The Learning Disabilities Mortality Review (LeDeR) Programme

University of BRISTOL

Annual Report 2019

Easy Read

University of Bristol Norah Fry Centre for Disability Studies

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

It tells you about the deaths of people with learning disabilities since July 2016.

This report looks more carefully at deaths that were checked in 2019.

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

We would like to thank those families who have shared their stories.

We haven't used people's real names in this report, but their stories are true.

Contents

The words we use

(these words are in **bold** the first time they are used)

Advocate	Advocacy is about helping you to speak up and get the support you need.
Annual	Each year
Asthma	Asthma is when your breathing doesn't work as well as it should. It causes you to have a cough, noisy breathing and difficulty breathing.
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.
Avoidable causes of death	Deaths that could be stopped by good healthcare.
Aspiration Pneumonia	An infection in the lungs caused by food or drink going down 'the wrong way'.
Bacterial pneumonia	An infection in the lungs caused by germs called 'bacteria'.
Best Interests	If someone is not able to make a decision, then the people helping them must only make the decision in the way they think the person would make it if they could.
Care Quality Commission	The Care Quality Commission inspects health and social care services in England.
Coroner	An official who looks into why somebody died. The Chief Coroner is the head of the coroner's service.
Deep vein thrombosis	A blood clot in a vein, usually in the leg. A blood clot is when blood becomes solid.
Dementia	A group of diseases that make it harder for somebody to think and remember things.
Diabetes	Diabetes is an illness where your blood gets too much sugar from the food you eat.

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	People who have epilepsy have seizures. Seizures are unusual flashes in the brain, which stop it working properly for a while.
Influenza	Influenza ('flu) is a virus that can make you feel very ill.
Initial review	The first check on a person's death.
LeDeR	**Le**arning **D**isability **De**ath **R**eview – we used some of the first letters of each word to make the name 'LeDeR'.
Mental Capacity Act	The Mental Capacity Act is all about making decisions. It is a law about making sure that people have the support they need to make decisions. If a person is not able to make a decision, it says what should happen.
Pulmonary Embolism	A blood clot in the lungs which stop them working.
Review	A check on a person's death.
Reviewer	Someone who checks up on a person's death.
Seizure	Unusual flashes in the brain, which stop it working properly for a while.
Sepsis	An infection that affects the whole of the body.
Speech and Language Therapist	Speech and language therapists help people who have difficulties with communicating and swallowing.

Chapter 1: Introduction

The LeDeR programme

The LeDeR programme is set up to:

1. Help improve health and social care services for people with learning disabilities.

2. Stop people with learning disabilities dying too soon.

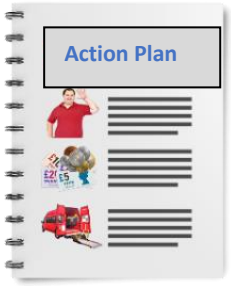
Everyone in England with learning disabilities has their death looked at in the same way.

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

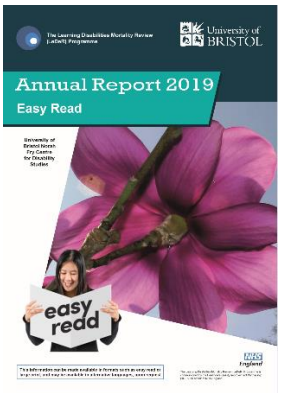
If any problems are found, the **reviewer** does more checks.

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.



When the reviews are finished, they are sent to the LeDeR team at the University of Bristol.

The LeDeR team look at all the reviews. They find out what we could do to improve services for people with learning disabilities.

This is our report for 2019.

The deaths the LeDeR programme has been told about

From 1st July 2016 to 31st December 2019 the LeDeR programme has been told about the deaths of 7,145 people.

There were 6,629 adults aged 18 and over.

There were 516 children aged 4-17 years old.

In 2019, we were told about the deaths of 3,060 people.

Of all the deaths we have been told about, around half of them have been reviewed.

More reviews have been completed in London than anywhere else in England.

Chapter 2: The people who have 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.

We think we should have been told about more deaths of adults from Black, Asian and Minority Ethnic groups.

Three out of every 10 people had mild learning disabilities.

Three out of every 10 people had moderate learning disabilities.

Three out of every 10 people had severe learning disabilities.

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

People who died the youngest were people from Black, Asian and Minority groups
and
people with profound and multiple learning disabilities.

Lots of people who died had a health problem that they usually lived with.

These were health problems such as **epilepsy**, problems with their heart, or problems swallowing.

Most people who died were usually taking medicines.

The most common medicines were to protect a person's stomach from acid and for epilepsy.

Chapter 3: The deaths of people with learning disabilities

The **average age** of men when they died was 61 years.

Men died, on average, one year older than we reported last year.

The average age of women when they died was 59 years.

Women died, on average, at the same age as we reported last year.

People living in the south west of England lived a little bit longer than people living in other parts of England.

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

This was the same as last year.

People with learning disabilities died in hospital more than people who do not have learning disabilities.

This was the same as last year.

Compared with others, fewer people with learning disabilities had their death reported to a **coroner**.

This was the same as last year.

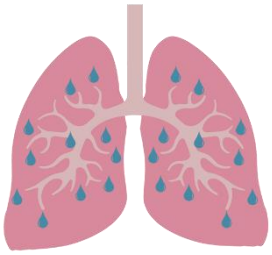
Sometimes, doctors can restart a person's heart if it stops. This is not possible if the person is too ill.

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.

This was a bit better than last year.

Most people died from one of five health problems.



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

24 out of every 100 people who died did so from pneumonia.

This is slightly less than last year.

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

16 out of every 100 people who died did so from aspiration pneumonia.

This is the same as last year.

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

9 out of every 100 people who died did so from a kind of dementia.

This is a little bit more than last year.

4. Sepsis.

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

7 out of every 100 people who died did so from sepsis.

This is the same as last year.

5. Epilepsy.

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

6 out of every 100 people who died did so from epilepsy.

This is a little bit more than last year.

More people with learning disabilities than others died from health problems that can be treated.

We call these '**avoidable causes of death**'.

44 out of every 100 people with learning disabilities had an avoidable cause of death.

This was the case for only 22 out of every 100 people in the general population.

Chapter 4: The quality of care given to people who have died

54 in every 100 reviews noted that the person had received the best possible care.

This is more than last year.

This was because:

- Everyone supporting the person worked well together.

- The care was what the person needed.

- People had **advocates** to help them get the care they needed.

- Services made ‘reasonable adjustments’ for people.

Most reviewers said there had been no concerns about the person’s death.

That was the case for 88 out of every 100 reviews.

When people did have concerns about the death, it was often because:

The person 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.

Sometimes there were problems with how services worked together to support a person.

They sometimes didn't share information well enough.

Sometimes the person did not receive the services they needed.

For example, some people needed expert help from learning disability nurses, but they did not get it.

122 people with learning disabilities had very poor-quality care.

That was about 7 people in every 100.

Chapter 5: A special look at some things

How families are involved in making decisions

The **Mental Capacity Act** is all about making decisions.

It is the law so must be followed.

It makes sure that people have the support they need to make decisions.

If a person is not able to make a decision, it says what should happen.

If a person is not able to make a decision, the decision should be made in the way people think the person would have made it if they could.

We call that 'in their best interests'.

To make a decision in a person's best interests, family members should be asked what they think the person would want.

We looked at lots of LeDeR reviews to find out how families had been involved.

Most of the reviews said that families had helped to make the decisions and the law had been followed.

A few reviews said that families had too much power in making the decisions.

A few reviews said that families had not been asked to help make the decision.

Sometimes there were problems with families helping to make the decision.

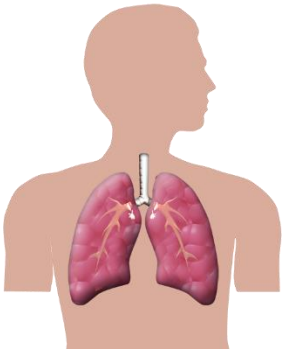
That was because:

- No-one knew where the family was.
- The family had different ideas about what the person would want the decision to be.
- The family didn't understand the law.

Families said that they need better information about the Mental Capacity Act.

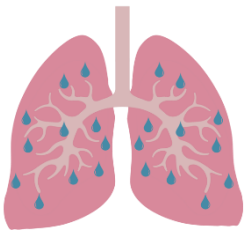
Families thought that some professionals need better information too. They could then follow the law properly.

Deaths from pneumonia



‘**Bacterial pneumonia’** is an infection in your lungs caused by germs called ‘bacteria’.

Another type of pneumonia is ‘**aspiration pneumonia**’. This is an infection in your lungs caused by food or drink going down ‘the wrong way’.



Bacterial pneumonia was the main reason why people died.

24 out of every 100 people died from bacterial pneumonia.

This was about the same as last year.

Aspiration pneumonia was the next most common reason why people died.

16 out of every 100 people died from aspiration pneumonia.

This was about the same as last year.

Pneumonia was more common in adults than children.

It was more common in people with the most severe learning disabilities.

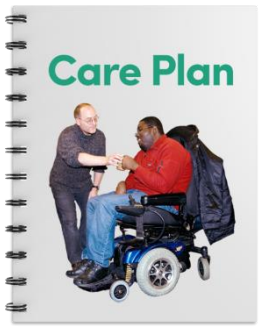
Some things helped people to avoid pneumonia.

Those were:

- Having help from a **Speech and Language Therapist**.

- Having regular check-ups on how well a person was swallowing.

- Carers quickly noticing when a person was becoming unwell and getting them to the doctor quickly.



Some problems people with pneumonia had were:

- Not having good care plans for eating and drinking.

- Problems with getting tests such as X rays done.

Deaths from sepsis

Sepsis is an infection that affects the whole of the body.

It was the 5th most common reason why people died.

7 out of every 100 people died from sepsis.

This was about the same as last year.

Sepsis was as common in adults as in children.

It was as common in people with mild learning disabilities as people with more severe learning disabilities.

Some things helped people when they had sepsis.

These were:

- Different carers working well together.

- Good care when people were dying.

Some problems that people with sepsis had were:

- Problems with people noticing that they were unwell.
- The person not being treated as quickly as they should have been.

Things that could help people to avoid getting sepsis:

- Information for families and paid carers about preventing infections and how to notice early signs of infection.
- Making sure that people have changes made to their care so that it is right for them.

Deaths from epilepsy

Epilepsy is when a person has seizures, which are unusual flashes in the brain. These stop the brain from working properly for a while.

Epilepsy was the 6th most common reason why people died.

Epilepsy was more common in children than adults.

It was more common in people with the most severe learning disabilities.

Some people had good care for their epilepsy.

They had regular reviews of their epilepsy.

Some problems that people with epilepsy had were:

- Problems with alarms that alert someone when the person is having a seizure.
- Carers did not take enough notice of changes in how often the person had seizures.
- A lack of training for carers about epilepsy.

Things that could help avoid deaths from epilepsy are making sure that:

- People receive good care for their epilepsy and know to tell a doctor about changes to their seizures.
- People have regular reviews of their epilepsy, and the medicines they take for epilepsy.
- People know how to use alarms that alert someone when the person is having a seizure.

Deaths from health problems that should usually be treated at home

We looked at 4 health problems that should usually be treated at home.

People shouldn't usually need to go into hospital for these health problems.

Most people shouldn't die from these health problems.

The first problem was a **blood clot** in the body. A blood clot is when blood becomes solid.

This usually starts in the leg and travels in the blood to the lungs. It makes it hard for people to breathe when it is in the lungs.

This is called **Deep Vein Thrombosis** and **Pulmonary Embolism**.

145 people died from a blood clot in their body.

Most of them were aged 25 and over.

There were 3 issues in deaths from a blood clot. These were:

1. Not walking around or moving much.

2. Signs that a person had a blood clot were not recognised.

3. Some people with blood clots did not get the right care from a doctor or nurse.

Things that can help avoid deaths from blood clots are:

- Giving people information about blood clots and how to avoid them.

- Helping people to keep moving and be a healthy weight.

The second health problem we looked at was **diabetes**.

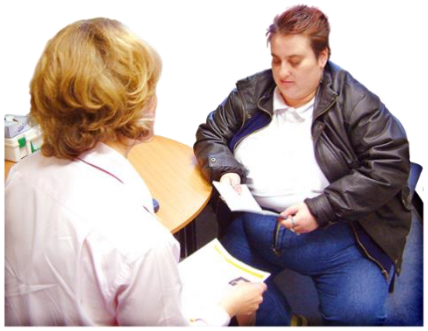
Diabetes is an illness where your blood gets too much sugar from the food you eat.

75 people died from diabetes.

There were 2 issues in deaths from diabetes:

1. Checking if a person could make decisions about managing their diabetes.

2. People making decisions about their food without understanding their diabetes.



Things that can help avoid deaths from diabetes are:

- Making sure that everyone follows the Mental Capacity Act.

- Making sure that people with diabetes get good support.

The third health problem we looked at was **asthma**.

Asthma is when your breathing doesn't work as well as it should.

51 people died from asthma.

There were 2 issues in deaths from asthma:

1. People had more chest infections than usual in the year before they died.

2. Some people had problems getting good care for their asthma.

Things that can help avoid deaths from asthma are:

- Making sure the person gets good healthcare and regular checks of their asthma.

The fourth health problem we looked at was **influenza** or 'flu.

'Flu is a virus that can make you feel very ill.

43 people died from 'flu.

There were 2 issues in deaths from ‘flu:

- Sometimes there was no information in a person’s records about the reasonable adjustments they needed to have a ‘flu jab.

- People only saw a doctor when they were very ill, not for things like annual health checks.

Things that can help avoid deaths from ‘flu are:

- Making reasonable adjustments so that people can be protected from catching ‘flu.

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 246 reviews into deaths of children with learning disabilities.

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

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

They were less likely to die from cancer or accidents.

They were more likely to die from epilepsy or health problems they were born with.

It worked well for children with learning disabilities when:

- Their care changed as the person needed it to.
- Everyone supporting the person worked well together.
- They had good care at the end of their life.

Where there were problems with the care of children they were:

- Problems with people noticing that they were unwell.
- Everyone supporting the person not working well together.
- Plans were not made soon enough for supporting the child and their family.

Things that could help children are:

- A main support worker to help link different services so they know what each other is doing.
- Good planning for the child's care.
- Good support for the child's family.

Deaths of young people aged 18-24 years

There have been 113 reviews into deaths of young people aged 18-24 years.

Young people with learning disabilities died from different sorts of illnesses than other young people.

They were more likely to die from epilepsy or pneumonia.

It worked well for young people with learning disabilities when:

- Children's services and adult's services worked well together.
- Services thought about all the needs of the young person and their family.

Where there were problems with the care of young people they were:

- Problems with people noticing that they were unwell.
- Moving from children's services to adult's services.
- Problems with making decisions about what was best for the young person.

Things that could help young people were:

- Services for children and services for adults to work better together.
- Families to be listened to.
- A check that people are following the Mental Capacity Act when decisions need to be made for young people aged 16 and over.

Deaths of people aged 75 and over

There have been 418 reviews into deaths of people aged 75 and over.

People with learning disabilities were less likely to die aged 75 and over than other people without learning disabilities.

People with learning disabilities who died aged 75 and over were more likely to be white British.

They were also more likely to have mild learning disabilities.

Lots of people had lived in long-stay hospitals in the past.

This had affected them in later life, such as having certain interests or ways of doing things.

Many had support from their family or friends over a long time.

They often liked to have friends and be chatty.

They often had strong interests and were able to speak up for themselves.

They often had a ‘role’ in life, such as looking out for others or doing a job.

It worked well for older people when:

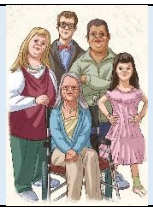
- Their care changed as they needed it when they got older.
- They had support from people who knew them well over a long time.
- Everyone supporting the person worked well together.

Things that could help older people are:

- For paid carers to be aware of the changing needs of people as they get older.
- To plan a person's care around their changing needs as they get older.

- For services to work together to support a person.
- To think about how past life events have made a difference to a person.

Chapter 6: 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.

There are some things that help people with learning disabilities to live longer.

We need to do more of these.

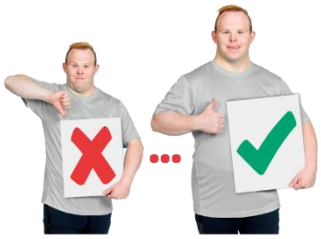
These are:

- Putting the person and their family at the centre.

- Services working well together to support the person.

- Having someone to make sure services work well together.

- Supporting the person to stay healthy, not just thinking about their health when they are ill.



We have made 10 recommendations for improving the care of people with learning disabilities.

1. We must keep checking up on the deaths of people from Black, Asian and Minority Ethnic groups.

   They died younger than other people with learning disabilities.

2. The Chief **Coroner** should make sure that deaths of people with learning disabilities are being reported to a coroner whenever they should be.

3. Inspections of services by the **Care Quality Commission** must check that people are following the Mental Capacity Act.

4. The government to look at the best way to make sure that people with learning disabilities receive the support they need with different services working together.

5. For the checklist called NEWS2 to be adapted for people with learning disabilities.

   NEWS2 is used to help notice early signs that a person's health is getting worse.

6. To test out having specialist doctors for people with learning disabilities.

7. New guidelines to be written about the care of people who are at risk of inhaling their food or drink and getting aspiration pneumonia.

8. More information to be made available about supporting people at risk of pneumonia or aspiration pneumonia.

9. We need to improve the safety of people with epilepsy.

10. We need to find out more about people going into hospital for health problems to do with constipation.

Thank you

There are lots of people we would like to thank.

We would like to thank the Advisory Group of people with learning disabilities:
Pam Bebbington, David Hanford, Tracey Hyde, Siraaj Nadat, Kevin Preen, Beth Sage and Jackie Scarrott.

We would like to thank the people with learning disabilities who talked to us about what we had found out:

Pam Bebbington, Adrian Chappell, Siraaj Nadat, Shaun Picken, Jackie Scarrott, Dawn Wiltshire.

They helped us with ideas for how to improve things for people with learning disabilities.

The LeDeR programme is paid for by NHS England.

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