The Learning Disabilities Mortality Review (LeDeR) Programme

University of BRISTOL

Annual Report 2019

Easy Read – short summary

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.

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.

By 31st December 2019, 4 out of 10 of these had been reviewed.

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.

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 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**.

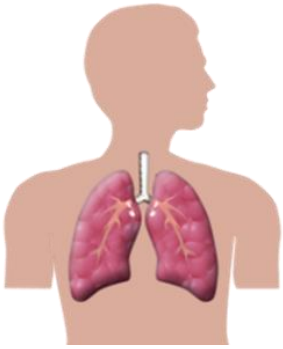
This was the same as last year.

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.

The most common were pneumonia and aspiration pneumonia.

This was the same as last year.

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

It was more than 3 out of 10 deaths of people with learning disabilities.

For people without learning disabilities it was less than 1 out of 10 deaths.

About 5 in every 10 reviews noted that the person had received the best possible care.

This is more than last year.

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

That was about 7 people in every 100.

What we think needs to change

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

We need to do more of these.

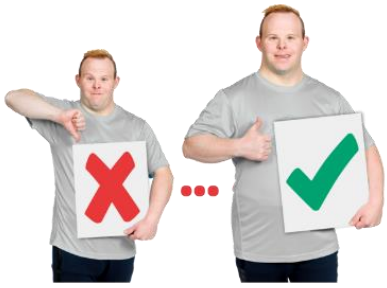
These are:

- 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.

Where you can get more information

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