The Needs of People with Learning Disabilities

What pre-registration students should know
# Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>2</td>
</tr>
<tr>
<td>1. What is a learning disability</td>
<td>3</td>
</tr>
<tr>
<td>2. Communication</td>
<td>3</td>
</tr>
<tr>
<td>3. Capacity and consent</td>
<td>4</td>
</tr>
<tr>
<td>4. Health of people with learning disabilities</td>
<td>5</td>
</tr>
<tr>
<td>5. Reasonable adjustments</td>
<td>6</td>
</tr>
<tr>
<td>6. Medication</td>
<td>7</td>
</tr>
<tr>
<td>7. Enabling independence and inclusion</td>
<td>8</td>
</tr>
<tr>
<td>8. Expressing distress</td>
<td>8</td>
</tr>
<tr>
<td>9. Health promotion</td>
<td>9</td>
</tr>
<tr>
<td>10. Working with families</td>
<td>9</td>
</tr>
<tr>
<td>11. Working with others</td>
<td>10</td>
</tr>
<tr>
<td>12. Profound and multiple learning disabilities</td>
<td>10</td>
</tr>
<tr>
<td>13. Lifespan</td>
<td>11</td>
</tr>
<tr>
<td>Resources</td>
<td>11</td>
</tr>
</tbody>
</table>

## Introduction

This booklet aims to highlight to all pre-registration nursing students what their programme of study should offer around the health needs of people with a learning disability, increasing the students’ competence, regardless of what setting they work in.

People with a learning disability must have the same access to health care as everyone else. Nurses need to have an understanding of the needs of people with a learning disability to ensure they can support reasonable adjustments. This is a mandatory requirement under the Equality Act (2010).

The Nursing and Midwifery Council (NMC) sets the standard that all pre-registration nursing students, regardless of intended field of registration, are expected to achieve. Therefore the programmes that you undertake in order to register with the NMC as a nurse will include both theory and practice components which must embed and reflect the needs of this often vulnerable population who have significant health needs. (The NMC Standards for competence for registered nurses were published in 2014 as a reference for nurses throughout their careers.)

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1. What is a learning disability?

**Student’s objective**

To be able to recognise, flag and alert when a patient has a learning disability and to be aware of the affects that this can have on a person’s life.

A learning disability (or intellectual disability) is a lifelong condition, resulting in a reduced intellectual ability and thus difficulty with everyday tasks – for example managing health needs, accessing health care, or recognising, responding to, or expressing changes in health. People with a learning disability may need support to understand complicated information and to communicate effectively with others. It may not be apparent that someone has a learning disability, so it’s important to be alert to this possibility and to remember that everybody’s different.

People with a learning disability have significantly greater health (and social care) needs, with, for many, the need for additional support and adjustments. Research evidence highlights the significant health inequalities that exist for many people with a learning disability and that they may die prematurely and avoidably from preventable conditions, with 1,200 people with a learning disability dying avoidably every year.

How much support a person needs varies. For example, someone with a mild learning disability may only need support with things like understanding health information, accessing health screening programmes or managing any complex health needs they may have. Whereas, people with a severe or profound and multiple learning disability (PMLD) may need full time support, especially with their health as they may have multiple complex health conditions including physical disabilities. They will therefore require access to a range of health services, from community and primary care through to secondary and more specialist health services.

**Nursing programme objectives**

- To teach students to be able to recognise a learning disability and flag and alert other health care professionals so that reasonable adjustments to care and treatment can be made.
- To enable a student to have direct contact with a range of individuals with a learning disability and to understand the principal health issues experienced by this sector of society.

2. Communication

**Student’s objective**

To understand the variety of ways a person with a learning disability may express themselves and understand information.

Many people with a learning disability experience particular challenges in communication. A learning disability can impact the way a person understands information and how they communicate. As a result they may have issues with speech, language, communication and sensory impairment that has implications when they access health services, where it is necessary to provide information about health history, symptoms, medications and other conditions. As a result health needs are overlooked and avoidable mistakes can occur where common diseases and conditions, or behaviours seen as ‘challenging’ may be an expression of pain, or attributed to the person’s learning disability and left untreated.

It is therefore important to be aware of the communication needs of the individual and plans that are in place to enable effective communication such as using Makaton, gestures, symbols, easy read and objects of reference, for example. Health services can minimise and reduce issues that contribute to communication difficulties and provide reasonable adjustments that may be needed. Families and carers are a valuable resource for health services as they have expertise of the patient’s communication needs and can share communication plans and advice on how the individual they support communicates. Community learning disability teams often have speech and language therapists and other professionals who can advise and assist with communication strategies and supports when people with a learning disability access health services.

**Nursing programme objectives**

- To enable a student to be confident that they are communicating using appropriate methods in a way that’s effective and two-way (reciprocal).
- To understand that people with a learning disability may not communicate verbally and experience a range of strategies that can improve and support their expression.
- To recognise that people with a learning disability may understand information differently and experience a range of strategies to support people in receiving information.
3. Capacity and consent

**Student’s objective**

*To be clear about the law and mental capacity in relation to people with a learning disability.*

One of the most common misconceptions about adults with a learning disability is that others can consent on their behalf. This is not correct. People with a learning disability have, by law, exactly the same rights as anyone else to make all their own decisions about their health care, their finances, their accommodation and all other matters that affect them. The only exception to this situations is where a professional multi-disciplinary team have agreed that for a specific decision they don’t have capacity in which case other legal arrangements need to be made and a “best interests” decision (please refer to your relevant legislation in respect of capacity for example, Mental Capacity Act, Adults with Incapacity etc. for further guidance).

A person with a learning disability may find that a personal advocate is a useful resource and these can be sourced via the local authority or through independent advocacy groups.

A person with a learning disability might be helped by having information presented in an accessible format specific to their needs to aid their decision making abilities.

As a nurse you must not assume:

- that because a person has a learning disability they are unable to make any choices and decisions
- that you always know what is best before trying to communicate and support the person to make a choice
- your values and choices are the same for someone else
- that making an unwise decision means a person lacks capacity.

As a nurse you must:

- facilitate opportunities for a person with a learning disability to be involved in decisions using materials that are accessible to them, for example, using augmentative communication strategies such as simple language, pictures, objects of reference, etc
- involve others important to the person who can help empower them or give information to identify what is felt to be the best decision for the person.

**Nursing programme objectives**

- To provide a student with the expertise to be confident in how to resolve any matters that concern capacity to consent to a course of action/intervention.
- To have an understanding of the Mental Capacity Act and how this applies to people with a learning disability.
- To understand processes when a person lacks capacity, how best interest decisions are made, and how families and people who know the person well are involved.
4. Health of people with intellectual disabilities

**Student’s objective**

To find out about the many and varied health issues that particularly affect a person with a learning disability.

People with a learning disability die prematurely compared to the non-disabled population: men will die 13 years earlier and for women 20 years earlier. People with multiple learning disabilities are more likely to die before the age of 50 from their complex issues. People with a learning disability often die from deaths that could have been avoided if they had received good quality health care. The three leading causes of death are respiratory disease, CHD and certain cancers.

People with a learning disability are more likely to develop a range of secondary health conditions (epilepsy, diabetes, osteoporosis, mental health conditions, and dementia) compared to the non-disabled population, and these conditions will develop at an earlier age.

**Determinants of health**

- **Genetic or biological** (i.e. people with Down syndrome, epilepsy).
- **Lifestyle styles** (poor diet, lack of exercise, reliance on medication, high levels of sedentary behaviours leading to higher levels of obesity).
- **Attitudes** (negative stereotypes leading to discriminatory practices).
- **Accessing health care and health promotion** (lack of knowledge, limited access to appropriate health literacy, poor access, poor uptake of health screening, non-engagement in preventive programmes, poor health condition management).

Numerous international reports have been echoed the same message that health care services consistently fail to work together and make reasonable adjustments to meet the health needs of people with a learning disability effectively.

You will find people with a learning disability of all ages accessing hospital wards, outpatient appointments and community clinics. As a student nurse and a registered nurse in line with the NMC you will be accountable to provide compassionate, effective care and treatment.

**Nursing programme objectives**

- Recognise the changing demographics and health needs of this population.
- Identify the risk factors for premature death and poor health.
- Reflect upon their knowledge, attitudes and skills in working with people with a learning disability across the lifespan and to address these health inequalities.
- Identify the appropriate health literacy to educate and empower people with a learning disability and their carers about promoting better health and managing these chronic conditions.
- Develop the skills and confidence to work competently with people with ID and their carers in a health care setting.
- Understand that a person with a learning disability will be at their workplace/placement. Review how the workplace affects people with a learning disability and how the placement/workplace adapts their intervention to meet this need.
5. Reasonable adjustments

Student’s objective

To appreciate that without “reasonable adjustments” many people with a learning disability are unable to access health care.

Given the identified health inequalities this population often encounters across the health service, it is therefore important that all student nurses and registered nurses make ‘reasonable adjustments’ as identified within each country’s legislation. This not only includes making physical adjustments to facilities (ramps, signs) but also adaptations to help someone with a learning disability to understand and engage in their health care (see examples below). Likewise, the negative attitudes and discriminatory practices that sometimes shown should be challenged.

Examples of some of the reasonable adjustments include:

- using a flag system to alert staff that the person has a learning disability
- ensuring the person has a health check
- developing a health action plan that addresses individual health needs and follow-up the actions
- encouraging the person to write a hospital passport that journeys with them through primary care, hospital appointments and acute care
- encouraging the person with ID to have the support of a family/paid carer, advocate, if needed
- offering a double appointment
- offering a first or final appointment
- ensuring you have user-friendly information available
- environmental adaptations (avoiding having to wait excessively, waiting in a side room, removing excessive noise).

Nursing programme objectives

- Know the relevant legislation covering this area.
- Reflect on their own attitudes, beliefs and practices in working with people with learning disability.
- Identify where such user-friendly information and resources can be found
- Liaise with the community learning disability team to work together in developing health action plans and a hospital passport.
6. Medication

Student’s objective

To find out about the many and varied medication prescribed for people with learning disabilities.

People with a learning disability are more likely to develop a range of secondary health conditions (epilepsy, diabetes, osteoporosis, mental health conditions, and dementia) compared to the non-disabled population, and these conditions will develop at an earlier age. They are likely to be prescribed a wide range of medications for these conditions.

In addition many people with a learning disability develop problem behaviours (also called challenging behaviours). A wide variety of psychotropic medications may be prescribed to help manage these challenging behaviours however there are concerns that they are overused and that people with a learning disability remain on them for too long.

The NHS England STOMP campaign (see reference in resources) is about stopping the overmedication of people with a learning disability, autism or both.

Determinants of overmedication

• A lack of access to alternative methods to manage problem behaviours, nurses and other support workers should be skilled in methods such as positive behaviour support to minimise the need for psychotropic medication

• Lifestyle styles (poor diet, lack of exercise, reliance on medication, high levels of sedentary behaviours leading to higher levels of obesity).

• Attitudes (negative stereotypes leading to discriminatory practices).

• Lack of review of medication (lack of knowledge about alternatives, limited access to appropriate review, poor uptake medication review as a part of health screening, non-engagement in preventive programmes, poor medication management).

Numerous international reports have echoed the same message that health care services consistently fail to work together and ensure that only those medications that meet the health needs of people with a learning disability continue to be prescribed.

You will find people with a learning disability of all ages accessing hospital wards, outpatient appointments and community clinics on all kinds of medication. As a student nurse and a registered nurse in line with the NMC you will be accountable to ensure that you are knowledgeable about the medications, and they are kept to a minimum to ensure effective care and treatment. As a nurse a vital part of your role is to support the person and their family to understand their treatment, including medication, so that they are empowered to make decisions about their care and treatment.

Nursing programme objectives

• Ensure a good understanding of the medications prescribed for people with learning disabilities.

• Understand the side effects of the medication.

• Reflect upon their knowledge, attitudes and skills about the use of medication in working with people with a learning disability across the lifespan and to address these health inequalities.

• Identify the appropriate health literacy to educate and empower people with a learning disability and their carers about their medication so they only take the medications that benefit them.

• Develop the skills and confidence to work competently with people with learning disabilities and their carers in a health care setting to administer their medications.

• Identify what is overmedication and know how to stop it.

• Develop the skills around medication to ensure that student and future nurses can advocate on behalf of the person with learning disabilities to get the best from their medication.
7. Enabling independence and inclusion

Student’s objective

To promote inclusion in all aspects of health care delivery to provide nursing care that enables maximum levels of independence and functioning.

People with a learning disability have the same rights to independence and inclusion as all. People should be able to access the same health care, the same community services and have the same opportunities as everyone else. However, for people with a learning disability, their disability and the environment can create many barriers to achieving this.

People with a learning disability don’t need “hotel staff” who care for their every need. They need enabling support that empowers them to do as much for themselves as they can, with just the right support to do this successfully.

Nursing programme objectives

- Support the person with a learning disability to do as much as they can for themselves and to be as autonomous as possible.
- To make adaptations and adjustments to environment and communication that enable people with a learning disability to be included in their health care and treatment.

8. Expressing distress

Student’s objective

To have opportunities to develop an understanding of how people with a learning disability display anxiety and distress, and that all behaviours communicate a need and have a legitimate function for the person displaying them.

We all experience distress. When we are distressed we have ways of communicating this and coping with this. Some people with a learning disability may not have these skills. As a result, people may communicate their distress in ways we feel are challenging. This could include aggression, self-harm, damage to property, or other behaviours that cause a disturbance.

It is important to remember that all behaviours happen for a reason and receiving health care can be a strange and frightening experience. We need to be empathetic to how the person may be experiencing what is happening, reduce as much distress as we can, and respond in a calm and supportive way. Imagine if you were in pain, or frightened and couldn’t tell anyone. What would you do?

Nursing programme objectives

- Understand how behaviour is expressed, and demonstrate an inquisitive approach when behaviour is unusual or challenging to understand what the person wants.
- Understand the impact of the environment (which includes people) on an individual’s behaviour.
- Plan in advance to reduce distress before it occurs and work with families and carers.
9. Health promotion

**Student’s objective**

To appreciate how you might help a person with a learning disability to have a healthier lifestyle.

Health promotion is about empowering the person with a learning disability to take control of the decisions in their life and to subsequently engage in healthy lifestyle behaviours change.

Many people with a learning disability do not engage in healthy lifestyle behaviours as they have limited knowledge about the detrimental effects of an unhealthy lifestyle, they are not given the opportunities to access community programmes, and they are dependent upon family/paid carers to support them to engage in such activities. Most people with a learning disability do not have access to appropriate health promotion material, as it is often not written in a user-friendly format. Evidence has shown that because some women with a learning disability are not sexually active that they do not need to engage in health screening and this not true. For those people with a learning disability who have a chronic secondary health condition such as type 2 diabetes, they are not offered structured self-management education programmes that are routinely offered to adults without a learning disability. Such unhealthy lifestyles, negative attitudes and discriminatory practices need to be challenged.

**Nursing programme objectives:**

- Support people with a learning disability to engaging in healthy lifestyle behaviours (eating a healthy balanced diet, engaging in regular exercise, not being sedentary, moderate drinking, not smoking, using protection in sexual activity).
- Provide user-friendly health literacy in order to improve the persons knowledge about the risk and protective health factors of specific health conditions.
- Remove the barriers to the uptake of health screening programs (breast screening, testicular checks, well women clinics).
- Facilitate better access to the primary health care (GP, practice nurse).
- Challenge the negative attitudes and discriminatory practices.

10. Working with families

**Student’s objective**

Work collaboratively with families and carers in care planning and care delivery to improve health outcomes and experience of health services.

In the UK the majority of people with a learning disability live with their family. Accordingly, family carers (also known as informal carers) are important people in the lives of people with a learning disability. Family carers therefore need to be recognised as valuable commodities in the support of their relative. Consequently, it is imperative that health services and professionals work in ways that value their expertise and include them in the care of relative. By working collaboratively and in partnership with families their individual needs can be identified so that they are treated with dignity and respect. This can be further facilitated by ensuring that carers have an assessment of their needs in accordance with national strategies and policy. It is highly likely that you will come across family carers wherever you may work as a nurse.

**Nursing programme objectives:**

- Adapt and deliver effective support that reduces the risk of families experiencing unnecessary hardship and inequality in their caring role.
- Recognise cultural and family diversity so that the needs of individual family carers are valued.
- Have an awareness of the changing needs of carers relative across the lifespan and the need to review care and support accordingly.
- Develop collaborative relationships built on partnership, involvement and respect.
- The experiences of individual family carers need to be listened to and learnt from so that proactive support can be planned and delivered to meet their specific needs.
11. Working with others

Student’s objective

To know how to access specialist learning disability advice and help.

In most parts of the country there are community learning disability teams (CLDTs) who are an invaluable resource. They typically comprise of learning disability nurses, psychologists, psychiatrists, speech & language therapists, physiotherapists, occupational therapists and arts therapists. They normally have an open referral system and are experts in helping people with a learning disability access community facilities, especially health care. CLDTs as well as the local authority can also be helpful when the person with the learning disability is faced with a complex decision and needs support.

Many hospitals also now have a learning disability liaison nurse who can help with facilitating admissions to hospital for a person with a learning disability, especially when it is a planned admission.

Nursing programme objectives

- have contact with a CLDT
- understand the composition and role of a CLDT
- to be aware of what other health and social care services exist for people with a learning disability within secondary care, the local authority and the independent sector
- understand what a learning disability nurse does and how to contact a learning disability nurse.

12. Profound and multiple learning disabilities

Students Objective

To appreciate that people with both a severe learning disability and multiple physical difficulties often require highly specialised support to have both a fulfilled and healthy lifestyle.

Some people with a learning disability have a profound intellectual disability, which means that they have severely limited understanding. In addition, they may have multiple disabilities, which can include impairments of vision, hearing and movement as well as other challenges such as epilepsy and autism. Most people in this group need support with mobility and many have complex health needs requiring extensive support.

People with profound intellectual and multiple disabilities may have considerable difficulty communicating. Many people express themselves through non-verbal means, or at most through using a few words or symbols. In addition some people need support with behaviour that is seen as challenging, such as self-injury.

Nursing programme objectives:

- have direct contact with individuals with a profound and multiple learning disability
- to appreciate the health conditions this group are at risk of and to be aware of ways to help
- to experience the various ways to communicate with this group of and individuals
- to comprehend the vital role of families and carers for this group.
13. Lifespan

Student’s objective

To understand how the needs of people with a learning disability change as they progress through life from birth to death.

As a result of advances and developments in medical technology and practice babies are surviving premature births and children born with complex health needs and/or disabilities are surviving longer than previously. Also, adults with a learning disability, the same as those from the general population, are living longer. Therefore, people with a learning disability will come into contact with health services that provide support and care from across the lifespan from a variety of services. This is because they are likely to experience a variety of different physical and psychological health needs across the age continuum. Some of these needs can include, congenital conditions, dementia, diabetes, respiratory disease, obesity.

As a nurse your role will be to meet the specific needs of the person within the context of their lifespan dependent on where you are working. You should be able to recognise and understand that people with a learning disability may have different needs across the age spectrum and therefore you will need to develop skills to identify and meet these needs.

Nursing programme objectives

- recognize the health needs of people with a learning disability across the age spectrum
- have experience of working with individuals of all age groups
- understand the changing bio-psycho-social needs of individuals with a learning disability as they age
- identify and make reasonable adjustments to their practice that facilitates the involvement and empowerment of people with a learning disability in meeting the individual’s health needs in recognition of their age and ability
- facilitate individuals to lead lives which are fully inclusive and promote social participation.

Resources

The Learning Disability Made Clear Toolkit brings together a range of resources to promote understanding about what it’s like to live with a learning disability, allowing health care professionals to adjust the care they deliver and helping people with a learning disability access the services they need. Picture symbols and a communication app can be downloaded so that you have access at all times. http://learningdisabilitymadeclear.nhs.uk/toolkit/3-learning-disability-made-clear-toolkit -

Picture books to aid communication between health professionals and service users from www.communicationpeople.co.uk

Easy Health provides links to health information that is easy to understand and can be printed off free of charge from www.easyhealth.org.uk/

NHS England guidance for prescribing health care professionals about reviewing inappropriate prescriptions for people with a learning disability from www.england.nhs.uk/tag/stompld/