

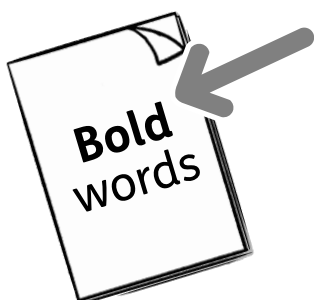
How our work affects people with a learning disability



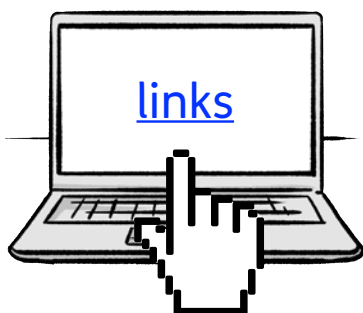
Contents

Page

Introduction	3
People with a learning disability	4
Improving people's health	8
Accessing support and care	12
Overmedication	16
Long term hospital care	18
Social care and support	22
What next?	25
For more information	26



In this easy read document, difficult words are in **bold**. We explain what these words mean in the sentence after they have been used.



Some words are [blue and underlined](#). These are links which will go to another website which has more information.

Introduction



NICE has written this report to explain how our guidance to health and care professionals affects people with a learning disability.

NICE National Institute for Health and Care Excellence

NICE stands for National Institute for Health and Care Excellence. We give guidance to health and care professionals about their work.



Mencap have talked to us about how our guidance affects people with a learning disability.

mencap
The voice of learning disability

Mencap is a charity that works to make things better for people with a learning disability.

People with a learning disability



There are about 1 million adults and about 300,000 children with a learning disability in the UK.



Many people with a learning disability have worse health than other people and die at a younger age.



On average people with a learning disability die more than 20 years younger than other people.



Healthcare

People with a learning disability often don't get the same healthcare as other people.



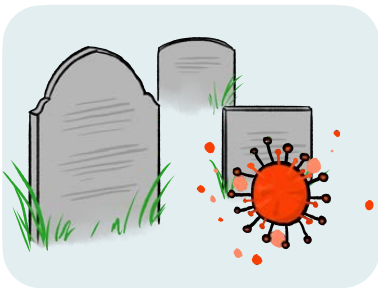
People with a learning disability are more likely to die from a health problem that could have been treated.



Many people die because the right treatment was not given at the right time.



People with a learning disability from an Asian family background are much more likely to die than people with a learning disability from a white family background.

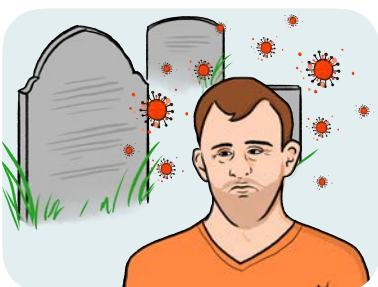


COVID-19

A lot of people with a learning disability died from **COVID-19** in 2020.



COVID-19 is also called Coronavirus. It is an illness that has spread around the world. It can affect your lungs and breathing.



In the spring of 2020, people with a learning disability were 6 times more likely to die from COVID-19 than other people.



Mental health hospitals

Over half of the people with a learning disability or autism who are in a mental health hospital have been there for more than 2 years.



Complicated health issues

Many people with a learning disability have more than 1 health condition. Some people have a mental health condition as well as other health issues.



Many people have as many as 10 long-term health conditions at the same time.



Many people with a learning disability have a lifestyle which isn't as healthy as it could be.



Some people with a learning disability have behaviour which makes it hard for health and care professionals to work with them.

Understanding people with a learning disability



Some people with a learning disability don't get the best healthcare, because health professionals don't:

- know how to communicate with them.
- understand how to help them.



Our guidance and advice

We have guidance and advice about care for people with a learning disability.



You can see it on our website:

[www.nice.org.uk/guidance/
population-groups/people-with-
learning-disabilities](http://www.nice.org.uk/guidance/population-groups/people-with-learning-disabilities)

Improving people's health



Learning disability health checks

We think that people with a learning disability should have a yearly health check.



With a yearly health check we can find and start to deal with health problems before they become too serious.



We have written guidelines for health and care staff which say how they should check for:

- physical health problems.
- mental health problems.



More people with a learning disability are having a yearly health check.



But nearly half of people with a learning disability are not getting a yearly health check.



More people with a learning disability are having a health check in some parts of England than in others. In some areas, only a few people are getting a yearly health check.



We want a lot more people with a learning disability in all areas of England to get a yearly health check.



Cancer screening

Cancer screening is a check to see if you are starting to get cancer.



We can treat cancer much better if we find it quickly, before it gets very serious.



Fewer women with a learning disability get screening for breast cancer than other women.



We think that older people with a learning disability should be offered the same regular cancer screening as other older people.



Health action plan

Many people with a learning disability have a health action plan.



This plan explains what all the different health and care professionals have to do to keep you healthy.



Your health action plan is written by you and your doctor.



We think that any health issues that are found during your annual health check should be put into your health action plan.

Accessing support and care

Your health record



Your health record is the information that your doctor keeps about your health and all your treatment and health checks.



All the health services that treat you should be able to see your health record.



If you have a learning disability, it should be written on your health record.



We think that health and care managers should use health records to see how many people with a learning disability live in their area.



They should use this information to plan better health and care services.

Most health records don't say if you have a learning disability



Only about a quarter of the health records of people with a learning disability say that they have a learning disability.



This means that:

- many people are not getting the health care that they should get.



- managers are not setting up the right services for people.

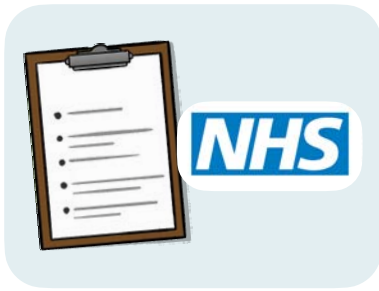
What health and care staff should do



Many health and care staff don't know how to tell if someone has a learning disability.



Health and care staff should find out how to do this.



NHS England has written guidance to help health professionals know if someone has a learning disability.

What people with a learning disability should do



Many people with a learning disability don't ask their doctor to make sure that their health record says that they have a learning disability.



People with a learning disability should ask their doctor to make sure their health record is correct.



Mencap has written information to help people with a learning disability to do this.

Reasonable adjustments



The law says that services must make changes so that disabled people get the same service as everyone else.

These changes are called reasonable adjustments.



The disabled person can ask for the changes that they need.



Having information in a way that you can understand is a reasonable adjustment.

Overmedication



Overmedication is when someone is given more medication than they need.



People with a learning disability have been given certain medicines when they don't need them.



Psychotropic medicines

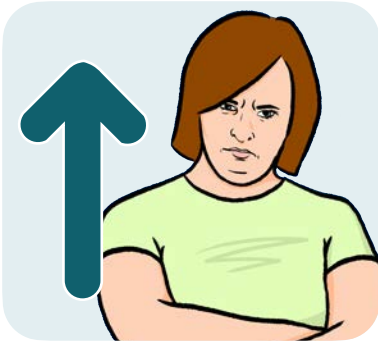
Psychotropic medicines help people with certain mental health problems. They help people remain calm.



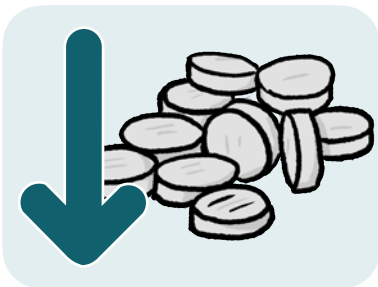
Some doctors give psychotropic medicines to people with a learning disability who don't have a mental health problem.



About 30,000 adults with a learning disability who don't have a mental health problem are given psychotropic medicines.



Psychotropic medicines are being used with people with a learning disability much more than with other people.



Reducing overmedication

The NHS has been trying to reduce the amount of psychotropic medicines being given to people with a learning disability.



But, so far, it has only reduced a little bit.



STOMP

STOMP stands for Stopping the Overmedication of People with a learning disability or autism.



The NHS wants to stop people with a learning disability from being given any medicines that they don't need.

Long term hospital care



People should only go into long term hospital care if a proper **assessment** has been done, and all other options have been tried.



An **assessment** is when you meet with a health professional or social worker to work out what care or support you need.



Some of these long term hospitals are called Assessment and Treatment units.



Parliament has found that people are being kept in Assessment and Treatment Units and other mental health hospitals when they shouldn't be.



Many people are being kept in these places for over 5 years.

Parliament says that some people in long term hospital care are:



- not being given their **rights**.

Rights are the things that every person should have or be able to do, by law.



- being kept there against the law.



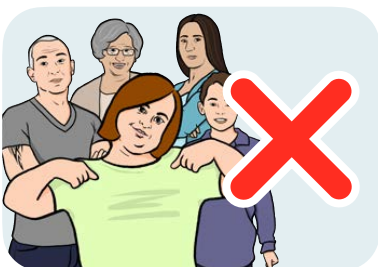
- sometimes being kept alone for long periods of time.



- likely to suffer from abuse.



- likely to try to hurt themselves.



- not allowed to have a family life.



Parliament says that there are not enough places for people to live safely that are close to their friends and family.

We have written guidelines that explain:



- what health staff should do to stop people going to a long term hospital or Assessment and Treatment Unit.



- that people should be able to get a mental health service when they need it.



- that if a person with a learning disability does go into a mental health hospital, health staff should straight away write a plan for how they are going to move out, back to their local community.



We think that local councils and health services should work together to make sure there are proper local services for adults and children with a learning disability who have difficult behaviour.

Care and Treatment Reviews



A **Care and Treatment Review** is when you have a meeting with your health and care professionals to look at your care and support.



We think that these Care and Treatment Reviews should look at how to care for you in your local community.



Only about 2 thirds of people in a mental health hospital have had a Care and Treatment Review in the last 6 months.

Social care and support

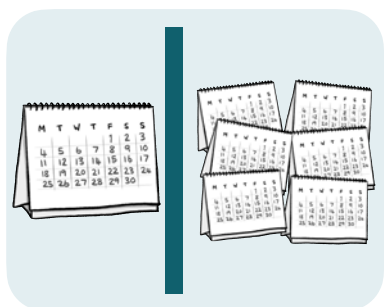


Social care is care and support that is given to people to help with day to day living.

Social care helps people to live in the way they choose.

It can be support with:

- finding friends or a relationship.
- taking part in activities in the local community.
- washing or dressing.



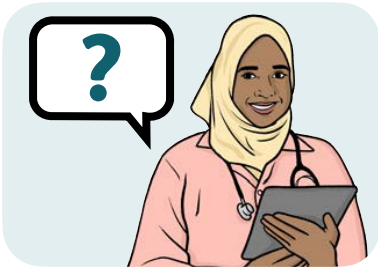
Social care could be for only a short period of time, or for your whole life.



Growing older with a learning disability

We have written guidance on how to give care and support to people with a learning disability as they grow older:

www.nice.org.uk/guidance/ng96



What people think about care and support

The NHS asked people what they think about care and support services.



Nearly everyone said that care and support helped to improve their lives.



Nearly everyone said that care and support helped them to feel safe.



About 3 quarters of people were very happy with the care and support they get.



But most people would like to have more control over their daily life.

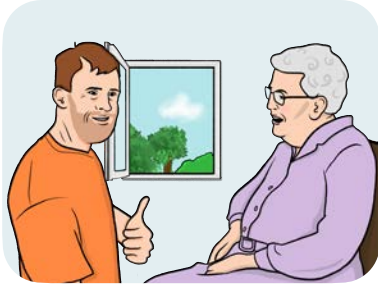


We think that care workers should think about what people want from their lives as they grow older. They should make sure that services help them with what they want.



Future planning

2 out of every 3 adults with a learning disability live with their families, usually their parents.



At some time the parent will be too old to look after the person with a learning disability.



If a parent dies, the person with a learning disability may have to find a new place to live very quickly.



We think that care and social workers should talk to people with learning disabilities about what they will want as they grow older.

We think that staff should look at how to help people with a learning disability:

- stay independent as they grow older.
- have the friends that will stop them being lonely in the future.



What next?



We are working with other organisations to:

- help more people to have a yearly health check.



- help services get better at communicating with people.



- provide more care and support for people to live independently in their local community.



- help health services and local councils to work better together.



- make sure we have enough workers in health and social care services in the future.

For more information



You can look at our website here:
www.nice.org.uk

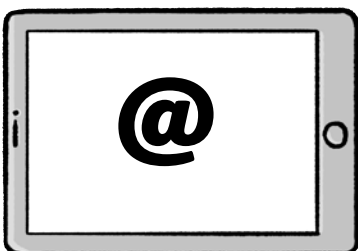
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