The Other Side of Profound Handicap

The 'New Approaches to Care' series

Patients are people. They have feelings, families and fears. Whatever the cause for their seeking help, the caring professional will find that he or she will be concerned with these other issues. All illness carries with it anxiety and each person has very individual and important feelings about it; feelings which can easily be forgotten or neglected when nurses become preoccupied with the details of treatments, procedures and ward routines.

The *New Approaches to Care* series aims to explore this 'other side' of care in a practical and realistic way, emphasising the importance of meeting all the patients' needs, while recognising the constraints and problems which so often make the 'other side' the forgotten side of patient care.

The books in this series examine the implications that treatments, procedures, investigations and routines can have for patients and their families. They also aim to help nurses gain some insight into the problems, feelings and anxieties which people can experience when they are being looked after in hospital or the community. The series will thus offer a tangible starting point for all nurses and other professionals, both in training and in practice, to give their patients the most complete and understanding care possible.

Series Editors

June Jolly, SRN, RSCN, has devoted most of her nursing career to the care of sick children, and was involved with establishing a new paediatric unit at Brook General Hospital, Woolwich.

Jill Macleod Clark, BSc, PhD, SRN, is a Lecturer in the Department of Nursing Studies, Chelsea College, University of London.

Will Bridge, BSc, PhD, is the Co-ordinator of the Learning Resources Unit at Brighton Polytechnic.

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The Other Side of Paediatrics June Jolly

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The Other Side of Surgery Janet Gooch

The Other Side of Medical Care Carol Flemming

Heaven's Very Special Child

A meeting was held quite far from earth
'It's time again for another birth'
Said the angels to the Lord above
'This special child will need much love

His progress may seem very slow
Accomplishments he may not show
And he'll require extra care
From the folks he meets down there

He may not run, or laugh or play
His thoughts may seem so far away
In many ways he won't adapt
And he'll be known as handicapped

So let's be careful where he's sent
We want his life to be content
Please Lord, find parents who
Will do a special job for you

They will not realise right away
The leading role they're asked to play
But with this child sent from above
Comes stronger faith and richer love

And soon they'll know the privilege given
In caring for this gift from Heaven
This precious child, so meek and mild
Is Heaven's Very Special Child.'

Anon.

For my friends in Harrow, all of whom are very special

THE OTHER SIDE OF PROFOUND HANDICAP

Pat Brudenell
RMN, RDTh, DipDTh, AIST, Cert Ed

Photographs by
John Crowson

Front Cover by
Gillian Simmonds

M
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Foreword

When asked to read the first draft of this book, I approached it with caution: having worked in the field of handicap for many years, was yet another expert going to tell us lesser mortals what to do? I was amply reassured. Pat Brudenell has brought together a book that explores *with us* the problems concerning profound mental handicap, rather than talking *at us*. Based on the author's own lengthy experience, we are guided through the important basic areas that all of us, professionals, parents and volunteers, need to address if we are to maximise our own potential and the potential of those with whom we work.

The book starts by putting the problems of mental handicap into a historical perspective from the Middle Ages until now, and pointing out the appalling conditions that so many disabled people had to live in, including total non-differentiation between themselves and people who were also mentally ill. The information on the legal aspects of handicap are clear and at times appalling: I had to remember that it was not until 1983 that the phrase 'educationally subnormal' was replaced by 'children with learning difficulties'. A very comprehensive section on the family deals realistically with so many issues besetting the family who have a handicapped child. The case histories are clear and helpful and point out how much more strain families of handicapped children have. There are various suggestions on helping with this, one of which I should mention: why must we all assume that the parents of a handicapped child *necessarily* want to spend all their spare time with other parents of handicapped children?

The book goes on to discuss the importance of professional staffing for Special Care Units. It is easy for this area to

attract less qualified staff because it is so often considered the Cinderella of the professions. Untrained staff are not dismissed — they have a valuable part to play in a total care programme. But what about staff support? Pat Brudenell makes the strong plea that staff working under such demands and in Units that are so often very isolated need a very strong support system.

The material on assessment and recording of progress is well described and most useful. We are then introduced to very basic, clear ideas in play, movement, art and music. The practical examples are most appropriate and will give heart to the most jaded worker. Often staff forget that creative ideas do *work* and regard structured rote learning as the only approach to the education of handicapped people.

Pat Brudenell brings a wealth of ideas to this subject. Her own zest for living and working is apparent throughout the book. There are some delightful glimpses of the author herself. For example, she says: 'I have always had a bit of a soft spot for manic patients . . . There is something quite splendid about feeling on top of the world.'

This book is both optimistic about mentally handicapped people in the 1980s and also realistic. No one will get false hope through this material. Rather I would describe it as creative realism with a lot of humanity! A pertinent example of the human side of the book is the somewhat chaste reminder to get out of our stereotyped ideas about presents we might buy for mentally handicapped people. Have we ever thought of 'buying a little luxury'?

I warmly recommend this book to all those working with profoundly handicapped people. I know they will find it both stimulating and supportive.

Hertfordshire, 1985

Sue Jennings, FRAI, RDTh,
Dip Soc Anthropol, LRAM, LGSM
Senior Lecturer and Course Leader
Hertfordshire College of Art and Design
and
Director, Dramatherapy Consultants

Preface

The 'New Approaches to Care' series looks at the other side of caring for a wide variety of people and patients of all ages. As part of the series, this book is primarily concerned with the care of the profoundly handicapped child and adult. Although much has been written about handicap, there has been very little written about profound mental handicap. Not having the benefits of being able to read about the experiences of others working in this field has made the task of developing new ideas all the more difficult. For myself, arriving at the point whereby I began to understand what profound handicap actually meant personally, enabled me to be far more receptive and resourceful in terms of what I was then able to do. If I can convey even a small part of this, then this book will have been worth while.

The idea stems from my own personal enjoyment and frustration of working in a Special Care Unit and with people with very special needs and is very much a personal statement. My rationale, interpretations and case studies are based upon my own experiences with my own groups. I have changed names and circumstances to protect the privacy and confidentiality that was entrusted to me. The views and attitudes expressed by parents are representative of those parents I interviewed. They may not be relevant to all family situations but they are nevertheless true of their own. I hope the reader will be able to relate to the various standpoints, as a parent, as a practitioner, as a friend or simply as an interested party.

I have deliberately kept off issues of benefits, equipment and theories as these areas and many more have been capably dealt with by other authors. There is little reference to specific diagnosis as I have tried to convey the entirety of handicap —

incorporating the whole person — bringing in aspects that go beyond the handicap itself.

Profoundly handicapped people are entirely dependent on others for all their needs. They can only rely on the voices of those around them to improve their quality of life, raise the standards of their care and protect their human and civil rights. The severity of their handicap prevents them from telling their own story. I only hope that my interpretations are somewhere near to their truth.

Harrow, 1985

P. B.

N. B. The views and opinions expressed in this book are personal to the author and are not reflective of the authority by whom she is employed.

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To friends who urged me to make a start, but especially to Jennifer. Her advice and guidance and share of the anguish and excitement of writing my first book tested friendship to the limits and beyond. To her, my very special thanks.

Mention must be made to the families I worked with and of course to their youngsters, who feature largely throughout the book. For allowing me the opportunity to see handicap from another angle and for teaching me so much, I am very grateful.

xviii *Acknowledgements*

To Sue Jennings, for not only agreeing to write the foreword but for being both tutor and friend. She has played a major role in my development as a therapist, and it was with her guidance and support that I was able to make the move to work with mentally handicapped people. For this and much more, my grateful thanks.

Finally to Robert. Throughout the chaos that this book has brought to our home, he has managed to hold onto his sense of humour and shared most of the traumas with a smile. To him, my very special thanks.