



Department  
of Health &  
Social Care

# The Government response to the third annual Learning Disabilities Mortality Review (LeDeR) Programme report



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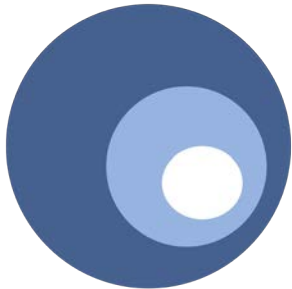


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# Introduction



The Government has asked an independent group to look at why people with learning disabilities tend to die younger than other people.



It is called the Learning Disabilities Mortality Review Programme (LeDeR).



## The LeDeR report

The programme produces a report every year. It is known as the LeDeR report.



The LeDeR report looks at all the deaths of people with learning disabilities.



It looks at whether each person got the best possible **social care** and **healthcare**.



**Social care** is support for people to live as independently as possible.



**Healthcare** is help to be as healthy as possible.



The LeDeR report also suggests things that the Government and the NHS should do.



## Deaths of people with learning disabilities

The LeDeR report says that on average, men with learning disabilities die 23 years younger than other men.



On average, women with learning disabilities die 27 years younger than other women.



Nearly half of the people with learning disabilities who died last year had good health care.



But about half of people with learning disabilities did not get the very best health care.



## This report

This is the Government's reply to the suggestions in the LeDeR report.



Department  
of Health &  
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It has been written by the Government's Department of Health and Social Care.



This reply explains:

- Where the Government agrees with the suggestions



- Where the Government has some other ideas



- What the Government is doing

# The suggestions



## Suggestion number 1:

Somebody in the Government should have the job of making sure the LeDeR suggestions are taken up.



## The Government's reply

We think that different people should be responsible for the suggestions about:

- Healthcare
- Social care



We think that **NHS England** should be responsible for the suggestions to improve healthcare.



**NHS England** is responsible for making sure all NHS organisations in England work as well as possible.



Social care is provided by local councils and many different companies and community organisations.

We can't tell them how they should run their social care.



We think that two organisations should be responsible for the suggestions to improve social care.

They are:



- The Local Government Association (LGA). This is an independent group of all local councils.



- The Association of Directors of Adult Social Services (ADASS). This is an independent charity for the directors of Social Services in each local council.





## Suggestion number 2:

**Clinical Commissioning Groups (CCGs)** should get support so they can look into why each person with a learning disability has died.



**Clinical Commissioning Groups (CCGs)** are responsible for planning and paying for healthcare services in their local areas.



## The Government's reply

We agree that CCGs should get support to do this.



This year the NHS are:

- Making sure that CCGs have people who can do this work
- Giving £5million to CCGs so they can do this work





CCGs now have to write a report every year about the deaths of people with a learning disability in their area.



### Suggestion number 3:

Services need to know which people have a learning disability.



Sometimes it is hard to know if someone has a learning disability or not.



Services often get confused when young people move from one service to another. For example from school to college to adult services.



They often get confused because different services use different words for 'learning disability'.



All services should:

- Talk about learning disability in the same way



- Agree the same rules for who has a learning disability and who has not



## The Government's reply

We agree. There are already good ways of explaining learning disability in the law and in **Government policies**.



**Government policies** are the rules that government workers have to follow.



The LeDeR group has also written a report that explains who has a learning disability and who has not.



## Suggestion number 4:

CCGs should keep records of the deaths of people with learning disabilities from black and asian minority ethnic groups (BAME).



## The Government's reply

We agree.

Some CCGs don't know about some people with learning disabilities from BAME groups in their area.



All deaths of people with learning disabilities from BAME groups should be included in the records.



There are more people with serious learning disabilities from BAME groups than the average for other people with learning disabilities.



## Suggestion number 5:

The Government and NHS should listen to families more.



## The Government's reply

We have a very good way for families to help us to make services better called "Ask Listen Do".



Ask Listen Do is a way that people with learning disabilities and their families and carers can tell the NHS what they think.



You can get more information from:  
<https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/>



Listening to families is an important part of the LeDeR programme.



## Suggestion number 6:

The Government and NHS should look at:



- How to spot when a person with learning disabilities is starting to get unwell



- Helping people with learning disabilities not to get **pneumonia**



**Pneumonia** is an illness of your lungs.



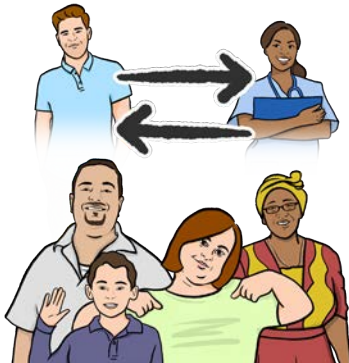
## The Government's reply

We agree that we should focus on these things.



## Suggestion number 7:

The Government and NHS should give more information about:



- How different health and social care services should work together for people with learning disabilities



- How different services should share information about people with learning disabilities



## The Government's reply

We agree.

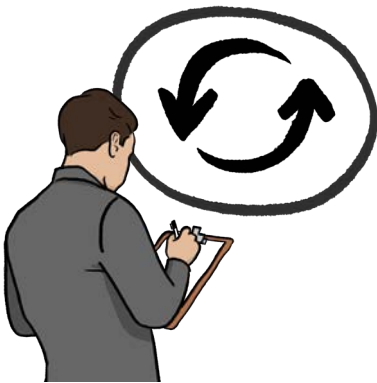


We are working with some people at Oxford Brookes University to look into the best way:

- For services to work together



- To safely and privately share information about people with learning disabilities



When they have finished their work, we will look at how we should change the way we do things.



## Suggestion number 8:

The Government should look at how services are working when a young person with a learning disability is moving up from children's services to adult services.



## The Government's reply

We agree that this is very important.

We will look at how services should work and see if they could work in a better way.



## Suggestion number 9:



The Royal College of Paediatrics and Child Health should look at better ways for health services to help young people with learning disabilities who are moving from children's health services to adult health services.



The Royal College of Paediatrics and Child Health look into new ways to help children who have health problems.



## The Government's reply

We agree that this is very important.

The Royal College of Paediatrics and Child Health is working to provide better information about this.



## Suggestion number 10:

The Government should tell doctors that it is wrong to:



- Say that someone should not be kept alive because they have learning disabilities



- Say that someone has died because they have learning disabilities



## The Government's reply

We agree that it is wrong to treat people worse because they have a learning disability.



Doctors should never say that someone has died from learning disabilities.



## Suggestion number 11:

The doctors who look at why someone has died, should look into any cases where a hospital doctor has said that a person with learning disabilities should not be kept alive.



## The Government's reply

Doctors who look into why someone has died, should always look into cases where a doctor has done something wrong.



## Suggestion number 12:

The Care Quality Commission (CQC) should ask to look at the treatment of people with a learning disability.



**The Care Quality Commission (CQC)** inspect hospitals and healthcare organisations for the Government.



## The Government's reply

The CQC should always look into cases where there maybe something wrong with someone's treatment.

# What the government is doing



Since the last LeDeR report was written in May 2018, the Government has been:



- Helping services to work together by giving some people with a learning disability their own Social Worker



- Looking at the best way for organisations to work together



- Looking at ways to train everyone who works in health and social care about people with learning disabilities



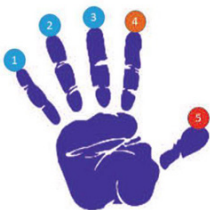
- Writing to organisations that work with people with learning disabilities to make sure they give their staff the right training



- Looking at what training social care workers have had



- Looking at the work of the **National Mental Capacity Forum**



**The National Mental Capacity Forum** looks at issues for people who can't make decisions for themselves.

# For more information



If you need more information please go to:

Website: [www.gov.uk/dhsc](http://www.gov.uk/dhsc)