Book reviews

Expert Opinions: A National Survey of Parents Caring for a Severely Disabled Child.

By Bryony Beresford

The Policy Press, Bristol, 1995. £10.50, 45 pages.

The Joseph Rowntree Foundation funded a national postal survey in 1994 of recipients of grants from the Family Fund. Over 1100 families took part, an 83% response rate. Recipients of assistance from the Family Fund all have children with severe impairments. Previous studies have demonstrated that Family Fund families are representative of the majority of families caring for a severely disabled child in the United Kingdom. The combination of the high response rate, and the inclusion of high proportions of lone parents and black families, means that the responses obtained are likely to have given a very clear picture of the situation of UK families.

The publication is potentially very influential. It is short, clearly written, attractively laid out, with summaries at the end of each chapter. Implications for services are clearly specified in the final chapter. I would recommend this publication highly to any professional involved in child disability services, particularly those coming into the field. It is a pity that the impact of the publication may be reduced by its cost.

There are a number of very striking findings of the survey. For example, just under half of the parents of children under 2 years of age used at least one item of medical equipment at home, with over one in ten using three of more items of equipment. As the author comments, 'Little if anything is known about the impact of these intense levels of nursing care on families.' Very many parents are coping in difficult financial and living circumstances. Families of disabled children are likely to have lower incomes in general through the double effect of reduced employment opportunities and higher expenses. Almost half of the respondents felt that their housing was unsuitable for reasons which include difficult stairs, not enough bedrooms, no downstairs toilet, etc.

One chapter concentrates on unmet needs both of the children and of the parents. There may be something of a problem of definition here, in that it seems possible for a parent to agree that her child needs more 'help with communication', but at the same time to feel that the child is receiving the input and therapy which is appropriate and that the child is making as much progress as might be expected. There are clearer items, such as 'the need to meet non-disabled children'. However, the main message of the importance of taking a 'needs-led' approach is spelt out. 'Translating these findings into what a good service for disabled children would provide, suggests a holistic, inter-agency approach is necessary in which the needs of the child, as opposed to the impairment, are considered'. It is salutary, though not unexpected, that nine out of ten parents reported at least one unmet need of their own, particularly in terms of insufficient financial resources to care for the child, help with planning the child's future, a break from

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caring for the child, and someone to show which services are available.

A positive note is struck in the chapter on being a service user. Although less than one in four families had a 'key worker', this proportion is certainly more than I expected. Key workers were found very helpful by families, and aided a positive relationship with other professionals. Families with a key worker did not, however, experience fewer problems with services than parents without a key worker. The effectiveness of a key worker in reducing service-related problems is dependent on inter-agency cooperation and availability of services.

The message for service providers includes the shortfall in particular types of services such as short-term care and holiday play schemes, but also the importance of style of delivery of services including the need for greater respect and improving availability of information. The report ends with the controversial suggestion that priority should be given to the most vulnerable groups, including parents from minority ethnic groups, those on very low incomes, lone parents and those caring for children with extremely severe levels of impairment.

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Muscle Disorders in Childhood (second edition)

By V. Dubowitz

W.B. Saunders, London, 1995. £70, 540 pages.

In the second edition of his book Victor Dubowitz aims to provide not only the current clinical perspective of childhood muscle disease but also a comprehensive, comprehensible presentation of the scientific issues. Overall this is admirably achieved in what is a clear, thorough and beautifully illustrated book.

Since the first edition of *Muscle Disorders in Childhood* the molecular genetics revolution has taken place and there have been huge advances in histological techniques. This has provided a clearer understanding of the underlying mechanisms of many muscle diseases and consequently the most appropriate classifications of many of these conditions is currently being re-evaluated. As yet there is little consensus as to which are the most suitable classifications (historical, genetic or histological). The author generally chooses to maintain a traditional and reassuringly familiar classification of the different disorders, an approach which in the main seems justified. The book has 15 chapters, all written by the author in a personal and chatty style. After a general introduction on the diagnosiss and classification of the muscle disorders, specific conditions are discussed, including the muscular dystrophies and congenital myopathies, the metabolic myopathies and disorders of the lower motoneurone. There is a useful chapter on the floppy infant syndrome and at the end of the book a genetics section, defining genetic terms and containing a glossary of currently recognized gene locations for the neuromuscular disorders.

Neuromuscular conditions are clearly described and most are illustrated with clinical photographs, full case histories and examples of the diagnostic tests (particularly muscle ultrasound and light microscopy) drawn from the author's high clinical experience. Readers may recognize some material from *A Colour Atlas of Muscle Disorders in Childhood* published by the author in 1989. The current text is, however, far more detailed and comprehensive.

This is a very ambitious book, which largely succeeds in its aims. The chapters on the muscular dystrophies and the spinal muscular atrophies I found particularly interesting. Clinical presentation, diagnosis and medical management are clearly discussed, as are many of the current clinical

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and scientific controversies. The author discusses recent animal and human research and speculates on future directions of treatment, for example the role of gene therapy in Duchenne dystrophy.

In such a huge subject it is difficult to know what should be excluded and overall the text is very comprehensive. I did feel that an initial resumé of basic muscle physiology and histology would have been useful. Malignancy and trauma are not discussed and there is only limited discussion on the connective tissue disorders. Some readers may feel that the more 'holistic' aspects of management in the chronic muscle disorders are neglected, for example the role of multidisciplinary teams and support groups is not discussed. In describing each condition, the text is written in an 'historical' order that reflects our evolving knowledge. Firstly an historical perspective is given, then clinical phenotypes and diagnostic tests; only finally are the latest genetics findings revealed. This format, I felt, sometimes detracted from overall clarity. Finally there is considerable overlap between muscle disorders and the central nervous system and perhaps these aspects could have been more fully illustrated, for example in the section on mitochondrial myopathies some neuroimaging would have been interesting. However any criticisms are minor.

This books is very easy to use, being both clear and beautifully indexed throughout. It covers all major aspects of muscle disorders in childhood and is extremely up to date in its bibliography. I would strongly recommend it for anyone involved in the diagnosis and medical management of children with neuromuscular disorders.

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The Child with a Disability, second edition

By David B.M. Hall & Peter D. Hill

Blackwell Science, Oxford, 1996. 386 pages, £65.00

Many readers will recognize this book as an update of *The Child with a Handicap*, first published 12 years ago. The new title reflects changes in terminology. David Hall has been joined by Peter Hill as co-author, the text has been significantly revised and there are many new tables, figures and flow charts.

The basic structure is unchanged. The first half covers childhood development and its assessment, the second discusses a range of disabilities from communication, behaviour, learning and educational difficulties to cerebral palsy, neural tube and motor problems, fits, faints and funny turns. There are familiar chapters on the assessment of hearing and vision and the management of their impairment. Sections on the genetic aspects of handicap and on non-accidental injury have necessarily been omitted but I would have welcomed more discussion about particular difficulties associated with identifying non-accidental injury in disabled children.

As is acknowledged in the foreword, breaking bad news is a topic that concerns parents and professionals and is difficult to do well. Therefore, I turned to the index to discover the tips offered in this book. There was no entry under 'breaking bad news' or 'diagnosis' but the appropriate section was found under disability, subheading diagnosis. There is a discussion about commonly encountered pitfalls, a reminder of what parents find helpful and a table of practical guidelines, with consideration given to face-to-face consultations and written reports. The chapter goes on to cover the bereavement reaction, the feelings of families and professionals including litigation and 'shopping around', and difficult issues such as the provision of long-term residential care and questions about life expectancy. There

is a good mix of theory and practical suggestion throughout.

Most of the book is well organized and easy to read, although I found the 30 pages on normal development, with a confusing mix of 'normal' and 'abnormal', difficult to follow. Perhaps this can be attributed to the recognized continuum of development within and outside the normal range, together with unclear definitions and cut-off points. These problems could have been discussed: they complicate not only this chapter but also clinical practice and evaluation of effectiveness.

These criticisms are minor and there is sufficient new material to recommend this book to those with an earlier edition on their bookshelf. I can also recommend it to those starting in the field who will gain insight into the theory behind their practice and a great deal of helpful advice for managing individual children with disabilities and for wider service considerations.

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