



Department  
of Health &  
Social Care

**NHS**  
**England**

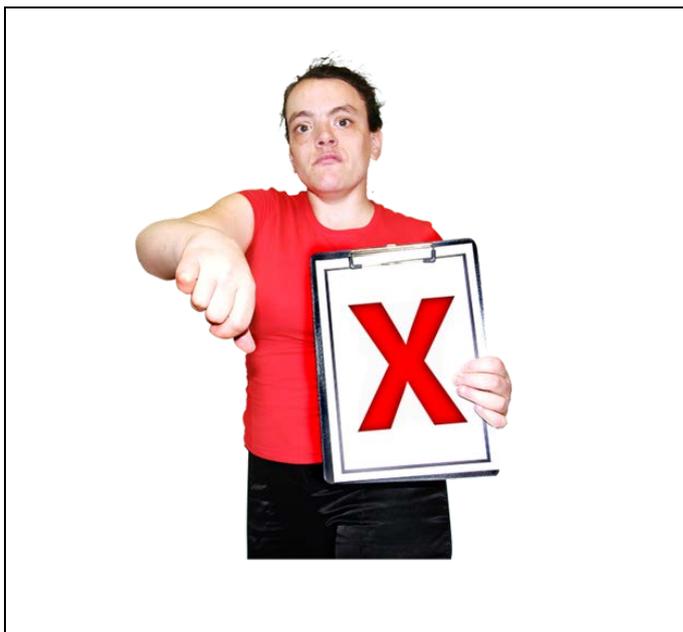
# A response to the LeDeR report on deaths of people with learning disabilities

The Government response to the  
Learning Disabilities Mortality Review  
(LeDeR) Programme Second Annual  
Report

## Easy Read

September 2018

# Introduction



We know that people with learning disability can die earlier than people without a learning disability.



The Government has asked the NHS to investigate all deaths of people with learning disability.

This project is called LeDeR.



When someone with a learning disability who is 4 or older dies, people are supposed to look at what happened.



People can tell the University of Bristol about what happened, so they can work out what was important.



In May, the University of Bristol published a report on the deaths of people with learning disability.



You can read an Easy-Read version of the report here:  
<https://www.hqip.org.uk/wp-content/uploads/2018/05/Le-DeR-annual-report-Easy-read.pdf>



The report said that more people with learning disabilities died in hospital than we would expect.



There were three main reasons why people died:

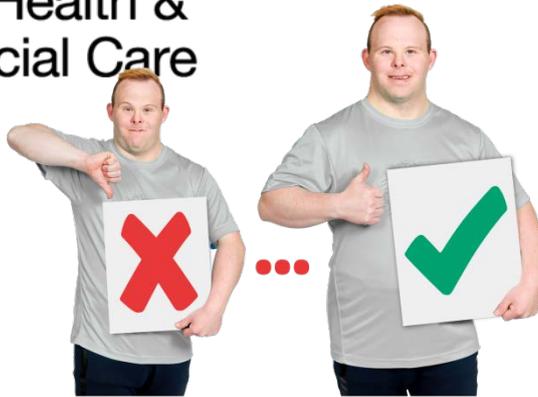
1. Problems with breathing
2. Blood or heart diseases
3. Sepsis – a serious complication of an infection.



Some of the people might not have died if they had received good quality healthcare or had been well looked after.



Department of Health & Social Care



The Government needs to do something to stop this. This report says what it will do.



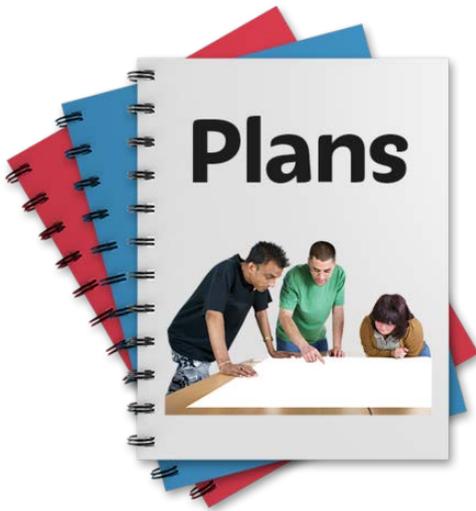
Department of Health & Social Care

**NHS**  
England

The Government has written it with other groups, like NHS England, which runs the NHS.



The University of Bristol said the Government and the NHS should do nine things. These are called recommendations.



The Government plans to do something for each of these recommendations.

## Recommendation 1



### Recommendation 1.

Communication between health and social care organisations should be better.



All services helping people with learning disability should be talking to each other, and to families and carers.



All NHS organisations have to make sure people have the information they need to stay healthy, in a way they can understand.



NHS Improvement has developed Learning Disability Improvement Standards to look at the quality of care for people with learning disability. This will improve the way services talk to each other.



**NHS**

**Improvement**



Action: The Care Quality Commission and NHS Improvement will look at how good the information is for people who access learning disability services.

## Recommendation 2

	<p>Recommendation 2.</p> <p>Health and social care records should be improved so that important information can be shared between services, using a computer.</p>
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	<p>Health and social care staff will use a Summary Care Record, a report on the computer which tells them about a person's health needs, and the care and treatment they receive.</p>
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	<p>Staff will be able to say on this report what the needs are of a person with learning disability and autism.</p>
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It will tell staff if they need to do something different to help a person with a learning disability. This is called a reasonable adjustment

It will be used to make sure that people with learning disabilities can use services as easily as everybody else does.



NHS England is also using computers to join up people's records from different services. They are testing this in five areas in England.



Action: NHS England and NHS Digital will look at how well information is shared on computers and if Summary Care Records help make services easier to use.

### Recommendation 3



The image shows a woman in a grey t-shirt with a large red heart on it, standing next to a graphic titled "Health Action Plan". The graphic includes a checklist with three items: the first is checked with a red tick, and the other two are unchecked. Below the woman is another woman in a pink t-shirt giving a thumbs up next to a large green checkmark icon.

### Recommendation 3.

Health Action Plans should be shared between services, if the person says this is OK.



The image shows two men, an older man in a dark green shirt and a younger man in a blue jacket, standing and talking. The older man is holding a piece of paper. In the background, there is a photograph of the Big Ben clock tower in London.

The Government is already working to make sure that Health Action Plans can be shared between services.



The Government wants to increase the number of people with learning disability who have Annual Health Checks with their GP.



Action: NHS England will look at the number of Annual Health Checks which are done and do more to encourage people to have them.



## Recommendation 4



### Recommendation 4.

People with learning disabilities with health problems that will last a long time need a named person to help different professionals work well together with them.



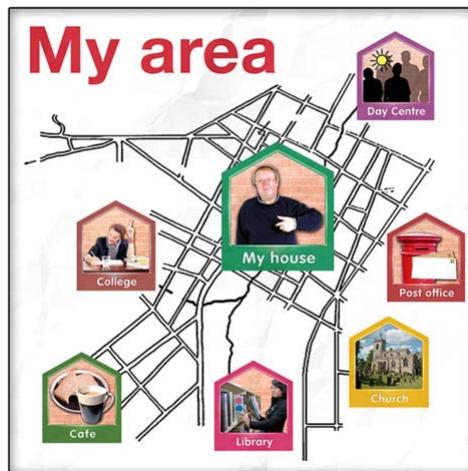
The Department of Health and Social Care has looked at how having a named social worker can support people.



Actions: The Department of Health and Social Care will share widely a report on how the named social worker can help people with a learning disability.



The Department of Health and Social Care will look at how different areas in the UK are using a named person to support people with learning disability.



## Recommendation 5

 An illustration of a woman with glasses and a red headband sitting in a wheelchair. A speech bubble above her says "I need ...". To her right is a stopwatch with a blue segment. Further right is a sign that says "easy read" with icons of people and horizontal lines representing text.	<p>Recommendation 5.</p> <p>Services must know if people need changes to the way things are usually done. These are called reasonable adjustments.</p> <p>They need to write this in people's notes and check that people with learning disabilities can use services as easily as everybody else does.</p>
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 An illustration of a woman with glasses and a red headband standing next to a laptop. The laptop screen shows the NHS logo. She is wearing a white t-shirt with a red circle containing the number '1'.	<p>NHS England and NHS Digital have a project to test a new system called reasonable adjustment flagging, which will tell staff the different support needs of each person that uses services.</p>
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 An illustration of a magnifying glass focusing on a group of three people looking at a document on a table. The document is labeled "THE PLAN". There are thought bubbles above the people.	<p>Action: NHS England and NHS Digital will test this new system, and issue guidance on it for the NHS.</p>
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## Recommendation 6

	<p>Recommendation 6.</p> <p>Those providing support to people with learning disabilities must have training about the needs of people with learning disabilities.</p> <p>The training should be provided with people with learning disabilities and their families.</p>
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	<p>The Government want all health and social care staff to have training on learning disability.</p> <p>Staff need to know how to support people with learning disability.</p>
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	<p>Training should be developed and delivered in partnership with people with learning disabilities.</p>
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**Actions:**

The Government will ask the public about proposals for all staff to have training on learning disability.



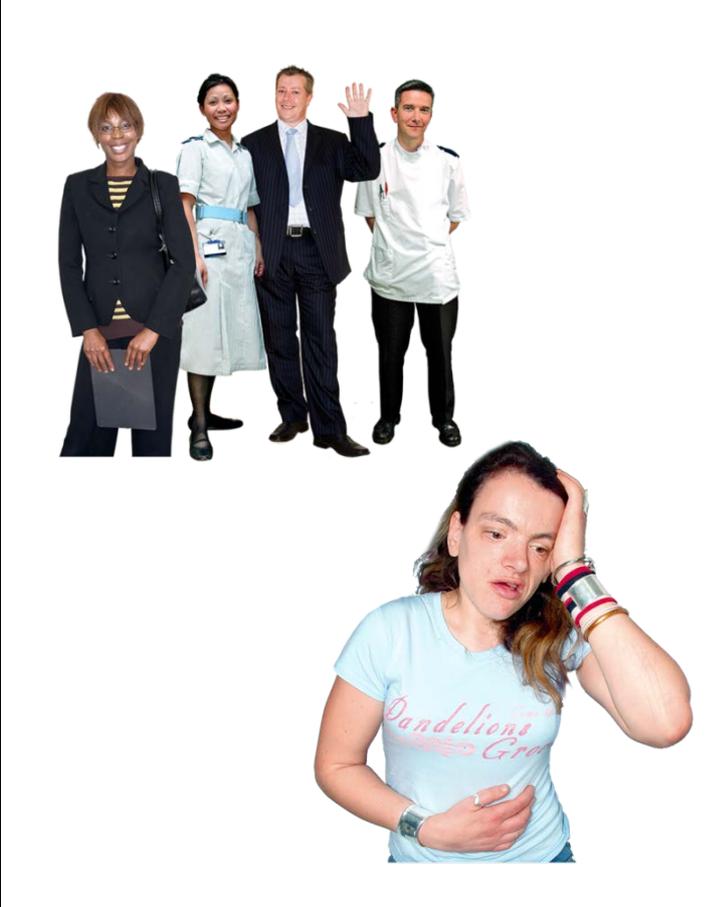
*Health Education England*

Health Education England will develop learning disability training which everyone can do.



The Care Quality Commission will make sure that training on learning disability is delivered.

## Recommendation 7

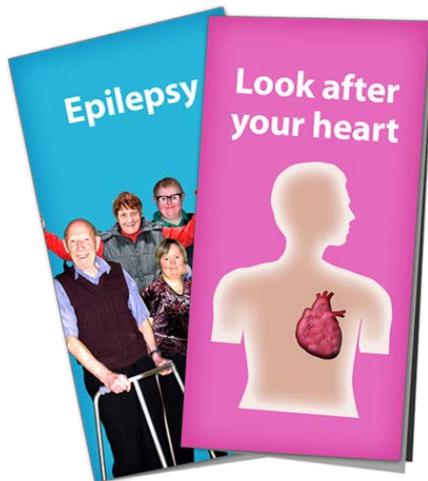


Recommendation 7.

People need to understand more about the problems with infections in people with learning disabilities.



NHS England is working to make sure that people with learning disabilities who have infections get treatment quickly.



**NHS**  
**England**

Actions: NHS England will publish guidance for services on illness like epilepsy and constipation.



**NHS**  
**England**

NHS England will report on how well people with learning disabilities with infections are supported.

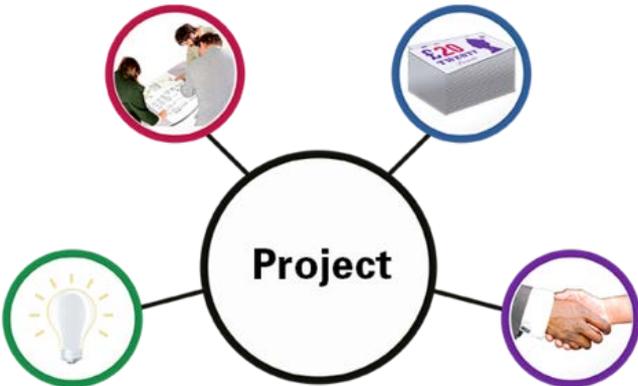




Public Health England will improve the numbers of people with learning disability being vaccinated against flu for the winter.

## Recommendation 8

 <p>The image shows the Royal Coat of Arms logo above the text 'Mental Capacity Act'. Below the text is a photograph of a man in a red shirt sitting in a blue wheelchair, shaking hands with a man in a dark sweater who is standing.</p>	<p>Recommendation 8.</p> <p>Professionals need to follow the Mental Capacity Act. Someone in each service needs to help make sure this happens.</p>
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 <p>A central circle labeled 'Project' is connected to four smaller circles, each containing an icon: a group of people, a box of 20 tablets, a lightbulb, and a handshake.</p>	<p>NHS England and the Department of Health and Social Care have lots of projects to make sure that local services follow the Mental Capacity Act.</p>
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There is a group covering England to make sure people understand the Mental Capacity Act. They will write guidance for urgent care.

There is a National Mental Capacity Forum to improve the way the Mental Capacity Act is used.



The Care Quality Commission is looking at how it can improve how the Act is applied.



## Actions:

The Department of Health and Social Care and NHS England will publish guidance on using the Mental Capacity Act.

The Care Quality Commission will make sure their staff are trained to look at the Mental Capacity Act in practice.

## Recommendation 9

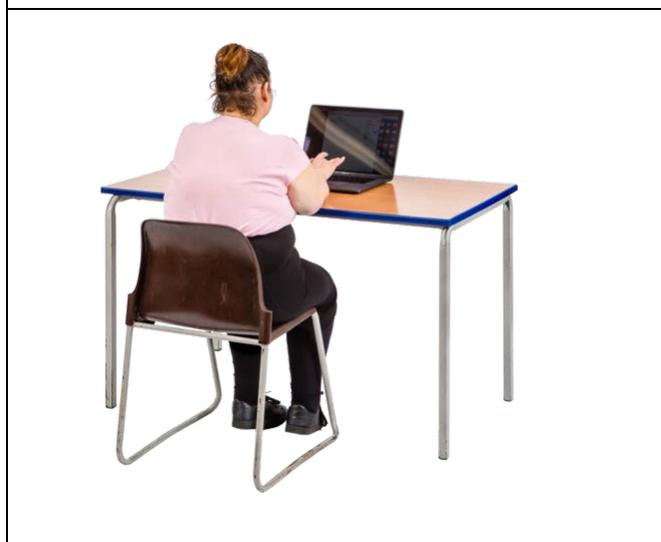


Recommendation 9.

Lots of people review deaths. We need to work together. We need to make sure that everyone is properly trained.



Health Education England has looked at the training people need to be able to review deaths of people with learning disability.



Action: Health Education England will provide training for people who review deaths which they can take on their computer.



A group of people, including people with learning disability and their families, will make sure that the Government and other organisations do all these actions.



If you want to comment on this report, please write to:

Dementia and Disabilities Unit  
Department of Health,  
1N14, Quarry House,  
Quarry Hill,  
Leeds  
LS2 7UE



Or e-mail us at:

[ddu@dh.gsi.gov.uk](mailto:ddu@dh.gsi.gov.uk)

## Who has helped with this report?

 <p>The logo for the Department of Health &amp; Social Care, featuring the Royal Coat of Arms and the text 'Department of Health &amp; Social Care'.</p>	<p>The Department of Health and Social Care is the part of the Government responsible for health services and social care.</p>
 <p>The NHS England logo, which includes a blue outline of the map of England. Below the logo are several British banknotes (£10 and £20) and a hand using a calculator with the number 12345 on the display.</p>	<p>NHS England is the organisation which runs the National Health Service.</p> <p>It handles the money which pays for health services.</p>
 <p>The Care Quality Commission logo, featuring a stylized white 'Q' on a purple background. To the left of the logo is a woman in a dark suit holding a clipboard and pen.</p>	<p>The Care Quality Commission inspects health and social care services to make sure they are safe and accessible.</p>



Health Education England trains health staff.



NHS Improvement helps hospitals to improve their care and treatment.



NHS Digital collects data on health services for the Government.