Ethical review

# Ethical review and reflexivity in research of children's sexuality.

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## Ethical review and reflexivity in research of children's sexuality.

Research in the area of children's sexuality is largely based on observational and retrospective studies. Childhood studies literature increasingly calls upon the inclusion of children's voices, yet with sensitive topics ethical positions often close research possibilities in the territories of children's worlds. Children are perceived as a vulnerable group, especially when the investigation focuses on their sexual development and activity – and that this research area is too sensitive and potentially harmful to children. Within the context of beginning a qualitative study on children's sexuality in New Zealand (including interviews with children), this paper reviews a number of studies of childhood research. These studies provide a glimpse at how research focusing on children has been conducted, and explores ethical issues arising in such research. The significance of researcher reflexivity is acknowledged for ethical research practice. The paper concludes that in research on children's sexuality a process of ethical review is limited, and that researcher competence in sensitive investigations is required. Among other difficulties for this researcher (with a professional background in child and family therapy) is the vulnerability of being a man choosing to research children.

**Keywords:** child sexuality; research ethics; reflexivity; sensitive topics

This paper explores the work of selected authors about their research of children's lives and worlds, and the effects of that research for those involved – including the researcher. These ideas are explored in the light of studying children's sexuality, and the ethical implications of such sensitive research.

Ethical review of qualitative research offers possibilities for researchers to engage in a reflexive process. I support a sense of ethics permeating the total process of the research, and not simply ticking a box on a checklist. The process of ethical review should not be, and is not simply one delegated to a committee. It is a way of thinking to be part of the research ideas from germination through development of the proposal, including review by ethics committee, but it neither begins nor ends there. The committee's sign off is simply for the explanation of the process *at that point in time*. These ideas are developed in this paper, with particular focus on a current research project: exploring discourses on children's sexuality in New Zealand, which is to include interviews with children<sup>1</sup>.

This article reports about a reflexive process for researchers - including dialogues on ethics: with the self; professional practice as a therapist; an ethics committee; and the literature. After reviewing three studies of research with children I give a brief introduction to the project I am undertaking and how reflexivity permeates the research and ethical review processes.

#### Why engage in research with children

<sup>&</sup>lt;sup>1</sup> "Why on earth are you researching children's sexuality? Where does that come from?" Questions like these are asked of me often with a tone of suspicion about my motives and intentions. Other researchers have also had questions like these asked of them (see Sikes 2010). This area of study comes from clinical practice as a family therapist, in which many families were referred because of a child's "sexual behaviour", usually with other children. The therapy work with sexuality "issues" for children and young people sometimes responded to a child's actions that were abusive. However, I became increasingly concerned about reactive *abuse* by adults: the parents, teachers, therapists (counsellors, social workers and psychologists) who judged, labelled, disciplined and totalised these children with identities and stories of limitation. These children were aged 8-12 years, and were often ascribed adult identities of "toucher", "sex offender", and "molester", limiting their social relationships and embodied lives.

Research with children is necessary. Regardless of the sensitivity or the nature of the research topic, research that is focused on children should not be avoided or shut down because of its difficulty or charged environment. Children's sexuality is one such area because of how this speaks to understandings of sexuality generally.

When exploring some of the sexuality research involving children, there is a clear distinction between literature that researches *about* children as distinct from that which is research *of* children. Lucia O'Sullivan (2003) records a range of studies on childhood sexuality, and that the concerns:

...often center on beliefs that involving children in studies of sexual behaviour will cause distress or spur sexual curiosity and experimentation. ...there is no obvious empirical evidence to support these concerns. Instead, researchers tend to limit their inquiry to more socially condoned topics of sexual science, such as variations in pubertal development..., child sexual abuse..., or the development of "problem behaviours"... These studies frequently employ clinic populations, or describe atypical experiences or outcomes, and as such, they may ultimately serve to perpetuate the perspective that children's sexual behaviour is essentially aberrant (O'Sullivan 2003, 23).

O'Sullivan then decries the record of Institutional Review Boards (IRBs), also known elsewhere as research ethics committees. She cites one study where "...proposals addressing "socially sensitive topics," such as child sexuality, were twice as likely to be rejected by institutional review boards as those involving less sensitive topics (Ceci, Peters, & Plotkin, 1985)" (O'Sullivan 2003, 23). In another study "IRB decisions...were based more on institutional risk aversion or precedent than a consistent assessment of participants risk or level of adherence to a standard of protection (Rogers *et al.*, 1999)" (O'Sullivan 2003, 23).

Further to this, the late Bill Friedrich wrote about moving to work at the Mayo Clinic, and being faced with a new institutional review board.

The topic of sexual behaviour was viewed as quite sensitive, and my proposal to obtain a large normative sample with the revised, 35-item Child Sexual Behavior Inventory required fairly constant shepherding through the IRB. I was required to keep an account of complaints received, and was asked to stop the study in response to any major protest (Friedrich 2003, 110).

Friedrich received four 'mild' complaints from the 1,231 'subjects' who were approached.

This result is indicative of a wider issue for the processes of ethical review for both researchers and reviewers involved. It is clear that institutional ethical review processes should focus more on researcher capability and experience, assessing their competency to engage in sensitive research. Such an accountability of the researcher, particularly by the researcher in the first instance, is more productive than a blanket caution related to risk aversion or perceived notions of participant protection. While questions about a project's value and usefulness must be considered together with design and methodological rigor, a researcher's account of their understanding, experience and ideas of responding to ethical issues within the process of sensitive research will provide a much more robust rationale for approving or declining such research projects. Any anxiety and fear the committee may have due to 'risk' can then be productively located in the researcher relationship and process, and not the research question or topic.

Emma Uprichard (2010) proposes that many of the issues considered in childhood research are really issues that affect all research: ideas of exploitation and vulnerability, for example. She claims

On the [one] hand, we need to involve children in social research that goes beyond childhood experiences precisely because they may be able to tell us something about the social world and how it works. On the other hand, we need to maintain good ethical practice such that children are involved in social research only if it is viable and worthwhile for them to be included in the overall research sample of any particular study. The paradox, of course, is that we cannot know beforehand whether what children say about the social world will necessarily help us to learn more about it. However, this is a paradox that researchers must necessarily wrestle with in *all* research, not just in research with children. Therefore, excluding children for this reason alone raises ethical issues in itself, since the counter implications of doing so suggest that there are no ethical considerations in sampling adult participants or that only child participants are viewed as 'vulnerable' participants, both of which are wrong (Uprichard 2010, 9-10).

Uprichard strongly challenges the idea of limiting research with children that "tends to focus on areas of social life that are predominantly child-centred", that is, the "accumulation of knowledge about children's life-worlds". She calls on including children in "research that explores children's views in order to contribute to fields other than 'childhood'" (2010, 6).

Furthermore, Uprichard calls on the work of Mayall (2002, cited in Uprichard 2010) who speaks of the 'relational processes' of the 'generational approach' – i.e. "that children are *necessarily* involved in constructing childhood, which itself is in turn also relationally constructed through other structural categories (e.g. 'adulthood', 'parenthood' etc.)" (p.4). So while children and their cultures are imbedded in social systems and practices, they are not outside of the wider social systems and practices that adults may perceive as adult business, and take up a position where children are overlooked and not taken into account. Uprichard is but one of many researchers who explore, describe and encourage

understandings of children, the constructions of childhood, and children's positioning or positionality within research. Children should not be excluded from research of sensitive topics simply because they are children.

Sexuality research with children is an important area for study. My focus will be narratives about children's sexuality. These narratives will tell not only of 'children's lifeworlds', but speak to broader ideas and contexts of sexuality that adults very often choose to ignore or assume are not possible, permissible, or question as abnormal or perverted.

If complex, difficult and sensitive, possibly highly emotional and politically thorny research with children should occur, what ethical concerns are to be considered?

#### Ethical research and ethical review of research with children

Ethics is now seen as a *practice* which bridges the gap between anticipation and reflection... In this sense our qualitative research can be ethical right through the research (Parker 2005, 19).

Each of us in our own professions will identify with specific codes of ethics or codes of practice. My own counselling professional association includes a section related to research within the code of ethics (NZAC 2002, Section 11), and my academic institution also has its own regulations regarding ethical conduct in human research and related activities (University of Waikato 2008). These also inform my ideas about my work, and form something of the body of ethics knowledge that accompanies me.

It is useful to survey the experiences of researchers and the pragmatics of ethics when engaging in research focused on children.

John Horton (2008) has written about a 'sense of failure'. Horton is forthright about "the realisation that the 'excess' and 'messiness' of (too-easily and too-often overlooked) everyday events, geographies and experiences ought to have far-reaching conceptual and methodological implications" (2008, 363). He writes about the reality of research situations with children: the comments they make; the questions they ask; the accusations that can fly – all in the face of a well designed methodology that has had rigorous ethical review. Horton reflects that the literature on ethical complexities of research with children "...is a succession of attempts to come to terms with uncertainties, anxieties and the possibility of 'failure' in/of research" (2008, 364).

Identifying the vast literature on ethics, Horton refers to a 'guidelines mentality' that is often reduced to the idea of 'Good Practice' – "in the form of a checklist, code of conduct or contract of obligations" (2008, 366). Guillemin and Gillam (2004) refer to practices around these sources as procedural ethics – attending to the processes of ethical review of an application, its design and methodology. Procedural ethics then, attends to what Horton outlines as 'Good Practice', consisting of five key sets of obligations, namely that research must be: legal; consensual; confidential; respectful; and demonstrably pay attention to these four obligations.

Horton also speaks of researchers who foster an 'ethic of care', and "Therefore ethics, and the need to act ethically, becomes recast as a *personal, everyday, ever-present* responsibility which we cannot 'get out of' by recourse to some higher notion of Research Ethics" (2008, 367). Perhaps the distinction made by Guillemin and Gillam (2004) between procedural ethics and "ethics in practice" can be useful here. Guillemin and Gillam's "ethics in practice" connects with Horton's 'ethic of care' – and each of these suggest 'reflexivity' in research:

Although reflexivity is a familiar concept in the qualitative tradition, we suggest that it has not previously been seen as an *ethical* notion. We propose that reflexivity is a helpful conceptual tool for understanding both the nature of ethics in qualitative research and how ethical practice in research can be achieved (Guillemin & Gillam 2004, 262-263).

In qualitative research with children ethics must necessarily be viewed and engaged with as a process from the genesis of a research idea, ongoing as a continual reflexive practice until its completion in written report and presentation forms. Research with children connects with the everydayness and messiness of human relational activity - a real and human engagement. When consideration of 'ethics' is limited or reduced to procedural tasks (the recruitment of participants, generation and collection of data, analysis and report) then a sense of a 'relational process' is kept at bay.

...we argue that there is considerable continuity between ethical concerns at the procedural and practical levels and moreover, there would be something drastically wrong if this were not the case. ... we suggest that at the level of "ethics in practice," the "homegrown" notion of reflexivity actually encapsulates and extends the concerns of procedural ethics. When the responsibility for ethical conduct falls, as it must, on the researcher and not on the research ethics committee, there is still a framework for thinking about ethical conduct that is not utterly divorced from procedural ethics and yet is already integral to the good practice of qualitative research (Guillemin and Gillam 2004, 269).

Lovisa Skånfors (2009) speaks of ethnography researchers needing to use "'ethical radar' in order to distinguish *children's* ways of expressing acceptance and withdrawal". As with Horton, Skånfors acknowledges that ethical problems can surface while actually doing the research with children and encourages documenting and discussing these ethical

challenges to learn to minimise occasions that could immediately violate the rights of the child.

How can ideas of 'ethical radar', 'ethics in practice' and 'a *personal, everyday, ever- present* responsibility' be encouraged for consideration by researchers? And can ethics
committees contribute to such reflexivity within research projects? I believe that any ethical
review process should support researcher reflexivity in both its own processes (including the
procedural documents that are required, e.g. the application) as well as in its relationship with
the researcher (whether via paper or e-communications). In other words, ethical review
committees or boards should themselves be reflexive in their working with researchers.

### Examples of childhood sexuality research – and questions of ethics

Two different approaches to research about the sensitive area of children's sexuality are now presented: each using different designs and methodologies. Each is explored for the possibilities for ethical issues arising that were not considered during formal review.

#### Research interviews with children about sexual behaviour

O'Sullivan (2003) describes a study of 98 boys aged 7-13 who completed interviewer-administered questionnaires about gender, heterosexual experience, and AIDS (O'Sullivan, et al. 2000, cited in O'Sullivan 2003). The interviewers noticed lengthy pauses from the boys when asked about sexual knowledge, although they were assured no repercussions would follow from their answers. Their reluctance was reported as a lack of information and a lack of vocabulary for the sexual anatomy. O'Sullivan writes that "a number of techniques were used to facilitate boys' responses in this study" (2003, 25). These included: the boys were told they could say anything without repercussion; all responses were kept confidential,

stressing that nothing would be reported to their mothers; interviewers acknowledged the boys' difficulty, explaining that other boys had overcome this difficulty in answering questions; sometimes boys were instructed to write or draw the word rather than say it aloud, spell the word instead of saying it, or whisper the word into a tape recorder after the interviewer left the room; and boys were rewarded for their cooperation with candy and access to games throughout the interview.

#### O'Sullivan reports that

...almost all the boys reported feeling positively about their participation in the study despite obvious discomfort in talking about sexual matters. In particular, they reported liking the rewards that they received for participation and interacting with the staff (2003, 25).

The boys who expressed some dislike or discomfort focussed on both the sex questions and the length of duration of the study. The majority of boys indicated they would be willing to participate again, while only one indicated reluctance due to the sex questions. Others expressed reluctance due to the duration of the interview. It is reported that "no strong adverse emotional reactions were noted", "no need for on-the-spot counseling for emotional problems", and no "interview-related referrals to mental health services". None of the mothers made contact about any adverse reactions. A finding was that "we do not have any reason to assume that the sex knowledge interview exposes children to significant emotional risk" (2003, 25).

When reading of this study I held questions and concerns related to ideas of 'coercion'. While researchers may present a design that includes 'child-centred' and child-friendly approaches, to what degree could these enact relations of power between researcher-child(ren) that unethically 'draws forth' responses by using lengthy periods of time, a range

of 'fun' rewards, and an outcome of relief – something akin to 'you can leave when we've finished!'? The child's consent does not appear relevant here, perhaps because his mother has consented for him.

O'Sullivan then proceeds to explore research that uses direct methods of assessment, as distinct from indirect methods (retrospective reports from adults and adolescents; surveys of parents). She claims:

Researchers need to be creative in their direct approach to the study of child sexual behaviour. Questions must be age-appropriate, in language familiar to the children, and tailored in ways that are most likely to facilitate children's disclosure (2003, 27).

O'Sullivan encourages piloting of measures for acceptability, interpretability and appropriateness. "Incentives should be chosen that children like and can understand" (2003, 27).

Little is known about the best means of asking sensitive questions of children, or about the impact of the data collection mode, question formats, or contexts. Moreover, there is little information available about the types of protocols that have worked best with children... (2003, 28).

I think this last point of O'Sullivan's is her most useful – the development of a protocol specifically for this kind of research. However, there are concerns for much of how this research was conducted. Particular questions for me include (this is not an exhaustive list): what a researcher would do in response to a disclosure of abuse (whether aggressive, sexual or emotional); or how researchers might explain to a mother their boy's 'emotional reaction or problem' given the blanket confidentiality promised; or how long would a researcher 'wait' if a boy chose not to speak, whisper, write or draw a response; and what effect do researchers think that 'incentives' have on the quality of the data? My hope is that a current

ethical review of this research would have questioned the possibilities for coercion and invited the researchers to consider other possible alternatives.

The next study develops a sense of children as having a role of authority within the research – both as participant sharing information, but also, and especially, as an agentic participant with ability to dissent.

#### Research with children who have been sexually abused

Mudaly and Goddard (2006, 2009) write about research with children who have been sexually abused, and their paper intends to contribute to "an emerging tendency to report on how ethical dilemmas encountered in research are addressed" (2009, 262). They identified two ethical dilemmas to address in their research: children's welfare and children's rights.

De Luca (2004/2006) notes that dissonance frequently occurs between ideals of child rights and actual practices of consent, particularly as children's research debates occur about child welfare and protection, and in relation to children's rights and agency. Mudaly and Goddard identified critical ethical questions for their research, such as: The possibility of retraumatising children involved in the research who had been abused; Balancing meeting research objectives with these children's particular vulnerabilities; Questioning the rights of children who have been abused to provide informed and voluntary consent; How much information about the study and about child abuse should be provided for these children to decide about their participation; And these children's rights to confidentiality when concerns about their protection and safety arise (Mudaly & Goddard 2009, 265).

They believe that particular issues must be considered carefully in any research on child abuse that involves children who have been abused, namely: Reflecting on the ethical issues as essential to the research design since ethical issues can arise at any stage of the research process; Setting clear criteria about safety for sample selection; That child centred

techniques are utilised throughout the research; Utilising a scientifically sound research design and qualified researchers who are careful and reflective about methodological issues; Utilising ethical principles (in the absence of guidelines to conduct research with children who have been abused) such as veracity (re autonomy, limitations to confidentiality), fidelity and justice; And a full moral analysis by the researcher explaining and justifying the researcher's choices throughout the research (2009, 276-277).

When considering what could be done differently, they suggest:

- The development of a research protocol which "should specify the research approach, the reason for the research, the possible impact on children, how consent will be sought, how the data will be used, how children will benefit from the research, and how confidentiality and child protection issues will be handled"
- Dissenting process practising with children how to dissent, "to empower them to be able to dissent" and possibly addressing "vulnerabilities and ... susceptibility to coercion and manipulation"
- Participant information Child-friendly techniques to convey information on the
  research: newsletters with "photos of the researchers and their expertise to conduct the
  research ... the use of drawings, spidergrams, speech bubbles, large print".
- Where a child's counsellor approves of the research whether "the child could feel coerced to consent" due to their counsellor's approval.
- Planning for researchers to debrief the effects for researchers "of listening to sensitive and emotionally distressing information" repeatedly, such as the interview, transcriptions, analysing, coding, writing up and disseminating results (2009, 277-278).

Mudaly and Goddard's work is pioneering in its developing attention to the care and sensitivity of 'in-the-moment' ethics in research with children. The emphasis on 'exposing' to child participants (and almost encouraging through practising) a dissenting process, and the innovation in this area of a research protocol, both contribute to ensuring the children's sexuality research can be more ethical, safe and useful.

I now examine how these ideas for research with children on sensitive topics sit alongside my research, and how this has been shaped by my own clinical practice and ethics in practice.

### Locating my research with children (my epistemological framework)

Over the past 15 years I have practiced professionally as a counsellor, in family therapy and counselling supervision. My theoretical approach has been informed by ideas of narrative therapy, developed by the late Michael White of Adelaide, South Australia and David Epston of Auckland, NZ (White and Epston 1990). These two men (David from an anthropology background, and Michael from mental health social work) met and connected over their ideas of working with clients – ideas that drew enormous variance of thinking and practice from mainstream and systemic family therapies. Their major concerns in the work with clients were the ethics of the relationship and the ethics of the process of therapy. Their ideas were informed by (among others) Foucault's writings about discourse, power/knowledge, and the relations of power. Also connected to their thinking and practice was the notion of 'Just Therapy' developed by the Family Centre of Lower Hutt, New Zealand. This approach specifically names the social and economic contexts of problems, and works towards a therapy that attends to the discourses of power within culture and gender (Waldegrave, et al. 2003).

The ethics of the therapy process relates to the work engaged: that therapy is a political action, located within socio-cultural contexts, and necessarily attentive to discourse, positioning, agency and deconstruction. Any assessment within this process focuses on assessing and pathologising the problem – not the person (White 2007).

These ethical positions are shaped within narrative approaches to therapy, where a client may come with a problem dominated story (Monk, et al. 1997). This story usually takes on a life of its own that attempts to totalise the identity of the client. Narrative approaches to therapy invite clients to tell this story, describe the effects of the problem, and tell of their responses to the problem in their life. However, within the storying of the problem's life, the client invariably shares pieces or snippets of information through which submerged or hidden stories come to light that speak of different experience, different identities, different skills and relationships where the problem has not had traction or where its influence has been minimised or shrunken. This process is what David Epston calls 'coresearch' (Epston 1999).

Together with the client a narrative therapist then *co-authors* narratives that tell other 'true' stories about the client that are in contradistinction to the dominant problem story, according to the client's expertise about their own life and what others know of these 'alternative' storylines. These preferred stories are shared with an audience that is significant to the client, evidenced often with documents or recordings. Frequently for children this audience may be a parent or caregiver, a teacher, or perhaps a psychologist or police officer. Rather than be identified by a singular, problem saturated story, the child can be known more fully through the range of stories that construct their life – and not just one.

So the stories that I have heard children tell about their lives, affected by labels of "engaging in inappropriate sexual behaviour", or "sex offender", or "toucher" have opened

opportunities for alternative stories of care and respect, fun and playfulness, alongside responsibility and accountability (Flanagan 2010a). These alternative stories speak of the child's action (sexual activity) as intentionally different and relational in contrast to the 'adult' stories of the child as deviant or criminal.

I am particularly interested in the discourses of childhood(s), sexuality, gender, culture and class: and how children's identities are shaped and positioned through parenting, education, social and psychological services, and the media - and specifically how children's identities are too easily constructed as 'sex offenders' (Flanagan 2010b, 2010c).

Definitions and meanings about the language used in research on children's sexuality are problematic. The Australian Childhood Foundation's literature review 'Children who engage in problem sexual behaviours: Context, characteristics and treatment' (Staiger 2005) noted that the literature on children's sexuality has three limitations: its conceptualisation of sexuality; a definition of normal sexual development is difficult because children's sexuality is not considered in a wider, social and cultural context; and that there is a dearth of research about children's understandings of sexuality and how these are shaped.

While attending to each of these ideas in part, it is the last limitation that I hope my research can specifically respond to.

What does this have to do with ethics approval for child research?

I recognise that as I plan and engage in research that my role is one of researcher, not therapist – but the knowledges and skills of my therapeutic practice will shape, enhance and check my research identity and practice.

From a perspective as a therapist where a reflexive stance is crucial to my work (ethically and politically), I value the idea of researcher reflexivity in qualitative research. To

me, this is not only within an application to a committee, but more importantly when engaging in the research process and interviews with children themselves.

Additionally, a particular vulnerability for me is that of being a man choosing to research children, and specifically children's sexuality. Many men experience discomfort and social unease about working with children. The teaching profession particularly is one where many men leave because of fear of how their gender is regarded in the work with children. Societal discourses around men and children are fuelled by stereotypical notions of (strange) men as potential child sexual abusers (Hodgetts and Rua 2008). There is currently an environment in which my research must necessarily work 'harder' toward ensuring safety and presenting a risk-free rationale.

The research intention originates from within my clinical practice and is located in my concern of the effects for children being ascribed totalising identities based on a sexual event in their lives. My hope is that the research will have effects for understanding children's embodied lives, expressions and meanings – so that policies and practices can be better shaped to improve responses for children and families who are referred to support services. I hope that this work could speak directly to practitioners in education, social services, and the psy-professions (counselling/therapy included).

#### Conclusion

This paper has brought together issues of ethics in children's research from studies about children's geography, child sexual abuse and child sexual behaviour. Ethical issues have been explored with particular focus on notions of sensitivity and risk. This paper invites a number of questions for ethics committees. How can ethical review processes encourage

and enhance researcher accountability to mitigate risk in sensitive projects? Should ethical review include and stimulate the idea of reflexivity, of encouraging 'ethics in practice' within the researcher's application and ongoing project? How might this be possible?

A further possible question for me is whether, and for how long, an ethics committee might see themselves available to a researcher for ongoing ethical review/consultation. In other words, is an ethics committee available only to responding to 'procedural ethics' review? Or would an ethics committee be available also to be consulted by researchers in response to reflexive questions and dilemmas that arise for them within the situational 'ethics in practice'?

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