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## Women, Assisted Reproduction and the 'Natural'

### **ROSAMUND SCOTT**

#### **Abstract**

This chapter considers aspects of the relationship between: the development and regulation of IVF, PGD and MRTs; critiques relating both to notions of the 'natural' and to 'control' over reproductive processes; and women's interests. It argues that hostility to new and developing reproductive technologies increases the difficulties and burdens that women face as they seek to live their working and/or family lives.

#### Introduction

Women who worked used frequently to be required by law to cease to do so when they married. The 'marriage bar', as it was known, meant married women were not permitted either to continue or to start certain forms of employment, such as in the civil service or as teachers; it applied in various ways not only in the United Kingdom, but also in its former colonies, such as Kenya and Australia, as well as in the United States. A married woman's place was in the home, at least until any significant social change was generated, from the 1970s onwards, by the feminist slogan "a woman's place is everywhere", supported legally by such measures as the UK's Sex Discrimination Act 1975. It may partly have been because the development of in vitro fertilisation (IVF) came, in the late 1970s, at a time when the women's rights movement was relatively established, that it was greeted, in some feminist quarters, with hostility. IVF was intended, after all, to enable women experiencing difficulties in conception to become pregnant and to bear their own genetically related child, or that of their partner and an egg donor. It was thus perceived by some as a threat to the idea of women's independence from the home, as well as to their 'liberation' from the 'natural' roles of mothering, and childrearing. An additional strand of critique of IVF focused on the 'medicalisation' of the 'natural' processes of conception.

Nevertheless, women who wish to become pregnant, to give birth and to raise their children, regardless of whether or not they work for all or part of this time outside the home, and who face difficulties achieving this by 'natural' means, need some form of medical assistance to do so. This may be IVF itself, now widely accepted and practised. Alternatively, if a woman and her partner face a considerable risk of passing on a genetic condition leading to serious impairment in a future child, they may seek IVF together with preimplantation

genetic diagnosis (PGD); or, in the case of forms of mitochondrial disease in relation to which PGD cannot assist, they may seek mitochondrial replacement treatment (MRT), recently licensed in the UK (The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015), though no UK birth has as yet been reported. In relation to these techniques, beyond the critique relating to selection against disability that I have discussed elsewhere (Scott 2007), there has been criticism, for example, that PGD results in 'designer babies', or that an MRT child is 'modified' in a way that is problematic. Here an idea of the 'natural' again surfaces. However, women's reproductive lives would likely be that much harder without the choice to access techniques such as these.

This chapter considers aspects of the relationship between: the development and regulation of IVF, PGD and MRTs; critiques relating both to notions of the 'natural' and to 'control' over reproductive processes; and women's interests. It argues that hostility to new and developing reproductive technologies increases the difficulties and burdens that women face as they seek to live their working and/or family lives.

### The 'Natural' – Possible Senses in Play

There are various senses of the 'natural' at play in these debates and, as a Nuffield Council on Bioethics (NCOB) paper has noted, it is important to be aware of this (NCOB, 2015). As regards use of the term in relation to women's roles, there may be the idea of 'natural purpose'; regarding medical intervention in reproductive processes, notions of the 'wisdom of nature' may in play, for example in relation to cautious attitudes to the possible risks in novel interventions; this sense of nature may also be linked to concerns about 'playing God' and to a general sense of unease about new reproductive technologies. As a recent NCOB report notes, "[t]he view that 'tried and tested' natural processes are more reliable than 'human tinkering' has a powerful influence in folk morality and attitudes to risk and uncertainty" (NCOB 2018: 219). Nevertheless, as early as 1988 the Warnock Committee took the view that:

The argument that to offer treatment to the infertile is contrary to nature fails to convince in view of the ambiguity of the concepts 'natural' and 'unnatural'. We took the view that actions taken with the intention of overcoming infertility can, as a rule, be regarded as acceptable substitutes for natural fertilisation (Warnock Report 1988: para 2.4).

The ability to become pregnant with and give birth to a genetically related child may invoke a further sense of the 'natural' – that of 'natural' function: six out of seven couples in the United Kingdom do not need assistance to have a child (National Health Service) and so, we might say, the 'natural' order of things entails that, *if* a woman wishes to have a genetically related child, she will be able to have one who is related in this way both to herself and to her partner.

This wish has been the subject of critique, with reference to alternative methods of family formation, such as adoption, and the argument that social and cultural pressures are partly responsible for the sense that genetic connectedness is the natural norm (e.g. Lotz 2016). However, from the Warnock Committee onwards, various policy and regulatory bodies have noted that many people have the desire to have genetically related children and have taken the view, with regard to policy formation, that this should be accepted. For example, the Warnock Report itself observed that "for many" there is "a powerful urge to perpetuate their genes through a new generation... [which] cannot be assuaged by adoption" (Warnock Report 1988: para 2.2). In relation to PGD, this urge is captured in a 2006 report of the Human Genetics Commission (HGC) which notes that "[f]or some couples, PGD is a preferable option to the use of donor eggs or sperm to avoid the birth of a child with a genetic disorder... [because it] allows them to have children who are genetically related, but at low risk of having a genetic condition that runs in the family" (HGC 2006: para 4.7). More recently, regarding the prospect of nuclear genome editing (NGE), the NCOB has suggested, in relation to many people's wish for a genetically related child for whatever reason (or lack of reason), that we regard this as the wish "of people for whom we should, a priori, have respect" (NCOB 2018: para 3.12). Despite such policy positions, there remains considerable hostility to this wish, as well as to the idea of reproductive technologies, as is evident in various ways in this chapter.

### The Start of IVF: Treatment for Infertility

The Warnock Report was deeply sympathetic to the position of women or couples facing fertility issues, noting the stress, disruption to life plans and sense of exclusion that may be caused by difficulties in conceiving (Warnock Report 1988: para 2.2). The Committee took the view that "an inability to have children is a *malfunction* and should be considered in exactly the same way as any other" and concluded that "infertility is a *condition meriting treatment*" (Warnock Report 1998: para 2.4, emphasis added). The Report was the precursor to the development of legislation governing assisted reproduction in the United Kingdom, in the form of the Human Fertilisation and Embryology (HFE) Act 1990, now amended by the HFE Act 2008.

Yet a cluster of 'radical feminists' saw the development of IVF as an additional means for men – scientists, doctors, embryologists – to affirm male power (e.g. Corea 1987). On this conception, women may be seen as the 'victims' of such technology, choosing to have children "because they were socialised or conditioned to do so" (Rowland 1987: 513). The relationship between such critiques and women's interests in the context of choices about reproduction has

already been much discussed. In the same year as the Warnock Report was published, for instance, Warren argued that the use and development of reproductive technologies was not against women's interests, although a broader societal response to infertility was needed (Warren 1988). Furthermore, with reference to the radical feminist critique of IVF, in the early 1990s Denny conducted qualitative research in the United Kingdom in which she interviewed women about their experiences of infertility and assisted reproduction; she concluded that "[t]he theoretical and often highly speculative nature of radical feminist writing has little in common with the lives of the women... interviewed"; and that "[m]ost of them are well aware of the pressures and constraints which influence their choices, and yet make informed decisions" (Denny 1994: 78). She also suggested that radical feminist criticism of assisted reproduction may actually increase the burdens on women with fertility problems, for example by putting pressure on them to challenge pronatalism (Denny 1994). As she notes, however, "[w]hereas radical feminists perceive infertile women as passively accepting the control of a male medical profession, women saw infertility as loss of control" (Denny 1994: 71, emphasis added). Indeed, rejection of medical assistance in reproduction leaves women with fertility problems who wish to become pregnant with the state of infertility (notwithstanding that assistance may or may not result in the birth of a child); if a given woman seeks pregnancy, childbirth and child-raising, this is both a problem and a burden for her.

Today, it is the more recently developed technologies, such as PGD and MRTs, which tend to attract critical attention. In the United Kingdom, for example, PGD is an option available on the National Health Service (subject to funding) for women and their partners who are at particular risk of passing on a serious genetic condition to their child.

### Selection against a Serious Genetic Condition: PGD

The care of children with serious impairments or disease frequently falls more heavily on women than on men, raising both equality and wellbeing concerns, as others have recognised (Buchanan *et al* 2000). In this light, the possible wish to avoid the birth of such a child can be seen to be supported, morally, by such interests, as well as by the interest in autonomy – the ability to try, so far as anyone can, to shape parts of one's own, and one's partner's and family's life. Such interests support the practices of prenatal screening and diagnosis, notwithstanding that the stage of pregnancy may have a bearing on the moral acceptability of termination. So, for example, a late termination on the grounds of fetal anomaly might be thought clearly justifiable when the fetus would be born into a life that, as a child, he or she might not consider

worth living – a 'fetal interests' termination (Sheldon and Wilkinson 2001). Where an impairment or disease is not that severe – far more common than not – instead it is parental interests in having a degree of choice regarding the birth of a seriously impaired child that morally supports the idea of termination, at least within reasonable (and contested) gestational limits. Women (and their partners) should have a degree of choice about what they feel able to go through, and to take on, in their quest to form, or to add to, a family.

For women whose children are at particular risk of inheriting a serious genetic condition, prenatal screening, diagnosis and termination present various possible problems: for example a greater risk of miscarriage; the possibility of repeat terminations; or, if there has been no testing during pregnancy, then either the death of a child after birth, or a significant risk of the birth of a child with a heightened degree of need due to the seriousness of his or her condition. These outcomes involve loss and/or burden in various ways, ones that impact particularly on women, given their central role, emotionally and physically, in pregnancy, childbirth and child-raising. Where there is a particular risk of such outcomes PGD – the testing of the early embryo on or about day 3 post fertilisation using IVF – presents the chance to avoid, not only the birth of a child with a serious genetic condition, but also significantly to reduce the chance of miscarriage or of the detection, in an established pregnancy, of an inherited genetic anomaly that may give rise to a reluctant choice of termination, and with it the loss of the emotional and physical investment in a given pregnancy. Use of PGD may also avoid the loss of time invested in such pregnancies when women's fertility may be starting to decline. The option of IVF, together with PGD, may thus have various enabling impacts on women's lives, supporting them, for instance: to have more children, over time, if this is what they wish; more easily to balance working lives with the care of children, if desired; or more fully to care for existing children, again if this is what they wish.

Given the impact on women, and their partners, of repeat miscarriages, terminations, the death of young children, or serious impairment or disease in a child, sensitive regulation should attend to their views, experiences and reproductive history. For this reason, it makes sense that the UK Human Fertilisation and Embryology Authority (HFEA) developed relatively supportive guidance by way of interpretation of the HFE Act 1990 (as amended). The legislation itself stipulates that PGD should, in essence, be available where there is a "significant risk that a person with the abnormality will have or develop a serious physical or mental disability, a serious illness or any other serious medical condition" (HFE Act 1990 (as amended): Sched. 2, para 1ZA2(b)). The guidance in the HFEA *Code of Practice* helpfully stresses that the views of those seeking treatment, their previous reproductive experience and

their family circumstances (amongst other factors) should be relevant to the interpretation of the statutory criteria, and the subject of discussion between health professionals and the couple (HFEA 2019: paras 10.5, 10.6, 10.9).

Curiously, however, this approach came under threat in 2009 when, after the amending Act in 2008 which put the PGD criteria on a statutory footing for the first time, the HFEA decided to consult on the appropriateness of this approach, as it was then instantiated in the seventh edition of the Code. This was apparently because at the time it thought that, in passing the 2008 Act, Parliament intended the legal criteria to be interpreted more stringently than had been the case. The HFEA's proposal was (in part) that the sentence in the 7th Code of Practice to the effect that "[t]he seriousness of the condition should be a matter for discussion between the people seeking treatment and the clinical team" should be dropped from the guidance, presumably because of concerns about subjectivity or stringency, and that "the view of those seeking treatment of the condition" should be changed to "the experience of those seeking treatment of the condition". Yet, following the work of the Joint Working Party (JWP) of the HFEA and HGC, tasked with establishing the pre-statutory legal criteria for PGD (HFEA and HGC 2001), there was clearly ethical, clinical and regulatory justification in favour of discussions between healthcare professionals and parents in relation to the seriousness of a genetic condition in a future child, and also in support of parents' views being taken into account (within reason) in relation to this issue; moreover, the UK Human Genetics Commission (HGC) had itself observed: "[i]t has proved impossible to define what 'serious' should mean in this context" (HGC 2001a: Annex D). While selection against the birth of a child with a serious genetic condition is thus a deeply personal matter, this does not mean that it is subjective in a sense that should necessarily give rise to concern about the degree of choice and control that is possible in reproduction.

The HFEA's 2009 worries as to the relationship between the legislation and subjectivity may have been driven by concerns about 'slippery slopes', 'designer babies' and 'playing God'. We can see such concerns in the work of the JWP, which noted that "[r]espondents to the consultation... indicated strongly that restrictions should be placed on the use of PGD to prevent it being used for frivolous or 'social' reasons, or for eugenic purposes" (HFEA and HGC 2001: para 25); similarly, an HGC meeting discussed "concerns as to 'designer babies'" (HGC 2001b: para 4.7). Although concerns regarding possible trivial preoccupations are held at bay, in the United Kingdom at least, because the availability of PGD hinges legally on a notion of seriousness (albeit one that is subject to discussion between health professionals and prospective parents), concerns as to 'designer babies' linger, particularly in public debate. Yet

a child born as a result of PGD is not a 'designed' child, with the connotations of 'made', not 'born' that may be captured by the phrase 'designer baby'. Rather, he or she is a *selected* one. While the parents selected each other, and their parents before them, genetic testing here enables the parents, not to *shape* their embryos, but only to try to avoid the transfer to the uterus of one that would result in the birth of a child with a serious genetic condition, or to avoid any of the other possible outcomes – such as miscarriage, or the death of a child after birth – alluded to above. How much choice in relation to embryos a couple may have in this process will depend on various factors, including the number of eggs retrieved from the woman during IVF, how many are successfully fertilised, and how many test negative for the hereditary condition that is the subject of testing. Beyond this, the couple will be advised by the embryologists as to which embryo or embryos have the best chance of successfully implanting in the woman's uterus and coming to term, so far as this can be judged at the embryonic stage.

Given the various losses that may be entailed absent the availability of PGD and the way these will hit women particularly hard, intervening – with the aid of science – to avoid the 'natural selection' that leads to miscarriage or fetal death is in women's (and their partners') interests, where this is their wish. This means that prohibitive approaches in relation to PGD, such as in Germany prior to 2011 – where fears of 'eugenic' matters of historical significance influenced reproductive laws - run counter to these interests in various ways. Fortunately for women (and men) at risk of passing a serious genetic condition to their future child, the German law was changed in 2011 to allow testing in such cases, and also to avoid miscarriage and stillbirth, at least where these outcomes are "highly likely"; this was achieved by way of an exception to a law relating to the protection of embryos (Act for the Protection of Embryos (The Embryo Protection Act) 1990, amended 2011: s. 3(a)(2)). The degree of risk required is notably more stringent than the UK approach discussed above. While it was reported that Ursula von der Leyen, herself a clinician (then Labour Minister, now President of the European Commission) was "firmly convinced that we should not choose to close our eyes to how we can use modern medicine appropriately to support and help these long-suffering families", it was also noted that "[m]any opponents fear the tests could lead to so-called 'designer babies'", a view attributed for example to Angela Merkel (then and now German Chancellor) (Spiegel *International* 2011).

An 'alternative', it may be said by those who object to PGD to avoid a serious genetic condition in future children, is not to reproduce – a matter of great loss where the birth of one or more children is sought – or to adopt or to use donated gametes, both options that entail foregoing a genetic connection. Where such connection is sought, this too will entail a loss.

(This is not to say that donor-conceived or adopted children are any less loved than those who are genetically related to their parents, or that such families do not function very, even just as, well as those in which there is a genetic connection between parents and offspring.<sup>3</sup>) These 'alternatives' have, more recently, been posited in relation to the development and legalisation of MRTs.

### The Arrival of MRTs: Avoiding Maternally Inherited Mitochondrial Disease

The night before the UK Parliament was to begin debate on the regulations that would permit the use of MRTs in the UK, pursuant to the 2008 amendments to the 1990 Act, a public debate was held in one of the many large rooms in the Palace of Westminster, at which both proponents and opponents spoke (PET 2015). While proponents put forward the sorts of points expressed above (in relation to PGD) about the hardship for women, and their families, of having no medically assisted way to avoid mitochondrial disease, opponents argued that women had numerous alternatives, including: childlessness, the use of donated gametes, or adoption (Taylor, PET 2015). On occasion, PGD has also mistakenly been suggested as an alternative; yet, if PGD were able to be used to avoid the birth of a child with a serious mitochondrial disorder, there would have been no reason to seek to develop mitochondrial replacement techniques.

Two techniques have been the subject of research in the United Kingdom – maternal spindle transfer (MST) and pronuclear transfer (PNT):

Maternal spindle transfer (MST). The 'maternal spindle' is the group of maternal chromosomes within the egg, which are shaped in a spindle. MST involves removing the spindle from the mother's egg before it is fertilised by the father's sperm. The spindle is then placed into a donor egg with healthy mitochondria (from which the donor's spindle, and therefore her nuclear material, has been removed).

*Pro-nuclear transfer (PNT)*. The pro-nucleus is the nucleus of a sperm or an egg cell during the process of fertilisation after the sperm enters the egg, but before they fuse. PNT involves removing the pro-nuclei (nuclear material) from a newly fertilised egg (which is regarded as an embryo under the Human Fertilisation and Embryology Act 1990) that has unhealthy mitochondria. The pro-nuclei are then transferred into a donated embryo, with healthy mitochondria, that has had its own, original pro-nuclei removed. (DH 2014: 5, emphases in original).

Clearly, either of these techniques entails a lot more than the removal and testing of the cell of a very early embryo at stake in PGD. For this reason, the public consultation materials relating to the legalisation of MRTs and the government rejoinder to the responses that followed, focused on trying to contextualise – indeed to *minimise* – the significance of what would be involved (Scott and Wilkinson 2017). A central driver for this related to longstanding

international concerns about the nuclear genome editing that was the target of numerous international conventions and statements, the ones that are now effective in relation to the current prohibition of techniques such as CRISPR-Cas 9, together with various domestic laws (e.g. Parliamentary Assembly of the Council of Europe, 1982; UNESCO, 1997). Indeed, the HFE Act itself (both the 1990 and the amended Act) prohibit this sort of reproductive interference, in line with concerns expressed in the earlier White Paper as to "artificial creation" through "modification" aimed at selecting or shaping specific characteristics, a precursor of the concern as to 'designer babies', points revisited by the HFEA at the time that it granted a licence for research into MRTs in Newcastle (HFEA 2005). Yet in two ways, the UK government stressed, MRTs are very different (Scott and Wilkinson 2017).

First, there is the distinction between the *mitochondrial* and *nuclear* genomes. In its attempt to distance MRTs from nuclear genome interventions, the government took the approach that, while MRTs involve a *germline* intervention, they do not amount to a *genetic* one. Professor Sally Davies, (then) Chief Medical Officer (CMO), explained the rationale for the Government's approach:

Germline is anything that is done to DNA that goes through the generations, and mitochondria go from woman to child through the generations. This is *clearly a germline modification because it passes through*, but we needed to make the *distinction between nuclear DNA*, which makes us who we are and how we are — our personalities, heights, weights and whether or not we get baldness — and the 37 genes in the mitochondria which are about energy for the cell, and which we describe as the power pack (Davies, House of Commons Science and Technology Committee (HCSTC) 2014: 25, emphasis added).

On this approach, MRTs do not intervene in relation to identity in a sense associated with the nuclear genome: they do not change the central characteristics of who will be born. That said, of course their purpose is to change the life experience of the person who will be born (and those around them) by the avoidance of serious mitochondrial disease.

Second, MRTs were justified by reference to the nature of the *methods* involved, ones distanced from genetic modification on the grounds that instead they amount to *donation* or *replacement*. So, while nuclear genome editing techniques may involve 'snipping' and 'splicing', thereby disrupting 'natural' patterns and links, MRTs 'simply' involve a process of 'swapping' the 'naturally' occurring but 'faulty' mitochondrial genome with another 'naturally' occurring but unproblematic one: selection and substitution (albeit not by 'natural' means) 'lock, stock and barrel'. The point that specific DNA sequences are not changed by mitochondrial replacement was stressed by various clinicians, such as Professor Peter Braude, a member of the HFEA Review Panel, who observed: "You are *not modifying the actual genome* of the mother and father; you are simply *moving* it into another bag" (Braude, HCSTC

2014: 14, emphases added). This was also stressed by the Wellcome Trust, a major funder of MRT research in Newcastle, which stated that mitochondrial replacement "allows for *unaltered* nuclear DNA to be transferred to an egg or embryo that has unaltered healthy mitochondria.... These techniques therefore only *replace*, rather than *alter*, a small number of unhealthy genes in the 'battery pack' of the cells with healthy ones" (Wellcome Trust, HCSTC 2014: para 4, emphasis added). To some degree, the same justificatory move was made by the US Institute of Medicine (IOM), which contrasted "[t]he replacement of whole, intact, and naturally occurring mitochondrial genomes" with "any approach for modifying nDNA, which would likely involve editing rather than en bloc replacement of chromosomes" (IOM 2016: 107, emphases added). Seen as involving replacement, MRTs are aligned with genetic selection long practised in PND and, more recently, PGD. They are thereby distanced from genetic modification and nuclear genome editing. Viewed in this way, and against the backdrop of disease prevention, children born through MRTs have no relation to the hypothetical one discussed in a US President's Council on Bioethics Report "who... designed to certain specifications might be viewed as more of an artefact – or more answerable to the will of his or her parents – than a child who is *merely selected* for his or her existing characteristics" (President's Council on Bioethics 2004: 109, emphasis in original).

Together, these various justifications appear to demonstrate a concern to downplay the degree of scientific intervention at stake in MRTs, in the light of historical concerns as to 'designed' children associated particularly with nuclear genome editing. These justifications, not only of the CMO, but also of clinicians, the Wellcome Trust and the IOM, might all be thought to have echoes of the 'wisdom of nature' sense of the 'natural' alluded to earlier. When involved in the development of policy, these parties seem firmly to place MRTs on the 'right side' of a possible line that might be drawn with regard to the acceptability of different kinds of intervention, and thereby to position MRTs as being closer to 'natural reproduction' than critics might have imagined. Such justifications acknowledge and respond to longstanding societal concerns about interference in reproduction. At the same time, as these parties are well aware, failure to develop or to legalise techniques such as MRTs exposes women, in particular, to the 'natural' consequences of unchecked disease in their future children: various accounts presented, for example, by the UK's Lily Foundation demonstrate, unsurprisingly, the extent of the burdens and loss that may be generated by the attempt to have children where mothers risk passing on mitochondrial disease. Moreover, given that mitochondrial disease passes through the maternal line, MRTs particularly address a problem relating to women's ability to

have genetically related children; they also address a man's interests, of course, where he wishes to have a child who is genetically related not only to himself, but also to his partner.

How the UK consultation exercises and debates will play out in relation to nuclear genome editing, the subject of a 2018 report by the NCOB, will become apparent in due course. Much of what it was possible to say about MRTs – aimed at minimising the significance of the intervention – will not be able to be said, for the reasons apparent above. Nevertheless, it is likely that, apart from concentrating on areas of serious genetic disease that cannot be avoided by means of other techniques, there may, for example, be a regulatory emphasis on replication of 'naturally occurring' disease-free genetic sequences, mainly because this may be thought to be less risky for the child and his or her descendants (National Academy of Sciences 2020). Further consideration of nuclear genome editing is beyond the scope of the current chapter. However, the sorts of interests that have been argued to support PGD and MRTs would also support carefully regulated nuclear genome editing, when – if possible – judged 'not unsafe', in the same manner that MRTs were judged "not unsafe" by the HFEA Review Panel in the United Kingdom (HFEA 2016: para 6.1).

As the above discussion has shown, while part of what is at stake in concerns about the 'natural' may relate to *safety* worries, as evidenced most recently by suggestions in relation to the scope of nuclear genome editing, other aspects appear concerned simply with minimising the degree of human intervention in natural processes. Here those natural processes are reproductive ones that, above all, involve and concern women. Control over reproductive processes was an early focus of the feminist agenda, with particular reference to contraception and to abortion (regarding the latter, see e.g. the US Supreme Court decision in *Roe v Wade* 1973). Yet women's interests are strongly served also by being able to control whether to choose to have a child with a serious genetic condition or disease or, simply, whether they are able to try to have a child at all, aspirations that are negatively impacted by critical attitudes towards IVF, PGD or MRTs. The damage that negative attitudes and prohibitions may do to women's interests is developed further in the next section, in which I focus on understandings of women's interests in reproductive health, with particular regard to human rights issues and the international context.

### Reproductive Health and the 'Natural': Contrasting International Approaches

The interest in achieving reproduction, or in avoiding it, where either of these outcomes is desired, has been recognised in the World Health Organisation's (WHO) conception of reproductive health as "address[ing]... the reproductive processes, functions and system at all

stages of life" (WHO). Around the time the Warnock Report was published, the WHO stated that reproductive health means (in part) "that people... have the capability to reproduce and the freedom to decide if, when and how often to do so" (WHO). Furthermore, as its definition of reproductive health makes clear with reference to infertility:

Implicit in [reproductive health]... are the right of men and women... to have... access to appropriate health care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant (WHO, emphasis added).

The WHO has produced a wealth of materials and reports of relevance to these points and further work has subsequently been done to develop this understanding in UN conferences (Cook *et al* 2003), such that the importance of protecting rights relating to reproductive and sexual health is now widely recognised in various international conventions (e.g. the 1979 UN *Convention on the Elimination of All Forms of Discrimination against Women*). Importantly, part of this work highlights that fertility problems are equally an issue in developing countries.

Despite this, there continues to be evidence of a conservative approach to assisted reproductive techniques, including at the highest judicial levels. The European Court of Human Rights' (ECtHR) attitude to aspects of assisted conception in its 2012 decision in S.H. v Austria (S.H.) is a case in point. Here, with reference to the right to respect for private and family life under Article 8 of the European Convention on Human Rights (ECHR), the Court upheld a ban on egg donation in Austria (together with sperm donation where IVF was also needed), noting the way the Austrian government highlighted the ability of Austrians to travel abroad for treatment. In this way, the Court enabled Austria to 'free-ride' to some degree on the more permissive approach in most Convention States of the Council of Europe. Underlying its analysis, in part, were concerns relating to what Baggini has identified as the unpromising objection of 'naturalness' (Baggini 2002). Thus, the Court recounted and backed several of the Austrian Government's arguments in support of its highly conservative approach, noting for example: "that medically assisted procreation should take place similarly to natural procreation, and... that the basic principle of civil law – mater semper certa est – should be maintained" (S.H., para 104, first emphasis added; second in original); that there was "unease among large sections of society as to the role and possibilities of modern reproductive medicine" (S.H. 2012: para 104, emphasis added); and that gamete donation involves third parties "in a highly technical medical process... which had to take into account human dignity, [and] the well-being of children thus conceived..." (S.H. 2012: para 113: emphasis added).

Each of these points can be related to a valuing of the 'natural' in various senses: 'natural' function, the 'wisdom of nature', and the supposed undesirability of any 'artificial' approach to achieve reproductive goals. Yet for those who need to avail themselves of reproductive aid, each of the above points is potentially offensive – as though the use of medically assisted reproduction is undignified, or necessarily a threat to the welfare of those born as a result. In *S.H.* the "unease" of the majority is permitted to override the needs of a minority: support for the above observations led the Court to endorse an unjustified intrusion into the applicants' Article 8 right to respect for private and family life, since it upheld the ban in question, stating that it supported Austria's "Artificial Procreation Act['s]... intention to prevent negative repercussions and potential misuse and to employ medical advances for therapeutic purposes only and not for other objectives such as the 'selection' of children' (S.H. 2012: para 64, emphasis added). Along with, and to some degree associated with the concerns as to naturalness touched on above, two lines of thought are implicit here.

First, there is an alignment of the use of donated eggs with the idea of *selecting* children, not simply with *having* them, and thus a distancing of this technique from the idea of *treatment*. At the same time, this move links the notion of using donated eggs with the idea of 'luxury of choice', rather than with what is, in truth, the idea of an important need for medical assistance. The idea of a surfeit of choice, associated with notions of excessive control, is somewhat absurd when women who do not have eggs of sufficient quality to enable them to carry a pregnancy to term and who wish to become pregnant with a child, say, of their male partner, currently have no choice but to try to use donated eggs as part of IVF. Banning what is rightly termed 'treatment', and is recognised as such in most Contracting States, makes such women's (and their partners') lives that much harder by endorsing a stigma in relation to their fertility problems and needs, and forcing them to travel abroad for treatment, if indeed this is an option for them, as Austria, sanctioned here by the ECtHR, was content for them to do. Such a ban also contributes to the negative psychological impact of infertility, as recognised by the Joint Dissenting Opinion in S.H. (S.H. 2012: para 9), a major part of which concerns the inability simply to choose, in the absence of successful fertility treatment, to give birth to and raise a child.

Second, the use of "selection" in the Court's judgment may allude to concerns as to 'eugenics'; yet most (though not all) Contracting States permit selection to avoid serious disease, for instance in the form of PND and PGD (*Costa and Pavan v Italy* (2012). In the case of donated gametes (where avoiding disease in the future child is not typically an issue for the couple seeking such assistance, at least now that PGD is available) if there is any selection, this

will likely be to try to achieve some physical likeness, if possible, to the features of the couple who need this treatment, for example for privacy reasons as to the role of donation in family formation (NCOB 2013).

Although the Court sought to justify its conservative stance with reference to the margin of appreciation it gives to Contracting States in relation to sensitive moral issues, which is typically broader in the absence of consensus, in fact it misconstrued the position on consensus, since most States permitted such donation at the time (Scott 2018). In this light, as regards both existing reproductive technologies and the development of new ones, where legitimacy is given to conservative conceptions that value, for example, the idea of natural reproductive processes, this will negatively affect women in particular: some jurisdictions, citing a series of concerns relating to interference in natural reproduction, may resist even the careful legalisation of possibilities such as mitochondrial replacement, already legal, as we have seen, in the UK, or of nuclear genome editing, if and when the latter passes appropriate ethical and safety reviews.

### **Conclusions**

Concerns about departure from the 'natural', associated with hostility towards medical assistance in reproductive processes, harm women. While we have moved beyond the idea that the roles of mothering and childcare are 'natural' for women in a way that work outside the home is not, reproductive critiques employing a notion of the 'natural' are prevalent – in public opinion, ethical debate or legal decisions - with regard to the use of existing or of new reproductive technologies. Such technologies either do or will alleviate fertility issues in various ways, either enabling the birth of a child per se, most likely genetically related to the woman and her partner, or enabling that of a 'healthy' genetically related child. The achievement of such outcomes is a goal the majority of people, who do not need assistance in reproduction, take for granted as the 'natural' order of things. At the same time, some people who likely do not need such assistance are hostile to alleviating the fertility problems of others and, thereby, their need for medical assistance in reproduction. Such hostility matters: as the case of Austria shows, it can result in restrictive laws upheld even by international courts. For women in such cases, reproductive options are narrowed and life choices disabled. In this way, deployment of the 'natural' again restricts women's ability to determine important parts of their life course, just as it did when their role was limited, in a way not necessarily of their own choosing, to the domestic sphere.

While consideration of the complexity of further issues at stake in relation to new reproductive technologies is beyond the scope of this chapter, as debates develop in relation to the possibility of techniques such as in vitro derived gametes (IVG) to relieve fertility issues for men and/or women, and nuclear genome editing to avoid the birth of a child with a serious genetic condition that is not avoidable by a technique such as PGD, we should be alert to the negative impact that conservative critiques associated, in whole or in part, with the 'natural' will have on women, and their families. We should engage with such ideas and show why, and how, such approaches will be detrimental to women's interests in wellbeing, equality and autonomy, here including the option to choose – or indeed not to choose – to carry, give birth to and care for a dependent child or children. Otherwise, it will be all too easy for restrictive conservative approaches to prevail and for majority opinions in some instances to negate the legitimate needs of the minority, namely those who wish to have genetically related 'healthy' children and who require the sorts of additional medical assistance that may, in the future, be on offer. The NCOB, for example, has recommended that nuclear genome editing be permitted in circumstances that attend to the welfare of future children, as well as to social justice and solidarity (NCOB 2018), at the same time recommending extensive and inclusive public debate prior to legalisation. If legalised, the technique could be carefully regulated with the development or modification of strong legal frameworks such as that established in the United Kingdom in relation to IVF, PGD and MRTs.

This chapter has sought to look sympathetically at – and respect – the interests of those, particularly women, struggling to form their desired families because of fertility problems or because of the risks of serious genetic conditions in the children who might be born. It has noted the burdens and loss associated with such difficulties and supported the continued development of scientific and medical responses that alleviate them, in line with the WHO's commitment to reproductive health.

#### **End Notes**

### **Related Topics**

Jackie Leach Scully, "Disability", ch. 12.

Susan Dodds, "Care and Dependency", ch. 2.

<sup>&</sup>lt;sup>1</sup> See also e.g. Parens and Asch (eds) 2000; Wilkinson 2010.

<sup>&</sup>lt;sup>2</sup> On this notion in public debate see e.g. NCOB 2018.

<sup>&</sup>lt;sup>3</sup> See e.g. Golombok et al 1996; Golombok et al 2002.

<sup>&</sup>lt;sup>4</sup> I.e. "by avoiding the possibility that two persons could claim to be the biological mother of one and the same child and to avoid disputes between a biological and a genetic mother in the wider sense".

Catriona MacKenzie and Natalie Stojar, "Autonomy", ch. 3.

Vikki Entwhisltle and Stacy Carter, "Empirical Feminist Bioethics", ch. 22.

Marian Verkerk, "Feminist Approaches to Family Making", ch. 23.

Sheelagh McGuinness, "Abortion, Reproduction and Regulation", ch. 24.

Inmaculado de Melo-Martin, "Genomic Technologies", ch. 44

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