Conclusion

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When making policy in areas as sensitive and emotional as human reproduction, regulators and legislators are likely influenced by their perception of public opinion and what public policy should embrace. In each of the countries considered in this narrative, which were selected primarily because of their similar jurisprudential traditions and because – unlike the United States – there has been legislative activity specifically targeted at this area, legislators have tended to adopt what might be called a precautionary approach and indeed, there may be expectations that they ought to do so. It has, for example, been said that:

> Many of the decisions about what to regulate or to legislate about depend on the approach taken with regard to the balance of harm and benefit or potential harm and potential benefit. It has become fashionable to specify that authorities (whether that be Governments, agencies, industry, watchdogs etc) should take a 'precautionary approach' or adopt the 'precautionary principle'.[1]

This principle, which is widely used in debates on the environment, has been described as follows:

> Simply put, the precautionary principle (PP) calls for the world to take action to make products, environmental activities and technology safer, healthier and accountable to everyone.[2]

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[1] HCSTC, Fifth Report of Session 2004–5, *Human Reproductive Technologies and the Law*, vol. 1, HC 7–1, 24 March 2005, p. 22, para. 47.

[2] See www.ehow.com/about_5184467_definition-precautionary-principle.html#ixzz1nackJtpt (accessed on 27/02/2012).

Expressed in this way, the principle seems unexceptionable. It is self-evident that we would wish products, technologies and activities to be as safe as they can be. However, one negative implication of this principle is that it can be used as a means of stifling innovation in the face of anxieties – whether or not realistic – about *possible* harms from *potential* developments. There have been criticisms in the UK of the 'excessive use' of a precautionary approach in regulating assisted reproductive techniques,[3] and we would suggest that this observation could be made in respect of regulation in many, if not most, of the jurisdictions considered in this volume. This kind of approach taps into public and regulatory fears about the advances in science and can in itself generate further distrust, or fear of so-called slippery slopes.

While science has contributed to making human life easier, more bearable and longer than previously, there is, in some quarters at least, suspicion about its goals and the way in which it is regulated. For example, a report by the (UK) Office of Science and Technology (OST) and the Wellcome Trust found that:

> There is concern about the effectiveness of the regulation of science, and the qualitative research found that participants saw regulation as being very secretive and bureaucratic. Having some idea of the end product brings more faith in the regulatory system – hence some respondents were more positive about engineering and technology than about science. Seven out of ten agree that:
> Rules will not stop researchers doing what they want behind closed doors
> But only a third believe that:
> Science is getting out of control and there is nothing we can do about it
> And two out of five agree:
> The speed of development in science and technology means that it cannot be properly controlled by Government.[4]

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[3] HCSTC, *Human Reproductive Technologies and the Law*, vol. 1, p. 117, para. 263.

[4] *Science and the Public: A Review of Science Communication and Public Attitudes to Science in Britain, Office of Science and Technology*, London: Wellcome Trust, October 2000, para. 4.26.

These findings clearly demonstrate the ambivalence sometimes shown towards science and scientists. On the one hand, people believe that it (or they) cannot be fully controlled, while on the other holding out some hope that control is indeed feasible. In any event, the precautionary principle is by no means uncontroversial. One of the problems that a review of UK regulation conducted by the House of Commons Science and Technology Committee (HCSTC) identified is that there are different interpretations of the precautionary approach that are used by various groups to seek to achieve specific goals. Indeed, the role of such arguments as part of the political process of influencing regulatory agendas has been documented in a number of chapters in this book. The HCSTC promoted a particular medical/scientific understanding of the precautionary principle and contended that in this sphere it had never meant 'proceed only where there is evidence of no harm'; rather that:

> In clinical practice it means proceed cautiously and in a manner amenable to ethical oversight and clinical audit while there is no evidence of sufficiently serious harm or potential harm to outweigh benefit or potential benefit, while being vigilant in looking for unintended and otherwise adverse outcomes.[5]

As a result, it concluded that 'alleged harms to society or to patients need to be demonstrated before forward progress is unduly impeded'.[6] Nonetheless, one author at least sees some potential (if somewhat cynical) benefits to the use of a precautionary approach, saying '[i]n one sense…the precautionary principle might have some utility. If we apply the precautionary principle to itself – ask what are the possible dangers of using this principle – we would be forced to abandon it very quickly.'[7]

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[5] HCSTC, *Human Reproductive Technologies and the Law*, vol. 1, p. 22, para. 47.

[6] Ibid., 'Conclusions and recommendations', p. 175, para. 3.

[7] Anon., 'Beware the precautionary principle', Social Issues Research Centre, available at www.sirc.org/articles/beware.html (accessed on 22/02/2012).

When the science in question relates to 'making babies', ambivalence can coalesce into something more forceful, with more than seven out of ten people interviewed for the above study into public attitudes to science agreeing that '[p]eople shouldn't tamper with nature'.[8] Leaving aside the question of what is so inevitably 'good' about nature – which after all gives us conditions such as cancer, which we are generally happy to use scientific knowledge to try to prevent and treat – the possibility of intervening in the 'natural' process of reproduction is anathema to some individuals and groups. Thus, assisted reproduction in and of itself is wrong; nature should be left to run its course, and if this means condemning hopeful intending parents to childlessness, so be it. This view is often associated with certain faith groups, from whose perspective all life is a gift from, and controlled by, a god whose will is supreme and who has a plan for each of us that may or may not involve parenting. Even from a more secular perspective, the *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (Warnock Report) described the response to the birth of the world's first *in vitro* fertilisation (IVF) baby, Louise Brown, as a mixture of:

> pride in the technological achievement, pleasure at the new-found means to relieve, at least for some, the unhappiness of infertility, and unease at the apparently uncontrolled advance of science, bringing with it new possibilities for manipulating the early stages of human development.[9]

This leads directly from the precautionary principle to an exploration of slippery-slope arguments. As is evident from the OST/Wellcome Trust Report, there does seem to be some unease about the possibility that science will create its own momentum and will inevitably take us to places we do not want to, or should not, go. The notion that scientists will 'do what they want behind closed doors' carries the implication that at least some of this work, of which the public generally may be unaware until a technique has

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[8] Ibid., para. 4.9.

[9] *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (Warnock Report), London: Stationery Office, 1984, at p. 4.

been successfully developed, will have unwanted or unacceptable consequences. In the area of human reproduction, this fear is perhaps at its most acute. The anxiety that science might allow for the birth of animal–human hybrids or the cloning of armies of dictators entered the public consciousness through popular literature and the media. However unlikely these outcomes may be, the unease that the mere possibility generated has probably tainted attitudes to certain areas of research and techniques developed from it and, in turn, has created an atmosphere in which the precautionary principle seems – to some at least – entirely appropriate. Doctors and scientists are accused of 'playing God' and legislators and regulators are encouraged to intervene to prevent the seemingly inevitable slide down the slippery slope towards Armageddon. Almond, for example, says '[e]ver since the development of the first atomic weapons…people have been aware that scientific advance divorced from ethical sensitivity is a Frankenstein'.[10]

Making policy in this area, in the face of these and other, perhaps less extreme, concerns can be very difficult. In liberal Western democracies, such as the countries we have considered in this volume, the tradition of a relatively 'hands off' approach to the role of the state vis-à-vis its citizens can seem inappropriate in the area of human reproduction, and therefore to be worthy of challenge. The assumption that essentially private matters – such as reproduction – are not the concern of the state seems especially vulnerable when medicine and science offer not just the opportunity to circumvent fertility problems but also to choose what kind of children to have. Fox, for example, argues that 'advances in biotechnology give special reason to rethink our liberal commitments. Liberal arguments about liberty, equality, and harm to others will not do when it comes to practices that seek to remake nature.'[11] The state, therefore, may on this argument have a legitimate role in shaping and controlling the decisions that intending parents can make. In a limited defence of the so-called 'nanny state', Calman says that 'the state has a duty to look after the health of everyone, and sometimes that means

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[10]Almond, B., 'Philosophy, medicine and its technologies', *J Med Ethics* 14 (1988): 173–8, at 173.

[11] Fox, D., 'Retracing liberalism and remaking nature: designer children, research embryos and featherless chickens', *Bioethics* 24(4) (2010): 170–8, at 178.

guiding or restricting people's choices'.[12] Even the relatively liberal report from the (UK) Science and Technology Committee conceded that 'assisted reproduction and research involving the embryo of the human species both remain legitimate interests of the state', albeit with the caveat that '[r]eproductive and research freedoms must be balanced against the interests of society but alleged harms to society, too, should be based on evidence'.[13]

For others, however, reproduction is an essentially private matter, even when it requires medical assistance, and the state should not intervene to prevent intending parents either from gaining access to the necessary technology or from using all of the technology at their disposal, particularly pre-implantation genetic diagnosis (PGD). This argument, as we have seen in some of the earlier chapters, is based on the concept of reproductive liberty; the idea that in the absence of evidence of harm, people should be free to make their own decisions about whether and when to reproduce and what kind of children to have. In fact, as Jochelson notes:

> The debate over the limits to state intervention and extent of individual freedom weaves through the history of public health. In the simplest terms, it divides between interventionists and libertarians. For interventionists, governments promote freedom for individuals by creating opportunities and leveling out inequalities in society. For libertarians, minimal government is the best way to protect individual freedom, which is about not being interfered with by others.[14]

This is no less true in the arena of assisted reproduction. For policy makers, then, the fundamental issue is which ethical position should be adopted.

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[12] Calman, K., 'Beyond the "nanny state": stewardship and public health', *Public Health* 123 (2009): e6–e10, at e9.

[13] HCSTC, *Human Reproductive Technologies and the Law*, vol. 1, para. 46, p. 22.

[14] Jochelson, K., 'Nanny or steward? The role of government in public health', *Public Health* 120 (2006): 1149–55, at 1150.

As we have seen, most of the jurisdictions we have considered have opted for a legislative response that assumes that some restrictions are appropriate. In other words, the emphasis on reproductive liberty that so dominated human rights rhetoric in the aftermath of the negative eugenics prevalent in the late nineteenth and early twentieth centuries has not been fully translated into policy. Not only may people be denied access to the technology, and therefore denied the opportunity to parent, but even those accepted as suitable to receive the technology may find the choices that could flow from this to be limited by state policy. So, how does policy come about?

While we might wish to believe that public policy is based on proven facts and shaped in a rational and deliberative manner, this is by no means a given. Page says:

> Insofar as they arise from conscious reflection and deliberation, policies may reflect a variety of intentions and ideas: some vague, some specific, some conflicting, some unarticulated. They can…even be the unintended or undeliberated consequences of professional practices or bureaucratic routines.[15]

Policy may also be, as Walsh says, 'peculiarly open to distortion by political and social ideology'.[16] The presumption that people should not be totally free to obtain access to assisted reproductive technologies, or the unfettered use of the options it makes available, seems to reflect (at least) a social ideology that prioritises speculation about the kind of parents people will be, or the kinds of decisions they will make, over reproductive liberty itself. In most of the arguments in favour of limiting choice (apart perhaps from those based on faith) dominant anxieties are about the welfare of future children, fitness for parenting or the creation of 'designer babies'.

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[15] Page, E.C., 'The origins of policy', in Moran, M., Rein, M., Goodin, R.E. (eds.), *The Oxford Handbook of Public Policy*, Oxford: Oxford University Press, 2006 (paperback, 2008), pp. 207–27, at p. 207.

[16] Walsh, P., 'Principles and pragmatism', *Medical Law Review*, 3 (autumn 1995): 237–50, at 237.

To be sure, the welfare of children is a legitimate interest of the state; hence, there are laws in place that seek to protect children from abuse or neglect. However, it is surely problematic for the state to regulate in an effort to balance the possible welfare concerns of potential future children with the deeply felt desire of people to reproduce. This is especially true where the outcome of the decision concerns whether or not technology should be used so that such a potential future child can be conceived. Equally, fitness for parenting is a concept intimately linked with the compulsory sterilisation programmes of the early to mid-twentieth century, and is – in any case – not a test that those who can reproduce naturally have to meet before becoming parents. Of course, it might be objected that assisted reproduction *is* different from natural reproduction because although we cannot prevent people in the latter case from reproducing, we can – perhaps should – attempt to ensure that people are suited to parenting when third-party (sometimes state) involvement is necessary and regulation is feasible. While this argument may have an immediate appeal, it should be remembered that unblocking fallopian tubes and reversing vasectomies also require third-party involvement, are done with the aim of restoring reproductive capacity, but do not require evidence of parental fitness. On what grounds, therefore, would those who require more advanced technologies be required to jump this further hurdle? The mere fact that we *can* limit choice is not a sufficient justification for doing so. Nevertheless, while reproductive decisions might reasonably be regarded as essentially private, whatever the context in which they arise, it seems that the temptation for states to interfere in them where they arise in connection with IVF and associated techniques has been irresistible, at least in the majority of the jurisdictions we consider here.

As to PGD specifically, objectors often use emotive language about ‘designer babies’ and ‘parental acceptance’ to show why its use should either not be permitted or be limited. Each of these has been canvassed already in this manuscript, but they bear brief reconsideration here. People seeking to use PGD (and they remain relatively rare) will often already have experience either of having a child affected by a genetic condition, or may have knowledge that such a condition is present within the family. The desire to avoid the birth of a child with certain disabilities is probably derived both from concern for the quality of the future child’s life and anxiety about their own ability to

cope with such a child, perhaps particularly when another affected child already exists in the family. The effort to avoid such births, however, has been criticised as not demonstrating the love that parents should have for their children, no matter what. Of course, it could equally be argued – and we would agree – that parental love is also evident in decisions to avoid future suffering for a child as well as in concern for their existing children.

Nonetheless, the argument that parents should be willing to accept whatever child they are fortunate enough to have is commonly used by the opponents of PGD. The notion of parental virtue is thereby introduced to cast doubt on the intentions or morality of those who would seek to prevent the implantation of an embryo known to be affected by a particular condition. A virtuous (good) parent would not make choices of the sort that PGD makes possible. To say that such an argument is naïve is, perhaps, an understatement. There is no rule of thumb that tells us what a 'good' or virtuous parent would or should decide. Is a virtuous parent one who chooses not to know that the child they are attempting to conceive may suffer and die young, or one who uses technology to avoid such suffering by choosing to have a different child?

Further, in support of their claim that the slippery slope really does exist, opponents of PGD will point to the next stage in 'designing' babies; the creation of a child who can provide matching tissue to save the life of an existing, but ill, child. This, they might argue, instrumentalises the child and shows it inadequate respect. Again, these arguments have been raised elsewhere in this volume, but it should be restated that while the precautionary principle might suggest that such choices should not be permitted because the child may be harmed, there is no evidence to support such a gloomy, and not entirely logical, conclusion.

Another argument that will be considered briefly here is the not uncommon one that PGD is just another form of eugenics, and on that basis alone it should not be offered as an option. It also follows on this account that we disvalue people already living with disability by selecting against embryos with the same characteristics. In effect, proponents of this argument equate non-implantation of specific embryos on the grounds of potential disability with the sterilisation programmes of Nazi Germany and some disability rights activists see such choices as discriminatory and demeaning for people

living with disability. The first point can be cleared up relatively easily. The Nazi sterilisation policies (and those which existed in the United States and elsewhere) were formulated by government and backed by state coercion – they were not based on the free and informed choice of intending parents. The denial of reproductive liberty, and the abuse that inevitably flowed from it, was the actual harm. No liberal supporter of PGD would wish to see it used as part of a mandated state programme; rather, they would emphasise the need for a free and uncoerced choice by intending parents. Of course, eugenics – for historically valid reasons – has a bad reputation, but as the HCSTC said, '[i]f ensuring that your child is less likely to face a debilitating disease in the course of their life can be termed eugenics, we have no problem with its use'.[17]

As for the second issue, it bears repeating that preferring to implant an unaffected embryo as opposed to an unaffected one in reality does not disrespect people already living with the condition. In choosing, for example, not deliberately to have a child suffering from a condition that would prove fatal early in its life, intending parents do not lose concern or compassion for those who are born with the condition. If intending parents could shape a future for their children that guaranteed the best possible health, or the absence of a specific disabling condition, might they not reasonably wish to do so? Making such a choice does not imply that they become aggressive, hostile or dismissive in respect of people who have the same condition; merely that, where choice is available, some might reasonably want to avoid the situation arising.

It is interesting to note that exactly the opposite concerns have arisen where people seek to use PGD in order deliberately to select an embryo for implantation that has a genetic make-up associated with a potentially disabling condition. Such possible choices have attracted even more widespread condemnation, perhaps reflecting the fact that, contrary to the fears expressed above, many people do think it is legitimate and even morally virtuous to seek to avoid having children that may be affected by disability. However, though it often seems to be ignored, this runs up against the same objections to imposing state controls on the kinds of children that people can and should choose to have as are raised by the earlier examples. Again, people who wish to select an embryo

[17] HCSTC, *Human Reproductive Technologies and the Law*, vol. 1, p. 55, para. 116.

because it has a genetic condition linked with disability are most likely to do so because they have direct experience of the condition. They will be in no doubt that any children they might have with the same condition have as much potential for a good life as anyone else's. They may go further and argue that a child without the condition might pose greater challenges to them as parents in providing what they consider appropriate care and support within the family and its social network. The extent to which a state is justified in regarding such views as so irresponsible as to be impermissible is surely open to question. On a liberal account, it would be necessary to demonstrate harm before state intervention would be legitimate. Given that the selected embryo only has the potential to be a child with that particular disability this poses distinct problems, as demonstration of harm to a future child would require it to be established that the balance of risks and benefits lies in avoiding its existence.

Finally, using PGD for sex selection on non-medical grounds has widely been dealt with by legislative prohibition, although the reasons for this may be regarded as far from convincing. For example, the UK's Human Fertilisation and Embryology Authority stated that one of the major arguments justifying a prohibition on this practice was the public response to consultation which, in its view, had indicated 'considerable alarm among consultation respondents that children selected for their sex alone may in some way be psychologically damaged by the knowledge that they had been selected in this way as embryos'.[18] Leaving aside the fact that the numbers who responded to the consultation were extremely small, such justifications have not passed by entirely without notice. The HCSTC was robust in its disapproval of this stance, commenting that '[t]hus the most persuasive argument was not that there was evidence of harm but that there was evidence of concern about harm. This is not a satisfactory use of evidence to support policy advice.'[19] It concluded that although sex-selecting embryos raised ethical issues concerning the creation and destruction of embryos which warranted some caution, in the absence of convincing evidence of psychological harm to children, arising from having been selected for sex, or wider demographic impact concerns, '[t]he onus should be on

[18] Ibid., p. 121, para. 272.

[19] Ibid.

those who oppose sex selection for social reasons using PGD to show harm from its use…On balance we find no adequate justification for prohibiting the use of sex selection for family balancing.'[20] Despite this, its recommendation was not followed in the subsequent legislation.[21]

However, if, as the HCSTC suggests, the onus of demonstrating harm from the use of PGD is on those who oppose its use, this hurdle would seem hard to overcome, at least at this stage in the clinical application of PGD. It must be recognised that it may be much more difficult to demonstrate certain types of alleged harm than others. Detecting that an embryo carries genes associated with medical illness or disability may well not enable accurate prediction of the extent to which a child will be affected. Even where the prognosis is reasonably clear, there is still room for a substantial difference of opinion over whether the effects on the child should be regarded as 'serious', and in consequence, whether an embryo should or should not be used for treatment. Another set of possible risks relates to safety concerns: that interventions upon embryos have the potential to cause them damage or affect their development, with a consequent reduction in successful live births or an increase in birth defects. Some kinds of harm may not be detected immediately, but would depend upon long-term studies of children born using these techniques, and possibly their own children, and establishing the existence of such risks may require many years of data collection. By way of comparison, the drug diethylstilboestrol (DES) prescribed for pregnant women at risk of miscarriage from the 1940s to the 1970s, was found to have a number of adverse effects upon the women themselves and their children, such as the risk of developing forms of cancer. However, it also affected these women's daughter's reproductive systems leading to increased risk of pregnancy loss and other complications.[22] Research suggests that additional health

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[20] Ibid., p. 64, para. 143.

[21] Human Fertilisation and Embryology Act 2008, amending and supplementing the Human Fertilisation and Embryology Act 1990.

[22] Hoover, R.N. *et al*., 'Adverse health outcomes in women exposed *in utero* to diethylstilbestrol', *New England Journal of Medicine* 365 (14) (6 October 2011): 1304–14.

problems may be suffered by the third generation, i.e. grandchildren of the women for whom DES was prescribed.[23] The existence of many of these adverse effects clearly could not be established until years after the drug was originally taken, and research is continuing. There is similarly an inevitable difficulty in establishing at the present time whether diagnostic procedures undertaken on embryos carry any significant health risks to children or subsequent generations. The same concerns arose when IVF was developed and we are still less than 40 years from its first successful clinical use. As the HCSTC put it '[t]he safety of assisted reproduction has been a matter of conjecture, since even the earliest children born using IVF are still only young adults'.[24] In commenting on the use of novel techniques in assisted reproductive techniques (ART), an independent working group, set up by the UK's Medical Research Council at the request of the HFEA, wrote that:

> Although there is widespread acceptance, based on experience, that current ART procedures are generally safe, the evidence for this, particularly in terms of long-term safety, is relatively weak when compared to other similarly well-established clinical techniques. Too little is known about the basic mechanisms of early human development – whether natural or assisted – about interactions between the mother and her growing baby, or about the overall risks and benefits of ART to draw firm conclusions about whether a new treatment may have any unforeseen adverse consequences.[25]

While the understanding of human development may have moved on since this report was drafted, many questions remain. However, it would seem that, despite some residual concerns and objections, much of assisted reproductive technology – perhaps

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[23] National Cancer Institute, Factsheet: Diethylstilboestral (DES) and Cancer, www.cancer.gov/cancertopics/factsheet/Risk/DES (accessed March 2012).

[24] HCSTC, *Human Reproductive Technologies and the Law*, vol. 1, p. 19, para. 36.

[25] Medical Research Council, 'Assisted reproduction: a safe, sound future', London, 2004, p. 2.

especially IVF – has become accepted in each of the jurisdictions addressed here, and of course in many others. Indeed, for many, IVF is a routine medical procedure, requiring only the availability of relevant resources and the agreement of individuals/couples and clinics. For this reason, regulation is muted, with its focus being primarily on safety and quality rather than an examination of the acceptability of the procedure. The same cannot, however, be said of PGD.

Here also, questions of safety and quality inevitably arise. It is of course impossible to state with any certainty that new procedures carry no risk, and even if some risks are found to exist, what is at issue is a risk–benefit analysis. While proponents of the precautionary principle would point to the lack of evidence as requiring a cautious approach, a liberal account would prioritise reproductive liberty unless and until evidence of harm is found. How a risk–benefit analysis is calculated will, of course, depend on which interests and concerns are prioritised. This, in turn, as we have seen in relation to making public policy, will depend on many factors, including the personal morality of legislators and regulators and their views as to what is, and is not, acceptable or important.

On this point the MRC may be seen to have adopted a view that is commonly taken; one that prioritises concerns about child welfare:

> Throughout their deliberations, the subgroup worked on the basis that the mother's health and well-being are important, but the health of children, who have no choice about how they are conceived, must be the overriding concern in demonstrating whether ART treatments are safe and effective.[26]

However, in reality, it seems that there was a certain level of ambiguity towards this prioritisation of child welfare, since the Report concluded that:

> Waiting to assemble enough information on long-term safety and efficacy to conduct exhaustive ART safety assessments would cause unnecessary delay and

[26] Ibid., p. 9.

> prevent rapid feedback to patients and their doctors. It would be more productive to focus initially on critical safety issues from conception to six months old, taking a healthy single live birth as a the key indicator of a technique's efficacy.[27]

Nevertheless, the MRC report recognised that improving data collection and access to information to enable long-term research on the outcomes of assisted reproduction are necessary to an informed assessment of risks and it recommended that a number of steps be taken to enable such research to take place.[28] Changes in both the practical processes and the legal requirements for recording information and making it available to researchers were put in place.[29]

In respect of the balancing of risks and benefits concerning health risks to children who may be born as a result of the use of ART, the approach that has been taken in the countries discussed has generally been to permit the use of PGD in some circumstances, despite the difficulty of establishing the level of long-term risk, if any. As discussed elsewhere in this volume, evidence relating to short-term health risks so far does not appear to indicate particular causes for anxiety. Accordingly, while the issue of safety of PGD remains current, the focus of concern may be seen to have shifted: notably from the *safety* of the procedure to the *reasons* for using PGD and its possible effects on children and the wider society. Here, the evidence base for determining whether any risks exist is at least as, if not more, limited. Establishing the existence or not, for example, of a negative psychosocial impact on children born as a result of assisted reproductive techniques poses significant challenges in devising appropriate studies and recruiting sufficient numbers to enable meaningful analysis to take place. Similarly, possible effects upon demographics or more abstract fears such as a change in social views about

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[27] Ibid., p. 10.

[28] Medical Research Council, 'Assisted reproduction: a safe, sound future', 2004.

[29] See for example 33D and 45(1) to (3A) of the Human Fertilisation and Embryology Act 1990, as amended by the Human Fertilisation and Embryology Act and the Human Fertilisation and Embryology (Disclosure of Information for Research Purposes) Regulations 2010.

disability or the possible commodification of children may be even harder to establish or quantify. Nevertheless, as we have seen, concerns about such risks often appear to pave the road to prohibitive regulation.

Part of the problem here is that the number of people who may wish to use ART, while not insignificant, will be a minority of the population and those seeking to combine it with PGD, will be even fewer. The use of speculative fears, even those that are alleged to be shared by society at large, to dictate the terms on which individuals may exercise choice should always engender the utmost caution. This is especially true where what is involved is the choice to engage in what is an area of private and highly significant decision-making: namely, whether to seek to establish a family, and in some cases, what kind of family to have. That reproduction is an area of critical importance to individuals and couples seems so obvious as to scarcely require comment here, and it is recognised in international instruments, such as the Universal Declaration on Human Rights.[30] However, the kinds of decisions that could be made as a result of the availability of PGD are beyond the range that was previously available to intending parents and will still be inapplicable to the majority who have no need of ART to procreate or who do not have specific reasons to seek to determine the genetic make-up of their children. Concerns that those who wish to have the opportunity to utilise PGD will make 'wrong choices' may suggest that those who wish to use PGD have different – unacceptable or inappropriate – ways of approaching decisions about founding a family from those who do not. They may also be based on a perception that because these are not the kinds of decisions that most people are faced with, or are able to make, they should not be available to anyone. This required acceptance of the status quo is reminiscent of arguments that mandate acceptance of childlessness for those who cannot procreate without medical assistance, and has generally been rejected.

Of course, it can be argued that the existence of choice is not an unmitigated benefit to individuals and furthermore, that decision-making may be influenced by many factors. As has been said in respect of prenatal diagnosis 'the very fact that a test is

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[30] Adopted by the United Nations General Assembly on 10 December 1948. Article 16 concerns the right to marry and found a family.

offered by doctors tends to suggest to a woman that its use is warranted and desirable'.[31] The exercise of choice may therefore be affected by third party views and pressure may be brought to bear to decide in particular ways. Nevertheless, it is one thing to seek to influence a person's choice, it is quite another to exclude certain matters from choice altogether.

Concluding reflections

As was suggested at the beginning of this chapter, it is possible that the concerns seemingly aroused by PGD stem in some part from a sense that science is progressing without the ethical scrutiny that many intuitively believe necessary, and that the kinds of decisions available to intending parents go beyond what virtuous parents should either want or make. This lurking unease is the result of apprehension based on assumptions that do not, it has been argued here, withstand robust scrutiny, and threatens the pursuit of reproductive liberty; a principle that has become increasingly important over the last century or so.

The final question then must be: what is it about PGD that has resulted in such regulatory interest? Given that – even as its possible scope continues to expand – PGD remains a relatively rare procedure, it may seem that legislative interventions are disproportionate to any harms that may result from its use. Indeed, as is clear from this narrative, it is the more unusual potential applications of PGD that now ground the remaining objections to its use at the discretion of intending parents. That is, issues like sex selection for non-medical reasons are now at the forefront of the debate about PGD, particularly for those who oppose a liberal approach to reproductive choice, including in some cases access to assisted reproduction itself. The tactic is to home in on the most extreme example that could be imagined and then use it to show the danger of the enterprise being permitted at all, even if the basis for objection is entirely speculative and rests on assumptions of dubious validity. What this form of argument does, then, is to

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[31] King, D.S., 'Preimplantation genetic diagnosis and the "new" eugenics', *Journal of Medical Ethics* 25 (1999): 176–82, at 177.

seek to engage people's innate anxieties about just where science may take us. Additionally, it appeals to a latent sense of discomfort with the reproductive enterprise being structured or manipulated as opposed to 'natural'.

Even if this is an intelligible response, it requires justification. The liberal project that prefers state non-intervention in essentially private matters provides a formidable objection to regulatory efforts based on speculation, anxiety or moral distaste. It also, by clear implication, requires us to question whether or not the law is an appropriate mechanism in this area. As Caulfield *et al*. argue:

> Too often, we believe, the search for a regulatory response to certain scientific developments has led governments to adopt simple bans and prohibitions…Using the law in such a manner is, however, frequently an inappropriate means of regulating behaviour in this complex and dynamic area.[32]

In other words, the knee-jerk response to innovation is often to use the law to impose moral values, even although these values may change over the years and may, in any case, be illegitimate. In addition, while it is clearly the case that individuals will be guided by their own moral values, it is less clear that concern for 'public opinion' or some aggregation of supposed moral values are in themselves sufficient justifications for preventing others, who do not share these values, from making choices that *for them* are morally appropriate. One major problem with the anti-liberal approach is that it imposes the views of one group on another. The liberal approach, on the other hand, coerces nobody and provides liberty for those who wish to exercise it in ways that others would not choose to.

Of course, were it clear that using PGD causes actual and significant individual or social harm, then even the liberal account might support state intervention, but compelling evidence to support this does not yet appear to exist. Perhaps it may become available in the future, and certainly it would be appropriate to keep a watching brief. For

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[32] Caulfield, T., Knowles, L., Meslin, E.M., 'Law and policy in the era of reproductive genetics', *J Med Ethics* 30 (2004): 414–17, at 414.

the moment, arguably, the harms most intimately connected to PGD are the restrictions imposed on its use.

We do not claim that all regulation is inappropriate, however. Manifestly, there are genuine individual and community goals served by requiring that PGD is offered safely and effectively by people with relevant expertise and in accordance with the existing legal rules concerning consent to treatment. Maintaining these standards may require state intervention. However, whether or not such intervention is a necessary or even helpful tool in other areas must be moot. Too often responses are prohibitory rather than permissive; conservative rather than liberal.

In the long run, it does not seem unreasonable to trust people to make decisions that are appropriate for them and their families in conjunction with their medical advisers. Many of the small number of people who would seek access to PGD will either be aware of a potential genetic problem within the family or may already have an affected child and there is no reason to suppose that the decisions they make will be harmful, immoral or unethical.

If and when harm can be shown to result from allowing intending parents this freedom of choice, it may well be time for the law to intervene in a reasoned and appropriate manner. While the first generation of children born following PGD is still relatively young, to date there seems no reason to believe that the process itself causes harm, nor is there evidence that significant numbers of people want to use PGD, far less is there evidence that they would wish to do so for what can be deemed to be 'inappropriate' reasons. While there may be some uses of PGD to which some will continue to object – for example, social sex selection – the importance of reproductive liberty should be the primary moral principle underpinning regulatory responses; not speculative fears, knee-jerk reactions, moral distaste or unreflective majoritarianism.