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 response to this book will be of particular interest as to how much attitudes are changing.

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

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Probably most, if not all, paediatricians believe that research using child subjects is not only ethically justifiable but essential to further improvements in the health and wellbeing of all children. This true even in 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 incorrect information 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 legislation 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. The book is designed for use in the UK and is based on previously published American law.

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, mortality and handicap in 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 for research and clinical purposes) 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 diseases 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, Beaudet, Sly, and Valle (McGraw Hill, 1989) is 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
Children as Research Subjects: Science, Ethics and Law

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