

Saviour Siblings and the Regulation of Assisted Reproductive Technology: Harm, Ethics and the Law, MALCOLM K SMITH, Ashgate, 2015, hardback, 240 pp., £75.00, ISBN 9781409460961

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Rapid developments continue to be made in the field of genetics and assisted reproductive technologies (ARTs). Such developments can offer a much-desired lifeline to families wishing to create a healthy child. However, varying opinions of legal, ethical, moral and social commentators on the use of the technologies are often difficult to reconcile. As a result, regulators are faced with difficult decisions when deciding what to allow and who should be granted access to treatment. Malcolm Smith's book concentrates on one aspect of ARTs - the use of tissue-typing technology to identify and select compatible embryos which will be a match to an existing child, with the intention that the resulting child will be a tissue donor to help treat the existing child. He terms these children 'saviour children' rather than 'saviour siblings', recognising that the intended recipient of the tissue does not necessarily have to be a sibling, although surprisingly, he preserves the term 'siblings' in the title of his book (p 1). Smith focuses on the regulatory systems in the UK and Australia to examine the restrictions placed on tissue-typing technology to create saviour children. He argues that ethical and moral arguments should not be relied on to restrict access to the technology, except in the limited cases where there is evidence of 'harm' to the resulting child or to others (p 8).

In Chapters 2 and 3, Smith examines the regulatory frameworks in the UK and Australia.¹ He identifies similarities between the two jurisdictions based on the harm principle used to justify restrictions to ARTs. There are regional variations within the Australian model. In New South Wales, for example, there was reference by the Legislative Council when passing the Bill to the need to 'protect potential harm to society from the devaluation of human life and dignity'² (p 17), whereas South Australia and Victoria refer to the welfare of any resulting child³ (pp 19-20). In addition, there are restrictions on access to treatment, such as the requirement in South Australia that couples must be 'medically infertile' before being granted access to treatment.⁴ This requirement necessarily restricts access to tissue-typing treatment (p 27). In contrast, the UK has a more clearly defined system of licensing. There is a requirement for healthcare professionals to consider the welfare of the resulting child, or any other child.⁵ If they do not put systems in place to achieve this, they will not be granted a licence to deliver any type ART services. Despite legal challenge,⁶ it is clear that licensing of tissue-typing technology falls within the remit of the Human Fertilisation and Embryology Authority (HFEA), whose consideration of the welfare principle helps to determine access to treatment.

¹ 'The Regulatory Landscape Relevant to Assisted Reproductive Technology'; 'Regulating Access to and the Delivery of Pre-implantation Tissue-Typing Services', respectively.

² New South Wales Department of Health, *Constitutional Draft, Assisted Reproductive Technology Bill 2003*, Information Guide (November 2003), para 3.1.

³ Assisted Reproductive Treatment Act 2008 (Vic) s 5.

⁴ Assisted Reproductive Treatment Act 1988 (SA), s 9 (1)(c); Assisted Reproductive Treatment Act 2008 (Vic), s 10; Human Reproductive Treatment Act 1991 (WA), s 23(1).

⁵ Human Fertilisation and Embryology Act 1990, s 13 (5).

⁶ *R (On the application of Quintavalle) v Human Fertilisation and Embryology Authority* [2005] UKHL 28.

The HFEA has a presumption in favour of treatment, unless there is evidence that the resulting child or another child is at risk of significant harm or neglect, in which case those seeking treatment will be denied assistance (p 63).⁷ However, it is worth remembering that this presumption *only* operates in the field of treatment options available under licence at each clinic providing treatment. Some treatments, such as sex selection other than to prevent a serious genetic disorder, remain prohibited and are, therefore, not subject to a harm-based analysis as they are not services currently available under licence from the HFEA. If these activities become available in the future, they may not enjoy the same presumption in favour of treatment currently applied to ART services.

In Australia, gaining access to tissue-typing treatment requires more scrutiny of applicants, with a set of criteria to satisfy before access will be granted, including consideration of the welfare and interests of the resulting child (p 67).⁸ The application of the welfare and harm principles in Australia and the UK are examined by Smith in Chapter 5 to challenge their use as a justification to restrict access to treatment in the context of creatingaviour children.⁹ In Chapter 4 he also provides an examination of some of the moral and ethical concepts which underpin the restrictions placed on tissue-typing technology and access to treatment.¹⁰ Smith considers reproductive liberty to be central to the regulation of ARTs; thus, individuals affected by decisions are best placed to make those decisions without state interference (p 84). He notes that wider moral justifications for restricting liberty do not provide a strong basis for interfering with decision making, but does not open the debate about whether they should or are worthy of more consideration. Instead, he goes further in the other direction and adopts John Stuart Mill's approach to liberty, which requires not only freedom from legal barriers, but also freedom from social, intellectual, psychological and religious limitations.¹¹ Following this liberal view, Smith argues that matters concerning the individual should not be restricted by the legal enforcement of morals. Rather, the harm principle, in this context, should be engaged at the point at which individual decision making could cause harm to others (p 86). Also relevant is the principle of autonomy, which overlaps with liberty. Colin Gavaghan's interpretation of autonomy as involving 'independence from controlling influences' and 'capacity for intentional action', are important to reproductive liberty as autonomy can be respected when the individual is at liberty to choose.¹²

Smith argues that the liberal approach of non-interference with access to treatment in the absence of evidence of harm, provides a suitable starting point for reproductive decision making (p 96), with a presumption against state intrusion. He supports this view citing John Roberston's argument that reproduction is central to personal identity, meaning and dignity, and is therefore deserving of respect and should not be interfered with without very good reason.¹³ Unfortunately, Smith stops short of identifying and examining what 'very good

⁷ HFEA 1990 s13(5).

⁸ The others are that the intended recipient of the donor tissue must be a sibling suffering from a life threatening medical condition for which there is no other treatment option available, and the parents must wish to have another child as an addition to the family and not merely as a source of tissue: set out by the National Health and Research Council in the *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (2007), para 12.3.

⁹ 'The Harm Principle as a Means for Justifying State Intervention and Regulation'.

¹⁰ 'Liberty and Reproductive Decision-Making'.

¹¹ J Gray (ed), *John Stuart Mill, On Liberty and Other Essays* (OUP 1991).

¹² C Gavaghan, *Defending the Genetic Supermarket: The Law and Ethics of Selecting the Next Generation* (Routledge-Cavendish, 2007) 35.

¹³ JA Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton University Press 1994).

reasons' may be put forward by opponents of his approach. He does, however, discuss the concept of 'harm'. Defining harm is not straightforward, and Smith examines Joel Feinberg's work, who identifies harm as wrongfully setting back an individual's interests.¹⁴ Smith analyses the different types of interests that may be set back within the concept of the harm principle – 'commercial-legal interests' and 'welfare interests', which can be set back if those affected by the decision (in this case by granting access to treatment) are put in a worse condition than they would have been in had the interference not occurred. Smith argues that interference with reproductive liberty *is* a form of harm, particularly when as in Australia, state imposed eligibility criteria restrict access to treatment, for example when a couple is seeking tissue typing treatment when they are not medically infertile.¹⁵ Such harm could only be justified where it could be shown that the interests of *others* could be wrongfully set back in a way which outweighs the harm (p 119), although Smith does not give any examples or suggestions of who else might be harmed and in what way. In order to predict whether a harm may arise, Smith advocates a risk assessment approach - the likelihood of the harm arising balanced against the severity of the harm which could be caused (p 122). This approach avoids the need for a blanket prohibition on services, and it allows for less restrictive measures to be provided in order to minimise the risk of harm or seriousness of harm, such as the provision of information or counselling.

Applying the concept of harm directly to the creation of saviour children, Smith notes that the HFEA position is that harm must be assessed at the pre-conception stage.¹⁶ The liberal approach advocated by Smith requires that the risk or likelihood of the harm eventuating must be more than a minimal risk, and that the resulting harm more than a minor harm (p 131). Smith identifies both physical and psychological harms which could result for the saviour child conceived following tissue-typing procedures. While scientific evidence indicates that the embryo biopsy procedure is not physically harmful to the embryo (p 140), the psychological harm which may be suffered by a saviour child is more difficult to dismiss. Smith notes that, inevitably, a saviour child is born into a family with an existing health crisis and may face further psychological stress as a result of finding out that they were born as a saviour child, particularly if any treatment which follows tissue donation is unsuccessful (p 143). He compares this situation with that of any child born into a family facing a health crisis, who may or may not be intended as a tissue donor, concluding that the psychological harm does not justify interfering with reproductive liberty, as long as the intention of creating the child is not only to cure a sick relative. He considers it important, if not essential, that the child will be a welcome and desired member of the family, and will be appropriately nurtured and cared for, with additional psychological support if necessary. However, this view does not necessarily follow an assessment of harm at the pre-conception stage. While psychological harm might be foreseen, Smith argues that the harm is not significant enough to tip the balance in favour of restricting reproductive liberty. However, he does not identify the relevant tipping-point where foreseeable psychological harm could justify interference.

Having examined the notion of harm, Smith goes on to look at the moral and ethical arguments which often underpin regulatory decision making. He identifies three issues; the moral status of the embryo, commodification, and the 'slippery slope' to designer babies. Regarding the moral status of the embryo, Smith is quick to dismiss this argument given the widespread acceptability of IVF procedures which regularly involve the creation of surplus embryos (p 170). The means-to-an-end objection is similarly overcome - saviour children

¹⁴ J Feinberg, *The Moral Limits of the Criminal Law: Harm to Others* (OUP 1984).

¹⁵ n4 above.

¹⁶ Human Fertilisation and Embryology Authority (HFEA), *Code of Practice* (8th edn, HFEA 2009).

may be welcomed as much-loved additions to families rather than being regarded as commodities (p 172). Smith also points to the birth of unplanned children in naturally conceiving families as evidence that children are not viewed simply for their ability to cure a sibling or other relative, thus concluding that this moral argument does not justify interference with reproductive liberty. However, this argument does not address the situation of all families who may be reluctant to extend their families for social or financial reasons, but who are desperate to cure a sick child. Sadly, not all children are desired and accepted into loving families and children can be considered a burden on families, adding social and financial pressures where there is already an existing health crisis. The final argument of the 'slippery slope' to designer babies is also dismissed using Feinberg's reasoning that to cause 'harm' in this way would involve setting back the interests of others.¹⁷ Smith argues that in the context of designer babies, it is not possible to identify anyone who could have their interests set back sufficiently by the creation of a saviour child to justify state interference under the harm principle (p 179).

In his final chapter, Smith proposes a new structure for the regulation of tissue-typing technology to create saviour children.¹⁸ He criticises the approach in Australia, in particular, as being too grounded in moral and ethical arguments which do not justify interference with reproductive liberty based on the harm principle. He also revisits his arguments about the overly-restrictive statutory criteria which limit access to treatment. Smith suggests an approach which is less restrictive than the current UK position, which requires that a saviour may be conceived only where the sibling (it must be a sibling) can be treated with tissue from umbilical cord stem cells, bone marrow or other tissue not including whole organs,¹⁹ arguing that safeguards post-birth *are* adequate to prevent harm being inflicted on the saviour child, which should not prevent its conception (p 185). He also criticises the need for a sibling to be suffering a serious condition before a saviour can be conceived, arguing that there is no justification in the harm principle for this restriction because the potential resulting harm is often less in the case of a less serious condition. This is because the resulting child is less likely to be subjected to repeated donation procedures because the sick child's condition will be more easily treated (p 188).

What Smith ultimately proposes is a case-by-case welfare assessment made following guidance on six key factors (p 198): (1) the starting point is recognition that there is some need for a regulatory response. However, (2) there should be a presumption in favour of access to treatment, (3) speculative risks should not be considered serious enough to restrict access to treatment, (4) cases should be considered on a case by case basis, rather than on broader ethical principles, (5) information and counselling should be provided in order to minimise risks of harm, and (6) risk assessments should not be burdensome to ART providers, as the welfare of prospective children is already taken into account during the ART process. Smith's approach is a firmly rooted permissive view under which access to treatment would be granted in almost every case and it is difficult to think of situations where restrictions on access to treatment would be justified. While straightforward on the face of it, this process may be over-simplistic in the context of treatment which can have severe emotional and psychological consequences for those involved. Smith has stated in his criteria that speculative risks should not be relied on to restrict access to treatment, but conducting a risk assessment at the pre-conception stage is always going to require a degree of speculation.

¹⁷ Feinberg, n 14 above.

¹⁸ 'Regulating Assisted Reproductive Technology Services for the Creation of Saviour Children: A Way Forward', ch 8.

¹⁹ HFEA 1990, Sch 2, para 1ZA(4).

Only restricting access to treatment in cases where harm is clearly foreseeable, or inevitable (it is not clear what level of certainty Smith requires), exposes prospective children to risks that may be unnecessary and avoidable, particularly given the emotional and psychological effects of ART treatment services.

Smith's book sets out an argument for revisiting the regulatory framework governingaviour children. He uses moral and ethical reasoning to justify the position that reproductive liberty should be free from state interference except where there is evidence of serious harm. However, whilst Smith argues strongly for a liberal approach to regulation, he bases this solely on a narrow concept of harm to the resulting child. He does not discuss in detail the other ethical and moral positions underpinning regulation in this area, such as those who object to ART on religious grounds or the utilitarian position that access to treatment should be determined by determining how the greatest benefit can be delivered to the greatest number of people. He does not consider wider ethical and societal opposition to tissue-typing where it falls outside the concept of harm. Thus, this book gives a rather narrow view of the complex moral arguments underpinning the regulation of this area of law. However, it does provide a useful overview of regulation and the law relating to the creation ofaviour children, and will be of use to students and academics with an interest in this area.

Advances in the field of Assisted Reproductive Technology (ART) have been revolutionary. This book focuses on the use of ARTs in the context of families who seek to conceive a matching sibling donor as a source of tissue to treat an existing sick child. Such children have been referred to as "saviour siblings"™. Considering the legal and regulatory frameworks that impact on the accessibility of this technology in Australia and the UK, the work analyses the ethical and moral issues that arise from the use of the technology for this specific purpose. The author claims the only justification for li This book focuses on the use of Assisted Reproductive Technology (ART) in the context of families who seek to conceive a matching sibling donor as a source of tissue to treat an existing sick child, referred to as 'saviour siblings'. The author considers the legal and regulatory frameworks that impact on the accessibility of this technology in Australia and the UK, and analyses the ethical and moral issues that arise from the use of the technology for this specific purpose.

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Malcolm's™ doctoral thesis examined the regulation of assisted reproductive technologies in Australia and the UK and considered whether families wishing to utilise in vitro fertilisation (IVF) and pre-implantation tissue-typing for the creation of "saviour siblings"™ should be free to do so. Malcolm has published a scholarly monograph on this topic, entitled, *Saviour Siblings and the Regulation of Assisted Reproductive Technology: Harm, Ethics and Law*, which was published by Ashgate (now Routledge) in December 2015. Alongside his PhD candidature, Malcolm was also employed as a Lecturer in Health