

learning disability nursing

Edited by

John Turnbull

Blackwell
Science

learning disability
nursing

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First published 2004

Library of Congress Cataloging-in-Publication Data

Learning disability nursing/edited by John Turnbull.

p. cm

Includes bibliographical references and index.

ISBN 0-632-06463-3 (softcover: alk. paper)

1. Learning disabilities--Nursing. I. Turnbull, John, RNMH

RC394.L37L428 2003

616.85'8890231-dc22

2003061755

ISBN 0-632-06463-3

A catalogue record for this title is available from the British Library

Set in 10/12.5 pt Palatino

by DP Photosetting, Aylesbury, Bucks

Printed and bound in Great Britain using acid-free paper

by MPG Books Ltd, Bodmin, Cornwall

For further information on Blackwell Publishing, visit our website:

www.blackwellpublishing.com

This book is dedicated to the memory of Stuart Crump,
a wise learning disability nurse, friend and colleague
who was taken from us too soon.

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Preface

In recent years, learning disability nurses have embarked on two important journeys. The publication of *Valuing People* (Department of Health, 2001) the White Paper signalled the fact that we have entered a different and exciting era in the care and support of people with learning disabilities and their families. This is an era in which the emphasis will no longer be on where people live but how people live and, in particular, how they can be supported to exercise their rights and to lead full and satisfying lives. I firmly believe that learning disability nurses can play a key role in this future by using their distinctive knowledge and skill to work with individuals with learning disabilities, to provide support to families and other professionals and to influence the course of social change for the benefit of people with learning disabilities. If learning disability nurses are going to achieve this, they will need to develop their understanding of nursing practice and the sources of knowledge that nurses draw upon as well as make positive use of the factors that have combined to shape a learning disability nursing identity. A book like this might not be able to fulfil all of these needs but it was written to help learning disability nurses make a start on this journey. It was also written to help others understand learning disability nursing better so that they can provide support for their colleagues.

At the same time that services in which nurses work are undergoing change, there has never been a greater demand on professionals to account for their practice. Part of this means describing and explaining their practice to others in order to build trust and confidence. Part of this also means being able to demonstrate where success has been achieved. In the past learning disability nurses have had problems in describing and providing evidence of their contribution to people's lives. Therefore, this book was written to provide some signposts for nurses in their other journey into a future in which there will be clearer role expectations of learning disability nurses.

Given this, the contributors to this book and I hope that readers will use it to approach the future with greater confidence in their practice but ultimately in the expectation of healthier and more valued lifestyles for people with learning disabilities.

John Turnbull

Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. Department of Health, London.

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Chapter 1

Discovering learning disability nursing

John Turnbull

Introduction and aims of the book

This book is about learning disability nursing practice, how learning disability nurses experience it, and how it fits into the lives of people with learning disabilities and their families. Learning disability nurses have had to become familiar with thinking about and reflecting on their practice in the face of increased scrutiny of their role and the changes they have undergone (Turnbull, 1997). In spite of this situation, this book joins less than a handful of others that have been dedicated to exploring the role of the learning disability nurse. After nearly one hundred years of professional practice some might feel it curious, and possibly scandalous, that there is such a dearth of publications about this branch of nursing. As this introductory chapter will show, this situation can be explained by a number of inter-related factors such as how others have viewed their profession, how nurses perceive themselves and a lack of systematic enquiry into their practice.

Most professional groups working in the field of health and social care would claim that the general public, policy makers, managers and, sometimes, the people they serve do not fully understand what they do. However, it would not be an exaggeration to suggest that learning disability nursing is the most poorly understood profession amongst them. Therefore, one of the aims of this book is to promote understanding of the role of learning disability nurses. Added to this is the fact that, although countless learning disability nurses apply their knowledge skilfully and confidently in everyday practice, it can be difficult for them to gain a perspective on the breadth and depth of practice within the profession. This is important to help nurses articulate their role to others, as well as providing a platform for building knowledge about their practice and making sure that it remains relevant. Therefore, a second key aim of this book is to develop learning disability nurses' understanding of the aims of their practice, the knowledge they draw upon to inform their practice and how this combines to meet the needs and priorities of people with learning disabilities and the demands of the policy context in which they

practice. Finally, although learning disability nurses are unique, they share a history that reveals common themes, and are subjected to the same assumptions about their role by others. For this reason a third aim of the book is to explore the identity of learning disability nurses and its impact on their practice.

The scope and structure of this book

When planning this book it became clear that, in order to achieve these aims successfully, there would need to be a focus on the day-to-day practice of learning disability nurses. Having realised this, the next key issue was to discover the best way of obtaining information about nursing practice. One option would have been to simply review the available literature. There are a small but growing number of nurses who have been prepared to write about their practice and, thankfully, an increasing number of journals in this specialist area to publish their work. There have also been a modest number of research projects into learning disability nursing. These would have provided a good source of information on which to reflect. However, it was decided not to use these sources as the *sole* foundation of the book. One of the reasons for this was that many of the published accounts of practice lack detail and insight into what it feels like to be a learning disability nurse, which is a key aspect of this book. Another reason was that the research projects have been inevitably carried out with certain aims and objectives and, therefore, could not cover the scope of this book. Therefore, it was decided to ask nine practising nurses to each write a chapter about their experiences in order to provide the reader with a greater insight into the aims and practice of learning disability nursing, as well as to provide information for the other contributors to draw upon in their more theoretical and reflective chapters.

When deciding whom to ask to contribute a practice chapter to this book, it quickly became evident that it would be undesirable, if not impossible, to try to include a representative sample of learning disability nursing practice. Not only is the breadth of practice too great but also every individual with learning disability and every context in which practice takes place is unique. Instead, the decision was informed by the editor's personal knowledge of the individuals and their high level of self-awareness that, in turn, enhances their ability to reflect upon and record their experiences. The nurses who were invited to contribute were asked to base their chapter on an individual or small group of individuals with whom they have worked and to write about an episode or an aspect of working with that individual that would, in their view, highlight an important facet of working as a learning disability nurse. The contributors were told that this could include episodes where their practice had not gone well because the aim of the book is to present a naturalistic picture of learning disability nursing rather than make judgements about what might be termed specialist, advanced or even best practice. Although such terms may be in common usage within nursing, there is little

agreement about their meaning (Woods, 1997; Scott, 1998). Furthermore, a key aim of the practice chapters is to provide readers with an opportunity to reflect on the descriptions of practice. This would be made difficult if a judgement had already been made about their value through the attribution of a label. Because of this, care has also been taken over the titles of the practice chapters. The chapters have inevitably focused on specific topics when working with people with learning disabilities. For example, in Chapter 2, Tim Riding describes working with someone who has offended. In Chapter 4, Colin Doyle describes working with someone who displays challenging behaviour and, in Chapter 12, Rebecca Welsh writes about working with someone who has epilepsy. In spite of this, it is important to note that all of the practice chapters do not set out to present a blueprint of how to work with such individuals. The fact that some people have epilepsy, autism or display challenging behaviour is incidental to the central aim of describing the experience of practising as a learning disability nurse.

Naturally, a major concern was to preserve the identities of the individuals with whom these nurses worked. Therefore, the contributors have gone to great lengths to maintain anonymity by changing either the name, gender or age of the person as well as those who were also supporting or related to them. They have also modified the setting for practice and, in some cases, the point in time when their practice took place. Some contributors chose to present a composite picture of two individuals. Despite the fact that the contributors disguised the identity of the people they worked with, their accounts retain their value because they are taken from the actual experience of a learning disability nurse.

Because one of the aims of the book relates to how nurses experience learning disability nursing, the contributors to the practice chapters were asked to preface their description with a brief account of how they came to be a learning disability nurse and their motivation to work with people with learning disabilities. These revealed many common themes that will be taken up later in this chapter. Before moving on to describe the theory chapters, tribute must be paid to the authors of the practice chapters. Committing one's thoughts to paper is always a courageous act because others are then in a position to judge them. In this case, the contributors deserve further admiration because they have been prepared to expose their practice, as well as their thoughts, to scrutiny.

Deciding on the structure of this book was not easy. There was a need to break up the sequence of practice chapters by including chapters that could reflect on some of the key issues relating to learning disability nursing. The contributors to these chapters were asked to reflect on the relevant literature in the field as well as the content of the practice chapters in order to:

- Describe what it means to be a learning disability nurse.
- Describe what a learning disability nurse aims to achieve and what they do to help achieve these aims.

- Describe the relevance of learning disability nursing.
- Describe a framework for how to practice as a learning disability nurse.

These reflective chapters do not have to be read sequentially. In fact, all of the chapters in this book are designed to stand alone and can be read in any order. Even in cases where the theory chapters refer to events in the practice chapters this has been done in such a way that it is not necessary to have read the practice chapters first.

Aims of this chapter

As far as this chapter is concerned, it aims to explore the context and assumptions within which learning disability nurses practice, and asks whether they combine to create a learning disability nursing identity and, if so, what lies at the heart of this identity.

All professionals in the field of health and social care over the past two decades have faced common challenges to their professional aspirations and the way in which they practice (Southon and Braithwaite, 1998). This has included the need to account more thoroughly for their practice, the need to explicitly support their practice by the best available evidence and to ensure their practice represents good value for money. These issues have applied equally to learning disability nursing. Learning disability nurses will also share values such as compassion and altruism with their professional colleagues. However, there have been a number of events, experiences and characteristics that combine in a distinctive way to shape the way that learning disability nurses feel about themselves.

Close relationships

Although many health and social care and educational professionals work with people with learning disabilities, learning disability nurses are the sole professional group that is educated specifically to work with them. This fact should not be underestimated because it forms the basis of how learning disability nurses think and feel about people with learning disabilities and how that explains their motivation and actions. Many learning disability nurses will say that they came into the nursing profession out of a motivation to work with people with learning disabilities rather than to become nurses. The nurses who wrote the practice chapters in this book explain the unique circumstances that brought them into the profession but the common theme is this desire to work with people with learning disabilities rather than a desire to be health care professional. Adrian Jones, in Chapter 11, says that he became a learning disability nurse to right the injustice to which he felt people with learning disabilities were subjected. Others, like Tim Riding in the

following chapter, saw working with people with learning disabilities as stimulating, challenging and worthwhile. Jill Turner, in Chapter 3, touches on a common feeling amongst learning disability nurses that their work brings opportunities to get close to people and to work with them as individuals, without the barriers of uniforms and diagnostic tools.

Rebecca Welsh, in Chapter 12, describes another significant aspect of working with people with learning disabilities – that it can be life-changing for the nurse as well as the individual with learning disabilities. In Rebecca's case, her assumptions about people with learning disabilities changed profoundly as she came to see them as equals with a common humanity. However, it is also common for nurses to have their views changed about a whole range of issues and aspects of life through their practice experience. Richardson (1997) has described poignantly the reciprocal nature of nurses' relationships with people with learning disabilities when he celebrated the brief life of a person whom nurses had supported. Richardson makes the key point that nurses should *expect* to be changed by the experience of caring and supporting people with learning disabilities.

These examples describe the experience of *reciprocity*, which is defined as the process of learning from each other. *Mutuality* is a complementary process that can be understood as undergoing a common experience. This can take many forms. There is a theme within learning disability nursing that nurses are making a journey with people with learning disabilities. For some nurses, this is represented by the journey of people with learning disabilities, from being controlled and devalued, to becoming a citizen and accessing their rights. In Chapter 6, Peter Dawson's account of knowing Judith provides a microcosm of this journey and its struggles. There are parallels between his feelings of powerlessness as a nurse in the face of the hospital and Judith's powerlessness as a hospital resident. When Peter acquires a new post outside the hospital, he is in a better position to help her. Stephen Rawlinson, in Chapter 8, describes a process in which he was learning how to be a supportive facilitator for the tenants' group at the same time as his tenants were learning how to be a group.

Finally, Duncan Mitchell's research (1996, 1998, 2000) into the history of the learning disability nursing profession illustrates further examples of mutuality. Mitchell claims that learning disability nurses have suffered a loss of esteem because they have undergone a process of stigmatisation which parallels that endured by people with learning disabilities (Mitchell, 2000). There is no doubt that nurses have been marginalised, and even exploited, and these issues will be discussed at greater length later in this chapter. However, part of the reason for the stigmatisation endured by nurses is the simple fact that there is a general misunderstanding of learning disability itself, both by the public and the media (Philpot, 1995). In addition, professionals in health and social care themselves frequently display low levels of knowledge about learning disability (McKenzie *et al.*, 1999). If people do not have a concept of learning disability then they will be unable to imagine the

type of care and support that people might need. The philosophical changes in the field of learning disability in recent years also play a role as far as nurses are concerned, in that they may be reluctant to tell the public that they are a nurse because they do not want to reinforce the impression that people with learning disabilities need medical care. The impact of this on learning disability nurses should not be underestimated. Although there are gender variations, a person's job, title and role plays a significant part in helping to develop that person's identity, and the public and profession's negative reactions to learning disability could be a source of frustration and a challenge to be met on a daily basis. Unfortunately, research has not explored this phenomenon or how nurses cope when it happens.

The pioneering spirit

The person-centred approach and strong commitment to people with learning disabilities that comes across in the practice chapters has perhaps provided the motivation for learning disability nurses to make some unique changes in their education and practice, showing their versatility and pioneering spirit. On a strategic level, for example, no other profession has undergone such a radical transformation in the setting in which their practice occurs. Learning disability nursing has moved from the hospital into the community. At an individual level, the impact of this transition is described eloquently by Stephen Rawlinson (Chapter 8) who entered into practice at a time when learning disability nursing in his area had only recently been moved into the community. Given the misgivings of some of his hospital colleagues, this must have required a good deal of courage.

The transformation of learning disability nursing has also been paralleled in terms of the aims of the profession. There have been occasions when the profession has had to revisit its value base and to develop a new vision for both the profession and a new system of education. One such occasion in 1982 is discussed in Chapter 5. At the present time, learning disability nurses are again revisiting their practice in the light of the new White Paper, *Valuing People* (Department of Health, 2001). In the next section, it will be seen that some learning disability nurses have had to give up their identity as nurses to practice in social care settings. It is questionable how many professions have members who would be prepared to do this but perhaps indicative of the loyalty that learning disability nurses feel towards people with learning disabilities.

The great divide

An issue that has created significant and unique problems for learning disability nurses is the distinction between health and social care. The NHS and

Community Care Act (Department of Health, 1990) introduced the need for a sharper distinction between responsibilities for health and social care needs within Health Authorities and Local Authority Social Services Departments. In the early years of implementing the Act, health care organisations seemed more concerned with demonstrating to authorities that they *weren't* providing social care, and vice versa, than they were about providing better quality care in line with their responsibilities. The newly formed NHS Trusts and the growing number of independent sector providers were encouraged to focus on their 'core business' in order to clarify and demonstrate accountability. This resulted in commissioning bodies, inspectorates and service managers spending much of their time policing the boundaries between health and social care rather than focusing on innovative and creative solutions to people's needs and wishes. The health and social care issue provoked considerable debate within the field of learning disability, and in other areas as well, where the focus for discussion was how professional practices could be linked with either 'health' or 'social' gain. Amongst learning disability nurses, there was a reluctance to talk openly and honestly about their skills because they found themselves in a dilemma – it was quite easy for them to demonstrate their contribution to both health and social care. However, given the atmosphere of the time, this would have given both health and social care organisations a good reason *not* to employ learning disability nurses. Although other professional groups faced difficulties over the health and social care issue, it was probably only learning disability nurses who had to suffer the indignity of having to play down the breadth of their skills and almost 'practice in disguise'.

In common with many other observers at the time, Cullen (Four Chief Nursing Officers, 1991) pointed out that the distinction between health and social care is largely an artificial one and that, in reality, people with learning disabilities, and the general public for that matter, have a mixture of needs. In more recent years, although Health and Local Authorities have still had to account for their respective spending on health and social care, there has been a greater recognition of the need for partnership between the two in order to help one another meet those needs.

Where this situation has had its greatest impact is on the employment status of learning disability nurses. For example, it is illegal for organisations to employ nurses to carry out social care functions. During the 1980s and 1990s the main alternative to hospital or health care provision became the residential care home. Nurses who had previously supported individuals in hospitals and wanted to continue to support them found themselves having to give up their status as nurses to work in these homes. The irony was that their aims, as nurses working with people with learning disabilities, had not changed and they were probably undertaking activities that could quite easily be construed as nursing (Turnbull and Timblich, 1998). It is understandable that learning disability nurses have felt great resentment about having to practice in what seems like a form of professional exile. As long ago as 1979,