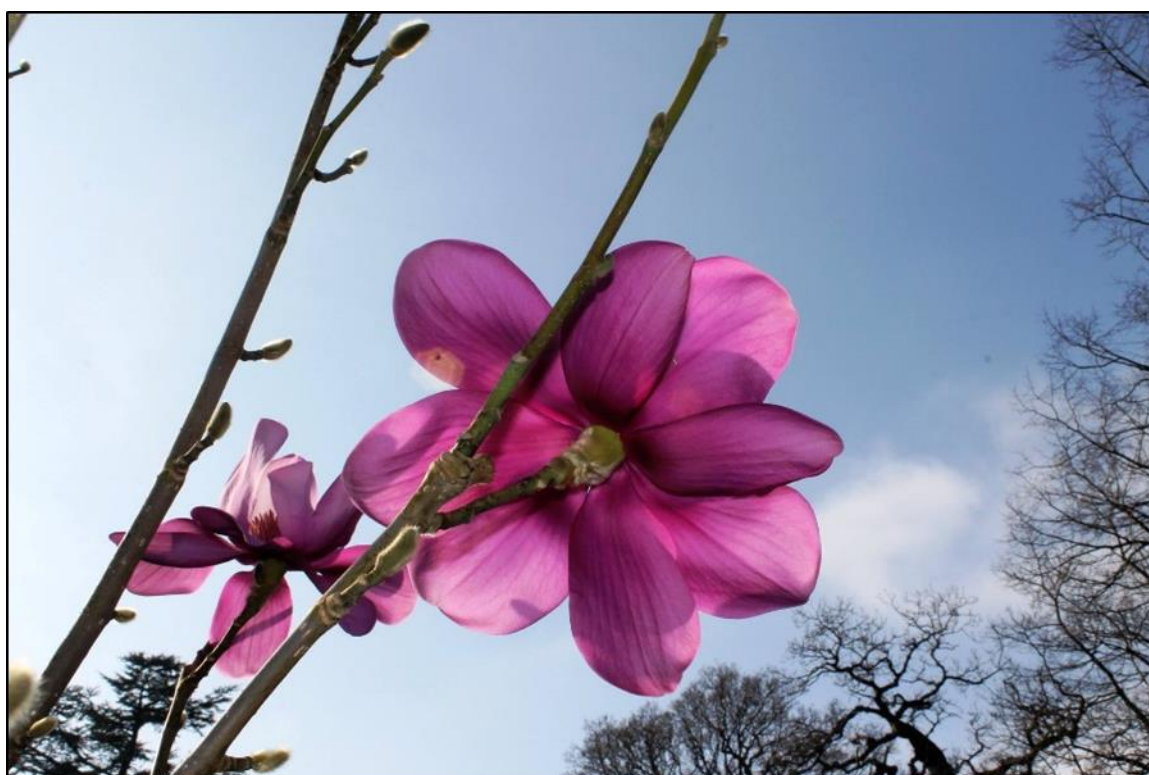


# Learning Disabilities Death Review Programme

## Yearly report 2015-2016

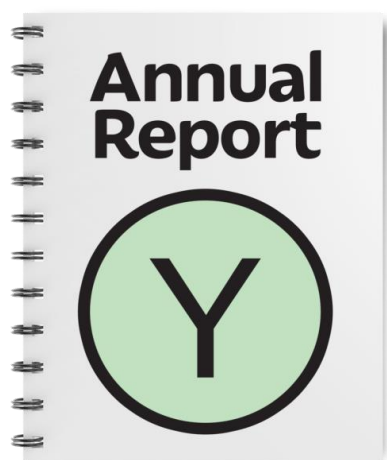


### EASY READ



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

## Introduction

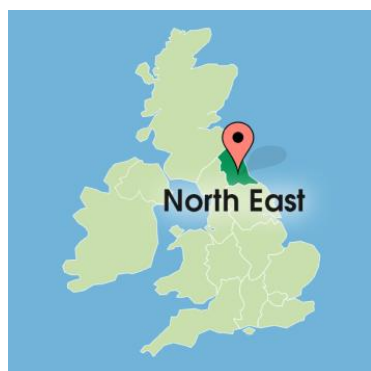


This is the first yearly report for the Learning Disabilities Death Review (LeDeR) programme.

This report will tell you how we set up the LeDeR Programme.



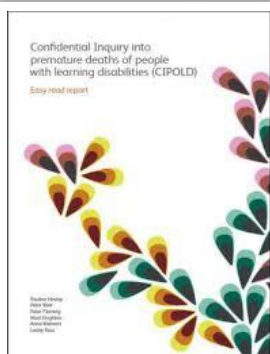
We have worked with people from health and social care services to find the best way to share information when someone with a learning disability dies.



We want to thank people in the North East of England who have helped us test how we review the deaths of people with learning disabilities.

# Chapter 1: Background

## Early deaths in people with learning disabilities



Some reports have said that people with learning disabilities in England are dying sooner than people who do not have learning disabilities.

Some people may not have died if their care had been better.

These reports have said that some people with learning disabilities are getting poor care from health and social care.

The health and social care system needs to be made better.



We need to find out more about why people are dying too soon and stop this from happening.

## Chapter 2: What the LeDeR programme is doing and how we are doing this



We want to make health and social care for people with learning disabilities as good as it is for people who do not have learning disabilities.



We want to stop people with learning disabilities dying too soon.



We will do this by helping health and social care services to look at why some people with learning disabilities in England are dying too early.

## Chapter 3: Starting-up the LeDeR Programme

### Recruitment



A team of people are working on the LeDeR Programme.

This team works at the University of Bristol.

### People checking we are working well



We also have some groups of people checking we are working well.

These groups include:

- People who work in health and social care and voluntary organisations.
- Families of people with learning disabilities.
- People with learning disabilities.



my Life my choice



The people with learning disabilities are members of:

- My Life My Choice
- Bristol Health Trainers
- Changing our Lives
- National Forum of people with learning disabilities

## Other 'set up' activities



We have worked with families and people with learning disabilities to write information leaflets to tell people about the programme.



We have set up a website to keep people up-to-date with the LeDeR programme.

This is the address of the website:  
[www.bristol.ac.uk/sps/leder](http://www.bristol.ac.uk/sps/leder)



We have also set up a telephone number for people to use to tell us about the death of a person with learning disabilities.

## Finding out what questions we should ask



**Questions**

1. What do you think about it?

Good

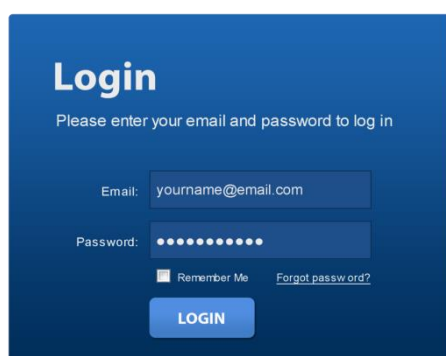
Bad

Not sure

We have spoken to a lot of people about the questions we should ask when we are told about the death of someone with learning disabilities.

We have also spoken to people who work in health and social care who might tell us about the death of someone with learning disabilities.

## Developing computer systems to review deaths



**Login**

Please enter your email and password to log in

Email:

Password:

Remember Me [Forgot password?](#)

We have set up a computer system for people to tell us about the death of someone with learning disabilities.

This computer system will also be used by reviewers of deaths of people with learning disabilities.

## Keeping information safe and private



We have set up safe ways of working. We want to make sure the information about the deaths of people with learning disabilities stays private.

## Chapter 4: Involving family carers and people with learning disabilities



Family carers helped us think about how the project would work.

We've had meetings with family carers in the Midlands, North and South England.



Family carers helped us write the information to send to paid workers and families of people who have died.

### Involvement of people with learning disabilities



We have an advisory group of people with learning disabilities.

Siraj Nadat represents the advisory group of people with learning disabilities at other meetings.



## Chapter 5: Testing reviews of deaths



We have been speaking to people in North East of England who are testing how to review deaths of people with learning disabilities.



Other areas in England are now also testing how to review deaths of people with learning disabilities.

These reviews are taking place in:

- Midlands
- South of England (Wessex)
- London

## Things we will look at more closely (Priority Themed Reviews)



In Year 1 we will look closely at the deaths of people from the black and minority ethnic communities (BME) and deaths of young people aged 18-24.



By looking more closely at the deaths of people from the BME communities and young people, we hope to learn more about these deaths and make health and social care better.

## Telling other people



We have made plans about who to share information about the LeDeR Programme with.

We have also made plans about how to share information about the LeDeR Programme with people with learning disabilities and family carers.

## Local Reviewer Training



We have made a training course to help people learn how to do reviews of deaths.

We have started to train people to do the reviews of people with learning disabilities.



We have started to train people in different places in England.



We have also started to train people to look at the deaths of young people and people from the black and minority ethnic communities.

## Chapter 6: Extra projects

We are also doing 4 extra projects:



1) Finding more reports about people with learning disabilities.



2) Looking at national information about the deaths of people with learning disabilities.



3) Making health care more equal for people with learning disabilities.



4) Making sure it is recorded that someone had a learning disability when they die.

## Chapter 7: Other similar work



We have helped write reports to make health and social care better for people with learning disabilities.



We have met with lots of people who are doing work like ours and are interested in our work.

We have also been to lots of events to speak with people doing work like ours.

## Thank you



We would like to thank everyone for helping us with the work

### **For more information about the LeDeR programme contact:**

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