

Genomics and world health

By the Advisory Committee on Health Research
Published by World Health Organization,
Geneva, 2002
ISBN 92 4 154554, price Sw.fr. 35

Redesigning humans — our inevitable genetic future

By Gregory Stock
Published by Houghton Mifflin, New York, 2002
ISBN 0 618 06026 X, price US\$ 24

“As I see it, the coming opportunities in germinal choice technology far outweigh the risks. What is more, a free-market environment with real individual choice, modest oversight, and robust mechanisms to learn quickly from mistakes is the best way both to protect us from potential abuses and to channel resources toward the goals we value,” writes Gregory Stock in Los Angeles.

“Because many of the medical benefits of genomics research may, at least at first, be very expensive, there is a danger that these new developments will increase the disparity in health care within and between countries. There are particular concerns that inequalities in health care will be accentuated by the current trends in the management of intellectual property, particularly the patenting of basic genomic information,” writes the Advisory Committee on Health Research in Geneva.

The Human Genome Project has focused the world’s scientific, intellectual and political attention on the possibilities genetic science and its technological applications hold out for understanding the causes of disease and ways of treating and preventing it. The two excellent books reviewed here offer wide-ranging and stimulating accounts of what possibilities are currently credible, what implications they have for human health and welfare, and what risks or challenges they may pose now and in the short- to medium-term future. Both volumes depend on a thorough knowledge and understanding of genetic research not only in human biomedicine but also in agricultural science, pathogen biology, and public health. Both volumes share the virtue of

lucid and engaging writing, and are easily accessible both to the general reader and to the scientist or policy-maker. I can warmly recommend either book; yet I want here to challenge some of the social and moral assumptions underlying each.

One consequence of the so-called “genetic revolution” has been the rapid growth of bioethics as an academic discipline. The influence of this discipline can be felt in both volumes. In the case of the WHO report, one of the co-authors is Professor Dan Brock, an internationally known and respected figure in bioethics, who has been a member of several high-level bioethics commissions in the United States. The other two authors are Professor David Weatherall (as lead author), a world expert on clinical genetics, with a particular interest in haemoglobinopathies, and Professor Heng-Leng Chee, a scholar of health policy and women’s health from Malaysia. The report benefits from the balanced attention paid to the scientific, ethical and policy implications of genetic research.

About half the book concerns the current state of scientific knowledge of genetics, and likely future developments. Quite a large part of this discussion is devoted to risks of genetic technologies, and to the benefits genetic technology is likely to bring for the health of the citizens of the developing countries. Following this discussion of risk and benefit, there are three important chapters on justice and access to genetic technologies in the global social, economic and medical context, on ethical issues in genetic research, screening and testing, and on education and public policy-making. To a bioethicist, this is a fairly straightforward and typical way of setting out the ethical and policy issues, unusual only in that the issue of distributive justice and fairness is treated before the issues of informed consent and confidentiality. To my mind, this is a useful and important shift in priorities. However, there are two peculiarities to this approach which remain unaddressed.

Firstly, the substantive issues, very widely discussed in the theological and philosophical literature, concerning the morality of modification of genomes

(human or non-human) and the consequences of taking a genome-centred approach to our understanding of human nature and human potential, are not discussed at all. This omission is not surprising in a book devoted to summarizing the state of genetic knowledge and its policy implications in a very practical and pragmatic way. Nevertheless, it contributes to a general tendency of assuming that genomics is the royal road to health and welfare. I suspect that the authors’ intentions were more modest: genomics offers many opportunities, and we should try to grasp them in a way which will benefit the health of the many rather than of just the few.

However that may be, this focus on genetic technology taken out of any current cultural context leads to a failure to grasp why genetic technologies are so troubling to many people in the world today. In particular, the strategy of arguing that a particular genetic technology (genetically modified rice, for instance) may be useful, beneficial, safe and cheap, and therefore should be widely adopted, frequently fails. And it is natural to attribute this failure either to a deficit in understanding (on the part of the unconvinced) or in explanation (on the part of the science and policy communities). Yet while more and better-presented information can remedy gaps in knowledge, it will not resolve conflicts of values. Furthermore even where values are shared, different participants’ interests — or perceptions of their interests — may well conflict, and the idea that there is a single objective account of the ethical and social merits of genetic technology which defines what is (or is not) in the “public interest” is highly problematic.

This takes me to the second peculiarity of this report. It can be read as a practical, but decontextualized, account of the generic benefits, risks and possibilities of genetic technologies for world health without explicit commitment to any particular political or moral philosophy beyond a minimal, reasonable account of some general moral principles shared by all. As such, it sits squarely in a long tradition of liberal

political thought about how to build a stable, but fair, society while respecting private dissent and disagreement.

Yet it is also possible to take this approach in a different way: as itself a substantive account of what is valuable. As such, disagreement with its principles is not so much private variation in views as simply wrong. Hence, on the “weaker” liberal view, if a genetic enhancement of some human capacity (such as intelligence or height) is safe and reliable, and if it is freely available in a way that everyone who wants it has a fair chance of getting it, and if no one is coerced into either using it or not using it (so they can choose freely what they want to do), then to ask further “Is it morally acceptable?” is merely a matter of private reflection, rather than a topic for public policy. Yet, understandably, many people will feel that there is something morally corrupting about such technologies, and they should be banned or regulated strictly. According to the “stronger” liberal theory, the attempt so to regulate this technology would be an illegitimate interference with personal liberties, and so wrong.

In the strong version of liberal theory, personal choice plays a particularly important role as the capacity possessed by agents for determining their actions and personalities. As such, it includes both the fragile capacity to be protected by the assignment of strong rights and civil and political institutions, and the source of personal responsibility and obligations to oneself and others. Many critics of bioethics have associated this strong liberal theory of the centrality of autonomous choice with the image of the human person as *homo economicus* drawn in the 1970s from the work of Adam Smith, to whom freedom of contract and rights of private property were all.

The WHO report is hardly a textbook example of economic liberalism. Yet its relatively weak response to the problems it identifies with gene patenting may reflect an understanding of bioethics which has few resources for responding to, refuting, or replacing the orthodox economic liberal approach to regulating genetics and biotechnology. The quotation at the head of this review,

as well as the special place the report gives to informed choice, are examples of this weakness. The report advocates a global approach to harnessing genomics in the service of the world's health, but if this is to succeed, at least some departures from liberal economic orthodoxy seem essential. The report's commentaries on its recommendations 9 and 10, concerning developing-country access, make this clear.

For a much more hearty and sanguine approach to genetic technology, we can turn to Gregory Stock's volume. This is a cut above the usual gee-whizz accounts of the applications of genetics to “improving” the human constitution, being rather carefully constructed in its account of what is technically plausible and likely from the point of view of present human interests and concerns. What is curious about this book is that while it takes much of human nature to be malleable — and improvable — it also takes certain facets of our nature to be fixed, and it is these fixed characteristics which determine that our “genetic future” is rather well-defined and indeed “inevitable”. Stock has no time for bioethical hand-wringing, and he scores some good hits in identifying ways in which many bioethical nightmares are either technically impossible or based on ignorance and confusion about the science or are in fact complicit in social conservatism of various kinds. What Stock is unwilling or unable to challenge, though, is the economic ideology which privileges the autonomous choice of the biotechnological consumer as the foundation of bioethical rights, while at the same time specifying the values which this consumer will, wittingly or not, promote — namely, effectiveness in the economic, social or biological marketplace.

Thus, the direction of inevitable genetic change is towards the prevention of all illness which would weaken one's earning capacity or self-sufficiency, the extension of one's lifetime (and hence one's consuming power) indefinitely, and the enhancement of one's physical and intellectual powers (and hence one's “edge” in the employment and relationship marketplace). That economic agency is the motor of this

process rather than merely a side-effect is evidenced in part by his choice of examples (for instance the ability to take part in professional competitive sports) and in part by the mechanism for progress he stresses most, which is fear of falling behind others whose capacities are naturally or artificially superior to our own.

Both of these excellent volumes can therefore be seen to embody the central paradox of biomedical science at the start of the 21st century: on the one hand perhaps unlimited potential for relieving human suffering and improving human welfare; on the other, profound entwinement with a system of production and consumption which both distributes these benefits so unevenly and convinces us that no other system is either possible or desirable. Both reports show us what is possible: perhaps the Stock book shows us where we are going if we fail to take the WHO committee's concerns seriously? ■

Richard Ashcroft¹

¹ Leverhulme Senior Lecturer in Medical Ethics, Imperial College of Science, Technology and Medicine, Reynolds Building, St Dunstan's Road, London W6 8RP, England (email: r.ashcroft@ic.ac.uk).