NHS
Bury
Clinical Commissioning Group

LeDeR programme Easy Read annual report

April 2019 – March 2020

This is Bury CCG's first yearly report of the Learning Disabilities Death Review (LeDeR) programme.

It tells you about the deaths of people with learning disabilities from Bury and from the rest of England.

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

Contents

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 a mental health problem where they hear voices, see things that are not there and have bad thoughts. It is given to help calm the person, so they are not distressed.
Do Not Resuscitate	If doctors think a person's heart could not be re-started, they fill in a **Do Not Resuscitate** form.
Liaison	A learning disabilities **liaison** nurse will make sure a person with learning disabilities gets all the information and help they need if they go into hospital. They also make sure the hospital staff get all the information they need to care for the person.
Pneumonia	An infection in the lungs making breathing more difficult. It is caused by bugs called 'bacteria'.
Reasonable adjustments	Making changes to how services do things to make sure people with learning disabilities can use the services.
Review	A check on a person's death.
Reviewer	Someone who checks up on a person's death.

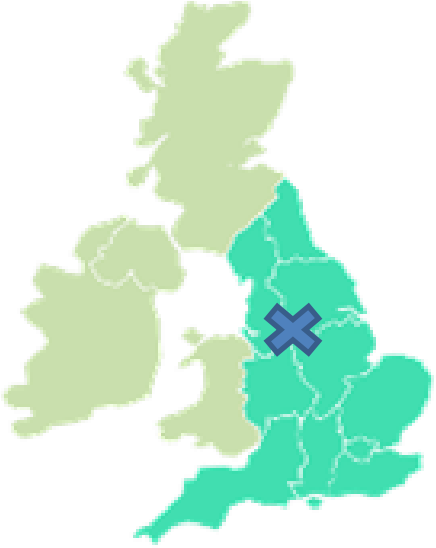
Chapter 1 - Introduction

The LeDeR programme plans to make the lives of people with a learning disability better.

It will do this by learning from how people with a learning disability have died.

The Learning Disabilities Mortality Review (LeDeR) Programme

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



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

We call this a 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.

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

The LeDeR programme does not review the deaths of children.

The death of anybody under 18 years old is checked up on by the Child Death Review programme.

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

Since it started in 2016, the LeDeR programme has been told about the deaths of 8,733 people with learning disabilities who lived in England.

36 of these people lived in Bury.

Some deaths are still waiting to be reviewed.

Reviewers in both Bury and in the rest of England found it difficult to get time to do reviews when they had their usual job to do.

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

Chapter 3 - The people who died

The **average age** at death in Bury was 56 years.

The average age at death in England was 59 years.

In Bury, 3 out of the 36 deaths were people from Black, Asian and Minority Ethnic groups.

In England, there were not as many deaths of people from Black, Asian and Minority Ethnic groups reported as we think there should be.

In Bury, 26 people who died were male and 10 people were female.

In both Bury and in the rest of England, most people died in hospital.

Chapter 4 - The deaths of people with learning disabilities

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

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

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

Doctors in Bury filled this form in correctly.

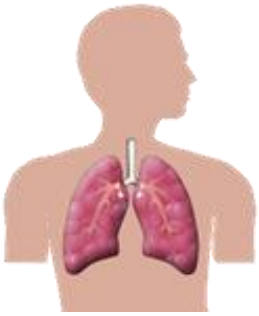
In the rest of England, a few doctors did not. They gave the reason for not restarting a person's heart as being because they had learning disabilities.

8 people who died in Bury were taking a type of medicine called '**antipsychotic medication**'.

Some people with a learning disability are wrongly given this medication because they have behaviour that is difficult for the people who support them.

In both Bury and in England, the most common cause of death was the same.

It was:



Pneumonia
This is an infection in your lungs making breathing more difficult.

It is caused by bugs called ‘bacteria’.

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

In Bury, nearly all our reviews found the person had received the best possible care.

In the rest of England, half of the reviews found the person had received the best possible care.

In both Bury and in England this was because:

1. Everyone supporting the person worked well together.

2. The care was what the person needed.

3. **Reasonable adjustments** were made to make sure the person's care was right for them.

4. When the person was at the end of their life their care was very good.

In Bury this was also because:

5. The person had help from the community learning disabilities team from Pennine Care Foundation Trust.

6. If the person went into hospital, the person, their family and the hospital staff all had help from a learning disabilities **liaison** nurse from Pennine Acute Hospitals Trust.

7. The person had a yearly health check at the local doctors.

Sometimes there were problems with how services supported people.

In both Bury and in England this was because:

1. Services did not know the person had a learning disability.
2. Services did not know how to meet the person's needs.
3. Services did not listen to families and paid carers.
4. Different services did not work together and share information well.

In Bury this was also because:

5. A person saw too many different local doctors.

One Bury review found the care had not been good.

It may have made them ill or made them die sooner than they should have done.

Chapter 6 - What we think needs to change

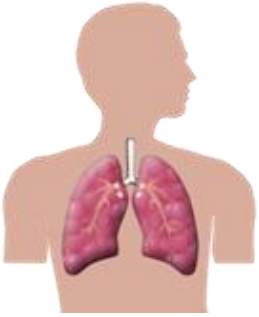
We met with local families and with local services when we did the Bury reviews.

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

Some of these were:

1. Training staff how to better support people with learning disabilities.

2. Making sure services work together.



3. Reducing the number of deaths from pneumonia.

Thank you

Thank you to the local families of the people who died and to the local services who talked to us.

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