
1 Understanding Learning Disability

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.

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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)'.

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,

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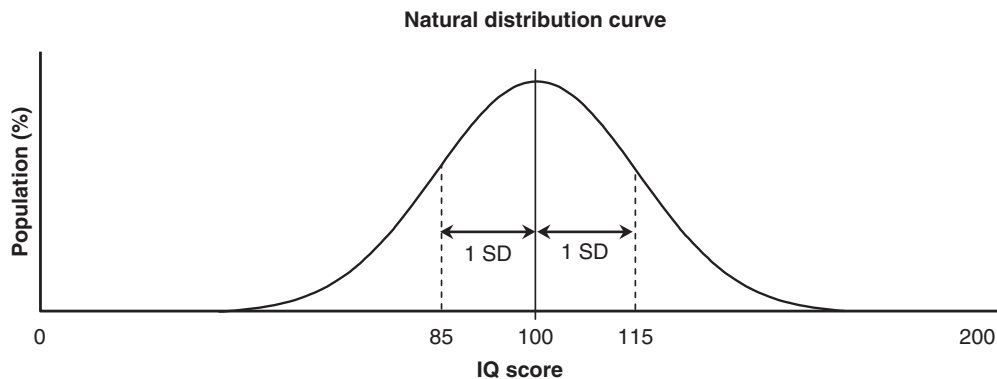


Fig. 1.1 Natural distribution of IQ. Adapted from Grant et al. (2005). Reproduced with the kind permission of Open University Press. All rights reserved.

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

IQ range	55–70 and below	71–85	86–100	101–115	116–130	131–145 and above
Population (%)	2	14	34	34	14	2

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

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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?





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Photo: Mencap (2009).

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

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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.

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They continue to state that:

People with learning disabilities have the same rights as any other individual to inclusion and participation in all the different levels of society. They are entitled to the provision of health care resources and treatment that meet their needs. This is so because people with a learning disability are individuals with *rights* that should enable them to pursue the same set of goals and aspirations as all other members of the community. Their rights and equal value in society should never be undermined by the nature of their disability. (Mencap 2002)

Caring for people with a learning disability in general hospitals can present a challenge even to experienced health care professionals. Learning disability covers a wide and complex range of clinical features and associated conditions, and each person has an entirely individual set of needs. The Royal College of Physicians (1998) described ‘disability’ as ‘a disabled person’s encounter with daily living, the environment and society’. They acknowledge that whilst some people may be independent at home, a hospital environment might prove to be disabling.

Summary of current evidence base

The Department of Health (1999, 2001a) and Mencap (1998, 2004, 2007) have all reported that people with a learning disability have increased health needs than the general population, yet these needs are often poorly met and people experience difficulties in accessing appropriate services. General hospital services show a wide variation in effectiveness of health care provision. There are a number of variables relating to the service user, the general hospital staff, and the organisation, which influence the success of the health care process.

Service user variables relating to people with a learning disability include:

- Difficulty in identifying and meeting their own health needs
- Difficulties in communicating – especially to explain when they do not feel well or to indicate pain
- A lack of awareness of the range of health services available
- A lack of understanding of why they need a particular health intervention – which may lead to a failure to attend appointments
- Difficulties in accessing appropriate services – either physical access or support needed to attend health appointments

In addition, many people with a learning disability are unemployed or living within lower socio-economic groups, and a higher level of ill health is associated with people within these groups.

The current evidence base highlights a number of key variables relating to general hospital staff and the organisation that influence access to general hospital services including:

- Hospital staff not understanding the specific health needs of people with a learning disability
- Problems with communication and behaviour – and a lack of knowledge of how to deal with these
- Under-/overprotectiveness
- Carers having to stay with people to provide basic care
- Negative attitudes and a lack of confidence of hospital staff working with people with a learning disability
- A lack of learning disability-specific training included within pre- and post-registration training for health care professionals

Table 1.2 Strength of evidence

Type	Strength of evidence
1	Strong evidence from at least one systematic review of multiple well-designed randomised, controlled trials
2	Strong evidence from at least one properly designed randomised, controlled trial of appropriate size
3	Evidence from well-designed trials without randomisation, single group pre-post, cohort, time series, or matched case-control studies
4	Evidence from well-designed non-experimental studies from more than one centre or research group
5	Opinions of respected authorities, based on clinical evidence, descriptive studies or reports of expert committees

From Muir-Gray (1997), copyright Elsevier.

Because of this and other compounding factors (such as perceptions and attitudes), there are high levels of health inequalities for this group of people. These factors, and the requirements within the Disability Discrimination Act (2005), dictate that additional measures, known as ‘reasonable adjustments’ must be taken to reduce the inequalities and remove barriers to access.

As the issue of general hospital care for people with a learning disability is a relatively new area of research (less than 20 years old), early studies provide good information to highlight the nature of the problem, but there are deficiencies in knowledge regarding interventions that may be effective in improving the process, and limited information is known about different stakeholder perspectives of the health care process.

Muir-Gray (1997, p. 61) describes five strengths of research evidence, which are illustrated in Table 1.2.

From this table it is apparent that the current evidence base is at Levels 4–5, with new research beginning to move this to Level 3. As this is a relatively new area of research that has only occurred within the past few years, knowledge is still developing, and further research is needed.

Dr. Mary Lindsay (1993) was one of the first professionals to identify access to health services for people with a learning disability as a problem area (Lindsay et al. 1993). In her original research, she found a literature search that revealed not a single article on the topic. She went on to chair the 1998 working party that produced *Signposts for Success* (NHSE 1998).

Signposts for Success explored the evidence base and highlighted:

a lack of good quality information on the effectiveness of many of the interventions used with people with learning disabilities and health related problems. The effectiveness of different models of health service delivery also requires further research. (NHSE 1998, p. 35)

They also state that:

It is unusual for research on general health problems to be specifically carried out on a learning disabled population. There are considerable ethical and methodological problems in carrying out randomised double blind controlled trials and these are a rarity. (NHSE 1998, p. 35)

This report further highlighted the issues and recommended that ‘mainstream National Health Services (NHS) need to become more responsive to the special circumstances and needs of people with learning disabilities’. They also reported that people with learning disabilities

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'have much higher needs than the general population yet visit the doctor less frequently, and use fewer preventative services. Services need to be more sensitive to their needs'.

Carers being required to provide basic care is a common finding in the evidence base along with:

- Illness or disease being missed or undiagnosed
- Poor understanding of specific health needs
- Negative attitudes of health care professionals
- Poor coordination of treatment
- Lack of accessible information
- Inappropriate use of control and restraint
- Inequality in service provision
- Need for training for health care professionals

Figure 1.2 illustrates the core themes relating to access to general hospital care, identified from the experiences of Acute Liaison Nurses (Learning Disability) in two trusts in England.

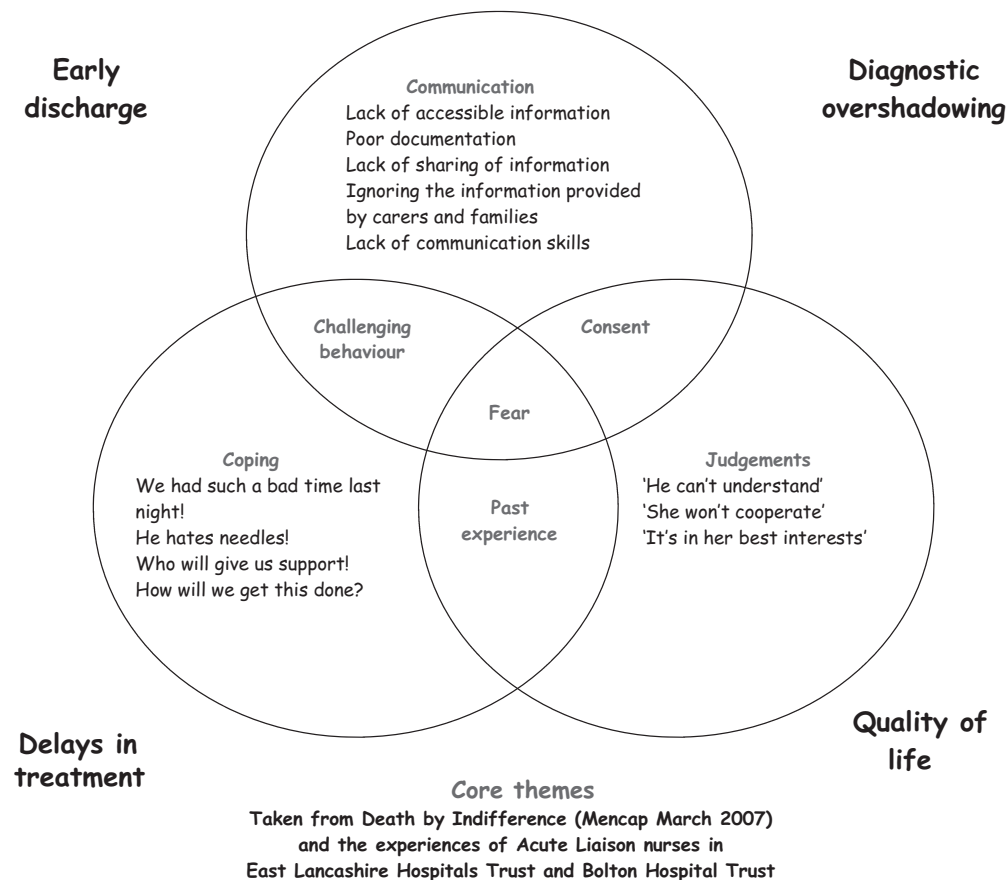


Fig. 1.2 Core themes in access to general hospital care.

Identifying and meeting the health needs of people with a learning disability

Over the past few centuries, much change in approach has occurred in the nature of caring for people with a learning disability. McClimens (cited in Grant et al. 2005, p. 31) reported that ‘the care and treatment of individuals with a disability is traced to prehistoric times’ and that ‘medieval times saw the caring function performed by families, the Church or the local aristocracy’. The Poor Laws of 1601 show the beginnings of social policy seeking to address the needs of vulnerable people in society, leading to centuries of legislation and medical theory developing different models of care. McClimens (cited in Grant et al. 2005, p. 33) describes this as ‘first a moral, then a legal and now a medical problem’.

The Human Rights Act (Department of Health 1998) highlighted that ‘everyone has a right to expect and receive appropriate healthcare’. The UK Government clearly recognised an emerging area of need and commissioned a number of studies over the past few years relating to identifying and meeting the health needs of people with a learning disability. Mencap (2004) outlined the following key reasons why people with a learning disability have poorer health than the rest of the population:

1. *An increased risk of early death.* People with a learning disability are much more likely to die before the age of 50, and life expectancy is shortest for people who have the most support needs. The leading causes of death differ from those of the rest of the population. People with a learning disability:
 - Are three times more likely to die from respiratory disease
 - Have a higher risk of coronary heart disease (the second most common cause of death)
 - Have higher rates of gastrointestinal cancer and stomach disorders
2. *A higher prevalence of certain medical conditions.* It is known that people with a learning disability experience a greater variety, complexity and range of health problems than the rest of the population. This leads to a greater risk of poorer health and includes:
 - *Epilepsy:* 22% compared to 1% of the general population.
 - *Dementia:* 21.6% compared to 5.7% of the general population. People with Down’s syndrome are also at a high risk of developing it younger.
 - *Schizophrenia:* 3% compared to 1% of the general population.
 - *Thyroid problems:* people with a learning disability, particularly those with Down’s syndrome, have a greater risk of having thyroid problems.
 - *Osteoporosis:* tend to have osteoporosis younger than the general population and have more fractures.
 - *Sight problems:* more likely than the general population.
 - *Hearing problems:* 40% of people with a learning disability have hearing problems.
 - *Poor dental hygiene and dental care:* 36.5% of adults and 80% of adults with Down’s syndrome have unhealthy teeth and gums.
 - *Underweight or overweight:* more likely to be under- or overweight than the general population.
 - *Mental health problems:* one in three people with a learning disability has problems with their mental health.
3. *Being part of a disadvantaged group in society.* People from disadvantaged groups have more illnesses and shorter lives than those who are well off. People with a learning disability are generally living on a low income. People with a learning disability from an ethnic minority are at an even greater disadvantage.

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4. *Having unhealthy lifestyles.* People with a learning disability are often dependent on others to enable them to lead active lives. They are also dependent on others for what they eat. Less than 10% of adults with a learning disability eat a balanced diet, while 80% do less physical activity than is recommended.

The Royal College of Nursing (RCN) (2006) reported that ‘the health of people with learning disabilities has steadily improved over the past 30 years; however, they still have higher levels of health needs than their non-learning disabled peers’. The RCN outline the following list of specific health needs of people with a learning disability, with further detail included in the publication of the rationale behind each of these needs:

- *Cancer:* different distribution from general population
- *Coronary heart disease:* the second highest cause of death
- *Dental issues/oral hygiene*
- *Diabetes:* higher than in the general population and may be attributed to increased levels of obesity, poor diet and inactive lifestyles
- *Epilepsy:* more prevalent and often more severe and complex than in the general population
- *Gastrointestinal problems:* including *Helicobacter pylori*, gastro-oesophageal reflux disease, constipation and coeliac disease
- *Mental health problems:* anxiety disorders, depression, schizophrenia
- *Obesity:* including links to some genetic conditions such as Prader–Willi syndrome
- *Respiratory disease:* the main cause of death in people with learning disabilities
- *Sensory impairments:* sight and hearing problems
- *Swallowing/feeding problems:* caused by neurological problems, structural abnormalities of the mouth, also rumination, regurgitation or self-induced vomiting
- *Thyroid disease/hypothyroidism:* annual blood tests for people with Down’s syndrome are recommended

They also note that:

Although people with learning disabilities now live longer than they did decades ago they still have higher mortality rates than people without learning disabilities. People with more severe learning disabilities and people with Down’s Syndrome have the shortest life expectancy. The highest causes of death for people with learning disabilities are respiratory disease followed by cardiovascular disease. The cardiovascular disease tends to be congenital rather than ischaemic. (RCN 2006)

The National Patient Safety Agency (NPSA) (2004) highlighted that their research confirmed that people with learning disabilities are more at risk of being involved in a patient safety incident than the general population. They identified a number of patient safety priorities as follows:

1. *Inappropriate use of physical intervention (control and restraint)* – people with learning disabilities may be receiving injuries and being harmed when physical restraint is used inappropriately. These should only be used when other less intrusive approaches have been tried and found to be ineffective.
2. *Vulnerability of people with a learning disability in hospitals* – more at risk of things going wrong than the general population, leading to varying degrees of harm being caused whilst in hospital.

3. *Swallowing difficulties (dysphagia)* – leading to respiratory tract infections, a leading cause of death for people with learning disabilities.
4. *Lack of accessible information* – people unable to understand information relating to illnesses, treatment or interventions.
5. *Illness or disease being mis- or undiagnosed* – leading to undetected health conditions and avoidable deaths.

Particular attention should be paid to feeding issues, and many people with a learning disability will need help to make their choice of food from menus. It is important to check if the person has any special dietary needs and how they usually take their food; does it need to be chopped up? What type of foods do they prefer and which utensils do they use? There may already be some specific feeding guidelines that their carers can pass on to you. A speech and language therapist should be consulted if there are any feeding or swallowing difficulties (e.g. choking and coughing). When feeding someone, you should attempt to make this a pleasant experience by sitting with the person, taking time with feeding and talking to them. Ensure meal is nicely presented, and they may wish to smell or touch the food, which should also be encouraged. Ensuring a person receives adequate nutrition and fluids is essential to their basic care during their stay in hospital, and a nominated individual should always take responsibility for monitoring this for people with a learning disability.

A person with Prader–Willi syndrome may have a tendency to overeat, and to eat inappropriate matter. You should seek specific advice from the Community Learning Disability Nurse about how to deal with eating/food issues for anyone with this syndrome.

Improved technology means that people with very complex and multiple health needs, who may not have done so previously, now survive and live longer. There are also improved interventions to support people to manage long-term complex health conditions. Both these reasons, in addition to the development of community-based care practices, mean that people with a learning disability and complex health needs are more likely to present in general hospitals than they did previously. Often health care professionals have limited contact with people with a learning disability, and it is an area where limited information is provided within their basic training. They often report a lack of knowledge and uncertainty when they have to care for someone with a learning disability.

Some learning disability conditions have associated specific health problems as a recognised feature of the condition, for example, the increased risk of developing hypothyroidism or Alzheimer’s dementia in people with Down’s syndrome, and regular health screening should be included as a routine process for people with these conditions. Whilst much of this is likely to take place with general practitioners in primary care services, it is also important for health care professionals in hospitals to develop an awareness of these specific health needs.

Learning disability varies a great deal between individuals, and what each individual needs to meet their health needs can also vary a great deal. Some people with a learning disability may find it difficult to adapt to a hospital environment, so the environment has to adapt more to them to accommodate and meet their needs (reasonable adjustments). Identifying how much and what kind of support each person needs is a key aspect of the health care process.

Mencap (1998) consulted widely with people with learning disabilities and their carers about their health care needs. They concluded:

People with learning disabilities who stay in hospital for treatment often have to rely on carers to ensure their needs are met. This is because of a lack of pre-admission planning, lack of knowledge and confidence amongst staff about supporting someone with a learning disability, and inadequate staffing levels. (Mencap 1998)

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Hart (1998) reported similar concern. Mencap (1998) highlighted a need for hospitals to 'have specific policies for people with learning disabilities, to ensure information exchange, and to meet the individual needs of people'. They believed that 'carers should not be expected to cover the care needs of a person with learning disabilities while they are a hospital inpatient'.

A number of strategies designed to increase the quality and effectiveness of general health care services were highlighted by Barr (1997), including pre-admission visits, assessment of needs, recognition of equal rights, coordinated teamwork, improved communication, and challenging stereotypes about people with learning disabilities. Each of these interventions needs further research to measure effectiveness and provide information for future service development.

The Health of the Nation for People with Learning Disabilities (Department of Health 1995a) recommended that 'people with learning disabilities should have access to all general health services ... with appropriate additional support as required to meet individual need'. The Mental Health Foundation (MHF) (1996), NHSE (1998) and Department of Health (1999) – all highlighted problems with access, understanding of health needs and appropriateness of services, with significant variation in practice across the country. Facing the Facts (Department of Health 1999) reported that health professionals were 'not in tune with the way that people with learning disabilities experience health interventions'.

The Department of Health commissioned the British Institute of Learning Disabilities to produce a report on secondary health care for people with learning disabilities. The authors, Cumella and Martin (2000), concluded that 'there is a broad consensus among service users, their families and professional carers, clinicians and managers about the kind of services needed to provide high quality secondary healthcare for people with learning disabilities'. They emphasise the need for a range of measures to improve communication, to support patients with a learning disability in hospital, and to improve the quality of health care.

Problems with access and poor understanding of health need were further highlighted in 'Valuing People' (Department of Health 2001a). The development of a health facilitator role is proposed as an intervention, and Bollard (2001) discusses how this role might be developed. Community Learning Disability Nurses are now recognised as a lead health care professional in acting in this health facilitator role. (*This role is explored further in Chapter 6.*)

Surprisingly, few professionals from hospital or learning disability services are familiar with the publication of the Royal College of Physicians (1998) Charter and Guidelines for Disabled People using Hospitals. The Charter, originally published in 1992, is based on the social model of disability, which identifies attitudes and the environment as being major causes of disability. It suggests that a named manager should be appointed in every hospital to deal with all disablement issues, and highlights a number of actions for hospitals to consider.

The Scottish NHSE (2002) published a national review of the contribution of nurses and midwives to the care and support of people with learning disabilities. They concluded that:

As the largest group of care providers in NHS Scotland, nurses and midwives have a vital role in ensuring people with learning disabilities have their health needs met and gain access to services. All nurses and midwives – not just those who have chosen to specialise in caring for people with learning disabilities – need to work in partnership with people with learning disabilities and their family carers across health, social and education systems, in order to promote health and support inclusion. (Scottish NHSE 2002)

The Royal College of Nursing (2006) suggested some key approaches to meeting the health needs of people with a learning disability during an inpatient admission including:

- Assess needs before admission if possible
- Health care assistants to be aware of needs and to adapt practice as required
- A visit before admission can help, including meeting members of the team
- It is important for staff to 'engage' with the person and actively provide their care – some people may be very dependant on ward staff
- Use communication aids and show staff how to use them
- Use photographs
- Develop a routine/accessible timetable that includes ward round, mealtimes and other activities
- Flexible visiting hours
- Use written strategies for behavioural issues
- Incorporate activities that the person enjoys where possible
- Provide accessible information at discharge

Helping people with a learning disability get the best health treatment possible was the theme of the Mencap (2008) report 'Getting It Right'. The key message from this report is to 'see the person – not the disability', and the following are identified as important factors in meeting health needs:

- ✓ Find time to:
 - Listen to the person
 - Listen to the family
- ✓ Find the best way to communicate:
 - Pay attention to facial expressions
 - Notice gestures and body language
 - Try pointing to pictures
 - Try signing
- ✓ Keep information simple and brief
- ✓ Avoid using jargon

They continue to stress that it is important not to make assumptions about a person's quality of life and that people with a learning disability get ill and feel pain too. They recommend that health care professionals get to know some of the health conditions that are more common for people with a learning disability and that they act quickly ensuring they do not confuse a learning disability with illness.

In considering how the health needs of people with a learning disability can be met, HFT (2009) explain that 'the Government has responded in a number of ways, through legislation such as the Disability Discrimination Act (2005), and an Independent Inquiry into access to healthcare for people with learning disabilities, led by Sir Jonathon Michael'. The resulting report, Healthcare for All, highlighted that:

High levels of health need are not currently being met and there are risks inherent in the care system. People with learning disabilities appear to receive less effective care than they are entitled to receive. There is evidence of a significant level of avoidable suffering and a high likelihood that there are deaths occurring which could be avoided (Michaels 2008, p. 53)

Whilst it was also acknowledged that there are examples of excellent practice in the process of health care, 'people with learning disabilities fare less well than other vulnerable groups in what can seem like a competition for political and local attention'.

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The report made 10 principal recommendations about the ‘reasonable adjustments’ that are needed to make health care services as accessible to people with learning disabilities as they are to other people:

The Department of Health should:

1. Amend Core Standards for Better Health to include the requirement to make ‘reasonable adjustments’ to the provision and delivery of services.
2. Direct Primary Care Trusts to commission enhanced primary care services to include regular health checks for people with a learning disability.
3. Establish a learning disabilities public health observatory.

Trainers should:

4. Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training must ensure that curricula include mandatory training in learning disabilities.

Commissioners should:

5. Identify and assess the needs of people with learning disabilities and their carers, and use the information to inform the development of Local Area Agreements.

Providers should:

6. Ensure they collect data to identify people with a learning disability and track their pathways of care.
7. Trust boards should ensure they have effective systems in place to deliver ‘reasonably adjusted’ health services, including arrangements to provide advocacy for all those who need it.
8. Ensure the views and interests of people with learning disabilities and their carers are included in consultation for planning and development of services.
9. Involve family and carers as a matter of course as partners in the provision of treatment and care.

Inspectors and regulators should:

10. Develop and extend their monitoring of the standard of general health services provided for people with learning disabilities, in both the hospital sector and the community.

These recommendations, if fully implemented, provide a framework for identifying and meeting the health needs of people with a learning disability, with some being specific areas for general hospital services to consider. (*The ethical and political issues are explored further in Chapter 6.*)

Factors and barriers that influence the process of health care

As outlined earlier in this chapter, the current evidence base highlights that people with learning disabilities have increased health needs than the general population, yet their needs are often

poorly understood, and sometimes not met. There is further evidence to suggest that some people experience difficulties in accessing appropriate health services to meet their needs (MHF 1996; NHSE 1998; Mencap 1998, 2004, 2008; Department of Health 1999, 2001a). Some of the key factors and barriers highlighted include:

- Hospital staff not understanding the specific health needs of people with learning disabilities.
- Problems with communication and behaviour.
- Under- or overprotectiveness.
- Carers having to stay with people to provide basic care.
- Negative attitudes and a lack of confidence of hospital staff working with people with learning disabilities.

The Royal College of Nursing (2006, p. 4) highlighted a number of other factors that influence why people with learning disabilities might not access the health services they need including:

- The philosophy of care in learning disability services moving from a medical to a social model.
- Confusion about consent leading to delays in treatment.
- Health screening not offered if people are not considered to be at risk (e.g. cervical screening).
- Barriers to attending such as poor physical access to health services and the expense of travelling to appointments.
- The need for support to access services.
- Signs and symptoms being attributed to the learning disability condition, rather than other causes, including ill health (known as *diagnostic overshadowing*).
- Health problems might be accompanied by unusual signs and symptoms.
- Health promotion materials may not be accessible to people with learning disabilities.
- People might have difficulties communicating and may not be aware of the health services available to them.
- People might be less inclined to take up screening if they do not understand the benefits.
- People may not understand the consequences their decisions can have on their health needs.

A number of other key factors that contribute to discriminatory practice which can influence the process of health care were identified by Mencap (2007) including:

1. People with a learning disability are seen to be a low priority.
2. Many health care professionals do not understand much about learning disability.
3. Many health care professionals do not properly consult and involve the families and carers of people with a learning disability.
4. Many health care professionals do not understand the law around capacity and consent to treatment.
5. Health professionals rely inappropriately on their estimates of a person's quality of life.
6. The complaint system within NHS services is often ineffectual, time-consuming and inaccessible.

Whilst all these factors may present challenges to health care professionals, there is evidence of positive experiences. Mencap (2004) consulted with 1000 people with a learning disability

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and showed high levels of satisfaction with the health services received, but they did also show examples of poor experiences.

Hannon (2003) undertook a research project which included exploring the experiences of people with a learning disability admitted to hospital for treatment. The results from this study show a much more positive experience than expected for people with a learning disability involved in a hospital admission. Whilst this was only a relatively small sample size, a good evaluation of health care was received, with good correlation of feedback across all stakeholder groups. Some of the key factors that influenced the health care process included:

- The nursing process – assess, plan, implement and evaluate – provided the basis for care planning in this project. All admissions were seen as successful in terms of treatment being completed. Everyone welcomed short admissions.
- The levels of support needed for people with a learning disability in hospital vary widely, and need to be assessed for each individual. Some people require little additional support, whilst others may need one-to-one support throughout their stay. Time is important, for physical and emotional support, and time to be with the person. Each individual needs a person-centred care plan that is flexible and responsive to their individual needs.
- Carers provide various levels of support, from occasional visits to 24-hour care. Carers generally felt this was for the service user's benefit. They felt that learning disability nurses are better able to communicate with hospital staff than they are, and also that hospital staff are more likely to listen to another professional.
- Very little environmental change is needed. Most people are able to mix with other patients, and blend into usual ward surroundings and activities. Whilst the choice of a single room is appropriate for some people, there is no need to put people there as a matter of course. This continues to isolate people within secondary health care services, and within the wider community.
- Hospital staff are more confident with more able people, but less so where there are any behaviour or communication problems, or other complex needs. They find it difficult to judge levels of functioning when people present as being more able than they actually are. A difference in approach is evident with hospital staff who had spent time in learning disability services. The experienced hospital staff in this study perhaps contributed to successful admissions.
- Of the key problems highlighted in the evidence base, the lack of knowledge, lack of confidence and negative attitudes did not seem to reflect the personal qualities of the staff, but rather a lack of experience, training and preparation to work with people with a learning disability. All hospital staff in this study showed a caring response and a willingness to learn. They felt they had a lack of information about learning disability, what it is and what it means for the individual, and that this should be included within their basic nurse training.

(See also section on pre-admission in Chapter 2.)

Considering feedback from the key stakeholders within this project, hospital staff valued carers staying with the person but mainly saw this as being of benefit to the service user rather than themselves. Many hospital staff were not aware that the majority of people with a learning disability live at home with their families. Hospital staff gave the highest overall rating scores (evaluating aspects of hospital admission) of all stakeholder groups. Whilst this is based on what they perceived as positive outcomes, this perhaps also reflects a sense of relief that the admission had been better than they expected. They were pleased that no problems were

highlighted, they felt prepared and supported, and all admissions were successful in terms of completing treatment. The fact that hospital staff rated the stay of a person with a learning disability on their ward as 'excellent' also indicates a more positive attitude than was expected, and they may have responded differently before taking part in the study.

Hospital staff had a positive attitude towards learning disability nurses even though knew little about them, and the training they completed. They were complimentary about the input of learning disability nurses, appreciated their support, and thought their intervention was very effective. The interventions from learning disability nurses closely correlated with strategies suggested by Barr (1997), designed to increase the quality and effectiveness of general health care services. They also supported the results reported by Davis and Marsden (2001).

The following are examples of factors that influenced the health care process during a hospital admission – reported from a focus group also undertaken as part of this project:

- The hospital admission was generally a positive experience, better than expected in comparison with evidence base.
- One bad experience involving another patient calling a person with a learning disability names was very distressing for the person involved.
- Service users showed a good understanding of their health needs, reason for admission and treatment received.
- People felt they were treated the same as everyone else, and had a positive attitude towards hospital staff.
- Support for carers is important.
- It is good to be prepared and take things with you that you need.
- Communication can be a problem. Suggested hospital staff use Makaton symbols and pictures. (*See Chapter 3 for information about Makaton.*)
- Things that help include being told what is going to happen, people explaining things, asking people what is wrong with them, and having support for the person.

One of the other key areas for consideration is the issue of patient safety. The National Patient Safety Agency (2004) in its document 'Listening to People with Learning Difficulties and Family Carers Talk About Patient Safety' highlighted a number of issues relating to the safety of people with learning disabilities accessing primary and secondary health care. The 12 most commonly talked about areas of concern for the people consulted were:

1. Lack of contact with primary health care services
2. Prescribing medication
3. The need for information in accessible formats
4. Treating depression
5. Care for people with severe mental health problems
6. Practical support when in hospital
7. Anxiety about being in hospital
8. The effect of long waiting times
9. Communication between health and social care services
10. Services for people with high support needs
11. Health awareness and screening
12. Informing health services when things go wrong

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Whilst a number of these areas are related to primary care services, the majority are also relevant for health care professionals in general hospitals. (*See relevant sections in each chapter for more information regarding these issues.*)

Reflective Learning Point:

What patient safety concerns would you have about a person with a learning disability accessing the area you work in?

Many of the people consulted by NPSA talked about finding being admitted to hospital stressful and frightening. This may lead to people with learning disabilities avoiding having procedures and discharging themselves early. Some people felt lonely being in hospital and wanted more attention from staff. It was noted that those people who received attention felt it had a positive effect.

For some people the anxiety is related to not being informed about what is happening. It is important to acknowledge that not everyone will understand what it means to have their blood pressure taken or have an x-ray. Being fully informed about treatment is important in preventing undue stress and anxiety. Another important issue to consider is that some people with learning disabilities may have memories of living in long-stay hospitals and the experience of institutional living. This may result in the person feeling fearful of not being discharged home or of experiencing aspects of institutional care that they did not like.

Overcoming barriers to care

People with a learning disability represent a wide and diverse range of conditions and associated health problems, and their actual reason for hospital admission may be completely unrelated to their disability. As explored earlier in this chapter, the perception and attitude of the health care professional can create a barrier before they even meet the person. The following summarises the key difficulties and barriers that influence the health care process:

- Hospital staff not understanding the specific health needs of people with learning disabilities.
- Problems with communication and behaviour.
- Under- or overprotectiveness.
- Carers having to stay with people to provide basic care.
- Negative attitudes and a lack of confidence of hospital staff working with people with learning disabilities.
- Confusion about consent leading to delays in treatment.
- Health screening not offered if people are not considered to be at risk (e.g. cervical screening).
- Barriers to attending such as poor physical access to health services and the expense of travelling to appointments.
- The need for support to access services.
- Signs and symptoms being attributed to the learning disability condition, rather than other causes, including ill health (known as *diagnostic overshadowing*).
- Health problems might be accompanied by unusual signs and symptoms.
- Health promotion materials may not be accessible to people with learning disabilities.

- People might have difficulties communicating and may not be aware of the health services available to them.
- People might be less inclined to take up screening if they do not understand the benefits.
- People may not understand the consequences their decisions can have on their health needs.

Whilst these factors and barriers may present challenges to health care professionals, it can sometimes be just simple adaptations to the usual process of care that can make the experience more comfortable for all concerned. These are suggestions of adaptations that could be helpful:

- Avoid long waiting periods and allow extra time for tasks.
- Having a cubicle that has as little equipment as possible on view.
- Taking a mobile telephone number so that the patient and carer can leave the waiting area until it is time to be seen.
- Being creative in producing health promotion resources.
- Minimising the number of people having to assess and treat the patient.
- Identify tests that can be carried out at the same time (especially if sedation is being used) to minimise distress for the person.
- Speaking to the carer away from the patient (if the patient lacks capacity and it is agreed that it is in the patient's best interest to prevent distress to talk away from the patient).
- Remember to talk to the person, especially to explain what is happening during health interventions, but also just to pass the time of day.
- Utilise the skills of other professionals in the unit. Hospital play coordinators may have some useful distraction activities or equipment that may be appropriate.

It is of no surprise that waiting time is a common concern for people with learning disabilities and their family or carers, especially those with complex needs. The time spent waiting often causes the person to become anxious, and therefore their ability to focus on the consultation and answer questions or be able to tolerate tests or investigations is very much affected. Making the appointment at the start of the list is an obvious solution to ensure that the person is seen as near to the appointment time as possible. It is also important for the health care professional leading the clinic to be aware of any problems occurring in the waiting area and to respond as quickly as possible when the patient needs to be seen as soon as possible, which may require them being seen before another patient. From experience of sitting with an anxious patient, other patients waiting are very supportive and are more concerned for the person's anxiety than missing their turn.

Reflective Learning Point:

Think about a situation where you have had to make 'reasonable adjustments' to overcome a barrier and enable health care to be provided to someone. How did this make you feel?

Hannon (2003) reported feedback from a focus group of people with learning disabilities who had been in hospital who suggested:

Things that help (with health interventions) include; being told what is going to happen, people explaining things, asking the person what is wrong with them, and support for the person. Some people need more help than others, and carers need support to provide shared care.

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One of the significant factors the group identified was time – time for explanation and time to be with the person. This could create resource problems when someone is admitted needing a high level of support. It was useful to do an introductory visit for some people, meet staff and be shown around. This was seen as part of the ‘health facilitator’ role of the Community Learning Disability Nurse (*see further information in Chapter 6*). They also felt it is important to be involved in discharge planning, and thought this did not often happen because of a lack of awareness of their role.

Community Learning Disability Nurses particularly highlighted communication and behaviour needs. They made the point that some people with a learning disability may present as being more capable than they actually are, and hospital staff do not always pick this up. (*See earlier notes on how to establish if your patient has a learning disability.*) Hospital staff need to ‘positively discriminate’ with regards to providing the health care needed to meet the person’s needs.

FAMILY/CARER’S NEEDS

People with complex health conditions now live longer, and the demand for care will continue to grow. Caring for a person with a learning disability can often be considered to be a lifelong role. The Department of Health (2008) strategy gave the following definition of a carer: ‘A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems’.

Reflective Learning Point:

Write a list of what you think would be the main needs of a carer of a person with a learning disability and how these could best be met.

Michael (2008, p. 20) in his report ‘Healthcare for All’ highlighted that:

One in 8 people (around 5.2 million altogether in England and Wales) is a carer. Most carers (58%) are women and some are children. Around 60% of carers look after someone with a disability, 15% care for someone with mental and physical ill health and/or a learning disability, and 7% care for someone with a mental health problem alone.

The inquiry team that produced this report held two consultation meetings with family members and carers of people with a learning disability. The most common concerns highlighted by carers related to the quality of care during a hospital admission for people with learning disabilities. The following key points were highlighted in their feedback (see Annex 5 in report) (cited in Michael 2008):

- Attitudes and values of health care professionals and the effect on health care provided.
- Gaps in communication, and problems with finding a balance between communicating with the person with a learning disability and the carer. Some staff did not communicate with the carer at all.
- The importance of clear accessible information.
- Gaps in partnership working, for example between primary and secondary care.

- Consideration of carers' needs, such as:
 - Taking account of their knowledge of the person with a learning disability.
 - Services working together with carers.
 - Services not being too dependent on carers to provide care, yet should provide carers with support to stay with the person if needed.
 - Carers often also have responsibility for other family members.
 - Carers may have their own unmet physical health care needs.

In the Michael (2008, p. 20) report, one carer (mother) explained:

My daughter needs 24/7 care and when she is in hospital I or another person who knows her well have to stay with her . . . I often have to sleep in her wheelchair, or the seat by her bed, or a mattress on the floor if I am lucky. I am not offered a drink or food, or access to a toilet for myself.

It is important for health care professionals to consider 'Who is the carer?' For people with a learning disability, this could be a family member/relatives, paid or unpaid carers, health or social care professionals – who may be qualified or not. The carer, particularly if a family member, may have many years of experience in caring for the individual. It is important for health care professionals to develop a relationship with the carers at an early stage in the health care process. They have much knowledge to share about the person, and listening to them now will prove to be valuable later.

It is vital to exchange information with the carers as they need to have a full understanding of the reason for admission, and any health interventions or procedures required. All carers will provide a valuable source of information, advice, guidance and support when caring for someone with a learning disability, and the importance of their contribution towards a successful hospital stay cannot be underestimated. Health care professionals must be prepared to listen to the carers and accept their advice about the best way of dealing with the individual they are caring for.

Mencap (1998) consulted with people with learning disabilities and their carers and concluded that people with a learning disability admitted to hospital often rely on the carers to provide basic care for the individual during their hospital stay. Whilst carers are usually happy to offer both their physical and emotional support to the individual, sometimes carers are expected to do too much and provide basic care that should be provided by the hospital team. This is not acceptable practice and health care professionals should not expect carers to undertake caring duties. It is the responsibility of the hospital to provide whatever care the person needs, including making any reasonable adjustments necessary to meet these needs.

Health care professionals need to be aware that the carer also has needs, and it is important to care for the carers and identify and meet their needs too. It should be remembered that the carer may themselves be anxious and emotional about the visit to hospital, and that they may transfer their own anxiety onto the individual, and need reassurance themselves. This may be a combination of anxiety about the health and well-being of the individual, but may also include their own concerns about dealing with health care professionals and feeling confused in the hospital environment. In order for them to offer the best support to the individual and the health care professionals caring for them, it is important they know what the health condition is and that they actually understand themselves what is going on. They may feel a lack of control about what is happening to the person, and it is important they are kept fully informed. Carers are often unsure about how much is expected of them, and they may also have other caring responsibilities that they need to continue. Helping carers to manage their anxiety will help to support the person during their hospital stay and contribute to successful interventions.

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Hannon (2003) reported that carers who stayed with individuals in hospital were happy with the support they received from hospital staff, and were positive about the multidisciplinary teamwork. They felt hospital staff do not always understand people with a learning disability, although this improves as they get to know the person. Carers worried about other patients being disturbed and felt it is acceptable, when appropriate, to put people in single rooms. They felt it is important to have familiar people around, and appreciated support from the learning disability nurse.

The Department of Health (2008) strategy for carers recognises the important role that carers play and acknowledges that carers need more help and support than has been available in the past. In this report carers explained (Department of Health 2008, p. 1, of summary report) that they want 'a system that helps them to manage the twin demands of work and caring responsibilities'. They want 'more personalised support and greater scope to control and customise services, including in healthcare where identifying needs and prompt access to services can be so critical'.

The report summarised (Department of Health 2008, p. 62) the largest categories for comments from 79 carers during the public consultation as follows:

- The importance of listening to carers (58% mentioned this)
- The need for better education and training for staff (55%)
- The problem of communication (52%)
- Better information and signposting (22%)
- The importance of being flexible about appointments and taking sufficient time (32%)
- Shortage of resources (32%)
- The importance of being able to stay close to their relative when in hospital (25%)
- The value of liaison or link workers (31%)

The 10-year strategy outlines a vision to be achieved by 2018 for carers to be respected as 'expert care partners', with access to the services they need to support them in their caring role. Specific mention was made of carers' relationship with the NHS: 'Carers have called for closer working between the NHS, Social Services and themselves'. To encourage this, pilot sites have been established to examine how the NHS can better support carers and this will involve:

- The active involvement of carers in diagnosis, care and discharge planning
- Greater support for carers at GP practices and hospitals
- Closer working with councils and voluntary organisations

They also highlight a need to pay attention to the health and well-being of carers, including introducing pilots of annual health checks for carers, and improving emotional support for carers.

INTRODUCTION TO PERSON-CENTRED APPROACHES

Person-centred approaches are very familiar to anyone working within learning disability practice. O Brian and Lovett (1992) set the agenda for a new model of working with people with learning disabilities. They defined person-centred planning as:

Refers to a family of approaches to organising and guiding community change in alliance with people with disabilities and their families and friends. Person-centred planning approaches include: Individual Service Design, Essential Lifestyle Planning, Personal Futures Planning, MAPS (Making Action Plans) and PATH (Planning Alternative Tomorrows with Hope). (O Brian and Lovett 1992)

Each of these approaches includes a range of techniques designed to enable a person-centred plan to be developed. Any or all of these approaches may be in use with a person with a learning disability, and their family/carer should be asked to explain about the person's plan if there is one in place. Your local Learning Disability Nurses can explain about the conceptual and theoretical framework, and provide examples of what a plan may look like.

The Department of Health (2001b) defines 'person-centred planning' as:

A process for continual listening and learning, focusing on what is important to someone now and in the future, and acting upon this in alliance with their family and friends. This listening is used to understand a person's capacities and choices. Person-centred planning is the basis for problem solving and negotiation to mobilise the necessary resources to pursue a person's aspirations.

This theme is continued in the white paper 'Valuing People' (Department of Health 2001a), with the requirement to develop person-centred individual Health Action Plans for people with a learning disability. Valuing People (Department of Health 2001a) defined the key aspects of person-centred planning as:

- The person being at the centre of the process
- Listening to and learning from what people want from their lives
- Helping people to think about what they want now and in the future
- Family and friends working together with the person to make this happen
- Reflecting the person's capabilities and specifying the level of support required

It is important to note that this approach applies to all areas of the individuals' life and not just to their time spent in hospital. Some people may present with a plan that has been specifically written for their hospital stay, and for others it may be an overall plan for how they access the health care services they need as part of maintaining a healthy lifestyle.

Person-centred approaches are based on the principles of humanistic psychology, and are about enabling the transfer of control and personal empowerment to the client from the person working with them. Carl Rogers is regarded as the founder, in the 1940s, of the person-centred approach. This was originally called 'client-centred therapy' as opposed to 'patient-centred', reflecting Rogers' belief that people, not therapists, know what is best for themselves. Jukes and Aldridge (2006, p. 1) explain that 'the premise is that the person is of centrality in the professional relationship, and that effective person-centred practices are based around skilled interactional and interpersonal processes'. They continue to state (Jukes and Aldridge 2006, p. 10) that, with regard to health care, what patients want is care which:

1. Explores the patient's main reason for the visit, concerns and need for information
2. Seeks an integrated understanding of the patient's world – that is, their whole person, emotional needs and life issues
3. Finds common ground on what the problem is and mutually agrees on management
4. Enhances prevention and health promotion
5. Enhances the continuing relationship between the patient and the health care professional

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Table 1.3 The seven Pendleton 'tasks'

1. Define the reason for the patient's attendance (ideas, concerns and expectations)
 2. Consider other problems (continuing and 'at risk' areas)
 3. Work with the patient to choose an appropriate action for each problem
 4. Achieve a shared understanding of the problem
 5. Involve the patient in the management and encourage the acceptance of responsibility
 6. Use time and resources appropriately
 7. Establish a relationship, which helps to achieve other tasks
-

From Pendleton et al. (1984). By permission of Oxford University Press.

The concept of patient-centred approaches became more visible in the 1980s when Pendleton et al. (1984) (cited in Jukes and Aldridge 2006, p. 9) suggested that good practice should be based on what is known as the Pendleton 'tasks', illustrated in Table 1.3.

These principles form the basis of how health care professionals work with patients, with the emphasis on developing a 'helping relationship'. Jukes and Aldridge (2006, p. 13) continue to explain that:

Person-centredness does offer different definitions and applications within different care arenas. They do, however, have a common thread which represents a cohesive approach. The person/patient is at the heart of practice and communication along with an attitude of value, equality, respect and partnership in care between the professional and patient/client. The ability to listen, engage and form an alliance is its central tenet.

Using person-centred approaches enables the health care professional to see the person with a learning disability as a valued individual with the equal right to receive the health care they need.

Whilst the concept of person-centred approaches may not yet be as familiar in general hospital services, it is beginning to influence clinical practice. Binnie and Titchen (1999) describe a project that successfully transformed a traditional task-based care delivery system within a hospital medical unit into a patient-centred service. They suggest (Binnie & Titchen 1999, p. 234) that 'developing patient centred practice means being prepared to review, and possibly to change, virtually every aspect of ward life'. The importance of the role of the 'leader' in influencing and facilitating this change in practice is demonstrated throughout the book and they explain (Binnie & Titchen 1999, p. 234) that 'experiential learning in a ward is facilitated by the presence of a senior practitioner who can demonstrate the living reality of patient-centred nursing and who can help nurses to learn from what they see, what they do and what they feel in their everyday work'. This closely correlates with the evidence base outlined earlier in this chapter, where it was clear that working with an experienced and confident practitioner when caring for a person with a learning disability really makes a difference.

Person-centred care is about being flexible and responsive to individual needs, and health care professionals who work within this philosophy will develop a more therapeutic relationship with the person and you will approach the way you work with them differently. Binnie and Titchen (1999, p. 171) reported numerous scenarios that were part of their research project and found that 'the nurses ability to "be with" their patients seemed greatly to enhance their ability to work with them'. Campbell (1984) described this as 'being with and not just doing to'. The patient's status changes from passive recipient of health care to that of an active partner engaged in the health care process. There may be significant barriers to overcome in order to practice this when working with people with a learning disability, but the rewards will feel worth it. (*See more on developing relationships in Chapter 3.*)

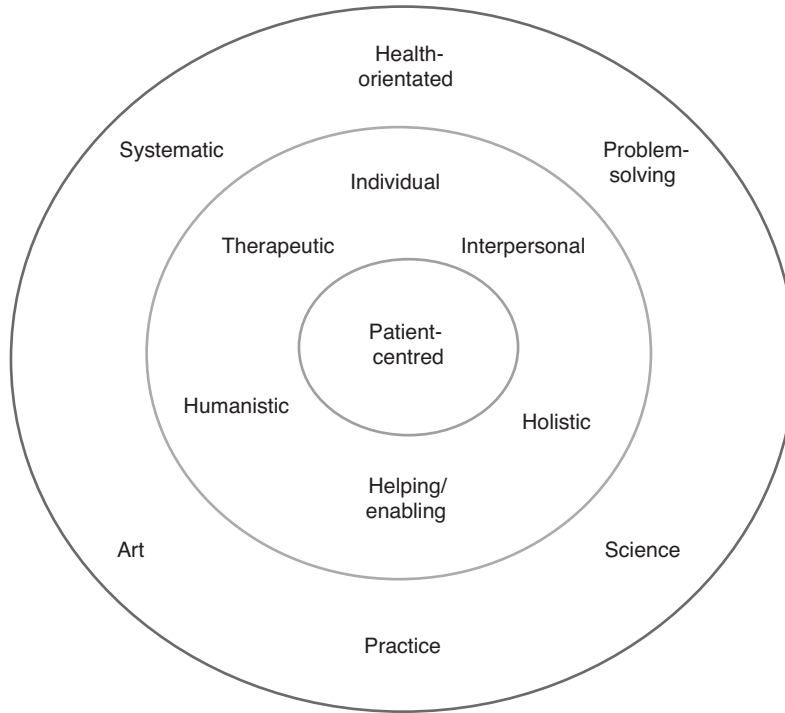


Fig. 1.3 Key attributes of nursing. Savage (2007) cited in RCN (2007). Reproduced with the kind permission of the RCN.

Figure 1.3 illustrates the key attributes of nursing using a person-centred approach – identified by Savage (1998) reported in RCN (2007).

Hannon (2003) found that although person-centred approaches were not familiar to hospital staff in her study, they found they could be effectively developed and implemented in secondary health care services. Hospital staff showed positive regard for service users and spent time helping people to settle. There was evidence of person-centred approaches being used, and services were responsive to individual needs. They were flexible and maintained usual routines for people where possible. One hospital staff felt going into hospital can be ‘scary for a healthy person’, and this could be aggravated by having a learning disability. Hospital staff also made comparisons with other vulnerable groups – elderly, confused, people with physical disabilities, people who could not read or write, or had poor eyesight – and felt that detailed pre-admission planning based on person-centred approaches, as implemented in this study, would be beneficial for the other vulnerable groups too. (*See further information on pre-admission assessment in Chapter 2.*)

CONCLUSION

This chapter sets out to provide an introduction to the nature of learning disability and insight into what this means for the person. A diagnosis of a learning disability has a lifelong impact on the person and their family/carers. Health care professionals need to develop a greater awareness and understanding of how to identify and meet the health needs of people with a learning disability. Working with experienced and confident people can help, and listening

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to and working with families/carers can support health care professionals to provide the best care possible. Person-centred approaches enable individual care plans to be developed that are flexible and responsive to individual needs.

Summary of Key Learning Points

The key learning points are:

- It is important to establish the presence of a learning disability early in the health care process.
- A diagnosis of a learning disability can help you to identify specific health needs that may be associated with this, which are more prevalent in people with a learning disability than in the general population.
- The perception and attitude of health care professionals influence the care you provide to people with a learning disability and can create a barrier to effective health care.
- People with a learning disability have a wide range of complex health needs, with some specific health conditions being more prevalent in this group than in the general population.
- Health services are required to make ‘reasonable adjustments’ to enable people with a learning disability to access the health care they need.
- It is important to work in partnership with carers and also remember to consider their needs.
- Person-centred approaches that are flexible and responsive to individual needs provide a framework for working with people with a learning disability to identify and meet their health needs.

Links to KSF Competencies – Chapter 1

	Level descriptors			
	1	2	3	4
<i>Core dimensions</i>				
1 – Communication	Communicate with a limited range of people on day-to-day matters	Communicate with a range of people on a range of matters	Develop and maintain communication with people about difficult matters and/or in difficult situations	Develop and maintain communication with people on complex matters, issues and ideas and/or in complex situations
2 – Personal and people development	Contribute to own personal development	Develop own skills and knowledge and provide information to others to help their development	Develop oneself and contribute to the development of others	Develop oneself and others in areas of practice
3 – Health safety and security	Assist in maintaining own and others’ health, safety and security	Monitor and maintain health, safety and security of self and others	Promote, monitor and maintain the best practice in health, safety and security	Maintain and develop an environment and culture that improves health, safety and security

4 – Service improvement	Make changes in own practice and offer suggestions for improving services	Contribute to the improvement of services	Appraise, interpret and apply suggestions, recommendations and directives to improve services	Work in partnership with others to develop, take forward and evaluate direction, policies and strategies
5 – Quality	Maintain the quality of own work	Maintain quality in own work and encourage others to do so	Contribute to improving quality	Develop a culture that improves quality
6 – Equality and diversity	Act in ways that support equality and value diversity	Support equality and value diversity	Promote equality and value diversity	Develop a culture that promotes equality and value diversity
<i>Health and well-being</i>				
HWB1 – Promotion of health and well-being and prevention of adverse effects on health and well-being	Contribute to promoting health and well-being and preventing adverse effects on health and well-being	Plan, develop and implement approaches to promote health and well-being and prevent adverse effects on health and well-being	Plan, develop and implement programmes to promote health and well-being and prevent adverse effects on health and well-being	Promote health and well-being and prevent adverse effects on health and well-being through contributing to the development, implementation and evaluation of related policies
HWB2 – Assessment and care planning to meet health and well-being needs	Assist in the assessment of people’s health and well-being needs	Contribute to assessing health and well-being needs and planning how to meet those needs	Assess health and well-being needs and develop, monitor and review care plans to meet specific needs	Assess complex health and well-being needs and develop, monitor and review care plans to meet those needs
HWB3 – Protection of health and well-being	Recognise and report situations where there might be a need for protection	Contribute to protecting people at risk	Implement aspects of a protection plan and review its effectiveness	Develop and lead on the implementation of an overall protection plan
HWB4 – Enablement to address health and well-being needs	Help people meet daily health and well-being needs	Enable people to meet ongoing health and well-being needs	Enable people to address specific needs in relation to health and well-being	Empower people to realise and maintain their potential in relation to health and well-being
HWB5 – Provision of care to meet health and well-being needs	Undertake care activities to meet individuals’ health and well-being needs	Undertake care activities to meet the health and well-being needs of individuals, with a greater degree of dependency	Plan, deliver and evaluate care to meet people’s health and well-being needs	Plan, deliver and evaluate care to address people’s complex health and well-being needs

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HWB6 – Assessment and treatment planning	Undertake tasks related to the assessment of physiological and psychological functioning	Contribute to the assessment of physiological and psychological functioning	Assess physiological and psychological functioning and develop, monitor and review related treatment plans	Assess physiological and psychological functioning when there are complex and/or undifferentiated abnormalities, diseases and disorders and develop, monitor and review related treatment plans
HWB7 – Interventions and treatments	Assist in providing interventions and/or treatments	Contribute to planning, delivering and monitoring interventions and/or treatments	Plan, deliver and evaluate interventions and/or treatments	Plan, deliver and evaluate interventions and/or treatments when there are complex issues and/or serious illness

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