General Hospital Care for People with Learning Disabilities

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Preface

This book is about general hospital care for people with a learning disability. It explores the nature of learning disability and highlights how to identify and meet the particular health needs of people with a learning disability.

The book takes the reader through all the key factors in the health care process from pre-admission assessment and identification of health needs, person-centred care planning, leading to successful treatment interventions and planned discharge.

It focuses on the key areas of communication, behaviour and consent, and highlights how multidisciplinary approaches can contribute to successful outcomes for everyone involved.

The Department of Health (1999, 2001), National Health Service Executive (NHSE 1998) and Mencap (1998), all have reported that people with learning disabilities have increased health needs to the general population, yet these needs are often poorly met, and people experience difficulties in accessing appropriate services.

The NHSE (1998) recommended that ‘Mainstream National Health Services need to become more responsive to the special circumstances and needs of people with learning disabilities’.

It is hoped that this book will serve as a comprehensive resource for health care professionals working in general hospital settings, who may come into contact with people with a learning disability in the course of their working life, providing information, practical examples and good practice guidance to enable them to understand and meet the health needs of people with a learning disability.

The first chapter explores the nature of learning disability and the specific health care needs of people with a learning disability. It considers the key factors that influence the health care process, and stresses the importance of person-centred approaches.

The book then takes the reader through the patient journey and the process of health care, through pre-admission assessment, care planning, intervention and treatment, liaison and discharge planning.

This is followed by chapters on the key aspects of communication, behaviour management and the often difficult area of consent.

The book finishes with a chapter exploring the ethical and political aspects of health care, abuse issues and safeguarding of people with a learning disability, the value of multidisciplinary approaches and good practice benchmarks.

The book is relevant to the care of both children and adults with a learning disability and case vignettes are used throughout to illustrate situations.

The use of case studies throughout this book are intended to help illustrate examples of situations explored in main text and are not intended to be a template for action in similar situations.

This book also includes reference to a research project looking at pre-admission assessment for people with a learning disability conducted by one of the authors.
REFERENCES

Acknowledgements

First and foremost, we acknowledge the journey we have made together in writing this book. As experienced nurses, but novice authors, it has been a real voyage of discovery and adventure. We feel that we have risen to the challenge, learning much along the way, and we are proud of our achievement in completing this book.

This book and the case studies used for illustration are based on our real-life experiences. We would like to express our thanks and appreciation to all the individuals who have been willing to share their stories with us and who have helped us along the way.

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Our thanks go to Mencap for permission to use their images, Rick Robson and A2A for permission to reproduce materials, and to the Makaton Charity for permission to reproduce their symbols. We also thank our publishers who gave great support and advice to us as novice authors.

Our most grateful thanks and respect go to all the people with learning disabilities and their families, who we have worked with over many years and who have taught us so much and inspired our practice.

This book is particularly dedicated to the memory of Martin, Emma, Mark, Ted, Tom and Warren, the six people with a learning disability whose stories provided us all with so many valuable lessons to be learned. We hope this book will contribute to enabling health care staff working in general hospitals to provide high-quality and effective care to all people with a learning disability in the future.
INTRODUCTION

This book is designed to provide a framework of good practice guidance to support health care professionals working in general hospital services to provide care to people with a learning disability. This first chapter provides an introduction to the nature of learning disability and insight into what this means for the person. It explores how to establish if your patient has a learning disability, and the perceptions and attitudes of health care professionals towards people with a learning disability. The chapter then continues to summarise what the current evidence base says about how to identify and meet the health needs of people with a learning disability, including factors and barriers that influence the health care process and how to overcome these. The needs of families and carers are highlighted and the important role they have to play in the process. The chapter concludes with an introduction to the person-centred approaches that are a central aspect of learning disability practice.

We do not always know who is disabled. Many people associate disability with wheelchair use, yet less than 5% of disabled people use a wheelchair. Anyone who meets the following definition from the Disability Discrimination Act (DDA) (Department of Health 1995b) is considered to be disabled:

**Someone with a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day to day activities.**

This includes physical impairments to senses such as sight and hearing, and mental impairments such as learning disabilities and mental illness. Conditions covered may include things such as severe depression, diabetes, dyslexia, epilepsy and arthritis.

**Substantial** includes:

- Inability to see moving traffic clearly enough to cross a road safely
- Inability to turn taps or knobs
- Inability to remember and relay a simple message correctly

**Long-term** means that the effects have lasted, or are expected to last 12 months or more.

**Day-to-day activities** include mobility, manual dexterity, physical coordination, continence, ability to lift, speech, hearing, eyesight, memory and recognising physical danger.

Considering the Disability Discrimination Act definition of disability, it is clear that a wide range of people and health conditions could be incorporated within this.
The new Equality Act 2010 will come into force in October 2010. The Act brings disability, sex, race and other grounds of discrimination within one piece of legislation, and also makes changes to the law. Further information about the Act can be found at: http://www.equalities.gov.uk/equality_act_2010.aspx

DEFINITIONS AND CAUSES OF A LEARNING DISABILITY

Definitions

A learning disability is a lifelong condition, which has its beginning before, during or after birth, or as a result of injury to the brain before the age of 18, which affects an individual’s ability to learn, communicate or do everyday things. A learning disability is not an illness, and whilst the condition cannot be ‘cured’, it is possible for an individual with a learning disability to develop new skills and progress.

A learning disability should not be confused with educational ‘learning difficulties’ such as dyslexia, and hyperactive disorders, or mental illness, which are other conditions, not covered within this book. People who acquire brain injuries after the age of 18 are not normally considered to have a learning disability, as the injury has occurred after the brain was fully developed.

Mackenzie (2005), cited in Grant et al. (2005, p. 49), explains that ‘the international Classification of Mental and Behavioural Disorders (ICD-10) (World Health Organisation 1992) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association 1994) are the main classification systems currently in use’. ICD is the system used in the UK. Both these systems use the term ‘mental retardation’ and this equates to learning disability. Whilst the term ‘mental retardation’ may be defined in the ICD, it is however unacceptable for use in clinical practice.

Mackenzie outlines the following (broadly similar) ICD and DSM definitions of learning disability:

**DSM-IV definition**

1. Significantly subaverage intellectual functioning: an intelligence quotient (IQ) of approximately 70 or below on an individually administered IQ test (for infants, a clinical judgement of significantly subaverage intellectual functioning).
2. Concurrent deficits or impairments in present adaptive functioning (i.e. the person’s effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.
3. The onset is before 18 years of age.

**ICD-10 definition**

Mental retardation is a condition of arrested or incomplete development of mind, which is characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities.

Mackenzie also explains that ‘each is based on the presence of impairments in adaptive function in association with low intelligence quotient (IQ)’.
Understanding Learning Disability

You may have heard of a variety of different terms used to describe someone with a learning disability, many of them are now considered to be inappropriate, and some are actually offensive and should never be used.

Reflective Learning Point:
Think about all the terms you may have heard to define a learning disability and how they would sound to a person with a learning disability and their family.

Mackenzie (2005), cited in Grant et al. (2005), continues to describe the following World Health Organisation (1980) definitions:

- Impairment – Any loss or abnormality of physical or psychological function
- Disability – Interference with activities of the whole person (usually described in learning disability practice as activities of daily living)
- Handicap – The social disadvantage to an individual as a result of impairment or a disability

The Mental Health Act (Department of Health 1983) uses the term ‘mental impairment’, and the term ‘mental handicap’ may still be used, though this is not considered acceptable any more. All these terms can be seen to represent what people may consider as features of a disability. A social model of disability, as opposed to a medical model, identifies attitudes and environment as being major causes of disability, and not the personal abilities of the people involved. The medical model focuses on the clinical aspects of the condition and how it is treated, and not necessarily the impact on the person.

The Department of Health (2001a) report ‘Valuing People’ defines a learning disability as having the following characteristics:

- A significantly reduced ability to understand new or complex information, to learn new skills (impairment of intelligence)
- A reduced ability to cope independently (impaired social functioning)
- Started before adulthood (usually considered to be age 18), with a lasting effect on development

Each individual goes through a comprehensive process of assessment before a diagnosis of learning disability can be confirmed. A syndrome is the medical term for a recognised set of clinical features which commonly occur together. Some syndromes (e.g. Down’s syndrome) are named after the person who first described them or others after a particular feature of the syndrome.

Mackenzie (2005) (cited in Grant et al. 2005, p. 49) outlines that ‘the term “special needs” refers to children who have been given a Statement of special educational needs by their local education authority. The educational category of severe learning difficulties corresponds more closely with learning disabilities as used in health settings’.

Intelligence is formally measured through a cognitive assessment by a qualified clinical psychologist, who gives people an IQ score. The Royal College of Nursing (2006) explains how IQ range is naturally distributed in the population and the average IQ (mean score) is 100,
with a standard deviation range of 15 points on either side. Therefore, anyone with an IQ score between 85 and 115 is said to be of average intelligence (Fig. 1.1).

The range of 1 standard deviation above or below the mean represents 68% of the population. Another 28% of the population has an IQ score within 2 standard deviations of the mean (14% above and 14% below), leaving a small number of individuals (2%) at either end of the scale outside of 2 standard deviations of the mean.

The range of IQ distribution in the population is illustrated in Table 1.1. From this table we can see that approximately 2% of the population can be considered to have a learning disability.

Impairment of intelligence can be presented at different levels and the British Psychological Society (2000) explains that:

- People with an IQ of 55–69 can be said to have a significant impairment in intellectual functioning.
- People with an IQ of below 55 can be said to have a severe impairment in intellectual functioning.

IQ tests are not routinely carried out for all people with a learning disability, so this information may not be available for the people that you see. A referral can be made when a need to measure intelligence is identified, for example when capacity to consent issues arises.

The term ‘mild learning disability’ may be used to describe a significant impairment, and the terms ‘moderate, severe or profound’ may be used to describe a severe impairment in intellectual functioning. The term ‘intellectual disability’ is commonly used in other countries. Some people with an IQ in the range 70–85 can find that their learning impairment is often not diagnosed at an early age, and they are not able to access services designed for people with significant or severe impairments.

### Table 1.1 The range of IQ distribution in the population

<table>
<thead>
<tr>
<th>IQ range</th>
<th>55–70 and below</th>
<th>71–85</th>
<th>86–100</th>
<th>101–115</th>
<th>116–130</th>
<th>131–145 and above</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population (%)</td>
<td>2</td>
<td>14</td>
<td>34</td>
<td>34</td>
<td>14</td>
<td>2</td>
</tr>
</tbody>
</table>
Prevalence

Mencap (2002) reported, ‘There are about 1.5 million people with a mild or moderate learning disability, and an estimated 210,000 individuals with severe or profound and multiple learning disabilities currently living in the United Kingdom’.

Michaels (2008, p. 14) reported that ‘estimates of the prevalence of learning disability vary reflecting differences in definition. Department of Health figures suggest that about 1.5 million people (around 2.5% of the UK population) have a learning disability’. He also cited Emerson and Hatton (2004), who suggest that ‘3% of children and 2% of adults fall into the category overall. Of these, 1.2 million people have mild-moderate learning disability and around 210,000 (about one third of 1%) have severe and profound learning disabilities. This latter group includes 65,000 children and young people, 120,000 adults of working age and 25,000 older people’.

Michaels (2008) continues to explain that:

The prevalence of learning disability in the general population is expected to rise by around 1% per annum for the next 10 years and to grow overall by over 10% by 2020. It is also expected that there will be a growth in the complexity of disabilities. This is attributable to improvements in maternal and neonatal care and improvements in general health care for adults which lead to increased life expectancy. Increasing use of alcohol in the UK and rates of unplanned teenage pregnancy are also expected to contribute to increases in the prevalence of foetal alcohol syndrome (which is a specific syndrome with associated learning disability as a clinical feature). In addition, there are increases anticipated in the proportion of younger English adults from South Asian minority ethnic communities where the prevalence of learning disability is higher.

It is clear then that a significant number of individuals can be affected by a learning disability. Severe learning disability is more easily recognised and diagnosed and is relatively evenly spread in the population. Accurate reporting of mild to moderate levels of learning disability is more difficult, with a number of people not diagnosed until adulthood when they are coming into contact with various health or social services. Some people are not correctly diagnosed at all and may even be given alternative labels such as a mental health diagnosis.

Some areas of the UK have higher levels of people with a learning disability in their community due to the previous existence of a long-stay learning disability hospital in the area. People were often resettled from the hospital to the local community instead of returning to the place they had been admitted from.

Causes and diagnosis

As outlined previously, a learning disability is a lifelong condition, which has its beginning before, during or after birth, or as a result of injury to the brain before the age of 18.

The main causes of learning disability can be considered as follows:

- **Before birth**: For example, genetic conditions such as Down’s syndrome, metabolic disorders and maternal infections
- **During birth**: For example, lack of oxygen and trauma
- **After birth and before age of 18**: For example, accidents causing brain injury and infections

The cause does not always give an indication of the level of learning disability; for example, people with Down’s syndrome can range in ability levels from mild to severe impairment. The
level of disability and the subsequent impact on the ability of the person can vary across a wide range, from people who can live quite independently with minimal support to people who need full nursing care and are completely reliant on others.

**Reflective Learning Point:**

Look at the following pictures – Who do you think has a learning disability?
The answer is we do not know for sure, but we do make assumptions based on what we see. Although it is not possible to explore the full range of learning disability conditions in detail within this book, there are numerous publications available through your local health library for anyone interested in condition-related information. Further information about specific health needs associated with a learning disability is outlined later in this chapter.

Mackenzie (2005), cited in Grant et al. (2005, p. 48), outlines the ‘bio-psycho-social’ model now taught in medical schools:

This model places the patient (as a unique individual with biological, psychological and social needs) at the centre of their interaction with health services. It is within this framework that the process of diagnosis and assessment of the health needs of an individual with learning disabilities and the planning of health services to meet their needs should take place.

She continues to explain (cited in Grant et al. 2005, p. 55) that ‘in 80% of people with severe learning disabilities, a specific bio-medical cause can be diagnosed’. This also demonstrates that there are a number of people (20%) with a learning disability where the exact cause cannot be defined.

The process of diagnosis begins with some routine screening tests that are offered during pregnancy (e.g. for Down’s syndrome). Where there is a family history of a particular genetic condition, specific screening can also take place for this. Other screening tests are carried out soon after a child is born (e.g. a heel prick blood test for phenylketonuria), which can lead to successful treatment and prevention of a learning disability developing.

Some conditions have clearly recognisable clinical features that can be identified at birth, though these would also be followed up with further bio-medical checks to confirm a diagnosis. Other diagnoses of a learning disability are not made until later when a child is not achieving
developmental milestones as expected, and this is investigated further. The assessment and diagnosis process also helps to identify any associated physical or developmental needs that may require specific treatment. Early intervention for these now can improve long-term health outcomes for the individual.

Some learning disability conditions have specific health problems associated with them, and the diagnosis should help with identifying and planning to meet these health needs. Mackenzie (cited in Grant et al. 2005, p. 63) outlines an example of the health problems known to be associated with Down’s syndrome:

- Congenital heart defects
- Respiratory infections
- Hearing and visual impairments
- Hypothyroidism
- Skin problems
- Gum disease and tooth loss
- Obesity
- Depression
- Alzheimer’s disease (early onset)

This example illustrates the multiple and complex health needs associated with one of the most commonly recognised learning disability conditions. Learning Disability Nurses have a good understanding of the health needs of people with a learning disability and can provide information and valuable support to health care professionals in general hospital settings.

A diagnosis of a learning disability has a great impact on a family, especially where there has been no indication during a pregnancy to cause any concern. Parents of a child with a learning disability often look for a diagnosis to explain how this has occurred, and also to help them to come to terms with what the impact will be on their present and future lives. This can be a very difficult time, and sensitive support from health care professionals can be very reassuring. It is also important to consider referral for genetic counselling where appropriate – though this is too detailed a topic to explore further within this book.

HOW TO ESTABLISH IF YOUR PATIENT HAS A LEARNING DISABILITY

You cannot always tell just by looking at someone if they have a learning disability. Sometimes it is obvious when a person has a recognisable condition (e.g. Down’s syndrome) or some physical disabilities, but most of the time it is not so easy to identify. It can be particularly difficult for health care professionals to judge levels of functioning when people present as being more able and capable than they actually are.

In order to establish if your patient has a learning disability, you will need to investigate the following key points:

- **Is there a diagnosis of learning disability?** This may be a more obvious condition such as Down’s syndrome, or conditions such as autism, or Prader–Willi syndrome. Is anything written in their medical records?
- **Do they access services that support people with a learning disability?** Day services, social services, special hospitals.
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- Where do they live? Do they have support in the home or do they live in a supported living environment?
- Did the person go to a special school, or receive support to attend a mainstream school?
- Do they have support from learning disability services? This could be a consultant psychiatrist, community nurse, social worker, speech and language therapist, psychologist.
- Can the person read and write?
- Check any records you may have access to for any previous reference to a learning disability.

Some behavioural indicators may be:

- Slow or confused response to questioning
- Difficulty retaining personal information, details or events
- Immature behaviour
- Inappropriate social behaviour, for example over familiarity

Some communication indicators may be:

- Unclear in relaying personal information
- Unable to tell you who they are and what is wrong with them
- Unclear about time of day, date or place
- Echolalic – repeats back to you what you have said

(See also further information in Chapter 3.)

People who have attained General Certificate of Secondary Education (GCSE) (or equivalent) at a–c level, drive a car, or attended mainstream school without support would not usually be considered to have a learning disability. However, this is just a guide and there may be exceptions. If you are unclear but suspect that the person has a learning disability and would benefit from support during the admission, information could be obtained from your local Social Services Department or Community Learning Disability Team.

PERCEPTIONS AND ATTITUDES TOWARDS PEOPLE WITH A LEARNING DISABILITY

Health care professionals may work in general hospital services for many years without having to work with people with a learning disability. A lack of exposure can lead to an associated lack of awareness or understanding of the health needs of people with a learning disability, creating a perception that working with them will be a difficult or unpleasant experience.

Perception can be explained as the process we use to collect, interpret and comprehend information from the world around us by means of our senses. We then use this information to recognise what will happen in a particular situation. Some people may be described as very perceptive because they are able to reach this conclusion quickly. An attitude can be described as your point of view or position on something, the way you think and feel about something.

Attitudes are created from your perception, whether this is based on fact or otherwise, and both your perception and attitude can create a barrier between the health care professional and a person with a learning disability before you even meet them.
Health care professionals’ initial perception of people with a learning disability is commonly founded on stereotypes or information provided by other people rather than based on their own experiences. This information is often exaggerated and is usually describing negative reports of the experiences of other people.

**Reflective Learning Point:**

Describe to a colleague how you would feel now if you were informed that the next patient you were to see has a learning disability.

- What would your initial thoughts be?
- What would you expect the person to be like?

A number of different studies have considered the attitudes of health care professionals towards people with learning disabilities. Biley (1994) reported that nurses’ negative attitudes towards people with disabilities admitted to acute hospital settings could make for a traumatic stay. She highlighted a general lack of awareness of the needs of patients with a physical disability and also that ‘although differing impairments have different disabling effects, most people with a disability are handicapped primarily by negative attitudes and the limited range of choices available to them’.

Shanley and Guest (1995) describe the stigmatisation of people with learning disabilities as ‘a barrier to good nursing care’. They suggested that ‘the educational preparation of general nurses must facilitate greater awareness of stigmatised groups’. This is a point that is often raised and yet has not been addressed fully by the training establishments and incorporated enough into basic training programmes for health care professionals.

The influences of contact, and graduate/non-graduate status, on the attitudes of nurses in a general hospital towards people with learning disabilities were explored by Slevin and Sines (1996). They reported that ‘attitudes held were more negative than would be expected from those in a caring profession’. The graduate nurses were found to be more positive than non-graduate nurses are. Nurses in the sample who had experienced higher amounts of contact with people with a learning disability were found to have more positive attitudes. This is consistent with the general lack of confidence of hospital staff in working with people with a learning disability that is shown in the summary of the evidence base later in this chapter, and also with the evidence that attitudes of health care professionals become more positive, the more time they spend with people with a learning disability.

Hannon (2003) found that whilst experience is identified in the evidence base as an influencing factor on attitudes, a positive attitude was seen in a hospital staff who had only been qualified for 2 years, and had only minimal previous contact with people with a learning disability. All hospital staff in the study felt they treated everyone the same, and the experiences of people with a learning disability in this research project were more positive than expected, with service users all reporting that they felt that they were treated the same as everyone else. It was found that what tended to stick in the mind are difficult situations and that this needs to be balanced out with positive experiences. Hospital staff were pleasantly surprised to meet people that they actually enjoyed having on the ward. Initial fear about caring for the person was changed in the light of their experience. This evidence of a more positive attitude after contact supports previous research (Slevin & Sines 1996).
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Hannon also noted that hospital staff were more confident with more able people but less so where there were behavioural or communication problems, or other complex needs. The hospital staff expressed that they felt they had a lack of experience, training and preparation to enable them to care effectively for this client group. They felt that they had a lack of information about learning disability and felt that it should be included within pre-registration education programmes.

The findings from this study agree with a review of other available research by Fitzsimmons and Barr (1997), who found a number of variables that influenced attitudes including the perceived severity of disability, confusion about the definition of a learning disability, behaviour, communication, and poor preparation and training. Melville et al. (2007) (cited in Michael 2008, p. 35) assessed the training needs of 210 practice nurses and delivered a bespoke training package that had a significant impact on knowledge and practice. People with a learning disability are also involved in some areas in providing this training themselves (e.g. at St Georges Hospital Medical School) with very positive feedback.

The following two case studies illustrate how the perceptions and attitudes of health care professionals were changed following their experience of caring for someone with a learning disability in hospital. The figures in brackets are references to interview transcripts recorded during the (Hannon) research project.

Understanding Learning Disability Case Study 1 – Steven

Steven is 17 years old and was admitted to hospital for the first time. He has a mild learning disability, minor communication difficulties, but no behaviour problems. He is fully independent with personal care, and did not need anyone to stay with him. Steven is quite a shy person. He was admitted to an adult ward, and was visited by his consultant paediatrician.

Steven lives with his father, who also has a mild learning disability. He stayed with Steven during admission process and then left. He was concerned to find out what was wrong with Steven, but not about the admission. [19.422] ‘(Community Learning Disability (LD) Nurse) helped a lot because she explained that he had never been in before and had a word with the nurse’.

The Community Learning Disability Nurse was present for the admission. She has 18 years’ experience, but has known Steven only for 3 months. She had previous experience of supporting people with learning disabilities in hospital. The hospital staff caring for Steven was a qualified nurse with 30 years’ experience, including previous experience working with people with learning disabilities in hospital.

Steven stayed in the main ward. He would have preferred a single room but there was not one available. He did not like listening to another patient vomiting, and was distracted by other patients moving around when he was trying to sleep. He felt hungry because he could not eat prior to investigation.

Following pre-admission assessment, the community nurse had liaised with hospital staff to discuss Steven’s fear of needles. He had blood samples taken through the sensitive approach of hospital staff, and support of his community nurse. What helped Steven was [20.584–592] ‘I would need the things explained to me, yes, so I don’t get confused, so they can tell me what they were going to do. So they didn’t do it behind my back, so they got me prepared for it’.
Father appreciated support from the community nurse and felt that carers do not get the same response as another professional. [19.544–548] ‘I still say with (community nurse) putting them in the picture it helped. It is better than me talking. Somebody speaking up and telling them before they do anything’.

Meeting Steven positively influenced the attitude of the hospital staff. [18.32–33] ‘Unfortunately people always have a perception about somebody with a learning disability and maybe you think they are going to be very noisy and very destructive. I think that is probably general. He wasn’t like that at all, he was very shy, a very quiet person’.

Steven felt that hospital staff overprotected him. Being on an adult ward could have influenced this, or perhaps it reflects the view that people with a learning disability are ‘perpetual children’ and need to be cared for. His father thought hospital staff were just caring. The community nurse felt that hospital staff [17.93] ‘were very friendly, but they were friendly in a way that they were talking to a child, and at 17 he is a young man’.

The researcher noted a point made by hospital staff about communication. [18.147–155] ‘Well if it’s more of a language barrier we get interpreters. If it’s deaf and dumb there are people we can get to do sign language. We have access to hearing facilities and Braille’. When the researcher mentioned that people with learning disabilities use a communication system called Makaton, hospital staff replied, [18.161] ‘We wouldn’t have a clue what Makaton is’. (See Chapter 3 for information about Makaton.)

The community nurse felt she had a positive opportunity to promote her role. [17.146] ‘I felt valued as a fellow practitioner and I felt valued that the contribution that I had for this young man’s admission and discharge’. Everyone involved saw the admission as successful.

Understanding Learning Disability Case Study 2 – Lucy

Lucy is a 47-year-old woman with a mild to moderate learning disability. She is friendly and talkative, and understands everything said to her if people talk slowly. She is very capable and needs minimal help with personal care. She does not have any behaviour problems. Lucy did not need anyone to stay with her, and had regular visits from people who know her.

Her carer was a social service staff with 8 years’ experience, but was not a regular carer for Lucy. She completed the pre-admission assessment but had no involvement in the admission. The hospital staff involved with the initial admission had 25 years’ nursing experience, and previous experience of working with people with a learning disability in hospital. She had also worked as a cadet nurse at a local learning disability hospital. The named nurse during admission had been qualified for 2 years and had met only a handful of people with a learning disability. Lucy’s community nurse has 24 years’ experience and has known her for 15 years.

Lucy reported that she had [11.18] ‘a nice welcome’ and that [11.28] ‘they were all right with me’. She was pleased that hospital staff showed her around the ward and took time to explain things. She was able to correct the spelling of her surname on her medical records. Hospital staff said, [10.41] ‘She was quite a nice lady’, [12.44] ‘She settled in really well, she was a really nice and friendly person’, and [10.62] ‘I would like to say Lucy was treated the same as other people, just taking a little bit more thought about her special needs’.

Hospital staff knew they needed to present information in a way she could understand. [12.151] ‘We needed to know about the reading and writing, about speaking slowly and
clearly’. They showed good awareness of the potential to over-protect, [12.47] ‘I was trying not to be patronising; I don’t want her to think I am talking down to her’. Lucy wakes early in the morning and enjoys a cup of tea then when at home. Hospital staff were able to continue this during her admission. Her community nurse said, [9.129] ‘Little things, but it means a lot to Lucy and the way she lives’. Hospital staff also liaised well with her carers to ensure support at discharge.

Lucy said, [11.53] ‘The nurses and doctors were very kind to me’, [11.214] ‘Talked to you nicely, they don’t shout they talk, they are not nasty, they tell you in front of your face what’s going on’. She commented that [11.130–132] ‘I couldn’t understand the doctors because they were talking too fast’. Lucy appreciated the support of her community nurse at admission, [11.298–305] ‘She just gave me a little talk, very nice and kind, and she tells you what’s going on and everything. I was all right after that’. Her community nurse felt, [9.114] ‘They were really good with her, fantastic’.

One hospital staff said, [12.112] ‘You think it’s going to be hard work, it’s going to be trouble, but it was completely the opposite’. Another hospital staff felt, [10.193] ‘For the ward I think it is probably a good experience for the ward. Like you say the more you come into contact with people with disabilities then the better it is for you’. One hospital staff thought ‘mentoring’ was a good approach to improve confidence, [15.105] ‘Working with people that are confident so they can see it is not quite as difficult as they imagined’.

Whilst none of the hospital staff involved were aware of Community Learning Disability Services, they were all very positive about the input from Community Learning Disability Nurses. Everyone involved saw the admission as successful.

These two case studies illustrate that the perception of the hospital staff involved was that the admission would be problematic and the person may be difficult to work with, and that this perception was changed in the light of their positive experience. It was clear that the preparation for admission and support provided by carers and the Community Learning Disability Nurse enabled the admission to be successful. (Further information about the pre-admission assessment process is outlined in Chapter 2.)

It is important to highlight the issue of ‘diagnostic overshadowing’. Mencap (2004, p. 13) outlines that ‘Many families of people with a learning disability report that some doctors look at their son or daughter and – consciously or unconsciously – believe their health problem is as a result of the learning disability and that not much can be done about it. This is a dangerous assumption to make: it can lead to undiagnosed or misdiagnosed conditions. It is sometimes called “diagnostic overshadowing” and is described as “dismissing changes in behaviour, personality or ability that would be taken very seriously in a person without a learning disability”’.

The following case study highlights the issue of diagnostic overshadowing and the actual impact on an individual.

Understanding Learning Disability Case Study 3 – Laura’s story

‘Laura was a very active, independent woman when I first knew her. That all changed when she went into hospital last year for an emergency operation. When I went in to visit Laura after her operation, I wasn’t surprised at first that she wasn’t talking at all. She’d been through
a major operation and I thought she must still be in recovery. I expected the old Laura to be back before long. But over the following two days I got more and more worried because she wasn’t improving at all. And she didn’t say a word, no matter how much I chatted to her. On the third day I asked one of the nurses if she knew why Laura wasn’t speaking. She looked surprised and said, “Can she speak?” I told her that Laura could speak as well as anybody else. There was no reason for anybody to assume otherwise.

I went back in to see Laura and I offered her a pen and paper, thinking that she might be able to communicate with me that way. Laura couldn’t even hold the pen. When I saw the pen roll onto the floor, I suddenly thought, oh my God, she’s had a stroke. Two days later, the doctors confirmed that Laura had suffered a stroke during her operation.’

Mencap (2004), Treat Me Right.

Reflective Learning Point:

How would you have noticed this if you had been caring for Laura? What would help you to avoid this happening again?

HEALTH NEEDS OF PEOPLE WITH A LEARNING DISABILITY

The majority of people with a learning disability have always lived in the family home; however, over the past 20–30 years there has been a significant shift in government policy towards reducing the number of people with a learning disability living in long-stay hospitals, the majority of which have now been closed. These institutional forms of care have been replaced by residential and supported housing schemes in the community and many people also live independently in their own homes.

Mencap (2004) reported that:

Thirty years ago 60,000 people with a learning disability lived in long stay hospitals. It was seen as the hospital’s responsibility to meet their health needs. These hospitals were regarded as specialist learning disability services. As a result mainstream health services did not see (and some still do not see) people with a learning disability as being their responsibility.

The health needs of people with a learning disability were previously met within the long-stay hospitals, and people did not often access general health services. Changing care practices and the emergence of community-based care have presented general hospital services with a new challenge.

Mencap (2002) suggest that:

Such a change in policy has been a major factor in bringing greater independence, freedom and choice to the lives of people with a learning disability, enabling them to make active, valued contributions to their communities. For such individuals any understanding of their own ‘quality of life’ is much the same as that of other members of the community: they value the control they have over their lives, and they reflect their own individual characters, dispositions and plans by making independent choices.