

# Learning Disability Nursing



**developing  
professional  
practice**

**Ruth Northway and Paula Hopes**

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# About the authors



## Ruth Northway

**Ruth Northway** is Professor of Learning Disability Nursing at the University of South Wales and has over 30 years' experience of working in nurse education. During this time she has been involved in curriculum development, and module and course delivery at both undergraduate and postgraduate levels. Her current role continues to see her directly involved in the education of learning disability nurses as well as in developing learning disability research and involvement in wider professional groups and networks. She was a member of the Thought Leadership Group that developed the Standards of Proficiency for Registered Nurses (NMC, [2018a](#)).



## Paula Hopes

**Paula Hopes** has worked as a senior lecturer in two universities, educating future nurses and other aspirant health professionals in meeting the health and well-being needs of people with learning disabilities. She is an external examiner at Limerick University and has worked in universities in England and Wales, so she has a knowledge of the varied drivers, policies and influences on nurse education as well as the experience of people with learning disabilities and their families. She has taught at pre- and post-registration level and has supervised the academic work of students and registrants. She is the Welsh representative at the Learning Disability Professional Senate and co-chair of the UK Learning Disability Nurse Consultant Network.



# Introduction

Registered learning disability nurses in the United Kingdom (UK) comprise one of the smaller fields of nursing and, over the years, there have been many challenges to the continued existence of this field of practice. However, there have also been many positive developments and learning disability nurses continue to play a key role in promoting the health and well-being of people with learning disabilities. Their roles have diversified, and the profession continues to develop to meet the changing needs of those it works alongside, and the changing context within which they work. This requires a questioning approach and critical thinking, it requires flexibility and creativity, and it requires a commitment to continuous professional development (CPD). This book aims to promote such professional attributes.

Whether you are a student or a registered nurse, we believe that this book will provide you with an important resource to facilitate your professional development. It is innovative in the approach taken which brings together theory and practice relevant to the development of learning disability nurses and nursing. This is achieved through exploration of a range of topics, the use of case studies and encouraging critical thinking through reflective activities. At the beginning of each chapter, specific links are made to the outcomes required within the NMC Standards for Nurse Education (2018a) and the NMC Code of Conduct (NMC, 2018b). This enables you to make direct links to the requirements of undergraduate nursing courses in the UK and to key areas required of registered nurses when seeking revalidation.

While aimed primarily at learning disability students and registered nurses in the UK, the material covered in this volume is also relevant to nurses who specialise in providing support for people with learning/intellectual disabilities in other countries. The terminology used in this book is 'learning disability' since this is the terminology applied in the UK to this field of practice. However, for international readers the terms learning disability and intellectual disability should be taken as meaning the same. It also has relevance for nurses working in other fields of nursing who wish to develop their practice to enhance the care and support they provide for children, young people, adults and older adults with learning/intellectual disabilities.

Each chapter can be accessed as a free-standing resource but many of the topics explored are interrelated and therefore you will be cross-referred to other chapters and sections where appropriate. We hope that this will assist you to integrate and use the knowledge effectively. The book is organised in three sections which each build upon each other.

## **SECTION 1: THE FOUNDATIONS OF LEARNING DISABILITY NURSING**

As the title of this section suggests, its focus is on key areas upon which learning disability nursing has developed: the foundations of learning disability nursing.

**Chapter 1** takes a historical view to explore the development of learning disability nursing from the nineteenth century to the current day. It does this in the context of how societal attitudes towards, and models of care and support for, people with learning disabilities have developed. It also briefly looks at international developments relating to nursing care for people with learning disabilities.

**Chapter 2** highlights the importance of a strong value base within learning disability nursing and some of the legal and ethical dilemmas that learning disability nurses may encounter. It also seeks to provide you with tools to assist you in responding to these challenges and dilemmas.

Communication is central to learning disability nursing and therefore **Chapter 3** brings together practical and evidence-based approaches to developing communication with people with learning disabilities and their families. Examples for augmenting and developing communication skills are given in line with best practice models. There is also identification of the skills needed to effectively communicate with other professionals, recognising barriers to communication and providing structured methods for imparting and receiving information.

**Chapter 4** clarifies the importance of evidence-based practice and identifies the issues that need to be addressed when seeking to promote such an approach. It also explores the need to further develop the evidence base for learning disability nursing recognising the challenges that may be encountered.

## **SECTION 2: KEY DIMENSIONS OF CONTEMPORARY PRACTICE**

Within **Section 2**, the focus moves to explore several key elements of learning disability nursing practice. The importance of working across the lifespan to identify challenges to health and well-being and strategies to prevent or the impact of such challenges are explored.

**Chapter 5** focuses on assessing need. There is exploration of the importance of holistic assessment and the contribution that registered learning disability nurses make to this. The chapter recognises the skills, knowledge and understanding of the Registered Nurse Learning Disabilities (RNLD) and the processes that support professionals in making their assessments. Discussion on skills required to undertake assessments in partnership and identification of specific tools and structures connects the chapter directly to the practical application to professional practice.

**Chapter 6** focuses on planning and delivering care in partnership with others. It explores person-centred planning and other approaches to planning and delivering care and



support. Care planning frameworks are introduced and there is detailed discussion on the various areas where you will develop care plans.

A key feature of learning disability nursing is that it takes a lifespan approach. [Chapter 7](#), therefore, explores the contribution of learning disability nurses at key life stages – children, young people, adults and older adults. The role of the learning disability nurse at different stages is identified with practical examples of the ways that nurses will work together with people and their families across the lifespan.

[Chapter 8](#) explores the importance of learning disability nurses understanding and adopting a public health approach. It introduces you to key public health concepts and considers some of the challenges in adopting a public health approach to addressing the health inequalities experienced by people with learning disabilities. It also explores how you can use such an approach to inform your practice.

[Chapter 9](#) focuses on supporting those whose behaviour challenges. It identifies the role of the learning disability nurse in understanding behaviours that challenge and working in partnership to support well-being using approaches such as positive behavioural support. Some influences on behavioural presentation, including sensory and environmental factors as well as the quality of life issues, are described.

## **SECTION 3: ADVANCING LEARNING DISABILITY NURSING PRACTICE**

As noted above, it is important that learning disability nursing, as a profession, continues to develop its practice. [Section 3](#) of the book therefore focuses on enabling you to develop strategies which will enable you to contribute to such professional development.

[Chapter 10](#) explores innovation in practice. Its emphasis is on recognising the need for learning disability nurses to adopt a creative and innovative approach to practice. There are examples of change in language, concepts, models and demonstration of the roles learning disability nurses have in identifying areas for change. The chapter goes on to describe tips for increasing your confidence in leading on innovation, managing change and evaluating impact, as well as advice for sustaining change in practice.

Effective leadership is central to advancing professional practice and [Chapter 11](#) therefore explores the need for leadership within learning disability nursing. Different leadership approaches and the importance of organisational culture are considered as well as the negative impact of poor leadership. It also encourages you to consider your own development as a leader.

[Chapter 12](#) is the final chapter and focuses on both the wider development of learning disability nursing and your own professional development. Links are made to the revalidation requirements that all registered nurses need to meet and a ‘tool kit’ to support your development is offered.

## **USING THIS BOOK**

We hope that you will find this book both useful and interesting. To gain maximum benefit, we would encourage you to complete the critical reflection activities either individually or with colleagues. We have also provided details of additional resources at the end of each chapter should you wish to read further.

# **Section 1**

**The foundations for practice**



# 1

## The development of learning disability nursing

### *Chapter aims*

This chapter provides a context for this book through an examination of how the profession of learning disability nursing has developed. It explores developments from the beginnings of institutional care in the 1800s through to the current day. Since this is inextricably linked with the development of care and support provided for people with learning disabilities, a brief overview of patterns of care and support is first explored. Finally, consideration is given to nursing care of people with intellectual disabilities in other countries.

In achieving these aims, it is necessary, at times, to use terminology that is not acceptable to use today to refer to people with learning disabilities. Terminology has changed over time and what is not acceptable now would, at the time, have been viewed as being appropriate. Indeed, the terminology we use today will likely be viewed negatively in the future. It is also important to recognise that change does not happen overnight and therefore differing terminology may be used at the same time: the new is introduced while the old gradually wanes.

### *Professional standards and expectations*

In the Standards of Proficiency for Registered Nurses, the NMC (2018a) notes the necessity of regularly reviewing such standards to ensure that they remain contemporary and fit for purpose. Accordingly, in developing the current standards, changes in society and healthcare, their implications for nursing practice, and the knowledge and skills required of nurses now and in the future were all considered (NMC, 2018a). This suggests two things. First, there is a professional expectation that nursing, as a profession, needs to keep its practice constantly under review to ensure that it remains relevant to the needs of individuals, communities and society. Second, that to achieve this, nurses and nursing need to have an awareness of the relationship between their practice and wider society. The latter also requires that we understand not only the present but also that we are able to place developments in a historical context.

## THE RELEVANCE OF HISTORY

You might be wondering why this book, which focuses on professional development within learning disability nursing, commences with a chapter that looks back and takes a historical perspective. The rationale for including this chapter is that to understand where we are today as a profession, and to build for the future, we need to understand where we have been, what has changed and why such changes occurred. Mitchell (2019) suggests that studying the history of learning disability nursing both provides us with perspective and helps to identify a body of professional work we can use to develop future practice and education. He also questions how subsequent generations of learning disability nurses will view today's practice (Mitchell, 2019).

### ***Critical reflection 1.1***

Imagine you are describing current learning disability nursing to a future generation of learning disability nurses.

- What are the key features you would mention?
- What do you think they would make of your description?

Of course, no profession develops in isolation, and this is certainly true of learning disability nursing. As has been noted above, the history of this field of nursing practice is inextricably linked with the history of those for whom it provides care and support, and the varying policies and legislation that have shaped service provision. This, in turn, has been shaped by wider societal beliefs and attitudes. However, another key influence on the history of learning disability nursing is the wider development of the nursing profession and (as will be seen later in the chapter) tensions have often been evident as to whether learning disability nursing should be viewed as part of the wider profession of nursing (Mitchell, 2000). Figure 1.1 illustrates this range of influences on the development of learning disability nursing.



Figure 1.1 Influences on the developing role of the learning disability nurse

Before exploring how learning disability nursing developed and has evolved, this chapter, therefore, first briefly considers changing views of people with intellectual disabilities and the differing historical patterns of care and support provided in the context of such views.

## PEOPLE WITH LEARNING DISABILITIES IN THE UK: A BRIEF OVERVIEW OF HISTORY AND CHANGING MODELS OF CARE

Ryan and Thomas (1987), in a key text documenting how people with learning disabilities have been viewed and supported by society over time, argue that:

*The changing definitions of difference constitute the history of mentally handicapped people. These definitions have always been conceived of by others, never are they the expression of a group of people finding their identity, their own history. The assertion of difference between people is seldom neutral ... The differences between mentally handicapped people and others have mostly been seen negatively, making them a problem to themselves and others.*

(Ryan and Thomas, 1987, p 13)

The terminology of ‘mentally handicapped’ was viewed as appropriate at the time Ryan and Thomas were writing and since that time both the terminology and the extent to which people with learning disabilities themselves have found a ‘voice’ in asserting their own identity have changed. However, a look at history reveals how this group of people have been viewed in different ways at different points in time and how this, in turn, has shaped public and policy perceptions about how their differences should be addressed and support provided.

People with learning disabilities have always existed within society, but since this chapter focuses on the development of learning disability nursing, it starts by examining their history from the nineteenth century onwards, given this is where the origins of nursing lie.

### **Critical reflection 1.2**

Think about how people with learning disabilities are viewed within current society.

- How does this reflect current patterns of care and support?

## **The development of educational institutions**

Ryan and Thomas (1987) note that the beginning of the nineteenth century saw the development for the first time of educational provision of those termed (at that time) as ‘idiots’. Building on the work of people such as Seguin, educational institutions started to develop whose aim was to provide education for ‘idiots’ with a view to improving their situation through a programme of instruction, occupation and leisure aimed at returning them to their families and communities. However, the number of people within institutions grew with Ryan and Thomas (1987) noting that in 1864 there were

approximately 400, rising to about 2000 in 1914 housed in six asylums. Many more were housed within workhouses and institutions for the 'insane' (psychiatric).

As conditions within institutions began to deteriorate, the focus shifted from education to containment and control, and management shifted to the medical profession (Ryan and Thomas, 1987). However, the 'failure' of the educational approach was 'attributed to the hopeless nature of the idiots' rather than to a failure to take account of wider societal factors that were leading to a more general move towards institutionalisation, and which were making it more difficult for those considered 'idiots' to survive in the community (Ryan and Thomas, 1987).

With growing numbers within the institutions, those living there increasingly became seen by wider society as 'different' with this difference being viewed as meaning they were perceived as being less than human and a risk to society. They were physically segregated from wider society, and this reinforced the sense of difference and being a danger to others. As Ryan and Thomas (1987, p 107) observe, 'An indeterminant linking of mental deficiency with all kinds of social problems became commonplace'. Coupled with a growing interest in genetics and eugenic fears, there was pressure to 'control' those considered 'idiots' and, in particular, to prevent them from reproducing.

The National Association for the Care and Control of the Feeble-minded was established in 1896. As the name suggests, a key area of focus was on ensuring 'control' and they campaigned for lifelong segregation of those considered to be mentally defective. The 1908 Radnor Commission examined this issue and sought to make recommendations for the development of new legislation. The Commission concluded that mental defectiveness was inherited and that the appropriate solution was to prevent them from having children through lifelong segregation and supervision in institutions for 'as long as may be necessary' (Radnor Commission, 1908, cited in Ryan and Thomas, 1987, p 107).

The resulting 1913 Mental Deficiency Act classified people as 'idiots', 'imbeciles', 'feeble-minded' and 'moral imbeciles' with those considered to be 'idiots' as having the greatest support needs. Inclusion of the category of 'moral imbeciles' made it possible for women with illegitimate children who were in receipt of poor relief to be institutionalised (Open University, 2022). Implementation of this Act was slow and in 1929 the Wood Committee reported that people considered to be mentally defective continued to be a threat to society (Ryan and Thomas, 1987). This committee concluded that:

*If we are to prevent the racial disaster of mental deficiency we must deal with not only the mentally defective person, but the whole subnormal group from which the majority of them come.*

(Wood Committee, 1929, cited in Ryan and Thomas, 1987, p 108)

### **A medical model of care**

The number of institutions and the numbers living within them continued to grow reaching 32,000 by 1939 (Ryan and Thomas, 1987). In 1948 when the National Health Service was established, the institutions became part of this service and became long-stay



hospitals. The medical model of care thus was firmly established. However, in 1959 the Mental Health Act removed the need for compulsory detention in such hospitals by introducing the category of informal patients who (in theory at least) were free to leave the hospital. This legislation also enabled the development by local authorities of community-based services although little progress was made in this area.

During the 1960s, research began to question whether institutional long-term care was appropriate. For example, studies undertaken by Tizard and colleagues in the early 1960s examined provision for children in long-stay hospitals. They concluded that smaller residential units were preferable but that reducing the size of such units alone was insufficient to ensure child-oriented care: attention to changing the pattern of care was also required and this required action in relation to both staffing levels and the training of staff (King et al, 1971).

In 1967, however, an expose in the News of the World Sunday newspaper revealed poor standards of care in Ely Hospital, Cardiff. A staff member had tried to raise concerns within the hospital and the health authority, but these had not been acted upon and hence they alerted the media. As a result of this, an enquiry into standards of care was established and this was reported in 1969. The report highlighted a range of issues relating to care, abuse, staffing and management and made several recommendations.

Publication of the Ely Hospital Enquiry Report shone a light on conditions within such hospitals and prompted a desire for reform. In 1971 the Government published the White Paper *Better Services for the Mentally Handicapped*. Described at the time as making proposals that were 'both simple and sweeping' (Jones, 1972), this document set several targets for reducing the number of long-stay hospital beds and the development of community-based services such as residential homes and arrangements for fostering. Change was to occur over a 15–20-year period and would see hospitals focusing on those who, due to their needs, required constant nursing care while local authorities would develop services and support the greater integration of mentally handicapped people into mainstream social, educational and health services (Jones, 1972).

## **Movement towards community-based care and support**

Progress towards achievement of the targets set in *Better Services* was, however, slow. The numbers living within long-stay institutions did not significantly decline and conditions in the hospitals (often old buildings not specifically designed for their current purpose) failed to improve. Indeed, other inquiries followed such as those in Normansfield Hospital (1977) and Leavesden Hospital (1978).

In 1983, the Welsh Office noted this lack of progress towards the 1971 targets arguing that 80 per cent of the funding for services for people with a mental handicap was being spent on the 20 per cent of people living in the long-stay hospitals while only 20 per cent was being used to fund the development of services for the majority (80 per cent) living with their families in the community (Welsh Office, 1983). To effect change they ring fenced additional funding for the development of community-based support in Wales. The provision of funding, however, was contingent on proposed developments complying

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with three key principles, namely that they would support the right of people with a mental handicap to be treated as individuals, to normal patterns of life in the community, and to receive support from their communities and from professionals.

These principles echoed those set out in the Jay Report (1979) (see below) and reflected the philosophy of normalisation that was beginning to influence thinking in relation to services for people with a mental handicap in the UK. Normalisation had its origins in Scandinavia with the Danish Mental Retardation Act stating in 1959 that services should create support for people with a mental handicap that enabled them to live lives 'as close to normal living conditions as normal' (Bank-Mikkelsen, 1980, p 56). This was expanded on by Nirje (1980) to encompass elements such as a normal pattern to the day, a normal rhythm to the week, progression through the stages of the lifecycle and equal access to economic standards in relation to either welfare benefits or paid employment.

However, in the UK more generally, it was the North American version of normalisation promoted by Wolf Wolfensberger that was adopted. Later becoming known as social role valorisation (Wolfensberger, 1984), this approach argued that people with a mental handicap are cast into devalued roles by wider society and that this influences how they are viewed and treated. To change such negative treatment, therefore, what was required was for services and support to promote positive social roles using culturally valued means.

Against this backdrop, there was a renewed focus on the development of community-based services (to prevent the need for admission to hospital), resettlement of those currently living within long-stay hospitals and eventual closure of such establishments. However, wider reforms were also taking place in relation to the development of community-based services across service user groups. A report by the Audit Commission (1986) called for radical change to address both the slow and uneven progress being made and the lack of organisational co-ordination between health and social care.

In 1989 the Department of Health (1989a) published the White Paper *Community Care in the Next Decade and Beyond*, which set out arrangements for the provision of community-based care. Alongside this, another White Paper *Working for Patients* (Department of Health, 1989b) set out future plans for the provision of health services. Taken together, these policies sought to make a clear distinction between healthcare (provided by health services) and social care (provided by local authorities) while recognising that they needed to work together. Community care was to be based on the assessment of need through a care management system; a move to a mixed economy of care in which independent service providers play a key role was also advocated.

The 1990s saw further development of community services and the closure of many long-stay hospitals. At the end of the 1990s, there was a move to devolution with health and social care becoming the responsibility of devolved governments in the different countries of the UK. While the general trend of policy development in relation to services and support for people with learning disabilities remained the same in each country, there were also some variations with countries publishing their own policy documents. It is these policies that shape current patterns of care and support for people with learning disabilities.

## THE DEVELOPMENT OF LEARNING DISABILITY NURSING

Many books on the history of nursing make little or no reference to learning disability nursing. As Mitchell and Smith (2003) observe, learning disability nursing has often been viewed as being ‘*on the margins of nursing*’. Its history is different from that of adult nursing and has been shaped by different factors (see Figure 1.1). However, it is also a history in which learning disability nurses themselves have increasingly shaped and led the development of their profession. This section therefore explores developments in learning disability nursing, broader nursing developments and nurse education since each of these has (and continue to) exert an influence. It will trace the history starting with the origins of the profession – the expansion of institutional care in the late nineteenth century. The terminology used to refer to the group of nurses will reflect that used at a particular point in history from Mental Deficiency (until 1940s), to Mental Subnormality (until 1970s), to Mental Handicap from the 1970s to the current terminology of ‘learning disability’.

### The rise of institutions

As noted above, the latter part of the nineteenth century saw the expansion of institutions as numbers within them grew and their focus moved away from the provision of education to containment. The workforce within these institutions was referred to as attendants. The 1913 Mental Deficiency Act, overseen by the Board of Control, led to the expansion of the institutions which required a suitable workforce. Mitchell (2001) argues that nursing was seen as the answer to this problem being viewed as useful by both the Board of Control and the Royal Medico-Psychological Association (RMPA) since as a profession it was ‘*cheap, efficient and pliable*’. Such characteristics were seen as ideal to support the development of institutional care (Mitchell, 2001).

The RMPA had previously provided a training scheme and qualification which allowed flexibility to allow for adaptation to the needs of individual institutions (Mitchell, 2000). However, the introduction of the 1913 Mental Deficiency Act led the RMPA to develop a separate, specific qualification for mental deficiency nurses. Prior to this, they would have been awarded an asylum nurse certificate which was the qualification for those working in the asylums primarily caring for those with mental illness. The first national certificates for mental deficiency nursing were issued by the RMPA in 1919 (Mitchell, 2019).

Alongside this, however, the General Nursing Council was also being established with a remit to develop and maintain a nursing register. There was considerable debate as to whether nurses working in the long-stay institutions should be considered nurses and included in such a register. Nursing was generally viewed within the context of a sickness focused, medical model its aim being to assist with ‘curing’ those experiencing ill health. Mental deficiency nursing (as it was then called) did not conform to this model and thus did not seem to be a suitable fit for the proposed register.

Eventually, mental deficiency nursing was included as a subsidiary section of the mental nursing supplementary register in 1920. Mitchell (2000) argues that this ‘secondary’

status laid the foundation for the 'constant challenge' faced by nurses working in this specialism to be recognised as part of the nursing profession. Indeed, as will be seen below, the debate as to their place in the profession has been a recurring theme throughout the decades.

The GNC introduced examinations for mental deficiency nurses in 1926. However, opportunities for training in this specialism remained limited. By 1936, of the 67 institutions with over 100 residents, only 30 were recognised by the RMPA for the provision of training and only ten of these were also recognised by the GNC (Board of Control cited in Mitchell, 2001). The RMPA produced a textbook (*The Manual for Mental Deficiency Nurses*) which became known as 'the green book' in 1931 (Stephenson, 2019) and, until the 1950s, psychiatrists (via the RMPA) maintained significant control over the examination of mental deficiency nurses (Mitchell, 2019). Many nurses in this specialism chose to register with the RMPA rather than the GNC until after the Second World War (Mitchell, 2000).

### **Institutions become hospitals**

When institutions became hospitals and part of the NHS in 1948, the central role of nurses within this model of provision was confirmed. The RMPA register was closed, and all Mental Deficiency Nurses registered with the General Nursing Council. However, the Mental Deficiency Nursing qualification was not viewed as being equal to other nursing qualifications even within the context of long-stay hospitals specifically focused on providing care for people deemed to have a mental deficiency. Nurses working in such institutions were often encouraged to undertake an additional (general) nursing qualification in order '*to be recognised as nurses*' by the wider nursing profession (Parrish and Sines, 1997, p 1123). The recruitment of nurses who were dually qualified (mental deficiency and general) was also encouraged for senior leadership roles (Mitchell, 2001).

As noted earlier in this chapter, the Ely Hospital Enquiry (DHSS, 1969) drew public attention to the poor conditions and abusive practices existing within such settings. Given that nurses formed the largest professional group within the hospital it is perhaps to be expected that their practice should be a key area of focus for the enquiry. However, in the report of the enquiry an entire chapter was devoted to nursing practice. The report notes that many of the nursing staff were having to work in poor conditions, with poor staffing levels, and that they were working hard to deliver care '*by their own standards*' (DHSS, 1969). Nonetheless, the committee also noted that standards of nursing care fell short '*not merely of the ideal which is attainable in the 1960s but of a standard which is obtainable and practical even in the hospital as it stands today*' (DHSS, 1969, Sect 227). Key areas of concern related to the use of seclusion, inadequate standards of personal care for residents, standards relating to management of deaths, insufficient medical supervision for practices such as suturing, the use of residents to undertake domestic work on the wards, a casual approach to reporting of incidents, arrangements for handovers and poor ward management.