Hereditary: Science and Society: On the Possibilities and Limits of Genetic Testing and Gene Therapy


This comprehensive report was prepared by a committee comprising three geneticists, two specialists in health law plus one other lawyer, two ethicists, and experts in philosophy, social medicine, medical information and toxicology. Thus, the feet of the geneticists must surely have been kept firmly on the ground as the uses of the new developments in genetic knowledge as applied to medicine were discussed. It is indeed a very balanced report, overall encouraging the application of new techniques but judiciously warning about possible danger areas. Since its submission, The Netherlands' government has formally endorsed many of its recommendations, by using it as a basis for a policy document.

The committee examined genetic diagnosis and counselling, genetic registers, cell banks, population screening, pre-implantation testing, gene therapy, and genetic testing outside the health-care system with special reference to insurance and employment. It considered associated issues, the social, ethical and legal implications and the consequences for individuals and for society as a whole and for groups within it.

Hitherto, advances in genetics have principally been influential in the realm of reproduction. This has been through counselling of couples who have had a child, or have a close family member affected by a genetic disease, to advise on risks in a future pregnancy, and, with increasing sophistication and accuracy, prenatal diagnosis of any conceptus which may arise. Now, we are on the threshold, not only of enhancing this area with pre-implantation diagnosis, but also of extending genetic diagnosis and risk assessment to all individuals, for genetic disorders they might develop in later life, such as cardiovascular disease. With the pace of genetic research increasing as plans for mapping the whole human genome materialise, it may not be long before we have genetic markers for many of the common diseases of advancing years, and it will be possible to predict, even in utero, whether an individual is at risk of developing, for example, diabetes mellitus, high blood pressure, ischaemic heart disease or duodenal ulcer, and probably some types of cancer too. The advantages of this are that it will lend itself to preventive medicine, for many of these disorders are not purely genetic: environmental factors are also necessary for their expression, and if these can be specifically circumvented, then much of such disease could be avoided. But not all late onset genetic disease can be prevented, or even treated, and it is questionable whether there are any benefits in knowing in advance that one is to develop these. The report discourages mass genetic screening per se as a goal. Most welcome too is its recommendation that the use of genetic testing by insurance companies for prospective clients, and also the disclosure of prior genetic information, should be banned. Similarly, it rejects genetic testing in the selection process for employment, save in certain circumstances when it is in the interests of a third party or to protect the health of the individual. There is a good coverage of the whole matter of privacy of information, for it is important in other contexts too. Basic information including genetic data about patients is kept in computer data banks, genetic registers form an essential part of genetic services and of research, and genetic information about a person can have important implications for other family members. It is generally agreed that limits must be put on access to this information to preserve confidentiality, but the report also recommends that the use of any genetic data should be restricted to the purposes for which it was collected, and asks for monitoring committees to be set up to ensure compliance in this matter.

The report is well argued, informative, all-embracing and a fair appraisal of the prospects for the future prospect - hope for, and acceptance of, the benefits which might accrue, while offering realistic safeguards and prohibitions. Dutch society has been well served by this committee: their report deserves to be widely read.

MARY J SELLER, Reader in Developmental Genetics, Paediatric Research Unit, Division of Medical and Molecular Genetics, 7th Floor, Guy's Hospital Tower, London Bridge, London SE1 9RT.

AIDS a Moral Issue – Ethical, Legal and Social Aspects


AIDS is a frightening condition, killing large numbers of young people; it has spread into all groups within the community and there are no clear means of prevention. Partly because AIDS is sexually transmitted it has
thrown into sharp relief a number of ethical, legal and social issues. This book is concerned with discrimination because of sexual orientation, the alienation of some groups in society such as drug users, theological responses to minority groups and doctors’ responsibilities concerning confidentiality. Additional chapters address the distortions and simplifications which occur in the popular press about complex issues such as sexuality and HIV infection and there is a particularly clear chapter on the legal aspects of being HIV-positive in this country and the United States.

A more enlightened attitude amongst health-care workers, including doctors and policy-makers, will be encouraged if the discrimination encountered amongst AIDS patients is placed in a more general context – which this book sometimes fails to do. I feel this book needs a clear statement of the ethical principles involved and their application to the topics discussed in each chapter. The intended readership is not explicitly stated but the issues are important to a wide audience. Some of the more contentious peripheral issues discussed in the book may detract from the important message for a general readership.

This book results from a conference held in 1986 and its delay in publication gives a dated feel to some of the discussion, for example, new advances in technology have rendered the problem of false positive and negative HIV tests virtually obsolete. Many doctors would also accept that asymptomatic HIV seropositive individuals can now be given treatment which will prolong life. This is bound to influence judgements about the value of HIV testing. The bibliography is often obscure and mainly pre-1986 – few readers for instance, will have access to the abstract of the Third International Congress on AIDS held in Washington DC.

This book addresses extremely important issues which confront all of us concerned about HIV infection. It should be widely available in university and medical school libraries and it is inexpensive enough for many of us to buy and ponder over.

**Social Science Perspectives on Medical Ethics**

Edited by George Weisz, 290 pages, Philadelphia, $17.95 sc, University of Pennsylvania Press, 1990

This interesting book is based on a selection of papers originally presented at a 1988 meeting of social scientists and ethicists carrying out research on issues related to medical ethics. Most contributors draw on data related to North America but Weisz writes on the origins of medical ethics in France, Stacey on the General Medical Council in Britain and Lock on heart transplantation in Japan.

The book has two purposes. The first is to present research on how ethical issues are handled in particular institutional or cultural settings. Decision-making and issues of informed consent are examined in the areas of neonatal care, family planning and psychiatry. Here, the researchers’ approach is mainly ethnographic. This allowed them to examine how ethical decisions were made in practice. Other papers look at policy-making in areas of public concern. Rothman examines the process by which the issue of experimentation involving human subjects became politicised in the United States, while Fox traces the evolution of bioethics. These chapters make fascinating case-studies available to a wider audience. They illustrate the dynamics of decision-making and the power relationships between interest groups. It comes as no surprise that medicine dominates but the nuances are important in developing a knowledge of the facets of power.

The book’s second purpose is to help bridge the divide between the ethics and social science disciplines. A number of papers draw attention to the limitations of moral theory with its emphasis on individualism and abstract concepts. They point to the importance of examining how mediating structures and institutions such as class, ethnicity, family and profession may expose people to different obligations. They argue for a ‘contextualised morality’. However, the problem remains that this is social science rather than ethics.

The issue clearly dogged the conference and could have been more fully addressed in the collection. In a somewhat tantalising introduction Weisz comments on the dynamics of the conference itself, mentioning ‘some’ friendly exchanges between ethnographers and ethicists and the ‘surprisingly silent’ anthropologists. He looks to ethnography as a possible method for developing the study of morality in practice where there could be common ground between social science and ethics, between the ‘is’ and the ‘ought’ in social life. No doubt a structural sociologist would comment that behind the academic endeavours lie concerns about ‘turf’ and the ownership of knowledge.

**Power to the People**

Edited by Liz Winn, 91 pages, London, £7.50, King’s Fund Centre, 1990

A coterie of a dozen authors, not medically qualified but working earnestly ‘in and around health services’, have each produced a chapter about their own sphere of activity to form an ‘anthology of approaches which are trying, not just to involve users of the health and social services, but to empower them when they come into contact with these services’. Their ‘initiatives are concerned with shifting the balance of power toward those using services and away from those providing them’ and we learn that ‘where initiatives have succeeded they seem to need at least a partial residual of service provider monopoly on ideas, debate and decision-making in favour of users’.

The booklet’s title and its depiction in graffiti form, as well as these preliminaries, hint at revolution. Those who believe our services stand in need of just such a thing, as well as others who think increased funding alone to be the sovereign remedy, may all find in the text items of interest.

Topics include ‘empowering older people in respect of their own health care’; tailoring services for those with learning difficulties to what they need and want; ‘user group involvement’ in mental health services to enable users ‘to exercise a greater control over their own lives’; ‘citizen advocacy’ and an ‘advocacy agency’; and what information is necessary to choose a GP or hospital.

The authors would have furthered their cause had their communicative skills been evident to readers. Instead,