The Learning Disabilities Mortality Review (LeDeR) Programme

University of BRISTOL

Annual Report

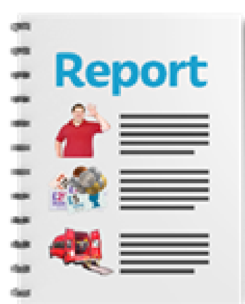
Easy Read - 2018

University of Bristol
Norah Fry Centre
for Disability
Studies

easy read

This information can be made available in formats such as large print, and may be available in alternative languages, upon request

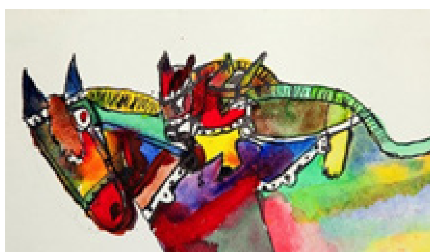
The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England.



This is the third yearly report of the Learning Disabilities Death Review (LeDeR) programme in England.

The report was made available to the public in May 2019.

It tells you about the deaths of people with learning disabilities. The deaths were checked in 2018.



We would like to thank Artists First, a group of artists with learning disabilities in Bristol, for providing some of the pictures used in this report.

You can find more information about them at: **www.artistsfirst.org.uk.**

This report is about people who have died, who were special to their families and friends.

Thank you to those families who have shared their stories.

Contents

Some difficult words we use 4

Chapter 1 Introduction 5

Chapter 2 The deaths the LeDeR programme has been told about 7

Chapter 3 The people who died 8

Chapter 4 The deaths of people with learning disabilities 9

Chapter 5 The quality of care given to people who have died 14

Chapter 6 The deaths of children 17

Chapter 7 What reviewers think needs to change 19

Chapter 8 What we think needs to change 20

Thank you 24

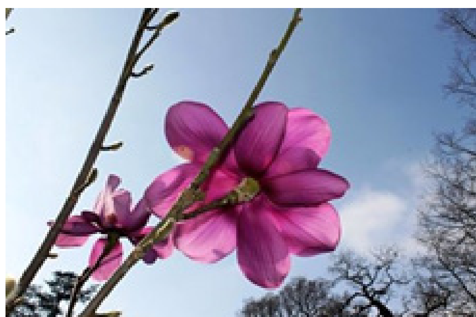
Who pays for our work? 25

Where you can get more information 25

Some difficult words we use
(these words are in bold the first time they are used)

Average age	To work out the average age we add up all the ages of everyone who has died. Then we divide that number by the number of people who have died.
Antipsychotic medication	Medicine given to someone with mental health problems. It is sometimes given when a person has behaviour that is difficult for the people who support them.
Aspiration Pneumonia	An infection in your lungs caused by food or drink going down 'the wrong way'.
Care Quality Commission	The Care Quality Commission inspects health and social care services in England.
Coroner	An official who looks into why somebody died.
Dementia	A group of diseases that make it harder for somebody to think and remember things.
Do Not Resuscitate	If the doctors think that a person's heart would not be able to be re-started, they fill in a Do Not Resuscitate form.
Epilepsy	Seizures, which are unusual flashes in the brain, which stop it working properly for a while.
Initial review	A first check on a person's death.
Ischaemic heart disease	A type of heart problem when the heart does not get enough blood.
Medical Examiner	Medical examiners are starting work in some places in England. They are doctors who will be looking into deaths to see if there were any problems.
Pneumonia	An infection in the lungs caused by bugs called 'bacteria'.
Review	A check on a person's death.
Reviewer	Someone who checks up on a person's death.
Sepsis	An infection that affects the whole of the body.

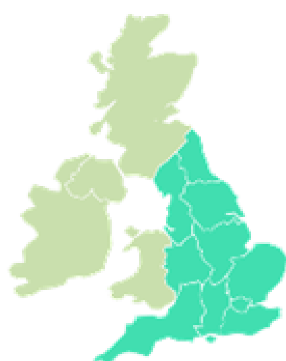
Chapter 1: Introduction



The aims of the LeDeR programme are:

1. To help improve health and social care services for people with learning disabilities.
2. To stop people with learning disabilities dying too soon.

All deaths of people with learning disabilities (aged 4 years and over) have a **review**.



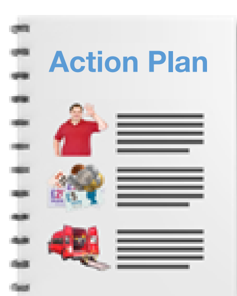
Everyone in England has their death looked at in the same way.

Every death has a first check. We call this an '**initial review**'.

If any problems are found, the **reviewer** does more checks.

They talk with other people at a meeting. Everyone who supported the person is invited to the meeting.

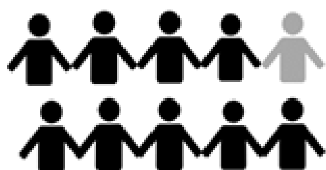
They talk about what happened and decide if they need to make any changes to services.



If changes are needed, an action plan is set up.

Chapter 2 - The deaths the LeDeR programme has been told about

The LeDeR programme has been told about the deaths of 4,302 people with learning disabilities.



This is about 9 out of every 10 deaths of people with learning disabilities.

One out of every four of these deaths has been reviewed.

Some deaths are still waiting to be reviewed.

Last year we said that some reviewers found it difficult to get time to do reviews when they have their usual job to do.

This is still a problem and it needs to be made better.

Chapter 3 - The people who died

Six out of every 10 of the people who died were male.

Four out of every 10 of the people who died were female.

There were not as many adults from Black, Asian and Minority Ethnic groups as we think there should be.

Three out of every 10 people had mild learning disabilities.

Three out of every 10 had moderate learning disabilities.

Three out of every 10 had severe learning disabilities.

One out of every 10 had profound or multiple learning disabilities.

Chapter 4 - The deaths of people with learning disabilities

The age of people when they died

The **average age** at death was 59 years.

Last year the average age at death was 58 years.

The month of the year when people died

More people died in October, November and December than we expected.

Where did people die?

More people died in hospital than we expected.

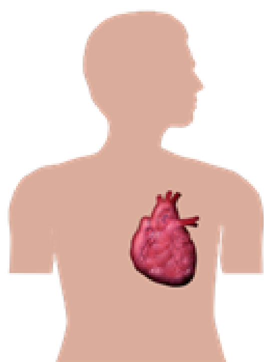
Was a coroner told about their death?

Fewer people had a coroner told about their death than we expected.

End of life care

When we know that people are going to die soon, they have an end of life care plan.

About half of all the people who died had an end of life care plan.

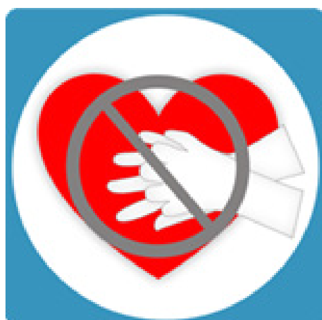


Restarting a person's heart if it stops

Sometimes, doctors can restart a person's heart if it stops. This is not possible if the person is too ill.

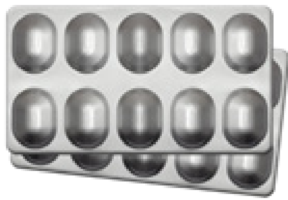
If the doctors think that a person's heart could not be restarted the doctor signs a form.

This is called a **Do Not Resuscitate** form.



Most doctors filled this form in correctly.

A few doctors did not. They gave the reason for not restarting a person's heart as being because they had learning disabilities.



Medication

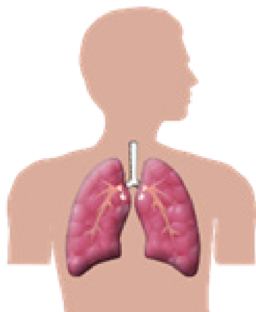
About one in every five of the people who died were taking a type of medication called ‘**antipsychotic medication**’.

This is given when someone has mental health problems.

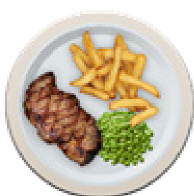
It can sometimes be given when a person has behaviour that is difficult for the people who support them.

Causes of death

The six most common causes of death were:



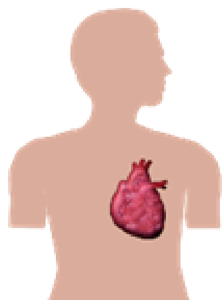
1. **Pneumonia.**
   This is an infection in your lungs caused by bugs called ‘bacteria’.



2. **Aspiration pneumonia.**
   This is an infection in your lungs caused by food or drink going down ‘the wrong way’.

3. **Sepsis.**
   This is an infection that affects the whole of your body.

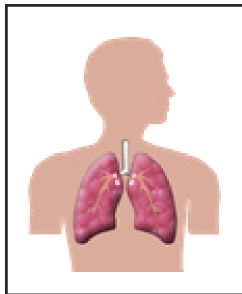
4. Different kinds of **dementia**.
   Dementia is a group of diseases that make it harder for you to think and remember things.

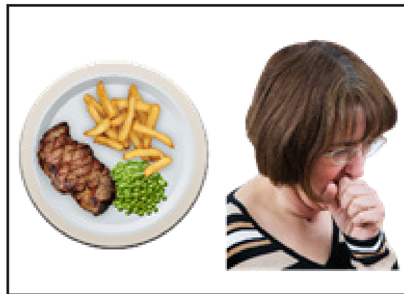


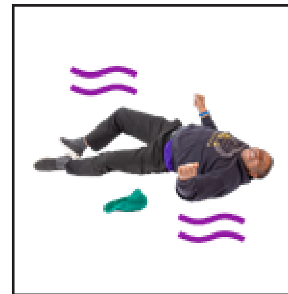
5. A type of heart problem called '**ischaemic heart disease**'.This is when the heart doesn't get enough blood sent to it.

6. **Epilepsy.**
   Epilepsy causes seizures, which are unusual flashes in your brain. The seizures stop your brain working properly for a while.

People with more severe learning disabilities were more likely to die from pneumonia, aspiration pneumonia or epilepsy than other people.







People with learning disabilities who did not have the services they needed were more likely to die from sepsis.

Chapter 5 - The quality of care given to people who have died

Three in every 10 reviews noted that the person had received the best possible care.

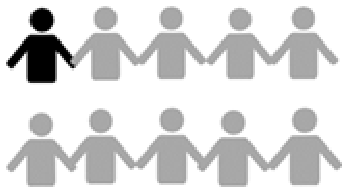
This was because:

- Everyone supporting the person worked well together.

- The care was what the person needed.

- When the person was at the end of their life their care was particularly good.

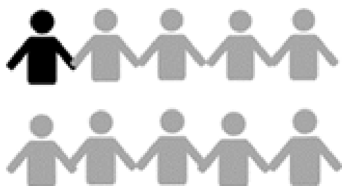
Some people said that they were worried or concerned about what had happened before the person died.



This happened in about one in every 10 deaths.

Some people had delays in their care or treatment.

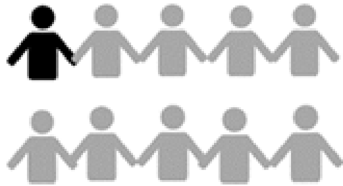
For example, it may have been a long time before the doctor knew what was wrong with them or gave them the right treatment.



This happened in about one in every 10 deaths.

Sometimes there were problems with how services supported people.

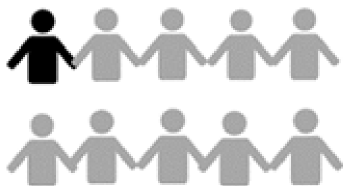
For example, different services didn't work together and share information as well as they could.



This happened in just over one in every 10 deaths.

Sometimes people did not receive the services they needed.

For example, some people needed expert help with their epilepsy, but they did not get it.



This happened in just under one in every ten deaths.

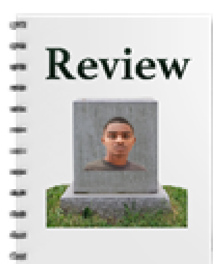
Reviewers thought that 71 out of 882 people received very poor quality care.

That is about 8 in every 100 people.

The poor quality care may have made them ill or made them die sooner than they should have done.

Chapter 6 - The deaths of children

The LeDeR programme does not review the deaths of children under 18 years old.



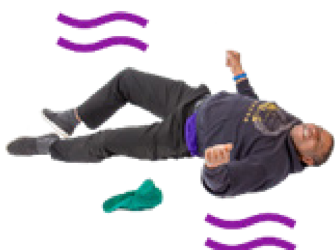
Their deaths are checked up on by the Child Death Review programme.

The Child Death Review programme sends the LeDeR programme the reports of the deaths of children with learning disabilities.

There have been 70 reviews into the deaths of children with learning disabilities.

Many of the children who died at a young age had profound and multiple learning disabilities or came from Black, Asian or Minority Ethnic groups.

Children with learning disabilities died from different sorts of illnesses than other children.



Children with learning disabilities were more likely to die from epilepsy or health problems they were born with.

Children with learning disabilities were less likely to die from cancer or accidents.

Most reviews into the deaths of children did not find any problems with the quality of care given to the child.

Chapter 7 - What reviewers think needs to change

Reviewers had lots of ideas about things that could change.

They wanted information about good services to be shared with other services.

Some of the other things they thought should change were:

- Training staff about how to support people with learning disabilities.

- Making sure that services work together when supporting people with learning disabilities.

- Helping people to notice when a person is ill, and treating them early.

Chapter 8 - What we think needs to change

We met with people with learning disabilities, families and professionals to talk about what we have found out.

Together, we had some ideas about how to make things better for people with learning disabilities.

1. NHS England and Local Authority social care should think about having someone in charge of the LeDeR programme.

2. NHS England needs to give some help to Clinical Commissioning Groups to help them do good quality reviews more quickly.

3. We need to explain the different words that we use for ‘learning disabilities’ so there is no confusion.

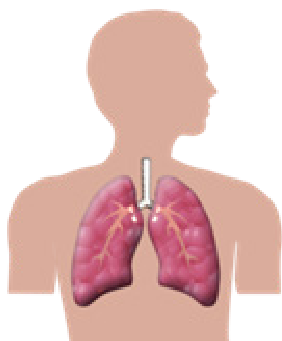
4. Local areas should find out about people with learning disabilities from Black, Asian and Minority Ethnic groups.

They need to make sure that their deaths are included in the LeDeR programme.

5. People who check up on deaths should agree a way for families to speak up if they have any concerns about their relatives’ death.

6. We must get better at:

- Noticing when a person is becoming unwell or their health is getting worse.



- Reducing the number of deaths from pneumonia and aspiration pneumonia.

7. We still need guidance about people working together and sharing information.

8. The law about helping people move from children's services to services for adults must be followed.

9. We need good examples of how to make the move from children's services to services for adults.

10. People should not be stopped from having treatment because they have learning disabilities.

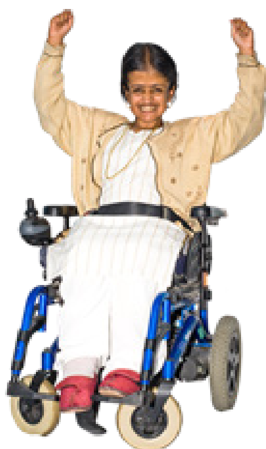
People should not have the cause of their death described as being because of their learning disabilities.

11. **Medical Examiners** must look for examples of care for people with learning disabilities that were unfair.

They should take action if they find this.

12. The **Care Quality Commission** should check that Do Not Resuscitate forms are filled in correctly.

Thank you



There are lots of people to thank.

Thank you to the advisory group of people with learning disabilities:

Robert Absalom, Pam Bebbington, Tracey Hyde, Kevin Preen, Siraaj Nadat, Beth Sage and Jackie Scarrott.

Thank you to the people with learning disabilities who talked to us about what we had found out. They helped us with ideas for how to improve things for people with learning disabilities.

Pam Bebbington, Adrian Chappell, Dave Hanford, Ben McCay, Siraaj Nadat, Shaun Picken, Beth Sage, Jackie Scarrott, Paul Scarrott, Dawn Wiltshire.

Thank you to Dave Hanford, Beth Richards and Stuart Neville for their work on the easy-read report.

Who pays for our work?

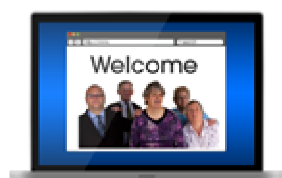
The LeDeR programme is paid for by NHS England.

Where you can get more information

The LeDeR team
Norah Fry Centre for Disability Studies
8 Priory Road
Bristol BS8 1TZ

0117 331 0686

leder-team@bristol.ac.uk



www.bristol.ac.uk/sps/leder