



The Learning Disabilities Mortality Review  
(LeDeR) Programme

Easy Read

University of  
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Fry Centre for  
Disability Studies



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# Annual Report

## December 2017



The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England.

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# Some of the words we use

Word	Meaning
Inequality	Not everyone having the same chance
General population	Everyone in England
Care Quality Commission	Checks up on the care provided in care homes, hospitals and GP surgeries
Review	Checking up on
Reviewer	The person who checks up on something
Respiratory System	To do with breathing and the lungs
Circulatory System	To do with the blood and the heart
Sepsis	An infection that spreads through the body
Mental Capacity Act	The law about how to decide if someone can make a decision or choice at a certain time
Coordination	People working together

# Chapter 1. Introduction



Not everyone shares the same chances of having good health. We call this **inequalities in health**.



People with learning disabilities tend to have poorer health than people in the general population.

This is an inequality, and it is unfair.



Often, people with learning disabilities also die at an earlier age than people in the general population.



Some of the people with learning disabilities who die could have received better healthcare.



The Care Quality Commission says that hospital Trusts are not doing enough to look at the deaths of people in their care

They need to learn what they could do better, and to make changes to improve care.



The government has set up a programme called **Learning from Deaths** to help with this.



The new guidance says that all deaths of people with learning disabilities aged four years and older should be checked up on as part of the LeDeR programme.

# Chapter 2. The LeDeR programme



The LeDeR programme is based at the University of Bristol. It is funded by NHS England.



The LeDeR programme helps local areas to **review** the deaths of people with learning disabilities.

This means having an independent person looking at what happened before somebody died.



The LeDeR programme has set up a system for reviewing deaths. It collects information about why people have died.

And what we could do to help other people with learning disabilities live longer.



### **How this Works...**

Anyone can tell us about the death of someone with learning disabilities

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Then, someone checks up on what happened before the person died.

The checks are done by someone who did not know them.

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They speak with family and others who worked with the person - for example, doctors or social workers.

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Then they write a report. They say if they think that any changes are needed to services, to make them better.



Sometimes, the reviewer decides to have a meeting.

Everyone who was involved with the person is invited.

They talk about what happened and decide if they need to make any changes to services.

Where changes are needed, an action plan is set up in the local area.

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We look at some deaths in more detail.

This year we are taking a closer look at the deaths of:

- People who were aged 18 to 24 years when they died, or
  - People from a Black or Ethnic Minority group
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The LeDeR programme includes people with learning disabilities and their families in the work.

That is very important to us.

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We wrote a report about setting up the LeDeR programme last year (2016). You can read this on our website.





This year we have tested out how to do reviews of deaths in four areas of England. We have trained over 1,000 reviewers, and updated our process for reviewing deaths. The LeDeR programme will be running across the whole of England from the end of 2017.

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Our biggest challenge is helping reviewers to get reviews completed.

Some have found it difficult to have the time to do reviews when they have their usual job to do. some give up being a reviewer because of this.

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# Chapter 3. What the reviews are telling us



From July 2016-November 2017, we were told about 1,311 deaths of people with learning disabilities.



## Who lets us know when someone with learning disabilities dies?

Mostly, this has been people who work in community learning disabilities teams, or staff from hospitals.



## Who were the people who died during this period?

Just over half were men.

Most were single.

Most were White.

Most had moderate or severe learning disabilities.

Most lived with other people.



### Where did they die?

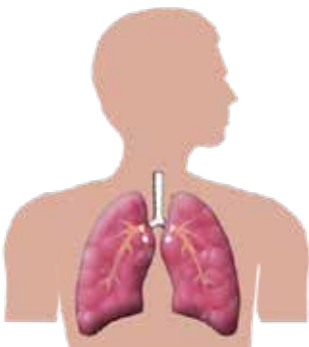
More people with learning disabilities died in hospital than we would expect.



### How old were they when they died?

The average age of death was 58 years.

People with more severe learning disabilities had shorter lives.



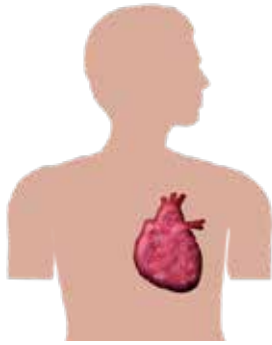
### Cause of death.

The causes of death that were most common:

1. Diseases of the **respiratory** system. These are to do with breathing and the lungs. They were mentioned in about 3 out of 10 deaths.



Lots of these problems were caused by infections or by people having food or drink 'going down the wrong way'.



2. Diseases of the **circulatory** system, which involves the blood or the heart (for example heart disease).

They were mentioned in 1-2 out of 10 deaths.

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**Sepsis** was mentioned in about 1 out of 10 deaths. It is caused by an infection, which spreads through the body.

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**Did any of these people experience poor care?**

Some people might not have died if they had received good quality healthcare.

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The reviewers felt that 6 people had received poor standards of care.

# Chapter 4. Learning from the reviews



From the reviews looked at so far, many have made recommendations for changes that need to be made to improve services.



Many of these focus on the need for better communication, and coordination of care.

An example of this would be: carers talking to hospital staff when someone goes into hospital.



This is to make sure they know the important information about what someone needs, and what they like.

Good communication is needed for people when they come out of hospital.



Another recommendation that was often made was for more training for staff. Training is required for staff, to raise awareness of the needs of people with learning disabilities.



An example of this is that staff need to understand that some people may communicate through their behaviour.

Changes in a person's behaviour could mean that they are ill.



Training is also needed so that health and care workers know about each other.



Training is needed about Annual Health Checks too.



Another recommendation was that lots of staff need to have a better understanding of the Mental Capacity Act.

This is important because the law says that someone who is able to understand the information, can then make their own decisions.



If someone cannot understand their choices about treatment, then there is a process that staff have to follow. They need to make decisions in their best interests.

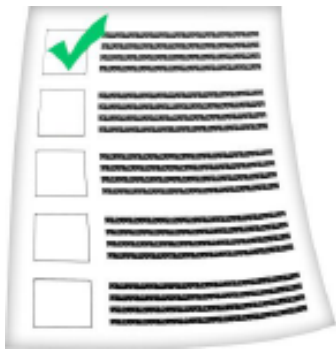


Staff need to write this clearly in a person's notes. They must explain how the decision about a person's care was made.



Because of these recommendations, changes are now being made to improve services in local areas.

# National recommendations



By looking at the findings from all of the reviews together, we can see the changes that need to be made across the whole country.

We think that these are:



1. There should be a senior person in each health and social care service to make sure that communication between services is good.



2. Health and social care records should be improved so that important information can be shared between services, using a computer.



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





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.



5. Services must know if people need changes to the way things are usually done. They need to write this in people's notes, and check that people with learning disabilities can use services as easily as everybody else.



6. Those providing support to people with learning disabilities must have training about the needs of people with learning disabilities.  
The training should be provided with people with learning disabilities and their families.



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



8. Professionals need to follow the Mental Capacity Act. Someone in each service needs to help make sure this happens.

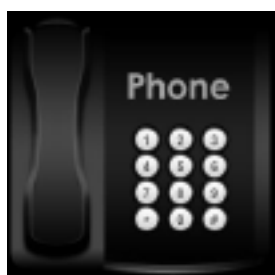


9. Lots of people review deaths. We need to work together. We need to make sure that everyone is properly trained.



Next year the LeDeR programme will be checking up on what services are doing to make things better for people with learning disabilities

# Thank-you for reading this report.



For more information about the LeDeR programme, please contact us:

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Or visit our website at

**[www.bristol.ac.uk/sps/leder](http://www.bristol.ac.uk/sps/leder)**



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