
Caring for People with Learning Disabilities

Edited by:

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*Associate Head of School, School of Nursing and Midwifery, University of
Hertfordshire*

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Dedication

I would like to dedicate this book to the many adults with learning disabilities I have had the pleasure to meet and work with over the years, who have enriched my life and taught me patience, understanding and compassion. The students I have taught have given me hope for the future of learning disability nursing and continue to inspire me.

Debra Fearn

I dedicate this text to all those who strive to ensure fairness in the delivery of healthcare for all members of society.

Ian Peate

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About the Editors

Ian Peate, EN(G) RN DipN (Lond) RNT BEd(Hons) MA(Lond) LLM

Ian began his nursing a career in 1981 at Central Middlesex Hospital, becoming an Enrolled Nurse working in an intensive care unit. He later undertook three years' student nurse training at Central Middlesex and Northwick Park Hospitals, becoming a Staff Nurse then a Charge Nurse. He has worked in nurse education since 1989. His key areas of interest are nursing practice and theory, sexual health and HIV/AIDS. He is currently Associate Head of School. His portfolio centres on recruitment and marketing and professional academic development within the School of Nursing and Midwifery.

Debra Fearn, BA (Hons), RNLD, MA, Post-graduate Diploma in Teaching and Learning

Debra Fearn is a Senior Lecturer in the School of Nursing and Midwifery at the University of Hertfordshire. She is a Registered Nurse (Learning Disabilities), and teaches on Learning Disability nursing across pre- and post-registration courses. Debra completed an MA in Health and Social Policy in 1998. The dissertation focus was centred on how Custody Officers recognise vulnerability, especially in people with learning disabilities. The research was carried out in a Shire police force. Publications include *Appropriate Adults and Appropriate Adult Schemes: Service User, Provider and Police Perspectives*, Ed: Brian Littlechild (2001), published by BASW, Venture Press and Debra has recently jointly edited *Mental Disorder and Criminal Justice: Policy, Provision and Practice* (2005) with Brian Littlechild, published by Russell House Publishing Ltd.

Contributors

Frank Garvey, RNMH, RGN, RNT, BA (Hons), Cert Ed, Cert Health Ed

Frank has worked in the fields of learning disability and general nursing for 25 years. Within that time he has been a charge nurse; a respite care home manager for children with complex medical needs and learning disabilities; a community learning disabilities nurse and a university senior lecturer involved in the education of nurses and social workers. He is particularly interested in the physical healthcare of people with learning disabilities and in the research of attitudes towards disability.

Currently, Frank works for Hertfordshire Partnership Trust (HPT) at a strategic level, promoting the equitable healthcare of people with learning disabilities when they are being cared for within general hospitals. He also leads on research development for the learning disability nurses within HPT and on the development of the Expert Patient Programme (EPP) in Hertfordshire for people with learning disabilities.

April Hammond, BSc (Hons), Nurse Specialist Practitioner, Community Learning Disabilities, RNMH, Senior Lecturer Hertfordshire University

April originally worked in a respite care setting for children and adults with learning disabilities. She then became a Community Nurse and Health Facilitator for people with learning disabilities and worked in four London boroughs, before taking up her current post as a Senior Lecturer for student learning disability nurses and student social workers. April's specialist interests are women's health, sexual health and relationship issues. She is particularly passionate about the welfare and rights of people with learning disabilities and keenly encourages service users' involvement in training student nurses.

Costas Joannides, BA, DipHE

Costas is a Placement Support Nurse (Learning Disabilities) working for Hertfordshire Partnership NHS Trust. He has supported and worked within Learning Disability practice for 20 years. His clinical interests are challenging behaviour, reflective practice, education and quality assurance. Costas comes from a family of nurses and educators so nursing has always been part of his life.

Outside of work his interests are restoring lambrettas to their former glory, collecting vinyl (northern soul) and managing a Sunday football team.

Jackie Kelly, MA, PgDip, Registered Nurse in Learning Disability, Academic/ Professional Group Leader, Senior Lecturer Learning Disability

Since commencing her career in learning disability nursing in 1987, Jackie has worked in a variety of contexts. Her work has provided diverse opportunities to work with and learn from people with a wide range of needs and experiences, as well as with their families. Jackie remains constantly grateful and humbled by the privilege of sharing such experiences. As a community nurse she became interested in the *whole family* experience of having a person with a learning disability within the family. This interest led to her undertaking a Masters in Applied Systemic Theory, giving her the opportunity and the tools to explore these connections from a systemic perspective. This has been invaluable both in her work with people with learning disabilities and in her teaching. Teaching within the University has been an exciting opportunity to convey this systemic viewpoint within the context of nurse and social work education. As part of Jackie's studies she carried out a small piece of empirical research exploring the experiences of siblings of a person with a learning disability. This remains a research interest, which she hopes to further develop in the future.

Paul Maloret, RNLD, Dip HE, BA(hons), PGCE

Paul's interest in working with people with learning disabilities was generated from an unforeseen situation. At the age of 18, like so many people of a similar age in the early 1990s, Paul headed to the US to work in a children's summer camp. The intention was to work as a kitchen hand in a camp in New York state, but upon arrival he was a little dismayed to discover that all the campers had 'special needs'. He was dismayed further when they informed him that they had recruited too many kitchen staff and would he mind stepping in as a carer, as someone had not arrived. The idea of living, eating and sleeping with eight teenagers with varying degrees of learning disabilities for three months horrified Paul; however, as the alternative was to go home, he decided to give it go! Having enjoyed the most amazing summer he signed up for the following year. Intermittently he gained further care experience in the UK. Paul then went on to become a qualified learning disability nurse and enjoyed many years working in a variety of settings. He is now a lecturer in learning disability nursing. Paul's main interest, which is reflected in his practice, teaching and indeed the topic for the chapter in this publication, is very much those who have a learning disability and associated mental health problems.

Dr Malcolm Peter McIver, PhD, MA (Dist), BA (Hons), RNT, RCNT, PDN, Dip Nursing (Lon), RNMH, ENG

Currently teaching in the faculty of Health and Human Sciences at the University of Hertfordshire, Malcolm has lectured on legislation and the rights

of people with a learning disability for many years in a number of universities across the UK, and as a visiting lecturer to the University of Washington.

Alan Randle, RNLD, MSc, Integrative Adult Therapist

Alan Randle is a Senior Lecturer at the University of Hertfordshire in Learning Disabilities (LD) and Counselling. He trained as a nurse for people with LD at North Warwickshire School of Nursing and subsequently qualified as a community nurse at Reading University. He further obtained an MSc in Learning Disabilities studies at Hull University. Alan became interested in psychotherapy and communication with people with learning disabilities and qualified as an Integrative Adult Psychotherapist. He has maintained his curiosity in these areas and has developed an MA in Psychotherapy and Disability. Alan maintains a private practice and also facilitates groups. He also provides supervision to therapists who facilitate groups for people with learning disabilities.

Tracey-Jo Simpson, RNLD, qualified lecturer in Further Education, External Examiner for City & Guilds

Tracey-Jo Simpson is a Registered Learning Disability Nurse and qualified lecturer in further education. Throughout her years working in the NHS she supported people within an assessment and treatment service, who had mental ill-health as well as a learning disability. Whilst in this service she was part of a pilot scheme which supported women who had a learning disability to receive cervical screening. Now a self-employed practitioner, her work is extremely varied and includes guest lecturing at the University of Hertfordshire, off-site Practice-Teaching students who are studying for the combined degree in Social Work and Learning Disability Nursing, running a range of workshops and being an external examiner for City & Guilds.

Jacky Vincent, Registered Nurse in Learning Disabilities (RNLD), BA (Hons) in Healthcare Care Management

Jacky has over 15 years' experience in learning disability nursing. For the past few years, Jacky has been working as a Senior Nurse for Hertfordshire County Council and Hertfordshire Partnership NHS Trust. She predominantly provides clinical leadership and advice to the Community Learning Disability Nurses across Hertfordshire, as well as leading on practice initiatives including Essence of Care.

Jacky is presently seconded as a job-share into the position of Lead Nurse for the Learning Disability Directorate, providing nursing leadership and professional advice for the nurses, ensuring that mechanisms are in place to support and facilitate staff in the delivery of safe and effective care.

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We would like to thank all of our colleagues for their help, support, comments and suggestions.

Debra would particularly like to thank her husband and children for their continued support, encouragement and love.

Ian would like to thank his partner for all of his continued support and encouragement.

Introduction

People with learning disabilities are one of the most vulnerable groups in society (Department of Health 2001). This book aims to provide readers – those who provide or wish to provide health care and support for adults with learning disabilities – with a foundation for their interventions. Contributors to this text come from a variety of backgrounds – in clinical practice and the academic world. The contributors are dedicated to creating and maintaining a positive environment for all; they believe that each person with a learning disability is a unique being, with individual needs and ambitions; they also believe that people with learning disabilities can lead full and rewarding lives – indeed, many already do so. Each chapter sets out to reflect these hopes and aspirations.

It is acknowledged that there are some people with learning disabilities who are marginalised by society, and experience prejudice, bullying, insensitive care and discrimination. The effects of these can have a damaging impact on the individual (Department of Health 2001). The majority of people with learning disabilities want to live an ‘ordinary’ life, having the independence and choice to make decisions about their lives (King’s Fund 1999). There may be those who cannot make the choice or decision themselves and the Mental Capacity Act 2005 sets out ways in which those who cannot make those decisions are protected (Department of Health 2005b). Caring for and supporting those who have a learning disability can be complex, but at the same time rewarding – contributing to the person’s well-being can be very satisfying for all concerned.

We are resolute in the belief that people with a learning disability are worthy of the best possible care and support; for you to do this, it is vital that you have an insight into and understanding of the key issues that impinge on the person’s life, both in the community and also in the various health and social care settings. Those people who have a learning disability and are supported effectively in the community can become full, participating members of the community. We encourage you to promote the possibilities associated with living with a learning disability, by providing innovative and creative approaches to care and support and by acting as a knowledgeable doer and, most importantly, an advocate. Partnership working is key to successful and client-centred care; it is essential if care and support are to be delivered in the most appropriate manner that you are encouraged to apply

this approach to care delivery in the situations in which you are working. Stressing the importance of partnership working and acknowledging the benefits that this may bring the individual mean looking beyond a disease-oriented approach to one in which the patient is central. Such an approach is on a par with the current Government's desires to make available a health service that is designed around the patient instead of the service (Department of Health 2006).

Nursing students, those who are undertaking NVQ/SNVQ, Access to Nursing and Cadet nursing programmes of study, and those who are returning to practice will be the prime users of this text – however, not exclusively those cited. This is not a text that will provide you with a panacea for all of the needs of those who have a learning disability; it encourages the reader to identify further areas of importance that may not have been discussed here and to investigate further and deeper. Within the text, the terms 'nurse', 'student' and 'nursing' have been used. The terms and the philosophies applied in this book can be adapted to suit a number of health and social care workers at various levels and in a variety of settings in order to develop caring, informed skills.

The book utilises up-to-date information that the reader will need in order to begin to understand how to help, support and care for those individuals with learning disabilities in the institutional setting (e.g. the hospital) and in the community (e.g. the person's own home setting). The information is arranged in such a way that it reflects current health and social care practice in a user-friendly manner; furthermore, information is related to practice issues that may be encountered when working with people with a learning disability, their families and friends. We would not anticipate that the text be read from cover to cover in one sitting; rather, it can be used as a reference book (a resource, a reader), be it in the clinical setting, the classroom or your own home.

The text can be considered as a handbook or a manual that has an up-to-date evidence base; it is anticipated that it will challenge and encourage the reader to acquire a questioning approach to care provision, emphasising the important relationship between theory and practice. You may be studying at the moment; if this is the case, in order for you to get the most out of this book, you are encouraged to attend all of your classes associated with your current programme of study, and we would suggest that you use this text to supplement your current learning.

Most of the content relates and refers to some key health and social care documents, publications and statutes that are used here to inform debate. One key government publication – *Valuing People: A New Strategy for Learning Disabilities for the 21st Century* (Department of Health 2001) – is central, explicitly or implicitly, to deliberations.

The wide-ranging aim is to facilitate understanding associated with essential aspects of care in an attempt to enhance safe and effective care, and to

encourage and generate discussion. It is anticipated that the outcome will improve the quality of care provision that is underpinned by an informed knowledge base. This book is a fundamental text that can enhance personal and professional growth in relation to learning disability care.

CONTEMPORARY SOCIETY

It is estimated that there are over 800,000 people in the UK aged over 20 years who have a learning disability (Department of Health 2005a); putting this into context can help you to understand the needs of those whom you may need to provide care and support for, as well as the extent of the challenges. This number is expected to rise by 14 per cent to 900,000 by 2021. Furthermore, the number of those with severe learning disabilities may also rise by 1 per cent per year for the next 15 years (Department of Health 2005a).

KEY TERMS

The choice of terms used in this text is diverse. It is important to define terms from the beginning; different terms may mean different things to different people. There are a variety of terms that can be used to describe people with learning disabilities. The use of any term has the ability to label the person to whom the term is being applied. Labelling may lead to prejudice and discrimination, and can result in stigmatisation. Stigma is powerful and can have negative consequences for an individual's identity.

Often, the term 'patient' is used in healthcare settings. Not everyone supports its use, as it has passive connotations associated with it; it can also highlight the medical focus of the relationship between the person and the service. On occasions, 'client' is used; this has the ability to stress the professional nature of the relationship. More recently, the term 'expert' has been used, with the emphasis on a participative approach, acknowledging a person's capacity to work towards his/her own rehabilitation. Experts are seen to be equal partners with experts who provide care, such as a nurse or doctor. Not everyone is keen on the term 'service user' or 'user'. The term 'user' may also have negative connotations associated with it. It may be used to single out those who use illicit substances.

'Adults with a learning disability' is a term that has been used in the title of this text and also in this introductory aspect of the book. This is a broad definition, often used by various health and social care agencies. It has the potential to recognise that many people can and do have a learning disability, but they may not necessarily have an illness or a disease.

Various terms are used in this text with the aim of promoting the care and support of individuals with learning disabilities. The terms we have used

address a wide range of experiences that may affect members of our society. In order to avoid stigma, prejudice and stereotyping, listen to and respect the terminology that is being used by those who are living with a learning disability.

The word ‘carer’ has been used on many occasions in this book. It is used to describe those who look after others, whether they be ill or healthy, or have a disability. ‘Carer’ has many interpretations and may refer to an employed healthcare provider or someone who provides care that is unpaid. It has been estimated that there are approximately 6 million unpaid carers in the United Kingdom (Carers UK 2005); this includes parents, grandparents and siblings who are looking after people with learning disabilities.

THE CHAPTERS

It is impossible to discuss all elements of health and social care related to the person with a learning disability. We have arranged the chapters in such a manner as to provide you with some insight into the intricacies associated with the care and support that may be required by an individual who has a learning disability. Primarily, we aim to provide you with the essence of care and a fundamental understanding of some of the issues that may impinge on a person’s well-being.

Central to Chapter 1 is the importance of fostering good working relationships with adults who have learning disabilities. Key concepts such as person-centred planning will be considered and debated in detail, as well as the diversity of the varying needs of adults with learning disabilities. Approaches to care are examined.

Chapter 2 focuses on effective communication strategies that can be used for adults with learning disabilities; processes and forms of communication are outlined. The chapter makes clear how important it is to assess social functioning, as well as communication skills, when determining need. There are those individuals who have communication problems, as a result of which communication policies must be developed to disseminate information in accessible formats; some of these formats are outlined. In addition, there will be discussion concerning barriers to communication, including non-verbal communication processes.

Caring for and supporting the individual who presents with behaviours that may pose challenges are outlined in Chapter 3. There are various methods that may be used to support and manage a person with learning disabilities when their behaviour poses problems. Interventions will be examined and placed within the context of ‘normalisation’ principles underpinning learning disability care and provision. The chapter points out that over-reliance on psychotropic drugs can often result in poor outcomes as a consequence of their use. Management strategies will be discussed and outlined.

Chapter 4 provides the reader with an understanding of how to protect the ‘vulnerable’ adult who has learning disabilities from exploitation and abuse; protection is seen as paramount. This chapter will outline policies and procedures that are in place to ensure the protection of the ‘vulnerable’ learning disabled adult and identification of the ‘vulnerable’ adult ‘at risk’. The chapter uses the *No Secrets* publication to demonstrate that there is no place to hide when it comes to exposing the abuse of vulnerable adults (Department of Health and Home Office 2000). The chapter draws upon the legal framework in place, identifying voluntary and statutory provision. Chapter 9 discusses the framework and other legal issues further.

The incidence and prevalence of mental ill health in adults with learning disabilities is higher than within the general population. In Chapter 5, vulnerability factors are discussed and highlighted, including how these may contribute to mental health difficulties. Issues around diagnosis and treatment are explored. The chapter emphasises the point that those who have a learning disability as well as a mental health illness should be able to access services and be treated in the same way as anybody else.

Chapter 6 focuses on the person with a learning disability who also has epilepsy. Epilepsy is defined and the categories of epilepsy outlined. The management of epilepsy will be examined and strategies discussed. The use of anti-epileptic drugs (AEDs) will be examined in the context of recently published National Institute for Health and Clinical Excellence (NICE) guidelines as well as the *National Service Framework for Long Term Conditions* (Department of Health 2005c).

Fulfilling the health potential of adults with learning disabilities is central to care; Chapter 7 discusses health promotion initiatives. These activities consider some of the special health needs of adults with learning disabilities and how they can be empowered to meet these needs. Discussion of opportunist health promotion and health promotion activities will be included; emphasis is placed on making health material accessible to those who have learning disabilities.

Since the text will consider a range of issues related to health and illness and the impact on adults with learning disabilities, Chapter 8 describes some biophysical aspects of anatomy and physiology, identifying how these may relate to specific syndromes, e.g. Down’s syndrome. Fundamental aspects of the physical characteristics of Down’s syndrome will be examined in relation to specific medical issues, such as heart and circulation, the digestive system, etc. This will be followed by discussion of potential difficulties that the adult with Down’s syndrome may encounter, such as congenital heart defects and hypertension.

Caring for adults with learning disabilities will inevitably involve ethical, moral and legal issues. Chapter 4 has already begun to address these issues;

Chapter 9 continues to address other concerns, such as civil rights. Often, these issues are complex; this chapter highlights ethical theories and focuses on the legal ramifications in such a way that the reader is able to relate them to practice.

The final chapter addresses the rights of adults with learning disabilities to marry and have children; this is at the heart of *Valuing People* (Department of Health 2001). The number of people with learning disabilities who are forming relationships and having children has steadily increased over the last 20 years. This brings with it many challenges, hopes and aspirations. This chapter discusses anti-discriminatory practice, drawing on the discussions made in other chapters, supporting parents and examining practical aspects of inter-agency working that can support parents with learning disabilities, whilst being aware of issues of child protection and children ‘at risk’.

We hope that by using this text to support your practice, you are able to advocate and support the person with a learning disability in a variety of settings. We are delighted that you have chosen to care for and support those who have learning disabilities and we are confident that you really will make a difference.

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