



Royal College
of Nursing

Meeting the health needs of people with learning disabilities

RCN guidance for nursing staff





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RCN Learning Disability Forum External Advisory Group

For a full list of advisory group members, see appendix.

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1

Introduction

This updated guide has been developed to support registered nurses and nursing students across the range of health services, who are trained in fields 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 in making their services more accessible, and includes sources of further information. While this guide is aimed at nurses who may find themselves working with adults with learning disabilities, those working with children may also find it useful.

This guidance was originally developed in 2006 in response to a resolution passed at RCN Congress 2004, demanding that people with learning disabilities have equal access to health care services. Members of the RCN Learning Disability Forum subsequently requested the development of a guide to support colleagues in other fields of nursing to achieve this objective.

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

All health professionals have a role in promoting the health of people with learning disabilities. The skills, knowledge and expertise of learning disability nurses are vital to this work, whether this be in facilitating direct assessment and intervention or supporting colleagues in general services. The RCN and UK Governments in all four countries recognise this unique contribution and the continued development of the profession (RCN, 2011; Scottish Governance, 2012).

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Defining learning disabilities

Learning disabilities affect about 1.5 million people in the UK; a learning disability is a common, lifelong condition which is neither an illness nor a 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
- typically the age of onset occurs before adulthood (in other words, in the developmental period) (BPS, 2000).

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

Measuring intelligence

Intelligence is formally measured through a cognitive assessment which gives people an intelligence quotient (IQ) 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 – usually a clinical psychologist.

The average IQ score for the UK population is 100 with a range of 15 points either side. Anyone with an IQ score between 85 and 115, therefore, is said to be of average intelligence.

People with learning disabilities can be said to have either a significant impairment in intellectual functioning (an IQ of between 55 and 69) or a severe impairment in intellectual functioning (an IQ below 55) (BPS, 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 peoples' life experiences.

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

Social functioning

The term 'social functioning' refers to the skills deemed necessary to deal with life and to function independently. These include communicating, taking care of personal hygiene, developing social relationships and using community facilities.

Developmental period

Most causes of learning disabilities occur before, during or soon after birth, but become apparent during the developmental period which extends from early childhood up to when an individual reaches the age of 18.

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

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 internationally.

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

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. This enables nurses to make adjustments to their nursing practice and provide signposting to services that may offer extra support.

Some people may 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:

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

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Health needs and services

The health of people with learning disabilities has been at the forefront of policy and service development over recent years, but sadly this has often been in reaction to damning reports and inquiries highlighting the inequalities and poor quality care these people have experienced.

Summary of key reports and inquiries	
Report	Summary of the main findings or recommendations
<p><i>Transforming care: A national response to Winterbourne View Hospital</i>, Department of Health (2012).</p>	<p>A Department of Health review that was undertaken following a BBC Panorama which uncovered serious abuse, neglect and malpractice at Winterbourne View Hospital. Winterbourne was an assessment and treatment service for people with learning disabilities, autism, ‘challenging’ behaviour, or mental health problems. The review addressed the wider context of assessment and treatment services, as well as what occurred at Winterbourne.</p> <p>Recommendations included:</p> <ul style="list-style-type: none"> • the Department of Health should develop proposals to strengthen accountability of boards of directors and senior managers for the safety and quality of care provided by their organisations • all individuals placed in assessment and treatment services must be reviewed in 2013, and everyone found to be placed inappropriately should be moved to community-based support as quickly as possible, no later than June 2014 • each area must have a joint plan by April 2014 to ensure high-quality care and support services for all people with learning disabilities, autism, mental health conditions or challenging behaviour. This must be in line with best practice • the Care Quality Commission must strengthen inspections and regulation of hospitals and care homes for this group of people, including unannounced inspections involving people who use services and their families.
<p><i>Six Lives: the provision of public services to people with learning disabilities</i>, Parliamentary and Public Health Service Ombudsman (2009)</p>	<p>Recommendations included:</p> <ul style="list-style-type: none"> • detailing the investigation into the deaths of six people with learning disabilities whilst in the local authority or NHS care • effectiveness systems should be in place to enable services to understand and plan to meet the full range of needs of people with learning disabilities in their areas • services should have the capacity and capability to provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities.
<p><i>Healthcare for all: report of the independent inquiry into access to health care for people with learning disabilities</i>, Sir Jonathon Michael (2008)</p>	<p>The report recognised examples of good practice but found a range of appalling examples of discrimination, abuse and neglect across the range of health services.</p> <p>Recommendations included:</p> <ul style="list-style-type: none"> • the Department of Health should adjust its <i>Standards for better health</i> to reflect the ‘reasonable adjustments’ service are required to make for vulnerable groups • clinical training must include mandatory training in learning disabilities • inspectors and regulators of health services should develop and extend their monitoring of general health services provided to people with learning disabilities • family and other carers should be involved as a matter of course as partners in the provision of care, unless good reason is given.

Summary of key reports and inquiries

Report	Summary of the main findings or recommendations
<i>Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust, Healthcare Commission (2007) (now called the Care Commission)</i>	<p>A request from the trust's chief executive initiated this independent inquiry, which found:</p> <ul style="list-style-type: none"> • care models based on the needs of the service rather than individuals • limited activities for service users • inappropriate use of restraint • lack of staff experience in supporting people with behaviour described as challenging • a number of serious incidents of sexual and physical abuse • poor living environments • lack of service user involvement • limited arrangements for governance. <p>Recommendations included:</p> <ul style="list-style-type: none"> • services should be based on the principles of person-centred care plans and health action plans • a range of activities for service users • develop a policy on and train staff in the use of restrictive physical interventions • develop the skills, experience and training opportunities for the workforce • provide appropriate advocacy services.
<i>Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust, Commission for Social Care Inspection and the Healthcare Commission (2006)</i>	<p>This independent enquiry was produced in response to serious concerns raised by the East Cornwall Mencap Society. It found:</p> <ul style="list-style-type: none"> • institutional abuse was widespread, preventing people from exercising their rights to choice, independence and inclusion • multiple instances of unacceptable restrictions on the lives of service users • poor assessment, care planning and record keeping, especially in relation to people whose behaviour was described as 'challenging' • limited training, policies and procedures. <p>Recommendations included:</p> <ul style="list-style-type: none"> • immediate action with regards to vulnerable adults, including processes, training and identified responsibilities • a plan to improve the skills and knowledge of staff • immediate community care assessments and ongoing health care assessments for service users • the redesign of the service reflecting a person-centred culture.
<i>Equal treatment: closing the gap, Disability Rights Commission (2006)</i>	<p>Recommendations included that the Government should seek to close health inequality gaps by:</p> <ul style="list-style-type: none"> • improving primary care access and health checks • enabling equitable treatment • targeting people with learning disabilities in national health inequalities programmes • working in partnership with people with learning disabilities to educate and improve 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 the wider population. When people with learning disabilities access primary and secondary services staff might experience difficulty in meeting their needs.

People with learning disabilities are at increased risk of particular health conditions. Although mortality rates for people with learning disabilities have improved over recent decades, they are still likely to die younger than other people. Preliminary findings from a recent study found that the median age of death for people with

learning disabilities was 67 years, with this significantly decreasing as the level of learning disability increases. The findings also found that over half of all deaths were cardio-respiratory related and 49.5 per cent of the deaths were unexpected.

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 these are discussed in more detail in the sections that follow.

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, which can result 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 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 known as '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.

The nature of problems for people with learning disabilities:

- communication difficulties (see section 7)
- awareness of available health services
- lack of understanding of the benefits of screening
- lack of understanding of the consequences of their decisions on their health needs
- risk of falling into social categories associated with poor health, including lower socioeconomic groups and the unemployed.

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Specific health needs

Although people with learning disabilities have the same needs as those without, they do have specific health needs which are listed here alphabetically, and 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.

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 and 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, and a more restricted lifestyle.

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 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, 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 regular 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 have 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

People with learning disabilities have a higher prevalence of sight problems, and over recent years ophthalmologists have been adapting assessments to meet their needs. Individuals may need reminding about the importance of eye tests and support in accessing them.

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 congenital 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, congenital 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-1000 men and becomes more prevalent with age. It is more common in people with learning disabilities and is associated with 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.

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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.

Policy and law

UK policies

Each of the four UK countries has its own policy on how the needs of people with learning disabilities should be met. These policies describe a holistic approach for supporting people with learning disabilities to reach their potential and find 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 equal rights and opportunities
- social inclusion.

The UK policies on people with learning disabilities are:

England:

Department of Health (2009) *Valuing people now: a new three year strategy for people with learning disabilities*.

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*.

Scotland:

Scottish Government (2013) *The Keys to Life: improving the quality of life for people with learning disabilities*.

Wales:

Learning Disability Advisory Group (2001) *Fulfilling the promises: report of the learning disability advisory group*.

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

- promoting collaborative working between general health services (primary and secondary care) and specialist learning disability services

- enabling people with learning disabilities to access general health services with support from specialist services when needed
- providing general health care staff with adequate training on the needs of people with learning disabilities
- ensuring people with learning disabilities are registered with a GP
- offering people with learning disabilities an individualised health care plan
- offering people in England and Northern Ireland with learning disabilities a health action plan and facilitating them to develop their plan and ensure it is implemented
- ensuring that people with learning disabilities are offered regular health checks and are included in health screening programmes
- making health promotion materials 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.

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 four countries of the UK have developed, or are in the process of developing, legislation regarding consent law. While these acts may differ in terminology and process all are based on similar principles and, with regard to consent to examination or treatment, have similar expectations of health care staff.

Law and policy in the UK on consent are:

- England and Wales, Office of the Public Guardian: Mental Capacity Act (2005) www.publicguardian.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

The underlying principles of consent to treatment is that no adult can make a decision on behalf of another adult (an individual over the age of 16 years), and that it must be assumed that a person has the capacity to make a decision unless proved otherwise. As health care professionals we may consider that there is an issue in regards of capacity if a person has a mental disorder. In England and Wales the *Mental Capacity Act (2005)* provides a list of what constitutes a mental disorder, of which learning disabilities is included. This does not mean that the person lacks capacity, just that you may need to assess the individual's capacity to make a particular decision. Other reasons why you may want to assess capacity include:

- the person has made several unwise decisions
- you believe the person is being coerced
- the person is suggestible and/or acquiesces.

When assessing capacity it is important to remember that 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.

Before you can conclude that a person has or does not have capacity, you must ensure that the individual has been given sufficient support and information to help them make the decision. 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 on the following points, in a format they will understand:

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

The clinician giving the treatment or implementing a procedure is responsible for assessing the person's capacity to make that decision. In the case of people with learning disabilities, who may have specific communication needs, it might also be appropriate to involve the person's family or specialists from the learning disability services, such as community learning disability nurses. Other professionals who can help this process include speech and language therapists who can advise on how to give the information to patients, and clinical psychologists who 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.

Once the person has been given the appropriate information about the proposed treatment an assessment of capacity should take place. The professional undertaking the assessment should prepare a semi-structured list of questions and have a clear idea of where the bar is set (in other words, what they want to hear for the person to be deemed as having capacity). The same standards should apply to everyone, regardless of whether they have a learning disability or not. However, the only difference may be the extra effort and support you may give people with learning disabilities to help them understand the information relating to the decision.

Questions should be directly related to the information that has been given to the individual and asked in a way that is appropriate to the individual's communication needs. In terms of consent to medical treatment Etchells et al. (1999) suggests the following:

- ability to understand the medical problem
 - what problem are you having right now?
 - why are you in hospital?
- ability to understand the proposed treatment
 - what is the treatment for?
 - what can we do to help you?
- ability to understand the alternatives to the proposed treatment (if any)
 - are there any other treatments?
 - what other options do you have?
- ability to understand the option of refusing treatment (incl. withdrawing treatment)
 - can you refuse?

- could we stop the treatment?
- ability to appreciate the reasonably foreseeable consequences of accepting the treatment
 - what could happen if you have the treatment?
 - how could the treatment help you?
 - could the treatment cause problems or side effects?
- ability to appreciate the reasonably foreseeable consequences of refusing the treatment
 - what could happen to you if you don't have the treatment?
 - could you get sicker/die without the treatment?
- ability to make a decision that is not substantially based on hallucinations, delusions or cognitive signs of depression
 - why have you decided to accept/refuse the treatment?
 - do you think we are trying to harm you?
 - do you deserve to be treated?
 - do you feel you are being punished?
 - do you feel that you are a bad person?

The judgement of capacity is based on the person's ability to understand the nature and effects of the decision to be taken, at the time it needs to be taken. The test of capacity is a four stage test and the individual must pass all four stages. This means they must:

- understand the information relevant to the decision
- retain the information long enough to make the decision
- demonstrate that they have used and weighed the information as part of their decision making process
- be able to communicate their decision.

According to the British Medical Association and The Law Society (2004), in regards to assessing health related decisions the person being assessed needs to:

- understand in simple language what the medical treatment is, its nature and purpose, and why it is being proposed
- understand its principal benefits, risks and alternatives

- understand in broad terms what will be the consequences of not receiving the proposed treatment.

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 any person is assessed as lacking capacity in relation to a specific decision, health care professionals can make the decision as long as it is in the person's best interest. The health professional making the decision would generally be the professional that would instigate the treatment. When making 'best interest' decisions, health professionals should consider:

- the person's past wishes and opinions
- the person's beliefs and values
- consult with family carers and friends (if it is a serious medical decision and none are available, advocacy should be accessed)
- consult with health and social care staff involved in the person's care
- you are not making the decision based on the person's age, appearance, behaviour or condition
- even though the person lacks capacity they should still be encouraged to be involved as much as possible.

When making a 'best interest' decision the health care professional should consider all the relevant circumstances, and these should include the possible advantages and disadvantages from the following perspectives:

- medical
- emotional welfare
- social welfare.

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 circumstances where carers, professionals and relevant others (such as advocates) meet to discuss the situation and support health care professionals to reach a decision.

6

Specialist services

The vast majority of people with learning disabilities live in the community and have the right to equal access to general 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 People with Learning Disabilities (CTPLD), but names differ in some areas.

The teams are generally made up of staff from a range 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 general health services, and CTPLDs promote this by providing specialist advice and support to their colleagues in general health care. Some CTPLDs pursue a lifespan 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 CTPLD.

CTPLDs 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. Local social service departments will have contact information for CTPLDs.

Specialist inpatient services

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

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

People should only be placed in these environments when they cannot be supported at home, even with extra support. From the day of admission, the aim should be for recovery and discharge. Services should be local and have a clear plan for each individual, including why the admission is necessary, a care pathway detailing what assessment and treatment will be offered, and the expected outcomes.

7

Supporting access to services

Accessible information and good communication skills are crucial if people with learning disabilities are to have equal access to all health care services. 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, secondary and tertiary, should have a summary of key points on:

- how to communicate with people with learning disabilities
- how to write accessible information
- duties under the *Equality Act* (2010).

All services should make reasonable adjustments for all people using them. The National Development Team for Inclusion has produced a number of reports on reasonable adjustments in a range of health care settings, which are available at www.ndti.org.uk. Family carers and friends can play a vital role in facilitating access, as can support workers and specialist services.

This section explains some of the difficulties faced by people with learning disabilities in accessing general services, and offers practical ideas on how these 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

these beforehand (Section 8 contains information on online sources offering advice relating to the use of 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 family, carers or support worker 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 supporter, 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, give the person some information to look at before you see them, or organise 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 loudspeaker (tannoy) announcements, the 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 family member or supporter, 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.
- Use straightforward language and short, plain sentences. Avoid medical or technical jargon.
- If you are giving the person new information, ensure you 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. Use positive language, for example, 'we will go out later' rather than 'we can't go out now'.
- 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 these in the sequence they will occur.
- 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 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 similar to that relating to verbal communication.

Comprehensive guidance can be found in the *Mencap Accessible Information* websites (see section 8). The following additional basic guidance may prove helpful:

- 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 size of 14 for printed materials
- you could check what you have written with people with learning disabilities who are part of service-user or self-advocacy groups; local CTPLDs and social services will have contact details.

Inpatient 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.
- Make sure the person and/or their family or supporters 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.
- It is important to consider how the person expresses when they are in pain and how the nursing team will recognise this.
- Nurses need to engage with people with learning disabilities and actively work with them to provide care. Additional staff should be provided if needed, and while families may want to be as involved as much as possible they should not be used to replace the staff required to meet the persons needs.
- 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 supporter to help write an accessible timetable that includes meal times, ward rounds and other activities.
- Visiting hours should be flexible to enable people's family and supporters to spend more time with them to help them feel as secure as possible.
- Some people with learning disabilities may perform challenging behaviour. This often occurs in response to communication issues, boredom, or environmental factors such as noise. The person's family and supporters 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 family and supporters 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.
- Take opportunities to work alongside the person's family or supporters in order to refine your skills in communication and care for the individual.
- Introduce yourself clearly to the person with learning disabilities and explain your role. Give your name.
- Explain to the person with learning disabilities how to get help.
- Provide orientation to ward/department for the person with learning disabilities and their carers.

8

Resources

Policy websites

National policies on learning disabilities

Equal Lives (Northern Ireland)

www.dhsspsni.gov.uk/learning-disability-report

Fulfilling the Promises (Wales)

www.wales.gov.uk

The Keys to Life: Improving the quality of life for people with learning disabilities (Scotland)

www.scotland.gov.uk

Law on consent to treatment

Office of the Public Guardian: Mental Capacity Act (2005)

www.justice.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

Equality Act (2010)

www.homeoffice.gov.uk

Human Rights Act (1998)

www.opsi.gov.uk

Mental Health Act (2007)

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

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Networks

Access to Acute Hospital Network

www.a2anetwork.co.uk

A national forum for people interested in improving access to acute hospital care for people with learning disabilities.

National Network for Learning Disability Nurses (NNLDN)

www.nnldn.org.uk

The NNLDN is a 'network of networks' which aims to support networks and nurses in the field of learning disabilities.

UK Continuing Care Network

www.jan-net.co.uk

A free-to-join network aimed at practitioners working in continuing care and learning disabilities.

UK Epilepsy Network

www.jan-net.co.uk

A free-to-join network aimed at practitioners with an interest in epilepsy.

UK Forensic and Learning Disability Network.

www.jan-net.co.uk

A free-to-join network aimed at practitioners with an interest in people with a learning disability in secure settings or at risk of contact with the criminal justice system.

UK Health and Learning Disability Network

www.learningdisabilities.org.uk/ldhn

An open network, hosted by the Foundation for People with a Learning Disability (FPLD), with a focus on health and adults with a learning disability.

UK Lecturers Network (Learning Disability)

www.jan-net.co.uk

Aimed at university lecturers in learning disability, this network is open anyone with an interest in workforce development in health.

Useful organisations

British Institute of Learning Disabilities (BILD)

www.bild.org.uk

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 as well as publications and training materials to purchase.

Challenging Behaviour Foundation

www.challengingbehaviour.org.uk

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

Down's Syndrome Association

www.downs-syndrome.org.uk

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

Elfrida Society

www.elfrida.com

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

Epilepsy Action

www.epilepsy.org.uk

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

Estia Centre

www.estiacentre.org

Specialises in the mental health needs of people with learning disabilities, and provides training, research and development along with downloadable resources.

Foundation for People with Learning Disabilities

www.learningdisabilities.org.uk

National organisation that promotes the rights, quality of life and opportunities for people with learning disabilities through research, development and influencing policy. It provides a range of free downloadable resources and publications to purchase.

Improving Health and Lives Learning Disabilities Observatory

www.improvinghealthandlives.org.uk

Provides information and statistics on the health of people with learning disabilities in England.

Mencap

www.mencap.org.uk

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

National Autistic Society

www.autism.org.uk

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.

National Development Team for Inclusion

www.ndti.org.uk

Promotes the rights and inclusion of vulnerable people. Provides information and guidance on services making reasonable adjustments for people with learning disabilities.

Royal National Institute for the Blind (RNIB)

www.rnib.org.uk

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

Royal National Institute for the Deaf (RNID)

www.rnid.org.uk

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

Useful websites**Contact a Family**

www.cafamily.org.uk

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

Down's syndrome: health issues

www.ds-health.com

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

Easyhealth

www.easyhealth.org.uk

A wealth of accessible information on a range of health related topics.

Fragile X Society

www.fragilex.org.uk

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

Intellectual disability health information

www.intellectualdisability.info

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

People First

www.peoplefirstltd.com

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

Prader-Willi Association UK

www.pwsa.co.uk

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

Scope

www.scope.org.uk

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

Tuberous Sclerosis Association

www.tuberous-sclerosis.org.uk

Supports sufferers, promotes awareness, and seeks the causes and best possible management of tuberous sclerosis.

Turner Syndrome Support Society (UK)

www.tss.org.uk

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

9

Appendix: contributors and steering group for first edition

The original edition of this document was written by:

Steve Hardy, *Training and Consultancy Manager*, Estia Centre, South London and Maudsley NHS Trust and a member of the RCN Learning Disability Forum

Peter Woodward, *Training Officer*, Estia Centre, South London and Maudsley NHS Trust

Petrea Woolard, *Lead Clinician, Speech and Language Therapy*, Southwark Community Team for Adults with Learning Disabilities

Dr. Tom Tait, *Director*, Growing Older with Learning Disability Ltd.

RCN Learning Disability Forum Committee

Dr Michael Brown (Chair), Nurse Consultant, School of Nursing, Midwifery and Social Care, Edinburgh Napier University

Professor Owen Barr, Head of School of Nursing, University of Ulster

Anne Campbell, Operations Manager, Learning Disability Services, Belfast Health and Social Care Trust

David Currie, Development Manager, Castlebeck Group Ltd

Daniel Marsden, Practice Development Nurse, East Kent Hospitals University Foundation NHS Trust

Ian Mansell, Lecturer, Faculty of Health Sport and Science, University of Glamorgan

External Advisory Group (from the first edition)

Mark Austin, *Community Nurse*, Royal Liverpool Children's NHS Trust

Sarah Burchell, Joint Clinical Director/Consultant Nurse, Oxleas NHS Trust

Melanie Coombes, Consultant Nurse Learning Disabilities, North Warwickshire Primary Care Trust

Peter Cronin, Service User Adviser

Guy Carlile, Service User Development Officer, Estia Centre, South London and Maudsley NHS Trust

Sandra Dawson, Primary Care Specialist Nurse for Adults with Learning Disabilities, Cheshire West PCT and Ellesmere Port and Neston PCT

Marcelle de Sousa, Adolescent Nurse Specialist, UCL Hospitals Foundation Trust

Meadhbh Hall, Health Care Co-ordinator, Norwich PCT, and representative of the National Network for Learning Disability Nurses

Patrick Healy, BN Post-registration Programme Manager, University of Dundee

Carol Herrity, Campaigns Manager, Royal Mencap Society

Dr. Geraldine Holt, Consultant Psychiatrist, Estia Centre, South London and Maudsley NHS Trust

Ian Hulatt, Mental Health Adviser, Royal College of Nursing

Christine Hutchinson, Consultant Nurse Learning Disability, Preston PCT, and representative from the UK Learning Disability Consultant Nurse Network

Dr. Theresa Joyce, Head of Psychology, Estia Centre, South London and Maudsley NHS Trust

Debra Moore, Regional Adviser – Yorkshire and Humber, Valuing People Support Team

Liam Peyton, Service User Adviser

Alison Pointu, Consultant Nurse, Barnet PCT

Rick Robson, Senior Nurse, Shropshire County PCT

Yolanda Zimmock, Service User Adviser



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