

Manipulating mankind

John Habgood

Perilous Knowledge: The Human Genome Project and its Implications.

By Tom Wilkie. *Faber and Faber*: 1993. Pp. 195. £14.95.

The Human Body Shop: The Engineering and Marketing of Life. By Andrew Kimbrell. *Harper San Francisco*: 1993. Pp. 348. \$22, £8.99.

THE Human Genome Project must be unique among major scientific programmes in having three per cent of its budget set aside for the study of its ethical implications. In a three-billion-dollar budget, that is a lot of money. It is a measure of the concern felt by some of the initiators of the project about its potential social impact.

Why is the project being done at all? In part it reflects the growth in the relative importance of genetic disease as other potentially fatal diseases have been eliminated. Thalassaemia, for instance, manifested itself in Cyprus only as malaria deaths declined. Given that there are some 4,000 diseases known or suspected to be due to single-gene mutations, a reliable and comprehensive genetic map could be an enormous aid to diagnosis, even though the problems of effective treatment are likely to remain formidable.

In part the project also represents a successful bid to bring biology into the 'big science' league, not least because the US weapons programme was looking for ways to diversify into the study of the genetic effects of radiation. The motive that finally prevailed, however, seems to have been the sheer challenge of unravelling such a massively complex structure, of finding, as some put it, "the holy grail of human biology". Time has tended to change all that. There is more emphasis now on mapping and elucidating the structure of identifiable genes, rather than trying to sequence the whole genome, a large proportion of which seems to have no clear function. And motives have become more mixed, as evidenced by frustrating disagreements over whether or not sections of the genome can be patented.

Commercial interests also loom large in some of the ethical issues. Knowledge is not always an unmixed blessing. Given that it may be possible to diagnose a genetic predisposition towards a wide variety of conditions from heart disease to schizophrenia, what are the implications for health care, for instance, and how will it be possible to avoid discrimination in employment? These problems are already with us, and at a conference last year in the

United States a main topic of conversation was whether a privately funded health system can any longer be operated without gross unfairness.

Bigger problems about the effective treatment of genetic conditions, and the potential for making genetic 'improvements' to individuals or their progeny, belong mainly to the future. But they will certainly arise. Tom Wilkie foresees a new generation of "snake oil salesmen" peddling illegitimate claims about what the new biotechnology can do for the desperate or the gullible.

Previous experience of the use of this kind of knowledge is not encouraging. Lessons have been learnt from the mishandling of the US screening programme for sickle-cell anaemia, which resulted in widespread discrimination against many who were at no risk of contracting the disease. But what, for example, are the ethics of screening for conditions where there is no effective cure? The commercial exploitation of genetically engineered human growth hormone is another unsavoury precedent. This was a product looking for a market, and finding one by trying to alter the definition of normal human height.

Wilkie writes attractively, forcefully and unsensationally. For those who want an accurate but not too technical account of what is happening in genetics, and the ethical problems to which the discipline gives rise, *Perilous Knowledge* could scarcely be bettered. He points beyond the immediate issues, which are difficult enough in all conscience, to the fundamental change in perspective which this completion of Darwin's work may produce. Perhaps the most destructive consequence may be the reinforcement of reductionism, the sense that humanity is now 'understood' in a newtonian sense, and hence the false idea that human beings are simply to be identified with their genes, and no more. He wrestles with the concept of human uniqueness and while, unnecessarily in my view, rejecting a religious interpretation of this, ends up with a high view of the moral worth and transcendence of human life.

The Human Body Shop paints an alarming picture of what could happen, and in many respects is already happening, when this sense of the transcendent significance of human life is ignored, and when the human body is made subject to commercial pressures. The book is much more balanced and sober than its title and a somewhat over-the-top foreword by Jeremy Rifkin might suggest.

Andrew Kimbrell is an American lawyer who in recent years has made a detailed study of the social impact of biotechnology. He surveys an enormously wide field from the sale of blood to the collecting of fetal parts, from transplant surgery to surrogate motherhood, and

from the search for a perfect baby to the patenting of life. His style is anecdotal. Much of his material is drawn from court cases in the United States. The use he makes of newspaper articles may arouse some doubts. But even if only half of what he records is accurate, it remains a powerful indictment of attitudes and practices that tend to treat the human body as a commodity, ripe for being serviced by suppliers of spare parts.

A single illustration must suffice. In June 1991, a 14-month-baby was used to provide bone marrow for her 18-year-old sister who was suffering from leukaemia. Their parents subsequently announced that they had conceived the child solely for the purpose of providing compatible bone marrow for their other daughter. In this instance there was a happy ending. But suppose prenatal diagnosis had revealed that the bone marrow would not be compatible. Would they have had an abortion and tried again?

Philosophies that treat the body as a machine and the market as the unquestioned supplier of human wants, are endemic to the whole of the Western world. As manipulative techniques become more powerful, the pressures to use them, initially no doubt in response to urgent need and eventually to feed human vanity and selfishness, could become irresistible. Choices need to be made now about the direction in which we wish our civilization to move. □

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