



Wellbeing for Life Access to Health Care



Learning Outcomes

- To have an understanding of how the NHS works.
- To understand and be able to ask for reasonable adjustments to ensure equity of access to health care.
- To be able to support a person with a learning disability to be involved in their health care.



The NHS covers everything related to health care, including GP access

The NHS was launched in 1948. It was created from an ideal that good health care should be available to all, regardless of wealth. This remains one of the NHS's core principle.

The NHS in England continues to be free at the point of use for all UK residents.

There are a few exceptions where charges are made, such as prescriptions, eye care and dental services. However, these charges are often free to vulnerable or low income groups.





The NHS covers everything related to health care, including GP access

The NHS covers everything related to health care, including routine screenings, for example the NHS Health Check; emergency treatment; treatments for long-term conditions; transplants and end of life care.

Some services, such as emergency treatment and treatment of infectious diseases are free for everyone, including visitors.

Funding for the NHS comes directly from taxation.

Fact:

The NHS in England deals with over 1 million patients every 36 hours.

The NHS can undergo changes. The new health and care system started on April 1st 2013.



Who does what?

The Secretary of State

Has overall responsibility for the work of the Department of Health.

The Department of Health

Provides strategic leadership for public health, the NHS and social care in England.

NHS England

Is an independent body, separate from the government. Its main aim is to improve health outcomes for people in England.

Local Clinical Commissioning Groups

Replaced primary care trusts (PCTs) on April 1 2013. Clinical Commissioning Groups (CCGs) buy services for people living in their area and can commission any service provider that meets NHS standards and costs. These can be NHS hospitals, social enterprises, charities or private sector providers. CCGs are made up of doctors, nurses and other health professionals. The secondary care services commissioned by CCGs are planned hospital care, rehabilitative care, urgent and emergency care (including out-of-hours and NHS 111), most community health services, mental health and learning disability services.



Who does what?

Health and Wellbeing boards

Are established by local authorities as a forum for local commissioners across the NHS, social care, public health and other services. Healthwatch provides a voice for patients and local communities.

Public Health England

Provides national leadership and expert services to support public health, and also works with local government and the NHS to respond to emergencies.

Vanguards

Were introduced in 2015 as part of the NHS Five Year Forward View. The 50 chosen vanguards are tasked to develop new care models and redesign the health and care system. It is envisaged that this could lead to better patient care and service access.





How is the NHS regulated?

Responsibility for regulating particular aspects of healthcare is now shared across a number of different bodies, such as:

- The Care Quality Commission (CQC).
- NHS Improvement – an umbrella organisation that brings together Monitor, NHS Trust Development Authority, Patient Safety, the National Reporting and Learning System, the Advancing Change team and the Intensive Support Teams.
- Individual professional regulatory bodies, for example the General Medical Council, Nursing and Midwifery Council, General Dental Council, Health and Care Professions Council.
- Other regulatory, audit and inspection bodies – some of which are related to healthcare and some specific to the NHS.



Why do we need to think about how people with a learning disability access the NHS?

Fact:

People with a learning disability must be involved in all decisions about their health, and be in control over these choices.

History or still continuing today?

In March 2007, Mencap published “Death by Indifference”, which reported the deaths of six people with a learning disability; deaths that the six families involved and Mencap, believed were the result of failings in the NHS. The report highlighted the tragic consequences of the healthcare inequalities experienced by people with a learning disability. These inequalities had been known about for years, but it took the deaths of Emma, Mark, Martin, Ted, Tom and Warren to bring about change.

In January 2012 an article was published in The Guardian based on 74 other deaths which highlighted that the NHS continues to fail people with a learning disability.

Further reports have shown that the NHS continues to fail people with a learning disability who have the same human rights as anyone else to pursue a fulfilling life.

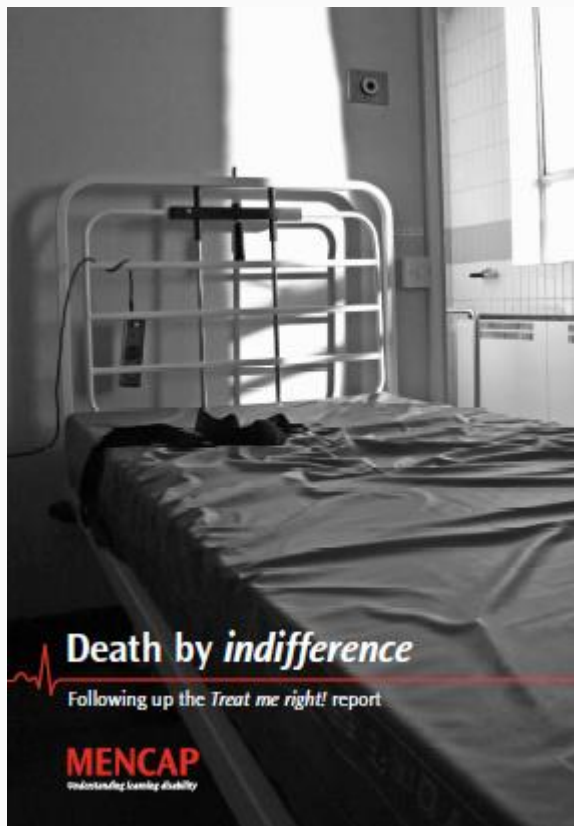
Why do we need to think about how people with a learning disability access the NHS?

Some of the barriers to equal access to healthcare faced by people with a learning disability are:

- Lack of information that is easy to understand.
- ‘Diagnostic overshadowing’ - when signs and symptoms are mistakenly attributed to the person’s learning disability.
- Family carers and others who know the person well are not listened to when they are often able to describe changes in the person in a way that will aid diagnosis.
- A hospital might assume that the person has 24-hour support, when in fact they only get a few hours’ support a week and will need some extra help to follow the post-discharge treatment plan.



Why do we need to think about how people with a learning disability access the NHS?



- Denied access to healthcare because their health needs are considered “too complex”.
- Unable to access healthcare because the right clinical procedures are not in place to adequately support their needs.
- Lack of organised and pre-planned systems designed to address the needs of persons with a learning disability.
- Attitudes that are negative and place a perceived value on quality of life without getting to know the person.
- Failure to recognise particular issues experienced by people with a learning disability who are ageing.
- Learning disability is still not clearly distinguished from mental illness.



How does The Equality Act 2010 ensure people with a learning disability have equal access to healthcare?

The Equality Act 2010

Protects people from being discriminated against because of their disability. The Equality Act replaced previous laws protecting people from discrimination, including most of the Disability Discrimination Act.

A person is defined as being disabled under the Equality Act if:

- They have a physical or mental impairment.
- The impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

For an impairment to have a "substantial" effect, it must have more than a minor or trivial effect on someone's ability to do everyday tasks such as preparing food, having a conversation, getting washed, walking or using transport. "Long term" means the impairment must last at least 12 months or be expected to last at least 12 months.



How does The Equality Act 2010 ensure people with a learning disability have equal access to healthcare?

The Act protects adults with disabilities from discrimination which includes:

- **Direct Discrimination:** Treating a person worse than someone else because they are disabled.
- **Indirect Discrimination:** Putting in place a rule or way of doing things that has a worse impact on someone with a disability than someone without one, when this cannot be justified.
- **Discrimination arising from disability:** Treating someone with a disability unfavourably because of something connected with their disability when this cannot be justified.
- **Failing to make reasonable adjustments:** For example not adapting to a person's current method of communication or not using picture aids to support a person to communicate what they need in a way that makes sense to them.

To ensure a person with a learning disability can use the services of a healthcare provider, as far as is reasonable to the same standard as a non-disabled person, the healthcare provider must make **reasonable adjustments**.

What are reasonable adjustments?

The Equality Law says to bring about equality for disabled people this may mean changing the way in which services are delivered. This is known as the '**duty to make reasonable adjustments**' - a duty is something someone must do.

The NHS has to follow the laws about being fair to everyone.

It also means making alterations to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities. As far as possible, the NHS has to think about what might be needed in advance, not wait until people get into difficulties or ask for help to use the health care service.

A reasonable adjustment could also be adapting to a person's Communication needs so they are always given an opportunity to tell you how they are feeling and what is important to them.





What are reasonable adjustments?

For example:

A community nurse makes a home visit to a person with a learning disability and dementia to dress a pressure ulcer. The nurse knows that the person gets anxious when they know that this is going to happen and may not allow the ulcer to be treated.

The nurse does not report this as a refusal of treatment, which may result in discharge from the district nurse service, as they might with a non-disabled patient. In behaving like this, the nurse has made a reasonable adjustment to the standards of behaviour they apply.

The Equality Law allows a healthcare provider to treat disabled people more favourably than non-disabled people. The aim of the law is to remove barriers that people with disabilities would otherwise face to accessing services.

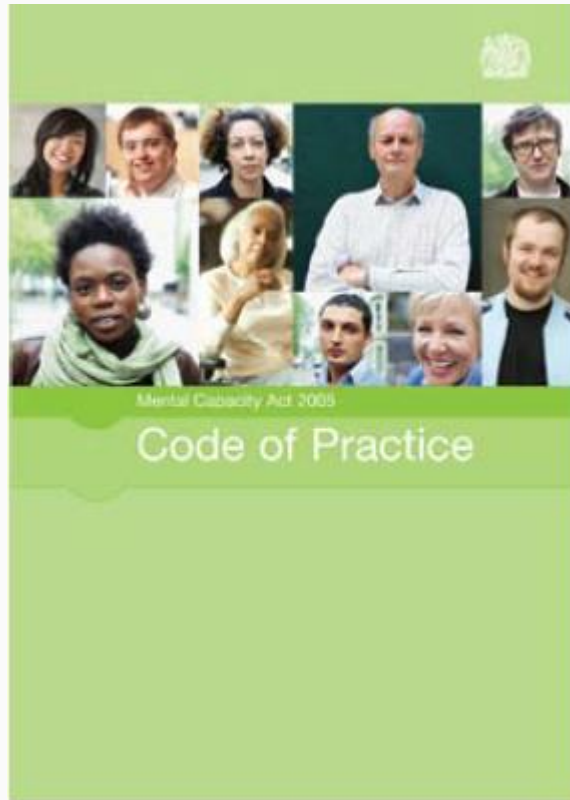


What are reasonable adjustments?

Here are some other examples of reasonable adjustments:

- Providing ramps and stairway lifts
- Making doorways wider
- Installing automatic doors
- Providing more lighting and clearer signs
- A portable induction loop for people with hearing aids
- British Sign Language interpreters
- Providing information in alternative formats such as Braille or audio CDs
- Extra staff assistance or a supporter's presence during an appointment
- Staff training to understand learning disability
- Staff training to understand dementia
- An integrated Mental Health and Learning Disabilities Service care pathway for people with dementia
- Multiple investigations in one day (when they usually would be done over a few days)
- First, last or a double appointment
- Support prior to an appointment i.e. this may be a visit to explain what will happen, a visit to the clinic or ward or scanner
- Meet the needs of carers or families if required to stay with person, e.g. breaks, food and drink

The Mental Capacity Act 2005 and access to healthcare



Under the Mental Capacity Act 2005 a person must be assumed to have capacity to make a decision unless proven otherwise.

‘All practicable steps’ must be taken to give them information in a way they understand and support them to make such decisions.

Sometimes health professionals assume that a person with a learning disability lacks capacity.

This means they do not make adequate efforts to explain information and options or to support someone to make a decision for themselves.



The Mental Capacity Act 2005 and access to healthcare

Similarly, health professionals may over-estimate the ability of a person with learning disabilities to process and retain information.

This can mean that a person seems to understand information about their health or instructions about treatment, but does not.

People may be able to make some decisions and not others, and capacity may fluctuate.

Remember no-one can 'give consent' on behalf of an adult.

Where a person is unable to make a particular decision about treatment, it may be necessary for clinicians to consult with the person and those who know them best and make a best interest decision.



What to do if things do not go well: The NHS Complaints process

If you are not happy with the health treatment or care that someone you support has received from the NHS, it is their right to have any concerns investigated and to be given a full and prompt response.

The NHS has a two stage complaints process - a local review and then an Independent Review by the Parliamentary Health Service Ombudsman.

If you want to make a complaint about the treatment someone you support has received in NHS care, you should put this in writing and send it to the Chief Executive of the Trust responsible for that hospital or the person responsible for commissioning the service.

You need to make the complaint within 12 months of the incident.

If you are not satisfied with the response to your complaint then you have the right to request an Independent Review of your complaint by the Parliamentary Health Service Ombudsman. This request must also be made within 12 months of the incident.



What to do if things do not go well: The NHS Complaints process

You can also share your own experience of a hospital or GP service that you have experienced with the Care Quality Commission.

There is also a service available called PALS (Patient Advice and Liaison Service). This will provide confidential advice, support in health related matters. You can find your nearest office on the NHS Choices Website.

Your local Healthwatch acts as the “consumer champion” for health and social care. You can contact them to give feedback and/or for support in making a complaint.



healthwatch

**It's time to
have your say**



Top Tips to involve someone you support in their health care

- Understand and apply the Mental Capacity Act. This means you may need to challenge the assumption because someone has a learning disability does not mean they do not have capacity nor cannot be involved in decisions.
- Include the support needed to attend health appointments in their Person Centred Plan and include all the reasonable adjustments needed from Health Care providers.
- Ensure their health history is clearly recorded and shared with health professionals.
- Prepare for any health appointments with the person – what will be discussed, how to make the appointment as accessible as possible, questions to ask, how they want you to support them, any questions they want you to ask on their behalf, what to do if they don't understand what is being said to them.



Top Tips to involve someone you support in their health care

- Support the person to attend all appointments and advocate for any reasonable adjustments needed to make this happen.
- Request easy read information about relevant health conditions and any treatments or investigations to share with the person you support before or between appointments.
- With the person's agreement, or as a best interest decision, ask the Health Professional to put onto electronic records or the person's health record, any reasonable adjustments needed to ensure these are always considered by all health professionals (this is also part of the NHS Accessible Information Standard – for example easy read letters).
- Find out if your local area has a person called a **Learning Disability Liaison Nurse or Acute Liaison Nurse** (sometimes they are called a **Health Facilitator**). They may work in the Community Learning Disability Team, GP Practice or General Hospital use this link to find out: <http://www.improvinghealthandlives.org.uk/aln/>

In Summary

- The founding principle of the NHS is that it is free at the point of delivery and available to everyone. We expect everyone to be treated with dignity and respect. This includes people with a learning disability.
- It is well known that people with learning disabilities have poorer health and die younger than other people who do not have a learning disability. The health inequalities faced by people with learning disabilities are often preventable and arise from barriers they face in accessing timely, appropriate and effective healthcare.
- You have a key role to support people with their health and advocate that they receive equitable access to healthcare.



Our Health Our Care



Other modules this links to:

Challenging Discrimination and Stigma –Theme 1 – Fit for the Future

Dignity, Respect and Compassion – Theme 4 – Good Support

Who Else Can Help? - Theme 3 – Health and Wellbeing

References

<https://www.theguardian.com/society/2012/jan/02/nhs-accused-disabled-patient-deaths>

<http://www.nhs.uk/chq/pages/1082.aspx?CategoryID=68>

<http://www.legislation.gov.uk/ukpga/2005/9/contents>

<https://www.gov.uk/guidance/equality-act-2010-guidance>



Produced by the MacIntyre Dementia Project with the support of an Innovation, Excellence and Strategic Development Fund Award from the Department of Health

A special thank you to Beth Britton, and for all her hard work on the MacIntyre Dementia Project.

<https://www.bethbritton.com/>

© MacIntyre 2018. All rights reserved
602 South Seventh Street
Central Milton Keynes
MK9 2JA
www.macintyrecharity.org