

8. Better by design?

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3 May 2003. The glossy cover of the *Guardian Weekend* magazine features a provocative image of a sonogram of a fetus reading a volume of Proust to accompany an article by Bill McKibben warning of the dangers of the designer baby era.¹ In provocative visual language, the image conveys the idea of a new era of genetic manipulation and made-to-order, 'superior' offspring.

Like the figure of the clone, the designer baby has become an iconic signifier of the dilemmas and risks posed by new genetic technologies. The cover is headlined: 'Condemned to be Super-human: the terrifying truth facing tomorrow's babies', leaving little room for doubt that the designer baby is a threat to humanity. This popular view is not only a ubiquitous media shorthand for genetic science going too far but is equally prominent in recent books by leading public intellectuals, such as Francis Fukuyama² and Jürgen Habermas.³

Both authors identify preimplantation genetic diagnosis (PGD) with 'designer babies'. As Fukuyama writes: 'In the future it should be routinely possible for parents to have their embryos automatically screened for a wide variety of disorders, and those with the "right" genes implanted in the mother's womb.' Based on such predictions, he warns of an inevitable collapse of the boundaries between genetic screening, diagnosis and enhancement. Fusing the imagery of information technology ('a few clicks of the mouse') with that of

‘routine’ genetic profiling, he imagines a scenario of embryos being ‘automatically analysed’ and ‘enhanced’. Importantly, it is PGD that provides the crucial interface between reproduction and genetics for Fukuyama, by offering parents ‘the first step toward . . . greater control over the genetic make-up of their children’.⁴

Similarly, Jürgen Habermas warns that the future of human nature is imperilled by the kinds of genetic choices PGD enables. In *The Future of Human Nature*, he claims that: ‘genetic manipulation could change the self-understanding of the species in so fundamental a way that the attack on modern conceptions of law and morality might at the same time affect the inalienable normative foundations of societal integration’.⁵

This view of genetic manipulation as *a force unto itself*, hostile to social order and integration, is repeated in many of Fukuyama’s and Habermas’s dire predictions about an ‘automated’ genetic future for the human species. As Habermas claims:

The deepest fear that people express about technology is . . . that, in the end, biotechnology will cause us in some ways to lose our humanity – that is, some essential quality that has always underpinned our sense of who we are and where we are going. . . . Worse yet, we might make this change without recognising that we had lost something of great value.⁶

Here, again, ‘biotechnology’ is attributed a sinister agency: it is in our hands but we *might not even recognise* its potential to change our very nature. Writing in the *Guardian Weekend* in a similar vein, Bill McKibben urges his readers to pause to consider ‘the terrifying truth’ ahead of us, and to decide to act – to draw the line against designer enhancements. Describing ‘where we are’, he claims that:

The genetic modification of humans is not only possible, it’s coming fast: a mixture of technological progress and shifting mood means it could easily happen within the next few years. But we haven’t done it yet. For the moment we remain, if barely,

*a fully human species. And so we have time to consider, to decide, to act.*⁷

Like Fukuyama and Habermas, McKibben depicts a process that is *out of control*, and in need of restraint. He attributes the ‘terrifying’ forward march of genetic modification to what he calls ‘a combination of technological progress and shifting mood’ and argues it is time to call a halt. We are becoming, in the words of his article’s title, ‘too clever, too fast, too happy’. What is sinister, then, is not only the *nature* of the change at hand, but the *process* by which it is occurring, without our consent, because we do not even notice. While scientists are busy producing a ‘super-race’, the general public remains unaware of the magnitude of the powers they have unwittingly allowed to threaten our species’ identity.

This popular but pessimistic view of scientists – as powerful, untrustworthy and socially marginal – positions them as both ahead of, and outside or beyond, social norms, while they increasingly control forces almost too terrifying to contemplate. It is a view closely associated with the image of Dr Frankenstein secretly creating a monster in his isolated laboratory. This stock characterisation emphasises a dramatic separation between scientists and society, and a conflict of interests between them. It exaggerates the remoteness of scientific knowledge, and its disconnection from ‘ordinary life’. While ‘we’ are getting on with business as usual, ‘they’ are designing made-to-order babies. Above all, it is a view that emphasises secrecy.

McKibben’s scandalised and denunciatory rhetoric is closely aligned to that of Fukuyama and Habermas, then, not only through their joint call to halt the sinister, ‘unnoticed’, forward march of cloning and genetic manipulation, but in their shared emphasis on the undesirability of genetic design, and the extent to which it is already routinised, automated, and out of control. The message from all three of these prominent authors is that the ‘designer’ revolution in genetics is moving ahead too quickly, without our consent, and that it is not something we really want because it will destroy who we really are.

Desires and designs

Yet other commentators on the ‘genetic design’ debate take a different view.

One prominent voice is that of bioethicist Gregory Stock,⁸ who argues that far from being ‘some cadre of demonic researchers hidden away in a lab in Argentina trying to pick up where Hitler left off’, the scientists and clinicians who are laying the foundations for ‘the reshaping of genetics and biology’ are pursuing ‘mainstream research that virtually everyone supports’, including treatments for infertility, which ‘is a source of deep pain for millions of couples.’⁹ In the conclusion to *Redesigning Humans*, Stock claims that rejection of new reproductive and genetic technologies is not only a misguided mission but a redundant one:

*There is no way we can permanently forego these enhancement technologies if they prove robust and useful. Those who shun healthier constitutions and extended lifespans might hope to remain the way they are, linked to a human past they cherish. But future generations will not want to remain ‘natural’ if that means living at the whim of advanced creatures to whom they would be little more than intriguing relics from an abandoned human past.*¹⁰

Stock’s advocacy of ‘greater germinal freedom’ stands in sharp contrast to the views of Habermas, McKibben and Fukuyama in that he emphasises the broad base of popular support for scientific intervention into reproduction, and the impossibility of separating biomedical innovation from treatment for conditions such as infertility.

But why are these arguments so focused on the idea of ‘design’? Why is ‘designer’ equated with genetic ‘modification’? Technically, the only difference between PGD and *in vitro* fertilisation (IVF) is that embryo selection is based on genetic information and morphology, instead of just morphology alone. And to be able to diagnose the presence or not of a known, single and specific mutation is not the

same as modifying it. In addition to the famously imprecise concept of ‘human nature’, a major area of confusion in the commentaries discussed above is the extent to which desire, demand and design are constantly conflated in the depiction of genetic modification as ‘out of control’.

McKibben, Habermas and Fukuyama view genetic ‘modification’ as a sinister force that is racing ahead ‘unnoticed’, driven by scientific desires, whereas Stock, and other prominent scientists including James Watson, argue that nothing could be more obvious than that parents would want to ‘apply the benefits of discovery’ to provide ‘our very best for our children’. But what, exactly, is the agent of change, and what is the change itself? Does it lie in the inexorable forward march of technology, as McKibben suggests? Or is it to be found in biologically determined parental desires? Is human nature the driving force behind technological innovation? Or is human nature itself at risk of being eliminated by the ‘automatic’ and unstoppable progress of science and technology? Habermas warns that ‘the deepest fear that people express [is that] biotechnology will cause us . . . to lose our humanity.’¹¹ But such warnings are confusing: is something taking our humanity away from us? Or is this something we are doing to ourselves?

Whether the terms ‘design’ or ‘designer’ are deliberately obfuscating, simply a shorthand for PGD, part of the usual media hype (or some combination of all of the above), the designer baby has become a highly contested nexus of conflicting opinion, much of which is confused, contradictory and ambivalent. Beginning with the more ‘high-brow’ commentaries of philosophers, journalists, scientists and bioethicists we see a range of divergent certainties, from the belief that the designer baby will be our undoing, to the conviction it is not in the least threatening, but rather as natural as the urge to parent itself. Such accounts reflect three significant tendencies in public debate about designer babies – be it in Britain, Germany or the United States. These tendencies are:

- 1 to depict PGD as a mixture of desire and design

- 2 to position PGD as a threshold technology or an interface to an improved or degraded future
- 3 to express ambivalence, confusion and equivocation about the ‘designer baby’ technique in terms of its future consequences.

Thus, although use of the terms ‘designer’ and ‘design’ to refer to PGD is technically inaccurate (as no design or modification is involved), and may be described as misleading and harmful (as many PGD patients do), they are still important from a cultural or sociological point of view as ‘placeholders’ for issues that may be difficult to explain, or even articulate. It is precisely because the term ‘designer’ is both so vague and so ubiquitous that it is worthy of further investigation.

Governing the future of PGD

To understand how PGD came to occupy such a pivotal position in contemporary debate about ‘designer’ reproductive futures, it is useful to return to its beginnings. PGD was developed scientifically in the UK, where it has played an important and distinctive role in public debate, and in the process of devising legislation. One of the striking features of this history is the role of PGD in focusing and clarifying public attitudes towards reproductive biomedicine. Consequently, one of the most important parts of the PGD story in Britain is the decisive role of this technique as early as 1985 in the elaborate process of devising legislation to govern ‘human fertilisation and embryology’ – a process that took more than a decade to complete, and which is ongoing. PGD’s significance to this history derives in part from its transformation from being a scientific possibility into a clinical reality during exactly the time period of legislative ‘gestation’ of the Human Fertilisation and Embryology Act, namely 1984–1991. Another striking feature of the PGD debate in Britain is the unusually prominent role of scientists and clinicians, and in particular embryologists, in both parliamentary and public debate.

The birth of Louise Brown in 1978 was seen to create not only a new kind of reproductive choice, but a legal vacuum surrounding its use, as well as an immediate practical imperative to produce regulation. A resolution to this legal and regulatory challenge was both lengthy in its evolution and comprehensive in its scope: Britain's renowned Human Fertilisation and Embryology Act of 1990 emerged 12 years after the world's first test-tube baby was born in Oldham, Lancashire. Its enactment concluded an unprecedented process of public consultation and parliamentary negotiation. The Act remains the most extensive, substantial and detailed legal framework ever created to regulate and govern what had previously been the legally uncharted territory of 'human fertilisation and embryology'.

Since 1990, the Act has been copied by countries all over the world and is widely seen as a unique, exemplary and distinctively 'British' achievement that continues to set the global standard for governance of the post-IVF reproductive 'revolution'.

However, IVF was not the only technique to play a leading role in the battle to establish governance over 'human fertilisation and embryology'. PGD played an equally influential role during the passage of the Human Fertilisation and Embryology Act, and its importance to the shape of contemporary regulation and debate of reproductive biomedicine in Britain has steadily increased, even to the point, in 2005, of precipitating a wholesale review of the Act, and the creation of the Human Fertilisation and Embryology Authority (HFEA), which oversees reproductively governed governance in the UK.

Thus, despite the numbers of actual PGD cycles and patients in the UK remaining in their hundreds, dwarfed by the vast demand for IVF, PGD has, from the mid 1990s onward, become such a pivotal technique, linking IVF to cloning and human embryonic stem cell research, that it is, more than any other issue, the source of questions driving changes to science, governance and policy. For these reasons and others, the 'UK PGD story' provides an essential background to the scientific potency, clinical urgency and political volatility of the 'designer baby' question.

Rather than science 'racing ahead' of society, it is the sociality of

science that emerges from this quick sketch of the ‘the birth of PGD’ in the UK. Rather than being a threat to the future of human nature, or evidence of an attempt to redesign or ‘manipulate’ human origins, PGD emerges as the centrepoint of a complex political history marked by unpredictable twists and turns, and variously aligned sets of interests. And the establishment of the HFEA demonstrates the capacity for science to be regulated through an extensive and far-reaching process of social negotiation and policy innovation which is ongoing.

Above all, in response to the question ‘What is PGD?’, it is possible to identify a number of distinct but overlapping analytical dimensions, from the technical to the legislative, and from the clinical to the philosophical. All of these demonstrate how the Warnock Committee’s strategy of promoting scientific progress subject to strict regulation has repeatedly set the course for ‘the British way forward’ in the field of reproductive biomedicine. From this point of view, it is difficult to describe PGD as anti-social, or to recognise it in the stock elements of the ‘blue-eyed, blonde-haired designer baby’ debate.

Contrary to Habermas’s claim that ‘people’s deepest fears’ about new reproductive and genetic medicine are that they will lose their humanity and forfeit the ability to determine their futures, what emerges from a brief scan of PGD and its future is the extent to which PGD in the UK, like stem cells in the US, is associated with public debate and regulation, *not their absence*. Part of the value of examining the history of PGD in specific national contexts is the ability to learn through comparisons, such as those that might be made with any number of countries in which PGD has had a distinctive historical profile, such as Australia, Belgium, Cyprus, Denmark, India, Israel, Russia, South Korea or Sweden. This alone will not settle the ongoing, and often unanswerable, questions posed by new combinations of technological potential, parental desire and the widely shared view of the need for limits to reproductive and genetic intervention. Neither will it be sufficient to point to the wide range of different strategies for regulating techniques such as PGD in the effort to suggest it is in fact society that is leading technology

along a consensual path of greater relief of human suffering. The effort to present a ‘thicker’ account of how people navigate the issues surrounding the use of PGD offers the possibility that some of the terms on which PGD has already been debated might play a larger role in shaping its direction in the future. However, it will not eliminate the gaps between these views and others, which is fortunate, as disagreement may be one of the most important resources ensuring an ongoing debate.

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Notes

- 1 The article was an extract from McKibben’s book *Enough: Genetic Engineering and the End of Human Nature* (London: Bloomsbury, 2003) on the eve of its British publication.
- 2 Francis Fukuyama is Professor of Political Economy at John’s Hopkins University, and a member of the National Bioethics Advisory Council appointed by George Bush and chaired by Leon Kass.
- 3 Jürgen Habermas is a philosopher who works in the tradition of critical theory; he initially delivered his thoughts on designer babies in response to a lecture by Peter Sloterdijk on ‘the human zoo’.
- 4 F Fukuyama, *Our Posthuman Future: Consequences of the biotechnology revolution* (New York: Farrar Straus Giroux, 2002).
- 5 J Habermas, *The Future of Human Nature* (Cambridge: Polity Press, 2003).
- 6 Ibid.
- 7 B McKibben, ‘Condemned to be Superhuman: the terrifying truth facing tomorrow’s babies’, *Guardian*, 3 May 2003.
- 8 Gregory Stock is the director of the Program on Medicine, Technology, and Society at the UCLA School of Public Health.
- 9 G Stock, *Redesigning Humans: Our inevitable genetic future* (New York: Houghton Mifflin, 2002).
- 10 Ibid.
- 11 Habermas, *Future of Human Nature*.