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# Health Care Provision and People with Learning Disabilities – A Guide for Health Professionals

JO CORBETT



John Wiley & Sons, Ltd



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# Foreword

Did you know that people with Down's syndrome are prone to hearing difficulties because of their relatively short and narrow-shaped ear canals and increased tendency for ear wax to become impacted? Well, if you are an established doctor, nurse or allied health professional you would think you should know such a basic fact, wouldn't you, to explain why people with Down's syndrome who consult you may not pay attention when you are talking to them. But, as health professionals working in primary care or community or hospital settings, it has been common to focus our interest on able people who choose to come to consult us. We tend to ignore the needs of harder to reach groups of people, like those who are housebound, have dementia, the homeless or – as in the subject of this book – those people who have learning disabilities.

So, has this stirred your conscience? Did you realise before I gave that example that those with learning disabilities may have a physical reason for being hard of hearing that you could remedy? Well, you should read this book – it is packed with loads of basic information about the physical, mental and social health of people with learning disabilities. It will make a difference to your everyday practice. The chapter on the communication needs of people with learning disabilities is particularly useful for all health professionals.

It will enable you to understand the difficulties that people with learning disabilities and their carers face, trying to access health care services through the normal routes. Looking at the NHS through their eyes you will appreciate the inequity that they experience compared with able patients.

Tricky areas such as gaining consent are covered – the legal stance in England and Wales for adults who have learning disability being the same as for those deemed to be competent unless proven otherwise.

There are plenty of tips about using non-verbal methods of communication to overcome difficulties so that you and the person with learning disability understand each other. After all, how can you do your job to the best of your ability if you cannot form a relationship and converse in a real way with people with learning disabilities? You need these insights from someone like Jo Corbett, the author, who has worked as a registered nurse in learning disability for about 30 years.

This book is a must read for all health professionals. You owe it to those with learning disabilities and their carers to learn how to practise at your best with all groups of patients who come under your care.

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Staffordshire University  
and  
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West Midlands Deanery

# Preface

High-quality health care that seeks to identify and treat needs is something all of us hope for and should be available to all people, irrespective of race, gender or disability. In its reforms the NHS plan (DOH, 2000) sought to redesign health services responding to individual needs and transforming health care.

The needs of people with learning disabilities vary greatly, from those having mild learning disability, requiring very little support, to those with severe learning disability, having complex needs and requiring support from others to achieve all basic needs. This can lead to people with learning disabilities presenting a range of challenges for the people around them. During times of ill health these challenges will become ever more apparent. For the health professional working in mainstream primary and secondary care settings these challenges can be difficult to overcome when attempting to identify health needs and deliver holistic care that is responsive to their individual needs.

This book provides clear information and aims to assist mainstream health care providers in gaining greater understanding of people with learning disabilities to enable them to deliver the holistic and effective care that people with learning disability deserve. The reader is provided with information that emphasizes the range of achievements and individuality of people with learning disabilities and, through looking back at the historical perspective of care provision, illustrates the importance of improving upon the negative attitudes that can still prevail and at times lead to inadequate health-related decisions.

Sections of the book highlight many problems and barriers faced by people with learning disabilities when accessing health care seeking to raise awareness and influence improvements in care. People with learning disabilities will use health services at all levels and, recognizing the difficulty some mainstream care providers have when interacting with people who have learning disabilities, the book provides guidance to influence improved communication and support by health professionals delivering at both primary and secondary care levels.

Each chapter gives the reader information and guidance on dealing with a variety of situations found in health care settings. Examples of good practice are explained using case examples and experiences of people with learning disabilities and their carers. The book describes what is expected from the various health care teams and offers solutions to potential challenges and barriers facing them. It includes information regarding specialist support services that can offer assistance to the individual and to the mainstream staff teams, ideas are also offered on how

to present information in a format that people who have communication difficulties can understand. For some considerable time, evidence has been presented that highlights the health inequalities experienced by this group, much of the evidence is explored and used to support the need to create improvements in care. Key legislation that offers a legal framework to protect the rights of people is explored and discussed in an attempt to raise awareness in particular about issues related to consent and capacity.

The evidence base for this book has been drawn from extensive research, personal experience, policy guidance, as well as from some of the current legislation that is applicable to this group. Since its publication *Valuing People: A new strategy for learning disabilities for 21<sup>st</sup> Century* (DOH, 2001c) has been the guide for those working to improve and develop learning disability services; its recommendations along with other government guidance are used throughout the text to help inform and remind mainstream service providers of their responsibilities to all patients.

As a registered nurse for people with learning disabilities, I have spent several years working in various settings and gaining an understanding of individuals who have learning disability and their families. Recently my time has been spent developing a greater understanding of health inequalities experienced by people with learning disability whose needs are often misunderstood by the mainstream health services.

Having spent time working with colleagues on a project that looked at implementing initiatives that were presented in *Valuing People: A new strategy for learning disabilities for 21<sup>st</sup> Century* (DOH, 2001c) regarding the concept of health facilitation, it became clear that improvements were required at all levels, including improved responses to health from within the specialist learning disability teams. For improvements in health to occur there is a real need for all services to work together in partnership with people who have learning disabilities and their carers taking a shared approach and responsibility for reducing health inequalities. It is hoped that this text will provide an additional resource that will encourage and support initiatives to improve the whole health experience for people with learning disabilities giving them greater opportunities.

My career has concentrated on provision of learning disability services in England in particular and as such the information presented largely reflects policy and legislation applicable in England and Wales. It is perhaps worth noting however that although there are differences in legislation as it applies, for example, in Scotland, many approaches advocated will be equally applicable to people with learning disabilities there and in other parts of the UK.

Jo Corbett

# Acknowledgements

This text would not have been completed without the tremendous support and encouragement of my family, friends and colleagues. There are a number of people in particular to whom I would like to express my gratitude who have helped to influence and shape the early thinking behind this text. Caron Thomas gave me tremendous support and had she not have encouraged the writing and publication of an article along with my colleagues Maxine Prior and Rick Robson (Corbett *et al.*, 2003), it is unlikely that this book would ever have been written. I am eternally grateful to them all for their continued support.

Much of my career has been spent working with the people of Wolverhampton and thanks are extended to all of those people with learning disabilities and their carers who gave me the benefit of experience and knowledge over a considerable period of time. I was able to utilize it all when preparing this text.

A huge thank you is also extended to all my colleagues in Wolverhampton who were always, and remain, immensely supportive with my endeavours. During the later stages of preparing the text my newfound colleagues in Staffordshire have been a tremendous help. Special thanks go to Sue Jackson for the benefit of her experience and ideas and to Sarah Cherry for sharing valuable information with me. Thanks also to Kevin Elliot and Esia Dean from Gloucestershire for allowing the use of their valuable assessment tool and to the team from CHANGE picture bank for allowing samples of their work to enhance this publication.

A final note to Tony, Sam and Jack – your support and encouragement was brilliant and without it this work may never have been completed. I am forever grateful.



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# Understanding learning disability

# 1

## Introduction

People who have a family member who has learning disabilities and those working in close contact through learning disability services will have a reasonable understanding of the terminology used; others express real difficulties in understanding what type of person may be referred to when seeking to define the term and apply it to describe an incredibly diverse group. There is often confusion with other groups in society in particular people who have mental health disorders. The lack of clarity about what is meant by the term 'learning disability' can at times extend to those working in the field of practice, as those providing specialist services for people with learning disability are known to debate who can access their services. This emphasizes how difficult it can be to categorize and identify this group of people.

This chapter seeks to give some insight into the various service definitions while also sharing the individuality and skills of this marginalized group. The chapter also offers a brief overview of factors contributing to a person having learning disabilities and discusses some issues arising from different attitudes held in society that can perpetuate negative responses.

Individual perceptions can lead to assumptions being made about the people for whom we provide care. It is perhaps useful to reflect on your own thoughts and feelings when faced with minimal information about an individual requiring health care support. Take some time to reflect on your own thoughts and perceptions of the group of people who have learning disabilities and who they are by looking at the question posed in Text Box 1.