

Learning Disabilities Mortality Review
(LeDeR) Programme

LeDeR programme annual report 2019

Main findings easy read





The Learning Disabilities Mortality Review
(LeDeR) Programme

Welcome

My name is Dave Hanford.

I am the programme
Information Officer.





Introduction

- This is the 4th annual report for the LeDeR programme.
- 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.





The number of deaths

- From 1st July 2016 - 31st December 2019, we were told about 7,145 deaths.
 - 6,629 were adults.
 - 516 were children aged 4-17 years.
- In 2019, the number of deaths we were told about was 3,060.





Age at death

- 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.





Those who died the youngest

People who died the youngest were:

- People from Black, Asian and Minority groups.
- People with profound and multiple learning disabilities.



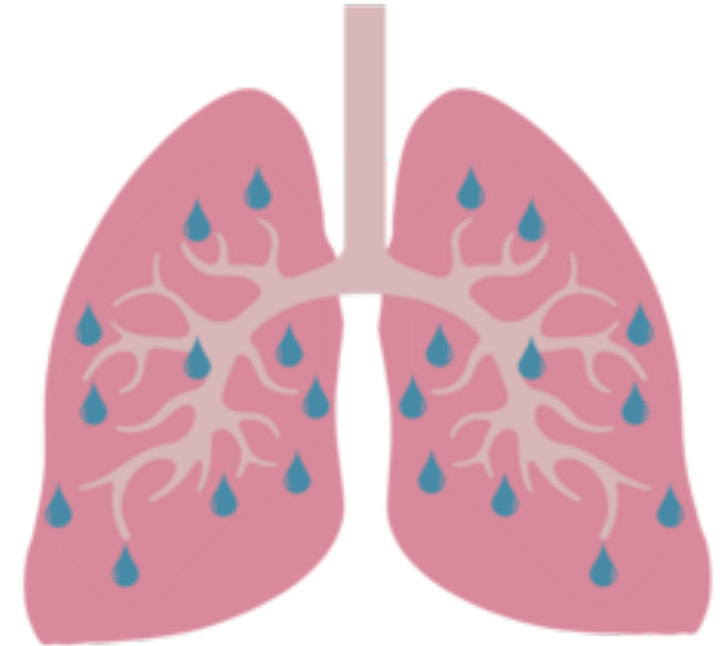


Most people died from one of five health problems:

- Pneumonia.
- Aspiration pneumonia.
- Sepsis.
- Dementia.
- Epilepsy.

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 than people in the general population.

More than 3 out of 10 people with learning disabilities died from health problems that could be treated.

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





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 that had died.

It was about the same as last year.





Best practice

The main areas in which best practice was most frequently mentioned were:

- Putting the needs of the person at the centre of everything.
- Different people from different services all working well together.
- The use of advocacy services.
- The use of reasonable adjustments - changing the usual way of doing things to meet the needs of the person.





Problems with care

The most common problems with care were:

- Delays in illnesses being recognised and treated.
- People from different services not talking or working well with each other.
- Not using the Mental Capacity Act properly.
- Not referring people to services, including learning disability services quickly enough.





A coroner is an official who looks into why somebody died. The Chief Coroner is the head of the coroner's service.

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

This was the same as last year.





Focus on specific issues

We looked at some things in more detail:

- How families are involved in making decisions.
- Certain causes of death (pneumonia, sepsis, epilepsy, illnesses that should be managed by a GP such as flu or asthma).
- Deaths of people of certain ages (children, young people aged 18-24 years and older people aged 75 or more).

These findings are included in the annual report.





Recommendations





What we need to do more of

Good quality support is:

- ✓ Having plans that put the person and their family at their centre.
- ✓ A named person to help different services to work well together.
- ✓ Planning ahead to meet health and care needs.

We need to make sure that this is done for everybody.





Recommendations: Addressing inequalities



1. Continue to look closely at deaths of all adults and children from Black Asian and Minority Ethnic groups.
2. The Chief Coroner to check up on the number of deaths of people with learning disabilities that they have been told about.
3. Care Quality Commission inspections to check up on how well a service follows the Mental Capacity Act.





Recommendations: The provision of care



4. Improve the way that services work together and share information.
5. Introduce ways of working that can help to spot when a person is becoming more unwell.
6. Think about creating specialist doctors for people with learning disabilities and make 'learning disabilities' a medical speciality.





Recommendations: Priority areas of focus

7. Have national guidelines to help prevent and treat aspiration pneumonia in adults and children.
8. Have a toolkit to help services know how to support adults and children at risk of aspiration pneumonia.
9. Make the safety of people with epilepsy a priority.
10. Have a national survey to see how many adults and children are admitted to hospital for constipation or illnesses related to constipation.





Conclusion

It is unfair that people with learning disabilities still don't get the same standard and quality of treatment as people in the general population.

We think it is very important that improvements in the way that people with learning disabilities are treated continue to be made.





The Learning Disabilities Mortality Review
(LeDeR) Programme

Contact details

Dave Hanford
Information Officer (easy read)

leder-team@bristol.ac.uk

Tel: 0117 3310686

Website: www.bristol.ac.uk/sps/leder

