Access to the Genome: The Challenge to Equality


This engaging and accessible book focuses on some of the broader social and economic implications of the Human Genome Project. It begins with a solid description of basic genetics and the Genome Project itself, and follows up with chapters on the practical applications of genetic information (in brief, genetic tests, gene therapies and genetic enhancement) and the impact such technologies might have. But these are just the warm-up for the core of the book which looks at the way genetic technologies might impact upon health care systems, and on society as a whole.

In the chapter “Access to genetic technologies” the authors address issues such as supply shortages, insurance coverage and access to genetic technologies via ability to pay with the use of both historical and contemporary examples from health care. Using cases such as debates around access to dialysis in the 1960s and the attempt by the US state of Oregon to increase the numbers of people covered by state health care by reducing the range of treatments paid for, the authors conclude that the general availability of genetic technologies is likely to be extremely limited due to the prohibitive cost. An important point about this chapter (and much of the rest of the book as well) is that it is written from a US position, i.e. there is in-depth discussion of the ins and outs of US private health insurance legislation, but no mention of life insurance, which is of far more relevance to the UK (and other, non-US countries). This is not a criticism of the book (which makes potentially esoteric and obscure legal issues quite readable), but a warning for potential readers perhaps looking for a broader discussion of the concept of insurance as a whole.

Chapter 6, “Genetic technologies and the challenge to equality”, is far more broadly relevant in that the authors suggest that genetic technologies present a threat to the foundations of most Western democratic societies. Initially they work through classic political/ethical theories (such as Utilitarianism and Rawlsian Justice), and look at how these theories would address the inequality which would stem from expensive genetic technologies only being available to wealthy individuals. They point out that such wealth-based access to these technologies could ossify social differences in society, with those unable to pay for such technologies (including genetic enhancement) and their children suffering in terms of job security and income as an enhanced “genetic aristocracy” took control. Such a situation prevents what Mehlman and Botkin regard as one of the most important values in a democratic society; the chance to be upwardly mobile; “If the reduction in upward mobility were substantial enough, the lower classes, who could not afford to better themselves genetically, would remain locked into their genetic class” (page102). The authors foresee various socially damaging consequences to this erosion of equality, but accept that they may be over-pessimistic, the “equivalent to Chicken Little alarming the barnyard due to a genetic acorn” (page105).

Personally I think that they argue persuasively for their worst case scenario, and propose an intriguing solution.

They consider total prohibition on genetic research and technologies, but having looked at the “war on drugs” and other examples, correctly conclude that such action does little in the long run. Their solution to the problem of genetic inequality is a genetic lottery “open to anyone, but everyone would have the same chance of winning” (page125). Those who objected to the use of such technologies could opt out, but it would give those people who could never afford to buy genetic enhancements or gene therapy, the possibility of leapfrogging any genetic class barriers. Intriguing and original as this idea is, the difficulties do seem rather obvious. If genetic technologies, why not other medical treatment? The authors would argue that genetic information is special, and hence genetic technologies more powerful than other medical treatments. Even allowing this, it would seem that the authors would have to defend the use of genetic enhancement technologies by a lottery winner to produce a son tall enough to play professional basketball, while denying gene therapy to a non-lottery winner’s child. The lottery system (as presented, though perhaps not in all forms) fails to distinguish between those who need to win on medical grounds, and those who would like to win for more “cosmetic” reasons. The line between genetic therapy and enhancement is notoriously difficult to define, yet the authors do not seem to appreciate that such a lottery would at least have to make some distinction (however arbitrary), if it were to be, not just egalitarian (we’re all equal before the dice) but also ethical.

A broader problem with the book is the underlying assumption that genetic information is all powerful. Although not as “triumphalist” as many others writing in this area, the authors’ arguments and scenarios do depend on a rather deterministic view of human genetics, to the almost total exclusion of environmental influences. Despite this, the book is highly recommended to the interested reader and perhaps as a course book.

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Deciding Who Lives

Renee Anspach, California, University of California Press, 1997, 303 pages, £12.95 (sc).

Deciding Who Lives is an analysis of the practice of medical ethical decision making in the neonatal intensive care nursery. As stated, the book seeks to study not philosophical principles of bioethics, but rather the practicality and reality of implementing these principles. Both the strengths and the weaknesses of this study emanate from the author’s basic lack of active participation in the field.

As an outsider observer of the intensive care nursery environment, the author is able to make some refreshing observations, unencumbered by the professional biases to which those of us working in the field are subject. I found her comparative analysis of the differential observations of doctors versus nurses, and the implications thereof particularly fascinating. There is much that we as practitioners can learn from
her critical dissection of some typical staff/parent interactions.

I also found Ms Anspach's observations on "producing assent" cause for a bit of introspective analysis. As she states (page 166): "Members of the nursery staff do not usually follow a policy of informed consent, but rather employ a set of practices to elicit parents' assent to decisions that have already been made". Her insights into the ways in which the staff appeared to coerce parental consent to decisions already made, with complete disregard for the parents' needs and desires was a recurrent theme in many of the conversations which she quotes. The perceived need to conceal from parents any signs of differences of opinion among the staff is symptomatic of a haughtiness which is unacceptable in the current medical climate. The arrogance with which the medical staff so often discounted parents' feelings about their baby was at times frightening.

On the other hand, medical inaccuracies such as referring to phototherapy lights as ultraviolet lights, do tend to make medical professionals look askance at any further conclusions. In a situation such as this, there exists a definite danger of overgeneralising from quite limited observations in the face of inadequate understanding. The author's observations are based on sixteen months' observation spent in two different nurseries. Both the breadth and depth of the data intake are potentially problematic. As clearly noted, the practice of medical ethics is influenced by cultural and socioeconomic factors which would be expected to vary with populations and locale. Observation in two nurseries hardly seems sufficient to characterise the behaviour of thousands of physicians and nurses across the world.

Secondly, the period of time is also limited: in sixteen months, even in the busiest of nurseries, how many life-and-death decisions can there be? Finally, I question the accuracy of some of the assumptions proposed. Throughout the book, physicians seem to come across as arrogant, cold, distant, and uncaring - the more senior the physician, the more out of touch. Is it possible that these senior staff members merely spent less time discussing and explaining their thought processes with the author? For example, on page 185 we are introduced to an attending physician who states: "And for your notes, this is a very difficult ethical problem, the problem of iatrogenesis. I'm not particularly anxious to be called into court and it is not in my self interest to have this baby survive". This is a highly incendiary remark which can cause a tremendous amount of harm and distrust if picked up by a parent support group. I am troubled by what I feel to be an underlying tendency in Deciding Who Lives to oversimplify - and as a result, to trivialise - a most complex issue.

Finally, I am left with a sense that this book is dated. I find it hard to imagine that some of the conversations cited took place in the current atmosphere, which has become increasingly sensitive over the last ten years. In addition, although the legal need for ethics committee approval is mentioned, the committees themselves are most conspicuous by their absence in any clinical decision making role in the representative cases cited. Furthermore, for a book released in 1997, I find it glaring that there is not one reference in the bibliography dated after 1990. The author states that this book is not a study of the philosophy, but rather of the practicality of decision making. There is a danger that as the realities of practical decision making change, observations such as those presented here will quickly become anachronistic.

In conclusion, this is an extremely important area of investigation and Deciding Who Lives offers some meaningful and eye-opening insights into the ways in which we function - both positive and negative. There is much we can all learn from Renee Anspach's analytical examination of the patterns of our decision making and interactions with patients, with parents and with colleagues.

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Who Cares? The Great British Health Debate


In 1948 could the health professionals and the public alike, have conceived of the changes which would shape the National Health Service (NHS) in the following fifty years? While we celebrate and reminisce at the time of the NHS's fiftieth birthday, Oliver Morgan takes the reader first into the fantasy world of 2048, stretching the imagination to consider new scenarios of health care provision. Following the back-to-the-future trip, Morgan takes the reader back in time, for a bird's eye view of the first fifty years of the NHS.

The strength of the book is in its well-researched, informative coverage of a number of themes (with frequent reference to the views of leading health policy formers, analysts and health professionals): the accountability and clinical freedom of medical professionals; the consistent difficulties in achieving an equitable provision of health services, and the government's role in shaping health services. These themes are explored with particular reference to the internal market; the role of doctors; accountability to the public; the funding of health care; the role of hospitals in health care; evidence and effectiveness, and rationing. Morgan's messages on these issues are lucid.

Morgan argues that Bevan's concession to general practitioners in 1948, to protect their independent contractor status, along with the sacred cow of clinical freedom, has never been successfully challenged. Consequently, the medical model of health care has been perpetuated and held domain. He suggests that replacing the Hippocratic oath with a "doctor's charter" would be the key to bringing practice in line with the changed structure of the NHS.

In addition, the rise in popularity of evidence-based medicine is a clear challenge to clinical freedom, and will increasingly be so if protocols and guidelines, accompanied by published information on outcome measures, are to be part of the NHS in the future. These changes in practice are clearly unpalatable to the medical profession, but this has to be balanced with the ethical implications of poor practice, and the ethical decisions which are currently hidden by individual clinicians' decisions.

The NHS has not yet won the battle to ensure an equitable provision of health services; Morgan frequently draws attention to the inequity at several levels. First to be highlighted is the tension doctors face between their allegiance to the Hippocratic oath, which puts the individual patient in the place of prime importance, and the need to consider the health of the total population.

The reforms at the beginning of this decade decreased equity through fragmentation; and whilst they were sold