methods and efficiency, not about ethics or child rights, and the questions do not necessarily challenge oppressive or exploitative approaches.

### **Rights respecting research**

In conclusion, I suggest that rights respecting research depends on several resources: understanding of the nature and history of rights, their origins in resistance to oppression and the 'adult' as well as the childhood literature; knowledge of research ethics, the relevant law and national and international guidelines and treaties; researchers' keen awareness of potential harms and limitations of their work and of how their views and values may differ from those of participants. The editorial authors very much support young participants' agency, but they present a one-sided theme of beneficent expert researchers providing children with opportunities to take part in research, instead of examining deeper historical concerns. These concerns include how to define, respect and promote the rights and informed autonomy of participants at every stage of research, through to the potential influence on policy and practice, and on professional and public opinion, which affect children's daily lives. If the authors had followed their own advice and involved young people as co-authors, including individuals who felt harmed as well as those who felt benefitted by research, they could have presented a more balanced multi-sided account of rights respecting research.

The editorial concentrates on research methods, though it briefly notes some uncertainty over whether research theories are constructed or discovered, grounded, inductive or deductive. 'The researcher is not the knower of truth but rather the recorder and interpreter of multiple "other" social subjectivities' (Beazley et al. 2009:369). This view opens up a central contradiction in the editorial and in childhood studies. If there is no truth and only multiple subjectivities, how can researchers avoid relativism? How can they respect universal principles of human rights, justice, equality, altruism and avoiding harm? If the data are reduced to "other" social subjectivities' what relevance can the research reports and possible recommendations have to people who might read and learn from and apply them? Such contradictions perhaps underlie the unease expressed by geographers about their subspecialty (Horton and Kraftle 2006, Jones 2008, Colls and Hörschelmann 2009, Skelton 2008). Perhaps critical analysis of current contradictory theories in childhood studies, to map new areas between the extremes of relativist social constructionism and naive positivism, is needed in order to develop new approaches to rights respecting research with children (Alderson in press 2012a, in press 2013).

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