



Royal College
of Nursing

Meeting the health needs of people with learning disabilities

Guidance for nursing staff

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RCN Learning Disability Nursing Forum Advisory Group

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1

Introduction

This guide has been produced to support registered nurses and nursing students in primary and secondary care, who are trained in branches other than learning disabilities, to deliver high quality health care to people with learning disabilities.

It highlights the specific health needs of people with learning disabilities, supports staff to make their services more accessible and includes sources of further information. The guide is aimed at nurses who might work with adults with learning disabilities, but those who work with children may also find it useful.

The guide was developed in response to a resolution passed at RCN Congress 2004 that demanded people with learning disabilities have equal access to health care services. Members of the RCN Learning Disability Nursing Forum requested the development of a guide to support colleagues in other branches of nursing to achieve this.

Many local learning disabilities services across the UK have already developed comprehensive guides and training packages in this area. This guide does not replace these, but has been developed because of the RCN's unique ability to reach the wider nursing workforce.

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Defining learning disabilities

First and foremost, people with learning disabilities are people. They are unique individuals with their own likes and dislikes, history and opinions, and have the same rights as anyone else.

Learning disabilities affect about 1.5 million people in the UK and are common, lifelong conditions which are neither illness nor disease. The term is used in relation to individuals who have the following characteristics:

- ◆ a significant impairment of intelligence
- ◆ a significant impairment of adaptive functioning
- ◆ age of onset before adulthood (i.e. in the developmental period) (BPS, 2000).

Measuring intelligence

Intelligence is formally measured through a cognitive assessment which gives people an IQ (intelligence quotient) score. An IQ test examines an individual's abilities, including comprehension, expression, knowledge, abstract thinking, memory and problem-solving skills.

The test is generally administered by a qualified psychologist, which in health services would usually be a clinical psychologist. IQ is normally distributed in the population, and the average IQ is 100 with a range of 15 points either side. Therefore, anyone with an IQ score between 85 and 115 is said to be of average intelligence.

People with learning disabilities can be said to have either a significant impairment in intellectual functioning (IQ of 55 to 69) or a severe impairment in intellectual functioning (IQ below 55) (BPA, 2000).

Sometimes people are classified as having mild, moderate, severe or profound learning disabilities; moderate, severe and profound learning disabilities all relate to a severe impairment in intellectual functioning.

In the past people with learning disabilities were given 'mental ages'. However, this is now accepted as a degrading term that takes no account of people's life experiences.

Not everybody who has learning disabilities has an IQ test. The test is generally used when it is not clear if the person has learning disabilities, and the information is used to help decide if the person is eligible to use specialist learning disability services.

Social functioning

The term 'social functioning' refers to the skills needed to deal with life and to function independently. It includes cooking, communicating, taking care of personal hygiene, developing social relationships and using community facilities.

Developmental period

Most learning disabilities occur before, during or soon after birth, but become apparent during the developmental period, which is defined as before the age of 18.

Some people experience brain damage in adult life, following an accident or through the effects of disease, which can result in a significant impairment of intelligence and social functioning. However, they are not considered to have learning disabilities since their disabilities were acquired after their brain developed.

Terminology

The term 'learning disabilities' replaced 'mental handicap' in the early 1990s and is used throughout the UK, although other terms, such as 'intellectual disabilities', are increasingly being used.

Some people with learning disabilities prefer to use the term 'learning difficulties', but this can lead to confusion since it is also used in some educational settings to describe specific conditions such as dyslexia.

Living arrangements for people with learning disabilities

Many people with learning disabilities used to live in long-stay hospitals or institutions. These have been closing down over the last few decades and only a few remain. This is in response to government policy that states people with learning disabilities have the right to live in their local communities alongside non-disabled people.

People with learning disabilities live in a wide range of settings, but the majority live in the family home. People with milder learning disabilities might live by themselves or semi-independently with a few hours of support each day. People who need a greater level of support, and do not live in the family home, might live in supported housing which is generally managed by private or voluntary organisations, although some are managed by health and social services.

Some people who present with severely challenging or offending behaviour, and/or have severe and enduring mental health problems as well as learning disabilities, might live in more specialist services, which provide assessment and treatment. People with learning disabilities who have committed offences might be given a custodial sentence and, therefore, live in prison.

Recognising people with learning disabilities

In the context of health care, it is important to be able to recognise if a person has learning disabilities since there are services that may be able to offer extra support, and because nurses need to be able to respond to people at the appropriate level.

Some people have obvious learning disabilities, due perhaps to their increased need for support, but it can be difficult to recognise people with milder learning disabilities.

There are a number of points nurses can consider, although they are not totally indicative of learning disabilities:

- ◆ ask the person if they have learning disabilities
- ◆ does the person have a social worker, care manager or keyworker?
- ◆ did the person go to a special school or attend mainstream school with special support?
- ◆ does the person go to a day centre?
- ◆ has the person ever been seen by learning disability service staff or lived in a learning disability hospital?
- ◆ can the person read or write?
- ◆ can the person tell the time?
- ◆ does the person have difficulty in communicating?
- ◆ can the person remember certain everyday facts about themselves (where they live, their birthday)?

3

Health needs and services

The health of people with learning disabilities has steadily improved over the last 30 years. However, they still have higher levels of health needs than their non-learning disabled peers. When people with learning disabilities access primary and secondary services, staff might experience difficulty in meeting their needs.

Although people with learning disabilities live longer than they did decades ago they still have higher mortality rates than people without learning disabilities. Within the learning disability population, 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. Cardiovascular disease tends to be congenital rather than ischaemic.

People with learning disabilities have the same health needs as everyone else, but their risk of developing certain conditions can differ. For example, people with learning disabilities are less likely to suffer some cancers, including lung cancer, than people without learning disabilities.

There are many reasons why people with learning disabilities experience poorer health and might not access the services they need, and some of these are discussed in this section.

The nature of learning disability services in the UK:

- ◆ the philosophy of learning disability services has moved from a medical model towards a social model of care. Staff roles and training now focus on social inclusion, choice, independence and rights
- ◆ social care services working with people with learning disabilities often have a high turnover of staff, resulting in staff having an incomplete knowledge of the individual.

The nature of health care services in the UK:

- ◆ confusion about the law on consent in treating people with learning disabilities can lead to delays in treatment
- ◆ health screening might not be offered to people who are not considered to be at risk of certain health problems. For example, people with learning disabilities might not be regarded as likely to be sexually active so might not be offered cervical screening
- ◆ there might be barriers to attending health services, such as poor physical access, expense of travelling to appointments, or the need for someone to accompany the person
- ◆ signs and symptoms, such as incontinence, can be attributed to the person's learning disabilities rather than other causes, including ill health. This is called diagnostic overshadowing
- ◆ surgery involving complicated rehabilitation might not be offered if there are concerns the person might not comply with after care
- ◆ health problems might be accompanied by unusual signs and symptoms, for example someone with severe learning disabilities might demonstrate discomfort by self-injuring
- ◆ health promotion materials might not be accessible to people with learning disabilities
- ◆ people with learning disabilities are sometimes at particular risk of certain conditions, for example people with Down's syndrome are at risk of developing Alzheimer's dementia. Health services need to be aware of this to be able to screen for such conditions.

People with learning disabilities:

- ◆ might have difficulties communicating (see Section 7)
- ◆ might not be aware of the health services available to them
- ◆ might be less inclined to take up screening if they do not understand the benefits
- ◆ might not understand the consequences their decisions can have on their health needs
- ◆ poor health is associated with people from lower socio-economic groups and the unemployed, and many people with learning disabilities fall into these categories.

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Specific health needs

Although people with learning disabilities have the same health needs as those without, they do have specific health needs which are listed here alphabetically, not in order of priority.

Cancer

Cancers predominantly found in people with learning disabilities differ from those in people without learning disabilities. People with learning disabilities have higher levels (roughly double) of gastrointestinal cancers, such as oesophageal, stomach and gall-bladder, and lower rates of lung, prostate, breast and cervical cancers. Down's syndrome is a risk factor for lymphoblastic leukaemia.

Coronary heart disease

Coronary heart disease is the second highest cause of death for people with learning disabilities. People with learning disabilities are more likely to develop hypertension and obesity, and lack exercise, all of which are risk factors for ischaemic heart disease. People with Down's syndrome are at higher risk of congenital heart problems.

Dental issues/oral hygiene

People with learning disabilities are more likely to have tooth decay, loose teeth, gum disease, higher levels of untreated disease and a larger number of extractions. This may be explained by a poor diet, poor dental hygiene and because oral health promotion may not be accessible to people with learning disabilities. Despite this they are less likely to visit their dentist. Their dental needs tend to be met through a community dentist and dental work tends to be reactive rather than preventive.

Dental work for people with learning disabilities might be awkward and require a general anaesthetic which can only be carried out in certain settings. This means that dental problems can take longer to treat.

People with Down's syndrome have a high rate of oral complications, including mouth deformities and gum problems.

Diabetes

People with learning disabilities are more prone to developing diabetes than those without learning disabilities. This may be attributed to increased levels of obesity, poor diet and inactive lifestyles.

Epilepsy

Epilepsy affects about one per cent of the population. It is more prevalent in people with learning disabilities where one third of this population have the condition. The prevalence rises with an increase in severity of learning disabilities, with nearly half of people with severe learning disabilities having epilepsy.

People with learning disabilities who have epilepsy often have more than one type of seizure and more complex seizure patterns. They are at risk of further cognitive impairment due to prolonged seizures, secondary injuries that might go unnoticed, hospitalisation, placement breakdown, a more restricted lifestyle and unexpected death.

Where more than one medication is used potential side effects, such as sedation and constipation, need to be considered. Specialist staff training in administration of rectal diazepam or oxygen therapy might also be necessary if this is part of the person's treatment plan.

Gastro-intestinal problems

◆ *Helicobacter pylori*

Many people with learning disabilities have high levels of *helicobacter pylori*, particularly those who have lived in institutions or shared accommodation, or attended day centres with other people with learning disabilities. *Helicobacter pylori* is associated with peptic ulcers, which can perforate if left untreated. Gastric carcinoma is seen in greater levels in people with learning disabilities, and *helicobacter pylori* has been cited as a possible predisposing factor.

People with learning disabilities are prone to re-infection with *helicobacter pylori* and might require testing and treatment throughout their lives.

◆ *Gastro oesophageal reflux disease (GORD)*

GORD can affect as many as half of people with learning disabilities, and has a higher prevalence in those with more severe and profound learning disabilities. It has also been associated with fragile-X syndrome.

GORD is easily treated yet often goes unnoticed, possibly because of communication difficulties and/or the lengthy diagnostic process. GORD might

account for the higher levels of oesophageal cancer seen in people with learning disabilities.

◆ *Constipation*

Constipation is more prevalent in people with learning disabilities than in those without. It is more likely to occur in people with profound learning disabilities, in those who are less mobile, where there is inadequate hydration or limited food choice, and in people on long-term medication with constipation as a side effect. In certain situations or environments, there can be an over reliance on laxatives rather than adequate nutrition and fluids.

◆ *Coeliac disease*

People with Down's syndrome are prone to coeliac disease. People with coeliac disease must have a gluten free diet.

Mental health problems

People with learning disabilities are vulnerable to all mental health problems through a range of biological, psychological and social factors that they are more likely to encounter. Common mental health problems include:

◆ *Anxiety disorders*

These include general anxiety, phobias and panic disorders. The physical signs of anxiety, such as rapid breathing, muscle tension and motor agitation, can be observed in people with learning disabilities, but other psychological symptoms might be harder to detect.

Anxiety is often seen in people with autistic spectrum disorders, especially when their routine and structure is disrupted.

◆ *Depression*

Depression can be diagnosed in people with mild learning disabilities in the same way as people who do not have learning disabilities. But in people with more severe learning disabilities, or with communication difficulties, it might be physical signs such as weight loss, a change in sleep pattern, or social withdrawal that suggest depression. There might also be atypical indicators such as self-injury or aggression, uncharacteristic incontinence or screaming.

◆ *Schizophrenia*

Schizophrenia is three times more prevalent in people with learning disabilities than in those without learning disabilities. People with learning disabilities can experience the full range of psychotic symptoms associated with schizophrenia,

but these tend to be less marked and less complex.

Schizophrenia is very difficult to diagnose in people with severe learning disabilities since the diagnostic criteria rely on the person being able to communicate their internal experiences.

Obesity

Levels of obesity are higher in people with learning disabilities and are more notable in those with milder learning disabilities, especially women. Obesity can have secondary affects on health and increase the likelihood of heart disease, stroke and Type II diabetes. People with learning disabilities are at increased risk of obesity because they:

- ◆ are less likely to have a balanced diet, particularly those living independently who might rely on pre-packaged convenience food
- ◆ are less likely to take physical exercise
- ◆ may have trouble understanding health promotion material that encourages a healthier lifestyle
- ◆ may live in restrictive environments where there are lower rates of activity
- ◆ may be on medication, such as antipsychotic or anticonvulsive drugs, that has weight-gain side effects.

Some genetic conditions are associated with obesity, including Down's syndrome and Prader-Willi Syndrome.

Some people with learning disabilities are at risk of being underweight. This is seen more in people with profound learning disabilities or in those with metabolic disorders such as phenylketonuria.

Respiratory disease

Respiratory disease is the main cause of death in people with learning disabilities. They are at risk of respiratory tract infections caused by aspiration or reflux if they have swallowing difficulties, and they are less likely to be immunised against infections.

People with Down's syndrome are particularly at risk because they have a predisposition to lung abnormalities, a poor immune system and a tendency to breathe through their mouth. Pulmonary complications are also seen in people with tuberous sclerosis.

Sensory impairments

Sight and hearing problems are common in people with learning disabilities; it is estimated that up to 40 per cent of people with learning disabilities have sight

problems and a similar number of people with severe learning disabilities have hearing problems. Additionally, people with learning disabilities are prone to ear and eye infections.

◆ *Sight problems*

Although people with learning disabilities have a higher prevalence of sight problems, they are less likely to visit opticians and might be disadvantaged by high street assessments which use the alphabet in eye tests.

Sight problems may be acquired as people get older, or as a result of brain damage or cerebral visual impairment. Some causes of learning disabilities, such as Down's syndrome, cerebral palsy, fragile-X syndrome and foetal rubella syndrome, are associated with vision problems.

◆ *Hearing problems*

People with learning disabilities are more likely to need a hearing aid, but many have never had a hearing test. Hearing problems might further compound already poor communication skills.

Although some hearing problems are caused by structural abnormalities such as abnormal shaped ear canals or by neural damage, other reasons, like impacted earwax which has a higher prevalence in people with learning disabilities, should not be overlooked.

Some diagnoses, including Down's syndrome, foetal rubella syndrome, cerebral palsy and fragile-X syndrome, are particularly associated with hearing loss.

Swallowing/feeding problems

Problems with swallowing are more prevalent in people with learning disabilities than in those without, with the highest prevalence in those with profound disabilities. These can be caused by neurological problems or structural abnormalities of the mouth and throat. Problems can also arise from rumination, regurgitation or self-induced vomiting.

Swallowing problems can lead to choking, secondary infections and weight loss. Some people with severe problems may need a percutaneous endoscopic gastrostomy (PEG) to ensure they receive adequate nutrition. This can be used in conjunction with oral feeding so that they can develop appropriate swallowing and eventually have the PEG withdrawn.

Speech and language therapists can carry out assessments where there are concerns about swallowing and, along with occupational therapists, might be able to provide advice and adaptations.

Thyroid disease – hypothyroidism

Common symptoms of hypothyroidism include weight gain, constipation, aches, feeling cold, fluid retention, tiredness, lethargy, mental slowing and depression. If hypothyroidism is not treated it can lead to further problems, including heart disease, pregnancy complications and, rarely, coma.

Hypothyroidism affects 1 in 50 women and 1 in 1,000 men and becomes more prevalent with age. It is more common in people with learning disabilities and is associated with Turner's syndrome and Down's syndrome. Annual blood tests for people with Down's syndrome are recommended.

Hypothyroidism might also occur as a side-effect of medications such as lithium and amiodarone.

Older people

People with learning disabilities, like everyone else, have health care needs associated with ageing, but they also have more specific needs. Older people with learning disabilities have higher rates of respiratory disorders, arthritis, hypertension, urinary incontinence, immobility, hearing impairment and cerebrovascular disease.

They are also more vulnerable to mental health problems, such as anxiety and depression, and have an increased risk of dementia. People with Down's syndrome are at particular risk of developing Alzheimer's dementia with an earlier onset.

All people with Down's syndrome show changes in brain anatomy associated with Alzheimer's in middle age, although not all will go on to develop the disease. Down's syndrome is also associated with premature ageing and there are additional health needs that accompany this.

The signs and symptoms of dementia in people with learning disabilities are similar to those in people without learning disabilities, but the disease is often recognised later. This may be because problems around orientation, memory or loss of skills may go unnoticed in environments where routine and structure are provided by carers or staff.

5

Policy and law

UK policies

Each of the four UK countries has its own policies (see below) on how the needs of people with learning disabilities should be met. The policies describe a holistic approach for supporting people with learning disabilities to reach their potential and take their place in the community.

The policies aim to improve quality of life and are based on broad themes:

- ◆ citizenship
- ◆ empowerment
- ◆ having choices and making decisions
- ◆ having the same opportunities as other people
- ◆ having the same rights as other people
- ◆ social inclusion.

The UK policies on people with learning disabilities are:

England:

Department of Health (2001) *Valuing people: a new strategy for learning disability for the 21st century*, London: HMSO.

Northern Ireland:

Department of Health and Social Security (2005) *Equal Lives: Review of policy and services for people with a learning disability in Northern Ireland*, Belfast: DHSSPS.

Scotland:

Scottish Executive (2000) *The Same As You: A review of services for people with learning disability*, Edinburgh: Scottish Executive.

Wales:

Learning Disability Advisory Group (2001) *Fulfilling the Promises: Report of the Learning Disability Advisory Group*, Cardiff: National Assembly for Wales.

Each policy addresses health needs in various ways, but focuses on similar issues, including:

- ◆ people with learning disabilities to access mainstream health services with support from specialist services when needed
- ◆ mainstream health care staff to receive adequate training on the needs of people with learning disabilities
- ◆ people with learning disabilities are registered with a GP
- ◆ offering people with learning disabilities an individualised health care plan
- ◆ in England and Northern Ireland, people with learning disabilities should be offered a 'Health Action Plan' and have a nominated 'Health Facilitator' to help develop the plan and ensure it is implemented
- ◆ ensuring that people with learning disabilities are offered regular health checks and are included in health screening programmes
- ◆ health promotion materials are made accessible to people with learning disabilities.

These policies have been specifically developed for people with learning disabilities, but it is vital to remember that all policies and laws are relevant to people with learning disabilities, including *all* of the National Service Frameworks.

Consent

In the past it was assumed that having learning disabilities meant people lacked the capacity to make decisions. However, it is now recognised that people with learning disabilities have as much right to make decisions for themselves as anyone else.

UK laws on consent to examination and treatment serve the population as a whole, which includes people with learning disabilities.

The UK has two separate laws on capacity to consent, the *Mental Capacity Act* (DH, 2005) England and Wales, and the *Adults with Incapacity Act* (Scottish Executive, 2000) in Scotland.

Northern Ireland has no statute on consent, but legislation is being developed as part of the overall Review of Mental Health and Learning Disabilities in Northern Ireland, see www.rmhdni.gov.uk. Until this time there is case law, which is based on precedents set from previous court cases, also known as common law.

In Northern Ireland practice should be based on the current guidance: *Reference Guide to Consent to Examination, Treatment and Care* (DHSSPS, 2003) which is based on case law.

Although the Acts and case law differ in terminology and procedures they are based on similar principles and, with regard to consent to examination or treatment, have similar expectations of health care staff.

The underlying principles in both Acts and the Northern Ireland *Guide to Consent* are that no adult can make a decision on behalf of another adult, and that it must be assumed that a person has the capacity to make a decision unless proved otherwise. Adults with or without learning disabilities can refuse examination or treatment, even if it is detrimental to their health, as long as they have the capacity to do so.

It is the lead health professional (i.e. the person who is likely to undertake the examination or instigate the treatment) who is responsible for assessing whether a person has the capacity to make a decision about examination or treatment.

The assessment determines whether the person understands and retains the information about the decision; that they are able to weigh and balance the information to make a choice; and they are able to communicate that choice through whatever means of communication the person uses (verbal, sign language, written).

People with learning disabilities might have difficulty understanding information, and health care professionals should take all the necessary steps needed to support them to make decisions. This involves providing people with all the relevant information in a format they will understand.

Information about the following should be given:

- ◆ the proposed investigation, procedure or treatment
- ◆ where and when it is proposed to take place
- ◆ duration of the procedure and if it will require admission
- ◆ what the procedure will involve and any aftercare
- ◆ benefits and risks of the procedure
- ◆ risks of not having the procedure
- ◆ any alternatives
- ◆ how day-to-day life after the procedure might be affected
- ◆ if the procedure will improve the person's quality of life.

Although people's capacity to make a decision is assessed by the lead health professional it might be appropriate to involve specialists from the learning disability services, such as community learning disability nurses.

Speech and language therapists can advise on how to give the information to patients, and clinical psychologists can

assess cognitive functioning (although this is not indicative of a person's capacity), test for suggestibility and assess the person's knowledge about the decision to be made.

Capacity can change over time. If a person was previously unable to make a decision it should not be assumed that they still cannot. Some people may be able to make some decisions, but have difficulty with others, so it is important that each decision is treated independently.

If a person is assessed as lacking capacity, health care professionals can treat them as long as it is in the person's best interests. Health professionals should consider the person's past wishes and opinions, and consult with carers/relatives.

Current medical evidence and opinion should support the chosen treatment and it should be the least restrictive option (that is, it should consider the effect on the person's quality of life). It is common practice, in services for people with learning disabilities, for 'best interest' meetings to be held in these circumstances where carers, professionals and relevant others, such as advocates, meet to discuss the situation and support health care professionals to reach a decision.

The Department of Health (England) and Department of Health, Social Services and Public Safety (Northern Ireland) have both produced leaflets on consent to treatment for people with learning disabilities, which are available at www.dh.gov.uk and www.dhsspsni.gov.uk (DH, 2001b; DHSSPS, 2003b).

Other relevant policies

All policies and laws that apply to the general population apply to people with learning disabilities. Policies that might be particularly relevant to people with learning disabilities include:

- ◆ Carers and Disabled Children's Act (2000)
- ◆ Disability Discrimination Act (1995)
- ◆ Human Rights Act (1998)
- ◆ Mental Health Act (1983)
- ◆ Mental Health (Care and Treatment) (Scotland) Act 2003
- ◆ NHS and Community Care Act (1990)

It is important to note that legislation might differ across the different UK countries. Websites with further information can be found in Section 8.

6

Specialist services

The vast majority of people with learning disabilities live in the community and have the right to equal access to mainstream health services. However, specialist services are sometimes needed to provide additional support.

Community teams

Most health districts across the UK have a team providing specialist health and social care to people with learning disabilities living in the community. These are commonly called Community Teams for Adults with Learning Disabilities (CLDT), but names differ in some areas.

The teams are generally made up of staff from a mixture of organisations, including social services, primary care trusts and, sometimes, mental health trusts.

National policies advocate that people with learning disabilities should be able to access mainstream health services, and CLDTs promote this by providing specialist advice and support to their mainstream colleagues. Some CLDTs operate a life-span approach, but the majority work with people from adulthood onwards.

Most services operate an open referral system, accepting referrals from the person themselves, relatives or carers, or health and social care professionals. People with moderate to profound learning disabilities, and those with mild learning disabilities who have complex needs, will most probably already be known to the CLDT.

CLDTs employ a wide range of specialists, including:

- ◆ community learning disability nurses
- ◆ occupational therapists
- ◆ physiotherapists
- ◆ psychiatrists
- ◆ psychologists
- ◆ social workers/care managers
- ◆ speech and language therapists.

Some teams also include hearing and visual therapists, challenging behaviour workers, and community psychiatric nurses.

Specialist in-patient services

Some health districts in the UK provide specialist in-patient beds for people with learning disabilities with additional needs, such as mental health problems, severe challenging behaviour and, occasionally, for the acute management of epilepsy.

These services are for people who are unable to use mainstream services due to vulnerability or the complexity of their needs, and who require specialist assessment and treatment.

7

Supporting access to services

Accessible information and good communication skills are crucial if people with learning disabilities are to have equal access to primary and secondary health care. People need to be able to access information they can understand and with which they can make decisions about their health. People with learning disabilities also need information on how to stay well.

All health care settings, primary and secondary, should have a summary of key points on:

- ◆ how to communicate with people with learning disabilities
- ◆ how to write accessible information
- ◆ duties under the Disability Discrimination Act (1995) to treat all patients equally, whenever reasonably possible, irrespective of their disability.

This section explains some of the difficulties faced by people with learning disabilities in accessing mainstream services, and offers practical ideas on how they can be overcome. The following advice can be applied to all health care settings, but includes specific advice for nurses caring for people with learning disabilities in hospital.

Preparation

- ◆ If possible, find out about the person's communication abilities before you meet with them and talk to the people that support the person. Check the person's file or contact their GP for a speech and language therapy report which often contains communication enhancing strategies.
- ◆ Check if the person uses sign languages, such as BSL or Makaton, or communication aids.
- ◆ If the person needs communication aids prepare them beforehand. (Section 8 gives details of websites that offer advice on using communication aids).
- ◆ Some people with learning disabilities become anxious waiting in the surgery or clinic, so try to offer the first appointment.
- ◆ Talk to the person or their carer to find out what time of day would be best for them.

- ◆ People with learning disabilities may have difficulty with medical or technical jargon, so think about alternative words before you see the person.
- ◆ People with learning disabilities might need more time to explain themselves and you might also be talking to their carer, so you may want to book a longer appointment.
- ◆ Some people with learning disabilities might prefer a home visit rather than going to a surgery or clinic.
- ◆ People with learning disabilities can get anxious when they do not know what is happening to them or around them, so make the appointment as predictable as possible. For example, giving the person some information to look at before you see them, or organising a visit beforehand so they can orientate themselves and meet the other health care staff.

Environment

- ◆ Make sure that lighting is not too bright or intrusive, especially when working with people with autism and those with hearing impairments.
- ◆ Noise can be very distracting, especially for people with autism, and sudden noise can be very stressful for people with cerebral palsy and can cause reflex actions. People with learning disabilities might be distracted by background noises like a tannoy, television or radio.
- ◆ Too much clutter can distract people and make it difficult for them to visually focus on you.
- ◆ Some surgeries and clinics use electronic signs to tell patients when they can go in for their appointment, which might be a problem for some people with learning disabilities. This should be recorded on their file and steps taken to support them.
- ◆ Make sure the environment is physically accessible for the person.

Verbal communication

- ◆ Always speak to people with learning disabilities first, not the person supporting them. If they have difficulty answering questions then ask their carer, but remember they may have different views from each other.
- ◆ Speak clearly and not too fast.
- ◆ To reduce anxiety and build confidence start by asking the person some questions you know they can answer.

- ◆ The average gap between a person listening and then responding during a conversation is three seconds. People with learning disabilities may need longer to think about what has been said and formulate a response.
- ◆ Avoid medical or technical jargon. Use straightforward language and short, plain sentences.
- ◆ If you are giving the person new information only use one 'information-giving' word or phrase (for example, 'blood test') per sentence.
- ◆ If you are talking about existing information you can use up to four information-carrying words or phrases per sentence (for example, blood test, clinic, 9am, Monday). For people with more severe learning disabilities, only use two information-carrying words per sentence.
- ◆ It may be helpful (or essential for people with severe learning disabilities) to have photographs or objects to accompany each information-carrying word. Some people might use symbols. Talk to the person who supports them, or contact their speech and language therapist, so you are prepared.
- ◆ Try to avoid abstract concepts. Use concrete terms wherever possible, especially for people with autism.
- ◆ Try to avoid using negative words such as don't, can't, no and won't. People with learning disabilities, and especially those with autism, can find them confusing and harder to understand.
- ◆ Avoid abbreviations.
- ◆ People with learning disabilities find nouns easier to understand in conversation. Do not use pronouns to indicate something you have already mentioned. For example, say: "The blood test is on Monday" rather than "It will happen on Monday".
- ◆ People with learning disabilities may have difficulty recalling when things happened, so you could use anchor events in the person's life, like Christmas, birthdays or holidays, to help them remember.
- ◆ When talking about future events, introduce them in the sequence they will happen.
- ◆ To avoid suggestibility use open-ended questions. You can use closed questions later in the conversation to clarify understanding.
- ◆ If you think the person is acquiescing, ask the same question later but in a different way.
- ◆ If you ask a question that offers a choice of answers, be aware that the person might choose the last one. You can check this by asking the question again later in a different way.
- ◆ Use active language and avoid passive language. For example: "Joan will give you a blood test" (active). "Your blood will be taken by Joan" (passive).
- ◆ Check the person understands what you have said and ask them to tell you what they have understood.
- ◆ Make sure that the conversation has a clear beginning, middle and end.

Written communication

Much of the guidance for written information is the same as for verbal communication. Comprehensive guidance can be found in the Easy Info and Mencap Accessible Information websites (see Section 8). The following is some basic additional guidance:

- ◆ Write as you would speak.
- ◆ Use consistent words and phrases throughout the information.
- ◆ Use symbols for numbers (9) not words (nine).
- ◆ Use one photograph to support each idea that is expressed.
- ◆ Use matt paper rather than glossy.
- ◆ Start and finish sentences on the same page.
- ◆ Make sure that related information is in the same section.
- ◆ Refer to the person as 'you' and the service as 'we'.
- ◆ Use a minimum font of 14.
- ◆ You could check what you have written with people with learning disabilities who are part of service-user or self-advocacy groups. Local CLDTs and social services will have contact details.

In-patient care

- ◆ Nurses should assess the needs of people with learning disabilities before they are admitted to hospital if possible (in emergency situations this might not be possible).
- ◆ Health care assistants should be made fully aware of people's individual needs and how to adapt their practice as required.
- ◆ A visit to the ward before admission can help people orientate to the environment and reduce their anxiety. Meeting members of the team, including their doctor, would also be helpful.

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Resources

- ◆ Make sure the person and/or their carers bring any communication aids in with them and show the staff how to use them. Ask patients to bring their handheld health record or pre-prepared hospital book in if they have one.
- ◆ Use photographs of key areas and people on the ward and around the hospital to support communication.
- ◆ Nurses need to work in partnership with people with learning disabilities and their carers. Families and carers will provide as much support as they can, however, this should not be relied upon. Health services should provide extra staff if required.
- ◆ People with severe learning disabilities may be very dependent on ward staff. They might have difficulty expressing their needs, such as hunger, thirst and the need to use the toilet, so staff should anticipate these.
- ◆ Predictability is often important to people with learning disabilities, so developing a routine as soon as possible can reduce anxiety. Ask the person's carer to help write an accessible timetable that includes meal times, ward rounds and other activities.
- ◆ Visiting hours should be flexible to enable people's carers to spend more time with them to help them feel as secure as possible.
- ◆ Some people with learning disabilities may act out behaviour that others consider challenging. This often occurs in response to communication issues, boredom or environmental factors such as noise. The person's carers will probably know what prompts any challenging behaviours, so you could try to minimise potential triggers. Some people might have written strategies for coping with challenging behaviour, so you could ask for copies and talk to the person's carers about how to implement them.
- ◆ Being in hospital can be very boring, so find out if there are any activities the person particularly enjoys and try to incorporate these into the daily ward routine.
- ◆ When people with learning disabilities leave hospital they should be given a discharge sheet with accessible information covering diagnosis, treatment, when to return for follow up, any possible side effects from medication, and details of someone on the ward to contact if necessary.

Policy websites

National policies on learning disabilities

Equal Lives (Northern Ireland)

www.rmhdni.gov.uk

Fulfilling the Promises (Wales)

www.wales.gov.uk

Same As You (Scotland)

www.scotland.gov.uk

Valuing People (England)

www.valuingpeople.gov.uk

Law on consent to treatment

Department of Constitutional Affairs:

Mental Capacity Act (2005)

www.dca.gov.uk

Northern Ireland:

Guidance on Consent to Treatment(2003)

www.dhsspsni.gov.uk

Scottish Executive: Adults with Incapacity Act (2000)

www.scotland.gov.uk

Other laws and policies

Carers and Disabled Children's Act (2000)

www.opsi.gov.uk

Disability Discrimination Act (1995)

www.opsi.gov.uk

Human Rights Act (1998)

www.opsi.gov.uk

Mental Health Act (1983)

www.dh.gov.uk

Mental Health (Care and Treatment) (Scotland) Act 2003

www.opsi.gov.uk

NHS and Community Care Act (1990)

www.opsi.gov.uk

References and further reading

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- Prasher VP and Janicki M (2002) *Physical health of adults with intellectual disability*, Oxford: Blackwell Publishing.
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Networks

Mental Health in Learning Disabilities Network

A free to join email network for anyone interested in the mental health needs of people with learning disabilities.

www.estiacentre.org

National Network for Learning Disability Nurses (NNLDN) and the Access to Acute Network

The NNLDN is a 'network of networks' which aims to support networks and nurses in the field of learning disabilities. The website contains lots of information on access to acute services.

www.nnldn.org.uk

UK Health and Learning Disabilities Network

A free to join email network for anyone with an interest in the health needs of people with learning disabilities.

www.ldhealthnetwork.org.uk

Useful organisations

British Institute of Learning Disabilities (BILD)

BILD provides research and training on a wide range of issues affecting people with learning disabilities and has a range of free leaflets to download and publications/training materials to purchase.

Campion House
Green Street
Kidderminster
Worcestershire
DY10 1JL

Tel: 01562 723010

Fax: 01562 723029

www.bild.org.uk

Disability Rights Commission

National organisation that fights for a society where all disabled people can participate fully as equal citizens.

DRC
FREEPOST MID02164
Stratford upon Avon
CV37 9BR

Tel: 08457 622 633

Fax: 08457 778 878

www.drc.org.uk

Down's Syndrome Association

This organisation helps people with Down's syndrome to live full and rewarding lives. It provides a range of downloadable information.

Langdon Down Centre
2a Langdon Park
Teddington
TW11 9PS

Tel: 0845 230 0372

Fax: 0845 230 0373

Email: info@downs-syndrome.org.uk

www.dsa-uk.com

Elfrida Society

The Elfrida Society researches better ways of supporting people with learning disabilities and provides a wide range of accessible information on health issues.

34 Islington Park Street
London
N1 1PX

Tel: 020 7359 7443
Email: elfrida@elfrida.com
www.elfrida.com

Epilepsy Action

National organisation that aims to improve the quality of life and promote the interests of people living with epilepsy. It provides free information and materials to purchase.

New Anstey House
Gate Way Drive
Yeadon
Leeds
LS19 7XY

Tel: 0113 210 8800
Fax: 0113 391 0300
Email: epilepsy@epilepsy.org.uk
www.epilepsy.org.uk

Estia Centre

Specialises in the mental health needs of people with learning disabilities, and provides training, research and development. Has a number of resources to download.

66 Snowfields
London
SE1 3SS

Tel: 020 7378 3217/8
Fax: 020 7378 3223
Email: estia@kcl.ac.uk
www.estiacentre.org

Foundation for People with Learning Disabilities

National organisation that promotes the rights, quality of life and opportunities for people with learning disabilities through research, development and influencing policy. Free resources to download and purchase.

9th Floor
Sea Containers House
20 Upper Ground
London SE1 9QB

Tel: 020 7803 1100
Fax: 020 7803 1111
Email: fpd@fpd.org.uk
www.learningdisabilities.org.uk

Mencap

National organisation that fights for equal rights and greater opportunities for people with learning disabilities.

123 Golden Lane
London EC1Y 0RT

Tel: 020 7454 0454
Fax: 020 7696 5540
Email: information@mencap.org.uk
www.mencap.org.uk

National Autistic Society

National organisation that fights for the rights and interests of all people with autism to ensure that they and their families receive quality services appropriate to their needs. Produces a number of free leaflets and publications/training materials for purchase.

393 City Road
London EC1V 1NG

Tel: 020 7833 2299
Fax: 020 7833 9666
Email: nas@nas.org.uk
www.nas.org.uk

Pavilion Publishing

Provides training materials and conferences on health and social care, including materials for staff on learning disability issues and materials directly for people with learning disabilities.

Richmond House
Richmond Road
Brighton
East Sussex BN2 3RL

Tel: 0870 890 1080
Fax: 01273 625 526
Email: info@pavpub.com
www.pavpub.com

Royal National Institute for the Blind (RNIB)

Offers information, support and advice to over two million people with sight problems.

105 Judd Street
London WC1H 9NE

Tel: 020 7388 1266
Fax: 020 7388 2034

Email: helpline@rnib.org.uk
www.rnib.org.uk

Royal National Institute for the Deaf (RNID)

Offers information, support and advice to over two million people with hearing problems.

19-23 Featherstone Street
London EC1Y 8SL

Tel: 0808 808 0123
Fax: 0808 808 9000

Email: information@rnid.org.uk
www.rnid.org.uk

Useful websites

Ask Mencap

Provides lots of downloadable information on issues relevant to people with learning disabilities and their carers, including health.

www.askmencap.org.uk

Care and Treatment of Offenders with Learning Disabilities

Provides information on people with learning disabilities who have or are at risk of committing offences.

www.ldoffenders.co.uk

Challenging Behaviour Foundation

Provides guidance and information on supporting people with challenging behaviour, including fact sheets to download.

www.thecbf.org.uk

Contact a Family

Provides information on the health needs and syndromes associated with children with disabilities.

www.cafamily.org.uk

Down's Syndrome: Health Issues

Offers advice on the specific health needs of people with Down's syndrome.

www.ds-health.com

Easy Info (how to make information accessible)

Provides guidance on how to make information accessible.

www.easyinfo.org.uk

Fragile X Society

Advice and information about the needs of people with fragile-X syndrome.

www.fragilex.org.uk

Intellectual Disability Health Information

Provides a wealth of information on the health needs of people with learning disabilities.

www.intellectualdisability.info

Mencap's Guidance on Making Information Accessible

Guidance on how to make information accessible.

www.mencap.org.uk

People First

A national self-advocacy organisation run by people with learning difficulties for people with learning difficulties.

www.peoplefirstltd.com

Prader-Willi Association UK

Organisation offering advice, support and information on Prader-Willi syndrome.

<http://pwsa.co.uk>

Scope

Promotes equal rights and improved quality of life for disabled people, especially those with cerebral palsy.

www.scope.org.uk

Tuberous Sclerosis Association

Supports sufferers, promotes awareness and seeks the causes and best possible management of Tuberous Sclerosis.

www.tuberous-sclerosis.org

Turner Syndrome Support Society

Support and information to both girls and adult women with Turner Syndrome, their families and friends.

www.tss.org.uk

Valuing People Support Team

Government agency that supports the implementation of Valuing People. Provides many resources on health needs.

www.valuingpeople.gov.uk

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Appendix: Contributors and steering group

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