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Sarah Franklin & Celia Roberts: Born and Made

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Introduction

Babies by Design?

Couples (or lone mothers) will soon be able to sort through a collection of embryos and select for a place in our midst those with the most desirable gene profiles. And why indeed would those parents in our age of excess, who can afford to press on their offspring all the advantages that health and education can afford, choose to deny them any available genetic privileges at birth?
—Walter Gratzer, “Afterword” to James D. Watson, *A Passion for DNA: Genes, Genomes and Society*.

I can understand it is a very grey area. Because obviously . . . we’ve used PGD [preimplantation genetic diagnosis] because we didn’t want to have another child that was going to die within 12 months. But I mean, . . . at what point do you draw the line? At a child that dies at 2 years, 5 years, 10 years, 20 years, 30 years? Where? . . . What conditions are we going to allow PGD to be used for? . . . I don’t know where the line should be drawn.
—Anne, PGD patient

One of the late twentieth century’s most infamous offspring, the “designer baby” has become, alongside the clone, a familiar figure in debates about new reproductive and genetic technologies in what has come to be known as the “postgenomic” era. Like the iconic image of the “test-tube baby” that preceded it, the “designer baby” signifies a disturbing mixture of newfound biogenetic control, consumer demand, and parental desire. An ambivalent figure, the designer baby is at once celebrated as a medical-scientific breakthrough and decried as an example of “science gone too far.” Alongside media celebrations of joyful parents enabled to have a healthy child with the assistance of modern medical technology are ominous depictions of too much choice and control over reproduction. Above all, the “designer baby” symbolizes and embodies the question of limits: How far should science be allowed to go? Who should decide, and how? How will “society” be protected against the possibility of reproductive biomedicine “going too far”? And how can the needs of “desperate” individual parents and families be balanced against the needs of society “as a whole”?

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The very form of these familiar questions—full of vague, uncertain agencies and urgencies—is indicative of the difficulty of finding adequate language to address what are increasingly prominent and, in the twenty-first century, increasingly intimate questions about reproductive and genetic choice and control. This same question of finding adequate language is evident in the very term “designer baby,” which, as the contrast between the two opening epigraphs demonstrates, evokes very different images, from choosy parents seeking “genetic privileges” for their children to cautious parents who feel obligated to avoid future harm to their potential offspring. For the last half century new forms of reproductive and genetic intervention—from the early research on the manipulation of mammalian embryos in the 1950s to the development of in vitro fertilization (IVF) in the 1970s, and its rapid expansion since—have been the subject of increasing social, ethical, and political concern, almost always framed as a conflict between the need for greater medical-scientific progress and the risks of “going too far.” But who are the “we” of the “society” in need of protection against “science” going too far? What is “too far,” and who speaks for “science”? How is the future being imaged and imagined in such debates, and how will limits be devised and implemented? Whose interests will prevail, and who is put at greater risk by medical-scientific intervention into not only reproduction but, increasingly, heredity?

Born in Britain

It is a measure of the degree of controversy surrounding IVF, embryo research, and more recently cloning and human embryonic stem cell derivation that, from their inception, such techniques have been topics that generate widely divergent responses, not only at the level of individual opinion, but equally at the level of national governance and policy (Banchoff 2004; Jasanoff 2005). Britain has in many respects been at both the center and the forefront of the controversies surrounding a cluster of new technologies associated with reproductive biomedicine, not only because so many “firsts” were born in Britain but also because it has played a more substantial role than any other country in the creation of rigorous legislation and policy strictly limiting technological manipulation of “human fertilisation and embryology” (Gunning 2000; Jackson 2001; Morgan and Lee 1991).

Home to the world’s first test-tube baby (1978), first clinical use of PGD (1990), and first cloned “higher” vertebrate (1996), as well as being one of the leading countries involved in human embryonic stem cell derivation and “banking,” Britain has simultaneously pursued an arduous

course of legislative and regulatory innovation to establish a uniquely robust-but-flexible system of laws and codes of conduct. These are backed up by criminal law, enforced through a licensing body, and subject to constant revision, while being bound by the “will of Parliament” expressed in the 1990 Human Fertilisation and Embryology Act.

This much-admired and widely emulated system of governance has its roots in the Committee of Inquiry chaired by the Oxbridge philosopher Mary Warnock in the 1980s, which both provided the rationale for and then successfully established the very liberal but highly regulated climate of reproductive biomedicine that is increasingly seen to be distinctively British (Warnock 1985). Significantly, however, and as Mary Warnock herself was at pains to make clear in her report, the basis for the committee’s recommendations, while informed by perspectives from moral philosophy, theology, and bioethics (fields in which several of the committee members held prestigious positions), *was essentially sociological rather than philosophical*. Conspicuously, and often controversially, eschewing the perennial jousting match over “the moral status of the human embryo,” the primary question guiding Warnock was “what kind of society can we praise or admire? In what sort of society can we live with our conscience clear?” (1985, 3). The first premise of Warnock’s approach was “to take very seriously the . . . wide diversity in moral feelings” and to determine which feelings were most strongly held in common. For Warnock, the most strongly shared social consensus was that “people generally want *some principles or other* to govern the development and use of the new techniques. There must be some barriers that are not to be crossed, *some fixed limits*, beyond which people must not be allowed to go. . . . The very existence of morality depends on it. A society which had no inhibiting limits . . . would be a society without scruples, and this nobody wants” (1985, 2, emphasis added).

“The Warnock position,” as sociologist Michael Mulkay has argued, was the outcome of an effort to acknowledge fundamentally opposing views and find the path of greatest social consensus among them (Mulkay 1997). The report’s primary recommendation—to establish a licensing authority that would provide overall regulation—was based on an original “social contract” devised by Warnock, through which maximum scientific innovation would be encouraged, so long as it was subject to the very strictest levels of government regulation. This “Warnock strategy” in effect substituted robust regulatory infrastructure for “principalism,” thereby establishing a pattern that has prevailed ever since in Britain.¹

¹ According to philosopher John Harris’s critique of the Warnock Report, “the crucial questions are fudged, or rather are never addressed” (1985, 130), and the committee

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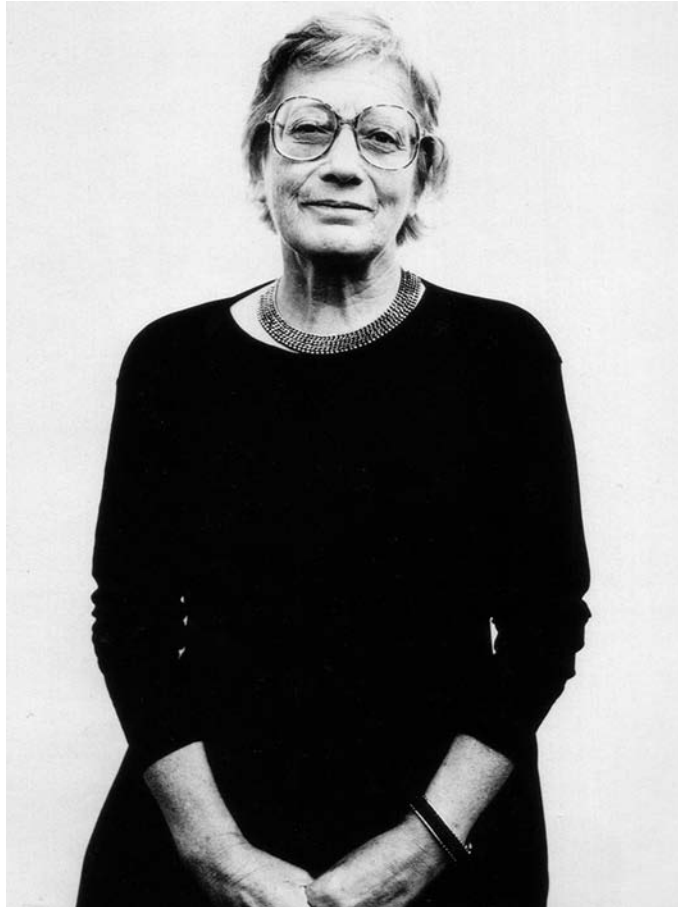


FIGURE I.1. This portrait of the philosopher Mary Warnock from the National Portrait Gallery in London was taken by the photographer Steve Pyke in 1990, the year in which the UK's famous Human Fertilisation and Embryology Bill was enacted, and the first year in which PGD was clinically practiced. Photograph © Steve Pyke.

It is a strategy that has been widely acclaimed, and more often emulated internationally, than any other.

“treat[ed] people’s expression of strong feeling as moral, whatever sort of world they are likely to produce . . . simply because they are feelings expressed sincerely about important moral matters” (1985, 132). He adds that “it is one thing to conclude that morality depends on barriers, and quite another to assume that barriers make morality” (1985, 132).

Importantly, it is a strategy that is based not on absolute values of right and wrong but on the “bottom line” of deliberation within an established legislative system. As Warnock herself described the process of her committee in retrospect, writing in her 2003 publication *Nature and Morality*:

An absolutely central consideration in the work of [our] committee . . . was the difference between what one might personally think was sensible, or even morally right, and *what was most likely to be acceptable as a matter of public policy*. . . Time and again we found ourselves distinguishing not between what would be right or wrong, but between what would be acceptable or unacceptable. (Warnock 2003, 98–99, emphasis added)

Instead of a resolution of moral differences based on philosophical principles, which Warnock has described as “impossible” (2003, 99), she chose “to try to assemble a coherent policy which might seem, if not right, then at least all right, to the largest possible number of people” (2003, 99).²

It is primarily for this reason—that the basic principle informing British regulation of new reproductive and genetic technologies is *to achieve workable and sustainable policy*—that the British government has, from 2000 onward, increasingly funded social-scientific research into the area we might call “reprogenomic studies” or the social study of biomedicine. Bioethics too is moving in this direction, as a new genre of empirically based “context-specific ethics” increasingly replaces debates over utilitarianism versus consequentialism, or dignitarianism versus liberalism (Haimes 2000; Hedgecoe 2003). The research presented in this book was funded under just such an initiative, coordinated by the Economic and Social Research Council (ESRC), which in 2001 commissioned a comprehensive program of more than forty studies on the topic of “innovative health technologies” (Brown and Webster 2004). The two-year study on which this book is based also benefited from funding by the ESRC Genomics Programme, inaugurated in 2002, under which more than thirty million pounds (US\$60 million) was committed to social-scientific study of genomics, stem cells, and reproductive biomedicine. This vast investment in the social science of biomedicine in Britain dwarfs that of any other country and is unprecedented. It is a further extension of the “Warnock strategy,” through which an essentially

² In her 2003 publication *Nature and Morality: Recollections of a Philosopher in Public Life*, Mary Warnock describes the crucial importance of her realization that “the language of ‘right’ and ‘wrong’ was inflammatory”: it was antisocial, and “it sounded arrogant” and “provoked conflict” (2003, 99); and see also Holloway 1999.

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sociological approach is pursued to address the questions of how to fill in the “we” of the “society” that needs to define acceptable limits to reproductive and genetic intervention, maintain a shared definition of progress in this area, and produce credible regulation, governance, and policy.

UK PGD

The research informing this book took place in Britain during a period of dramatic technological convergence that may take future historians many years to unravel, even with the benefit of hindsight. In the 1980s, few people saw in the infancy of IVF a platform for the successor sciences to genomics. Indeed few people imagined IVF as anything other than a treatment for female infertility or, even more specifically, blocked fallopian tubes. However, the expansion of IVF throughout the 1980s and 1990s was driven not only by its popularity, its commercialism, or its soon-discovered capacities to treat a much wider range of infertility—such as male infertility and infertility of unknown origin—but by its potential to be used both to prevent genetic disease and to enable research on human embryos that might lead to stem cell derivation. As Robert Edwards (one of the codevelopers of IVF) has insisted throughout the technique’s rapid clinical expansion to become, in less than two decades, a routine procedure practiced worldwide, IVF was always seen as an experimental research method with enormous potential (R. Edwards 2004, 2005a, 2005b). That potential began to become much clearer in the 1990s, with the successful cloning of Dolly the sheep by Ian Wilmut at Scotland’s Roslin Institute and, only two years later, with Jamie Thomson and John Gearhardt’s successful derivation of pluripotent human embryonic stem cells in the United States. These achievements were “crowned” by the publication of the first “complete” draft sequence of the human genome project in 2001. Britain’s first successful hES cell line, WT3, was created by Susan Pickering, Peter Braude, and Stephen Minger at the London clinic where this study was based in 2003, one year following the United Kingdom’s commissioning of a National Stem Cell bank (Pickering, Braude, et al. 2003).

As noted in the preface, it is a central argument of this book that the development of PGD played a pivotal role in relation to both cloning and stem cell research by providing the first “bridge” or merger between assisted conception, or more precisely IVF, and clinical genetics, thus establishing IVF as a platform technology not only for fertility interventions but for genetic diagnosis. In turn, the ability to “reprogram” embryonic development is at the heart of both cloning and stem cell technology. Increasingly, the genetic and the epigenetic, or the molecular

and the morphological, have been recombined in accounts of situated genetic action *within* cellular environments, in some cases even reversing the powerful “one-way” coding function of DNA. As Ian Wilmut’s experiments with somatic cell nuclear transfer demonstrated, the powerful egg cytoplasm “tells the DNA what to do.”

Consequently, IVF, PGD, and research on human embryonic stem cells are now so inextricably intertwined that it is impossible to debate the social, ethical, or political implications of any one of them separately. They have all, in a sense, become “frames” for each other. A key focus that unites these technologies is the possibility of harnessing, *and combining*, mechanisms of genetic, embryonic, and cellular repair. In May of 2005, in London, at the opening session of the Sixth International Symposium on Preimplantation Genetics, James Watson and Robert Edwards shared the platform for a session titled “Back to Basics,” in which the full implications of the merging of genomics and embryology could be seen in the potential not only to screen every child for abnormal polymorphisms but to discover the genetic and epigenetic causes of cancer. As the Nobel laureate and codiscoverer of the structure of the double helix began his talk in characteristically confrontational language, by asking “If we could make a better human baby by adding genes, why shouldn’t we?” (Watson 2005), so likewise did the codeveloper of IVF, Robert Edwards, decry the “disaster zone” of aneuploidy and point to the way forward for gene targeting in experimental embryology (R. Edwards 2005a).

A Social Science of Genomics

The past two decades have also seen the emergence of a new subdiscipline of literature on assisted conception and the new genetics, published since the mid-1980s, in which qualitative approaches, such as ethnographic fieldwork and interview material, comprise the main sources of data (see Thompson 2005 for a review). The effort to collect firsthand accounts of reproductive and genetic biomedicine has resulted in more than a dozen monographs (including those of G. Becker 2000; Bosk 1992; J. Edwards 2000; Finkler 2000; Franklin 1997; Inhorn 1994; Kahn 2000; Mitchell 2001; Rabinow 1999; Ragone 1994; Rapp 1999; Rothman 1986, 1994; Sandelowski 1993; Thompson 2005; and Throsby 2004). Already it is also possible to observe the rise of a number of important subfields including the anthropology of reproduction (Ginsburg and Rapp 1995; Franklin and Ragone 1998a, 1998b; Inhorn and Van Balen 2002; Strathern 1992b), the anthropology of genomics (Heath and Rabinow 1993; Goodman, Heath, and Lindee 2003; Rainbow 1996, 1997), and the anthropology of biomedicine (Brodwin 1999; Franklin and Lock 2003a,

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2003b; Konrad 2005a, 2005b). Moreover, these emergent fields are not entirely “new” in that they build on well-established subdisciplines such as medical anthropology, the sociology of health and illness, and social studies of science and technology—as well as other disciplinary traditions, such as nursing, psychology, and of course medicine itself.³ In the United Kingdom, where medical sociology is the largest of the subdisciplines of the British Sociological Association, reproductive and genetic technologies have been the subject of an increasing amount of research from as early as the 1980s (see in particular Homans 1985; McNeil, Varcoe, and Yearley 1990; and M. Stacey 1992), much of which was prompted by feminist concerns (see especially Spallone and Steinberg 1987; Stanworth 1987).⁴

A more recent surge of critical scholarly interest in social aspects of biomedicine has gained momentum in the context of what are often referred to as questions of “biosociality” (Rabinow 1992, 1997) and the rise of genetic technologies. According to Peter Conrad and Jonathan Gabe, coeditors of *Sociological Perspectives on the New Genetics*, published in 1999, we are at “the dawn of the genetic age” and “are also witnessing the dawn of the sociological study of the new genetics” (1, 3). As they note, most sociological work in this area began in the 1990s, and the number of sociologists working on such topics remains “small compared, for example, with those who work on problems like HIV/AIDS or stress and mental health” (1999, 3).⁵

Similarly, Alan Petersen and Robin Bunton, coauthors of *The New*

³ There are far too many “precursor” studies of “genomics” to comment on here (but see further in chapter 2), in particular because of the prominence of questions about genealogy, shared reproductive substance, and kinship within the social sciences—where “blood relations” are a very old “version” of genetic ties (Franklin and Strathern 1992). However, it is equally true that what might explicitly be called the sociology or anthropology of biomedicine has not become as large a subfield—in terms of active researchers and funded studies—as might have been expected midcentury, when the turn toward molecular genetics began to raise classically anthropological questions about what Goodman, Heath, and Lindee call “genetic nature/culture” (2003); and see further Silverman 2003 and Weiner 1995.

⁴ The role of early feminist critiques of reproductive and genetic technology is commonly overlooked and undervalued, and the enormous body of feminist scholarship on the social, ethical, political, and legal implications of new reproductive and genetic technologies has yet to receive due credit for anticipating, and very thoroughly examining, many of the issues that have since come to greater prominence in the context of the “new genetics” (see in particular Birke et al. 1990; Pfeffer and Woollett 1993; Corea 1985 and Rothman 1986).

⁵ To make this claim is not to overlook the very important contributions British sociologists have made to the emergence of social studies of genomics, as is evidenced by a number of anthologies (Conrad and Gabe 1999; Glasner and Rothman 1998; Marteau and Richards 1996; Corrigan and Tutton 2004; Clarke and Parsons 1997) as well as monographs (Kerr 2004; Kerr and Shakespeare 2002; Turney 1998; Ettore 2002). The point is simply that this recent flourishing of sociological interest in genomics is, in Britain as elsewhere, in its early stages. See also the British journal *New Genetics and Society*.

Genetics and the Public's Health, published in 2002, argue that although “the diverse imperatives” of new genetic knowledges and technologies are “changing how we think about our bodies, ourselves, and society,” and are consequently “affecting the lives of everyone,” we have only just begun to examine “the broader social and cultural contexts within which new genetic ideas arise, assume meaning, and are applied” (1–2). Countering the tendency to focus on novelty and transformation, Anne Kerr also points to the need to recognize that “genetic knowledge and the research and technologies with which it is associated mean many things to different people. They can be both mundane and unusual, helpful and oppressive. In order to understand these rich and dynamic processes we must move beyond the narrow categories of patient or lay expert, to look at genetics in the wider context of people’s lives” (2004, 168).

Writing in the early 1990s in the introduction to one of the first major social science anthologies published in Britain concerning what she termed “the scientific revolution in reproduction,” sociologist Meg Stacey drew attention to the neglect of social-scientific approaches in this area, and “the existence of a problem in the recognition of the social science role” (1992, 11). To illustrate, Stacey recounted her experience at a Department of Health consultation meeting on the new genetics in the 1980s, where she “failed to convince the assembled doctors and civil servants that there was an aspect to the developments [in genomics] which required fundamental social scientific analysis” (1992, 11), despite it being clear that “medical practitioners . . . are acutely aware of the immense responsibility using the new techniques places upon them” (1992, 13), and despite the overwhelming obviousness (to her) of the “social component of [genetic] research, particularly in relation to prenatal diagnosis” (1992, 11).

Importantly, it was not Stacey’s intention, nor is it the aim of this book, to position social science as providing “answers” to the challenging questions and dilemmas that arise in the context of new reproductive and genetic technologies. To the contrary, as Stacey spells out clearly, the study of “social dimensions” must acknowledge their irreconcilable multiplicity: “To think of such technologies as having ‘social’ dimensions provides a way of thinking about the multiple nature of their impact. For if social life is a manifold and complex phenomenon, then the one perspective it affords is that of the complexity and interrelatedness of acts and effects. In terms of the disciplines, that apprehension is social science” (1992, 2).

This definition of “the social” as multipartite, relational, and complex, and of social science as a means of apprehending its “manifold” nature, positions the social scientist within a specific disciplinary form of attention that differs from those of other sciences in terms of both the methods it uses and its “findings,” or results. Within social science, these methods

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and results are not, as in science or medicine, orientated toward identifying the best, or most robust, “answer” to a particular question. In fact, the reverse is true: precisely by suspending the presumption that we can even know what a “right” answer would be, social scientists often seek to reveal the formative processes by which both questions and answers acquire specific patterns and shapes. In turn, it is possible both to look within familiar questions for more unfamiliar ones and thus to widen the scope of the possible answers available to be “tested” or applied.

“The existence of a problem in the recognition of the social science role,” as Meg Stacey put it (1992, 11), has consequently both remained the same and changed amidst what Petersen and Bunton describe as an “outpouring” of social-scientific work on the new genetics (2002, 2) during the 1990s. While this body of work is substantial, and unprecedented, and has important continuities with many older branches of social-scientific inquiry, it is also, by definition, often exploratory and experimental, as it is at an early stage in its development. There is a challenge to this new field in terms of defining its “role,” both because of its divergence from bioethics and because social science approaches may not easily be recognized as scientific, or even legitimately scholarly, from the perspective of the clinical and scientific criteria on which biomedical applications of genomic knowledge are primarily based.

Although *Born and Made* explores the social significance of new genetic knowledge and technologies from the specific perspective of PGD, the account it offers of reproductive and genetic transformation crisscrosses many terrains, moving from clinics to laboratories to kitchen tables and press conferences. At one level PGD is a technique, but it is also a choice, an experience, a threshold, a clinical specialism, a scientific achievement, and, as we shall see, a place from which a particular kind of uncertainty and ambivalence is generated alongside confidence in its refinement, expansion, and success. Apart from its immediate uses, PGD is also a symbolic technology for many people who never come into any direct contact with it and who may not have any specific idea of what it involves, because it is the technique referred to in debates about “designer babies”—a term that has become central to wider public debate for reasons this book explores in some depth. The intensely contested meanings of new kinds of genetic choice, technology, knowledge, and governance are the subjects of this book, which presents the results of a two-year ethnographic study conducted in Britain during a period of considerable public, scientific, clinical, and legislative controversy over the use of PGD (2001 and 2002).⁶

⁶ Although the study on which this book is based was officially funded by the ESRC from February 2001 to August 2002, the period covered in this book is somewhat larger, roughly comprising late 2000 to early 2005.

The resulting account of PGD tries to avoid some of the pitfalls identified by Anne Kerr in her insightful review of the early sociological literature on “genetics and society,” for example the overemphasis on genetic choice and decision making, and the novelty of new “genetic identities,” to the neglect of the often more mundane and ordinary aspects of the “new genetics” (Kerr 2004). While these topics are central to the analysis presented here, this book has been written with the aim of moving beyond many of the stock characterizations that limit the terms of engagement with the difficult issues raised by new reproductive and genetic technologies such as PGD. While it is common enough to encounter the stereotypes of the ignorant lay public, the overambitious scientist, the patronizing clinician, the desperate would-be parents, runaway technology, or the toothless bureaucratic watchdog, these are often misleading and superficial depictions. Taking the trouble to look beyond these stock generalizations reveals a great deal more serious analytical thought, particularly among those closest to these new technologies, and reveals as well the often deeply paradoxical conditions they inhabit.

Whose Rights and Whose Wrongs?

Another limitation to contemporary debate about techniques such as PGD, both within and outside medical scientific circles, is that the debate is so often primarily judgmental: Is this the best technique? Is the technique morally right or wrong? Do the outcomes minimize harm for all involved? Such questions, like those concerning safety, are obviously essential and logically primary both in terms of maximizing care and in terms of moral responsibilities. However, these are clearly not the only questions that need to be asked, and neither is it at all obvious how, when, or even whether they can be answered—never mind by whom. As noted earlier, it is significant that many of the “solutions” provided by the Warnock Committee to questions such as “Should human life be inviolable?” were widely acknowledged to be “arbitrary,” such as the fourteen-day rule on embryo research.⁷ Similarly, there is no definitive “answer” in many clinical situations involving ambiguity or uncertainty, or even in cases that are completely straightforward medically but involve conflicts of interest, for example among closely related kin. At such times, the imperative of “right versus wrong” may itself be both inappropriate

⁷ The “fourteen-day rule” became the limit point for permissible embryo research on the basis of the argument that it is at about two weeks’ time that the “primitive streak” begins to become visible on the embryo (see further chapter 1, note 34). As the Warnock Committee noted in their report, “some precise decision must be taken, in order to allay public anxiety” (Warnock 1985, 65, see section 11.19).

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and harmful. For these situations, in which there may be several incompatible “rights” and “wrongs,” an approach that is primarily geared toward reaching a singular, definitive assessment obscures the importance of more equivocal, ambivalent, or hesitant “positions.” In such situations the primacy accorded the need to reach the “right” answer forecloses the option of asking whether existing definitions of “answers” are suitable to such questions to begin with.⁸ The extent to which the data collected for this study repeatedly indicated a pattern of emotional and ethical equivocation, or ambivalence, as a form of necessary moral contingency, suggests that this is a key area deserving further research, as well as being one that social-scientific approaches are particularly good at identifying (Kerr et al. 2000; Kerr and Shakespeare 2002; Kerr and Franklin forthcoming).

Toward a New Language of Social Description

Rather than responding to the inclination to provide advice, recommendations, answers, or guidance, which would involve reconciling several competing perspectives into a unified set of directions, this book addresses the oft-repeated question of how “society” addresses the challenges of new genetic technologies such as PGD, by allowing the various perspectives collected here to remain in an unresolved state. After all, there will not come a “point” at which all the questions raised by technological modification of human reproduction and heredity will be “solved.” It is difficult to determine which of the two problems encapsulated by the “genetics and society” formulation are worse: the vagueness of its two halves, or the void of the “and” connecting them. The main aim here, then, is to offer an account of PGD that makes more explicit the contested terms on which it is negotiated, and asks what these divergent views can tell us. To do so, it is necessary to challenge some of the unhelpfully superficial depictions of PGD, such as the one reproduced in the first epigraph to this introduction, and to provide a more substantial critical model of some of the neglected elements, patterns, and forces at work in the socialization of genetic medicine. Above all it is necessary to begin to develop a language of social description that can identify some of the divergent, ambivalent, and often contradictory responses to the new genetics—as well as the gaps between these and more confident and secure certainties. Do these have a social form or pattern? What are their identifying characteristics, and how might we classify them?

⁸ It should be noted that there are traditions within ethics, medicine, and also science that acknowledge the inadequacy of a “right versus wrong,” “good versus bad” model for decision making in the context of the new genetics, and indeed genetic counseling is founded on the principle of nonjudgmentalism.

Which factors, themes, or recurring motifs become more visible through sustained immersion in the world of PGD?

Repeated patterns already characterize this field, especially at the level of public debate, as we have seen. There are, for example, familiar generic forms in which the “social questions” of new reproductive and genetic technologies are often reproduced. The spatial and often geographical imagery of scientific knowledge “marching forward” into “uncharted territory” through “revolutionary breakthroughs” that will “transform the future of medicine” is so common as to have become one of the early twenty-first century’s most hackneyed clichés. The specter of new genetic technologies developing at “an alarming rate,” and in particular the idea of medical technology “racing ahead” of society, is so commonplace as to be almost taken for granted. The “horizon industries” of stem cell manufacture, regenerative medicine, tissue engineering, and cloning are frequently depicted through analogies to “a new dawn,” “a new era,” and “an altered landscape” of medical, scientific, and technological possibility, or as a “new frontier.” Added to these commonplace analogies are the impact models of technology, as in “the social impact of PGD,” which imply that, like some foreign astronomical body, a new technique has hurtled in from outer space and crash-landed into our living rooms.

This book tries to look both within and beyond the language of such analogies and their underlying premises, to ask what the knee-jerk repetition of them obscures and *what their alternatives might be*. Rather than depicting medicine and science as “ahead of,” “beyond,” or “outside” society, and pessimistically representing “the social” as perpetually lagging behind, science and society are depicted here as much more deeply intertwined. While it is not helpful to underestimate the radical novelty of many of the new techniques, choices, and dilemmas encountered in the context of new reproductive and genetic technologies, or the difficult issues they present, it is equally unhelpful to overprivilege technological innovation as if it were a force unto itself. Such a view limits the possible responses to the “genetics and society” question to mere reactions, precisely by building into that question the foregone conclusion that all we can ever do is respond to events that are always already out of control.

But what is the evidence on which such assumptions are based? After all, few are the scientists or clinicians in the fields of clinical genetics or reproductive biomedicine who do not encounter on a daily basis the immense moral and personal responsibilities of their work. Neither do patients involved in treatment programs take their moral and social implications lightly, as the second epigraph to this chapter demonstrates. In contrast to the “impact” and “racing ahead” models, evidence collected for this study repeatedly confirmed that *greater proximity to the actual decisions made during research and treatment involving genes, gametes, or*

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embryos engenders more, not less, respect for the moral issues at stake in them. This show of respect exists in many different forms: for some scientists a primary moral obligation is to make as much progress as fast as possible, in order to develop the most effective techniques and eliminate the greatest amount of suffering. Even scientists, such as James Watson, who advocate quite extreme measures such as offering genetic assistance to people with low IQ (or Walter Gratzer, whose advocacy of “genetic privilege,” reproduced as the first epigraph to this chapter, is offered in the “Afterword” to Watson’s [2000] book), would not see their views as either amoral or irresponsible. Likewise, leading PGD experts, such as Chicago’s Yuri Verlinsky, may be criticized for introducing “unethical” practices such as tissue-matching embryos to become donors for existing siblings suffering from a chronic disease, but it is notable that such innovations are often defended, both by their inventors and by others, as fulfilling a fundamental ethical obligation to help those in need (Kuliev and Verlinsky 2002).

In the Midst of Science, Science in Our Midst

Contrary to the image of genetic medicine “racing ahead” of society, or impacting upon it like some wayward meteor, the description here reveals an intensely social activity that is very much in our midst. Many of the choices and challenges described in this book may be “new” scientifically or medically, but the relationships involved—within families, between individuals and the medical profession, or between scientists and governmental regulatory authorities—are well established, and in some cases very old. Moreover, this social activity—the constant interactions that define and shape science and medicine as much as they do any other human activity—is exactly where to look to find out more about the value systems and judgments that are constantly being forged in the context of the myriad daily and difficult decisions to be made (from how to build a human embryonic cell line to whether or not to donate “spare” embryos to research) by the clinicians, scientists, health professionals, and patients involved in treatment. *Born and Made* tries to ask if there are ways of negotiating PGD “close up” that are relevant to the issues raised by the expansion of PGD as they are perceived from “far away.” This has become a particularly important question in the context of reproductive biomedicine because of the simultaneously intimate and far-reaching consequences of “how far” reprogenetic intervention should be allowed to go, and because the relentless focus on the future often obscures the importance of the past, and the “now” of living with PGD.

Far from being spectacular or remote, this ethnographic account emphasizes more often what is very ordinary, familiar, emotional, and

recognizable about “the topsy-turvy world of PGD.” Moreover, this emphasis also illustrates that it is not only in the hospital or the laboratory that social definitions of genes, genomes, and genetics are being tested and reworked. Genes surround us today as never before, having moved out of the laboratory and into popular culture, as well as literature, film, and everyday speech. We see visual images of genes in the form of DNA gels, markers, helixes, or chromosomes in advertising, cinema, cartoons, and on the evening news. Once a technical scientific term, “gene” has become an ordinary component of everyday conversation, used across a range of communications from the jocular to the juridical to the nonchalant. As Carlos Novas and Nikolas Rose argue, the gene has become a major component of our ideas of selfhood, identity, responsibility, and even citizenship in the twenty-first century (Novas and Rose 2000; Rose and Novas 2005; and see Rose 2006).

Genes are powerful, and consequently they are political—indeed they are a classic example of what historian Michel Foucault terms “biopower,” in that they are inextricably linked to the idea of management of the population (in terms of health, for example), while also being regarded as inherent qualities of the individual. Significantly, they are both highly technical and commonsensical—like atoms, they are invisible, yet few would deny that they exist or are, indeed, the essence of “real” life. Evelyn Fox Keller argues that the gene is one of the most powerful scientific concepts ever created (2000), and as feminist sociologist and historian Barbara Duden has argued, “gene talk” has become ubiquitous, as are its constitutive, repetitive, and cumulative effects on all of us who are interpellated by the very idea of having genes, being genetic, or embodying a genetic identity (Duden and Samerski 2003). This power of “genetic information” to enroll us in *the certainty of itself* is what Dorothy Nelkin and Susan Lindee famously named “the DNA mystique” (1995).

Whether increasing amounts of genetic information are enabling new forms of choice and control over one’s health and one’s future, disempowering the worried-well with abstract risk formulations, or depriving us of our humanity, as Duden’s German colleague Jürgen Habermas asserts, is difficult to determine empirically, for example in terms of quantitative measurement. The empirical evidence of how “gene talk” affects individuals has only begun to be systematically collected and analyzed (Condit 2004; Finkler 2000; Kerr et al. 1998a, 1998b, 1998c; Konrad 2000, 2003a, 2003b, 2005b; Nash 2004; Rapp 1999). While it is predictably the case that PGD can be used to reveal the ways in which new genetic “choices” create both benefits and burdens, the next step is to ask, as Monica Konrad does in her ethnographic analysis of “predictive” genetics, how corresponding social responsibilities and obligations take shape in and through these, and other, dilemmas (2003b, 2005b). This is

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yet another important arena in which the view that “society” can never keep up, and is always “behind” rapid technological innovation, is especially unhelpful—as Rayna Rapp has powerfully demonstrated in her account of the resocialization of “objective” genetic information among her female informants undergoing amniocentesis (1999), and Jeanette Edwards demonstrates in her account of how kinship is used to model ideas of blood and genes (2000, and see also Finkler 2000).

To point to the ways in which “gene talk” mediates and travels between the worlds of objective scientific fact and lived social relationships is neither to deny the “reality” of genes nor to “relativize” their connection. To the contrary, a major advantage of social-scientific description is that it is empirical, meaning evidence based, and thus “factual” while also being able to account for the ways in which different factual registers compete. This is a crucial feature of negotiating genetic information in a context such as PGD, where the “genetic fact” of cystic fibrosis, thalassemia, or a translocation cannot be separated from the equally important facts of existing relationships, family histories, individual identities, professional responsibilities, or public health priorities.

The suggestion that there is no such thing as strictly objective genetic information in the context of PGD could be seen as either a confusing or even a provocative statement, but it is nonetheless one of the most powerfully repeated themes to emerge from both the social-scientific and the psychological literature on genetic testing (Marteau and Richards 1996). As this book demonstrates repeatedly, the process of communicating genetic information in the context of PGD, where professionals come from widely divergent disciplinary backgrounds and patients, although highly motivated, rarely have any clinical or scientific training, is extremely labor-intensive. Yet, even here, where the accuracy and reliability of genetic information could not be of greater consequence, and the effort to eliminate any possible sources of error is relentlessly pursued, communicative outcomes of consultations are the result of painstaking accumulation of detail, repetition, clarification, qualification, and not uncommonly confrontation as well. This somewhat surprising feature of PGD thus adds yet another set of dimensions to the ongoing effort to understand “gene talk” in action, including all the odd and often paradoxical ways that *in order to be “perfectly clear,” genes can never make only one kind of sense* (Franklin 2003c).

What Is a Gene?

The multiplicity of “how genes mean” in the context of PGD is not only an effect of PGD’s having a social character or dimension—as if without

