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# Management for Child Health Services

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EDITED BY

Michael Rigby, Euan M. Ross  
and Norman T. Begg



SPRINGER-SCIENCE+BUSINESS MEDIA, B.V.

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# Management for Child Health Services

Edited by

**Michael Rigby**

Centre for Health Planning and Management  
Keele University  
Staffordshire  
UK

**Euan M. Ross**

King's College School of Medicine and Dentistry, London  
Mary Sheridan Centre for Child Health  
London  
UK

and

**Norman T. Begg**

PHLS Communicable Disease Surveillance Centre  
London  
UK



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# Dedication

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*The editors dedicate this book to their own children, who by their positive and cheerful drives to put the maximum value into life's opportunities have given their parents a continuous reminder of the incalculable importance of ensuring the optimum health and development for each and every young person. This book is for you, as the representatives of your peers.*

# Contents

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<i>Contributors</i>	ix
<i>Foreword</i>	xvii
<i>Introduction</i>	xix
<b>1 The development of British child health services</b>	<b>1</b>
<i>Euan M. Ross, Michael Rigby and Alison While</i>	
<b>2 Management skills in the new NHS</b>	<b>26</b>
<i>John Owens</i>	
<b>3 Working with parents</b>	<b>41</b>
<i>Kate Saffin</i>	
<b>4 Consumer orientation and service quality</b>	<b>56</b>
<i>Michael Rigby</i>	
<b>5 Rights, values and ethical issues in child health</b>	<b>76</b>
<i>Peter de Cruz</i>	
<b>6 Analysing and promoting the health of children</b>	<b>99</b>
<i>Eva Alberman</i>	
<b>7 Information in child health management</b>	<b>122</b>
<i>Michael Rigby</i>	
<b>8 Running a clinical service: a case study</b>	<b>142</b>
<i>Harry Baumer</i>	
<b>9 Health service finance</b>	<b>164</b>
<i>Nicholas Jennett and Andrew Wainwright</i>	

viii	Contents	
10	<b>Developing personnel skills in management</b> <i>John Edmonstone</i>	181
11	<b>Analysing and controlling risk</b> <i>Malcolm Lowe-Lauri</i>	194
12	<b>Working with other agencies</b> <i>Brent Taylor and Euan M. Ross</i>	209
13	<b>The law relating to child health</b> <i>Jane Fortin</i>	223
14	<b>Project management</b> <i>Colin Nolder</i>	247
	<b>Appendix A Wales</b> <i>Joyce Thomas</i>	259
	<b>Appendix B Scotland</b> <i>Alison Allen, Anne Maree Wallace and Helen Zealley</i>	278
	<b>Appendix C Northern Ireland</b> <i>Adrian Mairs and Leslie Boydell</i>	299
	<i>Index</i>	317



# Contributors

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## **Eva Alberman** FFPHM, FRCP, FRCOG

Professor of Clinical Epidemiology (London University – Emeritus)  
Research Director, National Down Syndrome Cytogenetic Register  
Department of Environmental and Preventive Medicine, Wolfson Institute  
of Preventive Medicine, Medical College of St Bartholomew's Hospital,  
Charterhouse Square, London EC1M 6BQ

Initially appointed a Research Fellow in 1960 in the Paediatric Research Unit of Guys Hospital, where she remained until 1978, Eva Alberman worked on studies of cerebral palsy and Down's syndrome, and on the initial and follow up activities of the National Perinatal Mortality Survey. Additionally, in 1972 she was appointed Senior Lecturer, and then Reader, in Social Medicine at the London School of Hygiene and Tropical Medicine, where she worked on outcome studies of low birthweight. In 1979 she was appointed Professor of Clinical Epidemiology at the London Hospital Medical College, a post held for 10 years in which she continued her earlier studies. From 1979 to 1996 she was Deputy Chairman of the Medical Advisory Committee of the Office of Population Censuses and Surveys.

## **Alison Allen** BA

Formerly Clinical Audit Coordinator, Lothian Clinical Audit Department

Mrs Allen's experience in child health has included three years as coordinator of the Oxford Growth Study, looking at the effectiveness of screening for short stature in preschool children. Also, between 1992 and 1994, she was coordinator of a Scottish national audit on preschool child health surveillance looking at the availability of data and quality standards for auditing preschool surveillance programmes.

## x Contributors

### **Harry Baumer** MB ChB, FRCP

Consultant Paediatrician

Department of Child Health, Level 12, Derriford Hospital, Plymouth  
PL6 8DH

Dr Baumer has been a Consultant Paediatrician in Plymouth for 14 years, and was the Clinical Director of the combined child health directorate from 1989 to 1994. He is presently South West Regional Council Representative of the Royal College of Paediatrics and Child Health and Regional Adviser in Paediatrics. His research interests include neonatology, diabetes, asthma and informatics, and he is currently coordinating a multicentre controlled trial of two forms of neonatal ventilation.

### **Norman T. Begg** MB ChB, FFPHM, DTM&H

Consultant Epidemiologist, Public Health Laboratory Service, Communicable Disease Surveillance Centre

PHLS Communicable Disease Surveillance Centre, 61 Colindale Avenue,  
London NW9 5EQ

Dr Norman T. Begg qualified in 1976 from Edinburgh University. He worked in general practice and community child health both overseas and in the UK before entering training in public health medicine in 1981. He joined the PHLS Communicable Disease Surveillance Centre (CDSC) as a senior registrar in 1984, and was appointed to the post of Consultant Epidemiologist in 1987 with responsibilities for the surveillance of the national immunisation programme in England and Wales and clinical trials of new vaccines and vaccine schedules. From October 1993 to 1996 he was Deputy Director of CDSC. He chaired the Child Health System Consortium from 1990 to 1994.

### **Leslie Boydell** MB ChB, BAO, DRCOG, MRCP, MFPHM

Consultant in Public Health Medicine

South & East Belfast Trust, Trust Headquarters, Knockbracken Healthcare Park, Saintfield Road, Belfast BT8 8BH

Dr Boydell has held a Consultant Post in Public Health Medicine since 1990, both with the Eastern Health and Social Services Board in Belfast and South and East Belfast Health and Social Services Trust. Previously within the Eastern Health and Social Services Board, she had responsibility for child health and subsequently has held responsibility for health promotion within South and East Belfast Trust. She has been involved in the management of several European Health Telematics Projects within the field of primary and community health and social care.

**Peter de Cruz LLB, LLM, PhD**

Professor of Law

Law School, Staffordshire University, Leek Road, Stoke-on-Trent, Staffordshire ST4 2DF

Peter de Cruz, formerly Senior Lecturer in Law at Keele University, is currently Professor of Law at Staffordshire University and has written widely on Child Law. He has been Director of the MA in Child Care Law and Practice at Keele University, where he taught Family Law for eleven years. He is Editor of the *Practitioners' Child Law Bulletin* and his book, *Child Abuse* (co-written with Professor Christina Lyon) is now in its second edition.

**John Edmonstone MSc**

Senior Research Fellow

Centre for Health Planning and Management, Darwin Building, Keele University, Keele, Staffordshire ST5 5BG

John Edmonstone is an experienced practitioner within the Human Resources field, having held a number of senior positions within the UK National Health Service. He combines an academic role at Keele University, contributing to a number of Masters and Diploma programmes, with consultancy and advice within the public sector. Mr Edmonstone is a regular contributor to publications within the management and organisation development sphere.

**Jane Fortin LLB**

Solicitor and Senior Lecturer in Law

School of Law, King's College, Strand, London WC2R 2LS

Jane Fortin is a solicitor and Senior Lecturer in law at King's College, London. She writes widely on child law topics and is joint-editor of the legal journal *Child and Family Law Quarterly*. For many years she was joint director of a specialised postgraduate course on child protection for a wide range of practitioners involved in this field of work.

**Nicholas Jennett BA, MSc, MBA**

Director, Moores Rowland Consulting

Moores Rowland Consulting, Tameway Tower, PO Box 30, Bridge Street, Walsall WS1 1QX

Nick Jennett is Director of Moores Rowland Consulting's Health Economics team. After an early career lecturing in microeconomics, he joined the Department of Health as an Economic Adviser, where he worked on the Prime Minister's Review of the NHS which culminated in the publication of *Working for Patients*. In recent years he has worked as a

## xii Contributors

management consultant within the NHS, with a particular interest in the application of economic techniques to issues faced by both purchasers and providers relating to the management of resources.

### **Malcolm Lowe-Lauri BA, MHSM, Dip HSM**

Chief Executive Officer, Peterborough Hospitals NHS Trust  
Peterborough Hospitals NHS Trust, Edith Cavell Hospital, Bretton Gate,  
Peterborough PE3 9GZ

Malcolm Lowe-Lauri is an honours graduate in modern history from Oxford University. He has a 'pedigree' background in NHS management, having held a range of senior posts at St George's Hospital, Tooting, and King's Healthcare NHS Trust, both being major London teaching hospitals. His postgraduate training included short spells at Cornell and Pennsylvania State Universities, and at the Nuffield Centre for Health Service Studies, Leeds.

### **Adrian Mairs MBBCh, DRCOG, Dip IMC, DPH, FRCS, MRCP, MFPHM**

Medical Officer, Department of Health and Social Services, Northern  
Ireland  
DHSS, Room C3.15, Castle Building, Stormont, Belfast BT4 3PP

Dr Mairs was formerly Medical Officer with responsibility for policy relating to Maternal and Child Health in the Department of Health and Social Services. His current areas of responsibility are Primary Care and Cancer Services.

### **Colin Nolder**

Business Partner, Lloyd-Nolder Associates  
Lloyd-Nolder Associates, Forum House, Stirling Road, Chichester  
PO19 2EN

Colin Nolder implemented the national Child Health System for health authorities in the North West Thames Region, prior to a career in community health management with Brent Health Authority (later Parkside Health Authority). He has been in independent business consultancy since 1989, working on national and international Information Management and Technology development projects, including quality assurance and accreditation for the Child Health System Consortium.

### **John R. Owens MB ChB, FRCP, FRCPC, DCH, Dip Hlth mgt**

Consultant Paediatrician  
Macclesfield District General Hospital, West Park Branch, Victoria Road,  
Macclesfield SK10 3BL

Dr Owens provides consultant paediatric services both in hospital and in

the community and has a special interest in childhood disability. In the past he has served on the Executive Committee of the Community Paediatric Group (now the British Association for Community Child Health), has been an examiner for the London Diploma in Child Health, and has been a member of the Disability Committee of the Royal College of Physicians of London. He has recently retired as a Clinical Director.

**Michael Rigby BA, FSS**

Lecturer in Health Planning and Management

Centre for Health Planning and Management, Darwin Building, Keele University, Keele, Staffordshire ST5 5BG

Michael Rigby is lecturer in health planning and management at the Centre for Health Planning and Management, Keele University, with which he has been associated since its establishment in 1988. His initial career was with Cheshire County Council in policy research, information, and planning in community health services, involving him in the development of pioneering computerised child health systems; the balance of his NHS career was in planning roles at district, area, and regional levels. His current research and teaching interests include health informatics, health management, and health sector reform in the UK, across Europe, and in overseas settings. He was vice chairman of the national Child Health Computing Committee, and its successor the Child Health System Consortium, from 1981 to 1995; a member of the Community Services Working Group of the Steering Group on Health Services Information; until recently an expert adviser to the Information Technology Committee of the British Medical Association and is co-chair of the Inter-Professional Forum on Child Health Informatics of the Royal College of Paediatrics and Child Health.

**Euan M. Ross MD, FRCP, FRCPC, FFPHM, DCH**

Professor of Community Paediatrics, King's College School of Medicine and Dentistry and Consultant Paediatrician, King's Healthcare and Lambeth Healthcare NHS Trust.

Department of Community Paediatrics, King's College, Mary Sheridan Centre for Child Health, 405 Kennington Road, London SE11 4QW

Professor Ross has worked in paediatrics since 1966 in Dundee, Bristol and London. He co-directed the National Childhood Encephalopathy Study, and is co-founder of the London MSc in Community Paediatrics. He is also former Chair of the National Child Health Computing Committee and of British Paediatric Surveillance Unit, and has had long involvement in management of children's services.

xiv Contributors

**Kate Saffin** MPhil, RN, RHV

Health Services Research Officer

Public Health Resource Unit, Institute of Health Sciences, Old Road,  
Oxford OX3 7LF

Kate Saffin spent fifteen years working in child health in Oxfordshire as a health visitor and professional head of school nursing before becoming a full time researcher. During that time she carried out a major evaluation of the personal child health record (PCHR) and developed an abiding interest in the complexities of empowerment for health service users, especially in child health. She has developed training materials and supported a number of health authorities and trusts as they have implemented the PCHR.

**Brent Taylor** PhD, MBChB, FRCP, FRACP, FRCPC

Professor and Clinical Director of Community Child Health

Department of Child Health, Royal Free Hospital School of Medicine,  
Rowland Hill Street, London NW3 2PF

Brent Taylor is Professor and Clinical Director of Community Child Health at the Royal Free Hospital and School of Medicine which operates a combined child health service linking hospital and community. His previous posts include training positions at the Great Ormond Street Children's Hospital, and senior lecturer positions in Christchurch, New Zealand, and in social paediatrics and epidemiology at Bristol and at St Mary's in London. His clinical interests include children with special needs and inter-professional working, whilst his research interests include the use of routine computerised child health information for epidemiological and audit studies.

**Joyce Thomas** OBE, MD, FFPHM, MB ChB, DCH

Consultant in Public Health Medicine and Senior Lecturer

School of Postgraduate Studies in Medical and Health Care, Maes-y-  
Gwernen Hall, Morriston Hospital, Swansea SA6 6NL

Joyce Thomas is based at the School of Postgraduate Studies in Medical and Health Care, Swansea. Previously, she was Consultant in Public Health Medicine in West Glamorgan Health Authority, with responsibility for Epidemiology, Information and Planning, from 1977 to 1989. Dr Thomas was Chairman from 1986 to 1989 of the Child Health System Consortium, and Project Manager for the Public Health Information Specification Project commissioned by the NHSME(IMG) from 1990 to 1992.

**Anne Maree Wallace** MB ChB, MSc, FFPHM

Consultant in Public Health Medicine

Department of Public Health, Lothian Health, Deaconess House,  
148 The Pleasance, Edinburgh EH8 9RS

As Consultant in Public Health Medicine, Dr Wallace has been responsible for services to women and children in Lothian since 1991. She helped to achieve the introduction of Parent Held Records, the Lothian Children's Family Charter and a Joint Regional Respite Care Strategy. She is presently Chairman of a multi-agency group developing a child health strategy, and of the Edinburgh and Lothians Child Protection Committee.

**Andrew Wainwright** BA, CPFA

Senior Consultant, Moores Rowland Consulting

Moores Rowland Consulting, Tameway Tower, PO Box 30, Bridge Street,  
Walsall WS1 1QX

Andrew Wainwright is an NHS Financial Management specialist. His professional career began in NHS finance, where he qualified as an accountant, and held several positions in the Trent and Yorkshire Regions. He has spent the past eight years in financial consultancy roles, working exclusively for NHS clients. He is currently a Senior Consultant with Moores Rowland Consulting, working from Leeds.

**Alison While** BSc, MSc, PhD, RGN, RHV

Professor of Community Nursing

Department of Nursing Studies, King's College, Cornwall House,  
Waterloo Road, London SE1 8WA

After graduating with a social science degree from Southampton University, Alison While worked for three years as a health visitor in the Notting Hill Gate area of London. In 1980 she took up a lectureship at Chelsea College, London, since when she has undertaken various studies in the field of child health, which have included research regarding health visiting support for children during their first two years of life, paediatric home care, day case surgery and care of dying children.

**Helen Zealley** QHP, MD, FFPHM, FRCPE, Dip Soc Med, DCCH (hon)

Director of Public Health

Lothian Health, Deaconess House, 148 The Pleasance, Edinburgh  
EH8 9RS

Dr Zealley was appointed Director of Public Health in December 1988, and is currently Chairman of the Scottish DPH Group. She was previously Consultant in Public Health Medicine responsible for services to women

and children, including coordination of a series of integrated changes to transform the former community child health service into a consultant led community paediatric service. Formerly a Board Member of the Faculty of Public Health Medicine, with the then President she brought together the key representatives of all professional bodies committed to the care of children, to agree the way forward for an integrated child health service. She is a founder member and former Chairman of the Management Committee of the DCCH examination.



# Foreword

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The provision of health care services for children is central to improving the nation's health and remains a key feature of every government's policy. This concept has been recognised in the United Kingdom since nineteenth century visionaries prompted increasing interest in the welfare of the country's school children. Successive generations have built upon these foundations and have been diligent in promoting effective service development. It is right that we follow their example, for the young have only one chance of a healthy upbringing. They are totally dependent on others to provide the right services, which are sensitive enough to address individual needs, yet sufficiently comprehensive to enable as many children as possible to reach adulthood with their potential uncompromised by illness. Our objective must be to enable today's children to enjoy a healthy childhood and to equip them to maximise the benefits of a healthy lifestyle in the years to come. We are making an essential investment in the future and must appreciate the challenges which come with that commitment. We need a multi-professional approach, positive management skills and the adoption of good management practice. I therefore welcome this book on managing child health services and commend the initiative of its editors in bringing together such an impressive team of contributors from different disciplines. This book draws lessons in good management practice from all quarters of the United Kingdom and describes important management techniques, including epidemiology and information, legal underpinning, finance, quality assurance and risk management. It should prove of value to all who are involved in commissioning or delivering services for children.

*Julia Cumberlege*

**BARONESS CUMBERLEGE**

# Introduction

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At first sight, the management of child health services might be envisaged as being one of the most respected and rewarding responsibilities in running healthcare services. Children are usually considered to be an important part of the community, health to be a highly valued commodity, and the management of resources for achievement of best effects to be a laudable organisational role.

Unfortunately, this view is seldom the reality. By no means every child is well looked after or cared for, and society often has ambivalent attitudes to children when they generate demands for resources. Health is difficult to measure, and health services have a history of focusing primarily upon the treatment of acquired illness rather than the promotion of positive health. Finally, management is too often viewed by public, politicians, and professionals as a wasteful interference in matters which would otherwise run smoothly – a stance which has little justification but is difficult to refute.

Since child health services are often smaller components of larger services, and are often split between community health and secondary care provider organisations, as well as having a major component in primary care, one has a potential management minefield. Additionally, the very high vocational calling of many health professionals working with children does not fit easily with establishing corporate values and goals, and prudently managing finite budgets. The legitimate rights of families to self-determination and privacy may cause conflict in balancing organisational efficiency with equity and choice, and difficulty in knowing when to intervene on behalf of the child. Finally, press coverage of events may be more orientated to news appeal than to a responsible management approach.

Management itself should have a very wide definition. Chief officers of health commissions and health trusts, as the leaders of purchasing and providing organisations, have a strategic management role, but at service delivery level the management role is undertaken by clinical directors and

their immediate support team, and by leaders of specific teams and services. Just as important, though, is recognition of the management role of the individual health professional, as it is at this level that quality of service and prioritisation of resource use are first determined.

This book has been prepared to help all the many contributors to the child health management process. We believe that all involved in child health are by definition also involved in its management, so they should have the benefit of material drawn together specifically for this purpose.

A progression through a number of themes will be found. Euan Ross and colleagues commence, by mapping out the chequered history of the development of professional education and services for children in the United Kingdom, and the contradictory values and attitudes which underwrote this history and which still prevail. John Owens then brings us fully up-to-date by describing, from a position of personal experience, the necessary management skills in the new NHS in the last decade of the current millennium.

Focusing directly on the child in their family environment, Kate Saffin discusses issues and challenges to professional attitudes when working with parents, and Michael Rigby follows by mapping out an approach to ensuring consumer orientation and quality of service. The underpinning ethical and legal issues are then spelt out in detail from a sympathetic lawyer's perspective by Peter de Cruz.

An empirical approach is introduced by Eva Alberman, who looks at the approaches and data available when analysing and promoting the health of children. Michael Rigby follows this with a guide to the manager on the information available and necessary for management of child health services. A practical example of establishing and running a clinical service is related by Harry Baumer in his case study of establishing a child health directorate.

The management of the essential healthcare resources is then addressed. First, Nick Jennett and Andrew Wainwright cover health service finance in a treatment which is intended to be clear without being obscurely technical. John Edmonstone follows with advice and guidance on how to manage the human resource. However, even with good guidance and good management life never proceeds smoothly and unchallenged, and Malcolm Lowe-Lauri therefore addresses the techniques of analysing and controlling risks. As healthcare is only one part of support for children – healthy or otherwise – Brent Taylor and Euan Ross deal with the important topic of working with other agencies.

The full scenario is then underpinned by Jane Fortin, explaining the totality of the law relating to child health from an experienced professional viewpoint. We hope that all readers will see a need for some change in services or practice as a result of this volume, and Colin Nolder's

concluding chapter on project management is intended to ensure that all planned changes are undertaken smoothly and effectively.

It is important to recognise that the United Kingdom consists of four principal countries. Wales, Scotland and Northern Ireland give important learning points, which should help the reader reassess values and approaches as well as learning from important initiatives. The three appendixes are therefore intended to cater for readers from those three countries, but equally to inform all readers of important service innovations.

However, we do not seek to provide a reference text book. Healthcare and health management continue to evolve rapidly, and it is the enduring understanding of principles, concepts, and approaches which is important. Many of the contributors are associated with the Centre for Health Planning and Management at Keele University (Rigby and Edmonstone as staff; Jennett and Owens as former management students; and Nolder as a project collaborator) – this is no coincidence, given the approach of that Centre to a perceptive approach to health management education. Even more of the contributors are or have been linked to the national development and promotion of the national child health informatics system (Alberman, Begg, Nolder, Rigby, Ross, Taylor and Thomas) – indicative of the work which has gone into establishing and supporting best practice, as well as of the commitment of those individuals to child health in the larger scene. However, the prime and overriding reason for the invitation to each contributor was their national (and in most cases international) expertise in the subject which they have contributed.

We hope that you find the contents enable you to think through and develop your own approach to the child health management process. We trust that you will then be stimulated to strive for yet higher goals in your part in that immeasurably important task – maximising the health and development of each and every member of the up-and-coming generation.

Michael Rigby  
Euan M. Ross  
Norman T. Begg

# The development of British child health services

# 1

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*Euan M. Ross, Michael Rigby and Alison While*

*In 1900 in terms of its children's health Britain was an underdeveloped country. Then, 150 of every 1000 children died without reaching their first birthday.*

*Joseph & McKeith 1966*

In 1994 the figure for England and Wales was 6.1 per 1000.

## INTRODUCTION

Child health in the United Kingdom has improved greatly during the 20th century [1]. The reasons are a compound of improved social conditions, smaller families, public health measures and medical advances. It is only this century that children's development and medicine has been studied on a scientific basis. The extent to which the major advances in the understanding of child illness and effective medical, surgical and psychological treatments have by themselves contributed to the great improvement in health statistics is impossible to quantify. The concept of child health services, paediatricians, children's nurses and therapists was rudimentary at the start of the century, but we now see a radically different use of much improved medical facilities.

British child health statistics, however, still show an unacceptable difference between rich and poor which drag them down below those of every Scandinavian country except Norway (as shown by the WHO comparative data [2]). This is to a large part because children's needs have never taken centre stage in the development of health services; paediatric medicine and children's nursing have always been, and remain, on the margins of the British health service. The concept of developing child health services which combine community based care, psychological services and the acute hospital service has been persistently thwarted.

## 2 The development of British child health services

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Even as we write, the cohesiveness of university departments of child health has been threatened by the Higher Education Funding Council's Research Assessment Exercise, which is driving smaller specialist groups such as academic paediatricians to band together into larger, less focused teams rather than act cohesively [3]. On the positive side the recent creation of the Royal College of Paediatrics and Child Health (RCPCH) in 1996 promises to lead to a higher status for the subject as a whole, and a more direct line to government.

Those who manage child health services need a grounding in the history of the subject and a realisation that long entrenched attitudes towards children have inhibited the development of child centred provision. Children are the one group who cannot speak directly for themselves, and the voice and the needs of parents may not reflect those of children. Currently the concepts of the rights of adults to bear children whatever the circumstances, and the best ways of educating children and influencing their moral development, are very high on the national political agenda; yet the balancing concept of the need to help children where the home or parental attitudes may be less than ideal raises major disquiet in a society which is nevertheless quick to blame professionals for late interventions. Those managing child health therefore have to go to their task with a very firm grounding in the epidemiology of child disorder and an ability to define and interpret statistical information, as well as management skills and policy awareness, if they are to be successful advocates for child health.

### **THE INAUSPICIOUS BEGINNINGS OF PAEDIATRICS IN BRITAIN**

The concept of paediatrics, and thus paediatricians, is quite different in the UK from that in most other parts of the world. This is outlined by Davis in his chapter about Britain in the *History of Pediatrics 1850–1950* [4] and in the historical accounts of the formative years of the former British Paediatric Association [5].

### **HOSPITAL SERVICES**

Children's hospitals, mostly on separate sites from the major teaching hospitals, started to be set up about 150 years ago in order to circumvent the restrictive policies of the major infirmaries whose charters forbade admission to children under twelve years of age. High infant and child mortality rates were seen as bad for charitable fund raising upon which the large voluntary hospitals depended. With the exception of London where only two free standing children's hospitals remain (Great Ormond Street Hospital for Sick Children and Queen Elizabeth, Hackney), many

of these children's hospitals remain to this day on their original Victorian sites, especially those allied to medical schools. It is only in the last 20 years that large new teaching hospital developments, particularly in London, have incorporated children's units. The fact that so many separate children's hospitals remain – usually in antiquated premises – is a testimony to the low central priority given to the needs of children. Does separateness ensure a better environment for children? The recent opening of a new children's hospital in Bristol with far ahead plans shows that some clearly believe so. There is much to be said for a free standing children's pavilion with its own entrance and child and family ambience yet physically linked to a major hospital, as in Los Angeles.

#### PUBLIC HEALTH SERVICES

Cholera epidemics in 1831–2 and 1848 acted as catalysts to public opinion in favour of statutory enactment of public health measures. Porter gives an account of this in his chapter on The Victorian British State in the *Oxford Textbook of Public Health* [6]. The 1848 Act for Promotion of Public Health was the first in a long line of Public Health Acts which emerged as an attempt to improve living conditions.

The appointment of a Medical Officer of Health for each local authority from the 1840s onwards led to the systematic collection of data about local disease patterns. Consequently, schemes were introduced whereby artisans had a small sum deducted weekly from their wages, which entitled them to participate in prepaid welfare schemes which provided a limited range of free medicines and hospital treatment. These schemes did not apply to children, mothers at home or the elderly [7].

#### MEDICAL EDUCATION

The first English language paediatric textbook, *The Boke of Chylidren*, was published in 1544 [8]. However, during their apprentice years and later as undergraduates medical students received much less formal instruction about children's as distinct to adult's diseases; specific clinical instruction for medical students was not one of the remits of the children's hospitals founded in the 19th century. It has remained a marginal subject in the undergraduate curriculum and thus in the thinking of the majority of British doctors over the last century.

The pioneer British paediatricians tended to be young hospital physicians forced by lack of adult private patients to extend their interests into children's medicine. Gradually the profession grew in numbers and diversity but the subject was even slower in developing an academic base. The first British University Department of Child Life and Health was

## 4 The development of British child health services

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created in Edinburgh in 1932 but it took until 1988 for every British medical school to appoint a professor of child health/paediatrics. The British paediatric journal *Archives of Disease in Childhood* did not begin publication until 1926.

The content of the undergraduate medical course is overseen by the General Medical Council. Medical schools are able to interpret the requirements and set their own examinations although external examiners are obligatory. The child health course currently varies in duration between 7 and 12 weeks and is tending to shorten, in competition with other higher status disciplines, and although it is an intense course the amount of teaching time is very limited.

Though the Membership of the Royal College of Physicians (MRCP) examination had the occasional question on child health matters from the late 19th century, most patients for examination were adults. Paediatricians thus had to carry a larger stock of knowledge to the examination than others who concentrated solely on adult medicine.

A totally postgraduate speciality examination in paediatrics leading to the MRCP qualification existed temporarily in Edinburgh in the early 1970s, but was ceased during the creation of a unified UK-wide examination; the discussions delayed until 1993 the advent of a qualification throughout the UK that could be taken totally in paediatrics. Meanwhile, a less searching examination applicable to a wider range of doctors, the Diploma in Child Health (DCH) had been founded in London and Glasgow. A Diploma in Community Child Health (DCCH) was set up by a consortium of the Royal College of Physicians of Edinburgh, the Royal College of General Practitioners and the Faculty of Public Health Medicine in 1983. The establishment of the RCPCH is leading to further restructuring of all these examinations.

### NURSE EDUCATION

The 1919 Nurses' Registration Act marked the formalisation of nursing as an occupation, with children's nurses being one of several alternative forms of nurse registration, reflecting recognition of the special needs of children in hospital.

For most of this century the majority of children with complex disorders have been cared for in specific children's hospitals, which has posed great difficulties for career children's nurses. As with trainee doctors, student nurses need a wide variety of formative experiences and much time is spent in adult nursing. Historically, children's nurses needed a general nurse qualification for career development and advancement. Prior to 1989, the Registered Sick Children's Nurse qualification could be taken either on direct entry into nursing or as an additional postregistration qualification for those holding another nurse registration. Frequently, this



second route was funded at a junior staff nurse level on a secondment basis. Since 1989 all preregistration nurse training has been at Diploma of Higher Educational level and the Registered Nurse (Child) qualification is taken as the only registration. This has increased the number of nurses qualifying and entering nursing practice with children, but because they are not qualified to nurse adults, regrettably they are also restricted in their mobility outside the UK as the training courses neither fulfil European Union nor North American registration requirements.

Registered Sick Children's Nurse training was focused upon the care of the hospitalised child with advice and support in the home falling to health visitors. Where hands-on nursing care was required, such care was given by district nurses. More recently, the undesirability of such an arrangement has been acknowledged and with increased closure of hospital beds and the consequent transfer of care into the family home, paediatric home care teams have been developed in many localities [9]. These teams are staffed by qualified paediatric nurses, some of whom also have a postregistration community nursing qualification. Prior to 1995, there were only two community nurse qualifications, namely health visiting and district nursing. However, new legislation has introduced two other registrations of relevance to child health care: community paediatric nursing and school nursing. These courses, together with health visiting and district nursing, can be taken in an academic year.

In general, this additional children's qualification has only been useful to those wholly dedicated to children's nursing and wishing to make a career in it, thus decreasing their range of job opportunities. Much children's nursing is extremely specialised and physically and emotionally demanding, particularly in neonatal intensive care and other high dependency areas. It is difficult to recruit to many branches of children's nursing, which has consequences for service provision. The cause of children's nursing has not been helped by the requirement that those in senior nurse positions take a totally managerial role, the skills for which do not always come easily to those whose motivation is towards the individual child.

## PROFESSIONAL BODIES

The ultimate sign of recognition of a discipline which needs special techniques or skills is manifested in the creation of professional bodies. The British Paediatric Association (BPA) was founded in 1928 with six members, very much later than (for instance) its German equivalent which in 1883 broke away from the existing German Society for Medicine.

The BPA admitted its 3000th member in 1995. In the same year, it obtained consent from the Privy Council to reform itself as a medical college and thus be recognised as the senior organisation which represents

## 6 The development of British child health services

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the medical aspects of child health to the government, and become the graduate examining body. In late 1996 it was granted a Royal Charter and became The Royal College of Paediatrics and Child Health.

### SUPPORTIVE COMMUNITY SERVICES

The first moves towards improving public health appreciated the adverse situation of the mass of children, but did not specifically single them out for particular benefits: indeed, they were more likely discriminated against as being unproductive in economic terms. Improvements in standards of personal health and hygiene were left to the nascent voluntary sector. Out of this background, the Ladies Sanitary Reform Association formed in 1862 in Manchester and Salford has been credited as the first public health visiting service (i.e. health visiting) in the United Kingdom [7].

The Health Visitors' Association was originally founded in 1896 as the Women Sanitary Inspectors' Association. In January 1997 the name and constitution changed to the Community Nurses' and Health Visitors' Association.

Space precludes a detailed review of the development and history of the many other professions apart from nursing and medicine that make up the professional team in child health services. In 1949 they were defined as 'medical auxiliary workers – persons who assist medical practitioners (otherwise than as nurses) in the investigation and treatment of disease by virtue of their special skill acquired through a recognised course of training'. A report was submitted to Ministers in 1951 which recommended there should be a statutory central council for these services under the aegis of the Privy Council [10]. The earlier history of these services needs to be written in an accessible form. A fascinating review of the development of occupational therapy is given by Hopkins and Smith [11]. The now Chartered Society of Physiotherapy was formed in 1984 to promote the delivery of respectable and ethical therapeutic massage, initially for adults. The past decade has seen a transformation of training in these professions, from small schools based in the larger hospitals to entry now being based on degrees obtained from recognised universities.

### BOUNDARIES OF CHILD HEALTH SERVICES

The very process of promoting child health services and thus clarifying understanding and facilitating management of the needs of children, can lead to the dangers of isolating these services. It is important to identify the role of child health services, and their place within the wider order of things.

### PROFESSIONALISM OR PARENT POWER?

The development of health visiting and support services increased professionalisation of health care. Whilst this was important and overdue, excessive professionalism can result in a medicalisation of expectations around physiological and behavioural norms, so that children are expected to reach milestones or achieve development patterns as though they were passing or failing performance tests. At worst this may lead to over zealous regimes being imposed on children, an unfortunate reversal of the original objective of ensuring that those who needed additional support received it.

A second potential perverse outcome of professionalisation of services, is the disempowerment of parents. Particularly in the preventive arena of child health, services should exist to educate, advise and support parents, but there is a great danger of the pendulum swinging too far to the extent that parents are expected to conform to particular child rearing stereotypes – this reached an extreme form in the former USSR. Barker [12] has identified the insecurity and feelings of inadequacy in parents which undue professionalisation can bring and has emphasised the importance of reintroducing the concept of empowerment as the objective of preventive child health services. By means of the First Parent Visitors programme in the United Kingdom and the Community Mother programme in Ireland, he has sought in a structured and monitored way to develop means of supporting parents in a non-condescending fashion. Parents are encouraged to identify and report developmental progress themselves.

### INTERFACES WITH SOCIAL WORK AND SOCIAL POLICY

The interface between medical, nursing and other health professional skills with social and economic environments has been clear since the days of the social and public health reformers of the 19th century. From that time, too, the problems of the split between health and social care provision has been a problem as demonstrated by the minority report of the Poor Law Commission at the turn of the century[13].

### SOCIAL WORK FOR CHILDREN

Prior to 1974 preventive health services and social services were both local authority services, a link which was broken with the health service reform of that year. However, management by a single body does not guarantee perfect working relationships. In Northern Ireland, health and social services are run by common Boards, but though this may have many merits it is not a panacea.

Social work as we now know it is a product of the 1972 restructuring and integration of local authority children's and welfare departments, and hospital almoners, based on the recommendation of Lord Seebohm's Committee [14]. Up till then social workers in major hospitals were known as almoners (whose original obligation was to collect payment from those not entitled to free treatment). Subsequently social workers have been through profound changes with their work pattern being repeatedly reorganised and, to a large extent, radicalised. The long-standing 'knock for knock' basis whereby social services and health services did not charge each other for services rendered is becoming hard to maintain.

Child health services and social services for children both have a distinct role to play, and each requires different professional knowledge and skills. Integrated support for the child can only occur if each works together in mutual trust. There continue to be well publicised cases where the services have failed to cooperate and children have endured avoidable suffering or have died. In almost every case the subsequent formal enquiry shows that warning signs passed unheeded, frequently because services had failed to collaborate. The answer is in good working relationships, emphasising strengths and individualities where appropriate, yet interlinking in safe and ethical ways to ensure coordinated support.

### POLARISATION OF HOSPITAL SPECIALISMS

Not only have children's medical services developed in a somewhat spasmodic way from general acute hospital services for adults, but the interface with nursing and therapy has been poorly defined. The question of size of paediatric units and their ability to give optimal quality treatment to all children is becoming a highly charged issue. The increasing shortage of specialist nurses and reduction in the working hours for trainee doctors coupled with the pending retirement of a large number of experienced paediatricians and the flight of senior clinical nurse specialists into management, is leading to an inexorable crisis. On the one hand society expects high quality treatment to be available locally and protests loudly when hospitals are closed, yet it is becoming clear that it will not be possible to maintain as many small paediatric hospital units as in the past. The development of league tables of hospital performance too will lead to increasing pressure for smaller numbers of highly specialised teams to look after children with complex health problems.

Repeated surveys have shown that the quality of health and the length of survival dramatically improves in complex conditions such as leukaemia, cystic fibrosis, diabetes and asthma when specialist teams devoted to these conditions look after the children. To what extent can this be provided at reasonable cost for the whole nation and what is the point at which social difficulties for the family posed by long distance travel

outweigh improved health outcomes for the child? This can be partially avoided by the specialists travelling to outlying clinics and cascading knowledge from the specialist centre to the periphery. The matter comes to a head in paediatric surgery where the issue of improved outcome is clearly demonstrated: surgeons who are constantly working with children have much better results than those who only do occasional operations. Surgery, however, is becoming increasingly fragmented into subspecialties, making it very difficult for all but the largest centres to be able to employ surgeons who wholly specialise in children, as a wide range of surgeons is needed to provide for children's ophthalmology, ENT, plastic surgery, cardiac services and orthopaedics, let alone those who specialise in renal, liver and heart transplantation in tertiary care centres.

The target is not the endless search for the optimum model, but rather the continual interlinking and reassurance to guarantee the best integrated service for children in a particular geographical and organisational setting. It is principles and objectives, rather than structure, which will determine the locally appropriate interface between specialist child health services and clinical specialisms.

#### THE INTERFACE WITH PRIMARY CARE

The UK has a different policy towards primary health care services from most other developed countries. The British emphasis is upon family doctors who treat all members of the family as individuals with the diagnostic process being illuminated by knowledge of the family circumstances. This is in contrast to the European and North American separate speciality of primary care paediatrics. For example, Italy has totally separate paediatric general practitioners. There is scope for further study of the actual merits and disadvantages of the different philosophies. Whilst there are clear advantages in assessing the ill health of children in a family context it also raises two kinds of problem.

1. Ethical issues arise as the child matures and may wish to be treated as an individual in their own right, even to the degree of seeking or accepting health interventions with which their parents would not agree. Life style and contraception are obvious areas but religious views on permissible treatments can also pose difficulties.
2. The requirement that British GPs are truly generalist and have the skills and knowledge to give equally level primary care across the ages from neonate to the elderly.

The European separationist approach involves the parents and children having to visit separate practitioners each of whom may be dealing with clinical problems directly affected by the health and stresses of the rest of

the family without being aware of them. The children will need to start a new professional relationship with a different doctor at an arbitrary age. The great majority of teenagers are healthy, but for those with chronic disability the transfer to 'adult' specialists is erratic and often unplanned in the UK.

Another, but now rapidly fading, model came from East European countries where large numbers of paediatricians were trained as such at undergraduate medical schools and subsequently employed to undertake tasks which would be performed by nurses in Western countries. The wane of communism has revealed that this almost indulgent level of provision was over-concentrated on an invalidated series of frequent (often monthly) health checks and long stays in hospital at the expense of effective primary prevention and health promotion. Most serious was the over-medicalisation of trivial problems and a dependency culture where all health problems were seen as a medical responsibility. When the Soviet regime fell, Estonia with a population of 1.5 million had as many career paediatricians as the UK with a thirty times larger population.

Current UK policy is to integrate routine child health services into general practice, as part of the philosophy of integrated care for the family, with child health services dealing with specialist issues. Family doctors are now tending to work in increasingly large group practices in which a number concentrate on children though very few totally devote themselves to children. Gradual decline in the size of family doctors' lists of patients, improving undergraduate education in paediatrics, and an obligation to postgraduate studies has made it possible to transfer child health surveillance and immunisation to many family doctors from the community paediatric services, and this process is still continuing with most child health surveillance work now being undertaken by general practitioners. In inner cities, however, many of the general practitioners are still not organised or trained to do this work and a community clinical doctor has to provide this work on a 'mission clinic' basis.

### SCHOOL HEALTH SERVICES

Though established more than one hundred years ago, the school health service has never attracted the professional respect or support due to it. School provides a child-specific environment, the objectives are clear and child-focused with a particular emphasis on promoting personal development. However, rather than taking this as an opportunity to focus and strengthen health support for children, the school health service has fallen victim to the traditional British failure to manage cross-sectoral activities. The school health service provides a well documented example of how policy makers, professionals and managers can allow a service to wither for want of leadership.

Professional focus, development and resourcing have been lacking, as health and education have each sought to pass a proportion of the financial responsibility to the other, with very limited success in establishing a scientific under-pinning. This is reflected in the absence of professorial chairs of school health. Both in determining objectives and support for the individual child, and in the means of working of the individual services, there is lack of formal coordination between health and education, which too often has overshadowed the objective of moving forward together. Moreover, children in private schools may not get a school health service as such at all. Occupational health services for large companies and those working in the better parts of the NHS could provide a role model.

School nursing has suffered seriously because of a national tendency to under-value the subject. It arose to fill a very obvious need which was evidenced by the poor health of the Boer War recruits [15]. The advent of free compulsory school in England in the 1870s meant that for the first time children were congregated together and their health needs became apparent. The original schools catered for all abilities and much of the teachers' time was spent coping with social and health related problems, so a system of repeated medical inspections were set up. The school health service, however, was not guided by legislation and its quality depended on the vigour of the Medical Officer of Health and the resources of the local authority. It gradually became apparent that particular attention needed to be paid to hearing and vision. The school health service was inherited by the NHS with the other local authority based services in 1974. The nursing element in this service, however, did not fit neatly into the community nursing hierarchy which tended not to have practical experience in school matters.

Difficulties persist regarding interagency collaboration especially in meeting the needs of children with complex disabilities. Failure to provide enough high quality therapy and educational support are frequent causes of stress for families. The school health service, which celebrated its first 100 years in 1992, was seen as a resource for plundering by cash strapped health authorities. The fact that policies varied, and a feeling that at times school nurses were being used as a substitute for social workers, has led to the service being a target for euphemistic 'cost improvements' and reductions in the service. In part this reflects the low status of the school health service relative to other areas of health care but also the limited professional training of the nursing workforce. It was only in 1995 that a school nursing qualification became registerable. Prior to this, there was a three month course which was noted for its limitations [15]. The school health service has been the subject of a number of reports and studies highlighting how it has been thwarted from achieving its full objective. These reports include those by Harrison and Gretton [16] and the Audit Commission [17]. The latter stated that the absence of a sound basis for

health care provision within the school health service was a major deficiency.

This coincided with the very time when it was being realised that health promotion has its best chance of working when targeted at the young school child [18]. Psychological issues among school children are receiving much more public interest than in earlier years; with antisocial behaviour in children being seen at least in part as a medical problem. The future of the school health service is the subject of an interdisciplinary working party chaired by Polnay published in 1995 [19].

Harris [20] in a history of the school health service asserted that its establishment marked an important change in health care policy making as it did a departure from a concern solely with the environment to a concern also with the individual. It also presented the opportunity for the systematic collection of child health data.

Macfarlane in Oxford has developed a host of innovative programmes to encourage teenagers to take charge of their own health. His *Diary of a Teenage Health Freak* [21] and subsequent television programmes achieved much more health gain than has ever been possible through more conventional means. The 3rd edition of *Health for all Children* [18] in 1996 marked a swing away from the concept of health screening to health promotion.

### INTERSECTORAL BOUNDARIES

What should be the limitation of the areas of interest of child health services? Should they be perimeters or blockading boundaries? Arguably those professionally responsible for the health and well-being of children should address any issue or aspect which has an adverse influence, or should seek as an ally any ethical agency which can bring resources or ideas to bear. For instance, there should be legitimate concern that the biggest killer of ambulant children is accidents which frequently occur in the home. Some argue that child health services should be involved in a whole range of issues concerning house design and exert influence on road traffic management. A good example of successful lobbying has been the introduction of child-proof containers for the dispensing of medicines, and changes in the retailing of hazardous substances such as bleaches, which resulted in a great reduction in accidental poisoning.

In one of the few examples of intersectoral interest in health, the Department of the Environment undertakes regular surveys of the causes of accidents requiring treatment at hospital accident and emergency departments. The potential of intersectoral collaboration, and good examples of how to mobilise community support, will be found in the work of the Healthy Cities movement coordinated by the European Office of the World Health Organisation [22].



## CHILDREN'S SERVICES AND THE NATIONAL HEALTH SERVICE

### IN THE BEGINNING ...

The National Health Service was conceived during World War II, as part of a new social order striving for betterment for all citizens. In policy terms, the trigger was William Beveridge's report [23] which was a technical analysis of problems and methods of social insurance as a strategy to overcome poverty, ill health, ignorance, unemployment and squalor. Important elements of the post-war reforms included state income support for poor families and a publicly funded health service for all.

Primary care services were provided by self-employed general practitioners, their services being contracted and controlled by local executive councils who were separate both from the regional hospital boards and the local authority. Thus in a classic example of pragmatism, opting for less than organisational perfection in order to ensure acceptance by all interested parties, Aneurin Bevan as Minister of Health at the time created a health service which achieved its ideal of providing services which were free at the point of consumption and equally available to all, but thereby produced a management system which was far from perfect resulting in a tripartite NHS whose disadvantages were to continue for 26 years.

In 1948 the provisions of the old National Insurance Act health scheme were made available to the whole nation and for the first time children were entitled to totally free hospital and general practitioner medical, dental and ophthalmic services including prescriptions for drugs and appliances. An enormous new demand for medical services imposed great strains on existing services at a time when national resources of finance and labour were scarce. Gross differences in provision of health care around the country became apparent.

The compromise structure and tripartite split of the newly created NHS had both strengths and weaknesses for child health services. On the negative side, the administrative separation of curative and preventive medicine persisted for a further quarter century. Activities assigned to health visitors included giving advice on the care of young children, illness in the home, expectant and nursing mothers and how to prevent the spread of infection. Although the 1948 Statutory Instrument No. 1415 included both physical and mental illness, health visitor duties did not extend to the care of the mentally handicapped child.

There are still difficulties in promoting integration between hospital acute nursing and community nursing. As with children's medicine the two arms of the discipline arose separately. A high proportion of community child health nursing support is carried out by health visitors who now require an additional twelve months college based training

following completion of their nurse training, but this additional training is not focused on clinical issues.

However, there was good news as well. Emergency hospitals, which had been built ostensibly for war casualties, resulted in a vastly improving range of hospital facilities for the civilian population and brought inpatient care nearer to home in parts of the country where it had previously hardly existed at all.

British paediatrics had a new beginning with the advent of the NHS; previously many areas had no consultant led paediatric service. As more money became available, a programme of hospital building began and with it the gradual appointment of career paediatricians who had no responsibilities for adults. Many more children's nurses were trained. Children with cerebral palsy and other disabling conditions benefited from the application of techniques developed to rehabilitate the war wounded. Infections became treatable with antibiotics and many more effective vaccines became available.

### THE COMING TOGETHER

1974 was a watershed year for NHS structure and management. It ended a period of 26 years of stability, and it saw the implementation of a major reform to integrate the NHS truly, but in so doing it also brought in an era of continuing structural changes. Whereas for its first 26 years the NHS went through little internal reform, since then there has been an unending series of reorganisations in the hunt to find a cost-effective service. Changing managerial methods, styles and jargon have come and gone. The point has been missed that the best achieving organisations thrive not through frequent radical change but from constant fine tuning. Worse, the acclaimed philosophy of devolution of management has led, paradoxically, to increased centralised control.

In the 1974 reorganisation of the NHS, the local authority public health service, which included infant welfare centres and the school medical services, were transferred to the new, now officially unified NHS authorities. This included the clinic buildings and the health visitors, therapists, child psychiatry and community child health doctors who worked in them. The new services were managed by integrated area health authorities, responsible for all services in areas broadly equivalent to a county council or London Borough (and co-terminous with these wherever possible).

### SHORT-LIVED RECOGNITION OF CHILDREN'S SERVICES

This 1974 reorganisation also heralded in the only period, and a short lived one, in which there was designated professional expertise responsible for

child health services. Every area health authority was required to appoint (using the new nomenclature for public health professionals) a specialist in community medicine (child health), and an area nurse (child health). For the first time the special needs of managing children's services, and above all in ensuring integration between the different sections of the NHS, and between the NHS and partner agencies, such as education and social services, had been recognised. However, the reality was less positive than the intention, given the radical amount of change undergone by both the NHS and by local government in a simultaneous major reform. Arguably, without these designated posts children's services would have suffered even more significantly in the 1974 reorganisation. In many areas some positive gains were accomplished and children's services acquired more cohesive direction and purpose, but in other localities there was a decreasing influence in the longer term as public health management became distanced from operational services. The existence of these professional champions of children's services lasted for only 8 years. The next restructuring of the NHS in 1982 abolished area health authorities and removed the requirement for designated officers.

## **DEVELOPMENT OF POLICY**

Throughout this period of professional self-discovery and organisational development and change, a series of uncoordinated initiatives has shaped child health policy.

### **PUBLIC HEALTH LEGISLATION**

The social and public health reformers of the 19th century had a greater effect on improving the health of children through legislation than that achieved by the ministrations of individual clinicians. Since it was necessary to pay the doctor, poor families, particularly those with many children, received little medical attention, though even if they had finance little treatment was available.

Legislation mandated the introduction of active preventive health measures. Jenner's discovery of the principles of vaccination against smallpox at the end of the 18th century, through introduction of compulsory vaccination, eventually led to the Vaccination Act 1853 which made smallpox vaccination compulsory for infants and was supplemented by further Vaccination Acts in 1867 and 1907. Environmental threats to public health, particularly bad sanitation, poor water supplies, and infected milk, the development of statutory notification of illness, and the Public Health Act 1872 made the appointment of a Medical Officer of Health compulsory for each local authority. Control of infectious disease was regulated by the 1875 Public Health Act. A patchy development of

infant welfare services ensued reflecting the ability and drive of the local Medical Officer of Health. With no central guidance, the local services varied widely in terms of the qualification of the staff and in the ratio of paid to voluntary helpers. The potential for influence by local authorities was demonstrated by the Huddersfield Corporation Act 1906 which introduced statutory local birth notification. A permissive national Act followed this example (Notification of Birth Act 1907) and national birth notification became mandatory in 1915 through the Notification of Birth Act (Extension) 1915.

Between 1907 and 1914 three statutory sources of preventive health care were introduced.

1. Poor Law Administration was the main source of state aid in health and was centred upon curative provision.
2. The Board of Education introduced medical inspection of school children as well as some treatment for minor ailments under the 1907 Education (Administrative Provisions) Act.
3. From 1908, provision was introduced for mothers who were still at school. These included baby clinics under the Regulations for Technical Schools, Schools of Art and other Schools and Classes (Day and Evening) for Further Education.

The National Insurance Act (1911) introduced a limited health insurance scheme funded by statutory deduction from the pay of workers. This, however, contributed little to public health and child welfare.

### THE PARADOXICAL EFFECT OF WARS

Revelation that 40% of the Boer War volunteer recruits between 1901 and 1902 were unfit for military service on medical grounds led to an Interdepartmental Committee (1904) which accumulated much evidence which revealed the inadequacy of child health and welfare. Similar concerns were noted about the health of conscripts for World War I.

Massive loss of life on the battlefield is shown by the gross differences in the numbers of young adult males in the 1911 and 1921 census statistics (Registrar General 1917, 1927). This coupled with a fall in the birth rate and continued high infant mortality rate formed the impetus behind the 1918 Maternity and Child Welfare Act which enabled the County and County Borough Councils to provide facilities for the well-being of expectant and nursing mothers and children under 5 years of age under the auspices of the Local Government Board.

The Public Health Act (1926) addressed the public health aspects of child health from the moment of birth. The Act required those attending a birth to notify a proper officer of the local authority health department so that epidemiological data on births could be recorded and preventive services

for the new baby provided. Notification of birth was rapidly exploited as the trigger for delivery of supportive services particularly by health visitors to ensure follow on from the service given by the midwife which ceased at 14 days after delivery. These health visitor led services addressed family and environmental health issues as well as clinically assessing the health and development of the child. Most of all the health visitor was in a position to advise about child care, nutrition, cleanliness and promote the idea of healthy living.

#### SERVICE DEVELOPMENT

The 20th century brought a refocusing on service development. Social policy legislation between 1920 and 1939 brought about few changes regarding infant welfare services though this period saw the creation of municipal, general, psychiatric and fever hospitals under the control of the local Medical Officer of Health. These hospitals were complementary to and often rivals to the long established voluntary funded city infirmaries and provided for children and adults. These new hospitals varied greatly in quality: some were housed in converted workhouses, others had superior facilities to the old voluntary hospitals. The concept of therapies – physio, speech and occupational as well as the beginning of child guidance services for those with behavioural problems – also gathered momentum in this period together with a gradual move towards age related specialisation.

The 1939–1945 war improved the health of children in the UK. There was public recognition that the nation could not afford to neglect child health, with childhood illnesses regarded as a needless burden. Welfare foods including powdered dried milk for babies, blackcurrant or orange juice and cod liver oil were supplied via clinics, and organised day nurseries released women for war work. Rationing and price control made sufficient nutritious food available to all. The lack of sugar improved dental health. The consumption of fish rose, and rickets was further diminished by the addition of Vitamin D to margarine supplied as a replacement for butter, and white bread was fortified with calcium.

World War II again exposed the effects of poverty on the health and well-being of children. The large scale evacuations of children from bombed cities to rural areas highlighted the problem. Two solutions emerged.

1. In the short term: special provision regarding health and nutritional needs of mothers and young children.
2. In the long term: social reforms especially housing and National Insurance.

In the immediate post-1945 period services for special groups of

children began to be developed. Voluntary societies such as the Spastics Society (now 'Scope' in England and 'Capability' in Scotland) began to vocalise parental demand for improvements in the care of affected children, and a series of abuses in large long stay hospitals for the mentally handicapped led to a demand for community based services. A committee led by Sir Wilfred Sheldon reported in 1967 [24] that special centres were needed where children with multiple disabilities could have in-depth assessment and full diagnosis and therapy for their many needs. Such centres – later known as Child Development Centres – began to spring up around the country.

### THE CHILD-FRIENDLY HOSPITAL

An important landmark of child health care provision was the publication of the Platt Report [25]. This government committee considered the welfare of children in hospital and set out clear benchmarks against which the child health service should be expected to perform. The recommendations of the Platt Report have been reiterated and extended in subsequent government publications. The most recent government guidelines require a 'child and family centred' service [26].

In the early days of the NHS, the focus in hospitals was primarily upon the clinical speciality, thus in many areas such as orthopaedics, ophthalmology or general surgery child patients might be treated alongside adults. Increasingly this was recognised as inappropriate to the needs of the whole child whose social and educational interests came to be recognised as important as the clinical needs. Much stimulated by external pressure groups such as the then National Association for the Welfare of Children in Hospital (NAWCH) (now Action for Sick Children), and partially through pressure from specialist professional interests, the need to treat children as a cohesive child group first and foremost gained supremacy, thus children's wards developed towards becoming a therapeutic and caring environment which was as far as possible child centred. The Department of Health has now forbidden the treatment of children on adult wards. This shift in focus from speciality centred to child centred treatment, though occurring too slowly in the eyes of the progressives, has been under appreciated as a major recent cultural shift in health care provision ahead of consumer and market forces.

Trained registered children's nurse coverage was mandated and supporting facilities such as play rooms and play leaders for the younger child and properly equipped and staffed hospital schools for the older children have moved from being an innovation seen only in the most progressive units to become a central part of the environment in a children's unit. Parents were encouraged to become part of this community, however briefly, facilitated by the provision of overnight sleeping

space for them, though much more needs to be done to make their conditions tolerable in all units. Specialist clinical skills now came to the child.

#### DEVELOPMENTAL PAEDIATRICS

This term was introduced by Dr Mary Sheridan in the 1960s, who appreciated that the future of paediatrics lay as much in the promotion of health as in the cure of existing disease and that a new generation would need a much deeper understanding of the principles of child development. Those who were determined to see the recommendations of the Court committee [27] succeed realised that there was a need to institute in-service training in developmental paediatrics; this led to a proliferation of courses mainly based on university centres. Most, but not all, were aimed at medical audiences. Gradually the number of teachers in community based aspects of paediatrics have increased. From these have developed degree courses, mainly MSc, in community child health, as well as special courses aimed at target groups such as GPs in child health promotion. Attempts are being made to promote interdisciplinary higher education in child related matters and a number of university departments of child studies have been set up.

#### THE EDUCATION ACT (1972)

This Act was important in taking away from community health services responsibility for the education of children with learning disabilities (then still referred to as mentally handicapped). At that time community health services were still part of local government, and mental disability was still seen as a health problem, with children being sent to junior training centres, for 'training' which was quite separate from educational provision for other children. The 1972 Act corrected this anomaly, by giving responsibility for the education of all children to local authority Education Departments [28].

#### THE EDUCATION ACT (1981)

As part of this continuous governmental policy of vesting educational responsibility with education services, but sponsoring closer formal working between education and health, the 1981 Act introduced a formal process whereby any special need of a child could be recorded formally in a 'statement' agreed between the two sets of professional experts supporting a child, in consultation with the parents. This was intended to be both a supportive and an enabling innovation, and parents themselves could request that their child be assessed if they thought there was a

significant health or developmental problem which was affecting, or might affect, their child's educational needs [28].

### THE CHILDREN ACT (1989)

The most recent piece of significant legislation has been the Children Act (implemented in 1991). Its purpose was to clarify, simplify and modernise legal processes for children, since children's law had accrued piecemeal through the centuries. That child abuse was a major problem in the UK had come slowly to the medical profession. The fact that medical help is in a different administration from social services and education makes for problems in coordinating efforts illuminated by *Working Together* [29]. The scale of the problem was emphasised by a number of widely publicised scandals both over the deaths of individual children, and over the management of child abuse [30]. The mismanagement of child protection arrangements – both for physical and sexual abuse – came to the fore with headlines identifying Cleveland, Rochdale and Orkney.

An enormous educational effort accompanied the introduction of the Act. This, probably more than the wording of the Act itself, led to a great deal of increased interest and knowledge around children's legal and protection issues.

### CHILD HEALTH PROMOTION

It becomes increasingly clear that all intervention and surveillance schemes must be evidence based. The result of Butler's longitudinal cohort studies [31], and the evidence-reviewing Hall report *Health for all Children* [18], have championed movement away from routine surveillance to the positive promotion of health.

By contrast, an imaginative move by the Department of Health to base policy development on intended health goals, was disappointing in respect of child health. The highly influential document entitled *The Health of the Nation* [32] identified target areas where health could and should be improved by the year 2000. However, this virtually excluded any specific reference to the health of children, with the exception of a target of reducing the number of accidents. Though this latter is laudable in its own right, as indicated earlier it is an issue best addressed intersectorally, and the individual health professional or health provider organisation working on their own is unlikely to have a direct influence in this particular area. However, at a more modest level, Wales has shown a way forward with the initiatives of the Welsh Health Planning Forum to plan for health gain. They have addressed the issue of child health services more pragmatically [33–35]. The more recent NHS Executive publication [26] provides the beginning of a framework for community child health



provision, but the extent to which service development follows the recommendations will only emerge with time.

#### PURCHASING CHILD HEALTH SERVICES: THE INTERNAL BAZAAR

Until the late 1980s the level of provision of child health services was a historic matter that reflected the ability of local individuals to seize resources for children out of a regionally allocated fund. In most of the disadvantaged parts of the country funds were declining as part of a policy that dictated that resources would be diverted from the inner cities that were receiving a higher per capita income to the less well resourced periphery taking no account that those areas with higher expenditure tended to be in places with the greatest levels of need [36]. The hiving off of purchasing health services from those who provide services was instituted to bring rationalisation and justification to health service provision.

The concept of commissioning is still developing. It gives the opportunity to plan child health services on a rational basis according to need rather than clamour. As this process proceeds it will become increasingly necessary to ensure that sound advice is both given to and acted upon by purchasers; there is a risk that partisan theory, 'political correctness' or favouring of certain services at the expense of others on spurious grounds could distort provision. Effective purchasing involves the objective interpretation of the views of providers which are informed by the reality of the case load but with subjectivity of potential self-interest; the objectivity of epidemiology tempered by understanding of the inadequacies of available data; and attention to the views of consumers as pressure groups whilst constraining these to the achievable and to the interests of all, especially the non-vocal needy other groups. Such issues readily come to the attention of the media, and difficult choices have to be made. Such ethical problems were starkly spelled out by George Bernard Shaw in his 1911 preamble to his earlier play *The Doctor's Dilemma*[37] and have returned as the century closes, with dilemmas (and misinterpretation in public debate) such as were presented by the 'Child B' case [38].

## CONCLUSIONS

### STRUCTURES

Children's services present an organisational dilemma in any care delivery structure. Fragmentation into separate components for inpatient and community care is particularly unhelpful, but identification of a single leadership is difficult. Within England and Wales, the most common solution is for community services to manage child health services, but

they seldom have real influence over acute paediatric services which are normally in a separate acute trust. An alternative model in some districts is for the acute trust to have total responsibility for the service including clinical policy, purchasing the time of health visitors and others from the community trust. The risk here is that an organisation geared primarily to treatment and to expediting the discharge of patients will have little empathy with the concepts of ongoing support to prevent deterioration or with putting effort into maintaining and monitoring the health status of currently healthy children. Southern Scotland has established children's trusts which provide acute and community integrated services as needed. Properly conducted comprehensive studies are needed to determine how the different systems function and whether there is a potential best practice. It is, however, not yet clear whether this approach will be organisationally viable outside major cities as it cuts across the current tendency to merge smaller trusts.

The nature of British health services whereby the old universities and teaching departments are congregated in the poorest inner city areas means that they tend to be focused on acute inner urban need and crisis intervention and less well adapted for looking more philosophically at conditions which affect a wide diversity of children. International pressures to develop the role of specialist primary care paediatrics are likely to increase. Parents from overseas find it very difficult to understand why they cannot have direct access to a specialist paediatrician in the UK. On the other hand, UK paediatric specialists have grown up to value the generalist general practitioner and as a whole see no reason to change their mode of working.

The debate about structures continues even as we write, and inevitably will continue. In 1976 the Court Report [27] advocated closer integration of health services for children: a vision achieved only in part. Twenty years later the Health Services Committee of the House of Commons was covering the same ground, also constructively [39]. It differentiated between combined health services within secondary health care, and integrated health care drawing together all sectors. It also drew attention to the (then) British Paediatric Association's vision of Combined Child Health in 1991 [40]. Matters have still not been resolved, and frustration will continue to push against inertia.

### MAINTAINING COHESION

Current issues include ways of working more effectively with the local authority, social services and education services; there is a need for very much closer work between the specialist children's services in hospital and in the community and general practice and there is need for properly formulated experiment. The National Children's Bureau, formerly called

the National Bureau for Cooperation in Child Care, has been most effective in bringing the various interested parties together; they publish a regular journal, *Concern*, and fact-sheets on topical issues as well as running a meeting programme around the country. Action for Sick Children documents command attention: particularly *Health Services for Children and Young People*, a guide for commissioners and providers [41].

### ... AND INTO THE FUTURE

The history of the development of child health services, and thus the attitudes towards them and the culture within them, has been an uncomfortable mixture of needs-push and opportunity-pull, and paradoxically the few opportunities which have been given for a particular child health lead have not had the productive results which had been anticipated. As we approach the end of the 20th century we find health care, like British society in general, in an environment with ever rising expectations of availability and quality, and with conflicting attitudes to specialisation and expertise and tight resources [42]. Above all, the move to flexibility, availability and consumer choice is heightening fragmentation, whilst the political debate revisits old ground.

### MANAGEMENT WITHIN CHILD HEALTH

This chapter has raised issues that are explored in more detail in the remainder of this book. Only by knowing something of the history of the subject and understanding the changing and conflicting attitudes and issues can management be successful. All children's specialists who assume a senior role, whatever their health care profession, need management skills. Nothing can be achieved without funds coupled with a highly skilled and dedicated workforce who believe that their work is instrumental in maintaining and improving the health of children. For this reason they must be prepared to devote a proportion of their efforts to management.

Conversely, generalist managers responsible for child health services must understand the conflicting views of society, the strongly focused demands of interested parents and pressure groups but above all, need to recruit, cherish and maintain highly committed health professionals in child health.

Child Health is an important and often emotive topic. It is part of everyone's future: that of the children themselves, that of society and that of the older generation who initially pay for children's services but in turn become dependent upon the growing generation. Managers in this arena are neither born nor made, but grow with experience and maturity. Many will fail to cope given the complexities of the task, the problems posed and

the sensitivities, dogmatism and rigidity. Three key attributes are essential for the successful child health manager: understanding, knowledge gained from formal teaching, and much experience and compassion. We hope that this book contributes to all of these.

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# Management skills in the new NHS

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# 2

*John Owens*

*If Florence Nightingale were carrying her lamp through the corridors of the NHS today she would almost certainly be searching for the people in charge.*

*Griffiths 1983*

## INTRODUCTION

In 1983 a small committee of inquiry headed by Sir Roy Griffiths was set up to advise on management of the NHS. The committee comprised people with a considerable amount of business experience and found the lack of leadership in the organisation remarkable. This was particularly true at Regional and District level where consensus management held sway, so much so that any professional officer in the management team had the right of veto. When inquiry members suggested to those they interviewed that management principles from the business world might be applicable to the NHS the response was unfavourable. It was held that the Health Service, unlike business, was not founded on the profit motive. However, Griffiths pointed out that the latter is not a significant factor in industry below board level and that levels of service, quality, meeting budgets, cost improvements, staff motivation and research and development were much more important. All these were also essential for efficient and effective management in the NHS.

Griffiths recommended the appointment of general managers at Regional, District and Unit level, i.e. one person who would be responsible for planning, implementation and control of performance [1]. Consensus management had been dealt a body blow. Urgent action was required if Units were to provide the most effective management of their resources. The involvement of doctors in management was crucial as, '... Their

decisions largely dictate the use of all resources and they must accept the management responsibility which goes with clinical freedom'. In spite of this only a handful of doctors and a somewhat larger number of nurses became General Managers, most being recruited from hospital administrators.

## WORKING FOR PATIENTS

The last two decades in the NHS have been marked by the conflicting trends of growing customer demand and increasingly restricted resources. Since the 1976 financial crisis, when the International Monetary Fund insisted on tight public spending controls as part of the terms of a loan to the British Government, NHS funding has been cash limited [2]. At the same time health costs have increased due to the needs of an ageing population and the steep rise in expensive new technology. Thus total central government spending on health over the 1980s rose from nearly £12 billion to £24.7 billion, an increase in real terms of nearly 20%. Waiting lists also rose steadily over this time, and by 1990 there were 900,000 awaiting inpatient treatment, an all-time high [3]. A prime ministerial review was followed by the 1989 white paper *Working for Patients* [4]. This recognised the increased demand and drew attention to the wide variations in quality in the NHS, for instance differing waiting times and costs between hospitals. The white paper stated the following two objectives:

1. Better health care and greater choice for patients.
2. Greater satisfaction and rewards for NHS staff who successfully respond to local needs and preferences.

Whilst stressing that the successful implementation of general management was the way ahead, the following key proposals were made.

## THE PURCHASER-PROVIDER SPLIT

The basis of the white paper was the establishment of the internal market, with competition between various providers of health care. District Health Authorities (DHAs) now have the function of ascertaining the health needs of the populations they serve, then meeting those needs by purchasing or commissioning health care from provider hospital or community services through contracts (see below). Funding for DHAs is calculated by a weighted capitation formula (WCF) which is based on the population's characteristics only (e.g. Standardised Mortality Rates) and not on expenditure and facilities of the provider units within their boundaries. DHAs must purchase health care which is cost-effective and of the highest quality. This may not always be obtainable in, for instance, the local hospital.

Health Authorities are governed by a Board of executive and non-executive directors. Since 1993 there has been a trend for DHAs to merge into larger commissioning agencies and they were merged with Family Health Service Authorities from 1994.

### SELF-GOVERNING TRUSTS

Both hospitals and community services are now able to opt out of DHA control (but not the NHS) and become what are in effect small, independent public corporations with a Board of executive and non-executive directors. The non-executives tend to be drawn from those with previous business experience rather than from the 'great and the good' of the local community. Trusts are able, within limits, to manage their own assets, to borrow money and to negotiate local pay and condition agreements with their staff outside of the Whitley Council regulations. The Department of Health encourages the emergence of separate acute and community Trusts as it is felt that when the two merge, hospitals inevitably asset strip community services. However, this arrangement could be a barrier to the establishment of combined child health departments unless all children's services in a district opt to join the same Trust.

Trusts have become increasingly popular and April 1994 saw approval of the fourth wave.

### GP FUND HOLDERS

Large GP practices can now manage their own budget to purchase various services, including hospital diagnostic tests, outpatient services and a variety of non-urgent inpatient and outpatient procedures. Since April 1993 they have also been able to buy community nursing services, including health visiting (although not their public health function). A further development took place in April 1995 when 51 'Total Purchasing' pilot projects were established in England. These fund holders can purchase all secondary care in partnership with their DHA, including emergency admissions. Like Trusts, fund holders have gradually increased in number. They are seen by some to be the cutting-edge in the NHS reforms but by others to represent destabilisation of a coherent purchasing function.

### MEDICAL AUDIT

Whilst there was a considerable degree of opposition from the medical establishment to many of the white paper's proposals, there was almost universal acceptance of the importance of medical audit. In the past doctors have insisted on clinical freedom, i.e. the ability to treat and manage patients according to their own favoured regime. Medical audit,



however, has shown that treatment regimes differ in both quality and cost-effectiveness. In a cash limited service where the customer (i.e. the purchaser) demands the highest quality it is no longer appropriate for every clinician to go their own way without reference to others.

There is now a move towards clinical audit where nurses, therapists and other health care workers, as well as doctors, compare the structure, process and outcome of treatment programmes. Medical and clinical audit, together with consumer satisfaction, which can be measured in various ways, define the quality of a particular service. Medical audit, that is the effectiveness of a particular treatment, in turn must be linked with resource management, i.e. clinical efficiency. These issues are dealt with in more detail in Chapters 4 and 9.

## CONTRACTING

DHAs and GP fund holders are now required to negotiate annual contracts with the provider units whose services they have decided to employ. There are three types of contract: block, cost and volume, and cost per case. Block contracts are based on historical and predicted activity, the two parties agreeing to a defined range of services in return for an annual fee. In a cost and volume contract a sum is received in respect of a baseline level of activity, but beyond that level, payment is on a cost per case basis. Finally, cost per case contracts do not require either purchaser or provider to specify the volume of cases that might be dealt with. At present block contracts are still very common; unfortunately they do not give any flexibility to the system and, whilst they predominate, money will not follow the patient as was promised by the reforms. Thus, if a Trust exceeds contract activity in a given year it receives no payment for this. Whilst block contracts involve high risk to the provider, cost per case contracts conversely put the risk on the purchaser as Trusts have an incentive to complete as much activity as possible [5].

Although purchasers have the responsibility for making contracts, the expertise as regards their content lies with the providers, so there must be sensible dialogue between the two. As well as defined levels of activity, contracts include service specifications, setting out quality standards for the service provided. It is essential that clinicians are involved in this process. Service specifications for children's services are particularly complex, as they cross the acute/community/psychiatry boundary as well as involving primary care and the local authority [6].

## CENTRAL ORGANISATION OF THE NHS

In England, the Secretary of State for Health is responsible to Parliament for the provision of Health Services. The Department of Health policy

board is chaired by the Secretary of State and sets the strategic direction of the NHS. Other functions of the Department of Health are to negotiate with the Treasury on NHS funding and to monitor the performance of Health Authorities and Trusts.

The NHS Executive stems originally from the 1983 Griffiths Inquiry. It was evident that whilst the Department of Health performed well at policy making it was not efficient at managing operational matters within the NHS. The NHS Executive thus acts as a bridge between the Department and the NHS as it monitors the performance of Trusts and facilitates implementation of Department of Health strategic direction and policy. Regional Health Authorities, which formerly acted as agents for the Secretary of State in the administration of health services, were finally phased out in April 1996.

### CLINICAL DIRECTORATES

Since Griffiths a series of initiatives have appeared in order to improve efficiency and effectiveness in the Health Service by involving service providers and making them accountable for the resources they use. Management budgeting [7], introduced in several sites in 1983, encouraged the development of Unit budgets with the involvement of clinicians. The aim was to relate workload and service objectives to financial and manpower allocations. For several reasons, including its finance dominated strategy, management budgeting was not successful, nor was it popular with doctors [8].

The Resource Management Initiative (RMI) was established in 1986 '... to enable the NHS to give better service to its patients, by helping clinicians and other managers to make better informed judgements about how the resources they control can be used to the maximum effect' [8]. RMI consists of four inter-related elements [9]:

1. Improved quality of care through giving professionals better information about the effectiveness of different treatments and greater authority to determine resource allocation.
2. Involvement in management by service providers whose decisions directly commit resources to patient care.
3. Improved information to identify how resources are being used and to what effect.
4. Stronger control of resources by using information rationally for resource allocation.

From the original six pilot sites RMI has since spread to a plethora of hospitals and more recently has involved community Units and Trusts. RMI has often evolved in tandem with clinical directorates (CDs) which are managerial subunits headed by a clinical director, a clinician who has

budgetary control for the whole of the directorate, including all staff, drugs, equipment and supplies.

Perhaps the most influential philosophy behind the establishment of CDs is the trend, seen in private industry as well as the public services, for decentralisation and the breakdown of professional hierarchies with the emergence of multiprofessional task orientated teams. The management team in the CD usually consists of a clinical director, who is usually but not always a consultant, a care/directorate manager who is often a nurse, and a business manager, together with any extra help in, for instance, accountancy. The clinical director should be a respected clinician, an effective manager and a good communicator. He/she should be the key strategist and decision maker [10], although there may be a need to become involved in specifically medical management matters on an operational basis. The care/directorate manager is responsible for implementation of directorate strategy on a day-to-day basis. Tasks will include the management of non-medical staff including their appointment and training, quality, and communication both within and across other CDs. The business manager's role includes information, resource management, budget monitoring and involvement in the details of the contracting process.

Many clinicians have been reluctant to take on the extra power and responsibility of holding a directorate's budget. Some of this has undoubtedly been due to time restraints in an already stretched clinical load. Another element is the dilemma a clinical director may face between as a clinician giving the optimum treatment to an individual patient and as a manager controlling a limited budget. Others also find it difficult to countenance having to control their consultant colleagues managerially, particularly when there may be some resistance to what may be deemed as a loss of clinical freedom. The Institute of Health Services Management study of clinical management models [11] published in 1990 described three organisational options which mirror these difficulties. The consultant manager is basically the clinical director as described above. The consultant coordinator does not control a budget but simply coordinates and monitors the activities of the CD on behalf of the Chief Executive. The clinical general manager is a non-clinician who manages the CD; relationships between consultants and the Chief Executive are through elected representatives.

As previously mentioned, some children's departments have encountered difficulties in setting up combined hospital/community CDs since the advent of NHS Trusts. The Department of Health has encouraged the evolution of separate hospital and community Trusts because of concerns that combined Trusts would focus on acute services to the detriment of the community. However, in the competitive environment in the current NHS it is sometimes difficult to encourage mutual cooperation between Trust

managers in spite of a willingness among hospital and community paediatric staff to work together. For those who find themselves in this predicament it is essential to impress on purchasers the importance of contracting for combined paediatric services.

### MANAGEMENT TASKS IN CHILD HEALTH

Operations management is concerned with the management of a system which provides goods or services to or for a customer, and involves the design, planning and control of the system. Its objectives are customer satisfaction and resource productivity [12]. In the new NHS the main customers of the children's department are the local Health Authority and GP fund holders. What are the operations management tasks which face those working in Child Health?

### QUALITY

This is of the utmost importance (see Chapter 4). Moores [13] argues that the supposed trade-off between quality and cost is a myth: in industry a poor quality product is an expensive unit of production. There is a current trend towards total quality management which seeks to create a culture of continuous improvement through a commitment of all employees at every organisational level to quality and customer awareness.

### INFORMATION

'If you can't measure it you can't manage it' is a much-quoted aphorism. The child health manager will require regular statistical information, for example with respect to activity, as well as library and database information which can be tapped into in order to answer specific questions (see Chapter 7). For information to be useful it needs to be timely, relevant and comprehensible [14]. Unfortunately, data systems in the NHS are frequently perceived as inadequate in these respects, particularly by clinicians. A major reason for this is that all too often computer systems are designed by informatics experts with little involvement of those who will use the data, thus the information produced is not 'owned' by the manager of the service.

### CAPACITY MANAGEMENT

Children's health services are affected not only by changes in organisational structures but also by seasonal and secular trends in the epidemiology of disease. Professionals need to know how to cope with peaks and troughs in demand: for example, how can a children's ward be efficiently

staffed with nurses when it experiences large variations in admission rates between winter and summer? Other issues include planning for the effect on services resulting from changes in staffing skill mix or the introduction of new technology, and estimating the level of activity possible within present resources.

## HUMAN RESOURCE MANAGEMENT

Staff costs make up about 75% of the budget of acute units; the figure for community units is 90%. Skills in personnel management are therefore essential (see Chapter 10). Two major ingredients of human resource management are an emphasis on quality and a trend towards increased flexibility of the workforce [15]. Flexibility may be in terms of task (e.g. nurse prescribing), time (e.g. flexible rostering), number (e.g. use of pool nurses) or finance (e.g. performance related pay). Changes in skill mix, i.e. the balance between trained and untrained, qualified and unqualified, and supervisory and operative staff in a service can lead to cost savings without reducing quality [16].

## THE MANAGEMENT OF CHANGE

At a time of major upheaval in the NHS it is imperative that the operations manager knows how to manage change. The reaction of individuals to adverse change is very similar to their reaction to bereavement: shock, withdrawal, acknowledgement and, hopefully, adaptation. Management of the individual depends very much on what stage they have reached in the process. Much time is required for discussion and communication with the workforce, particularly when major threats such as redundancy are possible. Leadership skills required include an ability to listen, honesty, decisiveness and being able to produce an action plan to respond to the change.

Pava [17] suggests that the methods of dealing with change vary according to both its complexity and the conflict it engenders. Four scenarios may be described:

1. Low conflict/low task complexity: a finely detailed implementation strategy ('master plan') can be produced (example: producing a protocol for medical management of children with Down's syndrome).
2. High conflict/low task complexity: a master plan will be resisted in this context. Progress needs to be disjointed, pragmatic and marked by bargaining and compromise (example: restructuring of Community Paediatrics, with staff redundancies).
3. Low conflict/high task complexity: as the change here is more

complicated, widespread participation from the workforce is necessary (example: establishing a new Child Development Centre). This is a situation in which project management is useful (see Chapter 14).

4. High conflict/high task complexity: an indirect approach to change is essential. For instance, Stoelwinder and Clayton [18] describe how an attempt was made to contain costs without central administrative directives. Patient care teams involving every occupational group were formed at ward level to discuss improving the quality of patient care and enhancing cost containment. Various actions were taken as a result of these team's deliberations and the outcome of these actions was debated from time to time. Definite improvements in quality of care and cost containment were made (example: closure of an acute paediatric unit).

### LEADERSHIP SKILLS

What sort of leadership skills are needed in the new NHS? A distinction is often made between the administrator of the 1960s and 1970s and the present day manager. The old-style hospital administrator was there to make sure things worked, to implement instructions from the Regional Board. Life was governed by rules, routines and responsibilities with an emphasis on avoiding mistakes and keeping the status quo. The environment in the NHS is now much more turbulent and a different style of leadership is required. Modern managers have to adapt and respond to specific situations inside and outside the organisation they are responsible for with an appropriate repertoire of behaviours. Adaptability, flexibility, creativity, innovation and a capacity for learning are important features of the successful manager. This manager is someone who takes risks, who is proactive rather than reactive, task oriented rather than focusing on responsibilities.

There is, of course, no one right way to manage successfully. Management methods may vary according to the leader's personality, the personalities of the team which is being led and the external environment. Two models are described [19]: the transforming leader and the transactional manager, and characteristics can be attributed to each model (Table 2.1). Leaders are visionary, have a grand view with long-term aims and encourage their team to take risks which may lead to mistakes being made. They prefer simplicity and thus find it difficult to become interested in the details of management. They enjoy challenges and encourage lively debate as team members ask searching questions about the organisation and its direction. On the other hand, transactional managers have much more of a short-term focus and prefer formality and conformity. They are task-centred rather than visionary, tacticians, fixers, makers of bargains. They see the complications of a problem and are good at detail. They are teachers rather than inspirers.

Table 2.1 Models of leadership

Transforming leaders:	Transactional managers
Empower	Bargain
Inspire with ideals/visions	Are task centred
Make implicit contracts	Make explicit contracts
Have long-term focus	Have short-/medium-term focus
Encourage mistakes	Encourage sheltered learning
Like contrariness	Like conformity
Are emotional	Are comfortable
Simplify	Complicate

Most people involved in leadership fall between these two extremes, having varying balances of the different characteristics described above. Common to all successful leaders is some measure of the following: an impulse to lead, self-awareness, a sense of direction, knowledge and intelligence, human sympathy, tough-mindedness and integrity. It is apparent that not all clinicians have the ability or the willingness to take on a leadership role.

## TEAMS

Mention has already been made of the importance of multiprofessional team work in our discussion about clinical directorates. Belbin [20] has studied the way successful teams operate and has drawn up a list of personality types who when working together in balance can be extremely effective. Leadership is vitally important and three models are described by him, each having useful skills in different situations.

Belbin described the chairman as not usually more intelligent than other members of the team but calm and self-confident with a strong sense of objectives and an ability to welcome discussion from all contributors. Chairmen are suited for balanced teams with a potential for coping with complex problems. Shapers are intelligent, full of drive and outgoing with an ability to challenge complacency or ineffectiveness and are most successful in established teams facing internal or external threats. Apollo chairmen are above average intelligence who can be tough and discriminating but never dominating: they give of their best in think tanks. Other personality types include monitor-evaluators, completer-finishers, plants (intelligent but impractical) and company workers (organised, sensible but lacking in vision).

What makes a team of people successful in any enterprise? Tjosvold [21] suggests the following ingredients.

1. They need a leader who imparts vision and a sense of direction. The leader is not necessarily someone with a very creative mind but he/she should be able to recognise and implement good ideas thrown up by the team.
2. There must be a sense of unity with a corporate sense of responsibility and achievement.
3. They must have the backing of the organisation of which they are a part and be able to relate their own vision to that of the organisation.
4. They should be able to be open enough with each other to allow every member to express their views, and flexible enough to promote constructive controversy to explore issues and alternatives.
5. There should be time set aside to reflect on past successes and failures and to learn from them.

### **ASSESSING MANAGERIAL PERFORMANCE**

Health workers have long been recognised as for the most part hard working and dedicated to the care of their patients, however their efforts have not always been organised and efficient. One of the basic tenets of management is the importance of setting targets by which performance can be measured. Thus, for instance, a technique called 'management by objectives' [22] lists the following principles.

1. Agreeing a common objective.
2. Focusing on results against time, which helps to concentrate the mind.
3. Objectives should not be imposed from above but should be agreed at all levels of the workforce ('top down' and 'bottom up').
4. Progress can only be measured against recognisable goals.

NHS Trusts are now required by the Department of Health to produce an annual business plan and a three yearly strategic plan and submit these to their relevant NHS Management Executive office [23]. The business plan is meant to identify the Trust's desired outcomes and the resources which will be made available to meet these. The strategic plan and a summary of the business plan must be published, thus encouraging accountability. They are also yardsticks by which managerial achievement can be measured.

At directorate level each service manager is required to submit their own annual objectives to the business manager whose task is to blend these into a coherent whole. Directorate business plans should, of course, be consistent with the aims and objectives of the Trust. At the end of each year the clinical director in conjunction with the business manager measures what has been achieved against the original targets set.

Individual performance review (IPR) is a means of measuring the



achievement of objectives by each member of the management team. IPRs are performed by line managers who themselves have their own IPRs from their superiors. Interviews should major on support and encouragement and should not be threatening; any disciplinary procedures should be outside the IPR process. There is no reason why clinical directors should not be involved in this.

More controversially, management performance can not only be measured but rewarded. Performance related pay (PRP) is based on quantitative or strictly based qualitative criteria and is related to corporate objectives. PRP can be used to reward team performance but is more commonly employed with individuals. Consultant distinction awards are theoretically a form of PRP but there is little evidence that they are actually related to quality performance. In addition they are manifestly unfair, being unequally distributed according to specialty, geography and gender [24]. In a move towards reform, from April 1996 the consultant awards were replaced by up to five additional discretionary points on the national consultant salary scale, these points being awarded at Unit level.

## TIME MANAGEMENT

Most child health workers live extremely busy lives. Whether their work is hospital or community based or a combination of the two they face a heavy workload with ward duties, clinics, audit, teaching, research, administration and liaison with other healthcare professionals as well as with the local authority. Work patterns can be very variable and it is all too easy to become inefficient and ineffective despite being eternally 'busy'. Time management seeks to bring some order to this chaos.

Many factors operate to eat into our time: meetings, vast amounts of paperwork to read, interruptions, telephone calls, poor filing systems, mechanical failures. On the other hand, some of the problems we encounter may be of our own making, such as an inability to say no to any request, a lack of prioritisation, procrastination or simply an inability to relax and take time off to rest adequately. Henry Mintzberg [25] suggested the manager has a number of different roles, and it is useful to know what these are before analysing our own workloads:

1. Interpersonal. This includes the figurehead role of representing the organisation at, for instance, certain social or ceremonial duties; the leader role in relation to subordinates; and the liaison role in the network of contacts outside the organisation.
2. Informational. The manager monitors information received from within and outside the organisation, and helps distribute that data to those that need it. In addition, he/she may act as a spokesman for the organisation to the outside world.

3. Decisional. Here the manager makes decisions about change and the allocation of resources and deals with the opposition these often engender.

With such a complex set of tasks it is vitally important to organise them so that they do not overwhelm us completely.

However, it must be stressed at the outset that for time management principles to be effective the individual must realise there is a problem: imposing them on the reluctant or the sceptical may have no effect.

The following is a list of important points.

1. It is essential to distinguish efficiency and effectiveness, i.e. we must not only do things right but be doing the right thing. For instance, as the head of a community child health service one might religiously wade through all copies of hospital discharge letters on children in our area but would this be an effective use of the available time?
2. Analyse your workload: this may seem tedious, unnecessary or downright impossible in the context of an extremely busy lifestyle. However, there needs to be some scrutiny of what we do day by day, perhaps by reviewing our diaries for the preceding month or two, if we are to manage our time better.
3. Prioritise your workload: it is essential to distinguish important and urgent tasks. A little reflection will show that not all urgent tasks are important, although it may be difficult in specific instances to persuade others that this is so. It may be useful, for instance, to set a regular time during the day when you are available for parents or colleagues to contact you by telephone rather than being interrupted regularly.
4. Plan your workload and set targets: the evidence is that managerial success is better when the planning/implementation ratio is high. A sense of purpose is essential if an individual or organisation is to work efficiently and effectively. A few achievable targets should be set and their level of implementation monitored regularly.
5. Elephant technique [26]: huge tasks can be divided into bite-size pieces, doing a piece on a regular basis until the task is completed. Other elephant sized problems are ignored to avoid becoming bogged down in the process.
6. Ensure that you get enough relaxation: Apart from humane considerations, people work better if they have adequate rest and holiday periods.
7. Delegate: successful clinicians are often of an obsessional nature and have very high standards which they may not feel many others of their colleagues are capable of attaining. Unfortunately, this is not a very useful character trait for managers who must be able to delegate even if this means that mistakes may be made. Giving responsibility to

subordinates is often very helpful to them in their own personal development.

8. Use your secretary (if you have one) and your diary in planning the management of your time.
9. Office management: if your time is to be used efficiently you will need a good filing system: again, a good secretary should be able to help you with this. No doubt the tidiness of one's desk is to some extent dependent on personality. Nevertheless, large piles of case notes and reams of pending papers can be daunting to the human spirit as well as wasteful of time. The time management philosophy [26] states that our preconscious brain cannot contain more than ten thoughts simultaneously, so we should sort things around our desk into logical groups of up to ten elements in each area. Being ruthless in consigning unimportant papers to the rubbish bin is also important.

## CONCLUSIONS

The Griffiths inquiry saw the need for the introduction of general management into the NHS, Unit managers being held individually accountable for performance. The introduction of clinical directorates and the implementation of the white paper *Working for Patients* have continued this trend. There are a number of important managerial tasks to be performed if children's services are to be organised efficiently and effectively and I have outlined some of the skills required for managers to be able to carry these out. It is essential that clinicians, doctors, nurses and therapists, become involved in management at all levels so that finite resources are targeted to children most in need of health care.

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# Working with parents

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# 3

*Kate Saffin*

## INTRODUCTION

As a nurse and health visitor my professional ethos – indeed duty – is to care for the patients for whom I am responsible. As a parent I care for my own children with very little input from the health service, in fact the service can do nothing with or for my child unless I allow it to. Perhaps the title of the chapter should be working with health services: but that would be another book altogether.

As I look at the services available to my family I know nothing of divisions between Trusts or the finer points of the purchasing habits of fund holders. I see the health centre, where my health visitor and general practitioner are based, and the hospital service with consultant paediatricians.

When my child is well I use my own judgement, with only occasional recourse to health professionals, and I expect to be treated as an equal partner in the work of child health. If my child is ill then I want to be involved, to understand what is happening but ultimately I need to trust the professionals to do their best for my child. And, broadly speaking, that has been my experience. However, as a health professional I know that not all parents are as knowledgeable, or as positively motivated, as I am. The key to a successful service partnership with parents is in finding the right balance.

It was not always so. Thirty years ago a title such as ‘working with parents’ would have been a euphemism for telling parents (itself often a euphemism for mothers) what to do, and in no uncertain terms. Over the last twenty years ‘working with parents’ and ‘partnership’ have gradually become buzz phrases, beloved of authors and editors alike. Partnership as an entirely new concept has been embraced with an almost evangelical

fervour which risks confusing rather than clarifying the reality, which is that there **has** been a huge shift in the underlying philosophies which govern child health services.

In the last five years these philosophies have also become formalised within NHS strategic planning. The *Priorities and Planning Guidance for the NHS: 1996/97* [1] specifically asks for 'demonstrable progress' in partnerships at all levels: between health authorities and general practitioners, between health and local authorities, between health authorities as purchasers and consumer groups and between providers and individual patients. At the centre of the children's charter [2] are standards concerning the use of parent-held child health records and prompt and appropriate information for parents about community and hospital services.

It is perhaps worth reiterating the answer to the question 'why does it matter?' It is now widely accepted that early patterns of child care have lifelong effects. Therefore any society must look to the quality of its child care and support that care in ways that parents find helpful.

Health services for children have traditionally been aimed at parents, usually mothers. The change over the last 15–20 years (although its roots probably lie much earlier) has been from **aiming at** to **working with**. That is not to suggest that any utopian ideal has been achieved. In fact it is doubtful whether such an ideal has even been adequately defined.

What do 'partnership', 'empowerment' and 'working with parents' mean? Are they a good thing? If so, how do health service managers support them? This chapter aims to explore the concepts involved in working with parents in the widest sense, define some principles and then explore some of the practical applications of notions such as partnership and empowerment in managing child health services.

The reader will find few absolute truths and fewer clear rules: the only thing that can be said with certainty is that neither the issues nor the implementation are simple.

## WHAT IS 'WORKING WITH PARENTS'?

The two most frequently used terms are 'partnership' and 'empowerment'. There have been numerous articles, especially in the nursing press, entitled 'Working in Partnership' or 'Parents as Partners'. Few, if any, have attempted a clear definition or discussion of the concept before leaping headlong into the assumption that it is A Good Thing, and should therefore be encouraged. The *Oxford English Dictionary* gives two definitions of partner: as a sharer and as a person associated with others in business in which he shares risks and profits. Empower is defined as to authorise, license or enable.

Implicit in the definitions of partnership is a sense of equality and a clear

knowledge or understanding of the undertaking in hand. In business there is a written contract of partnership and the risks and benefits are clear. Rarely are they so clear in health care. Herein lies the first difficulty: many of our attempts at partnership are not explicit to the parents. There is a general intention of good will without the parent knowing exactly what to expect or contribute. The knowledge and understanding of that undertaking in hand, child health care, also varies: between parent and professional, between mother and daughter, between one culture and another depending on knowledge, background and beliefs. Equality cannot be achieved by good will alone. Inequality is built into the relationship between the professional and the consumer because the former is recognised as possessing expert knowledge. Although this may be the reason the consumer consulted the professional in the first place the parent still wants his or her specific knowledge of the child recognised as important.

Going on to the definitions of empower is no simpler. To authorise, license or enable suggests that he who undertakes to empower must relinquish some. At the same time power cannot simply be given away by the powerful. To achieve a shift in the balance needs positive action, but it will always remain a balance. There are those who argue that a weighting of power on the side of the medical practitioner is necessary [3]. This argument is probably more sustainable in medical practice involving the sick child, than in multiprofessional health care for the well, as most child health services are.

Lastly, for many health professionals, working with parents probably conjures up images of work with individual families and yet there is also the dimension of partnership with, and empowering of, communities, whether in planning or delivering services. Most, if not all, of the same issues apply with the added complexity of achieving the greatest common good.

## **WHY IS IT DIFFERENT NOW?**

Shifts in ideological, political and economic background have all contributed to the shifting focus of child health services, as well as increased pressure on resources. There has been a growth in the consumer movement with demands for more openness in many areas of public life. At the same time the political agenda for the 1980s was one of individualism, whether in housing, health care or education. Increasing choice was the avowed intention; to what extent this has been achieved, and for whom, is probably beyond the remit of this work.

There are very mixed views on this shift to individualism in health care. There are those who see it as a way to empower parents, by redressing the traditional imbalance of power. Others see it as a way to blame

individuals for illnesses and problems whose causes may lie in factors beyond their control. Tones [4] quotes the Declaration of Alma Ata in saying 'To cajole the individual to take responsibility for his or her own health while ignoring the social and environmental circumstances which conspire to make them ill is victim blaming; it is not only unethical it is inefficient'.

The growth of the consumer movement has been significant. The health service response has been one of consultation: define the service and then ask the consumer whether they like it or not. This, argues Rodgers [5] is a top down approach and means that the service keeps control of the agenda.

Alongside consumerism came shifts in practice and beliefs among child health professionals. Parents are now increasingly recognised as the expert on their own child with health professionals available to help rather than to dictate. From a position where many professionals found it difficult to admit to not knowing all the answers (often considering it 'unprofessional' to admit to such weakness) it is now recognised that we do not have all the answers, and if we did, it is unlikely that the health service would have the resources to provide them.

Another vast area of change concerns legislation, much of which is relevant to a discussion on partnership. The Education Act (1981) [6] brought parents into the legal process: as participants both in discussion and as recipients of reports, correspondence and statements of special educational need. The Children Act (1989) [7] gave the child's needs and wishes a legal status and emphasised parental responsibility rather than rights. The Data Protection Act (1984) [8], although geared to computer based information, focused many minds on related areas such as medical records, a topic which occupied many heated column inches in the medical press during the 1980s. Finally the Access to Health Records Act (1990) [9] allowed consumer access to medical records with only a few restrictions.

The major legislation affecting the health service is, of course, the NHS and Community Care Act (1991) [10] in which the internal market was created. In terms of working with parents, its significance lies in the requirement for health authorities to involve communities in assessing need before purchasing services on their behalf. This brings one of the major thrusts of the Declaration of Alma Ata [11], that consumers should participate, both individually and collectively, in the planning and implementation of healthcare into the nation's policy and legislative framework. However, policy documents such as *Primary Care: Delivering the Future* [12] only refer to the giving of information when discussing partnership with users.

This changing climate extends to the NHS classroom. Textbooks and teaching for health professionals have begun to emphasise empowerment



and partnership. Nurse and health visitor education has changed from a didactic process to one in which the student leads the learning. There is an increasing use of learning contracts, in which the student identifies her or his learning needs and objectives and ways in which to meet them. The teachers' role is to facilitate the process, rather than to simply feed the student information. In addition there is now a general recognition of the health work undertaken by the consumer and their carers.

Thus, over the last 15–20 years there has been a sea change in political ideology and professional and consumer attitudes. Some of the social background to this sea change can be illustrated by looking at writings in the sociology of medicine, and in particular the way in which health care is discussed. Tuckett [13] and Jones & Jones [14] writing for health professionals in the 1970s, discuss the division of labour in health care only in terms of the divisions among the paid workers in the NHS with an emphasis on illness care rather than health. The consumer is described as a patient and as an actor (implying perhaps that there are lines to be learned in order to be a good one . . .). However, by that time many sociologists had challenged the old order and a redefined division of labour had appeared, one described in terms of the 'public' and 'domestic' domains. This framework is a useful one in considering work with parents because it both includes them and highlights the inequalities that must be considered. Its development is briefly reviewed by Stacey in Chapter 1 of *The Sociology of Health and Healing* [15] in which she describes a division of work that includes both paid and unpaid workers. Broadly, the paid workers are in the public domain and have the higher status, with the unpaid working in the domestic, less visible, lower status domain. She maintains that while parents and other carers have gained recognition as health workers it has been within a prescribed and limited framework, one in which imbalances of power are inevitable.

It may seem to be stating the obvious to announce that parents are health workers. However, in reality we know very little about how parents fulfil this role. Mayall [16] states that most work in this area has started from the perspective of the health worker and then asked how well parents fit in with existing services. She points out that 'the situation may look quite different if the parental perspective is the starting point'.

One area that has been explored over the last 40 years is the use of general practice by parents. In 1954 Horder & Horder [17] estimated that less than one third of illness episodes reach the general practitioner, a result duplicated by others [18,19,20]. Pattison *et al.* [20] found that on 75% of days mothers were making decisions about their babies' health but only on 6% of days was a doctor or health visitor consulted, suggesting that they were managing most health concerns themselves. There was no evidence that they failed to appreciate the severity of symptoms.

There is an interesting difference in the stance adopted toward the

mothers taking part, between Horder & Horder in 1954 and Pattison *et al.* in 1982 which illustrates the changing professional view.

Concerning the estimate that less than one third of illness episodes reach the doctor:

This result may seem a little difficult to believe. It needs to be quantified by the obvious fact that most of the items not presented to the doctor are trivial.

*Horder & Horder 1954*

There appears to be surprise that so much is going on without sanction from a doctor and this is dealt with by labelling it 'trivial' and therefore, presumably of no concern. In comparison Pattison *et al.* seem to take a more positive view of the mothers' contribution:

(mothers are) . . . making almost daily decisions about the babies' health, usually without medical advice.

and

. . . it does suggest that mothers with their first babies do not resort to the doctor with every minor upset, as is sometimes implied.

*Pattison et al. 1982*

Graham [21] supports this point but argues that health care is not simply a matter of recognising symptoms and making decisions about which, if any, health professional to consult. It involves a complex balancing act of environmental, physical and mental issues to maintain an equilibrium within the family. Having said this, like Mayall, she also points out that this is a poorly documented area of lay health care and that we know very little about how women achieve and maintain this equilibrium. In addition there is evidence [22] that men and women view their own, and therefore presumably their children's, health in different ways so working with parents will vary according to which parent(s) are present.

Another area that illustrates changing professional attitudes is that of record keeping. The service has moved from one where the existence of a health visiting record was kept secret from the parents [23] through a decade of argument and polarised views in the medical press (mostly related to access to records) into a world where parents of the majority of new babies born in this country now receive a Personal Child Health Record (PCHR) which is regarded as the primary record of their health and development [24].

The issues reflected by records are undoubtedly complex. Metcalfe [25] looked at some of them related to access, commenting, 'doubt and

hesitation among doctors (and some patients) should not be dismissed as unregenerate conservatism: the issues are complex'. He goes on to discuss these, including claims that access should allow the patient to take a share in responsibility for his health. He maintains this is possibly the most difficult concept although:

in a sense . . . information is power, and giving access to the record is the only way of ameliorating the gross imbalance of power in doctor-patient encounters.

*Metcalf 1986*

This begins to lead into some possible ways of addressing the practicalities of working in partnership. To do so risks sidestepping once again the question: is it A Good Thing? Perhaps it is the wrong question, for so many strands are leading in the same direction and few parents or professionals are likely to want to turn the clock back. Perhaps the question should be as follows. How do we best support and facilitate the changes and developments that parents and professionals want, in ways which do not risk a health service manifestation of the 'emperor's new clothes'?

## **PRINCIPLES OF PARTNERSHIP**

The discussion so far has looked at a range of influences and threads in the changing world of child health services. It is a complex scenario in which many influences – political, economic, environmental, social and emotional – are inextricably entwined and need consideration if services are to be provided in a way that allows staff to work in partnership and encourages empowerment. A framework of public and domestic domains has been identified illustrating the fundamental imbalances of power between consumers and health professionals.

At this point some principles on which to hang future consideration of working in partnership might be useful.

In terms of the benefits of working with parents rather than aiming services at them:

1. Resources will be better used if those on whom they are to be spent, whether individuals or communities, are involved in planning how those resources are to be used.
2. Services will meet needs more appropriately if they begin with identified individual or group needs as opposed to the services which have traditionally been available in the area.
3. Health care will be enhanced if the individual is informed and knowledgeable about health in general and their own in particular.
4. Users will feel they have choices and can exercise some control over the services they receive.

## TAKING PARTNERSHIP INTO MANAGEMENT

This is no easy option. Some of the difficulties have already been touched on: practicing partnership by stealth and how to achieve the right balance of power given that empowerment is not merely an abdication by health professionals of the power they have traditionally held. Furthermore, that balance is not a static concept amenable to definition or even objective setting: a 5% increase in the power shift year-on-year for example! Each relationship between a service and a community or a health professional and a client has a balance, and each transaction within that relationship a further balance. On such transactions are built the delicate edifice of partnership and empowerment.

Any change needs careful management; work towards partnership and empowerment probably needs more careful handling than any other. The question that we must all be seeking the answer to is: what are good, proven, effective partnerships?

It would be tempting at this point to provide a recipe book, examples from the literature which claim to have achieved 'Partnership with Parents'. A more useful exercise, however, might be to look at each of the principles in terms of its implications for managers, whether purchaser or provider.

### THE PRINCIPLES

1. *Resources will be better used if those on whom they are to be spent, whether individuals or communities, are involved in planning how those resources are to be used.*

The clear expectation that consumers will be involved in the assessment and planning process at commissioning level has already been identified. Actually putting this into practice is more difficult and is usually by a consultation approach such as that described by Kennedy & Williamson [26]. They describe a systematic approach developed by York Health Authority for involving the local population in policy decisions (giving an example in elderly care). Rodgers [5] suggests that the social service model of empowerment via advocacy, giving people the necessary support to exercise their power, is more valuable than this top-down consultation in the long run. Among the problems she identifies in the consultation approach is the tendency for the more articulate, least burdened, to respond, often reinforcing the original inequalities. There is then the risk that the organisation may be left with a comfortable feeling that the issue is being addressed when in reality little, if anything, has changed. She also highlights the issue that a commitment to empowerment is not the easiest option, it will almost certainly make life more difficult for managers but that it is probably the only way to significantly increase consumer

involvement. She concludes, 'without empowerment, consumerism is meaningless'.

The York approach is consultation rather than advocacy but the 'noisy but informed debate which lasted several months' appeared to have been a positive exercise, valued by all who took part. Unfortunately Kennedy gives no indication as to the timescale of the process, an important aspect, for such consultation is not a process that can be hurried.

Another approach adopted from Germany and the USA where it is used to explore opinion on a range of issues, is that of Citizens' Juries. The King's Fund annual review for 1995/96 [27] discusses the concept in detail and describes the experience and findings of the first example in the UK, a four day session held in March 1996 at the Cambridge and Huntingdon Health Authority. They suggest that there may be two useful models. One is a 'deliberative' model involving broad questions on which the jury guides policy-makers, offering feedback and opinion. The other is a 'decision-making' model in which the jury is engaged to adjudicate on a current issue of concern. They conclude that both could improve the democratic process.

These models provide examples of approaches to consultation and consumer involvement. However, there seems to be little in the literature to date on which areas and topics should be debated.

*2. Services will meet needs more appropriately if they begin with identified individual or group needs as opposed to the services which have traditionally been available in the area.*

Once strategic planning is complete there still remains the work of making the services operational. The views of consumers are just as valuable, as in Greenwich where parent groups were involved in planning child development centres [28].

There are initiatives such as the resource centre at 45 Cope Street in Nottingham [29] which offers a range of child health care services and health education opportunities. Much of the work with users (mostly mothers with young children) is undertaken in groups. The centre, led by a health professional, spends considerable time planning each group's work so that it reflects the needs and wishes of the participants, without a preset agenda and routinely asking users for their views as part of an ongoing evaluation.

Many Trusts have carried out surveys or interviews to evaluate and improve local services [30,31,32] although often this is intended for local use and remains unpublished.

Individuals and communities can also be represented by voluntary organisations. Fieldgrass [33] provides a comprehensive guide and examples of such broad partnership initiatives, both nationally and locally, and is a good resource for managers who are assessing the options to meet an identified health need.

3. *Health care will be enhanced if the individual is informed and knowledgeable about health in general and their own in particular.*

The focus here is broadly health promotion. The Personal Child Health Record, now in use in most if not all districts, is also intended to be a source of information for parents and therefore could be seen to be contributing to overall knowledge. Structured approaches to health visiting such as the Child Development Programme provide examples of tools in use in the quest for improved partnership via knowledge.

The Child Development Programme [34] originated at the University of Bristol and is in use in a number of health authorities, either on its own or in conjunction with 'first parent visiting' [35]. It involves regular home visits, usually by a health visitor, although some areas are beginning to use community mothers. Its aim is to empower the mother in her child health work by supporting her in her choice of approach and encouraging her to record her child's health milestones.

In some areas [36,37] the programme is used in conjunction with, and supplemented by, community mothers. Community mothers are local women with experience of their own families who work as volunteers (although payment is made to cover expenses) with families in their neighbourhood providing support and friendship. They usually visit monthly, not more frequently as one intention is to avoid dependence, which would undermine the whole point of the scheme. Suppiah [36] suggests that becoming a community mother is itself empowering: many go on to further training or paid work.

The cost of such schemes will need careful consideration. Many initiatives, especially those involving communities, which might initially appear to be economical, in reality are not a cheap option, although they may offer a very effective service. For example, a community mothers scheme needs careful selection and ongoing training and support. If they achieve their stated aim of empowering mothers then demands on health services may rise.

An important issue to address in introducing any initiative is evaluation. Evaluation of any health promotion intervention is always difficult and often requires a long term and qualitative approach. Most appear to be short term and to focus on user satisfaction, however, this can be valuable if it is used to influence and further develop the service.

Johnson *et al.* [37] demonstrated that a randomised controlled trial is possible for some initiatives and can demonstrate effectiveness of an intervention, in this case, introducing community mothers. The group of 262 first time mothers in a deprived area of Dublin all received the standard support from the public health nurse. In addition the intervention group (127) received monthly visits from a community mother for the first year. At the end of the study they found positive benefits such as improved immunisation rates, more appropriate diets for the children and

a greater sense of well-being of mothers among the intervention group. They conclude that 'non-professionals can deliver a health promotion programme on child development effectively', although they also go on to say that further study is needed.

4. *Users will feel they have choices and can exercise some control over the services they receive.*

All the discussion so far becomes pointless if consumers do not feel that they have some choices.

Parents will all be at different stages: the first time parent receiving a Personal Child Health Record will regard it as the norm, the third time one for whom it is an innovation may be a little more cautious. They will be affected by the setting and the child's current health needs, the more serious, the more anxious the parent.

This sense of control is as relevant for staff facing new ways of working as it is for parents. A major issue in implementing any initiative is to consider the training needs of staff and clients. New ideas, especially ones which challenge the old, comfortable order of things and threaten the individual's sense of being in control need time to grow and mature if they are to bear fruit. This is particularly relevant in the current climate where constant change has become the norm. This means time invested in preparation. The time needed adequately to prepare for any change or initiative depends on the setting (community based initiatives will take longer than changes in hospital), and the nature of the proposals. Some will be straight forward, evaluating views of a child health or outpatient clinic, others the vehicle for more radical change such as exploring the concepts and practice of partnership via the implementation of PCHRs.

#### THE PERSONAL CHILD HEALTH RECORD

One of the major tools in the quest for partnership and empowerment at an individual level in child health is the Personal Child Health Record (PCHR). First piloted in Oxfordshire in 1983 it has since developed into a national A5 loose-leaf booklet given to over 75% of parents of newborn babies in England and Wales by the end of 1994, and to all in Northern Ireland from January 1995 [24]. The loose-leaf format is both a strength and a weakness. It has been criticised for a lack of uniformity. However, this allows for local variation and flexibility and may contribute to the sense of local ownership.

Early concerns about loss and completion were not realised [38] and it has been welcomed by parents and professionals alike [39,40,41]. One of the major changes in using the PCHR is that it establishes a situation in which the transaction is a two way one – the parent brings the record, hands it to the health worker, discusses what will be recorded and receives

it back – unlike the one way transaction of being shown a record, in which the parent is a passive recipient rather than active partner.

Careful planning for implementation is important and Scott (quoted by Sutcliffe 1994) [42] found that a lack of preparation led to problems with professionals' reception of the record and difficulties in implementation. It can offer less duplication, readily accessible information for everyone involved and active involvement for the parent. However, it never promised to make life easier, or make difficult things easier to say or to turn a bad practitioner into a good one. The extent to which it empowers parents and contributes to partnership depends entirely on how it is used: unless the health workers use it as an empowerment tool it will not be one and parents will be disappointed [40].

Although the use of parent held records is now highlighted in the mainstream of health policy (via the children's charter) there has never been any central funding towards its development or evaluation. A review of the recent literature reveals only a number of small scale evaluations usually at the end of the first year. The Oxford study was an exception to this in that it covered two years and in more depth, however further work is urgently needed on ways to develop the record; its use as children grow older, and the needs of specific client groups: ethnic minorities, parents with learning disabilities, and families of children with special needs as examples.

#### PROVISION OF INFORMATION

This section has focused on the partnership initiatives that attempt actively to involve parents in decision making by providing tools to help that process. However, providing information is another aspect of the empowerment process. There are now many sources and routes for parents and children, ranging from leaflets and telephone help lines to the internet and interactive computer based systems.

One such resource is the family resource centre at Great Ormond Street Hospital for Sick Children which can be contacted via the World Wide Web, e-mail, telephone, fax or post. In the first year (1996) there were an estimated 1200 enquiries. The centre has not analysed the source of enquiries, but approximately three-quarters were from parents.

#### CONCLUSIONS

There is a need to recognise the complex nature of the world we live and work in and the multiple influences on any health service, especially ones as intimately concerned with the parents' sense of self worth as partnership and empowerment.

Proven, effective partnerships are those which listen to parents and give



them a voice, whether in district wide planning or in the care of their own child. Unfortunately this is a difficult area to evaluate and the initiatives that have proved popular, such as the PCHR, have tended to be those that are amenable to audit and simple measurement – do they get forgotten? are they filled in? – neither of which demonstrate any real evidence of partnership or empowerment (although the Oxford study [41] demonstrates the potential, when the record is well used). It may be that the resource intensive, difficult to measure, community initiatives such as the centre at 45 Cope Street, the Child Development Programme and community mothers will prove the more valuable in the long term, but they also need a long term approach towards evaluation.

The lessons to be learned from all this are: that consumers need to be involved as widely as possible in any discussion of change, that empowering staff is the first step to empowering parents and that a sensible timescale is essential when contemplating any change. Tools such as shared records, parent literature and structured approaches to care may help but all are rendered useless in the face of anxious, overburdened, disempowered staff. The key lies in ownership of the process, for both staff and parents; get that right and everything else will follow.

And a final word: the spell checker on my word processor does not recognise the word empowerment; it always offers impairment as an alternative. I have not updated it because, for me, it provides a timely reminder that good intentions are not enough. Efforts at empowering can so easily become impairing if we as health professionals do not constantly stay alert to our tendency to aim services at parents rather than gearing them to work **with** parents.

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# Consumer orientation and service quality

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# 4

*Michael Rigby*

## INTRODUCTION

Determining agreed quality measures and standards for services is a notoriously difficult challenge, whatever the service involved. This is primarily because of the subjectivity of consumers' attitudes to services, coupled with the difficulty of producing tangible measures of service activities. For instance, if one is considering restaurants, banking or holidays, individual consumers have very different preferences and expectations as to both style and quality, and these service industries go to some lengths to make different service products available, whilst also endeavouring to develop objective measures of quality.

Ensuring quality in healthcare is even more of a challenge, not least because of the major importance of good health, coupled with the personal and personalised nature of much of healthcare delivery. Additionally, there are problems in ensuring that the consumer is sufficiently informed as to what is reasonable and appropriate in a technical area, whilst at the same time ensuring that professional views (themselves partly subjective) do not totally dominate.

The World Health Organisation's Regional Office for Europe has established a process to consider key issues in the delivery of health care in Europe into the next millennium. Their first resultant publication [1] postulates common core values for health services in the future. These cluster into three categories: choice, quality and value for money. The authors suggest that quality will have three components: maximised effectiveness, care geared to the user's needs and not organisational convenience, and staff responsive to users and carers. However, choice as the first theme is also a key quality dimension, whilst value for money is also essential to quality as unnecessarily high consumption of resources

in delivering those services provided will preclude other service options. Thus the presentation of the WHO vision puts quality as totally centre stage and all-pervading. This exactly matches and mirrors an essential prerequisite for the achievement of quality in practice at the day-to-day level, namely a total quality culture.

## MANAGERS AND QUALITY

Given the challenges of determining quality, and the fact that the manager is not at the front edge of the organisation delivering care to individuals, what is the management role in ensuring quality? How is a quality culture achieved? How can quality of service be assured?

As leader and director of the organisation, the manager has four essential contributions to quality: policy, monitoring, education and empowerment.

### POLICY

The direction in which the manager commits the organisation can fundamentally determine quality, as can the price and the pattern of provision. In conjunction with professional and financial advice, and cognisant of the pressures from consumers and purchasers, the organisation must balance between concentrating on those areas for which it is most competent, and developing its own resources to meet unaddressed needs (including new clinical services). Also within this policy making environment, the manager will need to ensure that there is professional agreement, formally underpinned by policy decision, as to the philosophies and techniques of particular services. At the operational level, this will be confirmed through operational policies which are agreed, published and readily made available to all involved.

### MONITORING

This is a key management role. Its tendency to be perceived as threatening is unfortunate and should be avoided, as this militates against the open discussion needed as part of a quality culture. Rather, monitoring should be a process whereby the manager checks that the organisation is proceeding to target in its delivery of health care and in the resultant outcomes. It is closely tied in with the need for good management information, and the identification of key indicators as opposed to the time consuming studying of voluminous statistical analyses. Where deviations from expectation or target are identified, they should act as the trigger for further discussion and investigation, and not for recrimination. Such deviations can stem from many causes, including changes in demand or

changes in the operational environment, and the resultant way forward should be decided only after discussion with professional and other interests.

#### EDUCATION

Good performance can only be obtained through the combination of good professional training and full awareness of the organisational objectives and environment. Both these require ongoing education, by a combination of formal and informal means. Within the reality of finite resources, the manager will need to identify those areas where further investment in formal training is necessary, those areas where in-house tuition is appropriate, and the need for a common sharing of corporate objectives, methods and current performance.

#### EMPOWERMENT

Above all, though, the manager is as dependent upon the performance of staff in their day-to-day duties, as the staff themselves are dependent upon the manager to provide them with the right tasks and resources. Quality is ultimately achieved through implementation of the Churchillian challenge of 'give us the tools, and we will finish the job'. The healthcare product is delivered by the combined efforts of staff throughout the organisation, of all professions and all levels. Only by giving them the appropriate educational resources and shared vision will quality be achieved (and an essential part of that will be, on occasions, the acceptance of current resource positions). Additionally, however, staff must feel they have the authority, indeed responsibility, within agreed limits to tailor services to meet the needs of individual clients, and at the same time they must feel they are working in a supportive environment in which new ideas and issues can be raised and brought forward so as to further improve quality. This latter can be achieved in two ways: first, the assurance of being part of a 'listening organisation', where feedback and ideas for improvement are welcomed as constructive; second, structured activities such as quality circles [2], whereby cross-sectional groups of staff are given the task of reviewing total service quality from the operational perspective, will enable the reality of the 'coal face' to travel directly to the top of the organisation, avoiding any inherent tendency for a filtering or distancing between service delivery and management.

However, if the manager is to be effective in addressing these four areas, a sound knowledge is necessary of the concepts and principles of quality management, together with some of the techniques. Good generalist texts on quality in health care exist [3-5], and will be valuable to the reader, but the special issues of child health are not necessarily fully developed

therein. The balance of this chapter seeks to address this need, by outlining the principal quality dimensions and tools in a child health context.

## **STAKEHOLDERS, CHECKS AND BALANCES**

In this challenging but important setting of variety of personal choice and professional viewpoint, quality for child health services has always had its activists, to considerable effect, particularly within inpatient services. In the early days of the NHS, as described in Chapter 1, the priority was to ensure basic provision of inpatient paediatric services within reach of major centres of population. In the post-war rationing era the primary driving force was to ensure basic availability of services. However, there rapidly developed pressure for quality standards, driven by two separate forces: the professional and the consumerist.

The professional quality targets were principally of nursing and medical provision. There was the development of the principle that there should be qualified children's nurses in all settings where children were treated, whilst paediatricians realised that an adequate service could not be guaranteed by a sole consultant paediatrician with 24 hour responsibility, seven days a week, hence the increasing insistence that consultant paediatricians should never be single-handed in a hospital or district. Whilst it can be argued that neither of these standards were disinterested ones from the professional point of view, their prime objective was to ensure that if specialist skills intrinsically justified their development and investment then they ought to be adequately available.

The voluntary-led consumer-orientated pressure for quality improvements concerned principally the environment of care, a non-technical but equally important feature of the therapeutic process. A campaign by the then National Association for the Welfare of Children in Hospital (NAWCH) – now known as Action for Sick Children – resulted in recognition by the professions and the government of the day that certain basic standards should be universal. The most important of these was that children should not be nursed on adult wards, and other targets related to the provision of play facilities and subsequently professional play leaders.

This small piece of history illustrates the complementary (though sometimes conflicting) roles of the different 'stakeholders' in healthcare, with their different (and equally legitimate) viewpoints. These can be identified as follows.

### **CLIENT**

Increasingly it is being acknowledged that healthcare should be patient-focused, yet this is a fairly recent concept in terms of the style and

standards of healthcare provision. The obvious challenge with child health services is that there are two dimensions of the client interest: that of the **child** and separately that of the **parents**. Even young children are not without their views as to important issues such as food, environment, the people around them, and indeed the television channel to be watched! The parent has different views of the same topics, and also their own view as to the overall suitability and perceived quality and convenience of the service. Particularly with regard to preventive services, or the early seeking of assistance for perceived developmental or parenting problems, satisfaction with the service is not an optional extra, it is an essential aspect of ensuring that help is sought before a problem has become serious. Child health services have to be sensitive and responsive to both categories of clients, and to the individuality within each group. The King's Fund has been strong in developing this theme and methods, particularly through McIver's work addressing not only principles [6] but also specific settings including community care [7] and outpatient departments [8].

#### PROFESSIONAL

Health professionals are highly trained, and therefore will have views about appropriate quality standards. Many of these will be well based and scientifically founded. However, professional pressures should be no more adopted without constructive challenging than the views of consumers. First, professional viewpoints are not homogeneous, for instance nurses, members of the paramedical professions, and doctors may all have slightly different viewpoints of a particular issue. Second, branches within those professions, particularly within medicine and nursing, may also have differences. Third, there may be different schools of thought or philosophies as to care and treatment approaches. Last, the variable treatment rates for conditions such as otitis media indicate that demand for any particular level or style of service may be open to legitimate debate.

#### SOCIETAL

Society has its own views as to the appropriateness of particular services, and quality priorities. The significant achievements of the National Association for the Welfare of Children in Hospital have already been referred to. Children's health charities are popular causes with the public, yet not necessarily with a full debate as to the relative merits of particular proposals. Within healthcare provision, the societal interest has two principal manifestations. The first is legislation, the ultimate representation of consumer views and values, which may set particular standards as absolute. Second, purchaser organisations, initially district health



authorities (now health commissions), but increasingly general practitioner fund holders, are charged with the task of ensuring that each section of a community's healthcare need is met equitably, judging competing priorities, and that defined standards are achieved.

Given these different and sometimes conflicting pressures, the job of the child health services manager in ensuring quality can be confusing. The most important recognition should be that there is no instant answer; the manager must ensure that all relevant stakeholders are approached and different viewpoints noted. When a particular position needs to be reached it should be based on rational analysis which can be defended, even if it does not meet the wishes of all interested parties. This will necessitate balancing the preferences and attitudes of the majority with the legitimate interests of minorities and individuals, within the constraints of technical feasibility and overall affordability.

## MODELS OF QUALITY

In order to achieve such defensible positions, it is helpful to draw upon recognised models of quality. Such models are not new, probably the oldest being nearly 4000 years old in the form of the code of Hammurabi [9]. A key part of this ruled that where a doctor seeking to cure an abscess of the eye should cause that eye instead to be lost, he too should lose an eye: a somewhat draconian but very clear approach, if difficult to apply to paediatrics because of the age difference between patient and practitioner.

### NIGHTINGALE

Moving to somewhat more modern times, Florence Nightingale set an important lead by emphasising the importance of outcome. She identified the problems of nosocomial (or hospital-induced) illness; she developed statistical measures which differentiated between 'relieved, not relieved, and died' – a distinction which still eludes NHS statistical systems! She also recognised the challenge and the importance of determining true hospital outcome measures [10].

### DONABEDIAN

In most recent times, there have been two main contributions to concepts of quality in healthcare, one from the United States and one from the United Kingdom. In the USA, Avedis Donabedian developed his helpfully simple trilogy of structure, process, and outcome [11]. **Structure** is the totality of resources which are fixed at a particular time, principally this includes buildings and medical equipment, but equally important are the

staff composition and skills. For any given health intervention at a particular time, the practitioner has to work within this structure, and therefore its appropriate development and regular review are vitally important.

The **process** involves all the activities which are carried out as part of the assessment of the patient and the subsequent delivery of care. Unlike structure, which is comparatively easy to measure, process is almost invisible. It is normally carried out in the private setting of a consultation, is frequently very quick, and is difficult to record or measure. However, its delivery forms the focus of much of the training of healthcare professionals, particularly nurses and paramedical staff. It is therefore a quality dimension which has to be assessed largely from the periphery looking inwards.

**Outcome** is the most important but frequently overlooked part of the trilogy. Its importance is self-evident on reflection, because it is not the facilities or the activity of healthcare which are important, but the results. This includes the perceived results such as anxiety, or concern about quality or slowness of treatment, and it also includes interim results such as pain or distress. However, even in its most obvious and fundamental form, the outcome of treatment or the amount of health gain is difficult to measure given current available data. Whereas we should be capable of being more sophisticated than Florence Nightingale a century ago, this is often not the case. In particular, it may be difficult to identify the degree of health gain achieved through a therapeutic process, particularly when considering either preventive services or support to chronic conditions, where a 'no change' situation may indeed be the result of very positive and successful intervention, without which there would have been significant deterioration of health, or even death. A significant proportion of child health services fall into this challenging arena.

The value of the Donabedian principles, therefore, is not that they provide instant answers but that they provide a constant reminder of the three separate viewpoints which must be taken into account. Whilst outcome is the most important, it is the most problematic to study. Hence ensuring appropriate quality of structure, and through that the ability and awareness to deliver appropriate processes, are good targets only provided they are recognised as merely being proxies for the truly important dimension of outcome. It is reasonable to assume that good quality of outcome is severely jeopardised if structure and process are not right, but the converse cannot be argued, as it is still possible to deliver poor quality even with favourable circumstances. Goldstone has also helpfully pointed out [12] that in any healthcare setting the structure, process, and outcome trio are not a single global entity, but rather that the outcome of one component of healthcare delivery may be part of the structure or process of other parts, for instance the quality of radio-

graphers' films is part of the diagnostic structure available to inform the clinician's process, whereas the outcome of a professional education process contributes to the structure elsewhere.

#### MAXWELL

Whereas the Donabedian contribution is conceptual, the contribution of Robert Maxwell has been seminal in indicating the dimensions or viewpoints of quality. Writing in the *British Medical Journal*, and seeking to refocus professional attitudes onto consumer quality interests, Maxwell postulated the following key quality criteria [13].

1. Access to services.
2. Relevance to need.
3. Effectiveness.
4. Equity.
5. Social Acceptability.
6. Efficiency and Economy.

These principles have been well accepted, and have the power of enabling informed debate rather than yielding instant answers. Their catalytic value is in requiring decision as to the viewpoints, measures, and values to be used in managing quality in a specific instance. To take access as one example to illustrate the point, it can be considered from the professional viewpoint of availability and clinical thresholds; the managerial viewpoint of contract pathways and waiting times; and the consumer viewpoint of public transport, internal hospital signposting and pram access.

#### PROCESS FLOW MODEL

Finally, Sear and Rigby have produced a tool for clinicians or managers to identify threats to quality by taking a client-centred view of the delivery of healthcare to the individual, recognising the reality that this does not consist of a single process but rather a series of semistructured encounters ranging from the initial seeking of a service or process through to the discharge to the next process or support [14].

The five key stages of the flow are shown in Figure 4.1.

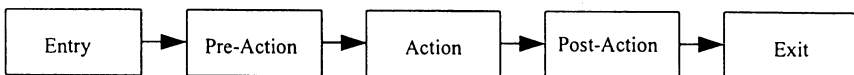


Fig. 4.1 The five key stages of healthcare flow.

For example, at a macro level, preschool immunisation for an individual child could be considered a key action. In order for this to be achieved the child needs entry into the possibility of the programme through registration with a care provider, and pre-action is represented by seeking appointment preferences and consent. Post-action would include follow-up of missed appointments and offering of other health advice, whilst exit should be positive rather than passive, for instance by ensuring entry to a school health programme. The same model can be used at a micro level, for instance with an individual injection the five stages would be by ensuring the appointment was made; reception facilities; administration of the antigen, answering parental questions as to next treatment; and ensuring results were recorded on the local computer system (with identified alternative action lines for defaulters). At a higher, population, level the model can be used to identify and test the quality of the overall programme management by reviewing district-level procedures; it can also be applied to processes such as completion of documentation.

### **OBJECTIVITY, RELIABILITY AND JUSTIFICATION**

The achievement of a quality service at the point of contact should not be a one-off event. Not only should optimal quality always be achieved for ethical reasons, but reliability and consistency are themselves quality dimensions valued by the consumer. In child health, both preventive and therapeutic techniques frequently involve repeated attendances, and therefore changes to policy or approach can be most disconcerting and annoying. Word of mouth features as a strong communication mechanism amongst client groups such as mothers of young children, and it is important that the messages on this grapevine are always positive ones: particularly so as it is a known phenomenon that bad news travels more widely in this setting than good news. Finally, in support of new staff or staff working in other than their usual location, it is important that they know what is expected of them, not just clinically but with regard to day-to-day procedures.

The teamwork that is essential for the delivery of good service quality requires a combination of sound professional training and unambiguous knowledge of what is expected in a particular post under particular circumstances. A good example can be drawn from the airline industry, where with the larger airlines' flight attendants may not know one another until shortly before they board the aircraft. Nevertheless, the teamwork leading to a consistent and quality service slips immediately into action, not just in the more obvious (but less important) tasks of serving drinks and meals, but in the hidden areas such as preparing the food, following procedures when a passenger is taken ill, or handling other difficult and unplanned situations, the ultimate being the emergency evacuation. The

secret behind this is that all the staff will not only have had the generic cabin crew training on customer service. They will also be able to rely totally on the equipment and supplies which will be on the aircraft, down to the individual locker in which each will be located. Above all, though, they will have been trained in all the policies and procedures for that aircraft, and they will be allocated to a particular location within the aircraft where they have specific well defined and documented duties as part of the overall team.

Delivery of health care quality requires a variant of this approach to be adopted. Good interpersonal skills, a willing approach, and a sound professional training are important, but alone they are not enough. The manager will therefore wish to see in place, and well understood, appropriate applications of the following tools and techniques.

#### OPERATIONAL POLICIES

Operational policies are clear written statements of procedures to be followed under specific circumstances. They will be readily available in all appropriate settings. Broadly speaking, they are related to the activities of the organisation and its interface with care delivery. There should be operational policies for a wide range of issues, from how to get maintenance and repairs on the building undertaken, procedures to be followed when the fire alarm sounds, through to patient-related and often sensitive areas. Arrangements for parents to stay in hospital overnight (including aspects such as payment, meals, and explaining their inter-relationship with nursing responsibilities), and the procedure to be followed when inexplicable bruising is observed on a child, are examples. Operational policies are intended to underpin a quality service; at the same time, they are also there to protect staff who may need to justify their actions.

#### CLINICAL PROTOCOLS

These refer much more specifically to clinical procedures, as undertaken by individual health professionals. They will range from topics such as administration of immunisation (with sections covering issues such as when to seek further clinical advice, and facilities necessary in case of anaphylactic shock), through to shared care protocols between secondary and primary care for the support of children with diabetes. Thus clinical protocols are within the domain of health professionals, and will be devised by them, but the manager will wish to ensure that they are developed, are related to the local circumstances, and are reviewed regularly.

#### ORGANISATIONAL POLICY DOCUMENTS

These often span the ground between operational procedures and clinical protocols. An example would be the policy document on obtaining consent, with the various aspects including the difference between emergency situations and non-emergencies, clarification of the roles of relatives who may accompany children (such as grandparents), and the identification of legal parenthood. Organisational policies thus do more than guide health professionals, they state the public position of the organisation, and though their use may be primarily by health professionals, they need to be understood by other staff, not least the receptionist.

#### EVIDENCE-BASED MEDICINE

A theme which has emerged strongly in recent years is that of evidence-based medicine, which has even developed its own acronym (EBM). This has emerged as a result of belated recognition of the inexplicable range of practice styles and alternative treatments used in otherwise similar situations. This clearly seems inappropriate, and so the concept has emerged of seeking to validate clinical protocols and treatment preferences by reference to underpinning scientific evidence. Many countries, not least the USA and the UK, are setting up established centres which will be the keepers of guidance on best practice, deduced from a process of systematically evaluating the published evidence according to its strength and its general applicability. However, it is also important not to take this to the extreme of resulting in formulaic practice – it continues to be important for the practitioner first and foremost to take a history, establish the evidence, and then deduce a way forward – the evidence base should be used to support the most appropriate method of achieving that way forward [15]. The manager's role should be to ensure that clinicians have access to the appropriate knowledge bases, that updates are drawn to their attention and that clinical protocols are established drawing appropriately upon this evidence.

#### CARE PLANNING

This is an important technique to ensure that care for the individual is objectively planned and consistently delivered, with specific intended achievements. Nursing has long practised the nursing process, which includes the setting of a care plan [16]. More recently other professionals such as speech and language therapy have adopted objective approaches [17], and this technique has been recognised as the optimum multiprofessional standard, particularly with regard to community services [18]. Care planning includes the assessment of need, establishment of objectives of

treatment, identification of the interventions required, a time schedule for the delivery of these interventions, identification of the professionals responsible for each intervention, and finally an intended outcome. As appropriate it will harness clinical protocols, and thus be evidence based. This structure of the care plan should be shared with the patient (or their parents), so that they know not only what treatment is going to be provided, but they also know why, when, and to what purpose. The setting of a care plan is itself a quality standard, but in the context of the subject under consideration the care plan itself has a further advantage in becoming a quality yardstick to the individual. If care delivery departs from the care plan then clearly care is becoming suboptimal, yet at the same time the client has a basis upon which to approach the healthcare provider and ask for explanation and if possible rectification.

#### RESOURCE SCHEDULING

Historically, community child health services in particular have accepted all work referred to them, and then forced the existing resources to absorb this workload. This is potentially unfair to both client and staff, who may be significantly overloaded, with potential threats to quality. Modern information systems enable forward resources to be booked in the light of the care plans set. This will assist quality by ensuring that overload is avoided either by adjusting caseloads or redeploying staff. Moreover, scheduling systems can also identify failures in service delivery either because the resources were not available or because the patient did not attend, in either case enabling the key worker to be alerted to the treatment omitted [19,20].

#### CONTRACTS

The agreeing of contracts is very much a managerial responsibility, though prudence dictates that this should only be done after full involvement of clinicians. Contracts can determine quality in two ways. First, if the price is set too low, it will be impossible to deliver a quality service. Second, the contract itself may specify particular clinical techniques or protocols to be used, and particular quality standards to be achieved.

#### COMPLAINTS

The defensive manager resents complaints, but this is not a healthy attitude. The positive manager sees complaints as a very important form of consumer feedback. In any service setting the customer is loath to go to the trouble of making a formal complaint; in health care the natural wish not to upset the care givers provides even stronger motivation against the

complaints process. Thus when a complaint is received it is either an indicator of a failure of service delivery, of poor quality within a service, or of a failure by the organisation to communicate with customers what is occurring. There are appropriate procedures for handling complaints which fall outside this chapter – the importance for ongoing quality development is to analyse the pattern of complaints received as an important source of management information.

#### COMMENTS AND SUGGESTIONS

Whilst complaints are the important and negative aspect of views of users and staff, comments and suggestions should be welcomed just as much. This is not to seek simplistic praise, though of course it is important that staff are commended for doing a good job when this is clearly the case. A more thoughtful pattern of comments and suggestions, though, will lead to the improvement and strengthening of the organisation, and these ideas are as likely to be cost neutral or to save money in the long run as they are to have additional costs. Various forms of seeking comments and suggestions can be applied, ranging from formal suggestion schemes and the handout of feedback cards or questionnaires, through a system of comments books like visitors' books prominently displayed at hospital ward entrances. What is important in these situations is to ensure that these sources of feedback are analysed regularly, and the results published. A system which is seen to be valued and to have positive results will gain strength; one which is ignored will rightly wither. Though comments and suggestions are sometimes scorned as being unscientific and from an over-awed source, this is to belittle the importance of seeing services from the viewpoint of consumers and staff who are constantly at the delivery point of the service.

In summary, therefore, the manager has a number of tools and techniques which are available. In some cases the managers themselves will directly create or employ these tools, but in most cases they are approaches which should be used by clinicians, with the managerial role being to ensure that they are developed, put into place, and utilised.

#### AUDIT AND STANDARD SETTING

The effective manager will also want to ensure that quality is monitored. Increasingly this is being seen as a basic responsibility of the clinical professions.

#### AUDIT

The concept of audit originated with Lembke's work in the USA [21], but this was arguably ahead of its time and was not taken up widely at that



stage. Within the UK, the principal motivating force was the Confidential Enquiry into Perioperative Deaths (CEPOD) [22], which looked at deaths during or immediately after surgery and found that not only were some of these deaths potentially avoidable, but that there was an unacceptable variation in the mortality rates between locations. Though a stark example and itself not directly applicable to the majority of child health services, the CEPOD study was pivotal in that it led rapidly to recognition by the professional bodies and government that this situation was unacceptable, and therefore that structured audit was necessary to ensure the maintenance and development of good standards. Psychologically and sociologically this should have not have been a surprise, as many other professions ensure regular review of performance and tests of competency, for instance among airline pilots, but the health professions had hitherto found it difficult to accept that they could deliver less than optimal care on every occasion. Such a hypothesis, of course, does not allow for human variation or human frailty.

Thus audit was introduced into the UK in a comparatively structured way, with a particular leadership from Dr Charles Shaw at the King's Fund [23]. It was endorsed by the Standing Medical Advisory Committee [24], and thereby became established as an essential component of normal good practice.

However, though the medical role in healthcare provision is important, it is a minority contribution in terms of the number of staff and the number of interventions. Other professions such as nursing also established their own audit processes, but more significant has been the development of clinical audit. This looks at the totality of the therapeutic programmes as delivered by the whole clinical team. Audit has been well developed organisationally through the establishment of audit assistant posts to collect and analyse data, and the provision in the early stages of special funds to fuel the audit process.

Audit can be undertaken at a number of different levels, which include general unit-wide procedures, frequent clinical conditions, and rare but particularly significant conditions. Additionally, audit can be undertaken at a wider, regional level. In order to extend the practice of audit and to enable units to learn from previous successful audit protocols, the British Medical Association now hosts the national centre for clinical audit on behalf of a consortium of health professions. Advice can be obtained about previous audits which have been undertaken on any particular topic, as a source additional to the still important literature search.

Most audit is undertaken, rightly, at local level, as this is where services are delivered to individuals, according to local policies and using local teams. However, even here there is a complexity, in that the nature of child health means that care not only draws in several professions, but these staff often come from different organisations to form one operational team.

Thus local audit will need to establish not only the subject, but the definition of the wider team involved, and it will have to obtain both their support and motivation if it is to be effective. In this sense it faces challenges similar to those in primary care audit (and indeed primary care is important within child health), and some of the lessons of developing primary care audit can well be applied to strengthening reviews within child health [25].

An example of the wider, population-level audit within child health, which benefits from the collaboration of a number of providers, is that which looked at neonatal screening in South London [26]. It has the valuable attributes of not only setting standards for, and measuring results against, particular aspects, but also the added dimension of taking particular minority stakeholder interests. It also analyses the accuracy of different sources of information.

However, it is rightly important that audit is targeted at the most important topics. Criteria for selection should take account of both priority [23] and feasibility [27]. There should be an overall audit strategy in any healthcare delivery environment, and identification of objective topics within that strategy. Here the role of the manager can be of particular significance, as a person who is dispassionate to the particular professional interests yet has an overview of all the issues and of all the stakeholder pressures. Thus the manager can ensure that the overall clinical audit strategy is relevant and balanced, and addresses important issues objectively. Managers may also be called upon to provide resources for audit, particularly computer support where large volumes of data are handled regularly. Dedicated computers are not necessarily a prerequisite for good audit, though they can be a major asset; guidance is available, which also emphasises the importance of utilising data and facilities already available [28].

There is, though, a second important role for the manager within audit, and that is following up the findings. In so far as the results of the audit suggest changes in professional issues, the manager should at the very least ensure that these are addressed, but may also have a role in facilitation, for instance through a change in professional skill mix. Other audit studies, though, may show a need for a different type of change, for instance modifying premises or acquiring equipment. In all these the manager will have an important role through their responsibility for use of, and change in, resources.

#### STANDARD SETTING

Audit is itself dependent upon another and wider technique, namely standard setting. A key part of the audit cycle [23] is the establishing of the standards which will underpin the audit study. Standard setting itself is

a sensitive subject, needing to balance the views of different stakeholders with the reality of resource availability (not just in cash terms, but also in terms of the availability of scarce skills). Three different approaches are possible, each perfectly appropriate provided that their status is clearly established.

**Absolute standards.** These are standards which must in all cases be met. They may either be clinical imperatives, or in other areas lowest common denominators.

**Interim standards.** In an organisation which is developing its services, it is realistic to recognise that perfect standards cannot be achieved in the short term. In order to ensure progress forward, interim standards may be set with a validity of, for example, one year. This is a constructive approach given the important proviso that it is clear to all parties that these standards are interim. If there is any suggestion that they are the final standards, and then are changed as soon as they are achieved, staff will become disillusioned through feeling that there is no point in trying to score better if the goal posts are constantly being moved.

**Normative standards.** These are the standards which are set to be achieved under normal circumstances. These have a higher degree of permanence, but recognition that they may not always be achieved. For instance, in the patients' charter [29], there are standards that a patient should be seen within 30 minutes of their outpatient appointment time, and that where exceptionally an operation has to be postponed twice for non-clinical reasons the patient will get priority for a further appointment. This recognises that the standard cannot always be achieved, but that it should be aimed for in all cases, and that if slippage is more than the specified amount then remedial action is required.

## TARGETS

Targets are different to standards. It has already been explained how standards should normally be achieved in a majority or all cases. Targets are unequivocally something to be aimed for over the longer term. Thus it may be unusual (indeed, exceptional) if they are achieved in the period under study. They do give staff and consumers the advantage of seeing that the service is steadily moving forward with clear objectives in mind, whilst recognising that a particular service is starting from a less than ideal state.

## ORGANISATIONAL AUDIT

A further dimension of audit which is being increasingly recognised is organisational audit. This looks at the fitness for purpose of the organisation itself, as opposed to the clinical practices within it. In

healthcare this also has primarily been promoted by the King's Fund, but as it has related primarily to the accreditation of community hospitals that work itself is not directly relevant to the concept as raised here. However, the concept of a self-administered audit tool is quite powerful, and an example of its development in the context of ensuring the organisation's fitness to deliver agreed programmes of integrated care has been put forward by Booth arising out of initiatives in the West Midlands [30].

### COMPARATIVE ANALYSIS AND SPECIAL STUDIES

Finally, but not less significant, quality can be monitored and improved by comparative analyses and special studies. Comparative analyses occur when a large number of providers send standard data sets on a particular topic to a central agency, which then calculates achievement rates against agreed parameters and feeds back the results in tabular form, normally identifying each provider only by a code reference so that the organisation can only identify themselves within the overall distribution. The effect is to stimulate those at the lower end of the performance league to strengthen their performance.

The classic British example of this comes from child health, and is the Cover of Vaccination Evaluated Rapidly (COVER) programme [31]. This has been instrumental in improving immunisation rates, by generating improvement where there was demonstrated to be scope for it. The same comparative analysis approach has been taken by the World Health Organisation's regional office for Europe, which has instigated similar improvement in dental health, hospital infections, and the treatment of diabetes [32]. Whilst individual managers cannot initiate such projects, they can be instrumental in ensuring success by arranging for their units to participate when such systems are established.

By contrast, special studies are normally one-off events which address an issue identified by an organiser or sponsor. The national child health consortium followed on a long tradition of considering quality review processes [33] when they undertook the Child Health Quality Evaluation (CHEQUE) project to identify how the national child health system could be used by individual community health care providers to improve the quality of their child health services. This study involved six participating study sites across the UK, and demonstrated and published a methodology available for any child health care provider to use [34]. The principles and techniques developed and described in this report should give important food for thought for child health service managers. Managers in child health may wish to follow the example set by this report in two respects. First, it picks up the philosophy of organisational audit by encouraging managers to look at the totality of their service and its delivery processes, in order to review its overall quality. Second, it

emphasises the wealth of data which already exists in an organisation, often held in electronic form amenable to processing and analysis, yet this vital resource is often left untapped and undervalued.

Managers may also wish to take quality as a leading dimension when undertaking new initiatives. Setting contracts is currently an obvious one, where there are inevitable pressures to put cost and volume high on the agenda, but without good quality the service will be both less effective and unattractive. Setting a quality dimension, within affordable limits, should provide an attractive ethos both for purchasers and for staff and consumers. However, there are also other examples when bringing in a consumer and quality viewpoint first is attractive, such as the approach in Derbyshire to run focus groups and workshops for children, parents, and staff prior to starting the design of a major new hospital [35].

## CONCLUSIONS

Ensuring quality in child health services is a significant challenge. Quality itself can be a variable and subjective concept, coupled with which child health services themselves are both dispersed and at the same time tailored to individual circumstances. Nevertheless, the challenge must be taken up or child health services will likely deteriorate through lack of clear direction and leadership. A process of objectivity, standard setting, and regular review, together with empowerment of staff with the appropriate knowledge and measurement tools, are essential. Managers can only ensure quality in partnership with their health professionals, but this should be a partnership between equals rather than domination by either discipline. It is a subject which is constantly developing, and therefore the prudent manager will constantly review the expectations of stakeholders, the reality of the ongoing environment and the publication of new techniques, in order to develop a quality strategy. As with so many aspects of child health, the ultimate motivation of the manager should be recognition of their responsibility to act as the guardian of the interests of children unable themselves to monitor the quality of services upon which they are dependent for life and for health.

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# Rights, values and ethical issues in child health

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# 5

*Peter de Cruz*

## INTRODUCTION

The notion of 'children's rights' was once described as 'a slogan in search of a definition' [1] and it is relatively recently that children's rights have been accorded a measure of explicit recognition both nationally and internationally [2]. In the UK, children's rights appeared to have come of age by virtue of the landmark House of Lords decision, the Gillick case [3] and the implementation of the Children Act 1989 which came into force on 14 October 1991. On the international front, the United Nations Convention on the Rights of the Child was adopted by the UN General Assembly on 20 November 1989, and was ratified by Britain on 16 December 1991 [4]. This convention has so far been ratified by more than one hundred countries. Nevertheless, neither the content nor the method of interpretation of children's rights may be taken as settled, either at the domestic or international level since the mere itemisation of rights does not guarantee their availability, not least because all laws are open to interpretation. Moreover, the mere enactment of rights, even though contained in an international treaty, will not, *per se*, improve the living conditions of children in need either in Britain or other parts of the world.

The proper enjoyment of children's rights would require the recognition of their 'rights' being a correlative of 'duties' so that a particular right would be enforceable or claimable if there was a recognised **duty** on the part of someone else or the State to give effect to it and an obligation to provide redress for its breach [5]. It is clearly necessary for children to have what various writers call 'autonomy' in order for a child properly to exercise his or her rights in law [6]. In any event, children's rights in Britain have now acquired a higher profile than previously so that parliament and the courts have a more authoritative statutory basis from which to translate rhetoric into reality [7].



## DETERMINING THE RIGHTS OF THE CHILD [8]

Under English law, there is no general statutory enunciation of children's rights *per se*, but case-law established various children's rights in particular contexts [9] and narrow statutory pronouncements under the Children Act 1989 appear to establish a form of negative rights ('the right to refuse') in specifically defined circumstances relating to medical examination [10].

### THE GILLICK CASE

In the well-known Gillick case [11] a majority of the House of Lords (3:2) ruled that a girl under 16 years of age had the right to receive contraceptive advice and treatment from a doctor (or other health professional) provided certain conditions were met. Broadly, the child possessed such a right if she was able to understand the implications of the proposed care and treatment. Five specific conditions were laid down by Lord Fraser. The under-aged girl was entitled to such advice and treatment provided:

1. the doctor was satisfied that she understood his advice; and
2. could not persuade her to inform her parents or to allow the doctor to inform her parents that she was seeking contraceptive advice and treatment; or
3. that the girl was likely to continue having sexual intercourse with or without contraceptive treatment;
4. the girl's physical or mental health or both were likely to suffer unless she received such advice or treatment; and
5. her best interests required the doctor to give such advice or treatment or both without parental consent.

The case centred on the legality of the 1980 DHSS memorandum that contained these conditions and their implications for the scope of 'parental rights'. It considered whether this concept included the right of the parent to be informed of the child's decision to seek contraceptive advice and treatment and whether the parent could veto such a decision. The scope of the duty of confidentiality between doctor and child patient, although not raised directly, was very much in issue.

Following the Gillick decision, three sets of guidelines on confidentiality were published by the British Medical Association (BMA), the General Medical Council (GMC) and the DoH. The BMA stated that confidentiality must be respected by the doctor regardless of the circumstances of the consultation, but the GMC appeared to disagree by saying that doctors were now free to inform parents if they considered that an under-age girl was too immature to understand the issues involved. The GMC went

further by saying that if a girl refused to allow her parents to be informed despite the doctor's efforts at persuading her to do so, the doctor could then decide whether or not to proceed to give the child advice or treatment. If the decision was not to do so, the doctor was allowed to inform the child's parents but was not bound to do so. The DHSS released a 'revised circular' which merely reiterated the previous position including the Lord Fraser guidelines, and in effect, leaving it to a doctor's clinical judgement to decide what was the best course of action but stating that in exceptional cases, where family relationships have broken down or whether a doctor cannot persuade a young person to contact her parents, contraception can be prescribed.

The Gillick case has also been interpreted in the light of Lord Scarman's memorable statement that 'parental right yields to the child's right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision' [12]. This pronouncement suggested that the pendulum had swung from parental rights to children's rights, and indicated that a child with sufficient maturity, intelligence and understanding now had a right to make up his own mind on the medical care and treatment he wished to receive.

#### POST-GILLICK CASES

A number of recent cases have suggested that if the situation is a life-threatening one, the courts are inclined to adopt a paternalistic attitude and are prepared to override the wishes and therefore the autonomy of the under-aged child even if that child happens to be Gillick competent provided they believe that the result will be in the best interests of the child.

#### RE R

In the Court of Appeal case of *Re R* (1991) [13], which was heard before the Children Act 1989 came into force, R, a 15-year-old girl who was in local authority care, suffered cyclical mental illness and manifested disturbed behaviour and suicidal tendencies, becoming violent on one occasion. She was voluntarily sedated from time to time but was eventually admitted into a specialist psychiatric unit which sought permission from the local authority to administer anti-psychotic drugs to her because of her behaviour.

The case came to court following a dispute between the local authority and the unit over whether R should continue to receive the medication

since R had objected to taking it during what appeared to be a lucid and rational conversation with the local authority.

The court sought to determine the legality of administering medical treatment without R's consent. Both the lower court and the Court of Appeal ruled that R could be given the medication even without her consent primarily because she was regarded as not having the capacity to give valid consent to treatment. The Appeal Court held that the lower court was wrong in deciding that a Gillick competent child had a right to refuse treatment. Lord Donaldson, MR, declared that such a child could consent to treatment, but if she refused, consent could be given by some other person who had parental rights (or a body such as a local authority) or the High Court in the exercise of its wardship jurisdiction. The test of Gillick competence was not merely an ability to understand the nature of the proposed treatment but a full understanding of the consequences of the treatment and of its withdrawal [14]. It was a stage of development that a minor had irrevocably reached and could not be attained or lost on a day-to-day or week-to-week basis. In view of R's fluctuating mental state, she was not, in any event, Gillick competent. Consent could therefore be given on her behalf. This was sufficient to resolve the case at hand. However, Lords Justices Donaldson and Staughton also emphasised that even if R had been Gillick competent, the wardship court had the power to override the minor's wishes in the same way as it could those of parents or guardians.

#### RE W AND THE CHILDREN ACT (1989)

Three months after *Re R*, the Children Act 1989 (the 1989 Act) came into force and enacted a statutory form of Gillick competence. Basically, any child 'of sufficient age and understanding' has been given the right to refuse medical or psychiatric examination or treatment provided that child is adjudged to have the ability to make an 'informed decision'. *Re W* (1992) [15] was the first reported case to be heard under the Act and turned on the issue of consent, which involved directly the power of the court to override the consent of an anorexic girl aged sixteen.

The girl, W, was in the care of the local authority and had been admitted as an inpatient to a specialist residential unit for children and adolescents where she displayed violence towards the staff and injured herself by picking her skin. Her condition deteriorated until she had to be fed by nasogastric tube and have her arms encased in plaster to prevent her removing the tube. Court permission was sought to place W in a special hospital for necessary treatment. By the time her case came to court she had refused and therefore not taken any solid food for eight days and her life was in danger.

Both the lower court and the Court of Appeal ruled that the courts had the power to override *W's* refusal to undergo treatment; no minor of whatever age may refuse consent to treatment, if such consent has been given by someone with parental responsibility for the minor and *a fortiori* a court in the exercise of its inherent jurisdiction. Section 8 of the Family Law Reform Act 1969 gave a minor who has attained the age of 16 a right to consent to surgical, medical or dental treatment but it did not give the minor an absolute right to veto such treatment. The Court of Appeal affirmed that while the minor's consent could not be overridden by those with parental responsibility, a court could nevertheless override such consent as well as a refusal to consent.

Subsequent cases [16] have confirmed this approach, even where the child's refusal of consent did not have life-threatening consequences. However, in each case the child concerned had been suffering from some form of psychotic mental illness or mental disorder. The courts have therefore opined that in order to save the child's life, or because the child had threatened to kill herself [17] or because the child's parents have given their consent to the treatment or simply because the child is not Gillick competent, that minor does not have a right to refuse consent to medical treatment. The courts have also affirmed the earlier appellate court ruling in *Re R* that even if the child were Gillick competent, his or her refusal of consent would not expose the doctor to the risk of any criminal or civil proceedings should he treat the minor in an emergency or if he had obtained parental consent to do so. Where more than one person had parental responsibility for the child, only a refusal by all such persons would create a veto.

This may well be seen as a retrograde step for children's rights but it is arguable that many of the decisions have been broadly justifiable on the basis of their particular facts, although there is clearly a disturbingly paternalistic approach being adopted by the courts which appears to negate the child's right of self-determination [18] or autonomy. The courts appear sometimes to be a trifle too eager to authorise medication possibly in deference to the difficulties faced by carers in maintaining control over a difficult adolescent and because of the problem of closely monitoring the progress of such adolescents. Medication is often merely a short-term solution but dealing with the real causes of the child's disturbed behaviour may well demand time and resources from the State which are regarded as not being cost effective in the present economic climate.

Our main cause for concern is therefore not the court's decisions in 'life-threatening' cases but their more general statements indicating that a minor does not have the right to refuse consent even if Gillick competent. If applied to cases of normal children, this would surely make a nonsense of the statutory right explicitly laid down in the 1989 Act [19] giving

minors of sufficient age and understanding the right to refuse to submit to a medical, psychiatric or other assessment. These cases appear to set a dangerous precedent particularly when read with other case-law such as *Re P* (1992) [20]. There, the Court of Appeal emphasised that although the court had, under the Act, to consider the child's ascertainable wishes and feelings [21], it was not to be constricted by those wishes (even if express) and could disregard them if this was in the child's best interests. The ultimate arbiter, it stressed, had to be the court, not the child. One would hope that the courts will restrict the *Re R* approach to cases involving life-threatening situations or mentally disordered children who may pose a danger to themselves and others.

## PARENTAL RESPONSIBILITY

There has never been a statutory definition of parental 'rights'. The 1989 Act created the new concept of 'Parental Responsibility' which was intended to replace the existing notion of parental rights [22]. 'Parental Responsibility' is supposed to provide a comprehensive notion that comprises all the duties and powers related to a child's upbringing which enable a parent to care for a child and to take decisions on that child's behalf. The concept also enables **parents**, not the State, to take decisions on behalf of their children so that, in the majority of cases, parents will retain responsibility for their children. Non-intervention has become embodied as a statutory principle under the 1989 Act [23]. The exceptional case would be where it is proved the child is suffering, or is likely to suffer, significant harm as a result of a deficiency in the standard of care being exercised by someone caring for that child. However, parental responsibility has not been defined with any degree of specificity. Under s. 3 of the 1989 Act, it is described only as: 'all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property.' Thus some notion of rights remains relevant since there is still no comprehensive definition of parental responsibility. Accordingly, recourse must be made to other statutes and case-law in order to ascertain the scope of this concept. A study of these other sources suggests that parental responsibility must include at least the duty to provide one's child with essential health care, food, shelter and clothing [24] and education [25] and to protect him or her from physical and moral harm and from activities deemed inappropriate or dangerous [26]. Failure to fulfil these minimum duties may result in criminal or civil proceedings (such as care proceedings) being taken against the parents. Another parental duty which has been widely

criticised in the context of 'absent fathers' is the duty to provide financial support for their children which has been extended not just to divorced parents but also to unmarried fathers for example under the Child Support Act 1991. Parental 'rights' which arguably fall within this concept include the following.

1. The right lawfully to discipline a child by using corporal punishment, although this can only be administered using moderate or reasonable force appropriate to the child's age, health, physical condition and understanding. Corporal punishment is banned in most state schools, as well as in places like community homes, secure units and residential care homes but not in all independent schools.
2. The right to determine the child's religious upbringing. Parents have the right to exclude their child from religious study lessons and school assembly but parental choice is not supposed to prevail over the views of mature children who understand the implications of their decisions. A child is not obliged to follow a religion which the courts deem harmful.
3. The right to consent to medical treatment on behalf of their under-age child [27].
4. Under the latest Circular on the Education Act 1993, the implication is [28] that parents have the right to be informed of their child's school policy on sex education. The school's statement of this policy must be made freely available to parents and schools should ensure that parents understand the right of withdrawal and how to exercise it [29]. Section 241 of the Education Act 1993 gives parents the right to withdraw their children from any or all parts of a school's programme on sex education, other than those elements which are required by the National Curriculum Science Order [30]. This parental right of withdrawal extends to all pupils attending maintained schools, including those over compulsory school age. Thus, a pupil in the latter category who wished to challenge the parental decision would, if he or she could not resolve that matter with the parents, ultimately have to apply to the courts. The parental right of withdrawal may be exercised by either parent or by a person who has parental responsibility or care of the child. Again, any unresolved dispute between them would also have to be referred to the Courts [31].
5. The right to consent to the issuing of a passport to a child under 18. Children under 16 can be included in their parent's passport.

Other rights include: the right to represent a child in legal proceedings provided there is no conflict of interest; to appoint a guardian; to consent to the child's adoption; to administer the child's property and inherit that

property on intestacy. It is clearly important to know who has parental responsibility for the child since such a person (or local authority) will have the right, *prima facie*, to determine the welfare and future upbringing of the child.

Under the 1989 Act all mothers, married and unmarried, have automatic parental responsibility (PR) for their children but only married fathers have automatic PR. Unmarried fathers may acquire PR by either entering into a parental responsibility agreement [32] with the child's mother or by obtaining a court order under s. 4 of the 1989 Act. PR will not terminate upon divorce and can only be lost by death, adoption or court order. It can also be shared by several persons and with a local authority.

## CONSENT

In general, the notion of informed consent [33] is as central to medical treatment for children as it is for adults. In English law, a doctor is only required to inform the patient of the broad nature and purpose of the procedure, or the 'nature, purpose and effects' of the proposed treatment [34].

It has been said that consent plays two different functions in the doctor-patient relationship. In *Re W* (above), Lord Donaldson stated that the first was 'clinical' in that it stemmed from the fact that in many instances the cooperation of the patient and the patient's confidence in treatment is a major factor in the treatment's success; the second was a legal purpose, namely to provide those concerned in the treatment with a defence to a criminal charge of assault or battery or a civil claim for damages for trespass to the person. Consent did not, he stressed, provide a defence to a claim that the treatment was carried out negligently [35]. Consent was the 'flak jacket' that prevented the doctor being sued or prosecuted [36].

According to section 8 of the Family Law Reform Act 1969, persons over 16 years old can give valid consent to any surgical, medical or dental treatment irrespective of their parents' wishes. This does not cover organ donation or blood donations although 16-year-olds may, under the common law, validly consent to donating blood. Children under 16 can only give a valid consent to treatment if they are Gillick competent. It will be up to the health care professional to determine whether a particular under-16-year-old is 'Gillick competent' or not [37]. In the Gillick case itself, Lord Scarman stressed that it would not be enough for the under-aged child to merely understand the nature of the advice that she was being given but that she should also have 'sufficient maturity to understand what is involved'. Further, she would have to understand that

there were long-term problems associated with the emotional impact of pregnancy and its termination and that 'there are risks to health of sexual intercourse at her age, risks which contraception may diminish but cannot eliminate' [38]. On the question of how much the doctor is obliged to disclose, this is somewhat controversial as far as English case-law is concerned. Suffice it to say that the position appears to be:

1. that material risks of a procedure must be disclosed, subject only to non-disclosure because of therapeutic reasons, which a doctor might be obliged to justify [39]; and
2. a doctor is not negligent if he acts in accordance with what would be accepted at the time by a responsible body of medical opinion [40].

A risk would be material if it was such that a reasonable person in the patient's position, if informed of it, would be likely to attach significance to it and no reasonably prudent medical professional would fail to disclose it [41]. The point in children's cases is that, strictly speaking, the doctor would, under the Gillick ruling, have been satisfied that the child understood all these considerations, risks and implications. In the light of the other Gillick requirements, one would have some doubts as to whether a rigorous cross-examination is carried out in every case, particularly in the hard-pressed NHS context.

As the Gillick case also confirmed, consent is not required in emergencies, provided the treatment is necessary to safeguard the life and health of the child; and it is not required in exceptional circumstances where the child has been abandoned or neglected by those with parental responsibility [42]. What weight should be given to parental wishes if they are in conflict with those of the minor? As far as abortion is concerned, cases decided before and after the Children Act 1989 suggest that the wishes of parents are not determinative of the issue where child and parent disagree [43]. It is clear that although parental wishes are consulted as a matter of routine in everyday health care practice, these wishes are not determinative in law, but will merely be considered in determining which medical treatment to pursue. Lord Donaldson has also taken pains to point out [44] that despite the passing of the Children Act 1989, the court's inherent jurisdiction could still be invoked in an appropriate case to prevent an abortion which was not in the best interests of a child.

The inconclusive nature of parental wishes has also been illustrated in cases involving the decision of how to treat a handicapped newborn baby with a poor chance of survival [45] or a newborn baby who was terminally ill and hydrocephalic [46] or a very premature baby who had better prospects of survival but was nevertheless irreversibly and severely handicapped [47].



## ADOPTION

An adoption order vests parental responsibility in the adopter(s) rather than custody. The main ethical issues that have arisen in the context of adoption have centred on the maintenance of secrecy regarding the child's biological parents, the 'right' of the child to know its original parentage and whether adoption agencies and the courts should allow any links to be maintained between the adopted child and a sibling or a relative (including its biological parent) in special cases [48]. Current legislation now reflects the view that although the adoption of a child makes that child a member of a new family, information about that child's origins may still be important to that child and will now be available [49]. Health professionals may also be involved in conducting examinations or writing reports on birth parents and adoptive parents as recommended by the British Agencies for Adoption and Fostering. Although interagency cooperation is now the watchword, confidentiality should be maintained with regard to individual children and families and any breach of confidentiality must be justified on exceptional grounds, for example because the adoptive parents might pose a serious threat to the safety and welfare of the child [50].

## CHILD PROTECTION

The Children Act 1989 (the Act) introduced several new types of child protection orders, such as the Child Assessment Order [51] and the Emergency Protection Orders [52], which have replaced the old Place of Safety Order [53]. The former statutory criteria were seen as uncertain, confusing and open to misinterpretation and were consequently replaced under the Act by a single test of 'significant harm'. This test comprises a dual requirement:

1. there must be significant harm either being suffered or likely to be suffered by the child; and
2. this harm must be attributable to a lack of reasonable parental care on the part of the child's carers [54].

The Act also contains definitions of 'harm' so as to include physical, emotional, psychological and sexual abuse [55] and uses as a baseline the notion of the standard of care that a 'similar child' might be expected to have [56].

Case-law has begun to clarify the meaning and scope of the significant harm test [57] and it appears that the courts should not apply too legalistic an approach in its interpretation [58]. While some cases may be provable by virtue of unequivocal physical evidence, although this is by no means

always conclusive, cases of alleged sexual abuse of children tend to pose the greatest evidential difficulties [59] particularly where such abuse is strongly denied and there is no corroborative evidence. In such cases the main difficulty which faces both local authorities and the courts is the need to balance the interest and welfare of the child against the need to uphold the right of the child's carers to the presumption of innocence [60]. Child protection officers frequently have the dilemma of deciding whether the trauma the child might have to face in undergoing sessions of interviewing, cross-examination and a possible court appearance might be worse for him or her in the longer term than efforts to rehabilitate the perpetrator and to keep the family together.

A typically problematical ethical issue that troubles child health and child protection professionals and teachers, is whether it is in a child's best interests that the professional should regard the child's disclosure of child abuse as confidential. They have to weigh the need to respect the child's right to confidentiality (especially if that child is Gillick competent) against the need to protect that child from the likelihood of future harm, ill-treatment or neglect [61].

## **CHILDREN AND EDUCATION**

Under the Education Act 1944, as amended by the Education Act 1980, Local Education Authorities in England and Wales are under a duty to make education available for all school-age children in their area, appropriate to their age, abilities and aptitudes. This duty extends to all children residing in their area, whether permanently or temporarily, and includes the children of displaced persons. A recent development has been the publication of draft guidelines by the Department of Education that declare that teachers in schools will be prohibited from giving their pupils advice on contraceptive treatment unless they first obtain the parental consent of those pupils. This appears to be contrary to the advice that health care professionals are allowed to give, by virtue of the Gillick ruling. The Department of Education guidelines are apparently being revised and modified so that there will not be any apparent inconsistency with the guidance to medical professionals. Teachers face the same dilemmas as other child protection professionals with regard to disclosures of child abuse by children, particularly where such children request that the information they reveal be kept confidential. Conversely, there were media reports in 1993 suggesting that teachers themselves have been facing a spate of child abuse allegations.

There have also been recent media reports [62] that there are widespread breaches of the law with regard to the requirement that there should be daily acts of collective worship in school. The main difficulty here is that

certain headteachers have argued that the requirement that school assemblies be 'mainly Christian' was not sensible in areas where most of the children were from other faiths. The ethical dilemma here is whether to proceed with a predominantly Christian worship as required by the law or to respect the wishes of many of their children's parents to give equal weight to the right of the child not to have to follow a religious form of worship that was markedly different from that of his own faith.

## ROLES AND RESPONSIBILITIES: DOCTORS AND MANAGERS

A major change which was brought about since 1986 has been the implementation of interagency cooperation in dealing with child abuse and child protection [63]. The guide that currently exists takes account of the statutory changes brought by the Children Act 1989 and is called *Working Together under the Children Act 1989* (1991) [64]. This guide stresses that 'the responsibility for protecting children should not fall entirely to one agency: awareness and appreciation of another agency's role will contribute greatly to collaborative practices' (para. 4.1). Thus while social services are seen as the agency that bears primary responsibility for child protection, the contributory roles of the police, health services, probation service, education service and the NSPCC are all mentioned in the current version of *Working Together*.

Under the Children Act 1989, the key responsibility of health professionals is to identify children who are suffering or are at risk of suffering 'significant harm', ill-treatment or neglect. Exchange of information between agencies is seen as vital to the proper investigation of child abuse allegations. *Working Together* (1991) stresses (at para. 3.11) that: 'the degree of confidentiality in child protection work will be governed by the need to protect the child. Thus social workers and others working with a child and family must make it clear to those providing information that confidentiality may not be maintained if the withholding of information will prejudice the welfare of the child.'

The General Medical Council (GMC) has stated in its *Guidance to Doctors' Professional Conduct and Discipline: Fitness to Practise* (January 1993) that if a situation arises where a doctor believes that a patient may be the victim of physical or sexual abuse, 'the patient's medical interests are paramount and may require the doctor to disclose information to an appropriate person or authority' (para. 83). The guidance goes on to say that if a doctor believes that a patient does not have sufficient maturity or understanding to appreciate what the treatment or advice sought involves, he or she 'should attempt to persuade the patient to allow an appropriate person to be involved in the consultation. If the patient cannot understand or be persuaded and the doctor is convinced that the disclosure of information

would be essential to the patient's best medical interests, the doctor may disclose to an appropriate person or authority the facts of the consultation and the information learnt in it. A doctor who decides to disclose information must be prepared to justify that decision and must inform the patient before any disclosure is made' (para. 84). This appears to broaden the scope of the doctor's discretion. In an addendum to *Working Together* issued by a joint working party of the Department of Health, the British Medical Association (BMA) and the Conference of Medical Royal Colleges, it is declared that 'at all stages, a doctor needs to make a balanced judgment between the justifications for breaching confidence and the distress it might cause and the withholding of vital information obtained within the privileged doctor/patient relationship' (para. 4.2). It will not be easy in many cases for the doctor to decide what is in the child's best interest.

The GMC and BMA have now drawn a distinction between 'older' and 'younger' children who may be Gillick competent. In the case of young children caught up in abuse the view taken by the BMA's medical ethics committee is that there is an ethical imperative upon the doctor to inform the relevant statutory agencies where the child had made disclosures or the doctor had observed any form of abuse. For older children, the BMA's view is that the doctor should, wherever possible, encourage the child to agree to disclosure but disclosure to third parties might only occur after talking through the consequences of disclosure with the child, weighing the risks of danger to the child or siblings or other members of the family, and, where necessary, to recommend that the child be referred to specialist counsellors. The question may well arise, in marginal cases, as to how one might distinguish between 'young' and 'older' children since the Gillick principle has effectively removed any minimum age as a criterion for the capacity to make one's own decisions. It might have been more useful to simply employ the Gillick/Children Act test of 'sufficient age and understanding' in order to decide whether one has the right to breach confidentiality if this is seen as being in the child's best interests.

In *Child Protection: Guidance for Senior Nurses, Health Visitor and Midwives* (1992) [65], a central message is that in cases where the practitioner deliberately discloses or withholds information in what is thought to be in the public interest, that practitioner must be able to justify that decision. These matters should be discussed fully with other practitioners (not only, or necessarily, nurses, midwives or health visitors) and consultation with a professional organisation may be made before making a decision. Clearly, these guidelines do not go as far as to enunciate an 'ethical imperative' approach. The Department of Health publication, *Child Protection* (1992) [66] stipulates that the senior nurse should develop a communication system and establish links at the appropriate level with social services departments and managers of other agencies, such as family health services

authorities, local education authorities, housing departments and the police about current child protection concerns, as well as particular cases. Effective interagency liaison between staff members should also be established. It further declares that the senior nurse must give professional advice and information to other professionals and agencies about the specific role of the particular nurse in child abuse cases and to emphasise his or her role in prevention and detection.

Two other guidance documents, *The Children Act 1989 – An Introductory Guide for the NHS and Child Protection* (1992) [67] and *The Children Act 1989 – What every nurse, health visitor and midwife needs to know* (1992) [68] also asks the relevant authorities (district health authorities, family health services etc) to:

1. review and revise existing policies and procedures for handling child protection cases at all levels as outlined in *Working Together*;
2. contribute to the local area child protection committee's review of its procedures; and
3. identify a senior doctor, a senior nurse with a health visiting qualification and a senior midwife as the coordinators of all aspects of child protection work within their district;
4. appoint a named person to coordinate child protection [69].

The guidance documents also mention the need for health professionals to ascertain the 'wishes and feelings' of the child [70], and to work with the child's parents in partnership, in the course of performing their duties. The age and understanding of the particular child therefore remains an important consideration.

As far as maintaining confidentiality between doctor and patient is concerned, a general common law duty exists whereby a doctor is required to respect the confidences of this patient and is not allowed to voluntarily disclose, without the patient's consent, information gained by the doctor in his professional capacity. Medical records remain confidential as far as children are concerned, although in the case of a child who is HIV positive, a case might conceivably be made that this fact should be disclosed to a school in order to protect other children who come into close contact with the child and who might therefore be at risk. This might be justifiable as being 'in the public interest' and it is worthwhile noting that even under the Gillick principle, confidentiality is by no means absolute. In other words, if the underage child is not found to be Gillick competent, confidentiality can be breached and her parents may be informed about the consultation. The matter remains contentious.

As far as access to medical records is concerned, the rights under the Access to Health Records 1990 extends to children who are capable of understanding the nature of their application for access. Of course, a parent

or someone with PR may exercise that right of access to records on the child's behalf.

Finally, with regard to giving advice to schools about health problems of individual pupils, doctors remain generally bound to maintain the confidentiality of such pupils. In many cases, a parent or the child himself advises the school of the existence of conditions such as asthma, epilepsy or haemophilia. Forms are often provided by schools to parents for such conditions to be retained for the school records but disclosure by the parents is not compulsory. The situation is certainly unsatisfactory if a child happens to choose a career which is medically contraindicated and this is not discovered until schooling has ended. However, it would appear that children and parents must first be consulted and unless a threat to other children may be established, confidentiality has to be preserved.

## CONCLUSIONS

All health care professionals dealing with children now have a range of statutory duties and obligations under the Children Act 1989 and its related guidance documents. However, the typical ethical dilemmas remain, requiring a difficult balancing act to be performed in weighing competing interests. For instance, the need to preserve confidentiality must often be measured against the need to protect the child's health and safety. A key feature in child protection which currently affects health professionals is the interagency approach which demands multidisciplinary discussion, cooperation and consultation with other agencies so that no single agency should have to bear the sole responsibility for the assessment of child abuse and the furtherance of child protection. Children's rights are now firmly on the domestic and international agenda and, albeit in a narrow context, have been placed on a statutory footing in English law. However, current cases suggest that our ethical standards and fundamental values are still very much open to debate and are sometimes as mercurial as children themselves. How far should children be left to decide for themselves? Should their rights extend to the 'right' to die? How effective are children's rights if the courts continue to exercise a strong paternalistic influence on their behaviour? The way in which we respond to these and other ethical issues will set the scene for health care of children in the 21st century.

## NOTES AND REFERENCES

1. Rodham, H. (1973) Children under the law. *Harvard Educational Review*, 43, 487-514.
2. The American Supreme Court case of *Re Gault*, 387, US 1 (1967) ruled in the mid-1960s that children qualified as persons under the US Constitution and

- were therefore capable of possessing fundamental rights. Various writers on both sides of the Atlantic have, of course, been writing about the rights of children for decades; see e.g. Foster and Freed (1972) A bill of rights for children. *Family Law Quarterly*, 6, 343; Farson, R. (1978) *Birthrights*. Penguin, Harmondsworth; and Mnookin, R. (1981) Thinking about children's rights – beyond kiddie libbers and child savers. *Stanford Lawyer*, 24; see also Freeman, M. D. A. (1983) *The Rights and Wrongs of Children*. Frances Pinter, London; and MacCormick, N. (1982) *Children's Rights: a Test-case for Theories of Rights in Legal Right and Social Democracy*. Oxford University Press.
3. *Gillick v. West Norfolk and Wisbech Area Health Authority* (1986) FLR 224; [1986] 1 AC 112; [1985] FLR 224; ironically this case was initiated in order to clarify the scope of **parental** rights.
  4. This Convention came into force in the UK on 15 January 1992.
  5. See the classic exposition by Hohfeld, W. N. (1964) *Fundamental Legal Conceptions*. Yale University Press.
  6. See, e.g. Haworth, L. (1986) *Autonomy*. Yale University Press; Raz, J. (1986) *The Morality of Freedom*. Clarendon Press, Oxford; Murphy, J. (1992) W(h)ither adolescent autonomy? *Journal of Social Welfare and Family Law*, 529.
  7. Academic writers have also given the subject a considerable amount of thought; see e.g. Eekelaar, J. (1986) The emergence of children's rights. *Oxford Journal of Legal Studies*, 6, 61; Freeman, M. D. A. (1983) *The Rights and Wrongs of Children*. Frances Pinter; Freeman, M. D. A. (1987) Taking children's rights seriously. *Children and Society*, 4, 299; Alston, P., Parker, S. and Seymour, J. (1991) *Children's Rights and the Law*. Clarendon Press, Oxford. Newell, P. (1991) *The UN Convention and Children's Rights in the UK*. National Children's Bureau, London.
  8. In law, a 'child' is defined in different ways for different purposes: thus, 'child' has been used to denote a person of either sex who is under 18 years of age (see s. 105: Children Act 1989; s. 72: Adoption Act 1976); but for purposes of care proceedings, a person would be considered a 'child' and could be placed in the care of a local authority only if either under 17; or under 16 years old, if married (as more common in marriages contracted abroad). Special rules also apply to entitle a person who is already 18 years old to apply for and receive financial provision from a court in certain exceptional circumstances, e.g. if that person is or will be receiving educational training but periodical financial payments will not normally be extended beyond the child's eighteenth birthday (see paras 2, 3 and 6 and s. 105: Children Act 1989). A young person aged 16 years (although a 'child' for other purposes) can consent to sexual intercourse and get married, with parental consent or court permission; and consent to medical treatment but see also Gillick case discussion in text for 'mature' children aged under 16 years.
  9. For example, the right of the child to have access to both a custodial and non-custodial parent after its parents have been divorced: see *M v M* [1973] 2 All ER 71; under the Children Act 1989, access orders have been replaced by contact orders and custody orders have been replaced by residence orders and the new concept of Parental Responsibility (see text).
  10. For example, under s. 43(8) of the Children Act which states that 'if the child is of sufficient understanding to make an informed decision he may refuse to submit to a medical or psychiatric examination or other assessment'. However,

recent cases now suggest that this right to refuse appears to apply only at the point of assessment and that a court of law can always override a child's refusal to consent if it deems it is necessary to do so in order to save the child's life or if it deems this was in the child's best interests: see the Court of Appeal decisions in *Re R (A Minor) (Wardship: Medical Treatment)* [1991] 2 WLR 592, and *Re W (A Minor) (Medical Treatment)* [1994] 4 All ER 627, discussed in the text of this chapter.

11. For a selection of academic commentary see Hoggett, B. M. (1986) Parents, children and medical treatment: the legal issues, in *Rights and Wrongs in Medicine*, (ed. P. Byrne) King's Fund, London; de Cruz, S.P. (1987) Parents, doctors and children: the Gillick case and beyond. *Journal of Social Welfare Law*, 93; Eekelaar, J. (1986) The eclipse of parental rights. *Law Quarterly Review*, 102, 44; Bainham, A. (1986) The balance of power in family decisions. *Cambridge Law Journal*, 45, 262; Cretney, S.M. (1989) Gillick and the concept of legal capacity. *Law Quarterly Review*, 105, 356.
12. See the Gillick Case (1986) FLR at p. 251.
13. See *Re R (A Minor) (Wardship: Medical Treatment)* [1991] 4 All ER 177; for a sample of the academic commentary on the legal aspects of this case, see Bainham, A. (1992) The judge and the competent minor. *Law Quarterly Review*, 108, 194; Thornton R. (1992) Multiple keyholders – wardship and consent to medical treatment. *Cambridge Law Journal*, 51, 34; Urwin, J. (1992) *Re R*: the resurrection of parental powers? *Professional Negligence*, 69; Murphy, J. (1992) W(h)ither adolescent autonomy? *Journal of Social Welfare and Family Law*, 529.
14. One certainly has to question whether even every **adult** has a 'full understanding' of the consequences of treatment. A similar query must be raised over whether an adolescent will equally understand the full implications of contraceptive treatment in relation to her own body since it is well-known that adult women who have been using the pill for many years have difficulty 'fully' understanding its implications in relation to their own biological 'clock'.
15. See *Re W (A Minor) (Medical Treatment)* [1992] 4 All ER 627, the case was also known as *Re J* (see *Re J (a minor)* (1992) *The Times*, 14 May); discussed: de Cruz, P. (1992) Minors, medical treatment and the courts. *Practitioners Child Law Bulletin*, 9, 71.
16. See *Re K, W and H* [1993] 1 FLR 854; *South Glamorgan CC v W & B* [1994] 1 FLR 574; on the latter case see Lyon, C. (1994) What's happened to the child's 'right' to refuse? – *South Glamorgan CC v W & B*. *JCL*, 6, 84.
17. That is, as in *South Glamorgan CC v W & B* (1994) (see previous footnote).
18. Or even the child's 'right' to die? Or see Houghton-James, H. (1992) The child's right to die. *Family Law*, 22, 550 which discusses the *Re W* case [1992] 4 All ER 627 involving the anorexic child who did not wish to live and was on a starvation diet; see text of this chapter for discussion.
19. That is, under sections 38(6), 43(8), 44(7) and Schedule 3, para. 4(4): Children Act 1989.
20. *The Times*, 11 May 1992.
21. See s. 1(3) (a): Children Act 1989.
22. For some of the early literature on parental rights see Eekelaar, J. (1973) What are parental rights? *Law Quarterly Review*, 89, 210; Dickens, B. M. (1989) The



- modern function and limits of parental rights. *Law Quarterly Review*, 105, 462.
23. See s. 1 (5) which makes it clear that the court must be convinced that it must be better for the child to have an order made than not at all. Andrew Bainham regards sections such as this as representing a form of 'privatisation' of the family so that state intervention will be minimal unless justified by the 'significant harm' test: see Bainham, A. (1990) The privatisation of the public interest in children. *Modern Law Review*, 53, 206. Perhaps it is more a case of balancing various competing interests and the State is still struggling to strike the right balance.
  24. As required under the Children and Young Persons Act 1933, s. 1.
  25. As required under the Education Act 1944, s. 36.
  26. Such as gambling, begging or being tattooed.
  27. This is discussed in the section on consent.
  28. That is, from a reading of its wording and that of section 241 of the Education Act 1993 (see text, below).
  29. See Circular no. 5/94: *Education Act 1993: Sex Education in Schools*.
  30. That is, prohibiting the teaching, as part of the National Curriculum in Science, of any material on AIDS, HIV, and other sexually transmitted diseases, or any aspect, other than biological aspects of human sexual behaviour: see para. 16: circular 5/94: Education Act 1993.
  31. see Circular no. 5/94: Education Act 1993.
  32. Parental Responsibility Agreement is the title of the official standard form on which such an agreement may be registered; the father's PR may then be formalised by simply filling in the form with the names of the parties, signing it and registering it for a fee; the completed form will then be lodged in the central Registry. PR acquired in this way, however, is revocable.
  33. The so-called doctrine of 'informed consent' is not a full-blown legal concept in English law as it is in the United States of America whence it has been imported: see *Scholendoff v Society of New York Hospital* 211 NY 125 (1914); or in Canada: see *Johnston v Wellesly Hospital* (1970) 17 DLR (3d) 139 at pp. 144–5; for the English law approach, see *Chatterton v Gerson* [1981] 1 All ER 257 (QBD) and *Sidaway v Bethlem Royal Hospital Governors* [1984] 1 All ER 101 8 (Court of Appeal).
  34. See *Chatterton v Gerson* [1981] 1 All ER 257 (QBD); and Thorpe, J. in *Re C* (1993) NLJR 1642.
  35. Of course, if the patient suffers harm as a result of negligence in diagnosis or treatment, liability might also be incurred. If the harm occurs because one of the risks involved transpires, then the patient may yet have a course of action if he proves that the doctor was negligent in giving the advice about the treatment and that, had the patient been given all the material facts, he or she might not have given consent at all: see for an excellent discussion of these points and the Gillick case, Hoggett, B. M. (1986) 'Parents, children and medical treatment: the legal issues, in *Rights and Wrongs in Medicine* (ed. P. Byrne) King's Fund, London.
  36. *Re W (A Minor) (Consent to Medical Treatment)* [1992] 4 All ER 627 at p. 635; see also Nicholls, M. (1994) Keyholders and flak jackets. *Family Law*, 24, 81.
  37. Current NHS guidelines on consent recommend that a detailed note should be kept of the factors taken into account in assessing the child's capacity to

- consent. If a child discusses the situation without a parent being present, then efforts should be made to persuade the child that his or her parents should be informed except when this is regarded as not in the child's best interests.
38. See *The Gillick Case* [1986] FLR at p. 254.
  39. See *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1984] AC 871.
  40. As laid down in *Bolam v Friern Hospital Management Committee* [1957] 2 All ER 118.
  41. This is the effect of *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1984] AC 871.
  42. According to current NHS guidelines, if consent of urgent/life-saving treatment is refused, the court's permission should be obtained if time permits. Otherwise, hospital authorities should rely on the clinical judgement of the relevant health professional after full discussion with the parents. Written supporting evidence should also be obtained from a colleague, which should make an explicit statement that the child's life would be in danger if treatment is withheld. There would also be a discussion with the parents about the need to treat the child, and this should be conducted in the presence of a witness who should countersign the record of the discussion in the clinical notes.
  43. There were pre-Children Act cases where the minors wished to have abortions which were opposed by their parents. In the first case, the 15-year-old girl's wishes were given prominence, in view of the fact that this was her second pregnancy and she was living in a mother and child unit; see *Re P (a minor)* (1982) LGR 301. In another case, the girl, who was 12, also wished to have an abortion, which was opposed by her mother but supported by the 16-year-old father of the baby and the girl's grandparents who had brought the girl up. The court again chose not to follow the parent in opposition but justified their decision by saying it was in the child's best interests; *Re B (Wardship) (abortion)* [1991] 2 FLR 426; In *Re W* [1992] 4 All ER 627 itself, Lord Donaldson made it clear that abortions would not normally be carried out in reliance on the consent of parents in the face of the refusal of 16 or 17-year-olds. He said (at p. 635): 'Whilst this may be possible as a matter of law, I do not see any likelihood, taking account of medical ethics, unless the abortion was truly in the best interest of the child.' He then proceeded to say 'This is not to say that it could not happen' citing *Re D (a minor) (wardship; sterilisation)* [1976] 1 All ER 326 where the child concerned 'had neither the intelligence nor the understanding either to consent or refuse'; where a Sotos syndrome child was involved. In fact, the sterilisation operation was not carried out in that case because there was a strong likelihood the girl would understand the implications of the operation when she reached 18. Again, the girl's parent wanted the sterilisation to be carried out, in the belief that it would be in her best interests.
  44. At [1992] 4 All ER at p. 336.
  45. See *Re B (A Minor)* (1981) 1 WLR 1421 (the Down's syndrome baby).
  46. As in *Re C (A Minor)* [1989] 2 All ER 782.
  47. See *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930, dealing with a severely multi-handicapped newborn baby, where as far as resuscitation policy was concerned, the Court of Appeal declared that it is up to the court to decide on the quality of life the child would have if resuscitated, and to decide in all the circumstances of the case whether that child's life would

be so afflicted as to be intolerable. Thus, an inquiry into the child's 'quality of life' would be the means of determining the 'best interest' of the child which is the general criterion. If the child's disabilities were so extreme that his life would be 'demonstrably awful' (*Re B* (note 44)) or intolerable (*Re J*) non-resuscitation would probably be legally justifiable but there is still no clarification of how extreme the child's condition must be or which missing 'qualities of life' would be relevant to the decision. Note further *Re T* (A Minor) (Wardship: Medical Treatment) (1996) *The Times*, October 28 where for a baby with a life-threatening liver defect, Butler Sloss, LJ said that 'to prolong life was not the sole objective of the court' as this might not be in the child's best interest. There is clearly no absolute 'sanctity of life' policy currently endorsed by the English courts in these cases.

48. For example, where the child is an older child who has established bonds with a sibling or parent over several years and who may therefore be emotionally traumatised by the complete severance of contact with these relatives; see *Re C* (a minor) (adoption order; conditions) [1988] 1 All ER 705 (H/L) where the House of Lords attached an access condition to an adoption order in exceptional circumstances and only because the adoptive parents agreed to this.
49. The current law is that people adopted in England or Wales before 12 November 1975 are required to see a counsellor before they can be given access to the original record of their birth. All those adopted in the UK after 11 November 1975 and who are at least 18 years of age need not see a counsellor before being given such information although a counselling service is also available to such persons. Those living outside the UK, who were adopted in England and Wales before 12 November 1975 now have the right to see their birth records without having to travel to the UK for a counselling interview.
50. On the analogy of the principle in *W v Edgell* [1990] 1 All ER 835, where the Court of Appeal held that a real risk to public safety outweighed the need to preserve confidentiality and a psychiatrist was therefore justified in communicating his fears to the relevant authorities to prevent the release of a potentially dangerous prisoner.
51. This is a new order (s. 43) which is intended to deal with situations where there is reasonable cause to suspect that a child is suffering significant harm but where the risk is not immediate or imminent; the applicant (who can only be the local authority or the NSPCC) must believe that an assessment (medical, psychiatric, or other) is required and the parents have not been willing to cooperate. The order lasts for a maximum of 7 days from the date on which it comes into effect. The child would only be removed from the home in exceptional circumstances and the child need only be produced at a medical centre for assessment within the 7 day period. The court may only make the order if it is satisfied that there is 'reasonable cause to suspect' (my emphasis) that the conditions have been fulfilled. Directions for the medical or psychiatric examination of the child may be included when the Order is made.
52. This is in sections 44 and 45 and will only be made in extremely urgent cases where the child's safety is in imminent danger. It will only be made if a court is satisfied that there is reasonable cause to believe that the child is likely to suffer significant harm if it is not removed to suitable accommodation or

- remains where he is (e.g. if the child is already in a hospital). The usual case where this Order may be applied for is where there has been a denial of access to the child without a reasonable explanation. The order lasts for a maximum of 8 days but may be extended (if the applicant was the only party present at the initial application hearing) for another 7 days. Thus, if the parents/carers with parental responsibility were not present (having received a day's notice) when the order was made. The Order gives the applicant parental responsibility for the child but only to the extent necessary to safeguard and promote the welfare of the child. Directions for a medical or psychiatric examination may be given when the Order is made.
53. These began to fall into disrepute when it appeared that magistrates were granting these to local authorities somewhat indiscriminately and they were frequently perceived as a breach of civil liberties since there was no right of appeal against them until a court hearing could be arranged or until the period of their duration (which could be as long as 28 days) expired.
  54. See the key section s. 31(2) of the Children Act 1989.
  55. See s. 31(9): Children Act 1989.
  56. See s. 31(10).
  57. See now the important House of Lords' case of *Re M* [1994] 3 All ER 298.
  58. See *Newham London BC v AG* [1993] 1 FLR 281.
  59. For a fuller account of these evidential problems see Lyon, C. and de Cruz, P. (1993) *Child Abuse* 2nd edn Jordan. Bristol.
  60. As Waite, J. put it in *Re W (Minors) (Child Abuse: Evidence)* [1987] 1 FLR 297: 'Cases of alleged child abuse within the family... [pose] exceptional difficulty, because they ... contrast two principles ... fundamental to our society. One is the basic requirement of justice that nobody should have to face a finding by any court of serious parental misconduct without the opportunity of having the allegations ... clearly specified and cogently proved. The other is the public interest in the detection and prevention of parental child abuse which is liable, if persisted in, to do serious damage to the emotional development of the victim'.
  61. This matter is currently covered by various guidance documents issued by the Department of Health to doctors, nurses, health visitors and midwives and is discussed in the section on roles and responsibilities of doctors and managers involved in health care.
  62. See, e.g. *The Guardian* 3 June 1994.
  63. This was in response to the various child abuse inquiries such as the Jasmine Beckford Report (*A Child in Trust* (1985) DHSS) and the Cleveland Report: see *Report of the Inquiry into Child Abuse in Cleveland* 1987 (1988) HMSO, London.
  64. Department of Health, Department of Education and Science, and the Welsh Office (1991) *Working Together under the Children Act 1989: A Guide to the Arrangements for Interagency Cooperation for the Protection of Children from Abuse*. HMSO, London.
  65. Department of Health (1992) *Child Protection: Guidance for Senior Nurses, Health Visitors and Midwives*. HMSO, London.
  66. Department of Health (1992) *Child Protection*. HMSO, London.
  67. Department of Health (1992) *The Children Act 1989. An Introductory Guide for the NHS*. Health Publications Unit, Heywood, Lancashire.

68. Department of Health (1992) *The Children Act 1989. What every nurse, health visitor and midwife needs to know*. Health Publications Unit, Heywood, Lancashire.
69. Child health services also have a role to play in assessing a child's needs in relation to a proposed day care, residential or foster placement.
70. This is also stated in s. 1 (3) (a): Children Act 1989.

## FURTHER READING

### GENERAL BOOKS ON THE CHILDREN ACT AND CHILD LAW

- Bainham, A. (1990) *Children – The New Law: Children Act 1989*. Jordan, Bristol.
- Bainham, A. (1993) *Children – The Modern Law, Family Law/Jordan, Bristol*.

### GOVERNMENT PUBLICATIONS

- Department of Health (1989) *An Introduction to the Children Act 1989*. HMSO, London.
- Department of Health (1990) *The Care of Children: Principles and Practice in Regulations and Guidance*. HMSO, London.
- Department of Health, Department of Education and Science and the Welsh Office (1991) *Working Together under the Children Act 1989: A Guide to the Arrangements for Inter-agency Co-operation for the Protection of Children from Abuse*. HMSO, London.
- Department of Health (1995) *The Challenge of Partnership in Child Protection: Practice Guide*. HMSO, London.
- Department of Health (1992) *The Children Act 1989. An Introductory Guide for the NHS*. Health Publications Unit, Heywood, Lancashire.
- Department of Health (1992) *The Children Act 1989. What every nurse, health visitor and midwife needs to know*. Health Publications Unit, Heywood, Lancashire.
- Department of Health (1987) *Protecting Children: A Guide for Social Workers Undertaking a Comprehensive Assessment*. HMSO, London.

### VOLUMES OF CHILDREN ACT 1989 GUIDANCE (ALL PUBLISHED BY HMSO)

- vol 1: Court Orders
- vol 2: Family Support, Day Care and Educational Provision for Young Children
- vol 3: Family Placements
- vol 4: Residential Care
- vol 5: Independent Schools
- vol 6: Children with Disabilities
- vol 7: Guardians ad Litem and other Court Related Issues
- vol 8: Private Fostering and Miscellaneous
- vol 9: Adoption Issues

### BOOKS ON HEALTH ISSUES AND CHILD LAW

- Hendrick, J. (1993) *Child Care Law for Health Professionals*. Routledge Medical Press, Oxford.

Mitchell, B. and Prince, A. *The Children Act and Medical Practice*. Family Law/Jordan, Bristol.

UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD

Newell, P. (1991) *The UN Convention and Children's Rights in the UK*. National Children's Bureau, London. (This contains the UN Convention on the Rights of the Child as well as the European Convention on Human Rights in appendices.)

Alston, P., Parker, S. and Seymour, J. (eds) (1991) *Children, Rights and the Law*. Clarendon, Oxford. (This contains a copy of the UN Convention on the Rights of the Child in appendix)

*Bulletin of Human Rights* 9/13 Centre for Human Rights: Geneva: New York. 1992.

# Analysing and promoting the health of children

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# 6

*Eva Alberman*

## **INTRODUCTION**

Prevention of death and disability early in life makes the maximum contribution towards increasing life expectancy and its quality, and towards the saving of health care resources. Moreover, there is increasing recognition that maintenance and promotion of health from conception through childhood will contribute materially towards the quality of adult health.

Other, less tangible reasons, also contribute to the importance of monitoring the health of children. Infants and young children are the most vulnerable members of any society, since they are entirely dependent on adults for their survival. As with the elderly, the overall level of their care is a measure of the quality of the society in which they live. In most organised societies there are conventions to cover the care of those that are abandoned, and in the more developed societies there are legal safeguards which can be implemented where there is a breakdown of parental care.

It is the aim of this chapter to help health service managers use current knowledge about the epidemiology of child health in order to plan the adequate provision of preventive and curative services, and evaluate their performance. A further aim is to show that in the case of babies and young children who form a 'captive' population, monitoring of health status and evaluation of service provision should be relatively simple if good use is made of statutory and routinely collected data, supplemented by well-planned surveillance.

## **WHAT CAN BE LEARNT FROM PATTERNS OF DEATH, DISEASE AND DISABILITY?**

For the planning and evaluation of health services, managers need to define and measure the specific outcomes towards which the services are

targeted. At the most basic level these outcomes are death, disease or disability. For the evaluation of processes of health care, intermediate measures such as the uptake of immunisation or hospital admission rates may need to serve as 'proxy' measures where it is difficult to obtain data on the health outcomes themselves. Whichever means is used, it is necessary to be aware of patterns which may be determined by biological, demographic and socio-economic circumstances outside health care provision, as well as the interaction between the three.

The fetus and the neonate are largely protected from adverse environmental circumstances. Their deaths are most often caused by prenatal causes whether genetic or developmental, or associated with premature birth, or other maternal health complications. Over the age of one month infants and young children are increasingly vulnerable to external circumstances, and the circumstances of the family may be crucially important in determining outcome.

It follows that the age of the child needs to be taken into consideration in interpreting the significance of adverse outcomes in childhood. For this reason stillbirths and first week deaths are often considered together as 'perinatal' deaths. Infant deaths are often separated into neonatal (first month) and postneonatal (two to twelve months) age groups.

In considering outcome it must be noted that the fact of death is more easily recognised and counted than disease or disability (morbidity), and therefore much of the available literature relates to risk of death. In most cases, however, a high risk of death also implies a high risk of morbidity.

The following account can be no more than a broad overview. For more detail or references it is suggested the reader consults *Children, Teenagers and Health – The Key Data* [1].

## PATTERNS OF MORTALITY

### **Socio-economic factors**

The vulnerability of older infants to adverse circumstances is so marked that their effects can readily be observed from mortality trends. Figure 6.1 represents annual infant mortality rates since civil registration was introduced in England and Wales. It shows the deviations upwards at times of war, and in the period of profound depression in the 1930s. The figure however also shows the remarkable fall in infant death rates which occurred over the early part of this century, and is still continuing, albeit more slowly, up to the present.

Infant, and perinatal (not shown here), mortality rates show a gradient upwards from the least to the most economically disadvantaged social class, based on the father's occupation (Figure 6.2). Within each of these



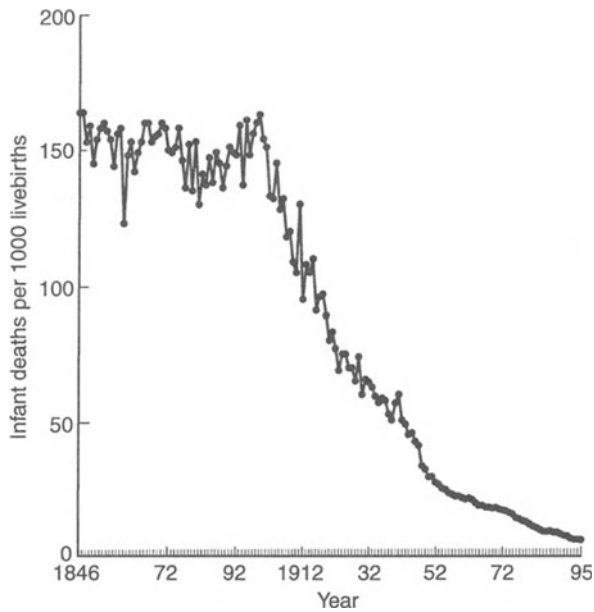


Fig. 6.1 Annual infant mortality rates since civil registration was introduced in England and Wales. Data from OPCS Annual Reviews, England and Wales, 1846–1995.

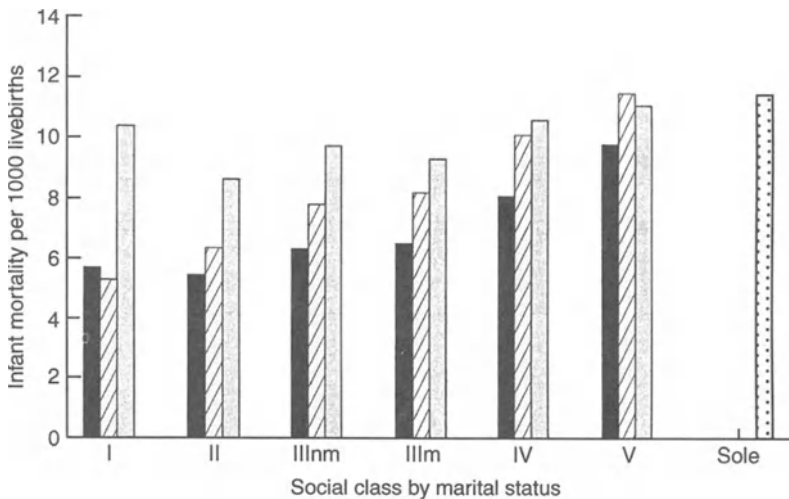


Fig. 6.2 Infant mortality by social class, depending on the father's occupation, and by marital status: ■ married; ▨ jointly registered and parents cohabiting; ▩ jointly registered but parents living apart; ▤ sole registration by mother. Data from OPCS, England and Wales, 1988–1992.

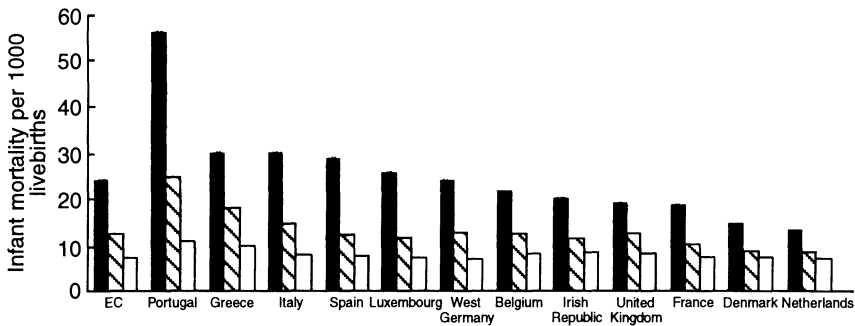


Fig. 6.3 Trends in infant mortality in European countries 1970–1990: ■ 1970; ▨ 1980; □ 1990. Data from OPCS and DHE.

social groups, there is a further gradient upwards, depending on the degree of maternal support, as indicated by the type of birth registration. The lowest mortality is where the parents are married; the next outside marriage, but where the birth is jointly registered and the address of the parents is the same. Infants of unmarried parents living at different addresses have a higher mortality; highest mortality is in those births where only the mother has registered the baby, and therefore no social classification was given. It is likely that where the family remains a single parent family, a situation which has increased markedly over recent years, mortality and morbidity remain raised over the average, but little data is available on this question after the first year of life.

The association between socio-economic disadvantage and high risk is so consistent that the level of infant mortality is used nationally and internationally as a measure of economic health. Figure 6.3 shows trends in infant mortality within European countries between 1970 and 1990. The lowest rates are in the Netherlands, recognised as having a high and rising standard of living, and the highest in Portugal where poverty is still widespread, but falling over recent years. Although the patterns for infants are the clearest, similar social gradients are seen for children over the age of one year (Figure 6.4).

### Immigrant status

In addition to occupational group and family structure, immigrant status can have a strong influence on health. New immigrants from particular countries are likely to be living under poor circumstances, to have a poor knowledge of English, and to be unaware of methods of accessing health care. Even established ethnic minority groups also tend to have poorer than average social and economic circumstances. Moreover, new im-

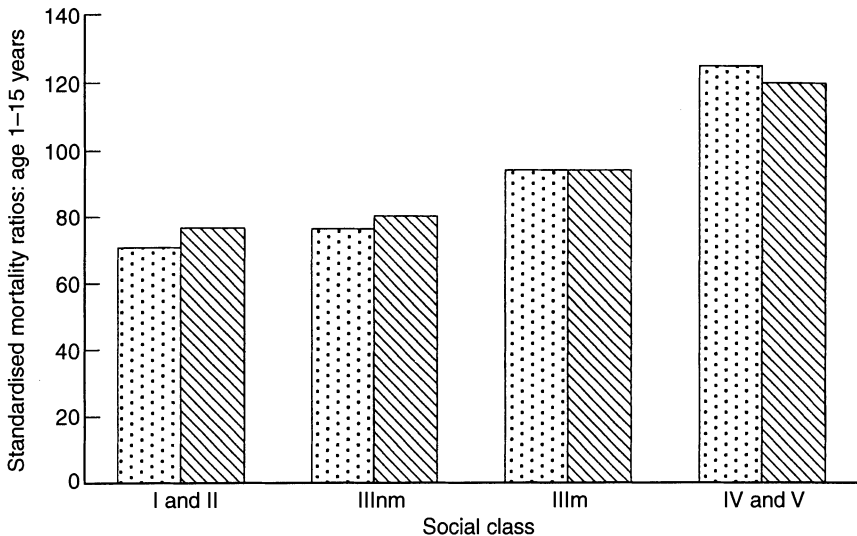


Fig. 6.4 Child mortality in England and Wales by social class: ▨ boys; ▩ girls. Data from OPCS England and Wales, 1979–80 and 1982–83.

migrants are often of child-bearing age, and may have lost family support that they had been accustomed to. Infants born to mothers born outside the UK tend to have consistently higher mortality risks than those born within.

### Birthweight and gestational age

It is well known that the risk of early (particularly first month) mortality is very closely associated with immaturity, either because of a birth occurring unexpectedly early (preterm) or because there has been a poor rate of fetal growth during a pregnancy of normal length. The latter is often found in association with poor home circumstances, but both are very much more common in multiple births. The highest neonatal mortality risk is in the small group of infants weighing less than 1500 g, who have usually been born eight or more weeks early. Nearly all these infants will need special or intensive neonatal care, and their overall mortality risk even now is about 30%. Survivors also have high risks of adverse health sequelae.

### Maternal age and parity

Births to mothers at the extremes of age and of high parity (number of previous births) tend to be at increased risk. This is in part because in this

society such births are unusual and often occur under poor circumstances, but also because there are specific adverse biological associations. Thus it is known that births to young teenagers are at particular risk of being of low birthweight, and that conceptions to mothers aged 35 or more are at particular risk of chromosomal anomalies such as that which causes Down's syndrome.

#### PATTERNS OF DISEASE OR DISABILITY

As mentioned earlier, the measurement of the burden of disease or disability is always more problematical than that of deaths. In part this is because there can be disagreements on definitions and degrees of severity, and in part because these are often only ascertained where the help of a health service professional has been sought. Moreover, in contrast to the registration of death, which is statutory and has a fixed format, the recording of the presence of a disease or disability may take many different forms, and these may not always be accessible to those seeking to measure prevalence.

It is also relevant that whereas for deaths there is general acceptance of the international classification of diseases, and related health problems (ICD [2]), this has been only reluctantly used for actual diseases. The international classification for impairments, disabilities and handicaps [3] is not in general use. This lack of consistency and standardisation of coding and classification has done much to hold back our ability to measure the burden of disease and disability in the population.

Nevertheless, the available data suggest that the patterns of occurrence and severity of children's diseases are similar to those of deaths. Most occur more commonly, and in a more severe form, in economically disadvantaged families in poor housing. This is certainly true of respiratory and ear infections, childhood accidents, and the common infectious diseases, many of which are now preventable by immunisation.

Psychological development also may suffer in conditions of deprivation, with a rise in the prevalence of learning problems, truancy and delinquency. All these are now known to predispose to later problems in adult life.

There are also specific biological risks, such as the increased risk of the birth of a child with Down's syndrome with advancing maternal age. Specific genetic conditions are more common in certain ethnic groups, and of course where there is a family history of a genetic disease. The prevalence of cerebral palsy, visual, hearing and convulsive disorders, is many times higher in survivors of very low birthweight or extreme prematurity.

### **Inherited diseases**

There are now increasing opportunities for pre- and postnatal screening for a number of relatively common genetic disorders, the risk of which sometimes varies with ethnic group. Thus cystic fibrosis is most common in Caucasians; Tay Sachs disease, which leads to an irreversible and lethal neurological deterioration in early childhood, is most common in Ashkenazi Jews; the blood disorder thalassaemia is most common in ethnic groups whose derivation is from Mediterranean countries; and sickle cell disease is most common in those of African descent. The risk of any of these will be increased by marriage between close relatives, and this is relatively common in some Asian groups.

Managers need to be aware of such risks relevant to the community in which they work, and to be prepared to provide appropriate services.

### **PATTERNS OF GROWTH**

The fact that children are constantly growing, and that this is reflected in changes of weight, height and other parameters, provides a unique opportunity to monitor changes in their health. Not all of these are easy or cheap to measure, but height and weight can be reliably measured by health workers after minimal training. Nutritional, health and emotional problems can be reflected very quickly by changes in the normal rate of growth, and may provide the first indications of adverse circumstances. Although there has been a surprising lack of systematic monitoring on a national scale, results of *ad hoc* studies over the years confirm that in England and Wales, as in other countries in the developed world, there have been overall increases in the stature and the weight of children. This has been shown both in distributions of birthweight and in later measurements, and is probably associated with improvements in the general health of the population over the years.

Nevertheless, children in disadvantaged families are more likely than average to have been of low birthweight. Low birthweight itself predisposes to subsequent health problems and these may inhibit a normal rate of childhood growth, so that such children are on average of shorter stature than those of the more advantaged families. Such differences have been shown to be reflected in adult life, and short stature in adults has been shown to be associated with poorer adult health.

### **PATTERNS OF HEALTH BEHAVIOUR**

Child health, like all other health areas, is strongly influenced by health behaviour, both of the parents and of the children themselves. Infant feeding practices, parental dietary habits, abuse of tobacco, alcohol or

drugs, exercise and other leisure activities all have important child health effects. These effects may be direct, such as placental transmission of constituents of cigarette smoking, or through breastfeeding, or postnatally as with passive smoking. There is now no doubt that maternal smoking is associated with intrauterine growth retardation, and that passive smoking is associated with childhood respiratory disease and the sudden infant death syndrome. Additionally, and very importantly, parental habits influence those of their children, whether this is smoking, drinking, exercise, diet or social behaviour. All these are strongly related to social class, and contribute to the differences in quality of health between the classes.

## **DEMOGRAPHIC AND HEALTH DATA**

Because of the importance of the patterns that have been described, and the use they have for planning and evaluation, health service managers should be aware of the available and potential sources of health data relevant to infancy and childhood. These are conveniently divided into those derived from information collected by statute, and others.

### **STATUTORY DATA COLLECTION**

The registration of births, deaths and marriages is statutory, and the methods of collection of data and the questions asked are governed by acts of parliament, as is the notification of birth to the local health authority. Also statutory is the collection of data for the censuses, normally carried out every ten years, the last one having been in 1991; and the notification of certain infectious diseases. The processing and reporting on most of these data is carried out by the Office of Population Censuses and Surveys (OPCS), now incorporated into the Office of National Statistics (ONS).

### **OTHER RELEVANT GOVERNMENT-COLLECTED DATA**

In addition to the statutory collection of data, the Department of Health expects the NHS, whether in the form of Trusts or not, to send in regular statistical reports on activities performed, manpower employed, and other costs. The DoH also commissions other agencies, such as the social survey division of ONS, to carry out surveys of representative samples of the population. These surveys include the continuous General Household survey, which has questions on the health of children and their use of health services; of infant and adult nutrition, smoking habits, dental health; and occasional surveys of the health and height and weight of adults, and of disability in adults and children. It also commissions regular

studies of the work carried out by GPs. In addition, ONS collects and analyses, on behalf of DoH, data on legal termination of pregnancy, the notification of births with visible congenital malformations, and provides a central collection and analysis of regional cancer registration data.

Centrally available statistics on child health are listed in Table 6.1 [4]. To this list should be added the public health common data set produced annually for each health authority by the Department of Health.

#### OTHER CHILDHOOD SURVEYS

The most important additional data on childhood health collected in Great Britain is derived from three national cohort studies of one week's births, the first in 1946, the second in 1958, and the third in 1970. In addition there have been two locally based cohort studies of note, one of 1000 Newcastle families with a member born between 1 May and 30 June 1947, the other of births in the county of Avon in the years 1990–91. These cohorts are characterised by high response rates, the collection of remarkably complete and good quality data at the time of birth, and detailed information on health, health behaviour and social circumstances collected at successive 'sweeps' during childhood and adult life. The earlier two national cohorts now include amongst their members children of the original cohort, so that intergenerational comparisons can be made. These studies have produced an immense amount of information on child development and the factors which influence it [5], on common childhood diseases and sequelae in adult life; on the prevalence of rare conditions; and on the relationship between birth events and later health.

In the long run it is to be hoped that such research studies which are expensive to mount and maintain, can, at least partly, be replaced by routine service generated information. This should be available from local computerised child health surveillance systems which both enable monitoring of child health and aid the organisation of preventive measures such as immunisation. Unfortunately, the quality of the health information recorded still remains considerably below that obtained by research teams, although there are renewed efforts to reach a common high standard [6]. The systems have, however, already been shown to be an effective way of monitoring the uptake of childhood immunisations, by generating at regular intervals uptake by age and district for the different antigens concerned [7].

#### USE OF DATA FOR THE MANAGEMENT OF CHILD HEALTH SERVICES

The management of child health comprises a number of different functions, broadly divisible into planning, implementation (not covered in

**Table 6.1** Centrally available statistics on child health. Reproduced with permission from: Dunnell, K. (1990) *Monitoring Children's Health. Population Trends*, 60, 16–22

Indicators	Description of data available	Publication	First available	Frequency
Stillbirths	Numbers and rates by sex, month of occurrence, cause, place of confinement, gestation, birthweight, area	DH3, Mortality – perinatal and infant DH6, Mortality – childhood		Annual
Early neonatal deaths	Numbers by sex, cause, month of occurrence, area			
Perinatal deaths	Rates by sex, cause, month of occurrence and area			
All infant deaths	Numbers and rates by sex, age-group, cause, month of occurrence and area			
Stillbirths	Linking of information from birth and death registration allows a wide range of tabulations by age of mother, parity, legitimacy, social class, country of birth of mother, month of birth, and birthweight	DH3, Mortality – perinatal and infant	1975	Annual
Perinatal deaths				
Neonatal deaths				
Postneonatal deaths				
All infant deaths				
Live births				
Trends in infant mortality	Deaths, numbers and rates, from selected causes in infants under one year are given for each of the previous ten years	DH3, Mortality – perinatal and infant		Annual



Birthweight	Since 1975 birthweight provided by health authorities has been added to birth registrations. This process has been virtually complete since 1983. Mortality of infants of different birthweights can be monitored as described above. In addition the birthweight of all live births can be tabulated by social class, age of mother, parity, and country of birth	DH3, Mortality – perinatal and infant	1975	Annual
Low birthweight babies	Number, number of deaths by time of death	DH Summary (Form LHS27/1)	1953	Annual to 1987
Childhood deaths at ages: 1, 2, 3, 4, 5–9, 10–14 and all ages under 15	Numbers of deaths by sex for each cause	DH3, Mortality – perinatal and infant		Annual
Childhood deaths at ages: under 1, 1–4, 5–14	(a) Rates per million population from principal causes for boys and girls	DH2, Mortality – cause		Annual
	(b) Also for each administrative and health area	DH5 fiche, Mortality – area		Annual
	(c) Numbers and rates are published in more detail for deaths due to accidents and violence, e.g. accidents at home, road traffic accidents	DH4, Mortality – accidents and violence		Annual
	(d) Detailed analysis of childhood deaths in terms of rates, SMRs and PMRs by parents' social class based on occupation, socio-economic group, and occupation order	DS no. 8 – Occupational Mortality, Childhood Supplement	1959–63	Ten-yearly

Table 6.1 – Continued

Indicators	Description of data available	Publication	First available	Frequency
Glue-sniffing deaths at ages 10, 11, 12, 13, 14	Estimates of deaths related to glue sniffing by sex	Series of reports from St George's Hospital Medical School	1971	Annual
Cancer registration rates for children aged under 1, 1-4, 5-9, 10-14	Numbers and rates by sex and site More details from the national Registry for Childhood Tumours	MB1 – general mortality Series of publications and regular reports to DH on incidence and survival	1962 1962	Annual Annual
Rare childhood disorders, e.g. AIDS, diabetes, galactosaemia, drowning and near drowning, Reye's syndrome	Notification of specific diseases by paediatricians to the British Paediatric Surveillance Unit – follow-up for clinical and epidemiological study	BPSU annual reports	1986	Annual
Notifications of malformations identified in the first week of life or at stillbirth	Rates per 10 000 births by condition, age of mother	MB3 – Congenital malformations	1964	Annual
Legal abortions due to fetal abnormalities	Numbers by condition	AB – Abortions	1968	Annual
Deliveries in NHS hospitals	Birthweight by maternal complications, outcome and parity. Anomalies and complications of babies by maternal age and parity, by birthweight, by mode of delivery, and by maternal complications	MB4 – Hospital In-patient, Enquiry, maternity tables	1955	Annual to 1985

Discharges and deaths from NHS non-psychiatric hospitals in England for children aged 0-4, 5-9, 10-14	Deaths and discharges by ICD 3 digit codes: Operations and sex	MB4 – Hospital In-patient Enquiry	1955	Annual
Hospital cases treated for children 0-4, 5-14	HIPE data providing rates per 10 000 population	DH Statistical Bulletins	1949	Annual
Operations on children aged 0-4, 5-14	Operation rates per 10 000 by sex and operation code	DH Statistical Bulletins	1949	Annual
Admissions to mental illness, mental handicap hospitals and units for children aged 0-9, 10-14	Numbers by sex and diagnostic groups – from the Mental Health Enquiry	Booklets on Mental Health Statistics for England (DH)	1959	Annual
Day care facilities in child and adolescent psychiatry	Number of attenders	DH Summary (Form KH14)		
Notifications for food poisoning, malaria, measles, meningitis, tuberculosis, dysentery, infective jaundice, whooping cough, scarlet fever for children aged 0, 1, 2, 3, 4, 5-9, 10-14	Rates per 100 000 population by sex. Based on data supplied by the doctor in attendance to each local authority under the Public Health Acts and Infectious Disease Regulations	MB2 – Communicable Disease Statistics		Annual
Home accidents to children aged 0-4, 5-15	Numbers for all notifiable diseases Rate per 1000 population per year by sex. Based on GHS questions. Further details on type of injury and accident from DTI Home Accidents Surveillance System	GHS reports (OPCS) DTI HASS reports	1981 1976	3 yearly Annual

Table 6.1 – Continued

Indicators	Description of data available	Publication	First available	Frequency
Episodes of illness presenting to GPs, detailed diagnosis for children aged 0-4, 5-14	Episode rates per 1000 persons at risk by sex, calculated from records of all consultations in a sample of practices during a one-year period	MB5 – Morbidity statistics from general practice	1955/6	1971/2, 1981/2
Long-standing illness at ages 0-4, 5-15	Proportions whose parents report long-standing illness by sex	GHS Reports (OPCS)	1972	Annual
Limiting long-standing illness at ages 0-4, 5-15	Proportions whose parents report a long-standing illness that limits normal activity by sex			
Restricted activity in the past two weeks at ages 0-4, 5-15	Proportions whose parents report limited activity due to illness or injury by sex			
Disability among children 0-4, 5-9, 10-15	Prevalence of disability assessed by detailed interviews with parents and classified by type of disability and severity	Prevalence of disability among children in Great Britain (OPCS)	1985	Ad hoc survey
Registrations of the blind and partially sighted aged 0-4, 5-15	Local authorities keep registers of these three groups of disabled children. Since registration is voluntary they cannot be considered as reliable indicators of prevalence	DH	1972	Triennially
Registration of the deaf with speech, deaf without speech and hard of hearing aged 0-15				
Registrations of the physically disabled aged 0-15				

Dental health at single years of age 5-15	Proportion of children with active decay, filled teeth, extractions, gum condition, crowding. Based on survey and dental examinations	Children's dental health in England and Wales 1973 and 1983, 1988 in preparation	1973	Repeated ad hoc survey
Dental treatments to children aged 0-4, 5-9, 10-14	Numbers provided from the General Dental Service and the Community dental service - covers fillings, extractions, etc	Dental practice board reports	1948	Annual
Prescriptions dispensed in general practice to children aged 0-15	Numbers from the Prescription Pricing Authority	Statistical Bulletin DH	1977	Annual
Conceptions to girls aged under 14, 14, 15	Numbers and rates of conceptions and proportions ending in births and terminations	Birth statistics	1968	Annual
Live and stillbirths to girls aged 11, 12, 13, 14, 15	Numbers of births	Birth statistics		Annual
Abortions to girls aged under 15, 15	Number of abortions	AB - Abortion statistics	1968	Annual
Children in need of protection	Numbers from local authority registers by age, sex, category of abuse, legal status, and whether in care	DH publication	1987/88	Annual
Height, weight for children aged 10/11, 14/15	Mean heights and weights by age and sex	The diets of British schoolchildren, DHSS/OPCS	1983	Ad hoc survey
Height, weight, anthropometry for children aged 5-9	Means and distributions obtained from a large sample of schoolchildren followed up through primary school	St Thomas' survey of height and growth	1979	Annual/continuous
Birthweight	See above			

Table 6.1 – Continued

Indicators	Description of data available	Publication	First available	Frequency
Diets of schoolchildren aged 10/11, 14/15	Intakes of main nutrients by height, weight, age, sex, social class based on parents' occupation, family type	The diets of British schoolchildren. DHSS/OPCS	1983	Ad hoc survey
Infant feeding at ages up to nine months	Proportions of babies breast and/or bottle fed at different ages by age of mother, social class based on parents' occupation, education, region	Infant feeding reports 1975, 1980, 1985	1975	Five-yearly surveys
Smoking among children aged 11, 12, 13, 14, 15	Prevalence of different levels of smoking by sex	Smoking among secondary schoolchildren in 1982, 1984, 1986, 1988	1982	Two-yearly surveys
Drinking among children aged 13, 14, 15	Prevalence of different levels of drinking by sex	Adolescent drinking	1984	Ad hoc survey
Vaccination and immunisation for diphtheria, tetanus, polio, whooping cough, measles, mumps and rubella	Uptake rates for completed primary courses in different years of life	Smoking among secondary school children in England in 1988	1988	Repeated questions
Rubella immunisation for schoolgirls aged 10, 11, 12, 13, 14, 15	Uptake and cumulative uptake rate as a percentage of the schoolgirl population	DH Summaries (Form SBL607/KC51)	1950	Annual
TB tests and BCG vaccinations	Numbers tested, found positive and negative, and vaccinated	DH Summaries (Form SBL607/KC51)	1950	Annual
		DH Summaries (Form SBL655/KC50)	1971	Annual

this chapter) and evaluation, each of which requires different types of information. There is an immense amount of relevant information from birth and death registration data and child health notifications at national and sub-national levels which managers should be familiar with. Hospital inpatient records, child and school health surveillance data provide a goldmine of health information which can be utilised if it is validated, well-organised and made easily accessible. Aggregation and linkage of such data where appropriate can greatly add to its value, but raises questions of data ownership and the consent of parents, and sometimes children. These are points which will need clarification at local level. Managers should also consider the quality of the available information, which if incomplete or inaccurate can be actively misleading.

## PLANNING

To plan, health care managers need to be aware of the needs of the population both in relation to the **numbers** of individuals involved, and any special health characteristics that they may have. They have to be aware of, and where appropriate, put into place, **health promotional services; preventive services** such as immunisation; and to commission the **curative services** needed by the children of their residents. They will also be required to learn of the existence of new health care developments and their implications. For instance current advances in prenatal diagnosis and the subsequent termination of pregnancy of fetuses with specific anomalies may reduce the predicted number of survivors with special needs, while the increased survival of high risk births, or of babies with malformations, may increase the predicted number.

## EVALUATION

Once the services are in place they must be evaluated in different ways: first in relation to their effectiveness and cost; second in relation to the coverage, uptake and efficiency of the processes involved; and third in relation to the satisfaction of the consumers with the service. Managers will also need to be assured that clinical audit of the services is on-going and that a process exists to ensure that the results are used to improve the service continuously.

## USE OF INFORMATION FOR PLANNING

### Population size and projections

The most basic use of information for planning purposes is in ascertaining the size and age distribution of the population to be covered. In its simplest

terms this means knowing the number of new births to residents, and keeping track of deaths, and movements in and out of the area. Figure 6.5 shows the variation that has occurred in annual numbers of births, and therefore subsequent numbers of children at all ages. This is due in part to changes in the birth rate which may vary with economic conditions, and social and political pressures. These changes also follow from the changes over time in numbers of women of reproductive age, changes which themselves depend on the numbers of births that occurred 18 to 40 years previously.

Ideally a computerised child health system should be able to provide the numbers of births (and deaths) and the movements of children between health authorities. These data contribute to the district's annual population projections and should be checked with results from the decennial census.

### Prevalence of special risk factors

Managers of family health services will also need to be aware of the prevalence in their residents of factors associated with special risks, and of their service implications. These include poor socio-economic circumstances, low birthweight or gestational age, high maternal age, new immigrant status, unsupported mothers, and the presence of ethnic

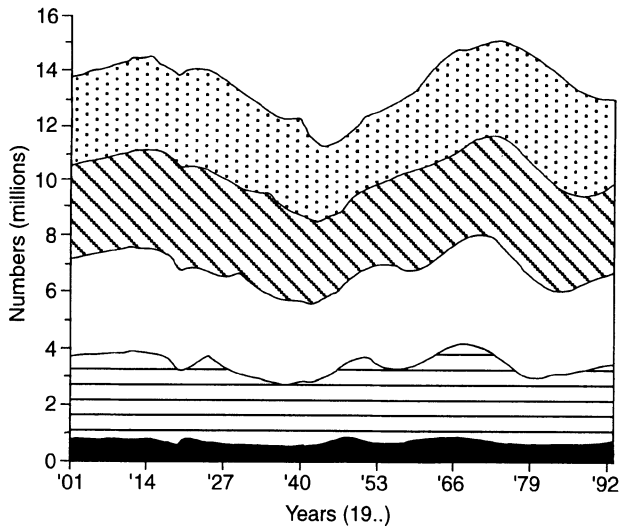


Fig. 6.5 Numbers of children in different age groups in England and Wales: ■ infants; ▨ age 1-4; ▩ age 5-9; ▧ age 10-14; ▤ age 15-19. Data from OPCS England and Wales, 1901-1992.



groups in whom there may be particular genetic risks. These should also be available from a well-run child health system. Currently available evidence suggests that little use is made of such data for evaluation, and because it is not used its quality is largely unknown. Proxy indicators of these high risk factors can be obtained from census data for specific areas, but this is inferior to purpose-designed quality birth notification data.

### **Children with special needs**

It is particularly important that managers are aware of the existence of any children with special needs, and the extent to which these needs are being met. This implies an active surveillance policy, and support for special assessment centres for children thought to have special needs. The completeness of prevalence data can be checked against expected numbers from published data [8].

### **Health behaviour**

Planners need to be aware of local health behaviour, such as eating habits, smoking, drinking and, particularly in the case of children, sexual behaviour, drug abuse and solvent abuse. Such information will be needed for the planning and implementation of local health promotion schemes, possibly in collaboration with local education departments. National information may well need to be supplemented with locally based data, derived from well-planned surveys, although these, if carried out well, are expensive and time consuming. Particular problems exist where there is a suspicion of parental neglect or abuse.

## **USE OF INFORMATION FOR EVALUATION OF SERVICES**

### **Effectiveness**

Health outcome measures should be used in evaluating the effectiveness of a preventive or therapeutic service. Evaluation is made simpler by clear statements of the aim of the particular treatment, and what it can or cannot achieve. Sometimes only a formal randomised controlled trial can provide an answer about effectiveness. More commonly, judgements will need to be based on careful analysis of data obtained by observation only.

**Adverse outcomes** include the fact of a death, the age at which it occurred, and the certified cause. Local health authorities have access to copies of death registration certificates relating to deaths occurring in their authority, and can obtain by arrangement those for residents occurring outside the authority. Advice may be needed to establish whether the death was one which could have been prevented by better immediate care,

or one which would have needed preventive action (if feasible) before conception or in pregnancy. For stillbirths and infant deaths such information is currently being collected by CESDI (Confidential Enquiry into Stillbirths and Deaths in Infancy). Similarly there is a national Confidential Enquiry into Peri-Operative Deaths (NCEPOD), but for other causes of death managers must rely only on local clinical audit.

For a balanced view of the overall effectiveness of local services, rates of adverse outcomes can be compared with those of the whole country, or neighbouring areas, bearing in mind the special features of the local population, and whether any differences are large enough to achieve statistical significance. The **benefits** of a service may be even more difficult to assess than adverse outcomes. Thus the effectiveness of a programme of immunisation will depend on the current prevalence and severity of the disease being measured. If it is effective this should become obvious over the years providing that notifications of the disease to be prevented have been conscientiously, or consistently, carried out. Failing this, secondary outcome measures, such as hospital inpatient days, or GP episodes attributable to the disease, can be used to assess prevalence before and after the programme.

Other important outcomes to be used for evaluation include permanent or temporary impairment or disabilities, sometimes leading to educational, social or psychological handicap. These are much more difficult to ascertain fully, or to assess in terms of importance, than death. The ascertainment of such adverse morbidity effects may be from medical records only or from personal interview, and must be relevant to the treatment being assessed. The treatment group being evaluated must be representative, and not biased. To assess the effect of a particular service all patients who had received it should be assessed, not just those who had complained of ill-effects. Similarly it is essential to weigh the full benefits of the service offered against the adverse outcomes.

#### DISEASE REGISTERS

The maintenance of registers of specific, usually chronic, conditions can be valuable aids for the monitoring of child health, as well as for the organisation and evaluation of the care of affected individuals. Examples are the national registers of children found by neonatal screening to have phenylketonuria, which if untreated leads to severe mental retardation; a number of regional registers of cerebral palsy, and a national register of Down's syndrome. ONS also runs a voluntary system inviting anonymous notifications of births observed to have a congenital malformation.

Registers of such disorders, many of which can now be diagnosed prenatally, can be used for evaluating the effect of genetic services. They also offer a method of ascertaining, for instance, what proportion of

Down's syndrome pregnancies are diagnosed prenatally, and in what proportion of diagnosed cases parents opt for the offer of termination of pregnancy. The ONS congenital malformation data has been used for neural tube defects, to follow time-trends in the ratio ending in termination of pregnancy and birth, evaluating the use and uptake of prenatal diagnosis and termination for these conditions. They can also be used for evaluating the use of primary preventive measures such as dietary supplementation with folic acid which will prevent the majority of neural tube defects.

#### BRITISH PAEDIATRIC SURVEILLANCE UNIT

A new development is the short-term registration of new cases of rare acute diseases, often in order to carry out intensive studies of possible causes, or to investigate the effect of rapid changes in medical care, as happened when the routine administration of vitamin K was stopped because of fears that it might increase long-term risks of malignant disease. This work is being carried out by the British Paediatric Surveillance Unit (BPSU) that has access to all consultant paediatricians in the UK, and routinely sends out cards asking for information on the current areas of study. This has proved a extremely useful and rapid mechanism for investigating new problems. Although it is more a clinical than a management tool, managers should be aware of the possibilities which it presents.

#### USE OF INFORMATION TO ASSESS THE EFFICIENCY, COVERAGE AND UPTAKE OF A HEALTH CARE PROCESS

The outcome measures for this purpose are self-explanatory, and easier to obtain. Coverage relates to the proportion of the target population that has been reached, and whether it was reached at the age targeted. Uptake will also involve the consent of those eligible, and depends in part on parental awareness and knowledge. The efficiency will depend both on coverage and uptake and whether the cost, and the resources involved in the process are low as well as feasible. A well-run computerised child health system should provide, with ease, the answers to these questions, certainly in relation to preventive programmes.

#### PATIENT SATISFACTION

In this area it is the parents who will express satisfaction, or otherwise, with the services offered, although children themselves have views which need to be ascertained and taken into account. Managers should ensure that parents have the opportunity to comment in a structured manner, and

should follow up findings of poor uptake of preventive services or clinic attendance to investigate the causes. Virtually all parents, regardless of ethnic group or culture, are very anxious to do the best for their children and will make great efforts to obtain the best service. There are generally good reasons for poor uptake of preventive services, which can often be put right.

Similarly consumer views should be sought of primary and secondary curative services for children, including opportunities for communication and counselling.

### **COMMISSIONING HEALTH CARE**

The purchasing process, as it now stands, requires the purchasers to ascertain the needs of the residents for whom they are responsible, and the providers to demonstrate how they are addressing the requirements set out by the purchasers. Opportunities exist in the commissioning process to include in contracts with providers the requirement to make available the necessary information. For instance, purchasers of maternity services should be informed of patterns of booking for care, how many mothers book early enough to allow prenatal screening for congenital defects, how many receive amniocentesis, and how common are Caesarian sections and admissions for special or intensive care. They should also have information on mortality and morbidity rates in different provider units, but must bear in mind the need to allow for case-mix and random variation. They should receive evidence of degrees of patient satisfaction. The collection of such information, and the assurance of its quality, must be adequately resourced by the purchaser. At provider level managers must become familiar with the best and most efficient methods of collecting patient data, and evaluating its completeness and validity, and comparability with national and sub-national data. Although much of the core-health data to be collected is now nationally specified there remains considerable freedom in regard to methods of collection and processing, and there are a number of private firms competing for the business.

Increasingly guidance is being provided at national and regional level on the best ways of collecting and interpreting such information and managers should know how, and when, to seek expert care or advice. The quality and completeness of hospital and community information would rapidly improve if more use were made of it.

Also important, but more difficult to monitor, are services directed towards health promotion, improvements in child rearing practices and those which will enhance the quality of life of children with disabilities. Managers should be aware of the need for such services and develop methods of assessing their availability, effectiveness and efficiency.

## CONCLUSIONS

The main aim of this chapter is to demonstrate the importance of maintaining child health at the highest possible level, both short and long term. It follows that managers have a duty to ensure that the necessary preventive and curative services are provided, and shown to be effective, accessible and acceptable. Purchasers have a duty to commission the necessary services, and must include in the contracts the resources which will enable providers to monitor and report on the effectiveness and efficiency with which these are provided. Both have a responsibility to the community to carry out these functions to the highest possible standard.

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# Information in child health management

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# 7

*Michael Rigby*

## INTRODUCTION

Information can be one of the most contentious issues in the management of child health services. Managers know that without good information they cannot manage effectively, but in most respects they are dependent for their information on its supply by others outside their direct control, and even the information which could be derived from sources within their directorate may be in practice inaccessible. Yet at the same time, they may feel that they are having to acquire and pass on to others information which they themselves feel is of little value and certainly which does not address properly the key issues.

Information supply has costs and benefits attached. Good information is necessary for good management decision making and for effective service delivery, therefore its absence will have a cost through inappropriate service development or service structure, through poor service delivery, and through lost opportunities to generate income. Yet the acquisition and provision of information also has its costs, and investment in this area is constantly under pressure in the attack on administrative costs. Obtaining or supplying information has a direct monetary cost: it has a staff time cost particularly when it involves data capture by operational staff in the course of their normal duties, and the infrastructure costs of forms, information technology, and dedicated information staff can be significant. It is therefore important for managers to be aware of cost benefit equations. For activities under their control they need to make sure that the investment in information services is structured so that optimised benefits from good information exceed carefully controlled costs, whilst for activities outside their control requiring information from them it is important that they identify costs incurred within their directorate and seek financial recompense.

## ADDING VALUE TO COST: FROM DATA TO KNOWLEDGE

A key to these processes is adding value whilst minimising cost. Healthcare delivery is one of the most information intense activities that exists. Every patient contact is documented within a medical record, and usually through other records including attendance returns and staff activity reports. There is an abundance of data involved in the business of running the NHS. In more commercial health care delivery settings such as in the USA private sector, business transaction costs alone are estimated as being 10% of total health care costs.

Yet low management benefits, and very limited management satisfaction, result from this constant emphasis upon recording and accounting. It is therefore important to understand the attributes and harness the purposes of information. In particular the three levels of the transformation from data to knowledge should be understood.

### DATA

**Data** are the raw items which proliferate in all settings: for example items locked into medical records, into staff absence records, into hospital admission records, and in the records of financial transactions. The NHS, and other health care organisations, are awash with data which cost a lot to capture yet which are little understood and which are generally inaccessible to managers.

### INFORMATION

**Information**, by contrast, is data collected, structured and presented in such a way as to provide a picture. It is information which enables managers to assess a situation and make decisions. In other words, through the processes of amalgamation and structured presentation the data have gained added value, and the value gained should be greater than the cost of the further processing.

### KNOWLEDGE

**Knowledge** is the highest end of the spectrum. Knowledge is information which has been enriched with meaning, for instance as to the cause, effect or significance of the phenomena which the information describes. Conversion of information to knowledge is primarily a selective cognitive process by the recipient. It enables the wisest decisions to be made.

Managers therefore need to be able to appreciate the value added in the process of transforming data into information, and in turn information into knowledge. Given the abundance of data, but paucity of information,

managers may find it cost effective to invest more into information processing activities, though it is frequently appropriate to do this by supporting investment in a shared information department within the organisation. Managers may similarly find it cost effective to hold other pressures at bay sufficiently to develop their own understanding processes – both in learning basic numeracy and interpretation skills, and in researching the context and thus the meaning of information supplied to them – in order to move from being information receivers to knowledge owners.

### **LEVELS OF INFORMATION AND MANAGEMENT**

Three levels of healthcare management can be postulated – caseload management, operational management, and strategic management. Each of these has its own functions and objectives, and thus its own information requirements. However, there are two further functions which should be recognised, one at each end of the range, namely case management and political accountability. These too have their own information requirements – and information costs.

#### **CASE MANAGEMENT**

This is the prerogative of the individual clinician, and though it is an area where the use of management skills is usually under-appreciated, the information used is normally derived from the clinical record and is therefore outside the domain of the manager. However, in child health there is a quite significant dependence by the clinician upon wider information systems. In particular, immunisation and other preventive services are undertaken with reference to integrated records often provided at district or Trust level. Secondly, in areas such as child protection the availability of key information such as child protection registers, and exchange of information on a case basis between agencies, requires an information environment created at organisational level between clinicians and managers.

#### **CASELOAD MANAGEMENT**

If health professionals are to organise their work optimally, they need overall management information derived from or about their caseload, its priorities, peaks and troughs, and how it relates to resources available. All too often general statements are made that health professionals could do more to optimise use of their time, but at the same time information systems often require health professionals to supply information but never give them any feedback as to their activities or outcomes. Empowering of



health professionals in their caseload management role is important, and can only commence with general management equipping them with management information derived from available data from within the organisation.

#### OPERATIONAL MANAGEMENT

This is the level at which the efficiency and quality of the organisation is mainly determined, but where investment in management skills and management information may not seem to be a priority. Whether at ward, team, clinic, or directorate level, the development of the organisation, its skill mix, and its priorities are of vital importance. In most organisations much more thought needs to be given to the information which operational managers, both unidisciplinary and multidisciplinary, should have available. In general this exists at data level but even this is not that often relayed to operational managers unless there is a particular crisis: the flotilla is frequently expected to navigate by the sun rather than share the navigation aids available in the flagship.

#### STRATEGIC MANAGEMENT

At this level the course of the organisation is determined, together with its performance against objectives and against perceived need and contractual commitments. Specialist areas including public health, epidemiology and the development of professional education are usually concentrated here. The strategic level is normally also the level at which data are gathered together and information is processed. Much depends upon the ability of the information function not just to handle routine data, but to enlighten the decision making processes.

#### POLITICAL ACCOUNTABILITY

Being a key public service, the NHS has a significant degree of public and political accountability. One less welcome manifestation is a requirement for routine information which appears to meet a need but is not as meaningful as at first appears. A classic example is that of waiting lists, where the political interest is primarily upon numbers. Thus a hospital with 100 patients waiting six weeks for admission is interpreted as being twice as bad as a hospital with 50 patients waiting for six months, and both appear worse than a hospital with a waiting time to first outpatient appointment of seven months but only three weeks subsequent wait to admission. Whilst needing to supply accurate and honest answers to questions, there is also a responsibility incumbent upon managers to provide more meaningful information as well as statistics.

## TYPES OF DATA

If the manager is to be an effective user of information, and is to empower those at other levels of the organisation by supplying them with information to enrich their own decision making, it is important to be aware of the sources and categories of information available. It is not possible here to identify every statistical return or external source of information, as that is a specialist topic in its own right. What is important is to identify the broader areas, together with an understanding of their relative strengths and weaknesses. Most healthcare organisations are highly unbalanced in their processes for turning ubiquitous data into readily available information. The greatest activity has tended to be in those areas relating to financial probity and political accountability, even though this has low impact upon operational management processes. At the same time there is a potential wealth of information of benefit to the manager locked into the clinical data of patient records, but not available to inform management processes because of the logistical and also the ethical issues of processing it, even though such information would benefit patient care by enabling the organisation better to adjust to meet the needs presented by patients. This next section gives a brief outline of the information types and sources which managers should seek to explore and exploit.

### CLINICAL RECORDS

In their immediate form, clinical records are maintained for the sole purpose of delivering clinical care, and are the preserve of clinicians as a record of their contact with, diagnosis of, and prescription of care for the individual. However, subject to very clear and agreed ethical protocols, aggregation of management information from these is one of the most accurate and relevant information sources possible. This source will give the best possible picture of expressed need (whether met or unmet) and the healthcare activity undertaken to address this need, together with the clinical outcomes. The development of electronic patient-based records (see below) opens up opportunity to tap this great potential, yet too often the marginal additional investment required is not made and so the gold mine of information remains untapped.

### POPULATION REGISTRATION

It is important to have a picture of the population served, particularly in child health, with regard to the numbers, mobility, and other attributes such as ethnicity of the client population. The NHS has never been good

at this. Family Health Service Authorities have a register of patients contracted with GPs for primary medical care, based on place of residence as well as place of practice of the doctor, but the information contained is limited and there are confidentiality criteria. District health authorities, and provider units within their catchment area, are dependent upon indirect and dated sources such as the decennial national census. It is intended in future in England and Wales that administrative registers should begin to address this need in a more structured way.

#### EPIDEMIOLOGY

The harnessing of epidemiological information is covered in Chapter 6. Suffice it to say here that the sources of information are multiple, are not coordinated, and in general fail to link key factors such as healthcare treatment and registration of death. Thus epidemiology continues to be not just an important science in its own right, but also something of a detective process.

#### HUMAN RESOURCES

Personnel or human resource information systems have traditionally been developed to address two specific functions: payment of salaries with related financial accountability, and to maintain overall records of the staff complement including their qualifications, sickness, and disciplinary record. They are therefore often operated by payroll or finance departments. These functions, like the financial and estates functions described below, are vitally important, but the data locked into them could be of major benefit to a much wider range of management decision making if it could be made available related to workload, activity and outcomes. More recently, additional information functions have been developed related to the workforce which are beginning to broaden horizons. Most significant of these are the development of rostering systems, particularly in hospital nursing, which match staff availability on duty to the nature of the workload at any given time, and second, the development of training databases which look at training received and required against tasks undertaken.

#### FINANCE

Information as to the functional pattern of expenditure in the health service is readily available, for instance differentiating between salaries, estate, and consumables budgets, and there are controls in place to ensure financial accountability. However, it was more than 40 years after its

inception before the NHS made any serious attempt at relating costs to healthcare activities or to the pattern of treatment of individual patients. This started with the clinical budgeting project [1]. Chapter 9 addresses current financial management issues.

#### ESTATES

In the last 10 years the estate management function of the NHS has moved a long way to develop effective information systems for the purposes of managing the estate, not least through the Works Information Management System (WIMS). However, information of benefit to clinicians or managers, such as the capacity, suitability, or running costs of physical facilities, is much more difficult to come by.

#### SUPPLIES

Like the other resources for which cash is paid, the supplies function is vitally important and one in which direct accountability, including stock control, is essential. However, supplies information is very seldom made available related to individual patients, particular programmes of care, or even to particular teams or directorates. It is difficult to think of any other major organisation which does not relate information on use of consumables to the structure or activities of its business units.

#### PATIENT ACTIVITY

From its inception the NHS has constantly counted the number of patients it treats, by programme and by setting. This information is particularly favoured in the political environment, though (primarily because of its availability) it has also become a feature of contracts. Activity measures bear no relationship to need, to resources consumed, to variations in clinical practice or to outcome. Even where there is an attempt to relate activity to the underlying requirement, for instance with the statistics on immunisations completed related to number of births, there are major problems caused by population movement changing the denominator and thus making difficult the percentage calculations.

#### OUTCOME

Outcome data are particularly scarce. During the Crimean war Florence Nightingale recorded the outcome of inpatient treatment according to the three very basic categories of 'relieved, not relieved, and died' [2]. The NHS has simplified this even further by eliminating the middle category, whilst relating death only to the inpatient period of treatment. There is

now a range of initiatives underway to produce more meaningful outcome measures, not least those related to Health of the Nation targets. This is an area of data, information, and knowledge which rightly will continue to grow. Managers need to enter into much more dialogue with clinicians to look at absolute and comparative outcome measures.

#### PATIENT SATISFACTION

When it was created, the NHS operated in circumstances of postwar rationing in which patients were satisfied merely to have a health service universally available and effectively free of charge at the point of consumption. Nearly 50 years later the environment is very different in terms of patient expectations, but the attitude of the health service to patient satisfaction is only just beginning to change. On grounds of human values alone the seeking of patient satisfaction information should need no justification. Add to that the fact that anxiety-free patients get better more quickly, and that preventive services will have much better uptake if they are user-friendly, and the importance of patient satisfaction information becomes self evident. This is an area where managers responsible for quality may take the lead, but managers of child health services should play an active part in seeking and utilising local and regular customer satisfaction studies.

#### EXTERNAL RESOURCES

The NHS works in a complex environment. Comparatively few of its services are provided in total isolation, and it is therefore important to be aware of the availability of services provided by other agencies (statutory, private and non-profit making), together with any strengths and weaknesses. These services and the NHS should seek to work together to provide a complementary whole.

#### INFORMATION TO PEOPLE

Finally, managers must realise that the seeking of information is not just a management prerogative. Patients, and in the case of children often parents on behalf of the patient, have a legitimate right and wish to know more about the services available, particular courses of treatment, and how to make best use of specific facilities (not least when admitted as inpatients). Services, including children's services, are only just becoming aware of the importance of the giving, as opposed to the receiving, of information. This process must be encouraged and stimulated, and above all quality must be maintained and the slippage into a routine process of displaying poor quality photocopied handouts avoided.

## THE DEVELOPMENT OF INFORMATION INITIATIVES

There have been a number of central or professional initiatives to develop information applications in the NHS, or in child health specifically, recognising the importance of this client group. The principal developments are outlined below.

### CHILD HEALTH SYSTEMS

One of the earliest yet most enduring initiatives has been the piloting of computer systems to support scheduling and record keeping for preventive services. The initial work was undertaken in West Sussex in 1962. This was in the days when preventive community health services were part of local government services. Local government in turn was an early application area for large mainframe computers, and the combination of expertise and large machines permitted this development. The early work in West Sussex was evaluated and written up [3,4], and other authorities followed suit fairly quickly, led by Leicestershire and Cheshire, the latter being the first to make coverage for preschool screening [5]. Over the next decade such provision moved from being unusual to being the norm. In the early days each authority wrote its own solution (this being well before the era of data or other standards), which was acceptable in the short term to support innovation, but wasteful in the long term, and authorities started to collaborate together. Implementation of computer support tended to be most advanced in the shire counties because of their larger size and comparative wealth, when arguably the needs (and therefore the potential benefits) were greater in the urban boroughs. Bussey's analyses [6,7] showed the approach to be universally beneficial in reducing morbidity.

With the advent of the unified NHS in 1974, the potential advantages were seen of developing common Crown copyright software to be used by any part of the NHS. This move had a somewhat compromised start, being driven by a fear that local authorities would cease their support on the day that health services transferred to the new Area Health Authorities, and because the resultant central top-down planning was insensitive to the special and local needs of community child health services. However, after a period of rectification the National Child Health System emerged in the mid 1970s as a powerful and respectable tool [8]. Whereas the child registration and immunisation functions were developed from existing good practice, the preschool and school health modules were designed from first principles by NHS-led working groups, and were fully evaluated before general release [9,10]. This thorough approach, comparatively seldom adopted then or now, paid dividends to the extent that twenty years later it has been difficult to generate support

and resources for desirable further developments because the original products were seen as perfectly sound.

Thus by the late 1980s there were two suppliers of the software (the Welsh Health Common Services Authority providing a virtual machine environment (VME) version for use on ICL machines, and South Western RHA computer centre supplying a Massachusetts University Medical Program Systems (MUMPS) version). Together, these were used by all the health authorities in Wales and Northern Ireland, and the majority of authorities in England, for birth notification, child registration, and immunisation scheduling, with an increasing proportion using the preschool and school health modules as well.

For all modules, the National Child Health System undertakes the following functions:

1. Registration of all children and their selected treatment centre.
2. Scheduling according to a local schedule and each centre's pattern of appointments.
3. Advising health professionals which children have been scheduled.
4. Advising parents of appointments.
5. Recording attendance and non-attendance, and rescheduling as appropriate.
6. Recording the clinical results.

Additional important routines advise health visitors of children falling outside the normal schedule, and advise general practitioners of summary results. The school health module also has a facility to advise schools of key information. Very importantly, there are also statistical facilities to enable the data to be analysed for a whole range of managerial and clinical purposes.

Overall, it can be argued that the National Child Health System has done much over the last 20 years to increase the proportion of children receiving preventive child health services on schedule. Paradoxically, its principal problem is that it has also suffered as a result of this. Because the product was very adequately designed and tested in its early stages, there are comparatively few staff remaining in any healthcare provider who were in post at the time of its implementation, and over the years much of the prime documentation will also have been consigned to archives. Thus in many settings the National Child Health System, with its well established and defined data set [11,12] will be significantly under-valued and therefore under-used by local managers as a source of managerial, clinical, and audit information [13].

Though the details of the mechanisms have changed, the National Child Health System has always been overseen by an NHS representative body. This has taken a constructive approach whenever new issues have arisen, resulting in particular in guidance on procedures to be followed under the

Data Protection Act [14,15], and more recently a structured project to look at quality as supported by the system [13].

#### STEERING GROUP ON HEALTH SERVICES INFORMATION

Another consequence of the unification of the NHS in 1974 was the recognition that statistical information systems were totally uncoordinated, and needed to be addressed. Consequently, the steering group on health services information (SGHSI) was established in February 1980, under the chairmanship of Mrs Edith Körner, then vice chairman of South Western Regional Health Authority. The committee, its reports, and the defined data sets and data items all subsequently became personalised to the chairman, an unsought attribution which Edith Körner herself thought inappropriate as she saw the developments as teamwork on behalf of the NHS.

Because of the opprobrium often heaped upon the work, it is important to see it in context. First, the steering group was working in an environment with absolutely no culture of thought out management information. What existed hitherto was a largely unhelpful mixture of activity statistics and counts of beds and other facilities. It said nothing about workload, levels of service to the public, or outcomes. Into that unstructured environment the steering group brought considerable order, very largely through original thinking drawing upon best practices of the time from other arenas. The sound principles established by the steering group have passed into the culture without recognition of their origins. These include the principles that information should be relevant, timely and accurate, and that management information should be a by-product of clinical information, with the hypothesis that it is difficult to think of any summarised information required at one level which cannot be drawn from aggregation of data required at a lower level [16], thus in one sweep hoping to banish information collected just for national or regional returns. Within community services the steering group defined the distinction for the first time between services to the community (particularly population-based programmes) and activity in the community (namely delivered to individuals in a non-hospital setting) [17]. Though individual staff might be involved in both sets of activities, the information, analyses and success measures required for one were for the first time recognised as being quite different from those required for the other.

The steering group also produced its recommended minimum data sets, under the pressure created by the fact that its *raison d'être* was to replace the hitherto largely unhelpful central statistical returns. The steering group put forward two strong caveats with its initial recommendations: first, that these were indeed truly minimum data sets, and that particularly at local levels additional information was likely to be needed for



management analysis to be meaningful. Second, it saw the data sets as the best that could be produced as mandatory at that time, given the overall lack of information culture and also the very limited information systems which existed. The steering group emphasised that it believed the data sets would need development and improvement in the light both of experience and of better opportunities for data gathering: in effect, its initial minimum data sets were necessary compromises. They were never expected to be long-enduring in specific detail [16].

The subsequent history was disappointing. Norman Fowler, Secretary of State of the day, accepted the immediate recommendations, disregarded the argument for further work and refinement, and turned the steering group into a coordinating committee under a different chairman. Even in that emasculated form it was short lived, and therefore the original vision of Mrs Körner and her steering group that they were starting on a voyage of development with an initial working solution turned into the unsatisfactory situation for all parties that their prototype became the rigid definitive model. The steering group produced a series of main reports, and reports from its individual working groups, all of which bear re-reading for the sound logic and principles they demonstrate, even if the management environments and individual data items have been made obsolete by subsequent events. The valedictory collection of essays edited by Dr Alastair Mason to mark Mrs Körner's achievements are also commended [18]: the title *Walk don't Run* poignantly summarises Mrs Körner's philosophy of making purposeful progress at a pace sufficiently steady to avoid the organisation tripping up; a philosophy which was proved counter productive with hindsight when Norman Fowler would not allow the journey to be completed.

#### COMMUNITY INFORMATION SYSTEMS

The environment created by the steering group reports, particularly in community health, led to an urgent requirement for better information capture. A series of products started to be developed, of which the first two were the financial information project (FIP) and Comcare. FIP was a development from the team set up to develop the financial information project, whereas Comcare was developed for users of the then regional standard ICL mainframe computers. Both were community activity systems based upon staff records; they sought to capture the activities individual staff members undertook. With the application of the later resource management initiative to community health services, a third major product, Comway, was developed, and this too was staff orientated. With further experience, and the recognition of a need for a client focus of community services, all these systems have been re-engineered to have a patient focus with various degrees of upheaval and success.

Another result of the move towards patient-based systems was the development of new products from commercial suppliers. This involved both the re-engineering of earlier products and development of new products which aimed to put together all activities for the same client, thereby overcoming the limitation of the National Child Health System in relating only to preventive healthcare activities in the community. This is now likely to be a quite fast-moving market, with specialist knowledge needed to evaluate competing systems not just for their inherent benefits and interlinkages with other systems, but their stability and that of their vendors. No effective child health service in the community can be envisaged where both clinicians and managers do not in future use computerised records in support of their activities.

#### HOSPITAL INTEGRATED SYSTEMS

Meanwhile, information systems in hospitals have become even more fast moving, though seldom with paediatric or child health services as a prime focus. A series of initiatives ranging from the early introduction of patient administration systems, through the resource management initiative to the development of medical and clinical audit as part of normal practice have meant the development of integrated systems of various forms. Only local knowledge will indicate the appropriateness of the data recorded to the specific needs of child health. What is still rare is the integration of hospital and community data into one comprehensive database, either as an integrated clinical record or for management purposes. What is also unfortunate is that few clinicians or managers realise the wealth of what is available if the two data sets can be brought together. One key to innovative and effective management must be the comprehensive harnessing of all locally available information wherever it may be located.

#### MATERNITY SYSTEMS

By contrast, one of the areas of early and significant patient-orientated computer record development in secondary care has been in maternity systems. Ranging from initiatives to generate standard data sets, through to integrated maternity systems of which many now exist, obstetricians have worked closely with management and information scientists to generate clinical and service management data for their needs. By their nature these hold key information about neonates; information which has various degrees of compatibility with the National Child Health System and other record systems for children, and which is passed on quickly and routinely with varying degrees of success. The ultimate goal, subject to confidentiality and data security safeguards, must be electronic transmission of data from one system to another, but this is not as easy as it sounds.

Apart from the need to ensure that the data sets match, child health managers will know the problems of cross-boundary flows where children are not delivered in the hospital of the district in which they reside, and there is the need also to add child health specific data items such as the identity of the health visitor and clinic.

Nevertheless, the situation over maternity systems gives two object lessons. The first is the power of particular client groups and professional lobbies compared with others, and the second is that the secret of good management is not just having the information, but having the information about who holds what information in what system, and then having the drive and negotiating skills to harness this.

## **CONFIDENTIALITY, SECURITY AND DATA PROTECTION**

Whilst child health managers may not be operating computer systems, it is essential that they ensure that all information (particularly person-based information) is kept confidential. Three concepts must be firmly established as part of the organisational culture.

### **CONFIDENTIALITY**

All information must be considered as totally confidential. Even apparently harmless information such as an address must be considered totally sacrosanct, as external parties may seek to obtain this for totally inappropriate reasons. Staff should operate a total confidentiality culture, and this should be supported by operational policies, induction training, and clauses in contracts of employment.

### **SECURITY**

Similarly, data should be kept in secure environments. This includes precautions such as locking filing cabinets and filing rooms, and ensuring that VDU screens cannot be viewed by visitors or through windows.

### **DATA PROTECTION**

It is often perceived that computer-held data are more open to misuse than paper records. Without computer access controls and audit trails this can be true. Given good procedures, however, electronic records are very secure, and safe from casual access or browsing. A further benefit is that back-up copies can readily be held in separate locations, as a precaution against the effects of physical threats such as fire, flood or theft.

In handling an operational information policy, managers should be aware of a number of specific requirements.

#### SUBJECT ACCESS

Under the Data Protection Act (for electronic records) and the Access to Health Records Act (for paper records), persons can gain access to personal information about them. There needs to be a local, clearly understood mechanism for this, with two important dimensions: enabling the person to make the application easily and speedily, and putting into operation the mechanism to consult health professionals (and if necessary social workers) prior to release.

#### RIGHTS OF PARENTS AND CHILDREN

Because children cannot look after themselves in infancy, parents act on their behalves. This comparatively simple approach contains several concealed traps.

These include problems of checking whether a natural parent still has parental rights, informal partners, and other relatives especially grandparents. Healthcare providers have to tread a narrow path of not revealing information, or meeting other requests inappropriately, whilst at the same time ensuring cooperation with normal family circumstances.

The rights of the child should also be respected. Parents have responsibilities rather than rights, and as soon as a child is able to make a reasoned and informed choice they can do so. Thus, specific to each child and each circumstance, parental responsibilities are replaced by self-determination, as was made clear by Lord Justice Scarmon's ruling in the Lords of Appeal ruling in the Gillick case [19].

A comprehensive guide to operational issues with regard to confidentiality has been produced in the context of the quality assurance project of the child health consortium [20].

#### NATIONAL INFORMATION INITIATIVES

Whilst most information requirements, and therefore situations, are best addressed locally, there are circumstances when a coordinated national approach is valuable. Chapter 6 deals with epidemiology, but in the context of information managers should be aware of the following schemes.

#### CONGENITAL MALFORMATION RETURNS

These are an important but imperfect means of identifying one dimension of potential health problems. All congenital malformations observable at birth should be reported to the Office of National Statistics (ONS),

formerly the Office of Population Censuses and Surveys (OPCS) on Form SD56. ONS then runs a central statistical programme to detect abnormal trends. The system is known to be flawed because of observer variations in reporting thresholds for minor problems, and because its system cannot accommodate more serious problems determined later in life. Nevertheless, this is one of the few databases of morbidity.

#### COVER

The system of monitoring the cover of vaccination evaluated rapidly (COVER) is an initiative devised to improve uptake by enabling individual districts to compare their performance with peers, ahead of the retrospective annual statistics. Operated on a voluntary basis, it has proved most effective, and its own coverage has increased rapidly. Each district sends a quarterly report of immunisation completion rates of specific cohorts of children whose immunisation programme is currently active, and receives rapidly in return an analysis showing their position alongside other districts, grouped by region [21].

#### CONFIDENTIAL ENQUIRY INTO STILLBIRTHS AND DEATHS IN INFANCY (CESDI)

Modelled on the earlier and successful Confidential Enquiry into Maternal Deaths, this has been set up in England and Wales by the Department of Health, and operated by the ONS. All stillbirths, and deaths in the first year of life, should be reported through a dedicated network of regional centres. Cases will then be followed up and reviewed anonymously to identify patterns and trends, as a means of auditing and improving clinical management policies.

### **NHS INFORMATION STRATEGIES**

In 1992, the NHS management executive launched the NHS information management and technology (IM & T) strategy. Based on the earlier publication of a strategic framework, and both applying only to England, this set forward a programme of developing a modern information management strategy and culture. The central focus is primarily upon developmental projects, establishment of standards, and enabling projects at a macro level, leaving individual health organisations to develop their own implementation strategies. Particular strands in the IM & T strategy have been as follows.

1. Development of a standard unique patient identifier (a re-issued structured NHS number).

2. Development of patient-based systems in community care.
3. NHS administrative registers.
4. An NHS network.
5. Data dictionary.

Many of these are of particular significance to child health services, though not necessarily progressed with the interests of that care group specifically in mind. In particular, the allocation of NHS numbers to newborn babies, and the provision of special functions for child health preventive services within integrated patient based systems, have been areas of concern.

Whilst the English IM & T strategy is an important enabling device, its implementation will only be as good as the solutions of the individual purchasing and providing organisations, and child health managers should be proactive in ensuring that the information needs for care delivery and service management of child health services are handled well. The other parts of the UK have their own strategic approaches, possibly of less high profile but with their own inherent strengths.

#### COMMUNITY INFORMATION STRATEGY FOR PROVIDERS (CISP)

The Community Information Strategy for Providers (CISP) is a component of the English IM & T strategy of particular relevance to child health. It is a demonstration programme to identify and promote good ideas. The broad aim has been to develop patient-based systems in community services to give them an approach and recognition more in line with the major investment already made in hospital patient-based systems.

CISP has had three broad phases: desk studies to identify issues; developmental projects to establish best practice at local level and development to computer demonstrator stage, and a third phase both to produce prototype systems from the demonstrators and to identify key factors to implementation. The information management group of the NHS management executive declined to give any special consideration to child health. It selected six (later reduced to five) developmental sites in phase two. Of these sites, two did not have children's services, and a third was not responsible for child health though providing health visiting and community paramedical services to an external child health directorate. Thus child health has not been well represented in this important programme. Moreover, though seeking to give community patient-based systems more appropriate attention than hitherto, the total investment at national initiative level was still very modest compared with central initiatives in hospital systems.

How child health ultimately benefits out of the CISP programme has yet to be determined, as it will depend very much upon the responses from

commercial suppliers to the demonstrator and prototype phases. A late piece of commissioned consultancy at the end of phase two tested the demonstrators against the requirements of child health and found some deficits.

## MANAGING WITH INFORMATION

Child health managers will normally wish to commission and use information in a fluent way, and in so doing will wish to ensure that data capture mechanisms are reliable in order to produce data and information of high quality. They should therefore ensure that their service has appropriate support from an effective IM & T service, but they themselves are unlikely to be experts in, or responsible for, the information technology which is utilised. The relationship between the child health manager and the director of information will therefore be vitally important, and child health services in particular need to have similar relationships with partner health provider organisations such as the providers of maternity services to ensure rapid and accurate transfer of data and information.

In looking at information gathering, commissioning and supply, it is important to identify four separate levels. **Data** which are the raw facts, captured at clinic and hospital level: for instance, details of new births or of clinic attendances. **Information** is data which have been processed into a meaningful format in a particular context, for instance a complete analysis of all new births in a structured way, possibly enriched by comparative information. **Information systems** comprise the complete pattern of information capture and analysis, including the relationship between different processes and functions within that activity, usually harnessing information technology. **Information management and technology** is the business function of running a comprehensive information service.

## OBTAINING SUPPORT FROM THE INFORMATION SERVICE

In the same way that child health managers will not normally be experts in information technology, so it is usually true that information managers are not expert in the special needs and requirements of child health services, including the importance of timeliness in information flow concerning neonates and young children, and the statutory and other specialist functions such as the supply of information to proper officers and registrars of birth. The dialogue between child health and information managers must therefore be a constructive one, in which the following stages are important.

1. Describing and obtaining an understanding of the issue in question.

2. Identifying the data required to address any particular issue, whether ongoing service provision or special investigative analysis.
3. Analysing the problems involved, such as ensuring comparability of data in definition, timeliness, or structure.
4. Presentation of results by common and understood criteria.

Particular issues which can cause problems unless fully appreciated are the differences between the population cohorts of children of a particular birth age who were born in and still remain in the locality; those who were born in the locality but subsequently moved out; those currently resident who moved in after birth; and those who moved in and subsequently moved out again. When analysing service activity, costs, health gain, or epidemiology each of those four definitions can be the appropriate one, but the information will only be meaningful if it is clear which definition is being used and if all related data (such as the population baseline) are provided to the same definition.

## CONCLUSIONS

Provision of, and utilisation of, information in the management of child health services is one of the most challenging areas. This is because of the special needs and statutory requirements within child health, the need for extremely accurate and timely data, the range of services undertaken in child health including screening and the need for resultant data to move round the service quickly, and the fact that though the proportion of the population who are children is small the amount of clinical activity is comparatively high. There is a constant low appreciation of the importance of the special information needs in child health, and this problem occurs at all levels from the national to the local. At the same time, child health managers are frequently unaware of information which is available to be harvested from the different operational systems and linked together, particularly drawing information from maternity systems, hospital systems, and community systems, and there is often no easy platform for amalgamating and processing that data. Yet the challenge is important, because the best clinical practice will be the best informed clinical practice, and the best management will be the best informed management. Child health managers therefore need both to brief themselves fully on issues of information management in child health, and to brief their information management colleagues on the nature and requirements of child health services.

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# Running a clinical service: a case study

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# 8

*Harry Baumer*

## INTRODUCTION

In order to meet the challenge of directing a children's secondary care service one must first understand the environment in which clinical services are functioning. A fuller account of the NHS environment will be found in other chapters. However, there are two major and quite separate changes to the way that providers of clinical services function. The first is the resource management initiative [1] and the second is the separation of the commissioning and provision of services under the NHS reforms [2].

The resource management initiative brings doctors into management, giving them authority over their budgets and providing them with managerial assistance. It involves the development of information systems to assist in the delivery of services. It implies an environment where there are real incentives to increase efficiency. The assumption was made that the investment in the resource management initiative would release annually 1% of expenditure on health services to invest in new services [1]. Subsequent assessments of resource management [3,4] emphasise the likely and necessary slow pace of its development, which remains patchy and incomplete.

The evolution of the purchaser-provider split in the health service continues. The numbers of directly managed units is decreasing rapidly and the numbers of GP fund holders together with the variety of services that they may purchase is increasing. In addition, the gradual diminution of block contracts for even emergency services is creating an increasingly uncertain environment for service providers. Even in Plymouth, a geographically isolated town, by 1996 there were two major secondary health services providers, and eighteen major purchasers with two joint commissioning authorities and sixteen GP fund holders (including three 'total' fundholders).

## SETTING UP A SECONDARY CARE CHILD HEALTH DIRECTORATE

There are a number of management models within which a directorate may operate [5]. In Plymouth there is a unit management board of eighteen, ten of whom are clinical directors, each with a business manager accountable to them. Barker [6] has described the structural changes in setting up a combined service. The formation of the combined children's secondary care service (child health directorate) occurred at the end of 1989, and was the second directorate to develop in Plymouth. Children's community and mental health services were approached with an explanation of the intended structure and aims of the directorate. All but the health visitors chose to join.

### ACUTE OR COMMUNITY TRUST?

The child health directorate had a choice between being part of the acute or community unit or trust. The relative merits can be summarised as follows.

1. A community trust is likely to have a clearer understanding of the community aspects of the service, and facilitate links with other community services.
2. Community child health may feel less threatened by hospital children's services in a community trust which understands their service better.
3. The largest part of the child health budget is the acute, hospital based service. It seems more logical therefore to be based in an acute trust.
4. Being part of an acute trust should lead to closer relationships with other hospital based clinical directors, and facilitate the development of a hospital 'child-focused' environment.

We chose the acute unit, largely on the grounds of local factors: the management culture and the clearer commitment to resource management at the time within the acute unit seemed preferable.

### AGREEING THE PHILOSOPHY

A statement setting out the philosophy is a way of identifying common goals and achieving a degree of mutual understanding. If undertaken at the outset, it should not need changing over time. Some potential elements for inclusion are:

1. the focus on the child within a family setting;
2. making the service equitable and accessible;
3. recognition of the value and needs of the staff;
4. importance of involving staff in decision making;

5. service orientation towards health promotion; and
6. encouragement of innovation and development of the service.

We agreed two statements, which were printed on glossy card, and continue to be displayed widely where both staff and families may see them. With hindsight, this exercise helped the management team and the staff within the directorate to develop cohesiveness, and it impressed the main purchaser.

## MANAGING A COMBINED CHILDREN'S SERVICE

### FINANCIAL CONTROLS AND RULES

The resource management initiative envisaged service providers agreeing objectives and priorities, with resources allocated to achieve these, followed by monitoring and review of the outcomes [3]. The advent of the purchaser-provider split and contracting has created a need for a financial environment that reflects this process and creates incentives for service providers.

The financial rules which operate within a directorate have to reflect those of the unit or trust overall. The advantages of having written financial rules are as follows.

1. They are explicit and agreed by all with budgetary responsibility.
2. Without written rules, details become forgotten, particularly as time passes.
3. They are clearer to individual budget holders.
4. A mechanism for rewarding good budgetary control can be agreed.
5. It is educational for clinical directors.

In our own unit the written financial rules allow directorates to keep a proportion of any underspend, at the discretion of the unit general manager (now chief executive). These rules apply within the directorate with three separate departmental budgets for hospital, community and mental health services: this was important to allay concerns about the financial security of community services. Each department has contributed equally to the cost improvement programme over three years (proportionate to their overall budget), despite varying contributions within an individual year.

Financial prosperity is perhaps the most important factor of all in ensuring a successful directorate. The directorate managed to maintain a balanced budget from its inception. This was in no small part due to the skill and efforts of two excellent successive business managers that assisted the directorate. A proportion of any underspend was returned to the directorate for capital projects, and has been used towards postcommis-

sioning work on new paediatric wards, as well as capital schemes for the community and mental health services.

## CONTRACTING

It is absolutely crucial for the clinical director to be involved in the detailed contract negotiations with purchasers and to agree the service volumes and prices for each purchaser, if major financial pitfalls are to be avoided. The contract documentation we used was divided into two sections.

### Schedule 1

This describes the clinical service agreement between a purchaser and provider. As a provider, it is important to decide whether this should be detailed or brief. We chose to write a detailed service specification, which in 1996 ran to 56 pages and incorporated a number of quality standards as well as a detailed description of the services provided. Our reasons were that:

1. It helps to emphasise the purchaser-provider relationship to staff. It ensures that growth and changes in service are recognised as such by service providers.
2. The purchaser welcomed it. It therefore contributed towards achieving a good reputation.
3. It educated staff about the nature and range of services for children.
4. It was educational for the purchaser, and particularly helped to explain the nature of the school health services which were under threat following a regional review [7].
5. The mental health service and child development centre are dependent upon staff from other agencies to achieve agreed activity targets. This proviso was incorporated into schedule one.

### Schedule 2

This describes the volume and type of contract. There has been a progressive move away from block to cost-per-case or cost-and-volume contracts, although in 1991/2 only 5% of contracts were of this type [8]. The major focus of purchasing attention is currently on waiting times for (mostly) inpatient surgical services. Cost-per-case contracts have a number of implications for a paediatric inpatient service.

1. Most of the hospital inpatient activity arises from emergencies, and is therefore not fully controlled by the wards.
2. It is in the child's interest to avoid admissions to hospital where possible. There is no incentive to reduce admissions, although there is an incentive to reduce the length of stay.

3. Fixed contracts for neonatal intensive care with wide limits achieve the certainty of a guaranteed income, but do not address any long-standing staffing shortages.
4. Neonatal intensive care activity does vary from year to year; a cost-per-case contract could make it necessary to reduce or increase staffing levels at short notice year by year. This is difficult when there is not a rapid turnover, and where numbers of trained staff are in short supply.
5. For neonatal intensive care, there is enormous variation in length of stay. The use of Diagnostic Related Groups (DRG's) has been proposed by the Clinical Standards Advisory Group [9]. However, in 1997 this approach has not yet been tested in practice despite the development of neonatal healthcare resource groups (HRGs) by the National Casemix Office.
6. The costing methods of neonatal intensive care vary, and it is difficult to make meaningful comparisons between the costs of the service in different units.

Our strategy has been to negotiate fixed contracts with the two main purchasing authorities for inpatient paediatrics with a wide upper and lower limit outside which financial rewards or penalties apply. We have a separate contract for neonatal intensive care, which is a fixed contract for all three purchasers, with wide thresholds.

We have used cost-and-volume contracts to avoid the financial uncertainties produced by two expensive drugs, growth hormone and for one haemophiliac boy's Factor VIII inhibitor bypassing agent (with an annual cost of £15 000 increasing to over £50 000). Growth hormone has long been a contentious drug, with hospitals shifting costs onto primary health care. It seemed more appropriate for the paediatric service to be funded for the drug as paediatricians, not general practitioners make all the treatment decisions. We agreed with our purchasers a written protocol detailing the indications and doses for growth hormone, and have a cost-and-volume contract for it.

The directorate has progressively increased its recording of outpatient activity, and is now able to have separate outpatient (fixed, with thresholds) contracts for mental health (all professionals), hospital paediatrics (all medical contacts including 'ward attenders'), and community child health (separate contracts for all medical, school nursing, physiotherapy contacts and children attending nursery groups). This has helped to bring unit outpatient costs down, and has increased purchaser recognition of the number of patient contacts.

#### INFORMATION

One of the pillars of resource management is the provision of service providers with information to monitor progress with service agreements.

Plymouth has a ward nursing system that is used to plan nursing staff requirements each day, and is also used to estimate nursing establishment requirements by the director of nursing in collaboration with each clinical directorate.

An enquiry system directly interrogates the patient administration system (PAS). It was possible to develop a model of how bed occupancies would look on new children's wards with a mixture of paediatric and surgical activity purely from PAS information. Bed occupancy was displayed as a frequency histogram, and allowed predictions as to how often beds would be unavailable with different numbers of beds.

The community child health service uses the MUMPS version of the National Child Health System (see p.131). The mental health service uses the patient administration system for recording its activity.

The following principles should underly any clinical database.

1. There should be overall clinical operational control. This ensures that the right information gets recorded.
2. The information put into the system is appropriately validated, both at data entry and by frequent searches for missing or incorrectly coded data.
3. Data is only input once to one system; transfers of information from one system to another are performed by direct electronic transfer wherever possible.
4. Operational systems provide information for management information, which is a by-product rather than the complete rationale for data collection.
5. Those inputting data are properly trained, and understand the purpose of the exercise.
6. There should be benefits, including feedback of information, to clinical staff inputting data. Once the data held can begin to substitute for the paper records, medical staff will be motivated to maintain the database.
7. The database should be developed incrementally. The most important information should be chosen first.
8. The main purpose of recording data should be established before making decisions about what to collect, and by whom.
9. There should be an overall vision of what is to be achieved. Be prepared to work slowly towards this goal. The vision should include all clinical staff groups.
10. The clinical director needs to understand about the available information and its potential uses, but should ensure that others with the necessary skill and knowledge are available to retrieve data.

#### BUSINESS PLANNING

The business manager writes an annual business plan. The benefits are as follows.

1. It is a formal way of reviewing progress and identifying objectives for the next year.
2. It allows a full consultation within the directorate about service development opportunities or aspirations.
3. It educates staff about the purchaser-provider environment.
4. It helps to link the directorate's objectives into those of the unit.

#### QUALITY AND AUDIT

The managerial interest in quality that was evident a decade ago [10] is helpful for children's services. An increasing number of standards are available against which to test services, for example *Welfare of Children and Young People in Hospital* [11]. The directorate actively encouraged an interest in quality, for a number of reasons.

1. There was a prevalent view that the children's services were of high quality, when some aspects were clearly not so.
2. Quality means different things, depending on the perspective. The rise of consumerism, and the development of GP advice to the purchasers demanded a fresh look.
3. It seemed better to develop our own quality standards rather than have them imposed.
4. Medical audit was just developing, and seemed likely to identify the need for some changes.
5. There was staff enthusiasm for quality standard setting.
6. There were a number of children being managed in an inappropriate hospital environment, and this seemed an opportunity to address the problem.

The directorate therefore undertook the following.

1. The development of ten quality standards for children in hospital, each with a mechanism for monitoring. These were formally approved by the unit management board.
2. Each of the three services defined a small number of internal quality standards which were already achievable.
3. Two outcome measures, as well as the above quality standards, were incorporated into the service specification (schedule 1).
4. The Community Health Council was commissioned to carry out a consumer survey of the hospital inpatient service using the National Association for the Welfare of Children in Hospital (NAWCH) quality review checklists [12].



5. A multidisciplinary steering group was set up to facilitate the conversion of medical to clinical audit and coordinate it with quality management within the directorate, with representatives from each of the major clinical groups.

The effect of this has been to raise awareness of quality within the directorate, and give us a reputation for being concerned about quality.

#### COLLABORATION WITH PURCHASERS

Purchasers are now required to take note of the views of clinicians [13] when commissioning services. They also need providers to supply them with information about demand; although they are required to commission services to meet the local population's needs, it has been argued that need is usually unknown, and so poorly defined that the exercise is unlikely to succeed [14], particularly with the increase in GP fundholding.

Purchasers need to have a strategic view of children's services, which requires them to listen to the local child health providers [15]. Without this, especially where secondary care services are fragmented between different providers, they cannot make informed decisions.

Plymouth health authority produced a five year children's health strategy under the nine headings of services for all preschool and school age children, for disadvantaged families, mental health, acute and chronic illness, newborn infants, disability and child protection. The format of the strategy follows that in the British Paediatric Association document on community child health services [16]. It remains to be seen whether this will assist in developing children's services.

#### COLLABORATION WITH OTHER AGENCIES

The 1989 Children Act [17] requires agencies to cooperate in planning and providing services for children. In Plymouth, the joint agency forum for children's services was adopted by health as a purchaser forum, but with provider representation. Although the changes within education made their involvement increasingly difficult, and primary health care representation was lacking, the combined secondary care service produced an effective voice for secondary health provision.

The Joint Review, Planning and Advisory Group (JRPAG) for children was a multi-agency purchaser-led committee with provider representation which facilitated the interchange of information and views on children's issues. As well as steering the disability register into being, in two years the JRPAG assisted in the development of services for bereaved children, and in reviewing respite care services. It disseminated much

information of value between agencies. The children's JRPAG is no more; with a merged district health authority and family health services authority covering an enlarged geographical area the function now operates within the patient-practitioner service agency (PPSA).

The area child protection committee in Devon had four geographical subcommittees which continued, until recently, to function relatively unscathed through the management changes in each of the main agencies. It serves primarily as a professional committee, and its recommendations are implemented through the purchaser-provider mechanism. In Plymouth, this resulted in a sizeable recurring sum of money being made available for the training of secondary care health staff in child protection, including the junior paediatric medical staff and medical staff within other key services, such as accident and emergency. However, recent changes in local government and the Social Services have resulted in a much reduced availability of such training.

#### COLLABORATION WITH OTHER PROVIDERS

One of the principles of the internal market is to encourage competition between providers [2]. Unfortunately, it can also discourage service providers from collaborating. It has been argued that children's services, like psychiatry and health care of the elderly, with the need for multidisciplinary and interagency collaboration, are likely to suffer as a consequence of an increasingly competitive environment [18]. There has certainly been a paucity of collaboration between the major secondary care providers for children's services in Plymouth.

#### THE COMPOSITION OF COMBINED CHILDREN'S SECONDARY CARE

##### HOSPITAL SERVICES

The largest budgetary component of a combined children's service is generally the hospital service. This can include both secondary and tertiary care, with some of the latter being very high cost, low volume services. The geographical boundaries served by the hospital often differ from those of community child health.

##### **The children's hospital department**

The audit commission has recently undertaken an audit on the value for money provided by hospital children's services (*Children First* [19]), and addressed a number of important issues including the use of tertiary services. Action for Sick Children (formerly NAWCH) published

guidelines for setting quality standards for children's hospital services [20]. More recently, the Department of Health has updated its guidelines for hospital services [11]. The main thrust of these publications is that children's needs for a child-focused environment generally outweigh their need to be nursed in a speciality-focused ward.

The following services should be available.

1. The hospital school.
2. Play helpers and materials [21].
3. A separate children's outpatient and medical day case facility. The work associated with ward attenders needs to be recorded and recognised [22]. In Plymouth, separate outpatient sessions are set up on the patient administration system for each day of the week to record these.
4. The children's outreach nurses.
5. An office base for the children's community medical staff.
6. The children's social work team.
7. Parents' accommodation.
8. Inpatient facilities suitable for adolescents [23,24].
9. An information centre, capable of providing written information on a wide range of subjects and with access to full library facilities.
10. A reception and waiting area.
11. Consultant and junior doctors' offices.
12. A seminar room.
13. The use of art to de-institutionalise otherwise intimidating surroundings.

### **High cost, low volume services**

Neonatal intensive care, like a number of specialist tertiary services, is a high cost, low volume service. Lengths of stay vary from overnight to several months. A detailed review of the need for, access to and availability of neonatal intensive care in the UK has been undertaken by the Clinical Standards Advisory Group [9]. The service is chronically underfunded, and the advent of the NHS reforms has been associated with an increasing tendency for district general hospitals to provide neonatal intensive care.

The concerns felt about whether children are receiving appropriate standards of care outside tertiary centres is the same concern that secondary care services have about primary care. The clinical risk index for babies (CRIB) score [25], a disease severity scoring system for premature neonates, has been suggested as a basis for comparisons of immediate outcome and the availability of recommended resources [26] between centres; the 1997 UK neonatal staffing study will examine the relationship between risk-adjusted outcome and medical and nursing staff

structures. The audit commission [19] recommended that the outcome at 2 and 4½ years of very low birthweight survivors should be collected nationwide; the National Perinatal Epidemiology Unit has produced recommendations for a minimum dataset [27] of health status at 2 years of age.

Intensive care facilities for children have been the subject of a recent in-depth review [28]. This recommends separate intensive care wards for children. Following the government's acceptance of the national coordinating group's report on paediatric intensive care [41,42], a national implementation plan should result in a network of lead centres with a transport service for transferring children requiring levels 2 and 3 intensive care.

### **Children's surgical wards**

The role of the paediatrician extends to having an oversight of the hospital children's facilities [11]. Diplomacy is needed to avoid the feeling that paediatricians want to 'take over' other consultants' territory. There are still many children's surgical wards that are managed by a surgical specialty, without reference to the rest of the children's services.

The directorate has budgetary responsibility for the two children's surgical wards. A single written operational policy covers all the children's wards, with shared quality standards. Two surgical wards have subsequently merged with the two paediatric wards into three mixed specialty wards including general, orthopaedic and ENT surgery, plastic surgery and burns and neurosurgery. The potential benefits of mixed specialty wards are as follows.

1. Medical paediatric advice and supervision, both formal and informal, is enhanced at all levels.
2. Practical assistance with medical procedures is facilitated.
3. Surgical advice and assistance is more readily available.
4. Wards can be arranged at least partly by age.
5. More efficient use of beds can be obtained.

The concerns of other specialities which must be addressed are as follows.

1. Children under their care will be scattered around many wards. We have a single designated ward for plastic and ENT surgery, neurosurgery and orthopaedics.
2. They will lose primary responsibility for their patients. Shared care is only by agreement with the consultant concerned.
3. Nursing speciality skills will be subjugated to their sick children's nursing skill. Many nurses have both skills.

The laudable increase in day case surgery for common elective children's surgical problems has required careful consideration of how best to achieve this as well as maintaining a suitable environment. The choice is often between an adult dedicated day case ward, and an inpatient children's ward. The options are considered in the document *Just for the Day* [29]. One option suggested is treating children on an adult day case ward with 'children only' days, the nursing establishment for these days being under the control of child health. It is suggested that with such an arrangement the child is more likely to be discharged on the same day than if treated on an inpatient children's ward. The ideal arrangement, however, was to combine the surgical day case unit with the children's ward or outpatient department.

### **Apportioning budgets**

There are different ways of apportioning medical, managerial, pharmaceutical and paramedical costs:

1. separate these budgets from the wards;
2. apportion the costs to each ward;
3. apportion all costs to each consultant, and have them 'purchase' ward services.

The third mechanism is complex to administer, requires excellent information systems, assumes consultant agreement to accept the responsibility, and is appropriate only if each consultant has a team of junior staff. It is designed to avoid overspending by consultants, and is frankly unnecessary: if there is sufficient consultant commitment, there are other ways of avoiding overspending.

In Plymouth we decided to apportion costs to each ward. A named consultant is assigned to assist each ward. The ward budget holder has greater awareness of overall costs, consultant involvement is achieved, and the calculation of contract costs is easier. Assigning ward costs to the appropriate speciality contract is undertaken by calculating the number of bed days, using information from the patient administration system. The disadvantage is that ward managers are not able to control medical and prescribing costs: an indicative budget for these elements may be a reasonable compromise.

### **Outpatient services**

Specialist clinics are held increasingly either by a local paediatrician with an interest alone (e.g. epilepsy and diabetes clinics with appropriate nursing and other support), with another local specialist (e.g. paediatric

haematology), or with a visiting specialist from a tertiary centre. Children have to travel less for their treatment, the general paediatrician is educated, and the tertiary specialist informed about the local facilities. Paediatric outpatient clinics can be taken to primary care, either in health centres or small peripheral hospitals, with similar benefits. These can be provided alongside extended day case services [30].

### **Medical staffing**

Medical staffing of many paediatric units is becoming increasingly difficult, as a consequence of the reduction in junior doctors' hours, the EEC requirement for a shorter training period [31], the Standing Committee on Postgraduate Medical Education (SCOPME) recommendations [32] for good practice in senior house officer (SHO) training, the emergency nature of paediatric hospital services, and the need for safety net middle grade staffing cover. The British Paediatric Association (BPA) estimate [33] that a substantial increase in consultant numbers will be necessary to cover these requirements. It seems likely that in the future there will be a service delivered much more directly with consultants who share on call with a greatly expanded number of consultant paediatric colleagues. In the short term there is to be a substantial increase in the number of higher specialist trainees in paediatrics and child health. These doctors will have had a shorter period of training with a greater degree of formal training away from the bedside but less clinical experience than in the past. A progressive loss of continuity of patient care can already be seen with these changes. The middle grade doctors providing the safety net cover will have had considerably less clinical experience than in the past.

### **COMMUNITY CHILD HEALTH**

The only children's services that are managed in a separate trust in Plymouth are health visiting, children's speech therapy, and two clinical psychologists who see severely handicapped school aged children with emotional and behavioural problems.

Community child health has needed to undergo more change than any other part of the children's health service. The rapid increase in general practitioner involvement in preschool child health surveillance [34] and, in some parts of the country, the running down of school health surveillance has left many community child health departments overmanned for the activities for which there are still contracts. Guidance on good practice has been issued by the Department of Health [35].

In Plymouth the number of medical staff below consultant grade in the

community was well below the national average before this change occurred, and the problem of overstaffing has not had to be met. One of the medical posts is a rotating SHO appointment [36]. When the various elements of the community child health service were initially brought together with the formation of the directorate, there was an opportunity to reformulate budgets to reflect the way the service wished to function.

The following principles were agreed.

1. Budgets encompass a complete service function, and include all the different professions, appliance budgets and other non-pay elements. This seemed better to reflect multidisciplinary working than the model described by Barker [6] with separate management of professional groups.
2. Each budget holder has the same level of authority for their budget as applied elsewhere within the directorate.
3. Money is only vired between budgets with the agreement of both budget holders.
4. Each budget holder is accountable to the head of community child health.
5. The overall community budget is required to balance as with the hospital and mental health services.
6. The community service contributes equally to the cost improvement programme, as a proportion of the annual budget.

### **Child development centres**

These centres provide for the multidisciplinary assessment and care of preschool children with developmental problems, disabilities and disadvantage. Nursery groups and clinics are held on the premises, and such services as physiotherapy, occupational therapy, Portage, social work, a toy library and clinical psychology may be based there. They should be seen as one component of services for children with disability [37].

There may be joint funding by education and social services. Clear lines of accountability and a single manager responsible for the operation of the service are especially important where staff are employed by different agencies. The siting of the centre is important, and should be accessible to families, especially those least able to travel: transport facilities are needed by some families. The nurseries run as group sessions, with each child's attendance being recorded as a day attendance.

Services for children with learning disability are now purchased by GP fundholders. They may choose to purchase alternative services that are not of equivalent quality (e.g. from a non-specialist physiotherapist), and the route of referral may be inappropriate, for example a direct physiotherapy referral, rather than via a paediatrician. In Plymouth the centre has

gradually developed explicit, agreed written referral procedures and priorities.

Staff from education tend to work during school terms, and nursery groups may therefore close for a significant proportion of the year. Extending these groups over the holiday period using nursery nurses or other suitable professionals can increase the capacity of the centre and provide a welcome service in school holidays.

Mental health services have a valuable contribution to the work of the centre; some families with a child attending the centre are very similar to those receiving mental health help, and families need help in coming to terms with their child's disability.

### **School health**

The need for regular health surveillance in schools has been questioned [7], and it is clear that the work of the service has had to change to accommodate the changing health needs of the population. The BPA issued a recent document recommending the services needed for school age children [38].

One of the benefits of the combined service is that contact between the school nurses and the rest of the children's secondary care services has increased. The mental health service is able to provide training and advice to school nurses. In Plymouth the paediatrician with an interest in growth has trained the school nurses in the technique of accurate measurement of height, and ongoing training is provided by the growth and endocrinology clinic nurse. The school nurses have extended their health promotion and education roles, and recognise their need to ensure good liaison with primary care teams. Their crucial role in addressing *The Health of the Nation* targets needs to be recognised [39,40].

School nurses are often managed separately from medical, physiotherapy and speech therapy professionals, even though they work as a team. The appliance budgets in Plymouth were fragmented, illogical and chronically overspent. We brought together the community physiotherapists, medical and school nurses into a team that includes an appliance budget, and authority to manage its budget within the overall rules. This streamlines the ordering of appliances and gives the team an incentive to use their resources efficiently, along the lines of the resource management initiative [1].

### **Community outreach**

The movement of resources from hospital to the community is particularly appropriate for children. There is less emotional disturbance for the child,



less family disruption and they have parents to care for them at home. Information can be presented at home in a calmer atmosphere, and a domiciliary service can better forge links with primary care teams and schools [40]. Primary care teams may need reassuring that they will not lose autonomy.

A combined service provides a great opportunity for the development of community specialist children's nursing services. Children with chronic or life threatening conditions need collaboration between hospital, community and primary services to achieve a seamless service.

In Plymouth, the service has built upon the long existing outreach nurses:

1. A domiciliary nurse for children with cancer and leukaemia.
2. A specialist health visitor for preschool children with disability, and for infants with cleft lip and palate.
3. Two part time paediatric liaison health visitors, who inform primary care of all children in hospital, and of children seen in the two local accident and emergency departments if there is thought to be a significant problem. They also organise the CONI (care of next infant) programme for families whose previous infant died of cot death.
4. Two midwives for small and premature babies (managed by the maternity service).

The service has expanded to include the following.

1. A full time specialist nurse for children with diabetes.
2. A part time nurse for children with growth or endocrine problems. The nurse helps train families to administer the injections, monitors the technique, and gives advice about problems; she is also responsible for training school nurses in the technique of accurate height measurement.

Further developments include the following.

3. A part time cystic fibrosis nurse funded from the ward establishment, reflecting the change to domiciliary care for courses of intravenous antibiotics using subcutaneous central venous catheters.
4. A community children's asthma nurse working with children seen by the paediatricians, and offering ongoing training to the asthma clinic nurses in primary care, and school nurses. Funding from ward nursing budgets has been agreed in the expectation that time in hospital with asthma will be reduced.
5. The children's service received one year's non-recurring funding for a specialist children's district nurse and two part time community neonatal nurses, to encourage earlier discharge of children and newborn babies from hospital and avoid admissions. (Unfortunately,

despite an evaluation which clearly showed the benefits of these services, it was not possible to obtain continued purchaser funding.)

The outreach nursing team is based on one of the hospital wards, and is close to the children's outpatient area, the consultant paediatricians' offices, the hospital social work service, and the children's wards. Since the directorate formed, it has been given its own budget for staffing and the equipment needed to get children rehabilitated at home. This avoids the difficulties that many families encounter when their child with a chronic or life-threatening condition is discharged home.

### **Computer services**

The National Child Health System, the most commonly used computer register of children for the immunisation and preschool surveillance programmes in the UK, has been used in Plymouth since 1979, together with the less commonly used school health and special purposes modules.

Being part of the acute unit, it was relatively straightforward to get the child health system transferred to the same mainframe cluster that runs the patient administration system. This has facilitated the development of programmes to transfer data from the hospital systems. It can also be accessed anywhere in any of the hospitals and some community sites in Plymouth. Health visitors have access via their own linked system.

Since the directorate formed, the clinical usefulness of the information held on the computer has been reviewed. Written procedures have been developed for validating the information, with arrangements for dealing with incorrect or missing data.

The school health module has been adapted to allow automatic determination of standard deviation scores from entered height and weight measurements (using a user definable reference file), as well as height and weight velocities. This is currently being evaluated, but already holds growth data on half the population of five to eleven year olds.

The computer is capable, with some slight amendments, of holding a disability register for Social Services under the Children Act [17]. Initial registration of children up to school leaving age is progressing slowly. Diagnostic information for each child is held, although not formally part of the register. Considerable collaboration with social services and education was required to get the disability register started. The joint development of the register was itself valuable in fostering interagency cooperation.

The child health computer needs to be linked to other systems in order to maximise its potential and facilitate high quality data:

1. The hospital based clinical database, which will allow the paediatric department to share information on newborn infants going through the

maternity department, and selected diagnoses on infants and children seen by the hospital service.

2. The patient administration system, allowing hospital and casualty contacts to be recorded: this is more difficult to achieve when there are several hospital and casualty services for the community.
3. General practitioner systems: this may prove hard to achieve, given the variety of stand alone systems used, and the lack of motivation for GPs to collaborate.
4. The FHSA population register, which will help to maintain both systems up to date, and should facilitate links with GPs.

The development of a new NHS number which can be read by computer will greatly enhance these links; unfortunately, newborn babies will not have their number allocated until up to 6 weeks of age, which will mean continuing difficulties.

#### MENTAL HEALTH

Mental health services tend to be multidisciplinary, and commonly include staff from other agencies in their teams. In Plymouth the service is organised into two parts, with an age division of thirteen years. The mental health service devotes a significant part of its time working through other professionals, both in health and other agencies.

#### **The child and family consultation service**

This provides outpatient and day case facilities. Separate clinics are held for:

1. children who have been abused;
2. behaviour therapy;
3. children with soiling;
4. young children with sleep and other problems;
5. children who are fostered or adopted with disturbed behaviour;
6. mothers whose parenting difficulties arise from their own background.

A liaison team sees children under the paediatricians and provides the nursing staff on the children's wards with a valuable source of support. Middle grade hospital paediatric medical staff get some experience in mental health.

The day case service takes whole families where there are multiple problems, which may include families with problems of abuse and neglect, and where a number of agencies are already involved.

### **The young people's centre**

This provides an outpatient, day case and a Monday to Friday inpatient service for young people aged 14 to 21 years. Specific clinics are held for:

1. young people with chronic fatigue syndrome;
2. teenagers who have been sexually abused;
3. teenage perpetrators of sexual abuse.

The closer involvement of children's mental health services is one of the most noticeable benefits to come from the combined service. They chose to become part of the directorate, and have been a very positive influence, particularly with their well developed management arrangements and their skill in managing people. They have also provided a consultant successor to the clinical director.

The mental health service has budgetary and management autonomy within the overall rules affecting the directorate. It now has a similar level of activity information as elsewhere within the service, having had no computerised information before 1989; it is very adept at using such information, at seeing service development opportunities and marketing its services to potential purchasers.

### **A COMBINED CHILDREN'S SERVICE**

The British Paediatric Association consistently advised that children's secondary care services should be provided within a common management framework, as a combined service. The BPA published examples of combined child health services in 1992 [5], in which it has recommended a number of alternative models for such combined services. These include the subcontracting of children's services in other trusts by a lead provider. In the longer term this is likely to lead to a completely combined children's service, but may be an evolutionary process.

A concern for community child health providers is that they will get swallowed up and their budgets plundered by the much larger hospital services. The advent of contracts, and devolution of responsibility and authority for budgets should ensure that this does not happen. Some benefits of a combined secondary care children's service are as follows.

1. It allows a cohesive service with a seamless provision between hospital and community.
2. It avoids unnecessary and unhelpful competition between services that operate against the overall interests of children.
3. It improves understanding between, and brings closer together, the three service elements.

4. It creates a powerful voice for children's services both with the purchasers of health services, and with other agencies.
5. It facilitates interagency planning and collaboration, including policy making.
6. It provides a model for some other service elements, such as care of the elderly, and gives a broader perspective at trust or unit management board level.
7. It achieves considerable commitment to working together and the directorate structure among staff.
8. It helps recruitment.

Our local experience of a combined service is that these benefits are achievable in practice, and should remain successful and enable the service to meet the inevitable further changes to the health service.

### ACKNOWLEDGEMENTS

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*Nicholas Jennett and Andrew Wainwright*

## INTRODUCTION

The introduction of an internal market for health services following the implementation of *Working for Patients* [1] has resulted in major changes in the roles of finance staff and the ways in which these staff work. Historically, the finance function was seen by those who delivered clinical services principally as a constraint. The role of the unit accountant was to account for expenditure, and to control it. This required certain technical skills, but did not require much knowledge of the nature of the services being delivered. This tended to result in finance staff being isolated from the delivery of patient services, and did not promote mutual understanding between clinicians and this part of the management team.

Perhaps the biggest single change since the implementation of the NHS and Community Care Act (1991) has been a new emphasis on the management of resources, not simply the control of spending. The introduction of contracts for services means that provider units are no longer simply allocated fixed blocks of money with which to pay staff, procure supplies and so on. The only income providers have is that which they are able to negotiate with purchasers as part of the contracting process. In this model, finance becomes a key resource for the delivery of quality patient care. The finance function must also change its role to one of enabling and supporting the clinicians who are directly delivering care. This support should include not only understanding the behaviour of costs and price setting, but also more general assistance to clinicians to enable them to provide the best quality and quantity of care from the resources available to them from contracts. Increasingly, this may also involve assisting clinicians to make the case to purchasers for more resources by demonstrating how their services provide cost-effective health gain.



Close working relationships between clinical and finance staff are, therefore, essential in successful provider units. This represents an important cultural change, and a significant degree of job enrichment for finance staff, who are increasingly required to understand the clinical services they are supporting. But it is also important that clinicians understand the business of finance. The purpose of this chapter is to introduce the way that finance operates in the NHS, and something of the constraints within which the finance function works. It covers a wide area: from the allocation of resources to the NHS as a whole to the management of budgets by individual clinical directors, and the importance of service costing. Finally, it discusses the role of internal and external audit, and how these services can be used to best effect by clinicians. The intention is that better understanding of respective roles and responsibilities between finance staff and clinicians will lead to more fruitful relationships and, ultimately, higher quality patient care [2].

## RESOURCE ALLOCATION IN THE NHS

### THE PUBLIC EXPENDITURE SURVEY

The overall allocation of resources to the NHS is determined annually through the public expenditure survey or PES. PES is an overtly political process [3]. In the early summer, the Cabinet will reach collective agreement about the public expenditure planning totals, expressed in cash, not real (or inflation adjusted) terms, that it will commit to over the next three years.

Having agreed an aggregate planning total, individual spending departments prepare bids for their share of the resources. It should be little surprise that the total of these inevitably exceeds the agreed planning total, and there ensues a series of bilateral negotiations between spending ministers and the Chief Secretary to the Treasury. These are complemented by negotiations in an important committee chaired by the Chancellor, at which the Treasury puts in its own views of the pressures on NHS and other areas of spending. Spending figures for each department are agreed by the Cabinet in late October or early November, with the outcome announced in the unified budget towards the end of November.

The outcome of these negotiations has more to do with politics and macro-economics than 'objective' considerations of need. Although particular components of bids are supported or defended on the basis of need or policy based arguments, political considerations tend to dominate. It is still the case that the extent to which a minister 'has a good PES', that is, achieves a generous settlement, is regarded as a clear sign of whether the individual's political star is in the ascendant.

### RESOURCE ALLOCATION

After PES has been finalised, the key issue for the Department of Health becomes the allocation of the resources secured by the settlement. At present, the total sum available for the hospital, community health and family health services is distributed over a number of headings:

1. national 'top sliced' sums which the department holds back, e.g. to fund innovative national pilot projects;
2. special allocations and adjustments, e.g. to cover, the service increment for teaching and research (SIFTR) and AIDS;
3. allocations to health authorities for their resident populations, including GP fundholder budgets; and
4. the non-cash limited part of the general medical services, e.g. expenditure on drugs in non-fundholding general practice. At present, this is the only part of the allocation which is demand led and not cash limited. In other words, the only part of expenditure which, ultimately, is not under the direct control of the Treasury.

From the perspective of purchasers and provider units, the key component of the allocation is that to health authorities. Resources are allocated to health authorities in England on the basis of a formula which seeks to adjust for their differential needs by considering such factors as the age and sex distributions of their populations, standardised mortality ratios and the extent of social deprivation. Health authorities then allocate resources to GP fundholders. Many people believe that formula-based allocations to GP fundholders will also be introduced to replace current arrangements in which fundholders are, in effect, resourced on the basis of the costs of their activity in the previous year.

The introduction of direct capitation-based funding for health authorities and, perhaps, GP fundholders is of great importance. It will be critically important to ensure that the formula is 'right' in the sense of capturing adequately the complex factors that drive needs for healthcare.

### CONTRACTS AND PROVIDERS

Since the introduction of the NHS internal market, providers in either the acute or community services have no source of income other than contracts with purchasers, be these health authorities or GP fundholders. All provider units must ensure, therefore, that they are able to negotiate contracts which enable them to cover the costs of the services they provide and meet their other financial obligations.

NHS trusts are now the predominant model for the organisation and management of providing. Trust status brings with it a number of

freedoms, but also an important set of obligations which managers must ensure are met. In terms of finance, the most important of these obligations are:

1. to break even year on year;
2. to achieve a 6% rate of return on the assets employed by the trust;
3. to stay within the trust's External Financing Limit, or EFL [4].

The first financial target is self explanatory. The trust must ensure that income is equal to expenditure. This constraint ensures that financial viability is maintained. It is permissible to have a short term shortfall of income over expenditure, however this situation cannot be allowed to prevail indefinitely. This mirrors the situation in the private sector, where an organisation would eventually run out of money, or its bank out of patience!

The implication of the second financial target, however, is that break even is not enough, and that an excess of contract income over expenditure should be generated. When it is first established, the physical assets required by a trust are transferred to it. However, this transfer of assets does not represent a gift from a generous secretary of state. In accounting terms, each asset owned by a trust will be backed by a corresponding liability of equal value. This liability is known as the trust's **originating capital debt**, which is 'owed' to the government. It is split between **interest bearing debt** and **public dividend capital**.

The interest bearing debt component is the equivalent of loan capital in a normal commercial enterprise. It is set at a fixed rate of interest with fixed repayment terms. Typically interest bearing debt is repayable over a 25 year term and set at the rate at which the government itself can borrow. Public dividend capital is the equivalent of share capital in a normal commercial enterprise. In this case, however, the government is the only shareholder. There are no fixed repayments on this form of capital and instead dividends are payable. The advantage of this type of finance is that dividends do not need to be paid before surpluses have been generated. This is equivalent to the situation in the private sector, in that, usually, dividends will only be paid when profits have been made. However, it is expected that in the long term the return on this form of capital should be the same as the return on the fixed rate loan.

Each year a trust must make a surplus before interest of 6% of the value of its assets to enable it to service its capital debt and make its dividend payments to the government. Accordingly, the trust's prices must be sufficient to enable it to meet this obligation.

A trust is free to borrow additional capital, subject to an overall limit on borrowing called the external finance limit (EFL). A trust's EFL is the difference between its planned capital expenditure and its internal resources. Internal resources include the amount for the depreciation of

assets it charges in its prices, its financial surplus after payments on the originating capital debt and any proceeds from asset sales. If the trust plans to spend £5 million on its capital programmes for the forthcoming year, then the EFL is the difference between planned capital expenditure of £5 million and internal resources, say, of £3.2 million. In this case the trust would have a positive EFL of £1.8 million. If on the other hand, the trust had capital expenditure plans of only £2 million with the same internal resources then this would imply a negative EFL of £1.2 million.

A trust will frequently not secure the EFL it wishes. A national total for trust EFLs is determined in the PES process described above. The NHS Executive then sets an individual EFL for each trust within the national total, taking account of trust business plans and, critically, evidence of purchaser support for proposed capital developments. Only purchasers can provide the resource necessary to service the interest payments on new capital, and meet any additional revenue costs. Accordingly, capital schemes which cannot demonstrate both purchaser support and viability are likely to be rejected. In order to improve the quality of business planning for capital development, the NHS Executive has released comprehensive guidance on the preparation of business cases for investment [5]. This includes the general requirement to test the feasibility of funding projects through the private finance initiative before public capital can be made available. Copies of this guidance are available from the NHS Executive, or trust directors of finance.

As indicated above, a trust may be given a positive, negative or zero EFL by the NHS Executive. Table 9.1 summarises the situation facing a trust for a given value of EFL. A positive EFL represents an authority to borrow. However, if a trust is given a negative EFL, it must either repay loans, or retain the surplus invested in an interest bearing account to finance capital expenditure in future years.

Once the EFL has been determined by the NHS Executive it is fixed and the trust is expected keep within this limit. There is, however, some limited flexibility in that a trust may borrow, in the last quarter of the year, and with departmental approval, extra funding of up to 1% of the sum of its

Table 9.1 The external finance limit

Value of EFL	Capital planning implications	Borrowing/lending options
Positive	Internal funds < Capital expenditure	Borrow
Zero	Internal funds = Capital expenditure	None
Negative	Internal funds > Capital expenditure	Repay loans/retain surpluses

total turnover and fixed asset expenditure. This increase in the level of borrowing will be deducted from the following year's EFL.

## MANAGING RESOURCES WITHIN DIRECTORATES

### BUSINESS PLANNING

The management of resources at directorate level must be seen within the context of the constraints and opportunities discussed earlier in this chapter. In particular, in planning for the business issues related to their directorate, clinical directors must recognise the following.

1. Purchasers are increasingly seeking to purchase for cost-effective health gain from within their fixed resources. In this sense, bids to support service and capital developments should attempt to demonstrate how the proposed development is consistent with purchasing strategy, and address explicitly the health gain to be achieved at what cost. In practice, this requires clinical directors and their finance advisors to attempt to link inputs to outputs in their business planning. Output, or programme based budgets, are still relatively rare; traditional input based budgets (see below) are much more common, although of much less value for real resource management.
2. Trusts are constrained by the requirement to meet their financial obligations. In particular, bids for capital must recognise the constraints of the EFL, and the absolute requirement to secure purchaser support for proposed capital developments. In practice, this means that capital developments must be supported by a robust business case.
3. Providers have no other sources of income than their contracts, and therefore managing to provide the contracted service level at the contracted cost is the key challenge. In practice, this means that clinical directors must consider carefully their information needs to support this requirement. Once again, this is a key area in which clinical directors and their finance colleagues must work together closely.

### RESOURCE MANAGEMENT

In all areas of management, the role of timely, accurate and relevant financial information is critical. The quality of the financial information available to managers has increased in recent years, particularly as the sophistication of information systems available to trusts has improved. The financial and other information required by clinical directors to manage their services should be a matter for on-going discussion with finance staff. In order to manage resources effectively, clinical directors will need to be able to consider financial performance in conjunction with information on activity, and other aspects of resource use. In recent years,

this has been recognised in an important national initiative known as **resource management** (RM) [6]. A large number of local RM projects have been undertaken in the acute and community sector, all designed to involve careful consideration of the information which clinicians will need if they are to take responsibility for the management of their services. Local work often went hand in hand with the introduction of a clinical directorate structure. The formal project period of RM has now finished, although important lessons are still being learned and applied. Unfortunately for managers of child health services, the investment in RM in the acute sector was well in excess of that in the community services. It will be necessary to discuss with local directors of finance how RM was implemented, and what work, if any, is currently being undertaken to take RM forward [7].

One of the consequences of RM is that the precise management and finance information that will be available to clinicians will tend to vary from site to site. The remainder of this section discusses some of the strengths and weaknesses of the information which should be available to all directorates, and the implications for management of resources at directorate level.

## BUDGETING

Budget setting and monitoring has become one of the key responsibilities of clinical directors in both acute and community trusts. Budgets remain the principal tool for expenditure control within the NHS, and so managers need to know how they are constructed, and how they can be controlled. Notwithstanding the benefits of programme or output budgets, referred to above, the majority of budgets will be input based, usually distinguishing between pay and non-pay elements [8].

### Pay budgets

Pay budgets are typically based on a fixed number of staff within an agreed grading structure. Information produced during the financial year is usually presented in the same way, which enables financial performance against each grade to be measured. Although pay budgets by directorate are becoming far more common in the acute sector, pay budgets within community and priority services are still often produced using functional divisions such as district nursing or health visiting.

Pay budgets are normally costed in one of two ways.

#### *Actual budget costs*

Here each member of staff is costed at the actual point of the pay scale with additional allowances for management **on-costs** (employers' National

Insurance and superannuation) where these are appropriate. In addition, but less typical, there may also be estimates of other salary enhancements built in, such as on-call payments, overtime or shift rota payments.

### *Mid-point budget costs*

This is now becoming rare, although costing at the **mid-point** of the salary scale used to be the most widely used method. As the name suggests, staff are costed at the middle point of their scale, regardless of their actual position. This is unsatisfactory as it builds in artificial under- or over-spends, known as **incremental drift**, depending upon the actual position of staff on the salary scale.

Regardless of the method used, managers should have a clear statement of the funded establishment for the service under their control. As part of the budget setting process, managers should agree the number and grade mix of staff with finance colleagues. This is then costed and expressed as whole time equivalents by grade. This funded establishment can then usually be changed only if authorised at a senior level within the organisation. This still leaves managers free to employ an alternative mix of staff, subject to the constraint that total costs should never exceed the cost of the funded establishment. Agreed establishments should be reviewed periodically to ensure they are still realistic. This could be annually, but may happen more or less frequently depending on the nature of the services, and the extent to which they are subject to change.

### *Managing pay budgets*

If pay budgeting has been carried out thoroughly, managing and controlling pay budgets should be relatively straightforward. Nevertheless, budget pressures will always occur, and there are some key steps managers should take to ensure they remain fully aware of how the resources they are responsible for are being committed.

A clear distinction needs to be drawn between the budget **holder** and the budget **manager**. The budget holder will normally have the responsibility for ensuring good budgetary performance, but may not be committing funds personally. Normally the budget holder will be the clinical or service director. Budget managers are usually the line managers who make the day-to-day decisions on the use of resources.

Controls need to be in place to allow budget holders to ensure resources are not being over-committed, whilst not restricting the budget manager's freedom to manage. The key elements to control within any pay budget are those liable to fluctuate with levels of activity, such as the costs of

overtime, on-call payments and employment of agency staff. In all of these cases, budget holders need to have close control over the level of expenditure, and should have formal authorisation procedures in place to maintain this. Authorisation needs to be at budget holder level to maintain an overview of the total resources available. A similar procedure should also be used for staff appointments, which will allow the budget holder and manager to consider the budgetary implications of employment decisions.

In conclusion, it is important for managers to be aware of the details of their staff budgets. Managers should take time to find out how the budget is put together and what it contains. This will also allow managers to play a far more active role in the budget setting process, leading to more responsive and realistic budgeting and, it is to be hoped, fewer major problems during the financial year.

### Non-pay budgets

Non-pay budgets tend to be made up of the major direct costs associated with running a particular service or department. Examples include drugs, medical and surgical supplies and equipment, and staff travel costs. As these costs are likely to fluctuate with activity, they are often difficult to cost accurately, and therefore problematic to manage.

Ideally, non-pay budgets should be built up annually on the basis of forecasts of what resources are needed to support anticipated levels of activity. This is known as **zero based budgeting**. However, this can be a time-consuming and complex exercise. Therefore, it is not unusual to see non-pay budgets simply **rolled forward** from the previous year, or adjusted in some way to take account of performance. This increases the risk of inefficiencies and inequities being institutionalised within the non-pay budget structure. If budgets are rolled forward in successive years, then it becomes more and more likely that they will bear little or no relation to actual activity. Managing within a fixed budget figure becomes far more difficult. This makes it doubly important to have strict controls in place to ensure no unnecessary expenditure is incurred.

#### *Managing non-pay budgets*

Management of non-pay expenditure centres around making sure that responsibility for control is exercised at the correct level. This should be near to the point of service delivery, but not so near that there is confusion between spending, requisitioning and authorisation. Using the example in the previous section, budget managers would seem to be in the ideal position to fulfil the authorisation role. In most cases, they will be the nearest level of management above the point of service delivery at which



non-pay resources are consumed. Budget managers should authorise expenditure, and are therefore the prime movers in managing non-pay budgets. The limits on their responsibilities need to be carefully thought through and set within a formal authorisation procedure. As a guide, managers can use the standing financial instructions of their organisation, which should detail the delegation limits for the organisation as a whole.

At the very least, budget managers should authorise all requisitions up to their delegated limit. This should allow control to be exercised before resources are committed, and also means that budget managers can estimate total committed expenditure against budgets. Monthly budget reports will normally detail the cost of goods paid for, and those delivered but not yet paid for. But this is not the whole picture as some goods will have been requisitioned but not delivered. These are known as a commitment against the budget. A budget manager using **commitment accounting** in this way will be given early warning of potential budget pressures and should be in a better position to stop any unauthorised or unnecessary expenditure that could result in more urgent priorities not being met.

Coupled with responsibilities for authorisation is the need for budget managers to understand fully the financial coding structure of the organisation, and how it relates to them. If service managers code requisitions at source this should ensure that those with the most to gain from accurate financial coding are fully involved at all stages of the process. In this way, source coding can be used as another element in the control mechanism.

To summarise, the key to good control of non-pay expenditure is having authorisation responsibility at a level that can provide sensible controls on requisitioning patterns, and also early warning of potentially problematic expenditure trends. The information gained at this level can supplement the expenditure information produced monthly, and combining the two should give as complete a picture as is possible at any given time.

## **COSTING**

The previous section has dealt with the important issue of the control of expenditure, but an increasingly important issue for clinical directors concerns the way in which services are costed, and prices set. Amongst the key uses of cost information is contract pricing.

### **CONTRACT PRICING**

The immediate need for costing information has arisen from contractual arrangements between purchasers and providers of healthcare. The basis

on which prices for contracts are to be determined has been made clear by the NHS Executive: prices are to equal costs defined on a full absorption basis [9]. In practice, this usually requires price setting on an **average cost** basis, although unplanned spare capacity can be priced at **marginal cost**. There is currently considerable diversity in the basis of contracts, and this is likely to increase. The further development of cost-per-case contracts will expose differences between providers in terms of efficiency and quality, but at present many price differences probably relate mainly to differences in the costing approach adopted. For example, decisions on the means by which overheads are to be apportioned to services can cause major differences in contract prices. For this reason, the NHS Executive has recently issued mandatory guidance on how overheads are to be treated with costs analysed across a classification of fixed, semi-fixed and variable costs [10].

#### RATIONING AND VALUE FOR MONEY

Given that the demand for healthcare will always exceed the available resources, better costing information is required to support decisions on how best to 'ration' resources. It hardly needs to be stated that these rationing decisions must not be based solely on cost information. However, responsible rationing decisions do require an understanding of the **opportunity cost** of the use of a resource in a particular way. This refers to the benefits lost by a decision to use a resource in one way rather than for some other valuable use. Clinicians and managers frequently face difficult choices about, for example, the expansion of one service at the expense of another. The concept of opportunity cost provides a framework within which these decisions can be considered. Robust information about the marginal cost of a service (that is, how costs are shed as the service contracts, and how costs increase as a service expands) will be critical in this.

#### COST IMPROVEMENTS AND EFFICIENCY

Using cost information to help secure cost improvements involves identification of areas where inefficiencies exist. This should lead to the release of capacity, which can then be redeployed to provide more care for patients. Traditionally, providers have relied on either ad hoc projects to secure their cost improvement targets or crude reductions in all budgets, usually pro-rata to their value. The former has often sought economy rather than efficiency. For example, simply cutting a service may achieve economies, but not efficiency improvements which require more output for the same cost, or the same output for less cost. Pro-rata cuts in budgets are even more crude, often leaving managers with no idea as to the impact

on quality of their decisions. Better cost information would enable comparisons to be made on a true like-for-like basis with other providers, or support comparisons against **standard costs**. A standard cost is an assessment of what the cost of a service or product **should** be, based on **bottom up** analysis (see below) of its component parts, and the quality standards that apply to it. This provides the best yardstick for assessing the scope for cost improvements.

#### DEPARTMENTAL COST CONTROL

As indicated above, cost control in the health service has traditionally operated through fixed functional budgets based on inputs, for example, the number of whole-time equivalent staff employed. However, costing and pricing of contracts will increasingly need to be based on outputs. This causes a difficulty of tracing functional overspends back to contracts, and better costing information is required to allow analysis of overspends, down to the level of individual services. Increasingly, a key factor in controlling costs will be an understanding of **cost behaviour**. This refers to the factors which influence or drive costs and, in particular, requires the identification of appropriate workload measures for each department.

Historically, costing in the NHS has focused on so-called **top down** costing. This takes the total expenditure of the unit and divides this down into departments and perhaps, ultimately, to a cost per case based on some measure of workload, for example, finished consultant episodes or a particular biochemical test. This approach is straightforward, but gives little indication of how costs will vary when workload changes, and also builds any existing inefficiencies into costs. In other words, if a laboratory is using excessive resources in performing its biochemical tests, these additional costs will be built into the costing uncritically. A much better approach is **bottom up** costing which starts with an identification of the resources required to deliver elements of care to a stated quality standard, derives a cost for each of these elements (so-called intermediate products) and builds up to a standard cost per case (so-called final products) based on these costed elements of care.

The major advantage of bottom up costing is that it gives managers a better way of identifying the resources they need to secure through contracts to provide a given quantity and quality of care. Finance staff can advise on some of the technical aspects of bottom up costing, but to get the most out of a costing project it is essential for accountants and clinicians to work closely together. In particular, if the work is to be taken forward to case mix costing to support contracting, clinical input will be absolutely essential. This is likely to be increasingly important as purchasers move towards contracting on a care group or condition basis.

In the acute sector, this type of costing of cases has usually been taken

Table 9.2 Example profile of care for the acute paediatric sector

Diagnosis:		Acute appendicitis
Length of stay:	Minimum:	3 days
	Expected:	5 days
	Maximum:	7 days
Mortality per 1000:	0	
Expected outcome:	Discharge home	
Procedures:	Radiology:	Abdomen
	Biochemistry:	Serum amylase
		Electrolytes
	Haematology:	Blood count
		Differential
		Absolute neuts
Operations:	Microbiology:	Urine screen
	Emergency excision of appendix:	80%
	Elective excision of appendix:	20%

forward through the definition of **profiles of care**. In the terminology above, a case is the final product to be costed. A standard profile of care defines the expected activities (or intermediate products) and outcomes associated with a particular case. An example of a simple profile of care for an acute paediatric case is shown in Table 9.2.

The derivation of a costed profile of care like that above will provide value in the areas of:

1. pricing;
2. cost modelling; and
3. auditing quality. By monitoring actual performance against the costed standard profile of care, clinicians will have information about the costs incurred and outcomes achieved from deviation from the standard.

The derivation of profiles of care is **relatively** straightforward in acute settings but potentially far more complex in non-acute environments. This is because much of the care delivered in the non-acute sector does not easily fit into the simple model of a package of care or a 'case' with a defined starting point, patient events, finishing points and outcomes. Thus an essential precursor to patient costing is the definition, as rigorously as possible, of exactly what is to be costed. One approach in the non-acute sector is to draw a distinction between three elements of care:

1. periods of care;
2. episodes of care; and
3. patient events.

The on-going nature of the commitment to individual patients by

Table 9.3 Example profile of care for the non-acute sector

Condition:	Preschool child with mild spastic quadriplegia and global development delay		
Period of care:	Six months from diagnosis		
Episode 1:	Paediatric physiotherapy		
	Event 1: Assessment	Events 2–25: Weekly contacts	Event 26: Equipment loans
Episode 2:	Occupational therapy		
	Event 1: Assessment	Events 2–6: Monthly contacts	
Episode 3:	Speech therapy		
	Event 1: Assessment	Events 2–6: Monthly contacts	
Episode 4:	General practitioner		
	Event 1: Surveillance		
Episode 5:	Community paediatrician		
	Event 1: Assessment	Event 2: Six-month follow-up	

professionals within the non-acute services means that the concept of a **period of care** may be much more appropriate than that of a care package. A period of care is defined as a given period of time during which care is offered. Within a given period of care, there may be a number of consecutive or overlapping **episodes of care**, each of which in turn will be made up of a number of **care events**.

A simple example of the application of this framework to the derivation of care profiles in non-acute services is given in Table 9.3.

Even this simple profile of care, if appropriately costed, would deliver a number of the benefits identified above. It would enable managers to identify prospectively the resources required to care for children with this condition, contributing to both planning and contract pricing, and enable the clinicians and professionals involved to monitor quality of care delivered against an agreed standard.

Defining the product for costing, at both final and intermediate levels, will require careful work with both professionals on the provider side, and also with purchasers if this is to be used for a basis for contracting. In the example given, agreement will be required that:

1. the definition of condition (preschool child with mild spastic quadriplegia and global developmental delay) represents a clinically meaningful case mix grouping to all the professionals involved;
2. an average or standard set of episodes for this condition over the relevant period of care can be defined; and
3. average or standard events within each episode can be defined.

Each episode and event occurring within the period of care represents an intermediate product. Once again, professional input is essential to the definition of the expected costs. For example, in terms of the physiotherapy input identified above, a different skill mix amongst staff may be required for initial assessment and subsequent therapy, and the time devoted to initial assessment and follow-up appointments may be different.

## AUDIT AND PROBITY

For many managers, audit of any kind is often seen as a necessary evil, something that has to be endured rather than employed as an additional management tool. Financial audit takes two forms, external and internal. This section gives a brief explanation of their respective roles.

### INTERNAL AUDIT

The objective and scope of internal audit in the NHS is described in the NHS internal audit manual [11] as:

... to assist the various levels of management in discharging their duties and responsibilities by carrying out appraisals and making the necessary and appropriate recommendations to management for operations under its control.

In recent times internal audit has principally been concerned with the well-known three Es of **economy**, **effectiveness** and **efficiency**. However, in the absence of good efficiency or effectiveness measures, in practice, internal auditors have tended to concentrate mainly on economy. In other words, they have concentrated solely on what is spent rather than considering what is spent for what output. This is changing gradually, but internal audit is still some way from being able fully to evaluate effectiveness, and efficiency.

Much of internal audit is **systems based**, with an emphasis on looking at the management systems in operation, and evaluating the contribution of these systems to delivering the three Es. This is sometimes ignored by managers, who tend to think of auditors only in their traditional role of stewardship and the prevention of fraud. Although this work on probity will always form an element of their work, good auditors will regard themselves as an aid to the management process rather than a restriction. Indeed, their ability to provide an independent view of management systems can give an insight that may serve to highlight failings that may otherwise go unnoticed. Managers should use internal audit constructively, and recognise that it too has a role to play in ensuring management

systems are geared to providing the best service within the resources available from contracts.

Internal audit, therefore, can be a highly valuable management tool, if managers look to use it creatively. The practical implication is that clinical directors should actively seek out the internal audit service and seek to use it positively. At its best, internal audit can play a valuable management consultancy role, at considerably lower cost than its private sector counterpart. Directors of finance should welcome this attempt to use internal audit constructively, and will be able to advise on suitable issues for the service to study.

#### EXTERNAL AUDIT

External audit in the public sector tends to have two roles. Both are normally carried out by the Audit Commission, the public body charged with monitoring local government and the NHS.

First, audit concerns stewardship; ensuring resources are used correctly by establishing that the annual financial statements provided by trusts and purchasers are 'true and fair'. This takes the form of a twice-yearly visit from the external auditors. The basis of this work is mainly financial regularity, that is, ensuring that expenditure is recorded correctly. However, external auditors will also be taking an increasing interest in the way in which contracts are costed, for example, ensuring that the latest costing guidelines, referred to above, are being complied with.

The second role is complementary to that performed by internal audit in seeking to promote value for money. Each year the Commission will target particular aspects of NHS services and examine them in considerable detail. Given its national coverage it is able to study similar services from a wide number of areas, to identify both good and bad practice. Results of these studies are published in reports that try to quantify the potential savings to the NHS as a whole if good practices were adopted at the expense of the bad. These reports may well be used as reference points by local auditors, who build upon them by carrying out local studies of their own. Once again, directors of finance will be able to advise on the current audit themes, and discuss their relevance to the work of individual clinical directors.

#### CONCLUSIONS

A key theme of this chapter has been the importance of better understanding, and better working relations, between clinicians and the finance function. Both operate under constraints, and better mutual understanding of these will lead to a more productive relationship. Finance staff have a key role to play in relation to supporting capital and service

developments costing and assisting the better management of resources at directorate level. All of these require finance staff to develop a better understanding of the clinical services being delivered. Similarly, the better clinicians understand the financial and resource allocation regime in which they operate, the better the service they will receive from finance and general management. Irrespective of the political future for the NHS, the need for ever closer integration of finance and service delivery is unlikely to be eroded.

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# Developing personnel skills in management

# 10

*John Edmonstone*

## INTRODUCTION

There is a very simple reason why personnel skills are crucial in the management of child health services. In the NHS as a whole over 70% of total expenditure is staff-related. While medical technology is expensive, health care is primarily a 'human service' and having the right numbers and mix of trained and motivated staff is the key to delivery of a high-quality service.

It is surprising, therefore, in such a labour-intensive service, that attention to the effective management of the staff, personnel or human resource aspects has been characterised as 'too little, too late'. The development of personnel management in the NHS only really began in the early 1970s, considerably later than in most industrial and commercial organisations, but also belatedly when compared to other parts of the public sector, such as local government and the Civil Service. The personnel function grew slowly and tended to concentrate largely on areas which were extensions of work previously seen as administration, such as manpower controls ('establishment' work); education and training (excluding professional education); recruitment and selection and the staff welfare function. The 1970s also saw the development of expertise in the industrial relations field (although this was largely confined to the highly regulated Whitley system) and in the field of manpower planning (largely located within Regional Health Authorities only). Recent research [1,2] confirms that the personnel function in health care is still generally of this nature. Nonetheless, there has been a broad development outside the NHS which is part of a change of emphasis from collective towards individual relations at work. At a tangible level it is related to the development of more flexible working patterns, with reward systems which link

remuneration more directly to performance and with direct forms of staff communication and involvement, such as quality circles [3] and team briefing, which bypass or supplement more conventional joint consultation processes between management and trade union representatives. At the conceptual level this has involved a move from industrial relations to 'employee relations' and from personnel management to 'human resource management' [4]. Many previous NHS personnel departments now have the new title of human resource management (HRM) departments or directorates.

This chapter deals with the main sub-divisions within personnel (or human resource) management: workforce planning, recruitment and selection, employee relations, reward and remuneration and training and development. It also examines the role of the HRM department vis-à-vis the clinical directorate or specialty; considers the importance of teamwork and the development of teams; and ends by focusing on those aspects of HRM which are most pertinent to professionals and managers in child health services.

## WORKFORCE PLANNING AND MANAGEMENT

The term 'workforce' planning and management is increasingly used in place of the previous term 'manpower'. Workforce planning and management involves:

1. being clear and accurate about the **demand** for trained and qualified staff, related to workload and activity as expressed through contracts between provider NHS trusts and their purchasers;
2. having arrangements in place to regulate and control the **supply** of trained staff, including the ability to increase or decrease this as circumstances demand;
3. actively managing the **deployment and utilisation** of staff to meet the needs of work, ensuring, for example, that staff undertake work which matches their level of training; and
4. having an effective **information** system which will inform and support the other aspects.

Additionally, the skills of all professional staff within child health services are key to the effective delivery of the service and it is important to hold on to such staff through policies for **retention**. It is vital that such key staff are identified and that policies and actions designed to retain the loyalty, motivation and ownership of these staff are pursued.

All this takes place within the context of the UK labour market generally and the NHS labour market in particular. Developments in the UK labour market over the last decade have been led by the government and have been marked by two key imperatives – that employers' needs should

become paramount and that the supply of trained and qualified staff should have a 'vocational' emphasis, i.e. that staff should be trained to undertake the work which their employers deem necessary: no more and no less.

In health care, by comparison, the internal labour market is highly regulated through statutory mechanisms such as the GMC (for doctors), the Council for the Professions Supplementary to Medicine and its Professional Boards (for the professions allied to medicine (PAM)) and the United Kingdom Central Council for Nurses, Midwives and Health Visitors and the four National Boards (for nurses). Attempts to de-regulate this labour market have been largely confined to the introduction of the health care assistant as a generic support worker to nursing and PAM staff.

Increasingly, as the contractual relationship between purchasers/commissioners and providers of care involves seeking 'more for less', there will be increasing emphasis on reducing unit labour costs at NHS trust level [5]; on aligning the planning and managing of the workforce more tightly with clinical workload and activity levels within clinical directorates and specialties [6]; generally seeking to 'reprofile' the workforce by challenging previous assumptions on such matters as skillmix and demarcation between different professional groupings; in moving to 'core and periphery' staffing and a system of personal contracts [7,8]. Reprofiting of the workforce raises the question of termination: the ending of the working relationship between employer and employee. This can be by processes of natural wastage (not replacing leavers); through pursuing early retirement or through a programme of redundancies. Organisations outside the public sector have been more willing to take rapid action to 'downsize' than has been the NHS. This situation is now changing and redundancy is now one among many measures (retraining, part-time working, etc.) which form part of the panoply of approaches available to managers.

Managers in child health services can best exploit opportunities in workforce planning and development by supporting the development of trust-wide and local information systems which will provide the basis for effective management of the workforce; and by taking the lead in reviewing skillmix issues while seeking to maintain existing quality of care levels.

## RECRUITMENT AND SELECTION

Recruitment and selection of staff is one of the core activities of HRM. It is an area which the HRM function in recent years has sought to embed firmly at operational management level, with appropriate safeguards and supervision from the HRM department. In many cases the recruitment and

selection process is relatively straightforward, provided a helpful and explicit person specification is available. However, in child health there is a particular need to exercise care and discretion following the Beverley Allitt case. Good practice here might involve:

1. having a requirement that all interviewing panels comprise at least two people;
2. identifying one of the interviewing panel as the 'appointing officer' with ultimate responsibility for the appointment;
3. making a written record of the appointment which identifies the interviewing panel members, the successful candidate, etc.;
4. seeking a minimum of two referees for each appointment, one of whom should be a current employer;
5. ensuring that no employment offer is made unless two satisfactory references are received;
6. checking previous criminal convictions for all applicants to whom it is decided to offer employment, through the Criminal Record Office; and
7. using probationary periods for staff new to the NHS or the trust.

For some managerial posts newer approaches to selection may be used. These include the use of psychometric testing and of assessment or development centre approaches. Psychometric testing must be undertaken by a trained occupational psychologist and is typically used as an adjunct to more conventional selection processes, such as interviewing. Useful tests tend to be of two types: of aptitude and of personality. Aptitude tests will indicate, for example, how well developed a candidate's verbal or numerical critical reasoning is. Personality tests (such as the 16 Personality Factor or the Occupational Personality Questionnaire) provide a profile of a candidate against a number of key dimensions of personality [9].

Personality tests are also often a part of assessment or development centre processes. An assessment centre involves a more sophisticated selection process whereby:

1. A clear profile is developed of a job or group of jobs and the broad areas of competence associated with them.
2. A series of exercises are designed which reflect likely aspects of the job and are likely to reveal the existence of these competences.
3. Candidates attend for up to two days and undertake these exercises observed by trained assessors.
4. The assessors meet to assess candidates' performance in the exercises against the broad competences as a means of deciding on success or failure for appointment.

Assessment centres are used for selection and appointment purposes.

Development centres involve more self-assessment and feedback and are typically used for identifying career potential and future development needs [10–12].

In seeking to improve recruitment and selection, managers in child health services should review existing procedures to ensure that good practice is followed. They should also take every opportunity to learn more about the possibilities of newer approaches, perhaps by using psychometric testing as part of the selection process for some posts or by taking on the role of a trained assessor in an assessment or development centre.

## **EMPLOYEE RELATIONS**

Had this chapter been written some ten years ago, this section would have been titled industrial relations. It is a sign of changing times that this term is now subsumed within a more global concept. Industrial relations was seen as being:

all the rules, practices and conventions governing interactions between managements and their workforces, normally involving collective employee representation and bargaining [13].

The rules of industrial relations defined procedures for settling wages and conditions of work, for resolving disputes and dealing with conflicts, and for implementing a wide range of grievance and disciplinary processes. Such a monolithic vision of the regulation of relationships between management and staff has become severely modified over the last decade. There have been two main causes of this. Overall in the UK there has been a decline in trade union membership and this has been reflected in health where the greatest concentration of numbers of union members were in the ancillary grades, which have been the subject of contracting-out of services or 'market-testing'. Secondly, a continuing programme of government legislation has made life increasingly difficult for trade unions, leading to mergers, such as the creation of the new public sector union UNISON.

In addition to this there have been a number of trends which have emphasised supplementing or replacing existing machinery for staff consultation. The creation of personal contracts for certain key staff, the introduction of performance-related pay for senior managers, the spread of systems of performance appraisal and the ability of NHS trusts to 'opt out' of national Whitley arrangements all emphasise the relationship between the individual employee and the employer, rather than between employees collectively and their employer.

This is not to say that 'traditional' industrial relations is dead. Changed circumstances might bring about a resurgence of union power, although probably never to the same degree as in the late 1970s. A change in the balance of power between employer and employee does not mean that unions can or should be ignored. The cultivation of a positive and constructive working relationship with union representatives is one contribution to effective employee relations, not least in the area of legislation affecting the workplace, ranging from Health and Safety at Work to Equal Opportunities. Yet there are also new areas of activity which fall within the employee relations ambit. They include an increasing emphasis on communications, positive discrimination in employment, a changed role for occupational health services and a focus on sickness and absenteeism.

'Communications' is an overused word and yet it is clear that in health care it is a key concern: both between the multifarious professions and occupations who deliver care, and between those groups and patients, families and friends and the public generally. Effective communications are particularly important in times of change and it is perhaps no great surprise that 'communications audits' [14] involving both diagnosis and prescription have become popular. Perhaps just as important is the notion that communications is an area which can and should be **managed**, rather than just simply existing. Often such audits point directly to inappropriateness in the personal style of managers, as well as to more 'structural' communications problems. Audits are also often the precursor of new initiatives such as open meetings, house newspapers and journals and 'team briefing'.

The latter is a highly structured method of ensuring that messages from senior management (the 'core brief') are communicated through special meetings and trained briefers through all the organisational levels, supplemented by local briefs. Although this is a fairly mechanistic process it can pay dividends, provided that adequate investment of time and training is made, and an infrastructure to support and audit it is available. Positive discrimination has been a fairly alien term within HRM in the NHS, yet the signing-up of the NHS in England and in Wales (but not in Scotland or Northern Ireland) to the Opportunity 2000 campaign commits employers to a system of quotas to overcome the discrimination against women in employment and the 'glass ceiling' preventing their career advancement. Ranging from targets for the number of women hospital consultants to similar goals for general managers and chief executives there is already evidence (particularly in South East England) of this making a significant impact in employment policies.

Occupational health services have historically occupied an ambiguous role between employer and employee and have been criticised (often unfairly) by each. Recent years have seen occupational health services

developing a more business-like approach to their work through development of a business plan, regulation of their service to customers through service level agreements and generally a tighter (and more employer-focused) approach. Improved information systems for handling workforce data have meant that employers have developed a sharper picture of problems of labour turnover, and sickness and absenteeism rates. This in turn has led to further investigation of these problems. Reductions in sickness and absenteeism rates in particular have been brought about by redesign of work to make it more interesting, but also through a 'Hawthorne Effect' as the spotlight of a formal study often seems to bring about such reductions.

Child health service managers should seek at all times to maintain and develop good working relationships with local employee representatives; should understand the trust's arrangements for dealing with unions; should review the approaches used in communications generally in their part of the organisation; should discuss with the human resources department the practical local implications of Opportunity 2000; and should be clear about the services which the local occupational health service offers, and how they are best used.

## REWARDS AND REMUNERATION

Remuneration in the public sector (and especially in the NHS) has often been used as an instrument of macroeconomic policy and this is likely to continue. There is a school of thought which sees the demise of the national Whitley system as one route out of this problem. Yet NHS trusts, which do have the opportunity to negotiate such alternatives, have been very cautious about doing so, not least because of the lack of expertise in this area within the HRM function.

It is difficult to forecast the future of reward and remuneration in health care, but it is fair to suppose that:

1. it will increasingly be seen as integrated with other HRM policies, rather than existing on a 'stand-alone' basis;
2. there will be a continuing emphasis on reward for **performance** but a recognition that much performance is team-based, rather than individual;
3. there will be increasing emphasis on the total remuneration package, rather than simply the pay element (annual leave, paid study leave, sabbaticals, etc. are all likely to feature in future);
4. there will be attempts to bring all incentives under the control of employers and this may even involve consultant merit awards.

Managers in child health should take every opportunity to work with the human resource management function to ensure that trust-wide

developments in remuneration reflect the real needs of the service and its staff.

## DEVELOPMENT AND TRAINING

The regulation of the NHS labour market through control of professional education has been one feature of the statutory bodies mentioned earlier. The 1980s saw the rise of a new body: the NHS Training Authority (later the NHS Training Division (NHSTD)) which made its mark in two different fields (see below). The onset of the NHS reforms in the late 1980s also saw changes to the system of professional education. *Working Paper 10* (Education & Training) [15] initiated a system whereby regional health authorities collected data on workforce demand from all health care employers within their area and used this as the basis for a process of contracting with educational providers (based either within the NHS or in the higher education system). The contractual relationship was introduced as a means of strengthening employers' hand vis-à-vis the professions and the educationalists.

The NHSTD was active in the development of systems of education and training for health care staff who had previously been ignored by the statutory machinery of professional education. All these new systems were competency-based [16,17] and based on the new system of National Vocational Qualifications (NVQs). They bring with them an emphasis on training for performance and the importance of the workplace and the immediate manager/supervisor as both trainer and assessor of progress. The other main area tackled by the NHSTD was that of management development. A 1986 report *Better Management, Better Health* [18] laid the groundwork for many of the changes which have taken place in the training and development of managers, including assessment and development centres, the creation of Masters in Business Administration (MBA) programmes and the creation of a single approach to performance review for managers: individual performance review (IPR) (appraisal of performance (AP) in Scotland).

Yet the advent of clinical directorates and locality management and the development of new roles, such as business manager, service manager, etc. have already made many of the NHSTD innovations seem redundant [19] and 1991 saw the launch of a new national management development strategy for the NHS in England [20].

Managers in child health should review local study-leave arrangements for all staff; examine the adequacy of the local training budget for staff needs; consider access to in-house and external training provision to ensure maximum value for money; and should consider the practical implications of developing systems of performance appraisal to cover all



staff, relating in an appropriate manner to the development of corresponding systems of clinical audit.

## **ROLE OF THE DEPARTMENT**

HRM staff (and personnel staff before them) have often agonised over what their appropriate relationship to line management should be. A textbook viewpoint has been that they should advise, support and influence line managers, yet many line managers have been content to abdicate responsibility for such (increasingly complex) matters to the 'experts'. The creation of clinical directorates and localities as basic 'building-blocks' of the organisation brings this question into sharper focus. It is quite clear that in some areas (interpretation of employment legislation, aspects of workforce planning) expertise will be scarce and valuable. Yet this does not automatically mean that it should be provided in-house. Some advice will only be needed on an occasional basis and can be bought in as necessary. Market testing of services is not confined to the more traditional areas and HRM (or aspects thereof) are potential candidates.

Whether this route is followed or not, there is a recognised need for the HRM function to become more customer-responsive. One way for this to be achieved is to regulate the relationship between the users of such services (typically clinical directorates/localities) and the providers of the services (the HRM function) through a service level agreement which specifies the quantity, quality and cost of the service provided. It also involves directorates and localities (usually in the person of the business manager) fostering good office practice and organisation and developing the appropriate level of expertise within the directorate/locality, in order to encourage the HRM function to 'let go'.

Child health managers should consider the HRM function as a potential 'overhead' cost to bed-holding clinical services within the contract culture and should therefore press and challenge the function to ensure value for money, either through Service Level Agreements (SLAs) or some other means. At the very least there should be clarity over what HRM work needs to be done centrally and what is best handled at the level of the clinical directorate.

## **TEAMWORKING**

Part of the development of HRM skills at a clinical management level turns on the question of effective teamwork. Teamwork has the same status as 'motherhood' in health care – it is something which is a 'good thing' and which everyone is in favour of, yet the practicalities are seldom recognised.

It is clear, for example [21,22], that all members of a team have two roles:

a functional role and a team role. The functional role is the contribution based on acquired knowledge and professional experience in a particular field, while the team role is the contribution the team member makes to the team based on personal ability and characteristics. A successful team is one in which there is an appropriate blend of team roles and where the team makes use of each member's strengths in both the team and functional roles. Approaches exist [21] for identifying, at the level of the team member, personal profiles of team roles which can form the basis for seeking to improve teamworking.

Such improvement is **not** a matter of resolving 'personality conflicts'. Research [23] suggests that there tends to be a natural 'hierarchy' of issues which all health teams need to address, the earlier ones being the most important. They are as follows.

1. Goals • Why does the team exist?
  - What is it there to do?
  - What is the team's rationale?
  - Is everyone clear and signed-up to this?
2. Roles • What are the functional roles of team members?
  - What are the team roles of team members?
  - Is the membership 'right' in both senses?
  - Are all the roles and relationships clear?
3. Procedures • How does the team work?
  - How formal/informal is it?
  - How does the team decide?
  - How do things get done?
  - Is all this clear to everyone?
4. Process • What is the nature of interpersonal relationships in the team?
  - Are there any unresolved conflicts?

Child health managers might usefully review the operation of the directorate management team (and other teams) to consider whether the balance between functional and team roles is satisfactory. Help from the local HRM function or from an external consultancy source in using the Belbin Team Role Self-Perception Inventory should be sought. It may also be helpful to use the goals/roles/procedures/process checklist to encourage self-review by all groups, teams and committees within the directorate.

### **HUMAN RESOURCES MANAGEMENT IN CHILD HEALTH: A SPECIAL CASE?**

All clinical specialties, functions and departments tend to see themselves as a 'special case'. However, it is important to examine those aspects of

child health services which, in human resource management terms, may mark out the services as having particular issues and problems which demand a more sensitive treatment.

It is probably true to say that the HRM principles are exactly the same in child health as in other spheres, but that there are also important differences. Child health, for example, is a highly emotive subject in society generally and this means that the service exists in a public spotlight. Equally, there is a powerful motivation and high job satisfaction among professional staff who work in the service, many of whom continue to see it as a vocation rather than a job or a career. This may lead to two potentially negative aspects: a perception among staff that they and the services that they represent are indispensable when needs may have changed; and an 'us and them' polarisation as 'them' (the management) seek to impose imperatives on 'us' (the professionals).

This argues for constant attention to communication issues within child health services: both externally through the news media and internally through a whole panoply of approaches. The normal problems of communication in health care are further exacerbated by the need for staff to communicate with both children themselves and with (often emotionally fraught) adults, sometimes with risks of personal violence: the latter also raising the important matter of staff protection in terms of physical safety, which has implications for hospital security services and the training of staff in measures of physical self-protection. The demanding and traumatic nature of this work suggests a degree of stress among staff which employers will need to recognise and address through appropriate counselling and other services, with a key role for occupational health services.

The worries concerning the importance of recruitment and selection, particularly in the light of the Beverley Allitt case, have already been mentioned. A final issue concerns the importance of teamwork. Dating from the Court Report [24] professionals have been arguing that the division between acute and community child services creates operational and strategic barriers which act against the interests of both children and parents. This has also been accepted in recent key reports [25]. The integration of hospital and community services and the development of effective teamworking are profound challenges, particularly as current relationships are unequal and tipped towards hospital services. Community services do not have the same emotional 'pull' and also operate within other agencies (schools, clinics, etc.). Examples exist of how such teamworking can be developed [26] and this is one of the principal challenges for the future.

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*Malcolm Lowe-Lauri*

## INTRODUCTION

The *Concise Oxford Dictionary* defines risk as ‘the chance or possibility of danger, loss, injury or other adverse consequences’. It is clearly the role of management to avoid adverse consequences. But hospitals are complex, sprawling, dynamic institutions. They use buildings in ways never intended; they use equipment only recently dreamt of; they have over 100 professional groups providing services directly or indirectly to the patient; they serve communities which are complex, increasingly vocal, and for whom the range of available treatments is growing. Meanwhile, the economic background presses public services to deliver more for less. In healthcare the relationship between demand (which appears infinite) and resources (which are conspicuously finite) continues to be tense. The annual financial crisis for hospital and community trusts is the established norm.

These pressures make the emergence of the concept of risk management understandable. The need to manage risk has always been there but we are now at the point where it becomes an exercise in itself. This does not divorce risk management from line management. Rather, it offers a way of thinking and a few tools to reinforce the line management process. It is about organisational culture but a culture backed by systems: for predicting, responding, implementing, monitoring and evaluating.

This chapter is not the last word on analysing and controlling risk. It offers suggestions on what to look for, how to look for it, and what to do when you have found it. With this in mind we will cover risks in the working environment, staff behaviour and practices, and issues particularly relevant to child health.

## ENVIRONMENTAL RISK

Healthcare premises, by their very nature, pose a big environmental control problem. The main risk areas are:

1. the way facilities are used;
2. the way equipment is used;
3. the way chemicals, radiation and other hazardous substances are used;
4. how the whole hospital site is (or is not) looked after; and
5. the security of the premises.

The facilities of a hospital or healthcare facility rarely add up to a coherent whole. Even purpose-built institutions quickly assimilate modifications and developments which make it hard to recognise the original. They amount in effect to a series of small business premises performing very different tasks. These have evolved, often with the addition of technology and work patterns which wards, offices, store rooms and ultimately any available space struggle to accommodate. Neither is the sponsorship always from the NHS. It is not uncommon to find a variety of interests from medical school or drug company to other benefactor claiming occupational rights to spaces in which there is already insufficient room to provide a clinical service. There are usually two consequences: a plethora of potential incidents because the space is in itself hazardous, and improper and even dangerous use of space elsewhere which takes the overflow from activities displaced by developments.

The types of incident range from trips and falls through to back injury sustained by moving dependent patients in confined spaces where the right equipment cannot be used. Space used for overflow purposes leads to overcrowding. This is typical of ward ancillary areas where waste disposal points are squeezed out of all relation to the frequency of collection. Fire or control of infection hazard will often result. A clandestine smoker will make the risk even greater.

The haphazard process by which space gets taken up is very often compounded by the arrival of new, interesting but invariably awkward equipment. There are various manifestations. Very common is encroachment by 'leading edge' medical equipment. This can pose a range of hazards, including:

1. the creation of noxious fumes e.g. from lasers installed in consulting rooms;
2. the potential for radiation hazards;
3. a veritable spaghetti junction of cabling awaiting the first unsuspecting visitor;
4. a serious fire risk; and
5. overload of the department's power circuit.

In child health the recent pressure to develop services prompted by the internal market can find the neonatal unit of the district general hospital cramming the apparatus necessary for intensive care cots into whatever space is available. A teaching hospital's determination to introduce paediatric intensive care to boost its portfolio of specialised services may create additional demands on scarce space.

More mundane environments can produce their own risks. The proliferation of the personal computer introduces the squint, the strained posture and the trip-wire into the humble office. This is especially the case if that office is poorly lit, has inflexible furniture, and lacks well-placed socket outlets. If the computer tasks are repetitive there is a risk of repetitive strain injury as adjudged in the case of *McSharry and Others v. British Telecom* (1991) [1]. This should be considered when evaluating the productivity of, say, the ward clerk or appointments staff in paediatric outpatients.

Modern diagnosis and treatment involve the use of chemicals, toxic substances and radioactive materials. In paediatrics there is the additional risk that children do not always make compliant patients and can be enthusiastic investigators of the dangerous. Modern, complex paediatric inpatient areas carry a range of risks where gas and liquid storage rooms have a tendency to overflow, where cleaning fluids are left unguarded during cleaning activities, or where medical gas cylinders are left free-standing. In child health this may sound surprising. But when a busy ward is compounded by a shortage of nursing staff, a temporarily assigned domestic assistant, and a sudden clinical crisis elsewhere it is not too difficult to bring about moments of extreme vulnerability. Suddenly, we have a variety of potential disasters: contact by patient with a hazardous chemical, the fracture of a cylinder head, or, worst of all, the outbreak of fire in an area in which a cylinder or flammable liquid is unknowingly stored.

The wider environment of a health facility poses a variety of risks, many of which are unpredictable. It is clear to all users that buildings and services have not always been maintained to the optimum. Hence the concept of backlog maintenance. At its worst, this could expose users to risk of loosening roof materials, old wiring, or the fall into the unexpected hole in the ground. Besides this, hospitals are not one-off constructions. There is almost invariably building or refurbishment work going on. This brings its own risks. While working, a contractor's staff may not always accommodate staff and patient requirements. The result may be noise, dust, obstruction or accidental power failure. After a contractor has gone there is the risk from what is left behind.

In addition to physical risks the environment, given its size, complexity and the need for access, is vulnerable to a range of security problems. At the extreme nuisance end this means theft of hospital, patient, visitor or



staff property. At the more serious end it means risk of attack, sometimes with devastating consequences, as when two consultant staff were killed at Pinderfields Hospital in Wakefield in 1990. Some parts are more susceptible than others. The accident and emergency department is a notorious trouble spot. But, depressingly, virtually anywhere with easy access is at risk. Yet health service culture is one of ready access. The plethora of front doors, side doors and fire exits held open with string testifies to this. We are ill-equipped to deal with this risk.

#### LEGISLATION AND THE WORKING ENVIRONMENT

Although the above is only a sample of environmental risks it indicates the need for proper analysis and control systems. Many are now mandatory. They build on the 1974 Health and Safety at Work Act [2] which stipulated that it was the duty of every employee to contribute to a safe system of work. In 1992 the Management of Health and Safety at Work Regulations [3] prescribed that:

1. assessments of all risks in the workplace are undertaken;
2. where the number of workers exceeds five the results of the assessment must be recorded;
3. the names of employees particularly at risk must be recorded;
4. employees must be informed of the risks;
5. employers must identify the preventive and protective measures they are taking in response to the risks;
6. employers must identify their procedures for handling dangers arising from those risks; and
7. staff responsible for procedures must be identified.

These regulations came into force on 1 January 1993.

Even the smallest provider of child health services will employ more than five staff. Consequently, risk assessments in the healthcare workplace are required to perform all of the above. To do this requires a systematic form of scrutiny. We will see providers developing forms of analysis which cover the type of risk, scale, the frequency with which it becomes an incident, the costs of an incident and the cost of prevention. This can be represented on a simple spreadsheet, giving the author a quick form of cost-benefit analysis. Already, the specialist health and safety consultancies are producing branded versions.

In addition to the 1992 Regulations, five specific European Union (EU) directives became statute law in the UK from 1 January 1993. These cover:

1. the provision and use of work equipment;
2. manual handling operations;

3. the workplace (health, safety and welfare);
4. personal protective equipment at work; and
5. display screen equipment.

These require employers to analyse systematically the risks in the working environment, this time in prescribed areas. Again, they are required to identify how the risks will be managed. Consequently, staff in clinical departments will find their safety officers and themselves researching into where and how they use equipment, what manual handling operations they perform and what equipment is there to assist them, how the need for protective equipment is met and its use monitored, how the environment for intensive visual display unit users is organised, kitted out, and its working practices regulated.

Besides EC legislation there are important UK initiatives. The most important is the Control of Substances Hazardous to Health Regulations (COSHH) [4] which have operated since 1989. COSHH regulations require employers to deal with hazardous substances by:

1. assessing the risk of exposure;
2. controlling or preventing exposure;
3. using control measures; and
4. providing information and training for staff.

Like the EU regulations COSHH develops the spirit of the 1974 act. Child health departments, for instance, are required to develop a comprehensive profile of their areas of risk, their responses (particularly their procedures) and the designation of responsibility. Risk management and line management thereby come together. The manager has a database with which to work. To sustain the process, however, the database must be subject to monitoring and review. There are two routes for this. The first is to conduct reviews on a planned, regular basis for each risk area (the legislation prescribes annual checks). The second involves drawing on any relevant development. Inside the department this may be an incident or occurrence which sheds new light on a particular risk. The importance of incident reporting and record keeping cannot be overstated. (We shall return to this in the context of staff behaviour.) From outside there will be information about risks or incidents elsewhere. This will reach the child health manager in the form of safety information bulletins, hazard warnings or, if the issue is of sufficient magnitude, a Department of Health circular.

## **STAFF BEHAVIOUR AND PRACTICES**

Management of the environment will be ineffective if it is not matched by management of staff behaviour. This even includes the control of practical

jokers. The judgement in *Hudson v. Ridge Ltd* (1957) held an employer liable for the damages owing to the actions of a known workplace prankster [5].

#### STAFF AND THE ENVIRONMENT

There are two perspectives from which staff-generated risks have to be managed. The first is the employees' contribution to their own safety and that of colleagues, patients and visitors through the way a given work area is operated. The second is in clinical care.

For the ward nurse or junior doctor the hospital day is filled with conflicting pressures. The existence of myriad procedures covering many aspects of behaviour and performance can, against this background, seem unappealing, even an unnecessary burden. Responses will vary. One is to prioritise tasks. This is difficult for the newly qualified staff nurse or doctor. Another is to delegate, not very helpful for the person at the end of the delegation chain. Another response is to cut corners. Yet another is to ignore the requirement if it seems irrelevant. In these last two lie the main source of risk. There are many examples. It must often seem sensible to a nurse to move a heavy patient or piece of equipment without the bother of using the designated lifting equipment or waiting for a colleague to become available. Yet the cost of claims against health authorities and trusts in respect of back injuries is the second highest, behind obstetric cases. When there is a rush on for clinical reasons it is easy to understand why a medical gas cylinder does not get secured in the appropriate bracketing equipment. The court and/or an injured party may not be so understanding if the cylinder falls over and its nozzle fractures, producing the impression of an unguided missile with possible warhead.

#### FOOD HANDLING

Some of these risks are common sense. Some are subtle but, if not observed, may have devastating consequences, such as non-conformance with food hygiene regulations. The 1970 Food Hygiene Regulations [6], together with the 1990 [7] and 1991 [8] amendments, and the 1990 Food Safety Act [9] cover the full range of responsibilities required of healthcare providers. Most of these relate to food storage, production and distribution for the catering service. But there are issues on the ward such as:

1. the preparation of breakfast and other snacks;
2. the storage of food in ward kitchens; and
3. the distribution of patient meals delivered from a central point.

The distribution issue may be complicated by the type of catering system: cook-chill, for instance, where pre-cooked food is stored in a central

kitchen then transported to the ward to be reheated in purpose-built trolleys.

The risks can arise from seemingly mundane situations e.g. where:

1. hot food cools long enough, before eating, to grow harmful bacteria;
2. raw and cooked foods cross-contaminate in ward refrigerators; or
3. staff hygiene practices are lax and hands are not washed between food handling and other operations.

Fit adults can often withstand these risks. Sick children may not, particularly if therapy leaves them immunocompromised. Although not related to children, the 1984 outbreak of food poisoning at Stanley Royd Hospital in Wakefield, which resulted in the deaths of seventeen patients, demonstrates the consequences of failure to manage this risk [10]. On the children's ward there is an additional risk from the highly desirable presence of parents who may be keen to supplement the hospital menu with unsafe food.

#### ROLE OVERLOAD

The working habits of junior medical staff may pose particular risks. The volume of work over an extended period, the associated fatigue, the tendency not to be based in a single ward or department: all of these contribute to lack of awareness of departmental procedures. Consequently, even the tightest local management regime can be broken. For instance, if cytotoxic drugs, in the absence of a pharmacy reconstitution service, are made up by a junior doctor, there is a risk that he or she will not dispose of the waste properly. The frequency of drug errors involving nursing staff shows that they are also susceptible to mistakes arising from a complex and demanding workplace.

#### RELATIONS WITH THE CONSUMER

The way staff relate to patients, relatives and carers exposes them and their hospital to risk. Historically, the relationship between health professionals and those who use their services has been deferential, with the users behaving compliantly. Today, the patient and representative still defer in general to professional knowledge but are more likely to question the message, to demand completeness, and will expect a civilised mode of communication. Where this does not happen there can be suspicion, resentment, and, quite possibly, serious offence might be taken. In extreme cases the relationship breakdown will lead to physical violence. At other times it will generate complaints and even litigation. So often, complaints and legal cases contain references to being treated in an off-hand or

patronising manner, not being given an explanation, not dealing with the anxieties of patients and relatives in an appropriate manner. If the initial response had been more effective, there may not have been a complaint.

## **IDENTIFYING AND CONTROLLING BEHAVIOURAL RISKS**

The key is good management backed by systems, monitoring and training. The management tasks relate to geography and hierarchy. The ward or departmental manager must accept responsibility for his or her work area and not tolerate risky practices. It is essential that all work areas have a designated safety officer. Generally, it is preferable if the role is separate from the manager's; thus a second opinion is immediately available. In terms of hierarchy, the manager of staff using but not based in a given area must ensure that subordinates conform to local standards. There is some novelty in this. Consultant medical staff are unused to regulating the behaviour of their juniors beyond clinical matters. But in an environment where doctors take an increasing role in management more must be expected here, just as it is for the completion of discharge summaries or for throughput in outpatient clinics. The argument from professionals may be that they are being saddled with additional tasks. The reality is that, from the patient's perspective, this is a route to the existing tasks being performed better. Moreover, it should limit complaint investigations, court cases, accident reports and inquiries, and loss of beds owing to infections.

There is a variety of systems available to managers. All providers and trusts use accident and/or incident reporting forms. These cover a range of issues from general staff and patient accidents through to drug errors and untoward clinical incidents. Forms may be separate or combined. They should be completed as soon as possible after the incident but are not simply reactive. They provide a database (often computerised) of which questions about the types, times and places of accidents can be asked. From this a manager can understand when, where and how the organisation is at risk: for instance when the numbers and mix of staff mean that certain types of patient are at risk of falling out of bed. There may often be a significant correlation between these risks and morale factors such as high sickness rates, high staff turnover and frequent use of agency staff. In child health there is the additional concern between the risk of an incident and the lack of availability of registered sick children's nurses (RSCNs) or those who have completed the child branch of Project 2000.

Some monitoring systems must be prescriptive. Checks on the temperature of ward refrigerators, the age of stored foods, and the temperature of food at the point of consumption will be undertaken routinely because this

is the only way to gather the appropriate information and because the pressure to do it encourages performance. These and other food hygiene standards are prescribed in the Department of Health handbook on food hygiene issued under cover of HSG (92) 34 [11]. Even so, the local authority environmental health officer, whose job it is to enforce the food hygiene regulations, may find deficiencies in practice sufficient for providers to face improvement notices or even prosecutions.

## TRAINING

Effective monitoring must be based on proper training. The purpose of training is to:

1. provide awareness of the risks and their potential consequences;
2. highlight staff responsibilities; and
3. provide the skills or competencies to manage the processes effectively.

There is a variety of ways to train. The straightforward lecture and practical demonstration is a perfectly satisfactory method of conveying the hazards of fire: especially if proper records are maintained to monitor coverage of the workforce. For more subtle risks it is vital to bind the training into the work process. This calls for a cascade system. The first step is to train the trainers. The instruction of managers and staff representatives for subsequent training of the work group will stress the relevance, ensure greater ownership and therefore performance. In areas like food hygiene it may be important to support training with a form of qualification. For example, the Royal Institute of Public Health and Hygiene's basic certificate in food hygiene. Local environmental health officers, who run courses leading to the certificate, are invariably keen supporters of hospital programmes.

Increasingly, there will be a focus on the interactive skills of staff. We have all noted how poor relationships generate complaints and even litigation. Most healthcare providers are developing customer care programmes. These are designed to make staff aware of patient needs and to programme their responses accordingly. In child health this applies more to administrative and clerical and ancillary staff. They will not have received any special training in the needs of children and parents. However, providers should also reflect on the competence of their junior medical staff. Juniors cannot easily make themselves available for non-clinical activities, given their commitments. Secondly, there is the difficulty of various juniors giving conflicting information to the patient, to the further detriment of the patient's confidence. Consultants must be brought into the programming of training to ensure its effectiveness.

Training records provide a database which gives a further opportunity

to monitor risk. It details the extent and type of coverage. It also provides an opportunity to cross reference training data with information on accidents and incidents. This will show whether an area without coverage is creating a risk, and whether training is effective in reducing or eliminating it.

Generally, clinical risks are about competence: the failure to diagnose, to treat, to perform the treatment appropriately. But, from the events culminating in the conviction of Beverley Allitt for murder, attempted murder and grievous bodily harm in May 1993, it is clear we must also consider malevolence [12].

#### AUDIT

The training and education of doctors, nurses, professional and technical staff are covered extensively by a range of statutory bodies. Risk management should not second guess the impact of these on clinical care. Instead, it should ensure that providers:

1. systematically monitor the effects of treatment processes on patient outcomes;
2. use accepted standards or protocols wherever applicable;
3. have a system for the clear reporting of untoward incidents in patient treatment;
4. investigate all such incidents; and
5. link 1–4 to the effective management of claims for damages arising from negligence.

Issues under 1 and 2 above are normally handled through the process of clinical audit. The definition given in *Working For Patients* (1989) [13] for medical audit was 'the systematic, critical analysis of the quality of medical care, including the procedures used for diagnosis and treatment, the use of resources, and the resulting outcome and quality of life for the patient.' Audit has been practised in specific disciplines (such as obstetrics) for some time but only became mandatory as part of the NHS and Community Care Act 1991 [14]. The legislation required that all district health authorities operate a system of medical audit governed by a local committee with a consultant as chairman. Guidance since 1991 has stressed the need to extend coverage to nursing and other clinical disciplines [15]. The intrinsic benefit is the opportunity to reflect on and improve clinical care. The additional benefit is the chance to intercept problem practices before they develop into a serious risk of adverse outcome to the patient and litigation to the provider. The peer review aspect of the process gives clinicians a secure environment, internal rivalries apart, in which to evaluate performance.

But there are limitations. Firstly, audit is usually qualitative. Most audit

processes will select cases, often at random, rather than consider the entire workload. Secondly, there is uncertainty about the relationship between audit and management. The separation of the functions was stressed in 1991 to make the participants feel safe; however, it has become clear that they are inseparable. If audit makes discoveries relevant to patient care but also to the greater welfare of the provider these must be disclosed, whatever the reflection on individuals. Managers and clinicians must take the bold steps necessary to address this.

#### INCIDENT REPORTING

Related to, but distinct from, audit is the reporting procedure for untoward clinical incidents. It can be a vehicle for events discovered by audit. Its primary function, however, is to identify any serious issue arising from clinical care. Most providers will operate an untoward incident procedure, although it may not cover clinical incidents specifically. Either way, the manager has two problems: first, to create a climate in which disclosure of an incident is encouraged; and second, to secure a working definition of what should be reported.

The right climate is about reducing the fear of punishment. This can be helped by a procedure which stipulates that disciplinary action is unlikely to follow a report unless circumstances overwhelmingly demand it, through gross misconduct, for instance. Even so, it is interesting how many consultants are reluctant reporters, fearing the personal liability for negligence which ceased (for NHS activity) in 1990.

An agreed definition is difficult to achieve. If the criterion is 'adverse outcome' does this apply if the treatment was perfectly reasonable? If it is 'near miss' yet the patient was unaffected is it worth reporting? If only disasters were covered the risk managed is limited to complaint or litigation. Thus there will have to be local judgement. If the climate is secure and there is an understanding of the need to prevent further incident, the reporting will be more comprehensive. There are advantages if reporting is standardised. Filling in tick boxes on a form (as long as there is also a free text area) provides fields for the creation of a database. This stresses the need for awareness, among those caring for children, of the possibility of malevolent intervention. Commentary in parts of the Allitt report suggests a more organised response to the early events may possibly have led to the quicker detection of the crimes. While there is no certainty about this the benefit of an established procedure for the rapid reporting and investigating of all untoward clinical incidents is underlined. The early and systematic collection of data, the identification of Allitt as the incident reporter in each case, against a background where there is no clinical explanation, may have prompted earlier suspicions.



## OTHER SOURCES OF RISK IN CHILD HEALTH

Much of what has been described above has considerable relevance to child health, but there are other risk factors. Broadly, these can be characterised as:

1. a tendency to fragmentation of responsibility;
2. problems in the management of staff morale; and
3. child health in the internal market.

### FRAGMENTATION OF RESPONSIBILITY

The fragmentation risk is considerable. To begin with, both the child and the illness have to be managed. This may involve different consultants and their teams. The more complex the condition the greater the number of experts involved. Consequences could include:

1. discontinuity of care and clinical decision making;
2. confused messages to patients and relatives and the consequent undermining of confidence;
3. a failure of the medical records to keep up with clinical events; and
4. a drug or other treatment error.

None of this fits the process of risk assessment and monitoring until there is an untoward incident. But it can sometimes be spotted through analysis of complaints. If these show a pattern where patients on a given ward repeatedly experience discontinuity, confusion and the appearance of new doctors with no casenotes the capacity for further and greater error is considerable. Managers and their clinical colleagues must act to designate responsibility and restore control in administrative systems.

Fragmentation may also exist within a single work group. In areas of high technical skill such as neonatal or paediatric intensive care there will usually be a concentration of highly graded nursing staff. This may confound the hierarchy needed to run a department effectively. All will be working but nobody will be leading. The complaints system may give clues (e.g. 'all the staff were very busy but no-one could tell me what was going on') but so will the measures of morale: sickness levels, staff turnover, difficulty in recruiting. This is because the confusion and uncertainty are hard for the workers themselves to carry.

Fragmentation is a sizeable risk in child protection. There are two dimensions, the clinical and the managerial. The clinical task is to understand when injuries are non-accidental or the clinical picture suggests abuse in other ways. This is a matter of training and monitoring which need not be explored in detail here. Suffice to say this requires the involvement of a named child protection advisor and medical leadership from a nominated consultant paediatrician. The need to train and monitor

must cover all parts of a hospital dealing with children, in particular the accident and emergency department. The managerial task is to avoid child protection cases falling between the agencies involved. The statutory lead agency is the local authority social services department. It invites the assistance of other bodies in investigating and monitoring through a system of area child protection committees (ACPCs). At operational level, however, social services staff deal with a variety of groups and individuals from whom they draw information. Sometimes this fails. Recent criminal proceedings have shown instances of health professionals failing to contact each other or social workers. There have also been times when social services staff have not communicated with each other. On such a difficult topic the healthcare provider's role is to operate a procedure where:

1. there is sufficient awareness of child protection as an issue;
2. the reporting steps are properly prescribed; and
3. staff including doctors have appropriate training and consultant support.

Heightened awareness invites the risk of overreaction, of the sort that emerged from the Cleveland cases in the late 1980s. But in reality for the child, the professional and the employer this is generally the smaller risk [16].

#### STAFF MORALE

There are particular morale problems in child health. The stress imposed by work with sick children is a significant factor. Recruitment is another. At the time of writing, consultant paediatrician posts are filled at the first attempt in only one third of cases. This means a shortfall in clinical leadership for many hospitals at some time. In turn, there is a difficulty in the recruitment of adequate numbers of juniors. In nursing there is a national shortage of registered sick children's nurses or those who have completed the child branch of Project 2000. One recommendation of the Clothier inquiry into the activities of Beverley Allitt stressed the need for two RSCNs to be on the ward at any one time (referring to the Department of Health guidance in its document on the welfare of children in hospital) [17]. There is also a shortage of neonatal nurses at the lower grades ('E' in particular).

Managers must look to their systems of morale measurement to identify risk. This means keeping a careful eye on sickness patterns, staff turnover, complaints and petty incidents arising between colleagues. Managers will also be keen to identify ways in which recruitment to their units can be made especially attractive (although this does not address the overall problem).

## CHILD HEALTH IN THE INTERNAL MARKET

Since the inception of the internal market in April 1991 some providers have become interested in developing services in which they have not previously majored. The early trusts were often keen to expand their complex obstetric and associated neonatal intensive care services. More recently, there has been pressure for paediatric surgical procedures to shift away from specialist regional or supra-regional centres. For the commissioning health authorities this is attractive: the local provider does the same work at less cost. The risks in this strategy are uncertain at present. Evidence will appear through local clinical audit, the wider audits undertaken on perinatal mortality, and eventually from complaints and litigation. Commissioners and providers must combine to limit the risks. It should be possible, for instance, for the commissioner to insist that the local hospital has a partnership arrangement with another unit with recognised expertise in neonatal intensive care, and that the mutual arrangements are backed by clear guidelines.

## CONCLUSIONS

The sources of risk are numerous and are often insidious. One could be forgiven for thinking the management task overwhelming. But the tools to analyse, control and monitor the risks are available. They are part of the mainstream job, not a luxury. Getting them to work requires creation of a culture in which they are understood to be usable and important. This needs the proper involvement of all those exposed to and with the potential to create risk.

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*Brent Taylor and Euan M. Ross*

*The purpose of the health service for children is to enable as many children as possible to reach adulthood with their potential uncompromised by illness, environmental hazard or unhealthy life style.*

*British Paediatric Association, 1991*

*Agencies should ensure... a concerted approach to inter-disciplinary and interagency working.*

*Working Together, 1991*

## INTRODUCTION

The duty of external services is to help parents in their responsibility to care for their children. The health services have a role in maintaining the health of children through health promotion, with particular involvement where children have special needs and for specific tasks such as immunisation. An increasing number of children survive previously fatal conditions, such as cancer or cystic fibrosis, as a result of medical advances. Other chronic conditions such as diabetes, eczema and asthma, appear to have increased prevalence, and raise difficult questions about environmental or dietary changes. New problems arise, for example new forms of cerebral palsy, and children with a repaired or transplanted heart, whilst more very preterm babies survive, sometimes with severe handicap. There is an increasing recognition that more could and should be done for children with the 'new morbidity', learning difficulties, including specific learning disorders, and children with emotional and behavioural problems, all of which are particularly associated with social and economic disadvantage.

However, these needs cannot be dealt with in isolation. The different

branches of health services must work together. Additionally, healthcare needs to interlink with social care and with education, and often with housing: all separate services. Further services for some children may include income support, and criminal justice agencies.

There are several problems which can make interagency working difficult.

1. Health services, and the others listed above, are often are not well coordinated internally or externally and need better integration.
2. Information on which to plan and manage effective services is usually inadequate. Better quality and more comprehensive data and integrated information systems are a priority.
3. Disadvantages particularly due to poor education and material deprivation, contribute greatly to sub-optimal health and developmental progress. The solutions to deprivation are a mix of political policy and a need for more effective support for families with children, better housing and better and safer environments. Much health service activity, particularly specialised health services, must be targeted to the disadvantaged individuals and/or sections of the population by individual practitioners and all the agencies concerned with child health, education and welfare.
4. Different services have different organisational and funding patterns. In these respects the NHS, local government services, social security, voluntary body services, and private sector provision work to very different frameworks, yet will be working to support the same populations, indeed the same individuals.

#### THE CHALLENGE

The influence of poverty, poor housing and poor environments on health and development are accepted, but health workers are not expected to undertake social welfare as part of their work. Health visitors, for example, are less able to address directly social and environmental issues and are involved increasingly with individualistic health promotion, emotional support and individual child surveillance activities or work for other age groups. In general, links are often poor between the health services and social welfare, housing, and employment services and voluntary agencies. The quality of such links depends greatly on individual effort.

The need to work together is one of the repeated themes emanating from central government for health services, local authorities, other agencies and professionals dealing with children. Surveys of individuals and parent groups [1] have demonstrated a strong wish for comprehensive, coordinated, integrated, accessible, participative, flexible, responsive and coherent services to children and families. Few, except the involved

zealous practitioners, understand the lines of demarcation drawn between service activities being provided by different disciplines or different agencies for the same individual. Flexibility, multiskilling and a willingness to try a new approach are required. Retreating behind 'professional' barriers is seldom helpful. Managers working with individual professionals and across disciplines or agencies can improve local team working; the resulting effective good practice can influence the attitude of professional bodies and associations.

Parents and voluntary groups should be helped to give their input to any service planning and involvement in decision making, as regards strategic locality and services planning. Their voice is particularly needed over practice matters such as the provision of car parking, ramps and parking facilities for prams. However, there are difficulties in obtaining representative input from parents and/or child/adolescent patients. Pressure groups and articulate individuals who often dominate discussions during consultation exercises may have their own particular beliefs or objectives, which can result in unrepresentative decisions, or important issues being neglected. The same, of course, can be said about much professional or managerial input to planning and discussions.

There are no clear directives from central government about how services should be organised for children or families. Children are mentioned only indirectly in the document *Health of the Nation* [2], in the context of accidents. Present legislation enables, indeed encourages, agencies to work together and to provide services but does not **require** it nor specifically finance it. Services working together need to clarify the purposes of the joint services they are to provide. Joint aims are required. Agreed fundamental principles do not guarantee a good service but do provide a necessary sense of direction and must underpin effective working together.

For example, among the issues which need to be agreed between agencies are the need for equity of provision without discrimination, principles of parental choice and the need for parental involvement, agreement on what is appropriate 'support' for families, and the need for and type of targeting required (positive action) whether for deprived groups or with priority for individuals with special needs. Training, most usefully on a multidisciplinary basis, is an important area; new service approaches will demand new skills. In-service training is at last becoming recognised as essential for all services.

#### SERVICE APPROACHES

The type of joint service needs to be agreed: whether 'interventionist' – concentrating on children from difficult families (with some monitoring of private and voluntary providers as well); a 'quality' service – open access

but concentrated in areas of disadvantage; or an 'enabling' service – largely self-help and parent run with a heavy voluntary sector contribution – although local authority grants will be required to ensure that the service is used by those who could not be expected to pay.

**Coordination, liaison and integration** are the key words which must be translated into effective action. Interagency planning for preschool, school age and teenagers needs to be short, medium and long term. There is a need for appropriate consultation and no point in reinventing the wheel. Investigation and utilisation of good practice in other parts of the country are important aspects of the planning process as is the need, in spite of the difficulties, to obtain information on what local people, especially mothers, fathers and children, want from local services. This is a necessary part of policy development.

Suitable services must be provided for teenagers who often feel that their health-associated concerns are not appropriately dealt with by conventional services including current school health provision. Health education advice such as not smoking is less important for most teenagers than coping with families, housing, employment and traffic. Drop-in clinics, often run by voluntary agencies, appear useful, particularly if sited in clubs, shopping streets and employment agencies. There is scope for the development in school of: a 'well teenager' clinic. Teenagers can be involved as counsellors and as discussants in groups.

Any new service should be evaluated in an effective way. Appropriate research methodology is required (but seldom used) when new policies or approaches are introduced. Managers often do not have a scientific training and should seek help from experienced researchers when planning major (and perhaps, most minor) service developments to ensure proper evaluation. The present drive to purchase and provide only those clinical services which have a firm scientific basis (evidence-based clinical practice) is wholly appropriate and is equally applicable to interagency work.

## WORKING WITH STATUTORY AGENCIES

### WORKING WITH SOCIAL SERVICES

The Children Act, 1989 set a new and more coherent framework for interagency health and social service working and replaced a mishmash of often conflicting regulations and guidelines. Child-centred care and the need, wherever possible, to maintain children within families, underpin much of the philosophy and requirements of the Act.

A central theme of the Children Act is **children in need**. Although the health services are involved in the wider social aspects of children in need,



most health attention tends to be focused on children with disability and on child protection issues.

Social services are required to establish a **disability register**, using as a basis for registration the, rather offensive to modern sensibilities, definitions of the 1948 National Assistance Act, to help in service planning and monitoring. Most social service departments have established working groups to help in the establishment of a disability register with representatives from health, voluntary agencies, education, leisure services and others. Developments in child health computing, particularly special needs modules, can provide a ready-made disability register. If parental/client permission is obtained information can be provided on paper or perhaps by electronic transfer from child health to social services. It is possible for a Social Services Department to arrange for another agency (e.g. health) to maintain and operate the register on their behalf. Some families do not wish information on their child to be passed to social services because of concerns about their perceived role as 'big brother' or because of experiences relating to child protection. Parents have no duty to agree to their child being included on the register. They must be regarded as partners in the assessment process and need clear and comprehensible information about the purpose and use of the register and what will be recorded.

There is, as yet, little evidence of benefit to individual children or families from the establishment of a disability register. Registered children and families do not get additional resources or enhanced care. From the point of view of service provision, accurate information on children with disabilities allows planning, resource allocation and priority setting. Agreement between agencies on criteria to be used in a combined, unitary register is essential at an early stage, with standardised (and subsequently validated) terminology and recording methods. Health service special needs registers are usually reviewed and updated annually. Regularised input from other agencies and groups would enhance the usefulness of this monitoring and facilitate the coordinated provision of services.

### **Child protection**

Child health services have an important role in child protection working with social services and others. Designated medical officers, designated nurses and midwives, required by the Children Act and the document *Working Together* [3] must establish practical health service procedures within provider units, hospital and community, and in cooperation with general practitioners, local medical committees, health authorities and with all other health workers who contribute to child health care. Deaths and other disasters associated with child abuse (Maria Colwell; Jasmine Beckford; the Cleveland child sexual abuse event) have been the stimulus

through official enquiries and media attention for improvements in the protection of children from abuse and neglect. Matters are still not perfect with gaps and overlaps in many districts.

All agencies must work together with parents and families. Interagency guidelines are laid down for each local authority district or borough under the coordination of an area child protection committee (ACPC). Health representation on these committees should include commissioners as well as providers. Local arrangements will vary but the work of an ACPC is likely to be most effective through sub-committees dealing with particular topics such as training, policies and procedures, prevention (primary, secondary and tertiary) and case reviews. Social services are the key agency with prime responsibility for child protection and usually take responsibility for the local child protection register. The National Society for the Prevention of Cruelty to Children is delegated this responsibility in many parts of the country, although less so in inner cities. There is a case to be made for an independent chairman of an ACPC.

Child protection consumes much health service and other agency time. Case discussions and case conferences (the latter usually now taking place with the parents present), monitoring and liaison are consumptive of resources both temporal and often of emotion. Ideas and examples of 'good practice' from elsewhere need to be considered by involved agencies, often at the ACPC or its sub-committees, or by individuals or groups of cooperating fieldworkers. The recent increased health service managerial input to the work of ACPCs could improve the cost-effectiveness of much current interagency activity. Timetabling of case conferences or case reviews at times when general practitioners can attend, and having programmed regular slots in the week reserved for interagency child protection activity like case conferences, improves working together to the advantage of children in need of protection, with more informed decisions resulting from a wider range of professional input and more ownership of the problem by attendees, together with increased understanding of each other's role and the development of mutual trust which follows when staff from different agencies meet regularly.

The administration of child protection conferences varies considerably from area to area. Agreement between agencies needs to be reached, and agreed practice adhered to regarding such matters as starting conferences on time, having a projected duration, prepared written summaries from the individual agencies attending, written reports from individual field workers attending and those not able to attend, clear policies on indications for registration or not, and rapidly available and accurate minutes with decision sheets.

Child protection is another area where present inadequate information impedes decision making. Even incidence figures are not available; children who are known to have been abused but who are now in a safe

placement are not registered on a child protection register and do not appear in the official statistics. Rates of registration vary considerably across the country as do the rates of different categories of abuse. Nationally standardised criteria need to be developed. Agreed criteria for registration and agreed policies and procedures must be adhered to locally and monitored by agencies and the ACPC.

Multi-disciplinary postgraduate training in child protection and related issues is likely to be more effective and beneficial to the safe care of children than training solely within agencies, as is the development of close working relationships between individual fieldworkers such as health visitors, school nurses, social workers and police officers, particularly members of the local police child protection team.

### **Fostering and adoption**

There are no statutory health requirements for adoption, but the adoption agencies' regulations require adopters to obtain a comprehensive medical report, usually from their GP, including present and previous health, family health history and habits such as smoking. The medical adviser on adoption panels, often a paediatrician, assesses the possible significance of health factors, in the wider context of the panel's discussion, and may have a role in counselling prospective adopting parents about children with disabilities or other special needs.

### **Material or emotional deprivation**

Local authorities may have to look after children because of problems resulting from material or emotional deprivation, often abuse or neglect. Disability is a common association. Children needing to be looked after away from their families may be accommodated in foster care or in residential settings such as children's homes. There has been a lack of emphasis on the health needs of these children, although the improved health information becoming available as a result of the requirements of the Children Act 1989 should result in more efficient identification of needs leading to appropriate treatment and support.

The health services need to be informed of children being looked after, then establish a positive approach to surveillance and preventive care, preferably by an interested GP who will provide primary care treatment of illness and shared care with secondary services where there are disabilities or complex problems, often with emotional or behavioural components associated with the child coming from a dysfunctional family. Social services have the coordinating responsibility, and a nurturing nursery or other preschool placement, sometimes on an assessment or therapeutic basis, can be very beneficial for the child's socialisation and

developmental progress. School age children often need intensive counselling or child mental health support.

### **Preventive work**

Preventive work for children and families 'in need' requires close and effective coordination and liaison between agencies, both with materially deprived families and with specific groups such as single mothers, refugees, drug abusers and certain cultural and ethnic groups. An interagency 'task group' including housing and welfare representatives, with responsibility for refugees or the homeless, can improve care considerably for children in such families. Health input, often led by health visitors, includes immunisation and assessment for infectious disease, documentation (including the provision of a personal health record documenting the present state as these families are typically very mobile). The community child health service may have a primary-care, safety-net role, but there are very effective examples of general practitioner centres being established, often with social service and welfare support, for refugees and other disadvantaged groups in inner city areas. This has a beneficial effect on the integration of these groups into appropriate use of the British health service and a reduction in the use of hospital accident and emergency departments for primary care.

Information about these social groups should be collected regularly as part of routine information gathering with normative data on the total population. Such information needs to be reliable and regularly updated. There are important data protection safeguards to be followed and information must be used appropriately with the permission and informed consent of the individual providing it. This need not be a major issue and individual consent is not required for many reviews of data undertaken for audit or research purposes where individuals will not be identified in any reports. A general, preferably written, statement (perhaps on a leaflet describing the service which is collecting the information as part of their work) to the effect that recorded information, including computer records, will be used for (clinical) audit, management and research purposes (with full confidentiality precautions), should be acknowledged by the parent or appropriate-aged child/adolescent.

### **WORKING WITH THE EDUCATION SERVICE**

Child health services and education must work together for all school age children but especially for children with special needs. The school health service, increasingly run by nurses rather than doctors, has an important role with health promotion (and health education in cooperation with teachers). There must be close liaison by the school health service with

individual schools and between child health provider management and education authorities regarding preventive activities such as immunisation programmes. The 1994 measles and rubella immunisation campaign where six million school age children aged between five and sixteen years were immunised against measles and rubella so preventing a major measles epidemic was a great health and education inter-departmental cooperative success. Health promotion campaigns need to be planned and announced far enough ahead to be timetabled into school health education teaching, preferably with appropriate school nurse input, within the national curriculum and the individual school's programme.

### **Children with special educational needs and the 1981 and 1993 Education Acts**

The school health service is increasingly orientating itself towards children with special needs, with the increasing trend to education of children with special needs, including special health care needs, in mainstream rather than in special schools.

Education authorities have the responsibility to assess children who may have educational special needs and, if these fit agreed criteria, to prepare a statement of educational need for that child. This statement is based on assessments undertaken by psychologists, and on a range of other inputs, particularly from the parents but also including relevant health service opinions especially from therapists and paediatricians. Health input must be effectively coordinated if the requirements of the 1994 code of practice on the identification and assessment of special educational needs are to be met [3]. The Education Act 1981 and following documents suggested that 70% of children who may have educational special needs should be identified by the age of three years to ensure appropriate planning for their education. Much of this identification and notification will be made by the health service. It is likely that those children with major problems in early life, for instance the survivors of the very preterm delivery or neonatal intensive care, would be the subject of close follow-up by hospital or specialist community child health services, with early notification if it seemed that they might have learning difficulties or health problems sufficient to affect their ability to undertake a 'normal' education.

Other children with future educational special needs will be detected by the preschool surveillance programme. This programme is increasingly undertaken in general practice, though still by clinical medical officers or health visitors attached to child health clinics in many inner city areas. The aim of surveillance is to detect children with possible educational or other special needs as early as possible with a view to effective interventions

being introduced if suspected problems on screening are confirmed by appropriate specialist assessments. If a parent thinks there is a problem, it is wise to take his or her concerns seriously. This often involves a referral for a diagnostic assessment by a specialist, e.g. to an ophthalmologist for suspected squint, even if the abnormality is not obvious to the primary health workers providing the screening.

Health input to statements of special education need must be relevant, concise and free from medical or other professional jargon. Care must be taken not to suggest input which is not reasonable or unlikely to be cost-effective. Health service involvement in panel decision making can help avoid raising unrealistic parental expectations through inappropriate health service recommendations for educational or other provision. On the other hand there is little point in assessing need if there is no possibility of need being met. Pressure from parents, supported by health workers or other contributors to the statementing process, can force local authorities to improve educational provision and services. The amount of health service input required to meet the needs of 'statemented' children is difficult to quantify especially for speech therapy. Therapy time can often be best spent as predominantly educative rather than in primarily providing individual treatments. Therapists can concentrate their activity on training parents, teachers and other care workers to help children overcome their difficulties, for example with speech and language, an approach more likely to improve the situation, with such total immersion, than an isolated hour or two of therapy here and there. Such an approach requires commitment from the therapists and cooperation and attitudinal change by educationalists.

A comprehensive children's service includes child mental health provision. Child psychiatrists, clinical psychologists, psychotherapists and children's community psychiatric nurses work with teachers, educational psychologists and educational social workers on individual children with special mental health or behavioural/emotional difficulties. School nurses are increasingly involved in the identification and management of educationally associated emotional and behavioural problems, all too often occurring in the context of social and material deprivation.

School nurses and doctors will be involved with educationalists in the required annual review of 'statemented' children with special educational needs. Paediatric community nurses (a rapidly developing specialty) provide specialist support to school nurses, to care assistants and to schools, regarding specific health problems such as diabetes, serious respiratory difficulties including tracheotomies, or gastrostomy feeding.

Paediatric community nurses are usually managed with local acute hospital services, where many of the children cared for by these nurses present. They have important liaison responsibilities with general practitioners but also need paediatric consultant support and advice.

This 'hospital-at-home/school' service functions best when managed as a combined (hospital/specialist community) child health service. Mainstream school nurses can be successfully managed within a community trust but because of the increasing special needs content of their work, school nurses too are best managed within a specialist child health service, ideally within a combined service. This arrangement facilitates clear lines of responsibilities within the health service and clarifies communication with education and other agencies.

Sensible policies need to be agreed between health and education (including educational trade unions), regarding the administration of drugs. All too often children with long-term problems miss schooling or other activities because of an inappropriately restrictive approach to the administration of medication. In general, anything a parent can do in the way of health care, a teacher or education-employed care worker can also do, after appropriate training and with on-going support from school or paediatric community nurses. If head teachers accept a child for education, they must accept all care needs as well, with appropriate support from the health service on an 'in loco parentis' basis.

There is much scope for collaborative working between health and education particularly in teenage sexuality, drug and alcohol use and abuse. The needs of young offenders, identified and potential, require close interagency cooperation. 'Drop-in' clinics in secondary schools run by school nurses can provide a contact point for troubled teenagers, as can the routine vision checks or health interviews.

#### WORKING WITH POLICE AND PROBATION SERVICES

The health service has an important interface with police regarding child protection and with police and probation services regarding young offenders. The police child protection team is represented on the local ACPC and has an initiating role with social services, in deciding whether a possibly abused child needs a medical assessment and in arranging that assessment with a suitable paediatrician with or without a forensic medical examiner.

A local child protection review group with police, social services, midwife, nurse and medical representation can promote good working relationships and provides a forum for the review of local difficulties (e.g. in social service input to hospital services or lack of feedback of investigations to a school nurse who has referred a child who has disclosed a history of sexual abuse), and to monitor local procedures in a more detailed way than would be appropriate or possible by the ACPC.

The school health service can monitor children on the child protection register or other individuals, e.g. young offenders, or other children being supervised by probation officers in an unobtrusive way (providing the

child gets to school). This information can supplement and deepen formal assessments by probation workers, police or court officers.

#### WORKING WITH THE VOLUNTARY SECTOR

The voluntary sector provides for over half of all preschool places in Britain, usually with little or no financial support from local authorities; through play groups and childminders. Many voluntary workers need increased access to training and advisory and support services.

There is some overlap between voluntary organisations and private service providers, e.g. preschool nurseries. Some voluntary sector input is advisory, as well as being a provider. Health-associated voluntary groups include those providing generic services, often for people with disadvantages and those providing condition-specific help, e.g. The Down's Syndrome Society. Health service management needs to ensure that health and voluntary agencies operate in a constructive, collaborative way without competition (causing duplication) and as comprehensively as possible (without obvious gaps). Regular structured meetings and the establishment and maintenance of good working relationships help ensure efficient provision of services.

#### EFFECTIVE INTERAGENCY WORKING

Different agencies have differing responsibilities and accountabilities. However, specific skills and training should be recognised and utilised on a cooperative, agreed, collaborative basis. Interagency working can be difficult, in part because of different expectations, different training and different orientation, in part because of different organisational structures, different terms, salaries and conditions of service and different support systems for senior staff. Most local authorities have joint consultative committees with an important input from health, including the local commissioning agency(ies) and providers.

The recently updated Department of Health document *Working Together* [4] required social services, working with other agencies, to prepare children's service plans. Much time has been spent preparing these plans. It is hoped that they will lead to improvements in child care and child health with more effective interagency working. Local authority staff including social services and education are accountable to local authority politicians and the local authority committee structure; financial pressures may also temper best practice. Local authority officers tend to follow a politically 'realistic' line, which is sometimes not in individual clients' best interests and often not with the agreement of, or even discussion with, other agencies.

The Audit Commission regularly produces reports in highly relevant



subjects including community services, health, education and social services, and information systems, and frequently has to draw attention strongly to the need for more effective interagency working. Their work is particularly useful as it is based on detailed studies and summarises good practice. *Healthy Cities* [5], another major initiative, has not been so effective, in part because it was introduced at a time of major re-organisational change, with many of the involved staff changing or losing jobs, with resultant loss of momentum and continuity. The *Health of the Nation* document [2] has, as one of its goals, a reduction in accidents. This is an area where local interagency work can be very beneficial. A multidisciplinary child accident prevention committee, involving the local community, can collect local data on 'black spots' with feedback to planners and local review and follow-up of individual accidents. This can influence environmental changes, the enforcement of safety legislation, including playground safety, and act as a focus for education on risks and avoidance. Other activity can include access schemes or the low-cost provision of smoke detectors, car safety seat loan or low-cost cycle helmets and 'first aid for all'.

All staff must learn to cope with change. Management re-organisations are of most interest to management and there is rapidly declining interest from section heads to field workers. Some staff often do not know that management arrangements have changed except when job security is threatened.

There is a need for ownership of work activity. This can be particularly problematic with interagency working. Sharing and open access to information with appropriate cascading of relevant proposals and changes help staff morale and maintain good working practices within and between organisations.

Finally, parents have prime responsibility for their children. In most families this means mother. Society has different expectations of men/fathers and of women/mothers. Until recently women have tended to be regarded as dependent in their role as child carers, financially dependent on the child's father or on the state whose financial support for households with dependent children is always meagre. Total reliance on socialistic planning however has a negative effect on health and social welfare/housing/employment services. Getting the optimal balance between government which can legislate for the building of or renewal of towns, and small-scale initiatives that empower individuals to take care of their own destiny, can never be easy.

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*Jane Fortin*

## INTRODUCTION

The UK law relating to the health and development of children is extremely complicated, partly because its sources are so diverse. Additionally, the law in England and Wales is different from that in Northern Ireland and Scotland. In Northern Ireland, though historically the law comes from the same source, reforming legislation usually lags behind that introduced on the mainland. Scottish law, because its roots are quite different, often varies significantly from English law and this is particularly true in the context of child law.

For reasons of practicality, the following review of the relevant legal principles has focused entirely on English and Welsh law. In England and Wales, the law remains confusing despite the achievements of the Children Act 1989. That piece of legislation greatly simplified matters by repealing and amending a host of acts and placing a great deal of the law applying to children all in one place. Nevertheless, there are many important legal principles that are still contained in a jumble of other Parliamentary enactments, such as the Children and Young Persons Acts and various Education Acts.

It is not easy to keep abreast of the changes in the law relating to children mainly because it is constantly being reviewed by the government through amending legislation and statutory instruments, and being reinterpreted by the courts. Indeed, it is a feature of our legal system that much of our law is judge made, the principles emerging in the form of legal judgements, on a case-by-case basis. A famous example of judge-made law was that laid down by the House of Lords in the *Gillick* decision [1]. Sometimes changes in the law have been influenced by official inquiries into tragedies such as child deaths and also into the mishandling of child abuse, for example in Cleveland and Rochdale.

Many of the legal principles applying to children in the context of child health and child protection have been particularly influenced by the following.

1. **The Gillick decision**

- established the broad principle that mature minors have the right to be involved in decisions relating to their upbringing.

2. **The Cleveland Report [2]**

- emphasised that children must be listened to by professionals investigating child abuse;
- emphasised that professionals in child protection work must liaise and work together effectively [3];
- emphasised that professionals in child protection work must be properly trained;
- emphasised that parents should be involved in child protection procedures.

3. **The Children Act 1989**

- stressed that the prime responsibility for the upbringing of children rests with parents but that the state should be ready to help parents discharge that responsibility where there is risk of family breakdown or where such breakdown actually occurs;
- rationalised the local authority's responsibilities towards children in need, including disabled children and their families;
- established that local authority services for families in need of help should be arranged in a voluntary partnership with parents;
- established that where local authority services include looking after children away from home, close contact should be maintained with their families so that where appropriate children can be reunited with them as soon as possible;
- clarified guidance to courts reaching decisions about children that the child's welfare should be their paramount consideration.

The legal principles relevant to children become more comprehensible if they are extracted from the mass of case law and legislation and placed in a practical context. Consequently, rather than attempting to set out the law relating to all children in all contexts, this chapter focuses on the legal principles relating to the following: the unborn baby; the severely disabled newborn baby; the handicapped school-aged child; the abused child and the mature teenager. Various hypothetical scenarios have been used by way of illustration. Many aspects of the law have been set out relatively shortly, but the footnotes should assist those wishing to follow up more detailed legal provisions. For the purposes of this chapter, references to 'he' and 'his' should be read to include 'she' and 'her'.

## THE UNBORN BABY

*Christine is 38. She has a daughter, Katie, aged 18 months and is now 27 weeks pregnant with a second child. Christine abuses alcohol and has just been evicted from her lodgings. She and Katie are now living in overcrowded accommodation with her new boyfriend. Christine does not want to go ahead with the pregnancy. Ultrasound at 26 weeks suggested but could not confirm that the fetus might have congenital cardiac abnormality and that it would need to be watched by further regular ultrasound examinations to determine whether there will be a definite cardiac abnormality.*

Historically, the law attempted to preserve human life from an early fetal stage by criminalising abortion. This did not deter those pregnant women who felt that their own existence and that of their existing families would be emotionally and financially impoverished by being forced to bear children against their will. Indeed the stance adopted by the criminal law merely drove women to seek clandestine abortions and led to countless numbers dying from the activities of unqualified back street abortionists in poor and unsanitary conditions.

It was not until 1967 that the **Abortion Act** introduced a more enlightened attitude to abortion. Under the present law, if the woman is less than 24 weeks pregnant, she will not find it particularly difficult to obtain an abortion as long as she can convince a recognised medical practitioner that she is utterly opposed to the idea of bearing the child to term [4]. Nevertheless, the law takes the view that the older fetus is entitled to a greater degree of protection and so the woman whose pregnancy has continued for longer than 24 weeks, as in the scenario above, will find it much more difficult to satisfy the law on abortion [5]. If the tests carried out on Christine's unborn baby had shown clearly that there was a substantial risk of the child being born seriously handicapped, then there is little doubt that she would obtain an abortion [6]. Unfortunately, tests do not always produce such unequivocal results and she may have to give birth to the baby before the extent of the disabilities can be clarified [7].

## THE SEVERELY DISABLED NEWBORN BABY

*Christine does not undergo an abortion and gives birth to a baby boy, Ben, who is mentally and physically handicapped. His birth defects create doubts over his ability to survive. Christine begs the doctors to 'let him die'.*

In the event of a woman giving birth to a child with multiple disabilities, the law provides the medical profession with few clear answers on how to manage the child's future care. Whilst it may be lawful to terminate the life of the severely handicapped child whilst in the womb, the deliberate

destruction of a newly born child with those same handicaps may amount to a serious offence punishable by imprisonment. Few would wish to encourage parents to demand perfection in their offspring, since this might lead to a downgrading by society of those born with even slight 'abnormalities'. Nevertheless, case law shows that the path trodden by those working in neonatal intensive care units is a perilous one [8] so far as the law is concerned. The relevant legal principles are not clear cut and depend largely on the degree of disability involved. At one end of the spectrum, the child's handicaps may be so severe that the medical team may wish to advise the child's parents that his life will be quite intolerable and that it would be better for him to be allowed to die. But at the other end, the child may be born with a relatively mild abnormality, such as Down's syndrome and with a good prognosis for a comparatively normal life. Whatever the medical prognosis, the child's parents may have their own views about the desired outcome of treatment.

In 1981, the celebrated trial of Dr Leonard Arthur, a distinguished paediatrician, charged with the murder of a child born with Down's syndrome warned the medical profession of the dangers of complying with parental wishes over the treatment of disabled children. The parents had indicated that they did not want their child to survive and so Dr Arthur set in motion a course of treatment described as 'nursing care only', having administered a sedative drug which suppressed the baby's appetite. The baby died of bronchopneumonia 57 hours after birth and Dr Arthur was charged with murder [9]. Although he was finally acquitted of all charges, the mere fact that they were brought against such a distinguished member of the medical profession reminded all involved in the care of handicapped neonates that parental wishes constitute no defence in law to criminal charges based on the deliberate killing of a child. Although the case did not particularly clarify the principles of criminal law relevant to the care of handicapped children [10], the trial demonstrated that the sanctions of the criminal law may provide a valuable deterrent to those tempted to follow Dr Arthur's example in following parents' wishes to hasten the death of a disabled newborn baby.

In practice, the principles of civil law provide a more direct and effective means of protecting a disabled child whose parents reject him. These may be used to ensure that he receives essential treatment, despite this being against their wishes. Indeed, this had been demonstrated in 1981, before Dr Arthur was charged with murder, when a local authority, against the wishes of rejecting parents, used the High Court's wardship jurisdiction to obtain authorisation for treatment of another Down's syndrome child born with an intestinal blockage [11].

Neither of the Down's babies discussed above was born with disabilities so severe that they were already dying or could only be kept alive with invasive life-sustaining medical treatment. This latter type of situation

presents even greater legal and ethical problems to medical practitioners. The courts have acknowledged that although a high respect for the sanctity of human life imposes a strong presumption in favour of taking all steps capable of preserving it [12], in some cases the quality of life available to the child will be so poor that it would be against the child's best interests to strive to keep it alive. The difficulty is to decide how poor the child's quality of life must be before it is reasonable to reach such a conclusion [13]. It is clear that doctors must exercise their own clinical judgement and care for the child in accordance with good medical practice, with the consent of the parents or the court [14]. If court authorisation is sought for withholding treatment which would prolong the life of a severely disabled child, the court will be guided by the views of the medical profession on what is in the child's best interests, including information on the predicted quality of life if treated and the type of appropriate treatment, including the amount of pain and suffering involved in such treatment [15]. It has been stressed, however, that though the courts may sanction the medical team taking no steps to prolong the child's life, they will never sanction steps to terminate the child's life [16]. In this way the law maintains the essential distinction between deliberately killing a child, which is a serious criminal offence whatever the circumstances, and failing to provide life-sustaining treatment, which may be in the child's best interests. Although court authorisation for withdrawal of treatment is strictly unnecessary if both the parents and their medical advisers agree that the child's quality of life will be intolerably poor if his or her life is prolonged, they may feel more secure having obtained it [17].

*Christine is persuaded to accept her baby Ben, who gradually gains weight and strength. Nevertheless, he develops severe central cyanosis by the age of three months and is shown to have tetralogy of Fallot. Open heart surgery is indicated. Christine however has recently become a Jehovah's Witness and is vehement that she would not permit a blood transfusion during the surgery which is rapidly becoming necessary.*

There may be times when doctors come into conflict with parents over the treatment of children, because of the parents' strong religious views about the type of medical treatment proposed by the medical staff. The most common situation where such a conflict may arise is that involving parents, who as Jehovah's Witnesses may be utterly opposed to their child receiving blood transfusions. Legally, medical staff do not need consent before giving life-saving treatment to a child against the wishes of his or her parents [18]. Nevertheless, the 'defence of necessity' is uncertain in scope, and case law indicates that court authorisation should normally be sought by hospitals, even in life-saving cases, if the child's parents oppose such treatment [19]. A court order will be granted overruling the parents'

objections and authorising such treatment, if it is considered by the court to be in the child's best interests [20].

### THE DISABLED SCHOOL-AGED CHILD

*Christine's child, Ben, survives his early illness and despite his physical and mental disabilities, his health improves. He reaches primary school age but his learning difficulties make it impossible for him to attend the local primary school. Christine, who now has two younger children, is finding it increasingly difficult to look after him at home.*

Ben's upbringing as a disabled child will be affected in numerous ways by the **Children Act 1989**. In particular, the duties of local authorities are increased in relation to families like Christine's. The Act promotes the principle that parents may require help and support in bringing their children up themselves and that the provision of family support services may be a far better option for a child like Ben, than arranging for him to be cared for away from home. So all local authorities are, through their departments of social services [21], required by the Act to offer a range of family support services to those children and their families within their area who come within the category of families containing '**children in need**' [22].

Every local authority is required to identify those children in need, in their particular area. Social services departments (SSDs) depend on the vigilance of professionals from other agencies, such as health visitors and community paediatricians, to identify families with children in this category who may need assistance. Although the definition of a 'child in need' is extremely wide, the wording is sufficiently vague to allow SSDs some leeway over deciding whether a particular child comes within this category, thus entitling his family [23] to support services. In relation to disabled children, there is far less doubt since the definition specifically refers without qualification to a 'disabled child', as being in need [24]. Once identified, the local authority is under a statutory duty to promote the upbringing of all those children in need in its area, if possible by keeping them within their own families, through the provision of a range of services appropriate to those needs [25]. Since many disabled children require a whole range of services, including, for example, physiotherapy, speech therapy, specialist teaching, nursing support and social work support, it is vital that the various service agencies collaborate and cooperate over provision. Prior to the Children Act 1989, the situation was unsatisfactory, in so far as the differing agencies were under a variety of duties to provide disabled children with services. The 1989 Act attempted to ensure that such children would benefit from a more integrated and coordinated approach to providing for their needs, overall responsibility being vested in the hands of local authorities through their SSDs [26].



Local authorities are encouraged by the 1989 Act to fulfil their coordinating role efficiently by placing them under a duty to maintain a register of disabled children [27] in their area; this should be drawn up in conjunction with local education and health authorities, who are also statutorily obliged to provide services for children with disabilities and special educational needs [28]. The Department of Health has stressed that there is no duty on parents to agree to their children being registered and that it should not be seen as a precondition to the provision of services [29]. Nevertheless, the register is essential since it enables a local authority to identify and then plan effectively for the needs of the children with disabilities within their area.

Once identified, the duty to provide services for disabled children goes further than merely to promote their upbringing; the local authority is required to 'minimise the effect of their disabilities and to give them the opportunity to lead lives which are as normal as possible' [30]. The resource implications of these duties are considerable, since the services provided should not only help in the identification, diagnosis, assessment and treatment of children with physical and mental handicaps, but also help them to adjust to their handicaps and overcome the limitations of mobility and communication in appropriate ways [31]. This may even include the funding and provision of equipment such as communication aids. When planning for an individual child, SSDs are expected to identify which agencies' services best suit the child's needs and draw up a plan for their provision, in partnership with the child's parents. In order to encourage an integrated service, SSDs are authorised by the 1989 Act to request help with their own obligations from any local education authority, housing authority, or health authority [32] and, if asked, these authorities should provide the help, if this would be compatible with their own statutory duties.

A decision on the suitability of services cannot be reached until the child is properly assessed and the Act envisages that all agencies required by other legislation to do assessment work [33] should be required to coordinate this with SSDs. For example, assessment work under the Education Act 1996 relating to a disabled child with special educational needs [34] could be combined with a 'child in need' assessment under the Children Act 1989. If it is possible to bring together in one process assessments for several different purposes, this avoids a family being involved in a confusing variety of different assessment procedures and also enables the child to be seen 'in the round' rather than his needs being viewed separately in terms of being linked to education, health or social care [35].

The promotion by the Children Act 1989 of the concept of partnership with parents, linked with the provision of services, enables SSDs to work with families more constructively than before. They have to plan properly

for children in need and their work with families has to be more open, to ensure that crises do not occur [36]. There is now a far greater willingness to involve parents in decision making and planning and a greater involvement with the child's extended family. The Act has also achieved an improvement in the social work skills involved in monitoring and working closely with families.

So in the scenario above, Christine's son Ben should be identified by his local SSD as being a child in need. He may then be placed on their register of disabled children. An assessment should then be arranged by the SSD, in order to determine what sort of family, health and educational services he and his family require, to 'minimise the effect of his disabilities and to give him the opportunity to lead a life as normal as possible' [37].

*When Ben is 5, his special needs are assessed by the SSD and the local education authority. It is arranged, with Christine's agreement, for Ben to attend a special school for children with learning difficulties. After the first six months, the staff become quite concerned that Ben no longer responds very readily to their attempts to communicate with him and the school head suggests to Christine that he may have a minor hearing problem and that he should be seen by a doctor. Christine tells them that she is 'fed up with doctors' and she has no intention of going near the local health centre again. After some months, it becomes clear to the school staff that Ben may be experiencing some discomfort in his ears but Christine still refuses to seek specialised medical advice about his condition.*

Although they might not categorise Christine's behaviour as abusive, the staff of the special school should be aware that the Children Act 1989 places the SSD under a clear **duty to investigate** [38] any cases where it is suspected that a child in their area is suffering or is likely to suffer 'significant harm' [39]. Despite the fact that it seems unlikely that Ben is currently suffering significant harm, there is a risk that this may occur in the future, since without immediate medical intervention, Ben's hearing might be severely and permanently damaged and his education jeopardised. Obviously, the sooner he sees a doctor the better. A member of staff at the special school should notify the SSD of their concern that Ben is not receiving essential medical attention. A quick examination could probably establish whether he is suffering a hearing loss and its cause, and if all else fails the SSD has the power under the Children Act 1989 to obtain a **child assessment order** to ensure that such an examination takes place [40]. Alternatively, as will be discussed later, the health authority could itself apply to the High Court under the 1989 Act for a **specific issue order** to ensure that Ben receives medical attention [41]. Christine should also be warned that she could be the subject of a criminal prosecution for failing to seek medical attention for Ben [42].

## THE ABUSED CHILD

*It is clear to the staff at Ben's school that at times he is suffering from severe earache and his teacher has also seen Christine being unduly rough with him when she collects him from school. Christine refuses to talk to the staff about Ben.*

If Ben's school head has not yet alerted the SSD of his staff's concerns about Ben, he should do so immediately; inertia cannot excuse an abused child being left unprotected. The SSD is the 'lead agency' in any child abuse investigation and is under statutory duties to investigate cases of suspected child abuse and take appropriate action to protect the child. *Working Together* [43] gives detailed official guidance on how these duties should best be fulfilled and how other agencies are to be involved [44]. This important document sets out the general child protection procedures to be followed; much of this material will have been incorporated into local inter-agency child protection policies and procedures developed by area child protection committees (ACPCs) and all health workers should be familiar with the latest versions of these.

*Working Together* stresses that staff from all agencies have a duty to protect children, are accountable for doing so and must be fully committed to giving interagency support to SSDs. All agencies involved with children, including of course education and health, are expected to be alert to signs of abuse and be ready to pass on concerns to the appropriate social worker so that abuse is detected and acted upon as quickly as possible. Child abuse investigations will normally involve joint working between SSD and the police; whilst the SSD will focus on protecting the child, the police will be primarily concerned with investigating the commission of a criminal offence. Like other practitioners, police officers doing child protection work follow specialised training and the conflicts between police and other professional groups which sometimes characterised child abuse investigations have now become very rare [45].

Sometimes a family doctor may gain information from an adult member of the family which indicates that a child in the family is being abused. In the above scenario, Christine might have confided in her general practitioner that she had been treating Ben roughly. Should he pass this information on to the child protection agencies? Official guidance [46] acknowledges that a doctor may be faced with a conflict between his ethical duties of confidentiality to a parent and his responsibilities to the child. Nevertheless, it stresses that the welfare of children must always be regarded as of first importance, as their age and vulnerability render them powerless to protect their own interests. Thus it concludes that although patients are entitled to expect that information which their doctor learns during the course of a medical consultation will remain confidential,

'Knowledge or belief of abuse and neglect is one of the exceptional circumstances which will usually justify a doctor making disclosure to an appropriate, responsible person or officer of a statutory agency'. In consultations involving children, promises of secrecy should never be given and doctors should also explain that any information gained through an examination may have to be passed on to other agencies such as social workers and the police [47]. Clearly, then, Christine's doctor should certainly pass on any information indicating that Ben may be the subject of abuse to the SSD. He should also ensure, if he examined Ben, that he has compiled contemporaneous and accurate, timed and detailed records with diagrams as appropriate. These should never be amended subsequently, though it is perfectly correct to add additional information, as long as this is timed, signed and dated [48].

Part of the investigation process followed by the SSD will normally involve convening a **child protection conference** at which a decision will be reached on whether protective intervention is necessary and whether to place the child on the **child protection register** in order for the child's progress to be monitored by the SSD. The conference will be a multi-disciplinary one and in the scenario above, all those professionals who have had any previous involvement with Ben and his family will be invited, in order to compile as much information as possible about Ben and his background. It is very likely that Christine herself will also be invited to attend the conference [49] so that as full a picture as possible can be compiled about the family's circumstances and Christine's problems, if any. The child protection conference plays an extremely important part in the child protection process by providing an opportunity for all those previously concerned with the family to pool and evaluate their information about the family in order to assess the degree of risk to the child. A decision to place him on the register would result in a **child protection plan** being drawn up in consultation with Christine to ensure that Ben receives better care in future and that Christine herself receives any extra help with his care that is deemed to be necessary. Since Ben is a 'child in need' [50], the SSD is obliged to provide his family with appropriate support services.

*No steps are taken to convene a child protection conference because Christine cooperates fully with the SSD and agrees to take Ben to be examined at the medical centre. He is diagnosed as having moderate deafness due to chronic secretory otitis media or 'glue ear' and is prescribed antibiotic medication; a referral is also made to the ear, nose and throat clinic for possible surgery. Christine is given extra assistance with Ben's care and with her other children.*

*Some months later, however, the staff at the special school become worried by Ben missing days at the school with no warning or explanation from*

*Christine. When he appears he looks rather dirty and unkempt. One day Ben turns up with a black eye and bruised cheek and does not reappear the next day. After a couple of days, the school head contacts the SSD indicating his concern. A social worker visits Christine at her flat and is refused admittance by Christine's new boyfriend. He also refuses to allow the social worker to see Ben.*

Obviously information of the kind passed to the SSD by the school head about a child who has previously been the focus of concern should be followed up quickly with further investigations to establish whether Ben is safe and well cared for. Few would argue with the presumption that parents are the best people to bring up their children but, sadly, family life can go badly wrong and under the Children Act 1989, the SSD has powers to intervene rapidly, on an emergency basis, to remove a child suspected of suffering from abuse from his parents, against their will.

But although social workers have wide powers to protect children by removing them from their parents on the authority of an **emergency protection order** obtained from the courts, such orders have to be used sensitively in order to maintain a proper balance between protecting children and respecting family privacy. In most cases, even after a child's removal from his parents on a compulsory basis, the social workers will have to continue working with the family; this continuing work will be made much easier if initial relations between the SSD and the child's parents can be constructive rather than hostile. Moreover, the general public quite properly voices extreme disapproval and hostility if emergency powers are exercised in an over-aggressive way, which ignores the parents' rights to be consulted and involved in what happens to their children. This was well demonstrated when in Cleveland and later in Orkney, distressed children were removed from their parents by social workers with no notice or proper explanation. Perhaps the most important point about these emergency powers, is that the sudden removal of a child from his home against the wishes of his parents is a traumatic action which may itself emotionally damage the child, particularly if he is not allowed any contact with his parents during his stay away from home. So this is regarded as a measure to be used only in the last resort.

In the scenario above, the fact that Ben's family refuses to let the social worker in to see Ben will almost certainly lead the SSD to seek an emergency protection order from the court. This is because as part of their duty to investigate whether Ben is suffering from significant harm, the SSD is obliged to take reasonable steps to obtain access to him [51]. If an adult unreasonably refuses to allow the social worker investigating the case to see the child, social services are obliged then to apply to the courts for an emergency protection order against the parents, authorising the child's removal [52]. And if the SSD decides to do this, it may also obtain a warrant

from the court for the police to assist them gain access by use of force [53].

An emergency protection order can be obtained from the courts very quickly, even over the telephone, and without the parents having a chance to oppose it. The order may last for up to eight days with the possibility of being renewed for a further seven. Nevertheless, as soon as 72 hours have elapsed after the order was made, the child's parents have the right to go to court to ask for the order to be discharged [54].

An emergency protection order gives the local authority parental responsibility for the child throughout its currency [55]. Even if the SSD obtains such an order and under its authority removes Ben from home, Christine will probably be allowed to visit him. This is because the statutory provisions contain a presumption that throughout the duration of such orders, parents have a right to maintain reasonable contact [56] with their children, unless the court directs otherwise. Continued contact with parents will reduce the trauma experienced by children being removed abruptly from home as in Cleveland and Orkney. In Ben's case, the court will almost certainly be asked by the local authority to include in the emergency protection order a direction authorising the SSD to arrange for him to be medically and psychologically assessed [57], in order to establish his physical and developmental state.

The emergency protection order can only last at the most for 15 days, and during that time the SSD may establish to its own satisfaction that Ben has been physically abused by Christine or her boyfriend or both and that they cannot trust them sufficiently to allow Ben to return home. In these circumstances the SSD may feel that it has no choice but to institute **care proceedings** in the local magistrates' court with a view to obtaining a **care order**. By virtue of such an order [58], the local authority will acquire parental powers and responsibilities over Ben until he reaches 18 [59], unless the court discharges it sooner. On the authority of this order, the local authority can decide all matters to do with his upbringing, in particular where he is to live, and they can keep him away from his parents for its duration.

Before obtaining a care order, the local authority must satisfy the court that the child is **suffering or is likely to suffer significant harm** attributable to the lack of a reasonable standard of parental care [60]. Although there are complicated definitions of the concept of 'harm', and there is none of 'significant', it is nevertheless clear that the formula will cover an extremely wide range of parental neglect and abuse. It is important to notice that unlike many other legal systems, the Children Act 1989 does not set out a long and detailed list of specific circumstances which justify taking a child into state care. Past experience [61] has shown that however carefully a list of grounds is drawn up, gaps are inevitable. The Children Act 1989 relies on the more general 'significant harm'

formula which concentrates on present concerns relating to the child suffering harm. Moreover, by also referring to the likelihood of harm in the future, it allows preventive action to be taken in cases of predicted harm.

The court can only make a care order if satisfied that the order is in the child's best interests [62]. Before the court grants the local authority's application, it must also be satisfied that the care order will be effective and will achieve an actual improvement in Ben's circumstances [63]. This last provision is very important since it is part of the underlying philosophy of the Act that the integrity of the family should be respected, and that the state should refrain from interfering, unless to do so through a court order would have some positive contribution to make towards the child's welfare.

## THE MATURE TEENAGER

*Christine's elder daughter Katie is now 13. Christine is very strict with her and is determined that she does not get involved with boys at too early an age. Katie has a boyfriend and wants to go 'on the pill' but is determined not to let Christine know that she is sexually active. She consults a doctor about this.*

The law is clear that a doctor is unable lawfully to treat without consent, a patient of whatever age, except to give life-saving treatment to a patient who is dying and who has not refused such treatment [64]. In the absence of a valid consent the treatment may result in criminal charges of assault or battery, or a civil claim for damages for trespass to the person [65]. This principle applies whether the patient is adult or child, but if the patient is a young child [66], consent will normally be provided by the child's parents or those with parental responsibility for him [67]. As discussed above, if the child's parents refuse consent to essential treatment, court authorisation could be obtained instead. The law becomes much more complicated however if the patient is a teenager.

One of the most celebrated court cases testing the law relating to teenagers involved Mrs Gillick who attempted unsuccessfully to prevent teenage girls obtaining contraceptive advice and treatment without the doctor first consulting their parents [68]. The decision of the House of Lords in *Gillick* is authority for the general proposition that a child under 16 may lawfully be given medical advice and treatment without parental agreement, providing that the child has achieved sufficient maturity to understand fully what is proposed [69]. If the child is suffering from a mental illness or emotional disturbance which undermines his ability to appreciate the implications of the treatment, then the consent of his

parents or court authorisation for therapeutic treatment should be obtained instead [70].

The *Gillick* decision also more specifically authorised doctors to provide a teenage girl with contraceptive advice and treatment, without consulting her parents. Nevertheless, at least one of their Lordships considered that a doctor should only do so if he is fully satisfied that five quite rigorous conditions are complied with. These are as follows:

1. the girl must understand his advice;
2. she cannot be persuaded to inform her parents of the matter;
3. she is very likely to have sexual intercourse with or without contraceptive treatment;
4. it is likely that her physical or mental health would suffer should she not receive the treatment; and
5. her best interests require her to receive the treatment without her parents' consent [71].

These requirements make it far from easy for a doctor being consulted by Katie, in the scenario above, to decide whether he may prescribe contraceptives without Christine's knowledge or consent. If he does decide that she is mature enough to receive contraceptive treatment, according to the majority of the House of Lords he will not be criminally liable if he goes ahead and provides it, as long as he honestly considers this to be in her best interests. He also has a duty to keep this matter confidential from her parents. By contrast, according to General Medical Council advice, if he is not satisfied that the girl is sufficiently mature to appreciate the contraceptive advice or treatment and is unable to persuade her to confide in her parents, he may then tell Christine himself about his consultation with Katie. Nevertheless, he should only do so if he is convinced that the disclosure is essential to Katie's best medical interests and he must inform her of this intention before telling them [72]. Such a disclosure could only be justified in the most exceptional circumstances; doctors advising teenagers will fully appreciate that a teenager experiencing such a breach of confidence might feel reluctant to seek medical advice in the future [73]. The situation is different if the doctor suspects that Katie is being exploited or abused. In these exceptional circumstances her interests are paramount and he should try to persuade her to agree to confidentiality being relaxed. Whether or not she agrees, he should normally disclose any relevant information to the SSD or to the police [74].

Although the *Gillick* decision had far-reaching medical implications, the effects of the decision were potentially much more dramatic. Many took it to indicate that the mature teenager, or 'Gillick competent' teenager, could consent to any action or procedure without involving his parents, providing he was mature enough to comprehend the full implications of



what was being consented to [75]. Consequently it was argued that a teenage child could now demand the right to take charge of his own upbringing and make decisions about where he would go to school or make his home, against his parents' wishes [76]. Nearly 20 years on, it is now clear that the law has not changed as radically in relation to the rights of teenagers as some had imagined in the aftermath of *Gillick*. Nevertheless, the decision clearly influenced the drafting of section 8 of the Children Act which allows mature children to apply for various orders determining differing aspects of their upbringing, including an order authorising them to live with someone other than their own parents [77].

*Christine's daughter Katie decides that she is too fat and starts trying various diets. One day she faints in school and when she is examined by the school nurse, it becomes clear that she is dangerously underweight. Christine says that she cannot get Katie to eat properly. Katie is admitted to a medical unit which specialises in treating eating disorders but she refuses to cooperate with their treatment.*

It had been assumed that the decision in *Gillick* not only enabled a *Gillick* competent teenager to consent to most forms [78] of health care, but also enabled him to refuse treatment against the advice of his parents and medical advisers [79]. This interpretation of the law is reflected in various provisions in the Children Act 1989 which ensure that a child involved in child protection litigation has the right to refuse to undergo an assessment if deemed to be old enough to reach an informed decision on such an issue [80].

More recently, however, the English courts were confronted with the question whether the wishes of a mature teenager could be overruled if he was refusing essential medical treatment, in circumstances where such refusal would seriously impede his development or risk his death. The judgements in two important cases [81] established that in certain situations, the courts and even parents have the right to prevent teenagers taking such life-threatening risks with their healthcare by refusing essential treatment. The most celebrated of these [82] involved a seriously ill 16-year-old girl suffering from severe anorexia nervosa, who refused to cooperate with her medical carers over her treatment. The Court of Appeal decided that her refusal to agree to treatment was not insuperable because the medical staff could obtain legal consent to her treatment from an alternative source, either her parents or the court. This was so even if she was *Gillick* competent and even if she was over 16 [83], as long as the treatment was in her best interests.

As a result of this case law, many consider that the law now presents an illogical and confused situation [84]. On the one hand, on the authority of the decision in *Gillick* [85], a medical team is legally entitled to rely on the consent of a *Gillick* competent teenager of any age, to provide medical

treatment that the team considers to be in his best interests, even if the teenager's parents oppose such treatment [86]. On the other hand, the medical team is entitled to go ahead with the treatment of a Gillick competent child of any age, even if the child himself is utterly opposed to the treatment [87], as long as consent to the treatment is obtained from some other source, such as the child's parents [88] or the court [89]. Thus the law maintains an important distinction between a teenager who consents to treatment, which consent his parents have no authority to veto without court assistance, and the teenager who refuses to undergo treatment, which refusal his parents can override, by consenting to it themselves, without court assistance [90].

By way of further complication, it appears that whatever the age and maturity of the child, certain types of medical procedures, by virtue of the danger attaching to them or their irreversibility or a combination of both, require court authorisation prior to being carried out. Thus court authorisation must always be obtained before a non-therapeutic sterilisation is carried out on a girl [91] under the age of 18 [92]. It is probable that court authority should also be required for organ donations [93].

As a postscript to the discussion of the case involving the anorexic teenager, it now appears from even more recent litigation that a patient with anorexia nervosa may be force-fed without court authorisation if the medical team is prepared to use the provisions of the mental health legislation [94].

## CONCLUSIONS

This chapter has discussed a number of situations which could confront any practitioner in child health. It is obvious that the law relating to the health and development of children does not always give clear or satisfactory guidance to those faced with difficult decisions. Unfortunately, not knowing the law, or being unclear about the impact of its provisions, is no defence to breaking it and when in any doubt about medicolegal matters, further and more specialised advice should be sought. Undoubtedly the Children Act 1989 has eased matters by incorporating many of the relevant principles in one body of legislation. Moreover, compared with many other pieces of legislation, the 1989 Act is couched in relatively user-friendly language and should certainly always be consulted over the scope of duties owed by local authorities to children and their families.

There are a number of guiding principles to bear in mind.

1. Ignorance is no defence to breaking the law. If in doubt, seek advice from your senior. If you are the most senior in line, you have a duty to know whom to consult.

2. Law and practice relating to children changes rapidly and up-to-date training on this should be available to all. If you have not been on a training course in recent years, however senior you are, you risk being placed in a position of some vulnerability.
3. You should be familiar with the latest version of the child protection policies and procedures developed by your local ACPC. These are routinely circulated to all hospitals, community paediatric headquarters and general practices.
4. Child health workers who suspect child abuse should always pass over this information, in the first place to the SSD, which has prime responsibility for investigating reports of children suffering abuse and for taking protective action. It is its responsibility to liaise with other agencies, such as the police; friction between agencies over joint working has almost wholly disappeared.
5. Issues of confidentiality arise in many medical matters. Knowledge or belief that a child is being abused is one of the exceptional circumstances justifying disclosure of this information to the relevant agencies.
6. As in all medicolegal matters, it is vital to compile contemporaneous and accurate, timed and detailed records, with diagrams as appropriate. These should never be amended subsequently, though it is perfectly correct to add additional information, as long as this is timed and dated.

## ACKNOWLEDGEMENT

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## NOTES AND REFERENCES

1. *Gillick v. West Norfolk Area Health Authority* [1985] 3 All ER 402.
2. *Report of the Inquiry into Child Abuse in Cleveland* (1987) Cm 412.HMSO, London.
3. The need for liaison is also emphasised by Department of Health, Department of Education and Science, and the Welsh Office (1991) *Working Together Under the Children Act 1989: A Guide to Arrangements for Interagency Cooperation for the Protection of Children from Abuse*. HMSO, London. Hereinafter referred to as *Working Together*.
4. Section 1(1)(a) of the Abortion Act 1967 (as amended by s37 of the Human Fertilisation and Embryology Act 1990) authorises an abortion to be carried out up to the 24th week of pregnancy as long as it is performed by a recognised medical practitioner and two registered practitioners have formed the view in good faith that the continuation of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental

- health of the pregnant woman or any existing children of her family. This provision is often liberally interpreted.
5. If the pregnancy has continued for more than 24 weeks, then according to s1(1)(b)(c) and (d) of the Abortion Act 1967 it can only be legally terminated if two registered practitioners have formed the view in good faith either: (b) that the termination is necessary to prevent grave permanent injury to her physical or mental health; or (c) that the continuance of the pregnancy would involve risk to the mother's life greater than if the pregnancy were terminated; or (d) that there is a substantial risk that if the child were born, it would suffer from such physical or mental abnormalities as to be seriously handicapped.
  6. Abortion Act 1967 s1(1)(d).
  7. See Mason, J. K., McCall Smith, A. (1994) *Law and Medical Ethics* 4th edn, Butterworths, Oxford, esp. Chaps. 5 and 6.
  8. *Ibid* Chapter 7.
  9. As a result of further evidence emerging, the charge was changed from murder to attempted murder. *R v Arthur*, *The Times*, 6 Nov 1981.
  10. Some claimed that the direction to the jury given by Farquharson J confused the legal situation: see *inter alia* Gunn, M. J. and Smith, J. C. [1985] Crim LR 705 and Kennedy, I. (1992) *Treat Me Right: Essays in Medical Law and Ethics*, Oxford University Press, Chapter 8.
  11. *Re B* [1981] 1 WLR 1421 involved an infant suffering from Down's syndrome, complicated by an intestinal obstruction which, though potentially fatal, could be remedied by surgery thereby giving her a 20–30-year life expectation. The child's parents, on being informed of the child's condition, refused consent to the surgery, being of the view that it would be kinder to let her die. On the intervention of the local authority, the child was made a ward of court and performance of the surgery was authorised and directed by the court as being in the child's best interests. N.B. In 1981, before the enactment of the Children Act (hereinafter referred to as the CA) 1989, it was appropriate for the local authority to utilise the wardship procedure to obtain authorisation for treatment. After the implementation of the CA 1989, a local authority should apply instead to the High Court for a **specific issue order** under s8 of the 1989 Act [see note 19, below] or seek the aid of the High Court through its **inherent jurisdiction**.
  12. See Taylor L. J. in *Re J* [1990] 3 All ER 930 at p. 943.
  13. Thus in *Re B* (note 11, above), Templeman LJ suggested that the court had to decide 'whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die' at p. 1424. In *Re J* [1990] 3 All ER 930, Taylor LJ suggested that there were 'extreme cases in which the court is entitled to say: "The life which this treatment would prolong would be so cruel as to be intolerable"' at p. 944.
  14. *Re J* [1992] 4 All ER 614.
  15. See *Re C* [1990] Fam 26, in which the court gave the hospital authority to give a 4-month-old massively handicapped and terminally ill baby, treatment which would relieve her suffering and allow her to die with dignity. See also *Re J* [1990] 3 All ER 930 at p. 943, *Re J* [1992] 4 All ER 614, and *Re C* [1996] 2 FLR 43.
  16. Per Taylor LJ in *Re J* above [1990] 3 All ER 927 at p. 943.
  17. E.g. *Re C* [1996] 2 FLR 43.

18. The defence of necessity would apply in most emergencies, as discussed by Brazier, M. (1992) in *Medicine, Patients and the Law*, 2nd edn, Penguin Books, Harmondsworth, at pp. 90–92. See also Kennedy, I. and Grubb, A. (1994) *Medical Law; Text and Materials*, 2nd edn, Butterworths, London, at pp. 324–325 and more shortly by Montgomery, J. [1993] 5 JCL 117.
19. The correct procedure for obtaining court authorisation is for the applicant [i.e. the local authority or area health authority] either to apply under s8 CA 1989 for a specific issue order, having first obtained court leave to do so under s10 CA 1989, e.g. *Re R* [1993] 2 FLR 757 or to invoke the aid of the High Court's inherent jurisdiction, e.g. *Re O* [1993] 2 FLR 149.
20. E.g. *Re R* [1993] above. See also *Re O* [1993] above – both cases involved opposition from parents who were Jehovah's Witnesses to life-saving blood transfusion treatment for seriously ill babies. This is discussed further below.
21. Hereinafter referred to as SSDs or the SSD.
22. Section 17(10) of CA 1989 provides that a child shall be taken to be in need if '(a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority under this [Act]; (b) his health or development is likely to be significantly impaired, or further impaired without the provision for him of such services; or (c) he is disabled'.
23. For the purposes of the Act, references to 'family' includes anyone with parental responsibility for the child and any other person with whom he has been living.
24. Section 17(11) CA 1989 mirrors the National Assistance Act 1948 definition of disability by defining a child as being disabled 'if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed; ...'
25. The range of family support services envisaged for families containing children in need is very wide. It includes the provision of day care [CA 1989 s18]; suitable accommodation if the child's parents are prevented from providing it [CA 1989 s20] and a further range of services such as *inter alia*: occupational, social, cultural or recreational activities; home help; holiday provision; day centre facilities etc. [CA 1989 sched. 2].
26. See Department of Health (1991) *The Children Act 1989 Guidance and Regulations Volume 6 Children With Disabilities*, HMSO, London, esp. Chap. 4.
27. CA 1989 Sched. 2 para. 2.
28. See Education Act 1996 Part IV esp. ss312–323. N.B. A child is deemed to have 'special educational needs' if he or she 'has a learning difficulty which calls for special educational provision to be made for him' [Education Act 1996 s312(1)] and is deemed to have a 'learning difficulty' 'if: (a) he has a significantly greater difficulty in learning than the majority of children of his age, (b) he has a disability which either prevents or hinders him from making use of educational facilities of a kind generally provided for children of his age in schools within the area of the local education authority, or (c) he is under the age of five and is, or would be if special educational provision were not made for him, likely to fall within paragraph (a) or (b) when over that age'. [Education Act 1996 s312(2)]. See generally N. Harris (1995) *The Law Relating to Schools*, Tolley Publishing, Croydon, Surrey, Chap. 9.

29. See Department of Health (1991) *The Children Act 1989 Guidance and Regulations Volume 6, Children With Disabilities*, HMSO, London, para. 4.2.
30. CA 1989 Sched. 2 para. 6.
31. Department of Health (1991) *The Children Act 1989 Guidance and Regulations. Volume 2 Family Support, Day Care and Educational Provision for Young Children*, HMSO, London, para. 2.18.
32. CA 1989 s27.
33. E.g. assessments under the Education Act 1996, the Disabled Persons Act 1986 and the Chronically Sick and Disabled Persons Act 1970 – see CA 1989 sched. 2 para. 3, as amended.
34. See Department of Health (1991) *The Children Act 1989 Guidance and Regulations. Volume 6 Children With Disabilities*. HMSO, London, para. 5.1.
35. *Ibid* n. 34.
36. SSDs are obliged to do more preventive work than before. See CA 1989 sched. 2 para. 4(1) which requires every local authority to ‘take reasonable steps, through the provision of services . . . to prevent children within their area suffering ill-treatment or neglect’.
37. CA 1989 Sched. 2 para. 6.
38. S47(1) CA 1989: ‘Where a local authority . . . have reasonable cause to suspect that a child who lives, or is found, in their area is suffering, or is likely to suffer, significant harm, the local authority shall make, or cause to be made, such enquiries as they consider necessary to enable them to decide whether they should take any action to safeguard or promote the child’s welfare.’
39. Although there is no attempt in the CA 1989 to define ‘significant’, ‘harm’ is defined by s 31(9) in a composite way. Thus for the purposes of the Act, “‘harm” means ill-treatment or the impairment of health or development; “development” means physical, intellectual, emotional, social or behavioural development; “health” means physical or mental health; and “ill-treatment” includes sexual abuse and forms of ill-treatment which are not physical’.
40. Under s43(1) CA 1989 the local authority can apply for a court order called a **child assessment order**, the grounds being that the applicant has reasonable cause to suspect that the child is suffering or likely to suffer significant harm, that an assessment of the child’s health or development, or of the way in which he has been treated is required to enable the applicant to decide whether or not the child is suffering, or is likely to suffer, significant harm, and that without such an order it is unlikely that such an assessment will take place.
41. According to *Re R* [1993] 2 FLR 757, the applicant (i.e. in this case the district health authority) could apply under s8 Children Act 1989 for a specific issue order, authorising appropriate medical treatment, having first obtained court leave under s10 to apply for such an order: see discussed in more detail below.
42. Under Children and Young Persons Act 1933, section 1(2)(a).
43. *Working Together*.
44. *Working Together* at pp. 17–20 contains guidance specifically directed at health services.
45. E.g. poor working relations between the police and social workers in Cleveland had contributed to the mismanagement of the child sexual abuse investigations; see *Report of the Inquiry into Child Abuse in Cleveland 1987*. Cm. 412, Chap 6.

46. Department of Health, British Medical Association, and Conference of Medical Royal Colleges (1994) *Child Protection: Medical Responsibilities, Guidance for Doctors working with Child Protection agencies. Addendum to Working Together Under the Children Act 1989*, HMSO, London, at paras. 4.1–4.4.
47. *Ibid*, at para. 4.4.
48. Thanks are due to Professor Euan Ross, for providing this guidance.
49. *Working Together* stresses the importance of involving parents in all stages of child protection work and in general of including all parents at child protection conferences; see paras. 6.11–6.15.
50. Under s17(10) CA 1989, see note 22.
51. CA 1989 s47(4).
52. Unless they are satisfied that his welfare can be satisfactorily safeguarded without their doing so: CA 1989 s47(6). The grounds for obtaining an emergency protection order are broadly that the applicant has reasonable cause to believe that the child is likely to suffer significant harm or if the applicant is a local authority or the NSPCC that access to a child (who is already the subject of investigation because there are suspicions of abuse) is being unreasonably refused and there is reasonable cause to believe that access to that child is urgently required: CA 1989 s44(1)(b)(ii).
53. CA 1989 s48(9).
54. CA 1989 s45 contains provisions about the duration of an emergency protection order.
55. Although the CA 1989 contains no helpful definition of the term 'parental responsibility', broadly it means that whoever has it has the right to make all important decisions relating to the child's upbringing.
56. CA 1989 s44(13). N.B. the SSD need allow only telephone or letter contact between child and parent if it considers such limited contact to be 'reasonable' in the circumstances.
57. See CA 1989 s44(6). The court must respect the refusal of a child to undergo such an assessment if it considers he is of sufficient understanding to make an informed decision: CA 1989 s44(7). Nevertheless, the local authority may use the High Court's inherent jurisdiction to obtain authorisation for such an assessment against the wishes of a mature child: as in *South Glamorgan County Council v W and B* [1993] 1 FLR 574, see note 80 below.
58. CA 1989 s33.
59. CA 1989 s91(12).
60. CA 1989 s31. See definitions of 'harm' set out in note 39.
61. Such a list of 'care grounds' was employed under the previous legislation, the Children and Young Persons Act 1969, which was replaced by the Children Act 1989.
62. CA 1989 s1(1). When deciding this the court must consider a list of factors having a bearing on the child's best interests, including the child's own wishes: CA s1(3). The court is also required to bear in mind that delay in reaching a decision will prejudice the child's welfare CA 1989 s. 1(2).
63. CA 1989 s1(5) which provides that 'Where a court is considering whether or not to make one or more orders under this Act with respect to a child, it shall not make the order or any of the orders unless it considers that to do so would be better for the child than making no order at all.'
64. i.e. the defence of necessity would apply in most emergencies: see note 18 above.

65. See Lord Donaldson MR in *Re W* [1992] 4 All ER 627 at p. 633.
66. i.e. a child too immature to be 'Gillick competent', see below.
67. If the parents oppose essential treatment, court authorisation should be sought, see notes 19 and 20 above.
68. *Gillick v. West Norfolk Area Health Authority* [1985] 3 All ER 402.
69. See Lord Scarman in *Gillick* [1985] above at p. 423 and comment by M. Brazier (1992) in *Medicine, Patients and the Law*, 2nd Edn. Penguin Books, Harmondsworth, at p. 335.
70. E.g. *Re R*. [1991] 4 All ER 177: girl of 15 suffering from mental illness and in her lucid moments refused to consent to drug therapy. Court of Appeal held that she was not Gillick competent and authorised the treatment on her behalf. See also *Re K, W and H* [1993] 1 FLR 854 in which the court held that there had been no need for the hospital to seek the court's authorisation before treating three mentally disturbed teenagers aged 15 with drug therapy, because their parents had already consented on their behalf.
71. See Lord Fraser in *Gillick v. West Norfolk Area Health Authority* [1985] above at p. 413.
72. See General Medical Council (1993) *Professional Conduct and Discipline: Fitness to Practise*, GMC, London, para. 84. This issue is discussed in Mason, J. K., McCall Smith, A. (1994) *Law and Medical Ethics* (4th Edn), Butterworths, Oxford, at pp. 178–180.
73. See *Confidentiality and People under 16: Guidance issued jointly by the BMA, GMSC, HEA, Brook Advisory Centres, FPA and RCGP* (1994).
74. *Duties of a Doctor, Confidentiality: Guidance from the General Medical Council* (1995), para. 11 and *Child Protection: Medical Responsibilities, Guidance for Doctors working with Child Protection agencies. Addendum to Working Together Under the Children Act 1989*. Department of Health, British Medical Association, Conference of Medical Royal Colleges (1994) esp. Part 4.
75. Lord Scarman said in *Gillick v. West Norfolk Area Health Authority* [1985] (see above) at p. 422 '... parental right yields to the child's right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision'.
76. E.g. see J. Eekelaar in [1986] NLJ 184.
77. Under s8 CA 1989 a child who has satisfied the court that he has sufficient understanding to make the application, can apply for a **residence order** determining where he is to live: incorrectly described by the media as 'an order divorcing the child from his parents'.
78. It appears that there are some types of treatment that by virtue of their seriousness or irreversible nature, are beyond the scope of the child's own capacity to consent and indeed are even beyond the scope of the parents' capacity to consent, e.g. non-therapeutic sterilisation. See below.
79. E.g. *Re E* [1993] 1 FLR 386. Boy of nearly 16, ill with leukaemia, refused to agree to undergo treatment involving blood transfusions because he was a Jehovah's Witness, like his parents. His condition deteriorated very rapidly. The hospital authority made him a ward of court and the court authorised them to override his objections on the sole basis that he was not Gillick competent. It was clear that Ward J felt that he would have been bound to adhere to the boy's wishes had he considered him to be Gillick competent.
80. Thus the court is warned by s38(6) that if, in the course of interim proceedings for an interim supervision order or an interim care order, it makes a direction



for the child to undergo a medical or psychiatric examination or other assessment, that if the child is of sufficient understanding to make an informed decision, he may refuse to submit to the assessment. Similarly, ss43(8) and 44(7) contain the same warning if the court makes a direction for an assessment to be carried out on a child in the context of an emergency protection order or a child assessment order. These rulings may be evaded by authorisation of the High Court under its inherent jurisdiction, e.g. in *South Glamorgan County Council v W and B* [1993] 1 FLR 574 a local authority gained the High Court's authority under its inherent jurisdiction to go ahead with the psychiatric assessment and treatment of a Gillick competent girl of 15 against her will. The court did not consider that the direction in s38(6) CA 1989 hampered their powers under the inherent jurisdiction.

81. *Re R.* [1991] above see note 70 and *Re W* [1992] 4 All ER 627.
82. *Re W* [1992] 4 All ER 627.
83. It was an extremely controversial aspect of the decision in *Re W* that it related to teenagers aged 16 and over. It had formerly been assumed that s8(1) Family Law Reform Act 1969 gave a teenager complete autonomy over his own health care on his 16th birthday. S8(1) states that 'the consent of a minor who has attained the age of 16 years to any surgical, medical or dental treatment which, in the absence of consent, would constitute a trespass to his person, shall be as effective as it would be if he were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be necessary to obtain any consent for it from his parent or guardian.' *Re W* established that though a 16 year old might refuse treatment, consent could be obtained from the parents or the court instead.
84. Cf. Thorpe J who, when giving his judgement in *Re K, W and H* [1993] 1 FLR 854, could not accept the view of a committee set up by the Northampton Area Health Authority that the law in this field was 'complex and confusing'; by contrast he considered it to be 'perfectly clear'.
85. [1985] see note 68 above.
86. If the team were prepared to commence the treatment in the teeth of parental opposition, the parents could only stop them by seeking a court order prohibiting it (a prohibited steps order under s8 CA 1989) arguing that it was against the child's best interests. Faced with opposition from vocal parents, most medical teams would prefer to seek court guidance before commencing any treatment.
87. See *South Glamorgan County Council v W and B* [1993] 1 FLR 574, see note 57.
88. In *South Glamorgan County Council v W and B* [1993] above, neither the 15-year-old girl nor her father was prepared to agree to the assessment required by the local authority and so the local authority instead obtained the court's authorisation.
89. But there may then be a practical difficulty to overcome: that of treating an uncooperative teenager. Sometimes, this may be overcome by the use of sedating drugs, as in *Re K, W and H* [1993] 1 FLR 854.
90. As in *Re K, W and H* [1993] above.
91. It is assumed that the same restriction also applies to male sterilisations.
92. *Re B* [1987] 2 All ER 206. If the sterilisation is a necessary form of treatment for health problems, e.g. for menstrual management, the court's authorisation is unnecessary: *Re E* [1991] 2 FLR 585. See discussion by J. Montgomery [1993] above at note 18 at p. 120.

93. See Neill LJ in *Re F* [1989] 2 FLR 376 at p. 404, discussed by J. Montgomery [1993] above, see note 18.
94. In *Riverside Health Trust v Fox* [1994] 1 FLR 614, the Court of Appeal (and the Family Division below) appeared to accept that the condition anorexia nervosa was a mental disorder within the terms of the Mental Health Act 1983 and that force-feeding of the patient (an adult in that case) could constitute medical treatment for that disorder if it was needed.

### FURTHER READING

- Department of Health, Department of Education and Science, and the Welsh Office (1991) *Working Together Under the Children Act 1989. A guide to arrangements for interagency cooperation for the protection of children from abuse*. HMSO, London.
- Department of Health, British Medical Association, and Conference of the Medical Royal Colleges (1994) *Child Protection, Medical Responsibilities, Guidance for Doctors working with Child Protection agencies, Addendum to Working Together Under the Children Act 1989*. HMSO, London.
- Department of Health (1991) *The Children Act 1989. Guidance and Regulations. Volume 6. Children With Disabilities*. HMSO, London.
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- Mason, J. K., McCall Smith, A. (1994) *Law and Medical Ethics*, 4th edn. Butterworths, Oxford.
- Kennedy, I. (1992) *Treat Me Right: Essays in Medical Law and Ethics*, Oxford University Press.
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*Colin Nolder*

## INTRODUCTION

Managing the volume of reorganisation, innovation and challenge that NHS senior managers confront, inevitably involves them in meeting situations, and being called to make decisions, for areas in which there is little precedent or established practice. For these areas it is unlikely that outcomes can be reliably forecast.

The principal task of the senior managers involved is to identify the need for change, and implement the most beneficial changes in a consistent and comprehensive way. Implementing such changes has risks and diversions. These can be reduced by designing and running a project within a structured environment which will enhance the chances of success and guard against uncontrolled influences.

## THE MAIN CHARACTERISTICS OF A PROJECT

A project is defined in the *Concise Oxford Dictionary* as 'a plan, scheme or planned undertaking'. It constitutes a discreet area of work, with a finite duration, and a clearly identifiable start and finish. It is most likely to be the responsibility of a single organisation or body, and in some cases one person.

A project is mainly associated with change within an organisation, and may form part of the implementation of a strategy or provide the solution to a business problem or opportunity. In either case the potential exists to call into play a wide variety of skills and resources and to involve significant costs. A project should have specific aims and objectives, and would normally be involved with the creation of unique deliverables or products. These may take the form of a study into feasibility or

consequences emanating in a report, or may take the form of physical or technical components.

The key components of a project are timetables, identification of expertise, clear determination of objectives and independent experts to ensure that unintentional drift does not occur. The programme can be planned and then budgeted, to facilitate monitoring and risks identified so as to focus preventative action.

### PROJECT OBJECTIVES

The aims and objectives of a project must be clearly stated at the outset. To be meaningful they must be aligned to the business objectives of the sponsoring or host organisation, and enjoy the full support of the organisation's senior managers.

### PROJECT MANAGEMENT

Project management affords 'the art and science for identifying and achieving beneficial change' [1]. This is managed through careful planning and by ensuring the timeliness, quality and cost-effectiveness of the necessary deliverables or products.

'The key techniques of project management are those which directly and effectively help project managers to complete their existing projects and identify other projects that should be undertaken' [1]. These include a full understanding of the nature of the project in hand, the role expected of the project manager and the tasks involved in setting up the project, planning and controlling it, the tools required to do the job and the criteria for ensuring its success.

### THE PROJECT MANAGER

The project manager needs to plan the project, organise the workload and control and coordinate its activities. Above all the project manager needs to demonstrate leadership.

It is the responsibility of the project manager to seek out and maintain the flow of sponsorship by providing regular feedback and by managing and enhancing the profile of the project. He is required to deliver the product(s) within acceptable cost and time limits and to a high quality. Therefore it is essential to ensure that the appointed manager has the necessary skills at the outset. They can be acquired, but this is unlikely to happen during the lifetime of a project.

The project manager constitutes the focal point for any project, and is in a key position to influence its success or failure. He is likely to have

specialist knowledge in one area of a project, and will have to rely on the advice of other specialists within the team. However, it is important that this must not be allowed to cloud judgement.

Senior managers should appoint a person with wide experience of the business area and a good working knowledge of the organisation involved. For example a project on information management and technology security in the NHS would require a project manager who has information technology (IT) and security skills and NHS user experience.

A good project manager should be prepared to devote energy and commitment towards a project at all times, but particularly in times of difficulty or conflicting demands or priorities. He will require organisational abilities, the vision to understand the wider picture and likely outcomes, objectivity to ensure that resources and effort are channelled to where they are most needed, and the ability to make decisions, often with limited availability of information on which to base them.

## **PROJECT ORGANISATION**

Because of its transitory nature a project often requires a temporary organisation to be established, unique to the needs of that project. This is particularly important where several departments or professional groups are involved, and where roles cross existing and well-established line-management structures. Examples would be projects for developing and implementing Integrated Mental Health Systems or Electronic Patient Records in a community health environment, where health professionals of all disciplines will be required to work together with IT and administrative staff.

The creation of a project organisation will not by itself ensure a successful outcome. The people participating, their experience, expertise, personalities, the roles they play and the way they interact with each other are all key factors. Careful consideration needs to be given to the ways in which individuals can best contribute towards the different stages of a project.

## **PROJECT TEAMS**

Project teams should consist of groups of people, each with specific defined skills, relative to the needs of the project. They need to be recruited from people with the right level of experience and expertise, whose capacity for effecting change is recognised, and who are capable of further development through relevant training or exposure.

However skilled or experienced, there needs to be an investment of

time, at the outset of any project, for team-building and harmonisation activities, and during the lifetime of a project for this to be maintained. Effective teamwork is reliant on good communication between team members. Although individual team members do need to be able to work on their own initiative, teams as a whole require proper supervision to ensure that they carry out that work to the agreed or required standards.

## **PROBLEMS WITH PROJECTS**

All projects carry some element of risk and it is the extent to which this is identified and controlled that significantly influences the outcome [2]. Project management is about exerting the necessary control to minimise those risks or eliminate them altogether, and to provide a speedy response when unexpected problems arise and thus limit their impact.

The scope of projects is increasing as the pace of change within the NHS itself gains momentum, and the strategic importance of running NHS organisations as businesses through project orientation is recognised, particularly as information management and technology (IM & T) infiltrates into more of the functional areas of the NHS and becomes the focus for linking different business areas.

The successful outcome of projects, particularly the larger or more technical projects, is highly dependent upon a wider range of management skills than previously. However, such skills are all too scarce and expensive a commodity. Without the required level of management guidance and decision-making, responsibilities within a project become unclear, progress becomes difficult to monitor and assess, and changes in requirements or environmental factors cannot be accommodated or controlled. Assumptions made at the planning stage might be wrong, project timescales may need to be altered or budgets reduced as a result of changes to management or user requirements. Mistakes happen even in the best project environment.

## **BENEFITS OF A STRUCTURED APPROACH**

Fortunately, to assist with the management of such projects, methodologies have been developed which link risk assessment and basic common sense into structured processes for planning and control. Also software packages have been developed to support these methodologies by providing tools for scheduling and monitoring resources, activities and costs, and providing output in graphical form. It is, however, important to keep their usefulness in perspective. There is no substitute for effective human project management.

## CURRENT INITIATIVES

The National Audit Office, in the report *Managing Computer Projects in the NHS* [3], stated that 'The Department of Health and the NHS Executive need to ensure that standards of project management are improved, based on recognised good practice'. With this in mind the NHS Executive launched their Methodologies Project in 1992. The objectives were to promote project management training activities, including centrally run events for NHS staff involved in projects, and produce and disseminate guides, manuals and packages.

A project, particularly in the NHS, usually represents a considerable investment of scarce resources over an extended period of time. Such investment must be recouped in the form of developments, deliverables or improved methods, and requires careful management. The application of a recognised project management methodology is therefore essential to ensure that investment is protected.

## PRINCE

PRINCE (P**RO**jects IN Controlled Environments) is a project management methodology developed in 1990 by the government's central computer and telecommunications agency (CCTA). CCTA is part of HM Treasury, responsible for information systems policy and information technology procurement.

PRINCE is the project management standard for government IT departments and for the NHS. As such it can be used without licence or fees and does not require any permission for its use. Although PRINCE was designed primarily for application with IT-based projects, the principles are suitable for any type of project. The optimum size of project for which it is appropriate to use it is debatable; however, the prescription pricing authority (PPA), one of the larger NHS organisations, declared that any project requiring more than 60 man-days of effort, or which is strategically or politically important, should be subject to PRINCE management'.

A postal survey of NHS staff responsible for information management and technology showed that 52% of respondents use PRINCE for their projects [4]. More than half of these use it for all their projects, irrespective of their size or value.

## COMPONENTS OF PRINCE

PRINCE methodology consists of three major components that should be applied to any project: organisation, planning and control. PRINCE

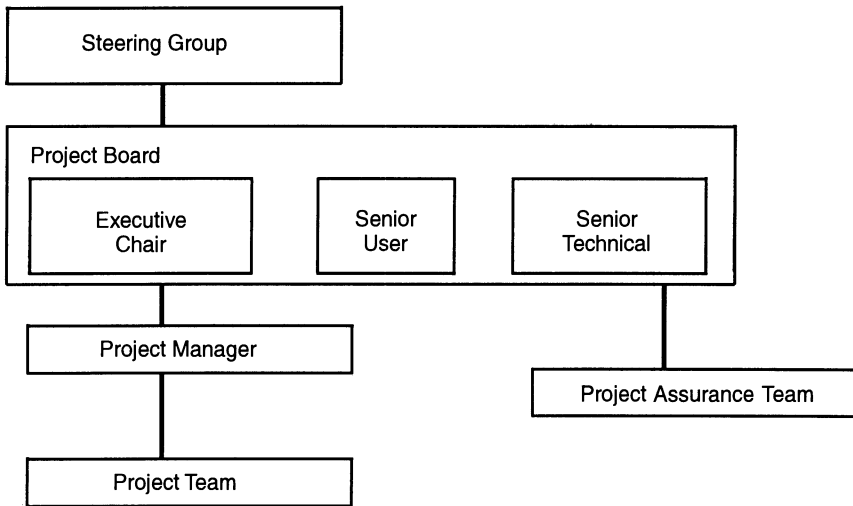


Fig. 14.1 Model organisational framework under PRINCE.

provides a project with an organisational framework that defines roles and responsibilities to ensure that tasks are correctly assigned and defines standards for the performance of those tasks.

Planning is seen as a prerequisite of facilitating project control by PRINCE. This is achieved through the definition of both technical and management deliverables or products and planning of activities to develop them.

Control procedures are prescribed for monitoring and reporting progress on resource utilisation, for ensuring that deliverables or products meet quality standards and specifications, and for controlling changes to project requirements (Figure 14.1).

## FEASIBILITY STUDIES

Although PRINCE does not formally support the concept of feasibility studies, it is recommended that these are undertaken for all projects using PRINCE organisational methodology. Before projects are commissioned, however, it is essential for both sponsors and senior management to have realistic expectations at their outset.

Numerous projects have exceeded the scheduled costs of development or have not produced the expected benefits, because the task of assessing feasibility and viability has been underrated. Indeed, based on the outcomes, some projects should not have been started at all.



## PROJECT PLANNING

The agreement to commit the level of professional and management resources that are required for many projects undertaken in the NHS must be made based on well-informed business decisions. Feasibility studies, where they have been undertaken, should afford the decision-makers both a sound business case for the proposed project and the realisation of identified benefits. The expectations arising from the recommendations in the feasibility study report should be converted through planning into an organised sequence of activities and a detailed set of products or deliverables. All those should be reflected in the project plan.

The production and maintenance of plans are key tasks in any project and therefore require a discreet allocation of project resources. Project plans present an effective means of communication within a project and to project sponsors that the requirements have been correctly understood and interpreted. The work of any project should be broken down into a number of manageable time periods or stages, each with a set of discreet activities and products and requiring specified skills or resources. Each should be no longer than three months, and should represent the opportunity for controlling and where necessary limiting damage to a project (Figure 14.2). Whilst each stage of a project should be regarded as a 'mini-project' in its own right, it is possible to run a number of stages in parallel or to have overlapping stages.

## PROJECT SCOPING

The scoping of a project defines the boundaries of the work to be undertaken, the main business processes and products, and the organisations, departments, locations or groups of people likely to be affected.

## PROJECT INITIATION

PRINCE places emphasis on the need for project initiation, requiring significant resourcing. An investment of time at project initiation will save

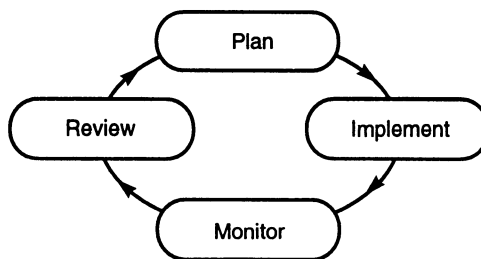


Fig. 14.2 Model project control cycle.

time later in the project resolving difficulties arising from unclear roles and responsibilities and work boundaries.

The emphasis is placed on the production of a project initiation document (PID), defining the business case, scope, aims and objectives, constraints, assumptions, project organisation, roles and responsibilities, deliverables, overall plans (with detailed ones for the first stage) and plans for review. A good example of a PID may be found in the NHS Executive's practical guide to project initiation.

#### RISK ANALYSIS

Risk analysis is an integral part of PRINCE methodology and should be undertaken as part of the feasibility study for a project, and the outcomes recorded in the project initiation document (PID). The risk factors that should be taken into account are those which affect the probability of a project being completed on time, within budget, and to the right quality standards. Each risk factor should be assigned a level based on the likely effect upon the project if it is realised.

#### QUALITY WITHIN A PROJECT

Conflicting demands within a project between scope, schedule, budget and quality often lead to the last of these being compromised. As a consequence the quality of deliverables or products from many projects is suspect, costing more than anticipated and with limited life and usefulness.

To ensure quality within a project, there are a number of requirements that should be in place first. These include defined quality objectives, procedures for detecting quality variations and management commitment to quality. Therefore it is necessary to plan these into a project from the start, and to control and maintain them throughout a project's duration.

A quality plan should be produced at the outset of a project, defining the working methods and procedures to be employed, and the standards to which deliverables will be prepared. The plan should state the arrangements for supervision and review of deliverables, both during and following preparation, including detailed checkpoints and arrangements for user involvement.

Quality assurance is the process concerned with the development and definition of relevant standards. These should take the form of detailed specifications, and a range of techniques, all designed to ensure that quality is maintained within a deliverable or product. This should also include procedures or processes for ensuring that the defined standards are employed, together with those for ensuring that the agreed level of quality is attained.

Where deliverables or products from a project are to be used on a wider basis than just the organisations involved in their development, then it becomes important to appoint an external quality assurance panel of 'experts', drawn from the main business and user areas.

## **CHANGE CONTROL**

However carefully a project has been planned, and however much effort is put into controlling its progress and the quality of its products, there will inevitably be changes that can arise from unforeseen circumstances. It is vital to the successful outcome of a project that the need for change is identified at the earliest possible time, and that mechanisms exist within the project for incorporating those changes.

Change control is accommodated by ensuring mechanisms for measuring project progress, assessing the likely impact that changes would have and their incorporation into project plans.

## **CONFIGURATION MANAGEMENT**

One of the most common weaknesses in any project, particularly in the NHS, is the failure to manage products or deliverables throughout their life-cycle. Whilst configuration management is vital to the successful output from a project, it is more concerned with controlling the total environment of production rather than just those processes which just fall within the duration of a project.

Configuration management involves the process of identifying the individual components that make up a product or deliverable, and the relationship and dependencies that exist between them. In turn each of those components will have a number of stages to its own development. This is important to ensure that all change is monitored and managed, taking into account the 'knock-on' effect that changes to one component may have on others.

Once products or deliverables have been produced it is necessary to control carefully any further changes that are made, and to monitor them and assess their impact.

The work of configuration management is usually allocated to a configuration librarian, who would normally be a permanent member of staff within the sponsoring organisation. The configuration librarian may also fulfil other roles, according to the size or nature of the project.

## **PROJECT MANAGEMENT SOFTWARE**

In conjunction with a recognised project management methodology, it is helpful to use a project management software package. This will assist and

guide the project manager through the complex tasks of scheduling project activities and resources, estimating and monitoring timescales and costs.

There is a range of software packages available, which have been evaluated by the NHS Executive's Information Management Centre, in order to identify those packages most appropriate for NHS projects.

Larger projects commonly have in excess of 1000 tasks [5] and a large number of resources assigned. Several of the available software packages can handle twice that number; some can handle up to 16 000 tasks [5] for one project. To achieve this most packages will require up to 8 Mb of expanded and extended memory.

Graphical tools and packages are now considered essential for most projects, with Gantt and Pert charts as the main scheduling tools. Software packages at the more expensive end of the market are usually high in features, offer greater depth, and allow more facilities for coding, cost analysis, and resource allocation. They usually provide virtually unlimited reporting facilities, sometimes incorporating their own scripting language, and often have the capacity to cater for groups of projects.

The less expensive packages are, however, adequate in functionality and performance for most of the types of projects undertaken within the NHS. They also frequently have the advantage of being highly interactive, whilst still being relatively easy to use, even by those with limited training opportunities.

## **CRITICAL PATH ANALYSIS**

One of the key tasks performed by these software packages is that of critical path analysis. Any project consists of a number of tasks, all of which have to be completed in order for a project to reach a conclusion. The sequencing of those tasks or activities is vital to the successful outcome of a project. The technique for that sequencing is critical path analysis, which identifies those tasks or activities which run sequentially throughout the life of a project, and in particular identifies those for which timing and resource allocation are critical. Critical path analysis can be performed manually for shorter projects, and provides a means of monitoring performance against schedule in order to identify potential problems requiring management intervention. It does not, however, solve those problems.

## **BENEFITS MANAGEMENT**

Fundamental to the success of any project, and therefore the investment made by its sponsors, is the subsequent benefits realisation study to ensure that there is a return for the investment made. Benefits management is a

constructive method for identifying benefits, and planning for their achievement and monitoring, including those difficult to quantify in monetary terms [6].

The NHS information management group published guidance on investment appraisal and benefits realisation for information management and technology projects in April 1993 [6]. This is in three documents and is an integral part of the NHS Executive's *Information Management and Technology Strategy for England* (1992) [7].

## EVALUATION

Evaluation of any project is essential to provide feedback to the sponsors as to whether the time and investment made in the project have a real 'pay-off' for both sponsors and end users. It provides the opportunity to measure the success of a project in relation to its aims and objectives, and to validate the methods and techniques used in the project.

Evaluation can provide a guarantee of the robustness of project products or deliverables for their potential users and provide guidance for other future projects. It also allows the success of a project to be formally measured in relation to the achievement of its objectives as set out in the project initiation document.

Whilst PRINCE project management methodology does not make provision for a protocol for evaluation, there are similarities between evaluation and quality assurance. Each of these is a systematic review of the appropriateness, effectiveness, efficiency and acceptability of the design, construction and implementation of project deliverables or products.

A wide variety of techniques and approaches have been used to evaluate projects, ranging from quantitative to qualitative, and often using a combination of both. Currently the emphasis has been on more process orientated and subjective techniques, incorporating feedback gained from those taking part in projects and including more conceptual and developmental evaluations.

## CONCLUSIONS

Project management is both an art and a science that requires commitment from all concerned with a project to ensure success. With increasing demands for resources, both time and finance, in the NHS, and the ever changing environment in which it functions, it is more relevant than ever before to make the investment in people and their training, to ensure effective project management, and thereby increase the chances of a successful outcome to any project.

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# Appendix A: Wales

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*Joyce Thomas*

## **INTRODUCTION**

Wales is a nation of 2.92 million people (1995), with an age structure similar to that of Great Britain. Children aged 16 years and under comprise 20.7%, with 1.2% under one year, 5.1% aged 1 to 4 years, and 14.4% aged 5 to 15 years. In 1995, 34 477 live births were registered, of which 6.4% were of low birthweight (less than 2500 g); the perinatal mortality rate was 7.9 per 1000 total births; and the infant mortality rate was 5.9 per 1000 live births. This is the background against which services for children in Wales are considered in this Appendix.

A civilised society is organised to protect and support the health of its members during the vulnerable periods of their lives: childhood, pregnancy, disablement and old age. The determinants of the health of each individual start during pregnancy and childhood, and continue throughout life. They are multifactorial and include genetic inheritance, nutrition, the quality of the physical environment, the social environment and various deprivations, including a low level of free disposable income. In the UK, the provision of the NHS is one part of the network of resources contributing to the maintenance and improvement of the health of the population. Services for children in particular recognise the interdependence of various agencies, and the need for coordination in all parts of the NHS and outside.

Services for children in the UK have evolved over time due to the cooperative efforts to seek improvements by both professionals and consumers, including the British Paediatric Association (now the Royal College of Paediatrics and Child Health), the Royal College of General Practitioners, the Royal College of Nursing, Action for Sick Children, the National Children's Bureau and many others. They are based on the

philosophy embodied in law in the Children Act 1989 and in the United Nations Convention on the Rights of the Child, passed by the United Nations General Assembly in 1989 and ratified by the UK government in 1991. Thus the similarity in the policies for and the provision and practice of such services across the country far outweighs any diversity between the four nations. Nevertheless, there are some differences in organisation, and initiatives and areas of good practice in Wales, which this Appendix aims to define.

### **ORGANISATIONAL DIFFERENCES: ROLES AND RELATIONSHIPS**

Services for children in Wales must be considered in the light of the differences in the parallel organisation of the NHS in Wales and the devolved responsibilities of the Welsh Office.

The Secretary of State for Wales is responsible to Parliament for the NHS in Wales, and for personal social services, housing, transport, education and other functions which can have an impact on health. There is, therefore, potential for coordinated policy across the board, and even for the movement of resources across different areas of concern. There is no Minister of Health for Wales, but one of the two Parliamentary Under-Secretaries of State for Wales carries out a comparable role.

The Secretary of State is supported by the Housing, Health and Personal Social Services (HH and PSS) Policy Group of the Welsh Office, by the Welsh Office Health Department and by professional advisers. These are brought together in the **Health and Social Services Policy Board**, of which the Secretary of State is Chairman and the Under-Secretary is Vice Chairman.

**The Executive Committee** of the Policy Board discharges the Secretary of State's responsibility for the management of the NHS in Wales. It is chaired by the Director of the NHS in Wales, and members include the heads of divisions within the Welsh Office Health Department, the Chief Medical Officer and the Chief Nursing Officer for Wales.

A feature unique to Wales was the creation in 1988 of an advisory sub-group of the Executive Committee of the Policy Board, known as **the Welsh Health Planning Forum**, which was a multidisciplinary group drawing on clinical, managerial and consumer expertise to advise on the planning of health services. This group undertook or commissioned major studies resulting in documents [1,2], which provided the framework for the way forward for the NHS in Wales. The strategy was further developed by the Welsh Office Health Department in the publications entitled *Caring for the Future* [3,4]. In 1995, the Welsh Health Planning Forum was disbanded.



There is no Regional Health Authority tier in Wales. Before the purchaser/provider split and the creation of Trusts, District Health Authorities carried out functions performed at the Regional level in England, such as the holding of the contracts of consultant staff. Other comparable Regional functions are undertaken in Wales by the Welsh Health Common Services Authority (WHCSA). Until 1994, it aided development and gave operational support to the NHS in Wales in the fields of information systems and technology, estate development, supplies, prescription pricing, value for money, artificial limb and appliance service and blood transfusion service. The artificial limb and appliance service has since been devolved to three sub-regional centres managed by local Trusts, the prescription pricing service has been market tested, with the result that the contract for the data capture has been awarded to PPS, and most of the estate services privatised. WHCSA provides a wide range of information services to NHS Wales, including the Health Management Information Services. In 1996, IT services provided by WHCSA, including the National Child Health System, were market tested. In January, 1997, it was announced that the in-house team, Health Solutions Wales (HSW) had been successful in its bid. The bid was made in conjunction with Lysis Business Solutions, who will take over the running and technical support of the computer bureau. The HSW staff developing and supporting applications such as the National Child Health System remain with the NHS. WHCSA also provides administrative support to the Capital Audit Consortium and Community Health Councils, on behalf of the NHS and the Welsh Office.

**Commissioners** of health services in Wales included nine District Health Authorities (DHAs) and eight Family Health Services Authorities (FHSA). These have now been integrated in five commissioning authorities, which became operational in April, 1996. Wales delayed one year in the introduction of fund-holding by General Practitioners, and in 1993 elective services were purchased by GPs on behalf of one quarter of the population of Wales. By 1997, this has risen to over one third of the population.

**Providers** of health services comprise a mixture of directly managed units, NHS Trusts and the private sector. The introduction of Trusts was also delayed in Wales and in 1997 there are 26 hospital and community Trusts and four ambulance Trusts.

The **Healthcare Management Information Services (HMIS)** was set up in 1993 as a business unit specialising in the provision of information services to NHS Wales, to support both clinical and managerial decision making. HMIS collates a wide range of patient-related data, and maintains extensive databases which are used to provide information both to hospitals and commissioners of health care. The unit also provided data for the Welsh Cancer Registry, until its relocation to Velindre NHS Trust

in October 1996. HMIS provides data for the Welsh Public Health Common Data Set, and also supports the GP Morbidity Database.

Wales has its own special Health Authority, entitled **Health Promotion, Wales**, and an Institute of Health Promotion in the University of Wales College of Medicine. All-Wales surveys have been undertaken and a computerised database of lifestyle and health-related behaviour has been compiled, available to all Health Authorities. Both Health Promotion Wales and the Welsh Health Planning Forum were designated World Health Organisation Collaborating Centres by the WHO Regional Office for Europe, in recognition of their developmental work on regional health strategy and health promotion.

A Welsh Health Survey was undertaken in 1995 by postal questionnaire sent to 50 000 people, with 28 000 completed and returned. This provided a picture of the health of the people of Wales, the way the NHS is used, and areas where services could be improved. Findings were published in 1996 [5].

The need for the voice of the public to influence decisions made by the commissioners of health services is reflected by the participation of Wales' **Community Health Councils** in strategic issues and monitoring.

The NHS in Wales aims to target research and development (R & D) at issues of strategic importance, to meet the priorities set out in *Caring for the Future* [3,4]. In December, 1992, the NHS Directorate published an R&D framework for the NHS in Wales [6]. A Director of NHS Wales R&D was appointed, an NHS Wales R&D Forum established, and the agenda was set for action, including evaluating the cost-effectiveness of interventions. In 1995, a two-year programme costing over £1 million was funded, involving fourteen separate academic and health institutions in Wales.

## RELEVANT EARLY INITIATIVES

From 1984 to 1986, the **Wales Perinatal Mortality Initiative** involved obstetricians, anaesthetists, pathologists, general practitioners, nurses, midwives, health visitors, public health practitioners, geneticists, managers and consumers in a comprehensive review of maternity services throughout Wales, together with a confidential enquiry into causes of death, to identify deficiencies and recommend improvements [7]. The Perinatal Mortality Rate in Wales has fallen from 11.1 per 1000 live and still births in 1982 to 7.9 in 1995, a fall of 29%. One area highlighted was the lack of provision for perinatal intensive care, and this was further considered in depth by a working group chaired by Sir Eric Stroud. Their recommendations have been implemented by the earmarked investment of over £1m by the Welsh Office in the provision of intensive care cots, equipment and staff.

Pre-dating the work of the Welsh Health Planning Forum, the **all-Wales**

**Mental Handicap Strategy** pioneered the integrated working of relevant agencies and the involvement of carers and self-help groups in decision making. The strategy proclaimed the equality of the rights of all children, including those with learning disabilities, to a home life, integrated education, health services and other facilities enabling them to attain their full potential [8]. One county in Wales has the lowest percentage of children with special needs in special schools of all counties, including those in England, at 0.3% compared with the Welsh average of 1.8%.

## PURCHASER ISSUES

### AN ALL-WALES STRATEGY

Well in advance of the publication by the Department of Health in 1992 of *Health of the Nation*, in 1989 the Welsh Health Planning Forum produced two documents, the *Strategic Intent and Direction for the NHS in Wales*, and *Local Strategies for Health: A New Approach to Strategic Planning* [1,2]. The challenging intent stated:

Working with others, the NHS should aim to take the people of Wales into the 21st century with a level of health on course to compare with the best in Europe.

The strategic direction has three strands; services should be:

1. health gain focused, seeking to add years to life and life to years;
2. people centred, valuing people as individuals; and
3. resource effective, striving to achieve the most cost-effective balance in the use of resources.

The theme of health gain was further expanded to identify ten priority areas which offer substantial opportunities for health gain. These were:

1. maternal and early child health,
2. mental handicap,
3. injuries,
4. emotional health and relationships,
5. mental distress and illness,
6. respiratory diseases,
7. cardiovascular diseases,
8. cancers,
9. physical disability and discomfort, and
10. healthy environments.

The stated aim in the area of maternal and early child health is 'to improve the health potential of children by reducing disease and death

during the time of pregnancy and early childhood' for the following reasons.

1. Infant mortality accounts for 6% of the lost years of potential life for males, and 4% for females.
2. Attitudes and patterns of behaviour which affect current and future health are formed in childhood.
3. There is scope for the prevention of disability, particularly amongst children of lower socioeconomic families.
4. Children are major consumers of primary health care resources including prescribed drugs.

Issues relevant to children in other priority areas include the following.

1. Mental handicap: there is scope for preventing some of the causes of mental handicap, such as rubella and low birthweight.
2. Injuries: there is scope for health gain in the area of road and domestic accidents, particularly among the at-risk lower socioeconomic groups.
3. Respiratory diseases: this area is the commonest cause for consulting a General Practitioner, and is a major component of childhood morbidity, with a large impact on prescribing.

#### LOCAL STRATEGIES

The second of the publications in November, 1989, *Local Strategies for Health*, identified the steps that health authorities need to take to develop their strategies in the light of the strategic intent and direction for NHS Wales, by assessing local health needs and formulating a long-term response to meet them.

This was followed in 1990–1993 by a series of Protocols for Investment in Health Gain, to assist the local process by focusing on the major causes of premature death and ill-health and identifying where further investment could bring worthwhile health gain, where current practices are questionable and where reinvestment might be considered [9]. The protocols were developed by appointing appraisers to identify current research findings, and produce detailed reports surveying the current state of knowledge. These reports were then considered by review panels, each concentrating on one strand of the strategic intent (health gain, people centredness and resource effectiveness) in order to identify the key issues and actions underpinning the protocols. There was thus wide involvement across Wales and integrated working between people of different disciplines in the health service, academics, lay representatives and the Welsh Office. Each protocol contains both health gain targets and service

targets relating to the range of interventions identified under the headings of prevention and promotion, diagnosis and assessment, treatment and care, and rehabilitation and maintenance. In 1995, the protocols were reviewed and are being up-dated by the Directors of Public Health in Wales.

This structured approach has required and enabled services for children in Wales to be examined across the ten health gain areas, identifying present provision, setting and prioritising local health gain and service targets, and estimating the health gains that children will experience as a result of coordinated interventions in each area.

#### HEALTH AND SOCIAL GAIN FOR CHILDREN

Although each of the Protocols for Investment in Health Gain includes issues relating to children, it was agreed that they should be supplemented by a separate document drawing together material from the protocols and also reflecting the broader policy background against which health and social services for children operate. An expert panel, set up by the Welsh Health Planning Forum and chaired by Professor Jo Sibert, Department of Child Health, University of Wales College of Medicine, published a draft document *Health and Social Gain for Children: Guidance to Inform Local Strategies for Health* in August, 1993 [10]. This unique document takes a children's rights led approach and considers the child as a whole, with a requirement for services to address physical, mental, spiritual, moral and social well-being.

Three aspects of the environment that impact on health are considered in the document:

1. the family,
2. the socioeconomic background, and
3. the physical environment.

The role of health services and other statutory services are described in terms of:

1. the needs of children in five stages of life: preconception to birth, birth to the end of the first year, one to four years, five years to adolescence, and adolescence itself;
2. particular health conditions, including opportunities for health and social gain in acute childhood disorders; and
3. children in need of long-term support, or at risk, including joint working and children in the care of local authorities.

The document considers the future shape and organisation of children's services by outlining the principles of a child and family centred service; the principles of good practice and the benefits of a combined health

service, bringing together community and hospital services, and making the distinction between that and an integrated service between primary and secondary care. It recommends that Health Authorities and FHSAs should jointly consider designating a senior officer experienced in children's issues to be responsible for commissioning all health services for children. There is also a discussion of resource effectiveness, with the aim of achieving the most effective mix and use of providers within and outside the NHS by procuring, supporting and encouraging responses to specific health needs; and of the need for motivated staff, for a quality service with mechanisms for audit, and for information management.

Health Authorities in Wales responded positively to consultation on the document, with some minor criticisms and suggestions. The draft was revisited by the original expert panel, and a document entitled *The Health of Children in Wales* was published in spring, 1997.

#### HEALTH AND SOCIAL CARE 2010

In August, 1992, a subgroup of the Welsh Health Planning Forum issued a paper entitled *Health and Social Care 2010: A Framework for Services* [11]. This was aimed at helping the service to develop a view of what an appropriate framework for the delivery of services might be by the year 2010, in order to secure maximum health gain with the resources available. A set of assumptions described the main changes that would have occurred in the health delivery process by then, and districts were selected for piloting these assumptions: two in Wales, one in England and one in Northern Ireland. The pilot districts were asked to take interim benchmarks for 2002 as targets they must attain, and to identify the obstacles to be overcome and the ways of overcoming them, within the constraint of revenue neutrality.

The benchmark assumptions to be tested for 2002 included:

1. referrals from GPs to specialist medical services should be reduced by 20%;
2. 40% of outpatient consultations with specialist medical staff should occur in locations other than a District General Hospital (DGH);
3. 80% of surgical interventions should be by minimal access;
4. 60% of surgery should be performed as a daycase; and
5. hospital acute beds in DGHs should be reduced by at least 40%.

Preliminary results from this work indicate that the targets could be achieved, but questions remain about the scale and the speed of the changes [12]. All the assumptions and the responses from the pilot districts have implications for the future shape of services for children.

## PROVIDER ISSUES

### MEDICAL SERVICES FOR CHILDREN

In November, 1992, the NHS Management Executive issued the *Report of the Joint Working Party on Medical Services for Children* [13]. This identified the primary and secondary medical services required to meet children's health needs, and their medical staffing and training requirements in terms of a unified career structure for hospital and community staff. The working party represented the Department of Health, the British Medical Association and the NHS. Other UK Health Departments (i.e. the Welsh Office in Wales) were invited to send an observer, and to consider the implications of the working party's recommendations for the staffing of medical services for children in their countries in the light of their own circumstances.

The report was eventually circulated for consultation in the service in Wales, and most of the responses received by the Welsh Office were favourable.

### A COMBINED CHILD HEALTH SERVICE

In 1991, the British Paediatric Association published *Towards a Combined Child Health Service* [14]. In this it was stated that the appropriate model of care in the future was a combined child health service covering hospital services, both secondary and tertiary, and community child health services. The term 'integrated' is reserved for the broader objective of the integration of primary (General Practitioner) and secondary child health services.

Most districts in Wales are seeking to work towards such a combined child health service, with implementation of a unified career structure. Progress to these objectives can be affected by the configuration of NHS Trusts, and is perhaps more easily accomplished where a Trust is based on a geographical area comprising both acute and community services under one management.

The appointment of Consultant Community Paediatricians was slower in Wales than in England, but there are now many in post who are developing their own network. This is apparent in their work in adoption and fostering, and with children in the care of local authorities, aiming to coordinate across Wales with Social Services departments.

## THE WELSH LANGUAGE: AN ISSUE FOR BOTH PURCHASERS AND PROVIDERS

The 1991 Census [15] showed that 18.7% of the people aged three and over in Wales speak the Welsh language, but they are distributed unevenly

across Wales, with the greatest concentration being in the more rural counties of Gwynedd (91% of whom are Welsh speakers), Dyfed (43.7%) and Powys (20.2%), and a much lower proportion in the industrial south, including Gwent (only 2.4% of whom are Welsh speakers). Among children aged three to sixteen years, 24.3% speak Welsh, ranging from 77.3% in Gwynedd to 4.8% in Gwent.

For some years Gwynedd was the only Health Authority which operated an explicit bilingual policy, publishing all documents in both English and Welsh. Health Promotion Wales also produces its reports and materials in both languages.

The new Welsh Language Act and the formation of a new Welsh Language Board in January 1994 place obligation on all Health Authorities, FHSAs and NHS Trusts to have a Welsh language plan, with the rights implicit in the Patients Charter, and to make it clear how they will carry it out. This gives a linguistic and cultural dimension to services which will affect information needs, documentation and even staffing, with implications for resources. In many homes Welsh is the first language, and its use is very important in health services for children, especially the under-fives. It is also appropriate in the 'people centred' approach of the strategy for NHS Wales, and in Gwynedd, Clwyd and Dyfed it is already a quality issue for purchasers.

## ADVOCACY AND ADVICE

Across Great Britain the need for a holistic approach to children, their rights and interests, is expressed in organisations with membership including both individuals and representatives of bodies in the voluntary, statutory and private sectors, whose interests and activities concern children, young people and their families.

There are three such independent bodies, Children in Wales (financed largely by a core grant from the Welsh Office), Children in Scotland and the National Children's Bureau (England), which work together, with regular meetings between their three Directors and reciprocal representation on their Boards of Management. They are also active members of the European Forum for Child Welfare.

**Children in Wales** aims to promote the interests of children, young people and their families in Wales, to improve their status within a diverse and multicultural society, and to reflect the bilingual nature of Wales, as well as promoting a Welsh perspective on children's issues within the UK and beyond. By developing an informed and articulate membership, it influences policy and promotes effective service provision; creates links between the statutory, voluntary and private sectors, and encourages cooperation and the exchange of ideas; increases public and professional



awareness of relevant issues; and facilitates the participation of children and young people in policy and practice which affect them.

Within Children in Wales, the **Early Childhood Unit** has been established to provide specialist information, consultancy and advice services. It aims to raise awareness of the needs of young children; to improve service provision for them across education, health, social services and the voluntary sector; and to support the raising of professional standards of practice. An example of the work undertaken is a health promotion initiative in one county in Wales, known as the **Healthy Child Project**, which is developing an information pack by exploring the information needs of parents with regard to the under-fives.

## COOPERATIVE WORKING

### THE SAVE THE CHILDREN FUND

#### **Inner city deprivation**

In March, 1988, the **Save the Children Fund** established the Wales office of its UK and European Programmes Department in Cardiff. In October, 1993, Wales was established as a full Division of Save the Children's UK and European Programmes.

In Wales their work concentrates on a developmental and evaluative role, rather than service delivery, and Save the Children works in partnerships with statutory and voluntary organisations in order to identify key issues and to use its limited resources in the most effective way. They are well known for their work with those who are deprived and poorly served in various ways, such as traveller families, ethnic minority communities and residents of certain housing estates and social housing. Their aim is to support the development of a coherent plan for meeting the needs of children, young people and their families, enabling local people to participate effectively in the process.

#### **Rural deprivation**

Save the Children has become increasingly aware that its resources and experience should be applied not only in situations of inner city deprivation, but also in many rural areas. The report by Action for Communities in Rural England (ACRE) in 1990 [16] noted that:

... rural isolation, deprivation and poverty are getting worse: village shops, schools and public transport in many areas are disappearing; suitably priced housing and opportunities for work are becoming

more scarce and social support and services are being cut back under economic pressures. Such meagre facilities as exist generally are disproportionately more costly for their consumers than in urban areas.

This has particular relevance in Wales because of its demography. Save the Children therefore accepted an invitation from Powys Health Authority and the county's Joint Care Planning Team for Child Health to assist them in examining the needs of younger children and their families living in Powys. The reference group which supported and advised the study was a good example of inter-sectoral cooperation, including representatives of the Health Authority, the Rural Council, General Practitioners, Social Services, Nurses and Managers.

Another report, published in 1991 [17], provides an insight into the experience of bringing up preschool children with the advantages and disadvantages of such a rural setting. It was found that there was a lack of a coordinated policy on the provision of services for the under-fives, which are generally given a low priority, and a lack of mechanisms for communication across and within agencies that might enable information about needs and gaps in services to be addressed. Distance is the most significant factor in service provision, service delivery and service uptake in respect of under-fives and their families, with a lack of resources available to promote uptake and increase accessibility. The positive outcome of the study was the joint appointment with the County Council Social Services Department of a Development Planner, whose role is to bring statutory and voluntary agencies together to provide a better and more coordinated child care service, and make more efficient use of local voluntary resources.

### **Other cooperative projects**

The most recent example of cooperative working is in projects in partnership with Welsh Women's Aid, which will have a relevance to children and young people across the whole Principality. These include the production of a teaching pack in English and Welsh for use with the young, to encourage examination of definitions and expectations of family and society, and of gender stereotyping; and wider understanding of domestic violence, to contribute to the prevention of violence in future relationships.

### **DISABILITY WALES (FORMERLY WALES COUNCIL FOR THE DISABLED)**

There are many self-help groups working for disabled children in Wales, who recognise that cooperation with others increases their strength and

their ability to be heard and to influence health and social policies. The Wales Council for the Disabled, renamed as Disability Wales in 1995, works to promote the rights and recognition of all disabled people in Wales by developing and supporting local, regional and national disability associations and networks. Its member organisations relevant to services for children include:

1. ABCD Improving Access for Black Children with Disabilities,
2. Associations for Spina Bifida and Hydrocephalus,
3. Brittle Bone Society,
4. Cystic Fibrosis Research Trust,
5. Friends of the Young Disabled (Wales),
6. MENCAP in Wales,
7. Muscular Dystrophy Groups,
8. PHAB (Physically Handicapped and Able Bodied) associations,
9. Riding for the Disabled,
10. SCOPE (Cwmpas Cymru), and
11. Societies for Handicapped Children.

One of the most important elements of the work of Disability Wales is the provision of independent advice and information. Its Disability Information Resource Project has seen the ongoing use of the Disabled Living Foundation Database by four network sites in Wales, answering 1200 enquiries a year on aids and equipment. An enquiry logging system was developed which enabled them to monitor the nature of these enquiries and respond quickly to new demands. The development of a national database for Wales which will hold information on a wide range of services for disabled people is ongoing, in cooperation with the Wales Council for the Blind, the Wales Council for the Deaf and Wales MIND.

Working with a local radio project and the BP sponsored *Aiming for a College Education* programme, Disability Wales is involved in a number of initiatives to encourage and support those considering higher education, including an information pack for potential students; a counselling scheme to train disabled students to work with younger people and disabled adults; and a family careers advice programme to encourage parents to support disabled children considering a college education.

## HEALTH PROMOTION AND HEALTH EDUCATION

Health Promotion Wales (HPW) is a special Health Authority, providing a national source of health promotion expertise. It is funded by Health Authorities as a 'centre for expertise' and undertakes an agreed range of national programmes. It also provides support to local health promotion activity through separately negotiated contracts. HPW works within separate functional Divisions, including Public Health Services, and

Education and Training. One of the concerns of the Authority is the use of information to assist health strategy development. Youth Surveys of knowledge, attitudes and behaviour of 11–16 year olds have been undertaken as part of a World Health Organisation collaborative project between 1986 and 1996 in 24 mainly European countries, including Wales [18].

In 1996, HPW published the report *The health of young people in Wales: findings from the Welsh Youth Health Surveys 1986–1994* [19], with analyses relating to smoking, alcohol, diet and exercise by age and sex. Data on drug use and the sexual health of young people in Wales have also been published [20, 21].

In the Training and Education Department, collaboration with the Welsh Office Education Department complements that at the local level between Health Authorities and Local Education Authorities.

HPW has collaborated with the Curriculum and Assessment Authority for Wales, to produce guidance for schools on the opportunities for Health Education in the National Curriculum. This guidance has been jointly published in a series *Opportunities for Health Education* relating to the key stages 1,2,3 and 4 of the National Curriculum, together with guidance booklets and wallcharts for use by teachers [22]. This work assumes even greater importance now that not all local education authorities employ health education advisers, and is reinforced by HPW's work with the Office of Her Majesty's Chief Inspector for Wales to develop a Technical Paper on Health Education within the Handbook for School Inspectors. HPW has also produced guidance for school governors on their involvement, and that of parents, in health promotion and education issues in schools, in a series *Healthy Schools for Wales*. Five have been published [23] on general health promotion, sex and personal relationships, creating a smoke-free school, alcohol and food policies. Complementing these is further material offering guidance to schools on alcohol and sex education. Plans and suggestions are also available for primary schools to develop *Health Promoting Playgrounds*. In collaboration with the other UK national health promotion agencies, HPW coordinates the Welsh Project of the European Network of Health Promoting Schools [24].

In association with Life Education Centres UK, a mobile bilingual health education and promotion service is provided to primary schools throughout Wales by four mobile units equipped with computers, puppets and other educational aids. For the young children, *Cledwyn's Castle* is a pack comprising a floor and demountable walls, with puppets, which can be used by teachers in play groups and nursery groups. HPW also collaborates with BBC Wales in educational broadcasting for primary schools. So far, three series of *Health E/techyd A* have been produced for television.

The Authority is developing its work on the concept of population

health. This will lead to an integrated health promotion approach to the improvement of health at all levels of society, seeking change and improvement in policy, living and working conditions, community action, individual skills and better focusing of health care.

HPW is a WHO Collaborating Centre with responsibility for providing consultancy and advice on a wide range of health promotion strategies, policies, topics and settings. The Authority has a comprehensive library and information service, and is designated as a WHO Documentation Centre.

## INFORMATION SYSTEMS

THE NATIONAL CHILD HEALTH SYSTEM (see also p.130)

The most comprehensive computer system operational in the United Kingdom was developed in Wales, in order to organise and monitor preventive child health care. The technical specification for the national computerised Child Health System was developed since 1974 by the Welsh Health Common Services Authority (WHCSA). It is the only system in which agreement has been reached with the British Medical Association and the Health Visitors Association on ethical principles and a confidentiality and security protocol, thus allowing the sharing of patient-related data.

The system has evolved and developed in modular fashion with the advice and direction of users. Initially designed for one hardware, ICL, some regional computer policies required the development since 1985 of a second version on DEC hardware (an interactive MUMPS implementation), while maintaining commonality of the core specification and content. The ICL version was also re-written to provide a completely interactive version. There are five modules of the system: the Child Register containing personal details kept in a separate computer file from the medical details; Immunisation; Pre-School Health; School Health and Special Needs. These have been implemented in over 70% of Health Authorities and Health Boards in England, Wales and Northern Ireland, with all using the first two modules, the majority using the third, and the last two being progressively adopted. In Wales, four modules are implemented in all Trusts, with the Special Needs module running in four. In addition to the modules, the system includes a Statistics and Information package generated directly from service data, which generates central returns, the Körner requirements, COVER statistics on levels of immunisation, and performance indicators.

The system has contributed markedly to the completeness of Child Health Surveillance and the early detection of handicap, and to the uptake of immunisation programmes. While used for individual case manage-

ment and for operational management of caseloads, the database builds up a total picture of the child population, which can be used for strategic planning of services and for epidemiological research.

As a result of the changes in the Health Service, the advent of Trusts and the increased competition from the private sector, the system is currently being re-written to run on small local machines, using client/server architecture and Windows NT.

The system continues to develop and to be monitored for quality. The Child Health System Quality Assurance Project (CHEQUE) was established in 1991 for the development of measures of quality assurance for the system and its use. In the first phase, measures and indicators adopted were those upon which it was possible to reach agreement between the partner countries. These will be developed further to be country specific and incorporated into customised Child Health System software. A data protection, security and confidentiality checklist has also been developed.

#### WELSH PUBLIC HEALTH COMMON DATA SET

The Welsh Public Health Common Data Set has evolved since 1990 for use in the Annual Reports of Directors of Public Health and in the Annual Review meetings between the Executive Committee of the Policy Board and District Health Authorities. It has been developed by Healthcare Management Information Services to align the data with the health gain areas of the Strategic Intent and Direction for NHS Wales.

The section on Maternal and Early Child Health includes Caesarian section rates, trends in low birthweight babies, notifications of neural tube defects, Down's syndrome; and age- and cause-specific trends in the various childhood mortality rates. It also has data on the percentage of mothers registering for antenatal care by 16 weeks' gestation, the percentage of mothers breast feeding ten days and six weeks after birth, and the number of live and still births delivered at home per 1000 total births.

Computerisation began in June, 1992. The first computerised data, consisting of the previous five years' data for all Districts in Wales, together with all-Wales averages, were issued in March, 1993, in both paper and computer readable format.

Work began in 1995 on the development of an electronic Common Data Set accessed by 'executive information system' software. The first version, named HealthShow, was issued in May, 1996. This comprised an extended range of demographic and health status data arranged in a hierarchy of aggregation covering Wales, Health Authorities, and the 22 newly created Unitary Authorities, which could be accessed and displayed in a variety of numeric and graphic formats, including maps. A formal evaluation of

this release has informed the planning of future developments, which include extending the range of health and social status indicators, and enhancing the front end software to provide ad hoc enquiry and analytical tools.

#### POPULATION HEALTH SUMMARY SYSTEM (PHSS)

With the fragmentation resulting from the commissioner/provider split and the creation of autonomous Trusts and GP Fundholders, there is an increasing realisation that the future of the NHS will depend on the exchange of information between healthcare organisations and professionals. How to establish a standard which will overcome this fragmentation through the wider provision and secure management of the patient record is a question that has been addressed in Wales by the Population Health Summary System (PHSS) project.

The PHSS was developed through consultation with potential users, recognising the importance of user-led design for the clinical record, and consists of two parts.

1. The NHS Administrative Register (AR), a register of names, addresses and simple demographic data for the population, embodying the national administrative data set standard (CADS), which was piloted for the whole population in Wales and in five other sites in England, and then taken into operational use by WHCSA in 1995.
2. The Personal Health Summary (PHS), to establish a standard for the creation of a distributed database of clinical information relating to the health career of each member of the population, with the information collected in the normal course of clinical work by all healthcare practitioners.

The PHSS Project ended in 1995, and offered a strategic vision of future information development in the NHS, for the benefit of the care of all patients, including children.

#### CONCLUSIONS

This Appendix has attempted to highlight some of the issues in Wales relating to the management of child health in its broadest sense.

Several strands contribute to the freedom to be different in Wales. The organisational differences of the NHS have provided long experience of responsibility held at District, not Regional level, and a greater opportunity for those in the service and the policy makers to know and influence each other outside of formal channels. There is a sense of the importance of being an independent nation, not a region, with a relatively classless

society, and a history of pioneering in matters related to the health of the public.

These have all contributed to a facility for cooperative working across organisational boundaries, and have created an environment in which innovative thinking is encouraged and initiatives more easily supported, for the benefit of the future delivery of health care to children.

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# Appendix B: Scotland

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*Alison Allen, Anne Maree Wallace and Helen Zealley*

## INTRODUCTION

Scotland has a population of just over 5 million people: approximately one tenth of the UK population. The majority live in the central lowland belt which includes the cities of Glasgow, Edinburgh and Dundee as well as the industrial towns of Clydeside, Lanarkshire, Central Region, the Lothians and Fife. Inverness and Aberdeen act as population centres in the north and north-east, the latter with fishing and oil-related industries. In contrast, the remote communities of the Highlands and Islands comprise scattered households, villages and small towns where crofting, fishing and tourism provide the main occupations. Although these very different communities share many of the same health needs, the structure of health services to children varies according to the geographical density. The number of children living in the area of any one Health Board varies from 173 000 in Glasgow to less than 4000 in Orkney.

Of Scottish children, 95% attend local authority schools and over 50% now remain at school after their 16th birthday.

In 1991, the 957 208 children in Scotland up to 15 years of age comprised 19% of the total population: a reduction of nearly 150 000 since 1981 when they made up 21% of the population. Compared to the UK average of 1.76, the total period fertility rate has fallen to 1.62 in Scotland with 60 051 live births in 1995, the lowest number recorded since civil registration began in 1855. The perinatal mortality rate in 1995 was 9.6 per thousand total births; the infant mortality rate was 6.2 per thousand live births (England 6.0); and there were 165 deaths between the age of one and fourteen years of which accidents accounted for 47 (28%). The expectation of life at all ages is less in Scotland than for England and Wales. At birth, in 1993, male life expectancy was 71.4 years (E & W 73.4) and for females it was 77.1 years (E & W 79.0).

Although immigration has increased in recent years, including a significant inward movement of people from England, the percentage of minority ethnic groups in the Scottish population remains low. At the 1991 census, a total of 1.3% of the Scottish population were identified as belonging to minority ethnic groups compared to 6% in England and Wales. Their distribution was Black (0.1%), South Asian (0.6%) and Chinese (0.5%).

## THE HEALTH OF SCOTTISH CHILDREN

Scottish children share most of the same health risks and diseases as children elsewhere in the UK. Accidents are the commonest cause of death between the ages of one and fourteen years; and hospital admission rates for asthma have increased over recent years, even for children living in remote rural communities. HIV/AIDS among children in Edinburgh and Dundee is one of the sequelae of high rates of infection among injection drug users in these two cities. The proportion of children infected with, or affected by, HIV/AIDS is greater in these two cities than anywhere else in the UK because the epidemic pattern has contributed to higher rates of infection among women. Dental health is significantly worse among Scottish children and there has been a disappointing reversal, since 1990, of the downward trend in caries among 5-year-olds. In the UK national dental league table of 199 health authorities, the 15 Scottish Boards ranked between 127 and 199 for dental health among 5-year-olds. No water supplies in Scotland are fluoridated.

The most distinctive feature of health and disease among Scottish children remains the discrepancy, first identified in 1845 [1], between those living in deprived and affluent households. This discrepancy assumes greater significance than in other parts of the UK because more Scottish children live in poverty. A 1992 Government statistical survey *Households Below Average Income* [2] reported that 38% of Scottish children were living in poverty compared with 25% of the UK total; and in 1994, Benefits Agency returns showed that 26% of Scottish children aged less than 16 years were living in families dependent on income support [3].

The key indices of health status among children – such as low birthweight, infant deaths, deaths from accidents and hospital admissions – all show increased rates among children in deprived communities compared to those in affluent areas. Differences are also found between deprived and affluent communities in most of the factors which influence health: poor nutrition; parents unable to provide adequate stimulation; childhood smoking and drinking; teenage substance misuse; and early pregnancy. This creates a poor foundation for adult health and these factors have contributed to an increase in deaths among young adults (15–35 years) over the past ten years, particularly for young men.

An international study of health behaviour among children aged 11, 13 and 15 years in 1990 [4] showed poor nutrition patterns among Scottish children with diets high in fat and sugar content and low in fresh fruit, vegetables and wholemeal bread; low rates of physical activity; and high rates of sedentary activities such as TV, video watching and computer games, compared with young people in other European countries and Canada. Smoking and regular alcohol use were lower than in many other countries but drunkenness was reported more frequently among Scottish boys.

### **NATIONAL STRUCTURE OF THE NHS IN SCOTLAND**

The organisational structure of the Scottish Health Service is similar to that of Wales. The Secretary of State for Scotland is responsible for the Health Service with a designated Scottish Minister for Health. The Chief Medical Officer heads a Public Health Policy Unit within the Scottish Office Department of Health (SODoH) and management responsibility for the NHS lies with the Management Executive (ME) headed by a Chief Executive.

The Management Executive has a range of separate divisions. One oversees purchasers and another supervises the activities of provider Trusts. The ME has established a Joint Working Group to define a Common Core Work Programme of priorities for Scottish Health Boards. This covers mental health, cancers, cardiovascular and cerebrovascular disease but does not include any specific priorities relating to child health.

In addition the National Services Division of the Common Services Agency has responsibility for commissioning a number of small volume, highly complex 'national' contracts. These have included cochlear implant surgery and paediatric cardiac surgery. Gradually responsibility for these small contracts is being transferred to Health Boards.

### **PAEDIATRIC ADVICE TO THE SCOTTISH OFFICE**

The Joint Paediatric Committee of the Scottish Royal Colleges is responsible for providing formal advice to the Scottish Office Department of Health on matters relating to children's health and paediatric services. The Committee comprises all the Scottish regional representatives of the Royal College of Paediatrics and Child Health as well as representation from the Scottish Royal Colleges of Physicians and Surgeons, the British Association of Paediatric Surgeons, the Scottish Association of Community Child Health, the clinical Professors of Paediatrics, General Practice, paediatric trainees and the Scottish Office. The Joint Paediatric Committee meets with the Chief Medical Officer on an annual basis and

a representative of the Joint Paediatric Committee participates in more frequent meetings at the SODoH as a full member of the Scottish Joint Consultative Committee.

#### SCOTTISH HEALTH INFORMATION SYSTEMS

The Information Services Division (ISD) of the Common Services Agency supervises and coordinates the collection and analysis of all NHS statistical data. Computerised summaries of all hospital discharges (equivalent to consultant episodes) have been collected in Scotland since 1961. These Scottish Morbidity Recording (SMR) schemes were introduced to provide information about trends in ill health and demands on health services for planning purposes. More recently they have been used to inform the commissioning process within the purchaser-provider structure. Amongst the many specific statistical analyses the ISD has, since 1983, coordinated and published an annual review of all perinatal deaths in Scotland. In 1985 the review was extended to cover all fetal deaths from 20 weeks' gestation and all neonatal deaths.

National computer systems for the Scottish NHS were initially developed within ISD, including the Scottish Immunisation Recall System (SIRS) linked to a Community Health Index (CHI) of all patients registered with NHS GPs. This has subsequently been further developed by a separate Health Services Division (HSD) which was established within the CSA to develop computer systems for the Scottish Health Service. Three of these systems relate specifically to children: a Child Health Surveillance Programme (CHSP) for monitoring preschool surveillance, which is being introduced into the majority of Scottish Health Boards; a School Health Surveillance module, which is presently being piloted; and a Special Needs Register. When these are all fully operational they will provide valuable routine data for monitoring child health.

In 1995, HSD and all Scottish Health Board computer consortia were submitted to competitive tendering and are now owned by a private company. Health Boards contract directly for the provision of computer systems, including the Community Health Index (CHI) and the associated Child Health information modules.

Increasingly record linkage is being used to improve information about disease patterns in individual patients. Further, a system of continuous morbidity recording (CMR) now covers a 5% sample of the Scottish population through a network of sentinel general practices.

#### HEALTH EDUCATION

Health education in Scotland is led by the Health Education Board for Scotland (HEBS). This Health Authority is directly accountable to the

Public Health Policy Unit of the Scottish Office. In addition to developing and coordinating national health promotion campaigns, HEBS liaises actively with individual Health Boards and their Health Promotion Departments.

HEBS also supports teaching and research in all the four Scottish medical schools and certain other university departments.

#### RESEARCH AND DEVELOPMENT

Research and development within the NHS in Scotland is led by the Chief Scientist's Office (CSO) of the Scottish Office. Since 1982 the evaluation of service innovations and developments has been undertaken through the CSO Health Services Research Committee.

In addition to supporting individual research projects, the CSO funds a number of specific research units. These include the Edinburgh-based Research Unit in Health and Behavioural Change (RUHBC), established in 1982. In 1990, this Unit undertook the major survey on health-related behaviour among Scottish school children [4] to contribute to a cross-nation perspective. Adolescent health behaviours and lifestyles are developing as a major research theme for the Unit with surveys currently being undertaken on 'young people's perceptions of smoking in youth media' and 'adolescent risk behaviour and injury prevention'.

Another important CSO funded research unit was initially established in 1966 as the Social Paediatric and Obstetric Research Unit in Glasgow (SPORU). In 1991 this Unit's role and remit were changed to the Scottish Public Health Research Unit (SPHRU) for the investigation of 'social and environment influences relevant to the health and healthcare of the Scottish population'.

In its 25 years as a Unit investigating the social and environmental influences relevant to the health of mothers and children, SPORU's research has included:

1. studies of infant and perinatal mortality;
2. infant nutrition;
3. measures of children's development;
4. a register of congenital abnormalities and a number of related research studies;
5. a study of services for children with motor impairments of central origin and the development of the Scottish Cerebral Palsy Register;
6. the Scottish low birthweight study;
7. studies of child abuse, including the development of child abuse registers and new approaches to diagnosis and assessment; and
8. research into the use of illicit drugs among young people in Glasgow and perceptions of HIV infection risk.

In Aberdeen the CSO funds the Health Economics Research Unit (HERU) which has developed 'programme budgeting – marginal analysis' as a useful tool to assist strategy development and purchasing choices by Health Boards. It was used by Tayside Health Board to provide a framework for developing their Child Health Strategy. Also in Aberdeen is the Health Services Research Unit (HSRU) which provides leadership for service evaluation studies.

In 1993 the CSO and Management Executive in Scotland launched a national Research and Development Strategy with the stated objective 'to ensure that the content and delivery of care in the NHS is based on high quality research relevant to the improvement of the health of the people in Scotland'. The strategy aims to improve communication between the research community and the NHS to ensure that decision making and planning have a sound research basis and that services are evaluated in the light of research results. The strategy is being developed through local research networks to stress the importance of liaison at local level between the NHS and those undertaking research.

In addition a major task has recently been completed to identify the extent to which NHS resources are being used to support research. These are being separately identified as the 'R' component of the additional resources provided to teaching Health Boards (known in Scotland as ACTR and equivalent to SIFTR in England).

#### CLINICAL AUDIT

Clinical audit throughout Scotland has been promoted and encouraged by the Clinical Resource and Audit Group at the Scottish Office (CRAG). In addition to promoting the development of clinical audit throughout Scotland under the auspices of Area Clinical Audit Committees (ACACs), the group funds national audit projects and stimulates the exchange of audit outcome information between Health Boards, Trusts and the professional staff involved. It also collates a data base of audit initiatives throughout Scotland: currently around 250 projects relating to Child Health have been listed.

#### SCOTTISH NEEDS ASSESSMENT PROGRAMME (SNAP)

Coordinated contributions to the planning and commissioning of health services in Scotland have also been made in recent years through collaborative activities of staff working in the service. The Scottish Needs Assessment Programme (SNAP) has grown as a self-help group for public health physicians who agreed to work together on a common programme despite difficulties with coordination at a national level; problems of gaps

and duplications; lack of a recognised methodology; and difficulties with data availability. Out of this, a national framework for good practice in health needs assessment has been established consisting of a central core group and six national networks, one of which covers child health. SNAP Reports contribute to the Common Core Work Programme of the ME of the Scottish Office and many are circulated to Health Boards under cover of ME letters.

SNAP reports of specific relevance to children include:

1. congenital dislocation of the hip;
2. dental caries in children;
3. teenage pregnancies;
4. accidents, and
5. breastfeeding in Scotland.

#### SCOTTISH INTERCOLLEGIATE GUIDELINES NETWORK

The Scottish Intercollegiate Guidelines Network (SIGN) has been established more recently and involves all the Medical Royal Colleges and Faculties with participation by other healthcare professions. The initiative is being managed by the Royal College of Physicians of Edinburgh with support from the Scottish Office, ME and CRAG. Representatives of all Colleges and Faculties participate in the network, with working groups established to research the evidence and bring forward 'evidence based' guidelines for use throughout Scotland. The initial programme focuses largely on topics of particular relevance to adult health. The two which affect children are:

1. the guideline on the inpatient management of acute asthma which incorporates children; and
2. the guideline on the management of diabetic pregnancies.

#### POSTGRADUATE MEDICAL AND DENTAL EDUCATION

The strategic development of postgraduate training in Scotland is coordinated by the Scottish Council for Postgraduate Medical and Dental Education (SCPGMDE) which, from 1994, took on the same status as a Health Board. Funding from the SCPGMDE for medical and dental training posts (100% of core costs); study leave for those in training grades; postgraduate centres; vocational training for general practice; and the postgraduate education allowance arrangements for GPs is all routed via the postgraduate deans who are based in the four medical teaching centres of Aberdeen, Dundee, Edinburgh and Glasgow and in Inverness.

The SCPGMDE has, since 1974, been particularly supportive of



initiatives to improve training in community paediatrics. It has supported day release courses in Glasgow and Edinburgh, including an innovative scheme for GP 'paediatric trainees' in Edinburgh. These are six-month GP registrar appointments attached to carefully selected GP trainers who have a particular interest in health services for children. The GP registrar spends approximately 50% of his or her time in the practice. During the rest of the time, the GP registrar attends a 6-month part-time course at the School of Community Paediatrics in Edinburgh which offers a programme of seminars and practical clinical experience in the Royal Hospital for Sick Children.

Initiatives by the SCPGMDE also led, during the 1970s and 1980s, to the development of in-service training programmes in community paediatrics for clinical medical officers. In addition, training programmes in community paediatrics were developed for paediatric registrars and senior registrars well in advance of the establishment of a formal higher training programme by the SAC of the JCHMT. Indeed there was, at times, a sense of frustration in Scotland that the specialist status of community paediatrics took so long to be recognised by the UK medical establishment.

#### SCOTTISH CENTRE FOR INFECTION CONTROL AND ENVIRONMENTAL HEALTH

In 1994 the former Communicable Disease (Scotland) Unit and Scottish Environmental Health (Scotland) Unit were combined to form the Scottish Centre for Infection Control and Environmental Health (SCIEH). The Centre coordinates the communicable disease surveillance and control activities of individual Health Boards and local authorities. In addition it provides advice and support – particularly in the event of significant outbreaks which exceed the capacity of a single Health Board. Training programmes are arranged by the Centre, including an annual updating course for public health consultants and in-service training attachments for specialist registrars who wish to specialise in communicable disease control and environmental health. SCIEH is currently monitoring the effectiveness of the major school-based measles/rubella immunisation programme of 1994.

### LOCAL STRUCTURE OF THE NHS IN SCOTLAND

#### HEALTH BOARDS

Since 1974, the 15 Area Health Boards have been directly accountable to the Scottish Office without an intermediate Regional tier. They range in size from Greater Glasgow (population 916 000) to Orkney (population

20 000). This structure has been remarkably stable compared with that of the health authorities in England. Nevertheless, Health Boards have had to respond to the same changes in management organisation as the rest of the UK, including the introduction of the purchaser/provider structure in 1993 (a year later than England) and the operational structure below Boards has changed from Districts to Units to Trusts. The Health Board boundaries remain as identified in 1974 and their responsibilities have always included the management of primary care which has encouraged close working arrangements with GPs.

#### LIAISON BETWEEN HEALTH BOARDS AND LOCAL AUTHORITIES

Eleven of the fifteen Health Boards have also been coterminous, since 1974, with the Regional local authorities responsible for education and social work services. However, from 1 April 1996, the separate Regional and District local authorities have been replaced by 32 new single-tier unitary councils. This has had a major impact on joint planning arrangements for children and young people, such as Child Protection Committees and Review Groups for Children with Special Educational Needs. New joint planning structures are being developed with the unitary councils in preparation for the development of Children's Plans within the terms of the Children (Scotland) Act 1995.

#### CHILD PROTECTION

Effective structures to maintain and develop joint services for children at risk of abuse are essential. Although there has, for many years, been a high level of commitment in Scotland to joint child protection arrangements, the importance of this was reinforced by the 1992 Report on the Orkney Inquiry [11]. Issues of relevance to the health service identified in the Report included:

1. the need to ensure that children obtained a comprehensive medical assessment, including a psychiatric or physical assessment if required;
2. the importance of effective interagency consultation and coordination from an early stage of the investigation;
3. the need to involve parents;
4. the importance of treating children as individuals; and
5. the importance of developing clear plans, and the need for training and other positive initiatives to ensure they are effective.

Responsibility for ensuring that the NHS contributes effectively to local

joint plans lies with Health Boards. Liaison with GPs and contracts with provider trusts are used to ensure that the plans are fully implemented.

#### HEALTH PROMOTION WITHIN HEALTH BOARDS

In addition to commissioning health services, managing primary care and liaison with local authorities, Health Boards are responsible for maintaining and improving the health of the populations they service.

Each Health Board has a health promotion department which liaises with HEBS and is responsible for supporting the development of local health-promoting activities. They work in partnership with schools, communities, youth groups, employers, NHS Trusts, GPs and others.

For children emphasis is given to supporting schools in their development of health promotion initiatives. Schools are being encouraged to develop a coordinated health education programme which is revisited and developed throughout the child's school career. This is frequently incorporated into the personal and social education programme and schools are encouraged to complement these core topics with a cross-curriculum approach to learning within other subjects, e.g. English, science, drama, physical education. The health education curriculum in schools seeks to provide accurate information; to explore attitudes and values; and to develop interpersonal skills, with the aim of enabling young people to make their own informed choices about a healthy lifestyle.

Health promotion specialists focus on the development of teachers' skills to undertake this work with young people. Similarly, support is given to school nurses in developing their health-promoting role. Schools are also encouraged to consider their wider policies and the extent to which they impact on the promotion of health, for example, policies on smoking in school and catering arrangements.

#### COMMUNICABLE DISEASE CONTROL AND ENVIRONMENTAL HEALTH

Health Boards are also responsible for communicable disease surveillance and control for their local population, in association with the relevant local authority environmental health department. The Director of Public Health and appropriate public health consultants act as Designated Medical Officers to the relevant local authority with direct responsibility for investigating possible outbreaks. If necessary they may instruct the local authority's environmental health staff to implement control measures. Although appointments based on the English CCDC model are not precluded, all Scottish consultants in communicable disease and environmental health (CD/EH) are public health consultants. This reflects a

continued commitment to communicable disease control in Scotland during the 1970s and 1980s when it lapsed in parts of England.

Notifiable diseases in Scotland are reported to the Chief Administrative Medical Officer of the Health Board (*de facto* also the Director of Public Health), rather than to the CCDC acting as Proper Officer to the local authority. There are also slight differences between England and Wales and Scotland in the diseases which require to be notified within current legislation. Chicken pox is notifiable in Scotland but not England; and meningococcal infection replaces meningitis and meningococcal septicaemia.

Good liaison occurs throughout Scotland between Health Board consultants and SCIEH, and with CCDC colleagues in England and Wales, using EPINET and personal contacts. This ensures prompt action in response to the potential spread of infection and the control of environmental hazards.

#### NHS PROVIDER TRUSTS

Most hospital and community providers of health services to children in Scotland are now working within NHS Trusts. Organisational patterns vary from Trust to Trust. Some have achieved integration of acute and community paediatric services; others remain split between different Trusts. Despite more rigorous 'efficiency savings', services remain better staffed than in England. For instance, in 1994, there were 3.25 health visitors per 10 000 population in Scotland compared to an English rate of 2.10 per 10 000.

There is considerable variation between different parts of Scotland in the health services offered to children at school. Policy recommendations from the Scottish Office on 'Health Services in Schools' were published in 1996. Technically the statutory requirements remain as in the NHS and Education Acts of the 1970s, although the 1981 Education (Scotland) Act provided a more explicit structure for the assessment and 'recording' (equivalent to 'statementing' in England) of children with special educational needs. The Children (Scotland) Act 1995 makes specific provision for disabled children and those children affected by disability as well as defining a wider group of children 'in need' and the extent to which local authorities have a duty to support such children and their families.

#### GENERAL PRACTITIONERS

Scottish GPs have smaller lists (average 1408) compared to their colleagues in England (average 1834) and Wales (average 2015). Most are registered

to provide preschool child health surveillance working in partnership with health visitors.

There are fewer GP fundholders (GPFHs) in Scotland than in many parts of England, despite active encouragement by the ME. The highest percentage is in Grampian where over 50% of GPs had become GPFHs by 1995. Elsewhere other arrangements have developed with 'locality groups' of GPs working with Health Boards to influence purchasing decisions and negotiations with Trusts.

#### ADVICE TO HEALTH BOARDS

Health Boards seek and take advice from a range of professional advisory committees in addition to their local health councils. In addition, the five Health Boards where medical schools are located have formal liaison arrangements with the universities concerned.

#### NATIONAL HEALTH POLICY IN SCOTLAND

Although the 1990 GP Contract, *Working for Patients, Caring for People* and the 1992 NHS Community Care Act cover Scotland as well as England and Wales, *Health of the Nation* relates only to England. The equivalent policy statement for Scotland is *Scotland's Health: A Challenge To Us All* [5] with targets to reduce the high rate of deaths from heart disease, stroke and other circulatory diseases as well as cancers, for which Scotland has the highest rate of death compared to other OECD countries.

*Scotland's Health* stresses the need for action to reduce smoking, improve nutrition, combat alcohol misuse, promote exercise and improve dental health. It encourages Health Boards to discuss with their local education authority the development of policies to promote a healthy lifestyle in schools in areas such as smoking and diet, and through the role of teachers as exemplars.

Wider issues addressed in *Scotland's Health* included environmental influences on health such as lead in drinking water; health in the workplace; and brief reference to health inequalities. Although this policy statement provides, for Scotland, similar challenging targets to those provided for England in *Health of the Nation*, it has not received the same widespread support and publicity.

#### SCOTTISH POLICIES OF PARTICULAR RELEVANCE TO CHILDREN

##### INTEGRATION OF CHILDREN'S HEALTH SERVICES

The 1973 Brotherston Report *Towards an Integrated Child Health Service* [6] has provided the main framework for the development of children's

health services over the past 20 years, although implementation of its recommendations for the development of community paediatric services was delayed for many years pending UK agreement on the later Court Report [7] and the eventual reconciliation of hospital and community paediatricians during the late 1980s.

The Brotherston Report stressed the need for integration between primary and secondary care services for children; also for effective liaison between health, education and social work services. It identified the need to seek out vulnerable families to ensure that they received the medical and social help they need and the importance of following up 'high risk' infants. Effective child health information systems were identified as vital and their development has been delayed much longer than was anticipated.

#### HOSPITAL SERVICES FOR CHILDREN

The 1993 Report *At Home in Hospital* [8] provided a clear specification of high-quality services for children which provide for the complete physical and emotional wellbeing of the child and not simply for the condition for which treatment or care is required. It also stressed the need for services to be child and family centred, with children, their siblings and their parents or carers experiencing a 'seamless web' of care, treatment and support, as they move through the constituent parts of the NHS.

The Report laid out some basic principles for the treatment of children, as follows.

1. Children should be admitted to hospital only if the care they require cannot be as well provided at home, in a day hospital or on a day care basis.
2. Children requiring admission to hospital should be provided with a high standard of medical, nursing, pharmaceutical and therapeutic care to facilitate a speedy recovery and minimise complications and mortality.
3. Families with children should have easy access to hospital facilities for children without needing to travel significant distances.
4. Children should be discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
5. Good child health care should be shared with parents/carers to ensure that they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interests of the child. Accommodation should be provided for them to remain with their children overnight.
6. Accommodation, facilities and staffing should be appropriate to the

needs of children and adolescents. They should be separate from those provided for adults and should have an appropriate child and family-centred environment. Where possible separate accommodation should be provided for adolescents.

7. Like all other patients, children have a right for their privacy to be respected and to be treated with tact and understanding. They have an equal right to information appropriate to their age, understanding and specific circumstances.

## SCOTTISH LEGISLATION RELATING SPECIFICALLY TO CHILDREN

Child health in Scotland operates within the framework of Scots law, which differs from legislation in England and Wales in a number of important respects.

### CHILDREN'S HEARINGS

Most of the main elements of child care law in Scotland derive from the 1968 Social Work (Scotland) Act. This introduced, from 1971, Scotland's distinctive system for promoting the welfare of children embodied in the appointment of a 'Reporter to the Children's Panel' and the establishment of Children's Hearings. The system engages lay Panel Members and parents in the process of determining the welfare of the child, whether this involves protective care or measures to control a child who has offended. It removes from courts most of the responsibility for dealing with children under 16. The majority of juvenile offenders are dealt with by this system, except in the case of very serious crimes.

The strengths of the Children's Hearings system are seen to lie in the active involvement of parents and members of the Children's Panel who are drawn from the local communities. The Reporter has a duty to ensure that Children's Hearings look beyond the immediate grounds of the referral to attempt to find the underlying causes which need to be addressed, and to make practical recommendations.

Despite appearing to have failed in relation to the forcible removal of children from their homes following allegations of child abuse in Orkney in 1991, the Children's Hearing system continues to enjoy wide support. The 1993 Report *Scotland's Children* [9], which provided a review of child care legislation in Scotland, described the Children's Hearings as having 'a vital and continuing part to play at the centre of child care in Scotland'. Indeed, the UK recorded its support for the system in its qualification to ratification of the UN Convention of the Rights of the Child in 1991.

## EDUCATION (SCOTLAND) ACT 1981

The Education (Scotland) Act 1981 represented a fundamental revision of the arrangements for meeting the special educational requirements of children with pronounced, specific or complex educational needs who required continuing review.

Like its English equivalent, the act required that all children with significant and continuing special educational needs (SEN) have a comprehensive medical, psychological and educational assessment to define their 'needs' and that these (and the views of their parents) are incorporated in a 'Record of Needs' (equivalent to the English 'Statement of Needs'). While there is a statutory requirement to provide (and in the case of parents, allow) the assessment to occur, there is no statutory requirement on either the education authority or health service to ensure that the child's 'special needs' are met. However, having had their children's 'needs' defined, parents can identify the extent to which these are (and are not) being met and draw attention to unmet needs.

The process of 'Assessment' and 'Recording' is followed by a 'Continuing Review' of the child's needs and progress, and a further formal multi-disciplinary 'Future Needs Assessment' as (s)he comes towards the end of the period of compulsory schooling. Increasingly, children with SEN are continuing in school or further education placements, thus blurring the time of their transition from children's to adult services.

In addition, the Act required that parents' requests for the placement of children in specific schools be observed, except in certain defined circumstances. This includes the placement of children with special needs in mainstream schools wherever it is practicable to do so. Unlike the equivalent English Act there is no requirement on Scottish Health Boards to **ensure** the identification of preschool children with SEN. Comprehensive ascertainment in this age group was considered to be impractical and Health Boards were, instead, **encouraged** to identify preschool children with SEN so that they could be referred for joint assessment.

## AGE OF LEGAL CAPACITY (SCOTLAND) ACT (1991)

Scots law has traditionally assumed girls to be capable of consent from the age of 12 years and boys from the age of 14. However, the Age of Legal Capacity (Scotland) Act 1991 has now defined that the ability to give informed consent varies according to the child and the circumstances for which consent is required. Within the terms of this act, a person under the age of 16 years shall have the legal capacity to consent on his or her own behalf to any surgical, medical or dental procedure or treatment where, in the opinion of the attending qualified medical practitioner, he or she is



capable of understanding the nature and possible consequences of the procedure or treatment.

Clearly this requires care and sensitivity to ensure that the child understands both the immediate consequences and those of a longer-term nature. For example, where a child is suspected of being abused, (s)he may understand the immediate consequences of being medically examined but possibly not the longer-term consequences which could include the break-up of the family with a father or uncle being ultimately sent to prison. Clearly, if a child or young person has the right to consent, (s)he also has the right to refuse treatment. The possibility of a young person refusing treatment which has been agreed to by his or her parents has yet to be tested in court.

#### CHILDREN (SCOTLAND) ACT (1995)

The Children (Scotland) Act (1995) received Royal Assent in July 1995 purely because legislative time became available unexpectedly when the government withdrew its plans to privatise the Royal Mail. Most sections became law in 1996 and 1997. Like the 1989 Children Act in England, it represents the culmination of many years of reviews, reports and enquiries. These include the UN Convention on the Rights of the Child; the European Convention on Human Rights; the 1990 Report of a Review of Child Care Law for the Secretary of State [10]; the 1992 Reports of the Enquiries into (the problems in) Orkney and Fife [11,12]; the 1992 Finlayson Report on Reporters to Children's Panels [13]; the 1992 review of residential care *Another Kind of Home* [14]; and the 1992 Scottish Law Commission's Report on Family Law [15].

All these Reports have emphasised the importance of integrated systems of child care and protection and the need for improved liaison between statutory services. The Act covers four main aspects of child care and its main provisions have been summarised in a report from Children in Scotland [16].

#### **Part I: parents, children and guardians**

1. Parental responsibilities and rights are defined, including the right and responsibility to maintain contact if the child is not living with the parent.
2. It establishes the principle that, when making parental responsibilities orders, a court must make the welfare of the child its paramount concern.
3. A new legal procedure is introduced for unmarried fathers to acquire parental responsibilities and rights with the agreement of the child's mother.

4. It stipulates that children should, bearing in mind their age and maturity, be consulted by their parents or guardians on all major decisions affecting them.
5. The terms 'custody' and 'access' are replaced with 'residence' and 'contact' for court orders.

## **Part II: promotion of children's welfare by local authorities and by Children's Hearings etc.**

1. The principle is established that local authorities, Children's Hearings and courts must have due regard for the views of the child when making decisions affecting that child, and that the child's welfare must be of paramount consideration in these decisions (these principles are overridden only when there is deemed to be a risk of 'serious harm' to public safety).
2. The term 'in care' for those children in the care of the local authority is replaced by 'looked after'; 'voluntary care' is replaced by 'accommodation' and 'compulsory measures of care' is replaced by 'compulsory measures of supervision'.
3. Local authorities are given a duty to publish information about children's services, and to publish a children's services plan.
4. Section 12 of the Social Work (Scotland) Act (1968) is repealed and replaced with a new duty to provide services for 'children in need'.
5. New terminology is introduced for 'children with **and affected by** disability' as a group for whom services must be provided by the local authority. There is a requirement to assess the needs of these children and their carers.
6. In association with the Carers Recognition (and Services) Act (1995), the right to an assessment of need will cover those children and young people who act as carers.
7. The duty of local authorities to provide after-care support for young people is extended up to the age of 19, with further power to help until 21; while the duty to provide accommodation is extended by one year to age 18, with a further power to provide it until 21.
8. The inspection of independent and residential schools is widened, and the requirement to inform local authorities of children in hospital for more than 3 months without parental contact is strengthened.
9. Powers are conferred on local authorities to provide 'safe refuges' for those children who run away, repealing previous legislation outlawing the 'harbouring' of children.
10. Increased privacy is provided at Children's Hearings and the rights of appeal for children and their parents are extended.

11. Children and young people are given the right to speak to the Children's Hearing in private; Hearings and courts are obliged to consider the appointment of a safeguarder in most proceedings, and the grounds for appointment are expanded. Sheriffs are given the right to substitute their own decision for that of the Children's Hearing, on appeal.
12. The arrangements for Children's Hearings are eased to allow them to consider new evidence.
13. Revised child protection procedures are introduced, including a new child protection order, child assessment order and exclusion of alleged abuser order; Children's Hearings warrants, conditions and secure accommodation procedures are altered.
14. Local authorities are obliged to seek a court order to assume parental rights and responsibilities.
15. A new entitlement to legal aid is introduced for children.

### **Part III: adoption (sections 94–98)**

1. Key principles relating to children's rights in adoption proceedings are strengthened.
2. The requirement for a birth parent to 'adopt' their own child when a new spouse wishes to adopt the child is removed.

### **Part IV: general and supplemental**

1. Local authorities are allowed to hold inquiries into relevant children's services.
2. Panels for curators *ad litem*, reporting officers and safeguarders are established.
3. Various consequential and supplementary provisions are listed.
4. A commitment is given to necessary consultation before drafting regulations and giving guidance.

The Act's five schedules include important clauses relating to adoption, in particular post-adoption support, the regulation of adoption allowance schemes by the Secretary of State and new interfaces between Children's Hearings and adoption proceedings. They also address transitional provisions and savings, and minor amendments to this and other legislation.

## **UN CONVENTION ON THE RIGHTS OF THE CHILD**

In Scotland a Children's Rights Development Unit has been established by the Child Law Centre for a two-year period to encourage the fullest

possible implementation of the Convention. It has established a *Scottish Agenda for Children* and has defined the action required to improve Health and Health Care Services; Education; Adequate Standards of Living; Leisure, Play and Recreation; Children's Rights and the Criminal Justice System; Children's Rights and Employment; and Care of Children [17]. In addition, local initiatives have been developed.

#### LOTHIAN CHILDREN'S FAMILY CHARTER

In 1992, the Lothian Children's Family Charter was developed jointly between the Health Board and the former Lothian Region's Social Work Department and Education Department to demonstrate a shared commitment to children's rights and entitlements from all the agencies involved. Entitlements were spelt out under the headings of Choice, Health, Access, Responsibility, Thoughtfulness, Encouragement and Recreation. An independent 'adjudicator' was appointed to whom children could complain if they felt they were not getting what they were entitled to.

The Charter was the first of its kind in the UK. An evaluation by the Centre for the Study of the Child and Society, University of Glasgow, acknowledged it as an important demonstration of public commitment to children's rights by Lothian Region and Lothian Health Board despite its identified shortcomings against a gold standard.

#### **Child-friendly Edinburgh**

In 1990, a partnership involving the statutory agencies and private sector in Edinburgh agreed to develop Edinburgh as a 'Child-Friendly City' where children would be valued as future citizens. The first significant initiative arising from this decision was planned to coincide with the European Summit Meeting in Edinburgh in December, 1992. Children and young people from all over Europe were invited to participate in parallel summit meetings.

The vision for 'Child-Friendly Edinburgh' is to enable children to have a safe and enjoyable childhood; space to play and learn; and opportunities to develop their role in the city. It aims to develop Edinburgh as a city which welcomes children; listens to them; and responds to their needs. A 'child friendly' officer has been appointed by the City of Edinburgh Council to bring forward new initiatives to improve personal safety in public places; to enable children to participate in the life of the city; and to encourage more individuals and organisations to be 'child friendly'. A guide has been produced which lists places in Edinburgh which welcomes children and families, as well as a booklet on 'how to be child friendly' with hints, tips and advice for the business sector.

## THE FUTURE OF CHILD HEALTH SERVICES IN SCOTLAND

The implementation of The Children (Scotland) Act (1995) and the reorganisation of Scottish local authorities to create unitary councils from 1 April 1996 has radical implications for child health services in Scotland requiring Health Boards, NHS Trusts and GPs to ensure that effective collaboration arrangements exist with their local planning partners. This will be assisted by the introduction of the new child health information systems.

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# Appendix C: Northern Ireland

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*Adrian Mairs and Leslie Boydell*

## INTRODUCTION

Northern Ireland has a number of distinctive social and demographic factors which are of relevance when considering the management of health services for children. These include a relatively stable population with close family ties, low levels of staff turnover, a generally high standard of public housing, higher unemployment rates and high levels of deprivation leading to greater demands on the caring services compared with the rest of the United Kingdom. In addition attitudes are more conservative on issues such as premarital sexual relationships [1], abortion and divorce [2].

The population of 1.64 million is relatively young: 24% are under the age of 15 years. This compares with a figure of 20% in England and 19% in Scotland. In common with many other European countries the total period fertility rate (a measure of the number of children a woman in the population may expect to have during her life) is falling. Despite this it remains one of the highest in Europe at 1.94 [3]. The rate for England is 1.7.

The province has an international border with the Republic of Ireland. The existence of a land border across which there are no travel restrictions has public health implications. In 1992 the chief executives/chairmen of the four health boards that straddle the border (two in Northern Ireland and two in the Republic) formed CAWT (Cooperation And Working Together). This group meets regularly to discuss items of mutual interest such as child accident prevention, social deprivation and information technology. Their primary aim is to initiate programmes that will result in health and social gain for people living in the border region. In addition there is liaison between the consultants with responsibility for communicable disease control in the respective boards.

## **THE STRUCTURE OF CHILD HEALTH SERVICES IN NORTHERN IRELAND**

The Secretary of State for Northern Ireland is accountable to parliament for health and personal social services. A parliamentary under-secretary of State carries out the functions of a Minister for Health.

Unlike the rest of the UK, since 1973 health and social services in Northern Ireland have been integrated under a single administrative structure. The Department of Health and Social Services (DHSS) provides advice and support to the above members of the government. The Department's mission statement defines its responsibility: 'Our primary purpose is to improve the health and social well-being of the people of Northern Ireland'.

The integrated structure allows for coordination of policy across health and social services. Such coordination is further facilitated by the inter-departmental group on public health whose membership includes senior representatives of the main government departments in the province. The stated aim of the integrated structure is to facilitate the planning and delivery of more efficient, cost-effective and comprehensive services. It aids interprofessional cooperation and administrative efficiency. Such a service enables the expansion of community-based, family-centred personal social services as well as the development of community health and social care for those with learning disabilities, the elderly and other priority categories, including children and young people at risk [4]. Other benefits include the ability to perform comprehensive needs assessments of entire care groups, information systems which transcend separate administrative systems, efficient arrangements for planning discharge from acute care and the ability to re-deploy staff. While there are many potential benefits to be had from an integrated system there has been little in the way of formal research comparing the administrative system in Northern Ireland with systems in Great Britain [5].

The DHSS is assisted in its functions by its professional advisory structure. Specialities such as paediatrics, psychiatry and surgery have their own speciality advisory committees (SACs) which meet once a year. Paediatric surgeons, child psychiatrists and community child health workers are represented on the paediatric SAC. Members of the various SACs also sit on the hospital services sub-committee (HSSC). A separate advisory committee, the general medical services sub-committee (GMCSC), advises on matters relating to general practice. Members of HSSC and GMCSC sit on the central medical advisory committee (CMAC) which meets four times a year.

There are four health and social services boards in Northern Ireland. They have the responsibility to ensure that services are made available in a coordinated way across primary, secondary and community health



services and the full range of personal social services. The largest is the eastern board with a population of 666 200 followed by the northern board which has a population of 408 800, the southern with a population of 297 000 and the western which has 265 800 residents. There is no equivalent to a regional health authority.

With the introduction of the health and personal social services reforms and the purchaser-provider split, it was recognised that some vulnerable specialities might not survive in a competitive environment. This was one reason why the regional medical services consortium was established. It operates as a negotiation forum through which the four boards agree the level of specific services they will support in order to ensure that such services have a minimum viable level of activity. The purpose of the consortium has been defined thus:

To promote the health and well-being of the population of Northern Ireland by securing access to a range of specialised services and ensuring that these services are provided equitably, efficiently and effectively.

A number of paediatric services are subject to consortium arrangements. These include the regional neonatal intensive care service, paediatric cardiology, paediatric orthopaedics, paediatric intensive care and paediatric pathology.

General practitioners are contracted to the relevant boards. Responsibility for paying GPs rests with the central services agency (CSA) which is based in Belfast. GP fundholding was introduced into Northern Ireland in 1993. There are currently 115 fundholding units which collectively cover 53% of the population. In 1997 eligibility for fundholding was extended to include those practices or groups of practices with at least 4000 patients. Fundholders in Northern Ireland cannot purchase mental health services and health services for people with learning disabilities. Community fundholding which allows smaller practices with 3000+ patients to purchase staff, drugs, diagnostic tests and most community health services was introduced in 1997. In addition, three total purchasing pilots commenced in 1997. These pilots are responsible for purchasing both health and social care.

Providers comprise a mixture of health and social services trusts, the voluntary sector and the private sector. Because of the integrated structure an additional piece of legislation was required to allow boards to delegate responsibility for certain statutory functions to health and social services trusts, for example, those relating to child care.

The voice of the consumer is heard through the health and social services councils. There are four of these corresponding to the four boards. They are similar to the community health councils in England and Wales. In addition the current regional strategy for Northern Ireland (see below)

states that each board should have carried out at least one pilot project aimed at making it easier for lay people to participate in the decision-making process about their health and social care needs and the means to address them.

The health promotion agency Northern Ireland directs and coordinates regional health promotion programmes. The agency provides publicity, resources, training and research as well as support to boards and voluntary agencies. It has been involved in a number of projects aimed at children and young people including immunisation campaigns, the establishment of a 'smokebusters' club for primary school children (in collaboration with the Ulster cancer foundation) and the publication of a handbook to help youth workers involve teenagers in issues related to tobacco use. Health education is one of the statutory educational themes within the Northern Ireland curriculum. The agency, in collaboration with the Northern Ireland curriculum council, set up a joint project to produce guidance materials aimed at assisting schools in recognising that for health education to be effective, all aspects of school life must support the positive health messages promoted in the classroom. This guidance on health-promoting schools was published in 1994 [6]. It aims to help schools:

1. develop as health-promoting institutions;
2. develop an understanding of the processes involved in the teaching of, and learning about, health-related issues;
3. enhance their understanding of the nature of health education; and
4. develop a planned and coherent approach to the coordination, monitoring and evaluation of health education in the curriculum.

By promoting the health and well-being of everyone in the school community the individual's ability to effectively manage the physical, psychological, social and spiritual aspects of life will be enhanced. The importance of such an approach is emphasised by the fact that children in Northern Ireland are in general heavier smokers than their counterparts in Great Britain. While a higher percentage of children locally state they never drink, those that do are heavier drinkers than children in the rest of the United Kingdom [7].

## LEGISLATION

Northern Ireland has a similar legal system to England and Wales, although some of its legislation is different. Since the introduction of direct rule in 1972 much primary legislation relating to the province has been enacted by parliament using the orders in council process. Such legislation is referred to as an order rather than an act. However many acts of parliament enacted after 1971, such as the Human Fertilisation and Embryology Act (1990), do apply to Northern Ireland while some acts

enacted before the date in question do not, for example the **Abortion Act (1967)**.

**The Health and Personal Social Services (NI) Order (1972)** laid down the legal framework for an integrated service and the establishment of health and social services boards. It defined the primary responsibility of the DHSS as that of ensuring the provision of integrated health and personal social services in Northern Ireland designed to promote the physical and mental health and social well-being of the people of Northern Ireland. Boards, as agents of the Department, have a similar responsibility in respect of those individuals living in their area.

**The Health and Personal Social Services (NI) Order (1993)** enables boards to delegate certain statutory functions to health and social services trusts. These functions, from a number of statutes (including the Children and Young Persons Act (NI) (1968) and the Mental Health (NI) Order (1986)), confer duties, powers and responsibilities on boards to act in the field of health or social welfare such as the taking of a child into care or the detention of a mentally ill patient for assessment.

Adoption law is similar to England and Wales. The exception is that, under the **Adoption Order (1987)**, birth parents in Northern Ireland have the right to specify the religious upbringing of any child they wish to place for adoption.

Under the **Matrimonial Causes Order (1978)** the court requires a social work report on every family with a child of school or preschool age undergoing divorce proceedings. Elsewhere such reports are commissioned at the discretion of the court and may be made by the court welfare or probation service.

The Children Act (1989) does not apply in Northern Ireland. A **Children Order** was laid before parliament during 1994. This essentially replicates the Children Act but includes additional sections covering illegitimacy, guardianship and the employment of children, including their participation in public performances. It was implemented in late 1996 following the publication of regulations and guidance.

## A REGIONAL STRATEGY FOR NORTHERN IRELAND

In 1991 the third Regional Strategy for Health and Personal Social Services in Northern Ireland 1992–1997 was published [8]. It identifies the main health problems and social care issues facing people in the province in the 1990s. Objectives and targets are set for major improvements in health and social well-being through tackling those problems.

The strategy is primarily aimed at boards who, as purchasers of services, have the lead responsibility for initiating much of the action required to meet the targets. However, the document makes it clear that many others, from the individual to various government agencies, have a part to play.

Four main themes run through the strategy:

1. a greater emphasis on health promotion;
2. improving the use and enhancing the quality of acute hospital services;
3. developing care in the community and transferring people and resources from long-stay institutions; and
4. targeting health and social need.

These themes set out the main policy objectives which boards should use as guidance when procuring services.

In addition eight key areas are identified. These are defined as areas of particular concern where cost-effective prevention or treatment is possible. In each of these key areas specific objectives and targets are set. The key areas of concern are:

1. Maternal and child health
2. Child care
3. Accidents and trauma
4. Physical and sensory disability
5. Mental health
6. Circulatory diseases
7. Cancers
8. Respiratory diseases.

In maternal and child health, objectives and targets are set in relation to the rationalisation of obstetric units, the development of outcome measures for the child health surveillance programme, teenage pregnancies, the multidisciplinary assessment and management of children with severe chronic disease and complex handicap, immunisation uptake rates and access to genetic counselling services.

In child care the main objectives and targets relate to ensuring the provision of prevention programmes such as 'Kidscape' for primary school children. This is a self protection training package for young children which looks at themes such as 'good touch/bad touch' and teaches children about the integrity of their bodies. There is also a package for secondary school children called 'Teenscape'. Other major objectives are to ensure full implementation of the guidance on the management of child abuse and to ensure access to evaluated treatment and services for all children who have been sexually abused. There is also a target for the percentage of children in care who should be in a family placement. This is set at 75%.

A number of objectives and targets in other key areas are of relevance to children's services. These include reducing deaths from accidents; purchasing services to meet the needs of children with physical disabilities; developing services to meet the special needs of children and

adolescents with mental health problems and targeting health promotion strategies highlighting the dangers of tobacco smoking on children of school age.

In 1994 the regional strategy advisory group of the DHSS commissioned a number of task forces, one for each key area in the regional strategy except accidents and trauma which is being taken forward by the interdepartmental group on health. Their job was to draw up action plans for the targets in their key area which detailed the role of all those who have a part to play in reaching the targets. These plans have been published in the form of key area booklets [9,10].

While the guidance in these booklets remains valid for the remainder of the 1992–1997 planning period, and beyond, a new regional strategy covering the years 1997–2002 was published in 1996 [11]. In the area of child health and welfare this strategy sets the following targets.

1. By 2002 there should be a 10% reduction in stillbirths and deaths in children under one year old.
2. By 2002, of the children assessed by boards as children in need: those below compulsory school age should receive good-quality early years services; and those of school age should receive family support services operating out of school hours.
3. By 2002 there should be a reduction of at least 25% in the total number of acute hospital bed days occupied per annum by children aged 0–15 years.
4. By 2002 there should be a 50% reduction in the number of children abused or reabused who are on child protection registers.

## **MANPOWER ISSUES IN PAEDIATRICS AND CHILD HEALTH**

Northern Ireland is less well provided with consultant paediatricians than the remainder of the UK and, in particular, has not kept pace with the expansion in the number of consultant paediatricians in community child health (CPCCH). In 1990, in Northern Ireland, there were 18.5 thousand children per consultant paediatrician compared with 13.2 in England. It is also less well provided with doctors working in community child health and is losing senior clinical medical officers (SCMOs) and clinical medical officers (CMOs) at a greater rate than elsewhere. The net effect has been a depletion of resources in the community.

A sub-group of the SAC in paediatrics produced a report in 1993 which considered the changes that will be required to ensure closer coordination and eventual unification of the hospital and community elements of the child health service [12]. A combined service should be more accessible, better coordinated and child centred. The report was mainly concerned with medical staffing and training and the creation of a unified career

grade for all doctors interested in working with children whether that be in the community, in hospital or both.

Since the publication of the 1993 report there has been a significant increase in the number of consultant paediatricians whose job description includes an element of community child health. In 1994 there were only three such doctors. In 1996 this number had increased to 11.

## PAEDIATRIC MEDICAL AUDIT

Paediatric audit is organised mainly at trust/unit and area level. Each board has an area medical audit committee and produces an annual report.

Hospital audit coordinators are responsible for ensuring that all medical staff are participating in audit. Audit assistants are employed by the boards to facilitate audit both in hospital and in the community. Their function is to maximise the effectiveness of time spent by clinicians on audit activities. In most areas paediatricians hold regular audit meetings with their obstetric colleagues.

Hospital audit projects have included:

1. services available for neonatal resuscitation, which pointed out the lack of an adequate 'safety net' of skilled intermediate grade staff; and
2. the job content of medical paediatric training posts which highlighted the need for more training in the community.

In the community, projects have included:

1. the establishment of an area register of patients with epilepsy so that an indicator-based audit on the management of the condition may be undertaken; and
2. an analysis of medical advice in the statements of children with special needs. The help of an audit assistant was obtained to examine each statement for ease of understanding by a non-medical reader.

Following the government's response to the Winterton report [13] a regional neonatal intensive care audit was established in 1993. It, along with other small specialty groups such as ENT, dermatology and nephrology, reports to the regional audit committee.

Northern Ireland participates in the confidential enquiry into stillbirths and deaths in infancy (CESDI) which was established to determine which babies die, and why they die. The 1993 enquiry collected information on the deaths of all children born after 20 weeks' gestation (or who have a birthweight greater than 500 g) up until the end of the first year of life. In Northern Ireland, in 1993, there were 350 such deaths. In order to determine why certain babies die, a confidential enquiry is held which, each year, studies a different sub-population of deaths. In 1993 the

sub-group examined included all normally formed infants who weighed 2500 g or more and who died during labour or within the first 6 months of life. Locally these deaths numbered 14. The first CESDI report for Northern Ireland was published in 1995 [14]. It made a number of general recommendations, for example:

1. all junior obstetric staff should receive formal teaching on the interpretation of cardiotocographs;
2. induction programmes emphasising emergency procedures and resuscitation should be held for all new and inexperienced obstetricians, paediatricians and midwives;
3. units should consider undertaking an audit exercise on clinical notes; and
4. more emphasis needs to be placed on the diagnostic importance of a post-mortem examination.

Information on the small number of CESDI deaths in Northern Ireland will be added to information on deaths elsewhere in the United Kingdom so that lessons can be drawn that are of wide application.

## **CLINICAL AUDIT**

Following a review of the regional child health surveillance (CHS) programme the need to assess the effectiveness of activities carried out within child health surveillance was identified.

A multi-disciplinary group of interested professionals, both purchasers and providers, was established. The remit of the group was to initiate and coordinate audit in child health and to develop outcome measures. The group examined the CHS programme and the literature on outcomes in this area.

Sensorineural hearing loss was identified as the first audit topic. A working group was established which included a paediatric ENT surgeon. The group examined the effectiveness of screening in the identification of severe sensorineural hearing loss. The first element of this audit involved a retrospective review of hospital and health visitor records of known cases. It is planned to extend the audit to an examination of the sensitivity and specificity of the programme using the child health computer system.

## **INFORMATION SYSTEMS IN CHILD HEALTH**

### **NIPPERS (NORTHERN IRELAND PAEDIATRIC PATIENT EVENT RECORDING SYSTEM)**

This tailor-made clinical information system was designed by local paediatricians and developed by the regional directorate of information

systems (DIS) [15]. Set up to facilitate paediatric audit throughout the province, it is financed by the DHSS and the northern health and social services board. It fulfils the clinical needs of doctors and meets the provider units' administrative requirements. The system communicates with the hospital patient administration system (PAS) which is in use throughout Northern Ireland. This integration of clinical and administrative computer systems reduces duplication of effort in maintaining basic patient information. Körner inpatient data sets are automatically downloaded to NIPPERS.

Timely discharge notes to GPs are produced using Read codes. These are mapped by the system to the corresponding ICD code before being uploaded to the hospital PAS. A variety of audit reports may be generated, e.g. data on length of stay or the number of referrals by GP. The system is flexible and paediatricians, in conjunction with the systems analyst from DIS, can add new features or discard redundant ones as experience with the system increases. It is thus responsive to local requirements.

#### QUALITY ASSURANCE PROJECT (NATIONAL CHILD HEALTH SYSTEM)

The eastern health and social services board (EHSSB) participated as a field survey site in a project for the development of measures of quality assurance for the national child health system (CHS). This was a project undertaken by the child health system consortium between 1992 and 1994.

The national CHS was implemented in Northern Ireland using agreed regional parameters, building on the experience of the implementation of the CHS. While a few local adjustments were necessary, there was consistent and quality assured documentation, a regional training programme and established project boards as well as a regional coordination project board. It was considered that the experience within the EHSSB could benefit other participants in the quality assurance project at the same time as developing the expertise of the project manager. The EHSSB joined the project in July, 1993.

Following a review of four aspects of the CHS in the eastern board (user management of CHS; child registration; immunisation and vaccination; and data protection, security and confidentiality) it became apparent that there was potential for development and improvements in system management in the area of data protection, security and confidentiality. This was the primary area of work during the project. It was also recognised that there was potential for an audit of the birth notification information flow within the eastern area because there was concern that the relevant professionals may not have the necessary information on child health available to them in time for the first visit to the mother and child at home around the tenth day.



In January 1994 the eastern board child health project produced draft data protection guidelines. In addition a survey of the birth notification information flow was undertaken and led to recommendations which have now been implemented by the hospitals and community trusts to ensure that the relevant information is available to professionals in time for the first home visit. As part of this development an electronic link has now been established between the Northern Ireland maternity system and the CHS.

#### PERSONAL CHILD HEALTH RECORDS (PCHR)

The PCHR, which are kept by the parent, were introduced to Northern Ireland in January, 1995, with the aim of:

1. increasing partnership between parents and professionals;
2. improving communication between professionals caring for the child; and
3. providing parents with health information relevant to their child.

In Northern Ireland, entries to this record can be made by social workers as well as by health care workers.

### INITIATIVES TO ADDRESS IDENTIFIED AREAS OF NEED IN NORTHERN IRELAND

#### THE IMMUNISATION ACTION TEAM

This was a multi-disciplinary approach developed to tackle poor immunisation uptake levels. The World Health Organisation declaration to the European Nations in 1984, that by '1990 immunisation uptake by 2-year-olds in the UK should be 90%', was the stimulus to action. During the early 1980s uptake in some areas of the EHSSB had been among the lowest in the UK. The reasons were multifactorial and included parental attitudes and beliefs, social deprivation and professional uncertainty and disagreement. In regard to the latter an association had been demonstrated between doctors' attitudes towards immunisation and uptake levels [16].

The immunisation action team was composed of a health visitor, a community project leader seconded from Save the Children Fund, a clinical medical officer, a GP and a secretary. The team was coordinated by a senior clinical medical officer in child health. The team operated from November, 1988 to March, 1990 and was funded by the EHSSB. It visited individual general practices and met face to face with over 75% of GPs in the board area. The team also conducted seminars for child care workers both in the statutory and voluntary sector to ask them to share the responsibility for achieving the 90% target. Individual play groups were

visited and a public awareness campaign using the slogan 'be wise – immunise' was launched. This involved the production of leaflets and posters, promotional days in shopping centres and media coverage. The livery of many board vehicles displayed the logo.

A rise in immunisation rates was observed particularly in the most deprived areas. In north and west Belfast, for example, only 59% of children were immunised against diphtheria, tetanus and polio in 1987. In 1989 this figure rose to 80%. While the action team undoubtedly had an influence on professional attitudes to immunisation it is not possible to fully ascribe the positive result to their work as a number of other powerful factors were operating at the time [17]. These included the computerisation of child health records, the launch of the mumps, measles and rubella immunisation programme and the new GP contract.

#### TRAVELLERS' CHILDREN

Travellers are a self-defined group who cannot be characterised by specific criteria such as geographic mobility or type of living accommodation. There are over 230 families of travellers on a total of 26 sites in Northern Ireland. This increasing traveller population of more than 1100 individuals includes comparatively more young people than the general population with 53% under the age of 17.

Among the travelling community there is a level of ill-health which is significantly above that of similar socioeconomic groups in the settled community. In 1989 a study of over 300 travellers' children under the age of 16 was carried out [18]. It revealed that these children had:

1. a high level of hospitalisation,
2. a low level of immunisation (especially against pertussis),
3. a lack of developmental screening,
4. a high risk of congenital abnormalities, and
5. low levels of breast feeding.

Over a third of the children had parents who were first cousins, putting them at high risk of autosomal recessive genetic disorders. It was also shown that the death rate among children under the age of 10 years was ten times higher in the travelling community than in the settled community.

Many departments are involved in the provision of services to travellers, including health and social services, education, training and employment. These public services are coordinated through an inter-departmental coordinating group led by the Department of the Environment (DoE).

While the health problems of travellers' children are multifactorial the key to good health is the establishment of permanent sites with clean water

and sanitary facilities. Such sites are a prerequisite to the provision of effective health and social care [19], as well as for education. To promote the development of sites, the **Local Government (Miscellaneous Provisions) (NI) Order** enables the DoE to make 100% grants available to District Councils in respect of expenses they incur in providing caravan sites for travelling people. This is facilitated by the advisory committee on travellers NI (ACT) which advises and encourages councils and others involved in the provision of serviced sites. Currently over 65% of the traveller population are on such sites and a further 20% are on interim sites with basic amenities.

Child health clinics have been developed on some sites. These focus on immunisation and child health surveillance. A 100% immunisation record has been achieved on at least one site.

#### DENTAL INITIATIVES

Over the past 10 years levels of tooth decay among children in Northern Ireland have fallen by 30%, however they remain approximately twice as high as levels in England and Wales. For example, 15 year olds in the province have on average five decayed teeth compared with an average of two for children in England [20].

An oral health strategy has been developed to tackle this problem. Its two main strands are the introduction of a fluoridated water supply for the population and health promotion initiatives aimed at reducing the amount of sugar children consume. It is known that children in Northern Ireland consume a high level of dietary sugar [21]. Currently only two small areas of Northern Ireland have a fluoridated water supply (Holywood and Tandragee).

The EHSSB has in addition produced integrated nutrition guidelines [22]. These attempt to dispel some of the conflict which has arisen in the advice being given to the public by various professionals. One of the major problems is that the nutritional advice for dental health is to limit the intake of sugar-containing foods, whereas a reduction in fat intake is recommended to help prevent conditions such as coronary heart disease. The guidelines concentrate on between-meal snacking and set an interim target of a maximum of six sugar intakes per day, including meals, with a long-term target of four per day. A list of acceptable and suitable snacks and drinks is given.

#### INFANT FEEDING INITIATIVE

In Northern Ireland the incidence of breastfeeding is very low. Only 36% of babies are put to the breast compared to 64% in England and Wales [23].

In 1989, a small group of individual health professionals in the EHSSB became concerned at the low incidence of breastfeeding, the anecdotal reports of conflicting advice on infant feeding being given by health professionals and the differences in maternity hospital practices regarding infant feeding. It was decided that consensus infant feeding guidelines should be developed by a multidisciplinary group with the aim of improving the nutritional health of children under one year of age within the EHSSB area, by promoting clear and consistent advice on infant feeding. After widespread consultation, these guidelines were adopted in 1991. The guidelines were implemented using a cascade approach. Implementation teams were trained and established in each trust. These teams provided update seminars for all members of staff, including night staff. Extra financial, audiovisual and written resources were made available to teams to support the initiative. Regular meetings of a representative from each team were held with the project coordinator to discuss progress and share ideas.

Prior to the implementation of the guidelines a baseline survey was undertaken to establish health professionals' knowledge of infant feeding and attitudes to breastfeeding. The method used was a postal survey of all midwives, health visitors, clinical medical officers, dietitians, general practitioners and pharmacists. Attitude and knowledge scales were developed for the questionnaire. The survey was repeated in 1993 to assess the impact of implementing the guidelines. Knowledge of infant feeding was significantly greater in 1993 than in 1990/91. However, attitudes had not altered in the survey sample, although individuals who had read the guidelines had significantly better scores for knowledge and attitudes than those who had not.

#### YOUNG PEOPLE'S PEER EDUCATION PROJECT

In 1986 the EHSSB established a strategy for the prevention of the spread of HIV infection. One of the groups which was highlighted for high priority action was young people. At that stage a coordinator was employed to build up interagency links and to develop interpersonal strategies which had a sexual health focus.

One of the major strategies developed was the young people's peer education project. Peer education involves the sharing of information and exploring attitudes and behaviour by people who are not professionally trained instructors but whose goal is none the less to educate [24]. It is based on a concept which makes positive use of potential peer influence as it is considered that during adolescence, when the peer relationship often assumes a dominant position, young people will learn better from each other [25]. The primary aim of the project was to develop a model of

peer education which could be adopted by those agencies directly concerned with young people.

As it was hoped that other organisations would adopt this way of working it seemed most appropriate to develop a method of peer-led education which would complement the approaches of these organisations. The method of training adopted for the peer education project draws heavily on the concept of experiential learning, i.e. maximum participation in the learning process, e.g. small group work. Through the use of this approach individuals are encouraged to see success in terms of self-awareness and skill development bringing increased self-assessment and self-confidence [26]. This process of social learning involved the modelling and imitation of the behaviours of significant others. Hence young people are educating young people about sexual health.

The evaluation of the original pilot project showed that this way of working with young people and helping them to develop positive attitudes to sexual health was effective. The main findings were as follows.

1. The methodology worked but needed support from professional staff.
2. It is possible to help young people develop their full potential, to a point where they can take direct responsibility for educational work with their contemporaries.
3. Young people are a powerful force in peer education. More emphasis should be put on this kind of personal development because young people are in the best position to effect positive changes in health-related behaviour.
4. After peer-led sessions there was a significant increase in knowledge as well as a small but positive shift in attitudes and values.

Subsequently, this project has strengthened and peer education is flourishing within other organisations. At present the EHSSB has highlighted the issue of unplanned pregnancy and young people. A group of young mothers has undergone an intensive training course and is currently carrying out peer-led sessions within youth training projects. Early evaluation is encouraging.

## **INTEGRATED SERVICES FOR CHILDREN**

The integration of health and social care in Northern Ireland offers opportunities to develop integrated services. One example in the field of child care is the child care centre.

### CHILD CARE CENTRE

The child care centre, Belfast, was opened in 1988. At present it is located and managed within the south and east Belfast health and social services trust but serves the greater Belfast area.

The centre is a multi-disciplinary unit led by a paediatrician. The approach adopted by the centre is child-centred rather than task-centred. The aims of the centre are the following.

1. To assess, validate and, where appropriate, treat and review cases of child sexual abuse. Staff also offer an input into treatment plans and review of cases with which they are not directly involved.
2. To provide consultancy to other professionals working within the area of child sexual abuse. The expectation is that others involved in such work will find support and an affirmation of the work that they are undertaking.
3. To provide training in the assessment and management of child sexual abuse.

In the validation of child sexual abuse an emphasis is placed on the investigative interview of the child.

To date the centre has been involved in the investigation and treatment of some 1400 cases. This has involved court work at each level of court. From the opening of the centre there have been many cases in high court where videotaped interviews have been used.

The unit is a terraced house. Careful consideration has been given to the décor, provision of suitable toys and, most importantly, to the creation of a prevailing atmosphere of calmness, security and acceptability. The aim of this approach is for the children and their families and the professionals involved to find the security and acceptability needed at a time of crisis.

### CONCLUSIONS

While there have been considerable improvements in the health and welfare of children over recent years much work remains to be done. Indeed, important health and social differences remain between children living in poorer households and those living within a more affluent environment.

Many child health initiatives have required a multidisciplinary, multi-agency approach. The benefits of a team approach to the health and social care of children are clear. As an organisation the Department of Health and Social Services in Northern Ireland needs to foster team working and a child-centred service. A number of recent developments should facilitate these goals. For example, a primary care-led service, with an emphasis on empowering primary care teams, has the potential to deliver an integrated

service to children and families. In addition, the implementation of the Children Order will assist in the provision of a comprehensive, coordinated and targeted service for children in need.

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# Index

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Page numbers appearing in *italics* refer to tables

- 16 Personality Factor Questionnaire 184
- 1974 NHS Re-organisation 14–15, 130
- 45 Cope Street, Nottingham, initiative 49, 53
- Abortion Act (1967) 225
- Abuse, *see* Child abuse
- Access to Health Records Act (1990) 44, 89, 136
- Act for the Promotion of Public Health (1848) 3
- Action for Sick Children 18, 23, 59, 60, 148, 150, 259
- Adolescents
  - health programmes 12
  - legislation 235–8
  - services for 212
- Adoption 85, 215, 295
- Advocacy 48–9, 268
- Age of Legal Capacity (Scotland) Act (1991) 292–3
- All-Wales Mental Handicap Strategy 263
- Allitt, Beverley, case of 184, 191, 203, 204, 206
- Appraisal of performance (Scotland) 188
- Area child protection committee (ACPC) 206, 214–15, 219, 231
- Arthur, Dr Leonard, trial of 226
- Audit 68–72, 203–4
  - child health directorate and 148–9
  - clinical 29, 69, 283, 307
  - communications 186
  - financial 178–9
    - external 179
    - internal 178–9
  - local level 69–70
  - medical 28–9, 306–7
  - organisational 71–2
  - population-level 70
- Audit Commission 150, 151, 179, 220
- Audit cycle 70
- Behaviour, *see* Health behaviour, patterns of
- Behavioural risks 198–204
  - audit 203–4
  - incident reporting 204
  - recognising 201–4
  - training 202–3
- Belbin Team Role Self-perception Inventory 190
- Benefits management 256–7
- Better Management, Better Health* 188
- Beveridge report 13
- Births 16
  - notification of 16, 17, 131
- Birthweight, patterns of 103, 105, 116
- Board of Education 16
- Boer War, health of recruits 11, 16
- Boke of Children* 3
- Bottom up costing 175
- British Agencies for Adoption and Fostering 85
- British Paediatric Association (BPA) 5, 149, 154, 160, 259
- British Paediatric Surveillance Unit 119

- Brotherston Report (1973) 289–90  
Budget holder 171  
Budget manager 171  
Budgeting 170, 172  
Budgets  
    apportioning 153  
    pay 170  
Business manager 31  
Business plans 36, 148, 169  
Business transaction costs 123
- Cambridge and Huntingdon Health  
    Authority management model  
    49  
Cancer registration data 107  
Capability (Scotland) 18  
Capacity management 32–3  
Capital debt, originating 167  
Capitation-based funding 166  
Care events 177  
Care order 234  
Care planning 66–7  
*Caring for the Future* 260  
Care proceedings 234  
Case management 124  
Caseload management 124–5  
Censuses 106  
Central Computer and  
    Telecommunications Agency  
    (CCTA) 251  
CESDI (Confidential Enquiry into  
    Stillbirths and Deaths in  
    Infancy) 118  
Chadwick, Edwin, report (1842) 3  
Change, *see* Management of change  
Change control 255  
Chartered Society of Physiotherapy 6  
Child abuse 20, 86, 87, 90, 213, 214,  
    215  
    Cleveland event 10, 206, 213, 223,  
    233, 234  
    disclosures by children 86  
    emotional 85  
    legislation 231–5  
    Orkney cases 10, 233, 234, 286, 291,  
    293  
    physical 20, 85  
    psychological 85  
    Rochdale cases 10  
    sexual 20, 85, 87  
Child Assessment Order 85, 230  
Child B case 21  
Child Development Centres 18, 155–6  
Child Development Programme 50, 53  
Child-friendly Edinburgh 296  
Child guidance 17  
Child health directorate  
    business planning 148  
    collaboration with other agencies  
    149–50  
    collaboration with other providers  
    150  
    collaboration with purchasers 149  
    contracting 145–6  
    financial controls and rules 144–5  
    information 146–7  
    philosophy 143–4  
    quality and audit 148–9  
    setting up 143–4  
Child Health Quality Evaluation  
    (CHEQUE) project 72, 274  
Child health services development 1  
Child health statistics 1  
Child health surveillance 10, 12, 20,  
    107, 217, 281  
Child Law Centre 295  
Child mortality rates 2  
Child neglect, *see* Child abuse  
Child protection 20, 85–6, 90, 213–15,  
    286  
Child protection conference 232  
*Child Protection Guidance for Senior  
    Nurses, Health Visitors and  
    Midwives* 88  
Child protection officers 86  
Child protection plan 232  
Child protection registers 124, 214–15,  
    219, 232  
Child registration 130, 131  
Child Support Act (1991) 82  
Children Act (1989) 20, 44, 76, 78,  
    79–81, 85, 87, 89, 149, 158,  
    212–13, 215, 223, 224, 228–30,  
    234, 237, 238, 260  
*Children Act 1989, The – An  
    Introductory Guide for the NHS*  
    89  
*Children Act 1989, The – What every  
    nurse, health visitor and midwife  
    needs to know* 89

- Children in Scotland 268  
 Children in Wales 268–9  
 Children (Scotland) Act (1995) 293–5, 297  
 Children's Charter 42  
 Children's hearings 294–5  
 Children's hospital 2–3, 4  
 Children's rights, *see* Rights  
 Children's Rights Development Unit 295  
 Children's trusts 22  
 Choice 56  
 Cholera epidemics (1831–2; 1848) 3  
 Citizen's Juries 49  
 Cleveland child sexual abuse event 10, 206, 213, 223, 233, 234  
 Cleveland Report 223, 224  
 Clinical audit 29, 283, 307  
 Clinical budgeting project 128  
 Clinical director 31  
 Clinical directorates 30–2  
     *see also* Child health directorate; Directorates, managing resources within  
 Clinical medical officers 10, 217, 305–6  
 Clinical protocols 65  
 Clinical records 126  
 Clinical risk index for babies (CRIB) score 151  
 Clinical Standards Advisory Group 151  
 Clothier inquiry 206  
 Combined child health 1, 143, 160–1, 267, 305–6, 313–14  
 Combined children's service 150–4, 160–1  
     hospital services 150–4  
     *see also* Integrated children's health services  
 Comcare 133  
 Commissioning 21, 120–1, 142  
 Commitment accounting 173  
 Community child health 154–9  
     child development centres 155–6  
     community outreach 156–8  
     computer services 158–9  
     school health services 156  
 Community Information Strategy for Providers (CISP) 138–9  
 Community information systems 133–4  
 Community mothers scheme 7, 50–1  
 Community Nurses' and Health Visitors' Association 6  
 Community nurses, paediatric 5, 218–19  
 Community outreach 156–8  
 Community services 6  
 Community trust 143  
 Comparative analyses 72  
 Complaints 67–8, 205  
 Computer systems 107, 116, 119, 130–2, 158–9, 213, 281  
     audit support 70  
     patient-based records 126, 249  
 Comway 133  
 Confidential Enquiry into Perioperative Deaths (CEPOD) 69  
 Confidential Enquiry into Perioperative Deaths, national (NCEPOD) 118  
 Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) 118, 137  
 Confidentiality 89, 135, 231, 239  
     duty of 77, 236  
     guidelines on 77–8  
 Configuration management 255  
 Congenital malformations 107, 118  
     returns 136–7  
 Consent 83–4, 235–8, 292–3  
     to medical treatment 79, 82  
     refusal of 80  
 Consultation 48–9  
 Consumer Movement 44–5  
 Consumer relations 67–8, 200–1, 301–2  
 Contract pricing 173–4  
 Contracting 29, 67, 145–6, 166  
 Control of Substances Hazardous to Health Regulations (COSHH) 198  
 Co-operative working, *see* Interagency working  
 Corporal punishment 81–2  
 Cost behaviour 175  
 Cost-and-volume contracts 29, 145, 146  
 Cost-per-case contracts 29, 145

- Cost control 175
- Cost improvements 174
- Costing 173–8
  - contract pricing 173–4
  - cost improvements and efficiency 174–5
  - departmental cost control 175–8
  - rationing and value for money 174
- Council for the Professions
  - Supplementary to Medicine 168
- Court Report (1976) 22, 191, 290
- Cover of Vaccination Evaluated Rapidly (COVER) programme 72, 137, 273
- Critical path analysis 256
- Data
  - collection 3, 106
  - definition 123
  - demographic 106–7
  - disease registers 118–19
  - epidemiological 16, 99–106, 127
  - for evaluation of services 117–18
  - for management of child health services 107–20
  - evaluation 115
  - patient satisfaction 119–20
  - planning 115
  - for planning 115–17
    - children with special needs 117
    - health behaviour 117
    - population size and projections 115–16
    - special risk factors 116–17
  - Government collected 106–7
  - handling 70
  - human resources 127
  - statutory data collection 106
  - systems 32
  - types of 126–9
- Data protection 135–6, 216, 308–9
- Data Protection Act (1984) 44, 132, 136
- Data security 135
- Day care surgery 153
- Death, deaths 20, 99–104, 117–18, 213, 278, 279
- Decentralisation 31
- Decision-making models 49
- Deliberative models 49
- Deprivation 215, 269
- Developmental paediatrics 19
- Developmental surveillance, *see* Child health surveillance
- Diagnostic Related Groups (DRGs) 146
- Diary of a Teenage Health Freak* 12
- Directorate managing 31
- Directorates, managing resources
  - within 169–73
  - budgeting 170
    - actual budget costs 170–1
    - managing 171–2
    - mid-point budget costs 171
    - non-pay budgets 172–3
    - pay budgets 170
  - business planning 169
  - resource management 169–70
  - see also* Child health directorate
- Disability
  - legal requirements 225–30
  - patterns of 104–5, 99–105
- Disability register 118–19, 158, 213, 229
- Disability Wales 270–1
- Disclosure 84, 87, 236
- Disease, patterns of 3, 104–5
- Disease registers 118–19
- District Health Authorities
  - funding 27
  - role of 27–8
  - Welsh 261
- Doctors, roles and responsibilities 87–90
- Donabedian principles 61–3
- Drug abuse 106, 117
- Education Act
  - (1944) 86
  - (1972) 19
  - (1980) 86
  - (1981) 19–20, 44, 217–19
  - (1989) 20
  - (1993) 82, 217–19
  - (1996) 229
- Education (Administrative Provisions) Act (1907) 16
- Education departments, services 11, 19, 22, 86, 213, 216–19, 229
- Education (Scotland) Act (1981) 292
- Educational needs 20

- Effectiveness 117–18
- Electronic patient-based records 126, 249
- Emergency Protection Orders 85, 233
- Employee relations 185–7
- Empowerment 7, 42–3, 48–9, 53  
effect on quality 58–9
- Environmental risk 195–8  
food handling 199–200  
legislation and working environment 197–8  
relations with consumer 200–1  
role overload 200  
staff behaviour and 199
- Epidemiological data 16, 99–106, 127
- Episodes of care 177
- Equal Opportunities 186
- Estates, information systems 128
- European Community (EC) health and safety directives 197–8
- Evaluation 49, 50, 115, 117–20, 257
- Evidence-based medicine 66
- External finance limit (EFL) 167–9
- Family Health Service Authorities 28, 127, 261
- Family Law Reform Act (1969) 80, 83
- Family resource centre 52
- Family support 228–30
- Feasibility studies 252
- Finance  
child health directorate 144–5  
data 127–8  
directorate budgets 170–3  
GP fund holder budgets 166  
hospital services 153  
information systems 127–8  
*see also* Costing
- Financial controls 144–5
- Financial information project (FIP) 133
- Financial targets 167
- First parent visiting 7, 50
- Food handling 199–200
- Food hygiene 202
- Food Hygiene Regulations (1970) 199
- Food Safety Act (1990) 199
- Fostering 215
- Fundholders, *see* General practitioners
- General Household Survey 106
- General Medical Council 4, 77–8, 87, 183, 236
- General practice 10, 217  
*see also* Primary care
- General practitioners (GPs) 10, 13, 301  
as fund holders 28, 142, 166, 261, 275, 301  
rate of consultations 45–6  
in Scotland 288–9
- Genetic services 118–19
- Gestational age 103
- Gillick case 76, 77–8, 83, 84, 88, 136, 223, 224, 235–8
- Gillick competence 78, 79–80, 83, 86, 237, 238
- Government spending 27
- Great Ormond Street Hospital for Sick Children 2, 52
- Griffiths inquiry 26, 30, 39
- Growth, patterns of 105
- Hall report (*Health for all Children*) 12, 20
- Hammurabi, Code of 61
- Hawthorne Effect 187
- Health and safety at work 186, 197–8
- Health and Safety at Work Act (1974) 197
- Health and Social Care 2000; a Framework for Services* 266
- Health and Social Gain for Children* 265–6
- Health authorities 166
- Health behaviour, patterns of 105–6, 117, 264, 280
- Health education, *see* Health promotion
- Health Education Board for Scotland 281–2
- Health gain, *see* Protocols for Investment in Health Gain
- Health goals 20
- Health of Children in Wales* 266
- Health of the Nation, The* 20, 211, 221, 289  
targets 129, 156
- Health promotion 10, 12, 20, 50, 115, 120, 271–3, 281–2, 287, 302

- Health Promotion Agency, Northern Ireland 302
- Health Promotion Wales 262, 271–3
- Health promotional services 115, 271–3
- Health surveillance, *see* Child health surveillance
- Health visiting, visitors 5, 6, 7, 17, 216, 217, 228
- Health Visitors' Association 6
- Healthcare Management Information Services (HMIS) 261
- Healthy Child Project 269
- Healthy Cities* 12, 221
- Higher Education Funding Council's Research Assessment Exercise 2
- History of child health services 2–12
- boundaries of child health services 6
  - hospital services 2–3
  - interface with primary care 9–10
  - interfaces with social work and social policy 7
  - intersectoral boundaries 12
  - medical education 3–4
  - nurse education 4–5
  - polarisation of hospital specialisms 8–9
  - professional bodies 5–6
  - professionalism and parent power 7
  - public health services 3
  - school health services 10–12
  - social work for children 7
  - support community services 6
- HIV 89, 279
- Hospital at home 219
- Hospital services 2–3, 8–9, 150–4, 290–1
- apportioning budgets 153
  - children's hospital department 150–1
  - children's surgical wards 152–3
  - high cost, low volume services 151–2
  - integrated systems 134
  - medical staffing 154
  - outpatient services 153–4
  - in Scotland 290–1
- Huddersfield Corporation Act 1906 16
- Human resource management (HRM) 33, 182, 190–1
- role of 189
- Human resources data 127
- Immunisation 10, 14, 15, 64, 100, 107, 118, 130, 131, 137, 216, 217, 273, 281, 308–10
- in Northern Ireland 309–10
- Incident reporting 204
- Incremental drift 171
- Individual performance review (IPR) 36–7, 188
- Industrial relations 185
- Infant mortality 2, 100, 118, 259, 264
- annual 101
  - in European countries 102, 102
  - by social class 101–2, 101
- Information
- accuracy 70
  - child health/clinical directorate and 30, 32, 130–2, 146–7
  - community systems 133–4
  - costs and benefits 122
  - definition 123
  - development of initiatives 130–5
  - for evaluation 117–20
  - for planning 115–19
  - giving 129
  - levels of 124
  - managing with 32, 139–40
  - national initiatives 136–7
  - provision of to parents 52
  - systems
    - in Northern Ireland 307–9
    - in Scotland 281, 297
    - in Wales 273–5
  - see also* Data
- Inner city deprivation 269
- Integrated children's health services, Scotland 289–90
- see also* Combined children's services
- Integrated Mental Health Systems 249
- Interagency working
- challenge 210–11
  - co-operation 85, 87, 90, 149, 158, 269–70, 286
  - effective 220–1
  - problems 11, 210

- service approaches 211–12  
 working with statutory agencies  
   212–16  
   education service 216–19  
   police and probation services  
   220–1  
   social services 212–13  
     child protection 213–15  
     fostering and adoption 215  
     material or emotional  
     deprivation 215–16  
     preventive work 216  
   voluntary sector 220  
 Interest bearing debt 167  
 Internal market 27, 164, 207  
 International classification for  
   impairments, disabilities and  
   handicaps 104  
 International classification of diseases  
   104  
 Intersectoral boundaries 6–8, 12  
  
 Joint Review, Planning and Advisory  
   Group (JRPAG) 149–50  
*Just for the Day* 153  
  
 Körner, Edith 132, 133  
  
 Ladies Sanitary Reform Association 6  
 Leadership skills 34–5  
 Legislation 15–16, 19–20, 223–39,  
   291–5, 302–3  
   abused child 231–5  
   disabled school-aged child 228–30  
   mature teenager 235–8  
   severely disabled newborn baby  
   225–8  
   unborn baby 226  
   working environment, and the  
   197–8  
*Local Strategies for Health* 264–5  
 Lord Scarman, *see* Scarman ruling  
 Lothian children's family charter 296  
  
 Management, levels of 124  
 Management by objectives 36  
 Management methods 34  
 Management of change 33–4  
 Management of child health 23–4  
  
 Management of Health and Safety at  
   Work regulations (1992) 197  
 Management of resources 164  
 Managers  
   assessment of performance 36–7  
   roles and responsibilities 87–90  
*Managing Computer Projects in the NHS*  
   251  
 Marginal cost 174  
 Maternal age 103–4  
 Maternity and Child Welfare Act  
   (1918) 16  
 Maternity systems 134–5  
 Maxwell's quality principles 63  
 Measles immunisation campaign  
   217–19  
 Medical audit 28–9, 306–7  
 Medical education  
   postgraduate 4, 19, 154, 267, 284–5,  
   305–6  
   undergraduate 3–4  
 Medical Officer of Health 3, 11, 15, 16,  
   17  
 Medical staffing 154, 267  
 Mental health 159–60, 216, 218, 236  
   child and family consultation  
   services 159  
   young people's centre 160  
 Monitoring, effect on quality 57–8  
 Morale, staff 206  
 Mortality, patterns of 2, 100–4  
   birthweight and gestational age 103  
   immigrant status 102–3  
   maternal age and parity 103–4  
   socio-economic factors 100–2  
   *see also* Infant mortality  
 Multi-professional teams 34, 35  
  
 National Assistance Act (1948) 213  
 National Association for the Welfare  
   of Children in Hospital  
   (NAWCH), *see* Action for Sick  
   Children  
 National Centre for Clinical Audit 69  
 National Child Health System 130–1,  
   134, 147, 158, 261, 273–4, 308–9  
   quality assurance project 72, 274  
   in Northern Ireland 308–9  
 National Children's Bureau 22–3,  
   259–60, 268

- National Confidential Enquiry into Peri-Operative Deaths (NCEPOD) 118
- National Health Service, *see* NHS
- National Insurance Act (1948) 13
- National Society for the Prevention of Cruelty to Children 87, 214
- National Vocational Qualifications 188
- Neglect, *see* Child abuse
- Neonatal screening 70, 118
- NHS
- allocation of resources 165–6
  - central organisation 29–30
  - Executive 30, 168, 174, 251, 267
  - finance 165
  - funding 27
  - in Wales, *see* Wales
  - information management and technology (IM&T) strategy 137–9, 140
  - management skills in 26–39
  - origins 13–14
  - recognition of children's services 14–15
  - reorganisation (1974) 14–15, 130
  - restructuring (1982) 15, 142, 188
  - resource allocation 165–9
    - contracts and providers 166–9
    - public expenditure survey 165
    - trusts 28, 36, 166–8, 169, 185, 261, 275, 288
- NHS and Community Care Act (1991) 44, 164, 203
- NHS Training Authority 188
- NHS Training Division (NHSTD) 188
- Nightingale, Florence 61, 62, 128
- Northern Ireland 298–315
- child care centre 314
  - clinical audit 307
  - dental initiatives 311
  - immunisation action team 309–10
  - infant feeding initiative 311–12
  - information systems in child health 307–9
  - integrated services for children 313–14
  - legislation 302–3
  - manpower issues in paediatrics and child health 305–6
  - paediatric medical audit 306–7
  - regional strategy 303–5
  - statistics 299
  - structure of child health services 300–2
  - travellers' children 310–11
  - young people's peer education project 312–13
- Northern Ireland Paediatric Patient Event Recording system (NIPPERS) 307–8
- Notification of birth 16, 17
- Notification of Birth Act (1907) 16
- Notification of Birth Act (Extension) (1915) 16
- Nurse education 4–5, 11, 45
- Nurses' Registration Act (1919) 4
- Occupational health services 186–7
- Occupational therapy 6, 17
- Office for National Statistics, *see* Office of Population Censuses and Surveys
- Office of Population Censuses and Surveys (OPCS) 101, 102, 103, 106–7, 116, 118, 119, 136–7
- Operational policies 65
- Operations management 32–4, 125
- Opportunity 2000 campaign 186, 187
- Opportunity cost 174
- Organisational policy documents 66
- Originating capital debt 167
- Orkney child abuse cases 10, 233, 234, 286, 291, 293
- Outcome 61, 62, 99, 117–18, 119
- Outcome data 128–9
- Paediatric surgery 9
- Paediatrics, British concepts 2, 3
- Parent-held records 42, 52
- Parents
- disempowerment 6
  - partnership with 41–2
  - provision of information to 52
  - responsibility 81–3
  - rights 81–2, 136
  - support 6
  - working with 42–7
- Partnership 41–3, 52–3
- definition 42–3



- in management 48–52
  - principles of 47
  - with parents 41–2
- Patient activity measures 128
- Patient care teams 34
- Patient satisfaction 119, 129
- Patients' charter 71
- Pay budgets 170–2
- Peer Education Project 312–13
- Performance related pay (PRP) 37
- Period of care 177
- Personal Child Health Record (PCHR)
  - 46, 50, 51–2, 53, 216
  - in Northern Ireland 309
- Physiotherapy 6, 17
- Place of Safety Order 85
- Planning 36, 45, 115–19, 213, 220
  - see also* Project planning
- Platt Report (1959) 18
- Police 219–20, 234
- Policy, development of
  - child health promotion 20–1
  - children in hospital 18–19
  - developmental paediatrics 19
  - effect of wars 16–17
  - effect on quality 57
  - public health legislation 15–16
  - purchasing child health services 21
  - service development 17–18
  - structures of children's services 21–2
- Political accountability 124, 125
- Poor Law Administration 16
- Population Health Summary System (PHSS) 275
- Population registration 126–7
- Preventive services 7, 15–16, 115, 119, 120, 216
- Primary care 9–10, 13
  - European 9–10
  - North American 9
- Primary Care: Delivering the Future* 44
- Projects in Controlled Environments (PRINCE) 251–2, 257
- Priorities and Planning Guidance for the NHS: 1996/97* 42
- Probation service 219–20
- Process flow model 63–4
- Profiles of care 176
- Project 2000 201, 206
- Project management 247–57
  - benefits management 256–7
  - benefits of structured approach 250
  - change control 255
  - configuration management 255
  - critical path analysis 256
  - current initiatives 251–2
  - evaluation 257
  - main characteristics 247–8
  - manager 248–9
  - problems with projects 250
  - project initiation 253–4
  - project manager 248–9
  - project objectives 248
  - project organisation 249
  - project planning 253–4
  - project scoping 253
  - project teams 249–50
  - quality 254–5
  - risk analysis 254
  - software 255–6
  - teams 249–50
- Project planning 253–4
- Promotion of Public Health Act (1848) 3
- Proper Officer 16
- Protocols for Investment in Health Gain 264–5
- Psychometric testing 184–5
- Public dividend capital 167
- Public health 3, 15–16
- Public Health Acts 3
  - (1872) 15
  - (1875) 15
  - (1926) 16
- Purchaser/provider split 27–8
- Purchasing 21
- Quality 8, 30, 32, 57–73, 148–9, 254–5, 308–9
  - comparative analyses and special studies 72–3
  - measures 56
  - models of 61–4
  - targets 59
  - within projects 254–5
- Quality circles 182
- Rationing 174

- Record keeping 46, 123
- Recruitment 183–6, 191
- Registered Sick Children’s Nurse 4, 5, 18, 201, 206
- Registers
  - child protection 124, 214–15, 219, 232
  - disability 118–19, 158, 213, 229
  - disease 118–19
- Report of the Joint Working Party on Medical Services for Children 267
- Resource allocation 165–6
- Resource Management Initiative (RMI) 30, 142
- Resource scheduling 67
- Resources, managing 169
- Reward and remuneration 187–8
- Rights
  - children’s 77–81, 90, 136
  - parents’ 136
- Risk analysis 254
- Risk management 194–207
- Rochdale child abuse cases 10, 223
- Role overload 200
- Rostering systems 127
- Royal College of General Practitioners 259
- Royal College of Nursing 259
- Royal College of Paediatrics and Child Health (RCPCH) 2, 6, 259, 280
- Rural deprivation 269–70
- Save the Children Fund 269–70
- Scarman ruling 78, 136
- School health 10–12, 130, 131, 156, 216–17, 219–20, 273, 281
- School nursing 5, 11, 156, 218
- Scope 18
- Scotland 278–97
  - future of child health services 297
  - health of Scottish children 279–80
  - hospital services for children 290–1
  - information systems 281, 297
  - integration of children’s health services 22, 289–90
  - children’s hearings 291
  - legislation 291–5
  - NHS local structure 285–9
  - NHS national structure 280–5
  - NHS policy 289
  - statistics 278–9
- Scottish Centre for Infection Control and Environmental Health 285
- Scottish Council for Postgraduate Medical and Dental Education (SCPGMDE) 284–5
- Scottish Intercollegiate Guidelines Network (SIGN) 284
- Scottish Needs Assessment Programme (SNAP) 283–4
- Security of information 135
- Seebom Committee 8
- Selection of staff 183–5, 191
- Service increment for teaching and research (SIFTR) 166
- Sex education 82
- Sexual abuse, *see* Child abuse
- Sexual behaviour 117
- Sheldon Report (1967) 18
- Skill mix 33
- Social Services 8, 22, 158, 206, 212–16, 220, 228–35
- Social work 7–8
- Socio-economic factors 100–3, 116
- Spastics Society (Scope; Capability) 18
- Special educational needs 217–19, 286, 292
- Special needs 217–19
- Specific issue order, Children Act 230
- Speech and language therapy 17
- Staff behaviour and practices 198–201
- Staff costs 33
- Staff morale 206
- Staffing
  - activity reports 123
  - development and training 188–9
  - environmental risk and 199
  - medical 154
  - planning 182–3
  - records 127
  - recruitment and selection 183–5
  - relations between 185–7
- Stakeholders 59, 70
- Standard costs 175
- Standards 151
  - absolute 71
  - interim 71

- normative 71
- setting 70–2
- Standing Committee on Postgraduate Medical Education (SCOPME) 154
- Statements, educational need 19, 217–18, 229
- Steering group on health services information 132–3
- Stillbirths 100, 118
- Strategic management 125
- Strategic plans 36, 49, 263
  - see also Planning
- Structures 21–2
- Subject Access 136
- Suggestions 68
- Supplies information 128
- Surveillance, see Child health surveillance
- Surveys, childhood 107
  
- Targets 71, 304
- Team briefing 182, 186
- Teams 34–6, 64–5
- Teamworking 189–90, 249–50
- Teenagers, see Adolescents
- Termination of pregnancy 84, 107, 115, 119, 225
- Time management 37–9
- Top down costing 175
- Total quality management 32
- Trade unions 185
- Training 188–9, 202–3
- Travellers' children 310–11
- Trusts, see NHS, trusts
  
- UNISON 185
- United Kingdom Central Council for Nurses, Midwives, and Health Visitors 183
- United Nations Convention on the Rights of the Child 76, 260, 291, 293, 295
  
- Vaccination 15
  - see also Immunisation
- Vaccination Acts (1853, 1907, 1967) 15
- Value for money 174
- Voluntary societies, agencies 18, 49, 211, 213, 220
  
- Waiting lists 125
- Wales 20, 259–76
  - commissioners 261
  - cooperative working 269–71
  - health promotion and health education 271–3
  - information systems 273–5
  - NHS in 260, 262
  - organisational differences: roles and relationships 260–1
  - provider issues 267
    - advocacy and advice 268–9
    - combined child health services 267
    - medical services for children 267
  - providers 261
  - purchaser issues 263–6
    - all-Wales strategy 263–4
    - health and social care 2010 266
    - health and social gain for children 265–6
    - local strategies 264–5
  - statistics 259
  - Strategic Intent and Direction for the NHS in Wales* 263–4
- Wales Council for the Disabled 270–1
- Wales Perinatal Mortality initiative 262
- Welfare of Children and Young People in Hospital* 148
- Weighted capitation formula 27
- Welsh Health Common Services Authority 131
- Welsh Health Planning Forum 20, 260, 262, 266
- Welsh language 267–8
- Welsh Office, Health and Social Services Policy Board 260
- Welsh Public Health Common Data Set 274–5
- Whitley system 181
- Women Sanitary Inspectors' Association 6
- Workforce planning 182–3
- Working for Patients* 27, 39, 164, 203
- Working Together* (1991) 87, 220, 231
- Works Information Management System (WIMS) 128
- World Health Organisation Regional Office for Europe 56, 72

World War II 17

York Health Authority management  
approach 48–9

Young People's Peer Education  
Project 312–13

Zero based budgeting 172