

AUTUMN BOOKS

Children First. By Penelope Leach. (Pp 302; £14.99 hardback.) Michael Joseph, 1994. ISBN 0-7181-3813-9.

I am usually highly resistant to exhortations from reviewers that a particular book is 'essential reading'. But now and again one appears which should command our attention and I urge all paediatricians to read Penelope Leach's new book.

Her case is that 'post-industrial western societies', such as the UK, ignore or override the special needs of children to such an extent that they miss out and even suffer, the enthusiasm and commitment of parents is stifled and their effectiveness compromised while the long term social and economic well being of our nation is needlessly damaged. These arguments are presented in the first part of a fluently written, lively, challenging, and often uncomfortable book. The overview of children's needs and rights sweeps from pre-conception right through infancy and childhood to adolescence, with fascinating and often devastating insights into how far from child centred our society is and what are the effects of sidelining children. Some sections are outstanding in their own right. Examples are the chapter on gender issues; the section on breast feeding; the chapter 'Growing up takes time', an essential antidote to our norm obsessed approach to children's early developmental progress; and '7-up: the years we ignore', a disturbing commentary on the blackboard jungle and the relationship between parents, children, and their schools. The detailed discussion of day care will cause personal discomfort to many, including doctors, because of the constraints on family life which career demands have placed upon them.

In the second part of the book, Leach outlines her suggestions for achieving a more child centred society which, she argues, would benefit all sections of the community and which make long term economic as well as humanitarian sense. Her proposals include a 'child up' assault on poverty; domestic and international legislation to give children comprehensive human rights as a basis for changing society's attitude to childhood; and a planned reshaping of the 'post-industrial' work place which acknowledges the needs of parents, especially for time and space for parenting. If the programmes collectively seem radical, Leach argues that this is because they must be, and that if we do not choose to open our eyes now and respond proactively, we will be forced by demographic and social changes to do so reactively at greater cost.

Perhaps the most surprising aspect of this book's challenge is that its basis, in terms of insights into children and their needs, is largely accepted and uncontroversial. It is therefore the logic of the proposals for change which is so uncomfortable. Economists and social scientists may want to argue parts of Leach's case, but the gauntlet has been thrown down and should not be ignored. The resulting debate must surely be illuminating and constructive whatever the outcome.

What about the medical profession? Historically it has a poor track record of awareness of the wider needs of childhood, as the history of NAWCH demonstrates. The paediatric reaction to this book will be an interesting indication of whether and how much attitudes are changing.

A practical point – don't miss the valuable notes on each chapter which (for policy reasons on the part of the publishers) have not been clearly annotated in the text. They are at the end of the book and should be searched for, as they illuminate the argument with further authority.

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Children as Research Subjects: Science, Ethics and Law. Edited by M A Grodin and L H Glantz. (Pp 258; £30 hardback.) Oxford University Press, 1994. ISBN 0-19-507103-4.

Probably most, if not all, paediatricians believe that research using child subjects is not only ethical but is essential to further improvements in the health and wellbeing of all children. This is true even in some situations where there may be no direct benefit to the child subjects themselves, so-called *non-therapeutic* research. However, from time to time ethics advisory committees, members of parliament, and members of the public will question not only the ethics but the legality of such research. While such criticism is often based on ignorance of the facts and media exploitation of the circumstances, it does leave paediatricians uneasy about the possible consequences of embarking on research projects even when they may be of considerable potential value to future generations.

This American book is welcome as it gives further reassurance to paediatricians that responsible research using children is important, ethically acceptable, and unlikely to attract legal attention provided that certain conditions are met, notably a proper balance of benefits and risks; the consent of parent(s), the assent of the child where appropriate, and the approval of an ethics advisory committee. It complements the excellent 1986 UK publication edited from the discussions of a group set up by the Institute of Medical Ethics 'to encourage reflection and, perhaps, to help members of Research Ethics Committees in the discharge of their duties'.¹ The British book originated (and benefited) from distillation of the thoughtful deliberations of a large and distinguished group of scholars from many disciplines. The American book, after an interesting historical overview of paediatric experimentation (which provides ample evidence for the need for strict controls), consists of one or two author chapters on subjects grouped under two main heads, 'Science, ethics and the law' and 'Practical problems'. The core issues are well covered: the risks and benefits of research; the assessment of risks and their acceptability; the problems of consent, and the legal status of experimentation using children. British paediatricians will find the chapters 'Ethical issues in exposing children to risks in research' by Dan Brock, a philosopher, and 'Vulnerable children' by Robert Cooke, a paediatrician, of particular interest and value. In both the UK and the USA, the law has played a relatively small role to date. In the UK there is no law which specifically addresses paediatric research (and

no case law), though legal provisions which protect the interests of children also circumscribe the conduct of research. In the US, only one case involving research is quoted and there is no statutory law, but there are federal regulations though these are relatively unrestrictive. They are recorded in a useful appendix that also contains the 1947 Nuremberg Code, the 1989 World Medical Association Declaration of Helsinki, and a list of points to consider in proposing or reviewing research involving children.

In his chapter, 'The law of human experimentation with children', Leonard Glantz, a professor of health law, writes 'What the law has done in recent years, however, is set a general tone that indicates that children have some rights that they may exercise on their own behalf, and that parents and institutions have an obligation to protect children and not to exploit them'. He goes on to say that 'paternalism in regard to competent adults is viewed with suspicion, paternalism as applied to children is both common and desirable. It is the role of adults to ensure that children are not subjected to unnecessary or excessive risk of discomfort. The law is a crude tool for accomplishing this goal'. Hear! Hear!

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1 Nicholson R, ed. *Medical research with children: ethics, law and practice.* Oxford: Oxford University Press, 1986: 265.

The Inherited Metabolic Diseases. 2nd Ed. Edited by John B Holton. (Pp 596 no price stated, hardback.) Churchill Livingstone, 1994. ISBN 0-443-04497-X.

It is my perception that colleagues consider inherited metabolic disorders rare and esoteric, to be considered at the bottom of a list of differential diagnoses. For individual disorders this may be true, but as a group metabolic diseases are an important cause of morbidity and mortality, extending from the neonatal period into adult life. Rapid advances in the understanding of disease mechanisms have brought with them an increased ability to diagnose disorders accurately (both prenatal and postnatal) as well as introducing potential new therapies such as enzyme replacement or gene transfer. We live in an exciting era!

Of course, for some the only knowledge desired or required will be the telephone number of the nearest metabolic specialist. For others a sound grounding in the basic principles of inherited metabolic disease will enable them to perform a sensible range of investigations before transfer to a more specialised unit for more detailed investigation and management.

The undergraduate and postgraduate teaching of inherited metabolic disease is generally poor and there has been a shortage of readable, middle sized texts on the subject. For most workers within the field, *The Metabolic Basis of Inherited Disease* edited by Scriver and colleagues will remain the standard reference textbook. It is unsuitable, however, for the medical student and junior doctor who wish to have a taste of the subject rather than a feast. Holton has attempted to fill a gap in the market by producing a middle sized text which it is claimed is 'concise, but nevertheless comprehensive and accurate'. The first edition of the book published in 1987 failed to fulfil these commendable