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978-1-107-09096-5 - Regulating Reproductive Donation

Edited by Susan Golombok, Rosamund Scott, John B. Appleby, Martin Richards, and Stephen Wilkinson

Excerpt

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## Introduction

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*Susan Golombok, Rosamund Scott, John B. Appleby,  
Martin Richards and Stephen Wilkinson*

This book brings together empirical research with ethical, legal and policy analyses of key issues in the regulation of reproductive donation. The collection is primarily motivated by the thought that such analyses should be informed by relevant empirical data and that regulation should take account of this where possible. It is also shaped by the belief that empirical work which purports to have normative implications should be underpinned by a rigorous grasp of ethical and legal concepts and principles. The contributions have been chosen with an awareness of the importance of attending to the history of regulation, to social contexts, to the diversity of approaches in different jurisdictions and to the increasingly global nature of reproductive donation practices. Sometimes people, gametes or embryos cross borders and families are thereby formed.

In attending to the relationship between the empirical evidence, normative analysis and legal and regulatory responses, the work in this volume illustrates the complexity of the issues and hence the need for fine-tuned and sensitive law, regulation and policy. It also demonstrates the importance of challenging and ‘unpacking’ a range of assumptions, of identifying the diversity of the interests at stake and the ways in which these may or may not be aligned, and the scope for further empirical and empirically informed normative work, all of which are crucial for the development of appropriate legal, regulatory and policy responses.

The collection is the fruit of an international workshop held at the Centre for Family Research in Cambridge in April 2014. In addition to the contributing authors, there was a wide range of invited discussants, enabling discussion of pre-circulated chapters to be informed not just by a range of academics (from law, philosophy and the social sciences), but also by clinicians, fertility counsellors, practising lawyers, as well as members of regulatory and policy bodies.

Following an introductory chapter by Richards on ‘The development of governance and regulation of donor conception in the UK’, the book is divided into four parts.

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Part I – ‘International, cross-border and global issues’ – attempts to reveal something of the diversity of approaches in different jurisdictions, coupled with the complexity of cross-border donation and surrogacy practices. The remaining three sections each address a key issue or related issues, with a mix of empirical, ethical and regulatory analysis.

Part II – ‘How many children per donor?’ – addresses the under-considered question of regulatory approaches to the number of offspring from any one donor; it also considers the question of donation as an aspect of global justice.

Part III – ‘Donors: experiences, motivations and consent’ – considers a cluster of issues relating to the experience of donors and conceptions of what makes a ‘good donor’, their reasons for donation and the possible effect of certain reasons, notably financial ones, on future donor-conceived people, and the relationship between reasons for and consent to donation in the context of egg-sharing.

In Part IV – ‘Information about donors: the interests at stake’ – four chapters address the complex question of the provision of information in relation to genetic parenthood, considering the interests of donor-conceived individuals, prospective and actual parents, as well as donors.

Turning now to the chapters themselves, in Chapter 1, ‘The development of governance and regulation of donor conception in the UK’, Richards reflects on the history underlying the UK’s current system of regulating reproductive donation. The history of the governance of sperm donor conception in the UK is the story of a shift from self-regulated professional practice, developed in the face of much condemnation from church, public and fellow professionals to a legally regulated system set up in the wake of the coming of in vitro fertilisation (IVF) and the development of the commercial and National Health Service (NHS) practice of assisted reproduction. Though the practice of AIH (artificial insemination by husband) was much older, AID (artificial insemination by donor) began alongside AIH largely in the context of specialist infertility clinics in the late 1930s. While AIH was deemed to be acceptable by a Church Commission (The Wand Report) in 1948, this called for the criminalisation of AID on the grounds that it involved adultery, defrauded the begotten children and deceived both kin and society at large about ancestral heritage and bloodlines. In the 1950s and 1960s, the practice of AID developed slowly with increasing demand and growing public and professional acceptance. But without proper legal basis, the children born were regarded as illegitimate. The practice was carried out in secret by parents and clinicians so that the offspring would be protected

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from knowledge of their illegitimate status. A little over a decade after the birth of the first IVF baby (Louise Brown) in 1978, a legally regulated system of established limits for assisted reproduction was created under the Human Fertilisation and Embryology Act (HFE) 1990, ending professional autonomy for much infertility practice. In this system, the parental rights and duties of sperm and egg donors were transferred from donors to recipients. The law was amended in an important respect in 2004 to require the donor's identity to be made available to offspring at 18, thus ending anonymous donation.

This historical account of the development of regulation in the UK, a leader in the regulation of assisted reproduction in general and reproductive donation in particular, is followed by consideration of regulatory developments in a range of other jurisdictions, and of cross-border reproductive health care.

### **Part I – International, cross-border and global issues**

Taking an international approach, in Chapter 2, 'International regulation and cross-country comparisons', Pennings, Klitzman and Zegers-Hochschild reveal and discuss trends in the evolving regulation of medically assisted reproduction across three continents: Europe, North America and Latin America. Three different types of regulation are considered in this investigation: legislation (national and international), court decisions and professional guidelines. Although regulation is very different in each of the continents, three similarities are highlighted. First, tensions exist between the nation-state level and the supranational level. Second, the courts are increasingly influential in the field of reproductive donation. Third, a plurality of different regulations exists in the three continents. The challenge of having such a variety of regulations, at both national and international levels, is that these regulatory systems are frequently found to be incoherent, contradictory and complex. It is unclear how these regulations will evolve over time, especially as reproductive technologies evolve. The differences in regulation between these continents highlight the extent to which assisted reproductive technologies (ARTs) continue to raise controversial and competing ethical concerns that can manifest in a wide variety of ways in our increasingly globalised world.

In Chapter 3, 'Legal regulation of family creation through gamete donation: access, identity and parentage', Glennon makes in-depth international legal comparisons between the United States, UK, Canada and Europe with regard to three major regulatory issues: access to assisted

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reproduction, challenges to donor anonymity and disputes regarding parentage. Issues about access to donated gametes arise based on status – age, sexual orientation and relationship status – as well as financial ability. In addition, donor-conceived individuals have asserted human rights claims that they are entitled to know the identity of all those involved in their conception. Finally, contests have arisen regarding the legal status of families formed through gamete donation. Disputes are especially common when gamete donation occurs outside licensed clinics or when parenting roles are unclear or those involved have conflicting views regarding their roles. Parentage disputes have also challenged the assumption that a child can have no more than two parents. Glennon's chapter surveys the varied responses of these jurisdictions to the rapidly changing landscape of gamete donation, and looks at the sharply conflicting values that support these differences. Overall, she notes that the regulatory trend is towards increasing access to assisted reproduction and the provision of information about genetic heritage to donor-conceived individuals. While some states have greater certainty regarding parentage than others, all face the need to review and revise their rules as societal views of parenting roles and the technology used in gamete donation continue to change.

Debates about population and the ethics of climate change are also of significance in the international context of regulating reproductive donation. In Chapter 4, 'Reproductive donation in the context of environmental and global justice', Karnein and Iser critically assess an argument in favour of restricting access to ARTs in westernised nations in order to help reduce human influence on climate change. The argument in question consists of two steps. First, it is suggested that members of western industrialised countries generally create more emissions that contribute to climate change than do members of less industrialised nations. Second, it is argued that in order to help curb the impact of the human population on climate change, society should not provide ARTs to help prospective parents have children in western industrialised countries. Karnein and Iser reject this argument and instead argue that society should not specifically burden prospective parents who need ARTs with the issue of reducing population for the sake of curbing climate change. Instead, they suggest that the burden of population reduction should be assumed by everyone, and a fair way to do this would be to directly tax persons based on the emissions they produce rather than the number of offspring they create.

Regardless of the legal and broader regulatory position in any one jurisdiction, where individuals or couples wish to have a child or children, they may seek to have some or all of their treatment needs fulfilled in

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another jurisdiction, either because of need (e.g. arising from a shortage of donor eggs), or because of certain restrictions in domestic regulation. In Chapter 5, 'Normative and regulatory issues in cross-border reproductive health care', Pennings addresses a number of issues that arise in relation to cross-border treatment. The first concerns the responsibility of the doctors involved. In this regard, Pennings raises two important questions related to the complicity of doctors in their patients' cross-border treatment activities. First, is a doctor responsible for the end result of cross-border treatment even if he/she did not know the goal of the patient and had no intention of participating in the medical intervention? For instance, this question may arise when patients transfer their embryos to another country to perform a selection that is considered immoral or illegal in the home country of the physician. Second, to what extent is a physician complicit when she either refers a patient abroad or provides information about treatment abroad that is forbidden at home? The primary issue here is whether or not such actions conflict with a physician's duty to act in the best interests of the patient. A secondary issue results from the introduction of restrictions on foreign patients in the destination countries that offer treatment. For example, some countries limit the number of foreign patients (for instance for donor eggs), or demand prior legal approval at home (for instance for surrogacy). Pennings discusses three reasons for introducing such measures and reveals the ethical complexity behind allowing cross-border reproduction to take place while also attempting to regulate it.

In recent years, the prevalence of surrogacy as a means to family building has increased, offering a route to parenthood for infertile heterosexual couples, same sex couples and single men. This increased need for surrogacy has been met with a ready supply of surrogates from countries where commercial surrogacy is widely practised. In Chapter 6, 'Surrogacy: issues, concerns and complexities', Jadva summarises the available findings from research carried out with intending parents, surrogates and children born using surrogacy and highlights the shortcomings in our understanding of the impact of surrogacy. Legislation and practice differ from one country to the next, making surrogacy difficult to evaluate; further, surrogacy needs to be assessed at a global level. Surrogates from diverse cultures conceptualise their 'connection' to the child differently, perhaps in a way which optimises their ability to give the child to the intending parents. It is apparent from the available literature that what motivates many women to become surrogates is a sense of altruism. Even in countries where commercial surrogacy is allowed, financial motivations in themselves are often mentioned in combination with other motivations, such as wanting to help a childless couple, and enjoyment

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of pregnancy. Regulation (either real or perceived) can have immediate consequences for those involved, with changes in law leading to people finding themselves in difficult situations. Jadva also highlights that we know very little about the consequences of surrogacy for the resulting child. Ten-year-old children have been reported to feel positive or neutral about their birth; however, this may change as they grow older and gain a more sophisticated understanding of surrogacy. It is vital that more is understood from the child's perspective in order to fully evaluate the impact of surrogacy.

The UK is among many countries in the world grappling with a sharp rise in the numbers of children being born through surrogacy, both domestically and via international surrogacy arrangements. In the final contribution, Chapter 7, 'A better legal framework for United Kingdom surrogacy?', Gamble examines the development of the law governing surrogacy in the UK, including the restrictions in the Surrogacy Arrangements Act 1985, and the rules on parenthood created by the HFE Act 1990 and subsequently amended by the HFE Act 2008. She tracks the original policy underpinning the law and how this policy has been applied (and stretched) via the UK court decisions which have applied the law over the past thirty years. The chapter also considers the impact of the law on the current landscape for surrogacy, both with regard to how it has fuelled the development of informal and unregulated surrogacy arrangement in the UK, and with regard to how it has driven the demand of UK parents for overseas surrogacy. Highlighting the problems that the current law creates, Gamble's chapter considers how we could implement a better UK legal framework for surrogacy. Considering legal, practical and ethical issues, the case is made for a more structured legal framework in the UK (including written agreements, pre-birth orders and a more transparent approach to compensating surrogates for their inconvenience) in order to protect parents, surrogates and children. Overall, this collection reveals the complexity of the bioethical, empirical and regulatory picture. It also highlights the amount of important work that still needs to be done in this field, including with regard to issues – such as information disclosure and surrogacy – that have already been the subject of significant research to date. The global and rapidly changing nature of donation practices is particularly evident and the challenges this presents should not be underestimated.

## **Part II – How many children per donor?**

The question of what limit, if any, should be placed on how many children can be created with gametes from any given donor has been an

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important one since the start of regulation, but has received little in-depth consideration.

In Chapter 8, ‘Sperm donors limited: psychosocial aspects of genetic connections and the regulation of offspring numbers’, Freeman, Jadva and Slutsky address empirical questions raised by the regulation of donor offspring numbers. The chapter opens by outlining central ethical and regulatory debates about limiting the number of offspring conceived from any one sperm donor. Two key concerns are identified: the risk of unintentional consanguinity between half-siblings and the psychosocial impact of the discovery of large numbers of half-siblings. Freeman, Jadva and Slutsky suggest that arguments that respond to such concerns about limiting donor offspring numbers contain implicit assumptions about the meaning and significance of the ‘genetic connections’ created through donor conception, particularly with regard to donor-conceived individuals who share the same donor (referred to in this chapter as ‘same-donor offspring’). In order to shed light on how these connections are perceived and managed by those involved, Freeman, Jadva and Slutsky present new data from an exploratory study of ‘donor sibling’ groups in the United States, comprising the first in-depth interviews with mothers of young donor-conceived children about their experiences of seeking and finding families who share the same gamete donor. Key findings include: the close link between interest in same-donor offspring and interest in the donor (e.g. parents may use connections with same-donor families to counter lack of knowledge, especially medical knowledge, about their donor); the diverse, decentralised process by which connections are being established, including initiating contact at the ‘pre-conception’ stage as well as the occurrence of ‘unwitting’ meetings between same-donor offspring families; the complexities of relationships between same-donor family members, including similarities to other forms of interpersonal and family relationships as well as specific qualities of voluntary commitment, agency and choice (referred to as ‘elastic kinship’). The significance (or not) of these connections – and the number of same-donor offspring that one has – depends on the cultural and psychological meanings attributed to genetic relatedness. Freeman, Jadva and Slutsky propose a cautious approach to donor-offspring limits that recognises the way in which regulation is itself part of the cultural, social and personal framework in which people navigate the relationships that may be created through assisted reproduction.

The ethical concerns that underpin the perceived need to limit the number of people who may be born as a result of donations from a single donor also require analysis. In Chapter 9, ‘Limiting offspring numbers: can we justify regulation?’, Wright examines the potential harms that such limits are thought to prevent, and considers how the reasons behind



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these limits are changing. Limits were originally thought to be important in order to restrict the likelihood of donor-conceived people entering inadvertently into taboo relationships with unknown half-siblings (a fear that is real for many, regardless of the actual likelihood of it happening). As policy and practice has shifted towards more open attitudes to donor conception, and some donor-conceived people (and their parents) have attempted to make connections with their ‘donor-siblings’, a very different rationale has emerged: that of limiting the number of such connections in order to allow for the possibility of meaningful relationships with them all. The chapter explores assumptions about the significance of ‘pure’ genetic connection in the absence of any pre-existing social relationships that underpin these claims, and suggests that, where positive social relationships do subsequently develop, the genetic connection might better be seen as a ‘trigger’ for the initial encounter, rather than as a necessary element of the relationship that ensues. Wright concludes with an analysis of the role of regulation, suggesting that the evidence base for any specific limit on same-donor offspring is weak, and that further regulatory change (in either direction) would be unnecessary and would also send unwanted messages about the weight that ought to be given to genetic connection.

### **Part III – Donors: experiences, motivations and consent**

Chapters 10, 11 and 12 consider a range of issues relating to the experiences of donors and their motivations for donation, conceptions of the ‘good donor’, the relationship between different motivations and the welfare of the future child on the one hand, and between motivations for donation and consent on the other.

In the first of these, Chapter 10, ‘Regulating the “good” donor: the expectations and experiences of sperm donors in Denmark and Victoria, Australia’, Graham, Mohr and Bourne cross both international and disciplinary borders by drawing on an anthropologist’s account of the practices and donor experiences within commercial sperm banks in Denmark, and a counsellor’s interactions and interviews with past and current sperm donors in Victoria, Australia. The result is a chapter that explores different modes of regulating the ‘good donor’ and examines how donors themselves think about and experience this regulation. The authors use the term ‘regulation’ quite broadly, encompassing: formal legislation; guidelines created by regulatory authorities such as the Danish Health Authority or the Australian Reproductive Technology Accreditation Committee; the organisational practices of sperm banks and the interactions between sperm bank staff and donors, through which sperm donors’ compliance is enforced. Two case studies illustrate how the sperm



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donor as a person and a stakeholder with his own interests remains largely invisible in the regulatory and organisational contexts of sperm donation. Regulation is involved in making the ‘good donor’, as defined by other stakeholders – policymakers, sperm bank staff, recipients, as well as donor-conceived individuals. Donors are constructed as fulfilling a need and regulation ensures that they fulfil this need. However, it is argued that with a changing landscape of donation whereby identity-release donation is becoming more common and parents are encouraged to disclose their use of donor gametes, viewing sperm donors as a ‘means to an end’ is no longer feasible. Men who donate semen are themselves stakeholders and partners in donor conception and have their own perceptions and expectations of what being a ‘good donor’ entails. In regulating donor conception, whether formally or informally, the chapter concludes that it is important to ascertain the interests of all stakeholders: not only the recipients of, and offspring conceived through, donor sperm, but also the men who donate their semen.

Still attending to the question of motivations for donation, in Chapter 11, ‘Gamete donor motives, payment and child-welfare’, Wilkinson considers the issue of financial reasons for donation and the possible impact on donor-conceived people. He asks what implications would (and should) there be for ethics and policy if we accept a particular empirical premise: the claim that, when donor-conceived people find out that their donors’ motives were primarily financial, they are often psychologically distressed or damaged, and seriously so? His chapter argues that if this premise is true then, when they have a choice (and all other things being equal), prospective parents ought to use an altruistic donor in preference to a paid one. The basis for this, however, is not harm to the child created but rather an impersonal ethical principle: the Same Number Quality Claim. Is this ethical requirement one that ought to be legally enforced? Not obviously so. Given the absence of harm, political liberals probably should not attempt to translate it into law. However, public bodies such as the NHS may have good reason to facilitate and promote altruistic, rather than paid, donation, since they have a legitimate interest in the well-being of future populations, and in maximising the benefit created by the deployment of health service resources. Finally, and more controversially perhaps, it is argued that the ethics of shortage situations are quite different from that in non-shortage situations. If preventing payment to gamete donors will cause a reduction in the size of the donor-conceived population, arguments against payment which appeal solely to interests of future donor-conceived people are likely to fail. For to propose that payment should be restricted in such circumstances for the sake of the possible future children’s welfare implies either that the world would be a better place with fewer donor-conceived people, or that

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the children resulting from paid donation would not have lives not worth living (or both). Wilkinson concludes that such implications are highly implausible and so child-welfare arguments for restricting payments to donors in shortage situations should be rejected.

In the final chapter to consider issues relating to motivations for donation, Chapter 12, 'Egg-sharing, motivation and consent: ethical, legal and policy issues', Scott draws on relevant empirical research on the practice of egg-sharing in order to consider a number of ethical, legal and policy questions concerning the relationship between the reasons for egg-sharing on the one hand and consent thereto on the other. The practice of egg-sharing, in which a woman may donate half her eggs in exchange for reduced-fee or free IVF treatment gives a woman who needs, wants and is unable to afford such treatment a very precious chance – namely that of having a genetically related child. With reference to the empirical evidence, Scott first considers the significance of different kinds of reasons for donation, including altruism and financial constraints, noting that the (limited) available evidence suggests that the latter are the dominant motive for egg-sharing in most cases. She then addresses the implications of this discussion for the quality and legal validity of consent to donation. She argues that while, legally speaking, a woman can give valid consent to an egg-sharing arrangement, ethically speaking, it is important to recognise the limited options a woman has when she may decide to donate, thus drawing attention to the importance of viewing her autonomy in a broader ethical context which includes the restricted availability of IVF treatment on the UK's NHS, coupled with the high costs of private treatment. Scott also considers the extent to which either permitting, or not permitting, egg-sharing may benefit or harm a woman's interests, suggesting that, on the basis of the limited evidence that we have so far, the indications are that it may be more beneficial than harmful. Finally, Scott turns to address the broader regulatory position, analysing aspects of current Human Fertilisation and Embryology Authority (HFEA) policy against the backdrop of the European Union Tissue and Cells Directive (EUTCD) – which requires voluntary, unpaid and altruistic donation – and considers whether, or to what extent, the UK position permitting compensated egg-sharing is compliant with the Directive.

#### **Part IV – Information about donors: the interests at stake**

In Part IV, the book's focus shifts to consider issues of information disclosure and sharing regarding genetic parenthood.

In Chapter 13, 'Thoughts and feelings about the donor: a family perspective', Blake, Ilioi and Golombok examine the thoughts, feelings