County Durham Care Partnership

NHS County Durham Clinical Commissioning Group

Learning Disabilities Mortality Review (LeDeR) Programme

County Durham and Tees Valley.

Local Area Annual Report.

Easy Read summary.

June 2022

inclusion north

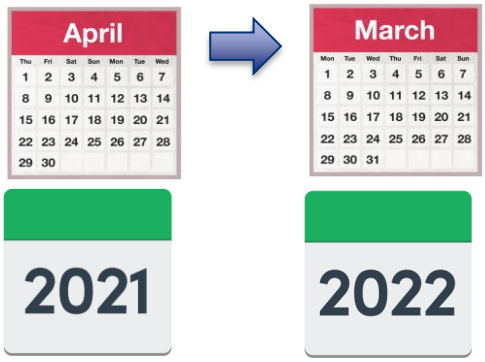
This Easy Read summary was created by Inclusion North with the help of the North East Stop People Dying Too Young Group

Thank you

County Durham and Tees Valley Clinical Commissioning Groups thank everyone who has been involved in the Leder reviews this year.

1. Introduction

This is an easy read summary of County Durham and Tees Valley's report saying what we have learnt in the last year about people with a learning disability dying too young and the action we have taken.



The report is about what happened from 1st April 2021 to 31st March 2022.

2. Understanding Leder

Learning Disabilities Mortality Review (LeDeR) Programme

Leder is an NHS England programme that is happening all over England. Leder means the Learning Disability Mortality Review programme.

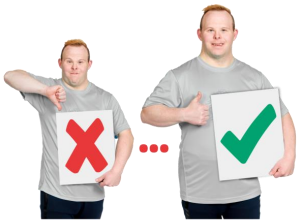
It started in 2015 after shocking reports showed that people with a learning disability were at risk of dying much younger than other people.

People with a learning disability face many health inequalities.

This was very clear during the Covid-19 pandemic.

The Leder programme looks at the life and death of every person with a learning disability who has died.

It looks at whether each person had good care and support during their life



The programme aims to learn from the things that could have been better, to support people with a learning disability to live longer, healthier lives.

From 2021, the deaths of autistic people will now be included in the Leder programme.

Last year, Southern, Central and West Commissioning Support Unit took over the job of running the Leder programme. They collect all the information from all the reviews of people's deaths.

Since then, there have been problems getting information back from this team to better understand which services need to get better.

3. The Leder programme in County Durham and Tees Valley

The are 3 staff members whose main job is to do Leder reviews.

The aim is to learn from the reviews and to make things better. This will help people with a learning disability to live longer lives.

The target is for all reviews to be done within 6 months of a death being reported.

We are on track to meet targets, as the latest available information toward the end of the year told us that -

NHS
County Durham
Clinical Commissioning Group

- County Durham have completed 87 out of 100 reviews on time.

NHS
Tees Valley
Clinical Commissioning Group

- Tees Valley have completed 85 out of 100 reviews on time.

Some reviews have not been finished because we are still waiting for information from people like the Coroner. A Coroner is a type of judge who investigates some deaths

4. How we make sure the Leder programme happens

A panel meets every 2 weeks to check that reviews are good quality and agree what needs to happen next.

The learning from reviews is shared with our Service Improvement Group. They agree what needs to change to make sure people with a learning disability get good care and support.

Some reviews show that the person did not get good care and support. We have looked at these reviews in more detail and we have a plan to make things better in future.

The way the Leder Programme is run across the whole North East and North Cumbria is changing.

This is because the region is becoming an Integrated Care System. An Integrated Care System is the way all health and care services will be provided for the area.

There will be a named person who is responsible for Leder in the North East and North Cumbria.

5. The Leder reviews we have done this year

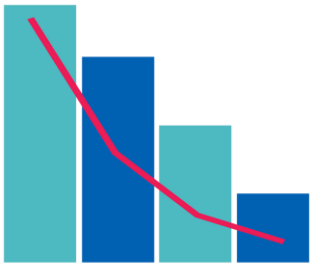
A total of 78 Leder reviews have been done this year.

NHS County Durham Clinical Commissioning Group

39 reviews were in County Durham

NHS Tees Valley Clinical Commissioning Group

39 reviews were in Tees Valley



This is less reviews than last year.

This is partly because the new computer system used by Southern, Central and West Commissioning Support Unit did not work for 3 months.

There have been no reviews done for autistic people yet.

We are making sure our systems work properly so we can see easily which reviews were for people with a learning disability and which reviews were for autistic people.

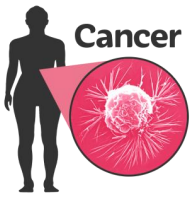
6. What did people die of?

From the reviews that were done, the things that most people with a learning disability died of last year were

- Covid-19

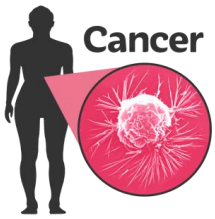
- Aspiration pneumonia. This is an infection of the lungs caused by food and drink going down the wrong way.

- Pneumonia. This is an infection of the lungs.



- Cancer.

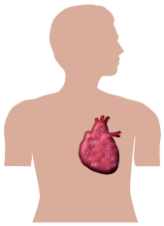
When we look at what people who do not have a learning disability died of last year, there are some differences.



Most people died of

- Cancer

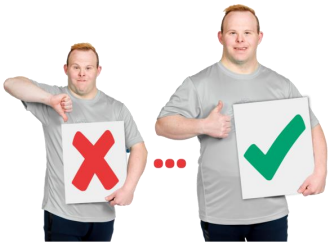
- Covid-19



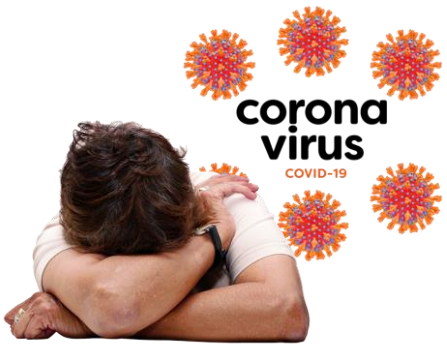
- Heart disease

- Dementia and Alzheimer disease

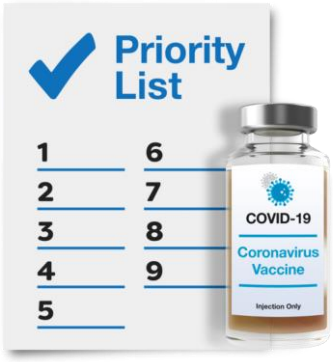
This means that people with a learning disability die from things to do with breathing difficulties more than other people.



We can use this information to make healthcare better for people with a learning disability.



There were signs during Covid-19 that the lives of people with a learning disability were not valued as much as other people's.



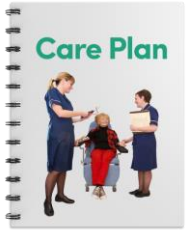
For example, people with a learning disability were not a priority group for the vaccine at the beginning even though they were dying more than other people.

We did lots of things to help keep people with a learning disability safe through Covid-19.

Some examples are

- Sharing Easy Read resources

- Accessible vaccination clinics



- Helping make sure people had Emergency Healthcare Plans and Hospital Passports

7. How old were people when they died?

We want people with a learning disability to live long, healthy lives, so the age they are when they die is important.

This year, 21 out of 100 people with a learning disability were between the ages of 51 and 60 when they died.

50 out of 100 people with a learning disability were over the age of 60 when they died.

24 out of 100 people with a learning disability were between the ages of 71 and 80 when they died.

8. What we have learnt from the reviews.

The reviews found examples of good practice which is good to see.

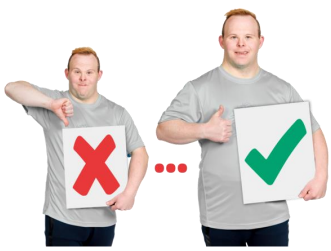
Examples of good practice were

- A care home learning about end of life care so that the person could choose to die where they felt most comfortable and people knew them well

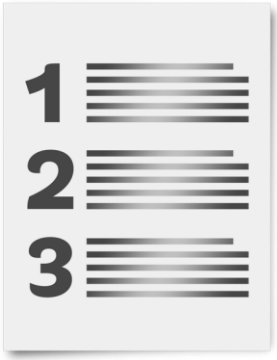
- A family carer said the care home where her son lived had been perfect and helped to make his last years very happy

- Excellent cooperation between the hospital and care home so that the person could come out of hospital

- Good support for someone to leave secure hospital and live back in the community, having a good quality of life

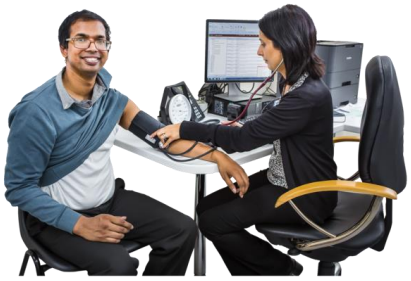


Reviews also found things that could be done better for people with a learning disability.



There are 9 topics for us to think about when we try to make care better for people with a learning disability and autistic people this year.

These are the 9 topics and an example of each one:



1. How we provide care

More support for people to attend Annual Health Checks and screening appointments.

2. Knowledge about learning disability

Staff understanding learning disability enough to know how to make reasonable adjustments.

3. How people's ongoing health needs are managed

The Mental Capacity Act not always being used to support people making decisions about their care.

4. End of life care

Some staff need more training and support to make sure end of life care is done better for people with a learning disability. This includes better communication and making sure the Do Not Resuscitate decisions are done right.

5. Training

Examples came up of staff needing more training. Topics include

- Epilepsy
- Supporting autistic people at the end of their life.
- Looking after people's bowels so they stay healthy and poo regularly

6. When someone's health suddenly gets worse

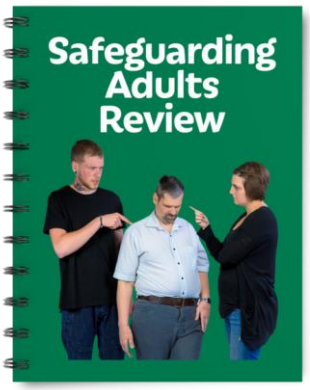
There were delays for some people getting to see a specialist when their health got worse.

7. Involving the coroner

A coroner is a type of judge who investigates some deaths. Some reviews found things on the death certificate that had not been diagnosed for the person.

8. Transitions

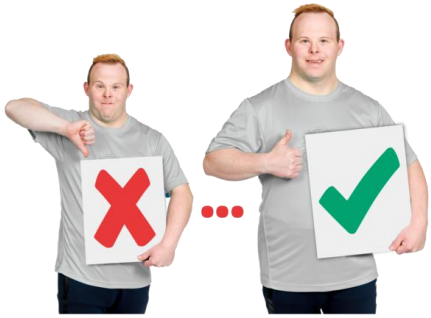
Better services needed for young adults as they move from children's services.



9. Safeguarding

One Leder review was also a Safeguarding review. There was learning about

- Understanding the Mental Capacity Act
- Lack of advocacy
- Listening to families



9. How we learn from the reviews and make things better

Everyone working in Health and Social Care has a role in making things better.

The managers of services will meet regularly to agree plans to improve care and services.

10. What we have done so far

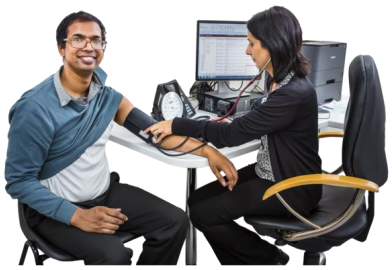
Here are just a few examples of some of the things that County Durham and Tees Valley have done so far:

- We have introduced a Quality Checker programme for GP Practices run by people with a learning disability

- We are reviewing our advocacy services and will report back to the Adult Safeguarding Partnership Board

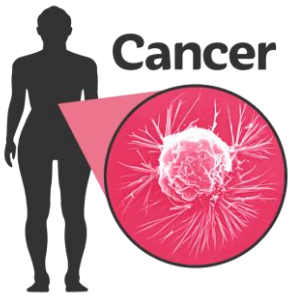
- We have introduced more training about learning disability for GPs

- We have introduced more Easy Read information and better reasonable adjustments in GP practices



- More resources to support people to attend their Annual Health Checks and screening appointments

- A stop smoking service for people with a learning disability



- We have updated our learning disability cancer screening resource pack

- We are working to improve communication between GPs and care providers

- Funding for the voluntary sector to help keep people with a learning disability connected, to support health and wellbeing

- More training about the Mental Capacity Act

- New ‘coming into hospital’ packs to support people with a learning disability.

- Individual support plans for people with a learning disability who are pregnant.

Thank you for reading this report.