



**Staffordshire and
Stoke-on-Trent**
Integrated Care System

LeDeR

Learning from the lives and deaths
of people with a learning disability
and autistic people

Yearly Report 2024 to 2025



**Easy
Read**

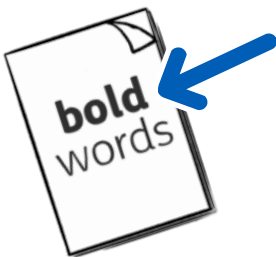
Easy Read



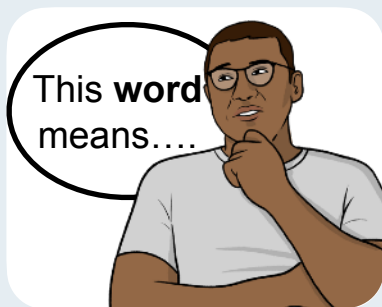
This is an Easy Read version of some information. It may not include all of the information but it will tell you about the important parts.



This Easy Read booklet uses easier words and pictures. You may still want to ask someone to help you read it.



Some words are in **bold** - this means the writing is thicker and darker. These are important words in the booklet.



Sometimes if a bold word is hard to understand, we will explain what it means.



[Blue and underlined](#) words show links to websites and email addresses. You can click on these links on a computer.

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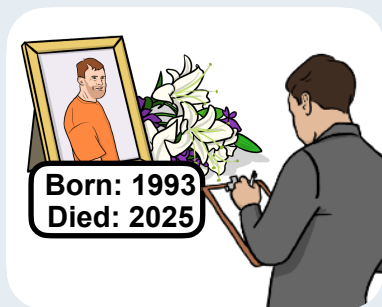


You can fill in a quick survey to say what you think about this Easy Read booklet:
<https://www.easy-read-online.co.uk/easy-read-feedback-survey>

About this booklet



This booklet is from Staffordshire and Stoke-on-Trent Integrated Care System (ICS).



Every year, we write a report looking into the deaths of people with learning disabilities and autistic people in our area.

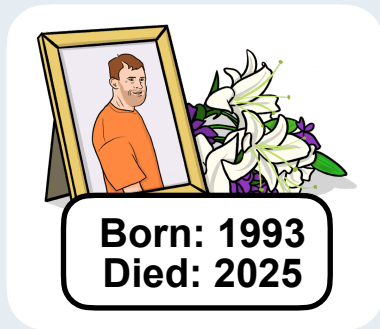


This is called our LeDeR report. It is about what we have done in Staffordshire and Stoke-on-Trent from April 2024 to March 2025.



This is an Easy Read version of the LeDeR report. It will tell you what we feel are the important parts of this report.

About LeDeR



In England, some people with learning disabilities and autistic people die at a younger age than other people.



LeDeR learns from the lives and deaths of people with a learning disability.

LeDeR looks into:



- Why someone with a learning disability or an autistic person may have died earlier than they should have.



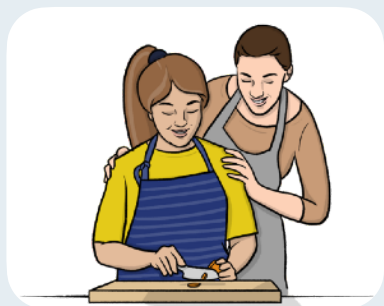
- Whether their care could have been better.



LeDeR can help **health and social care services** improve the way they care for people with learning disabilities and autistic people.



People in the **health services** look after your health - like your GP and staff in hospitals.



Social care is the extra support some people need to live their lives, like support with cooking or having a bath or shower.

Our goals



We want to use what we learn from our LeDeR reports to stop people with learning disabilities and autistic people from dying at a younger age.

Our main goals are:



- Make health and social care services better.



- Deal with the problems that cause **health inequalities**.

Health inequalities are when certain groups of people do not get the same good healthcare as others.

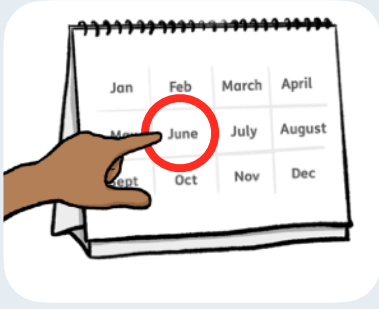


- Help people with a learning disability and autistic people to get better care so they can live better lives.



- Make sure patients and carers are happy with the care they get in their local area.

We are working to meet these goals by:



- Making sure the LeDeR team is told about deaths quickly and does reviews on time.



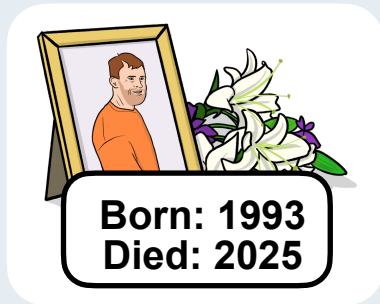
- Making sure that we have good rules about how to do LeDeR work.



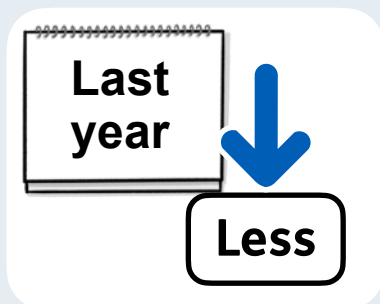
- Working with and listening to different groups and sharing information with them.

What we learned

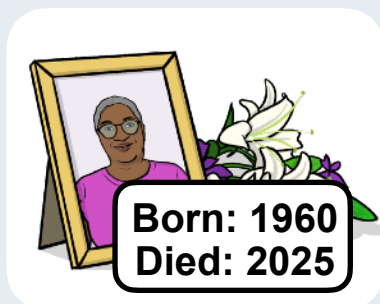
Deaths of adults



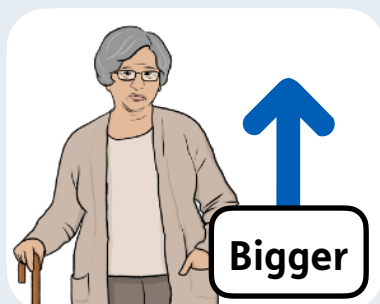
We were told about the deaths of 65 adults in Staffordshire and Stoke-on-Trent this year.



This is less than the number of deaths we were told about last year, which is good news.



Around half of these adults were aged between 50 and 69 when they died.



Out of the deaths last year, the group of people who were aged 70 or older when they died was bigger than in the years before.



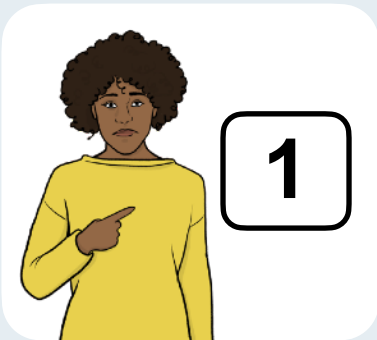
This is good, as we want to stop people dying too young.



More than half the people who died were men.



We were only told about the deaths of 3 autistic people.

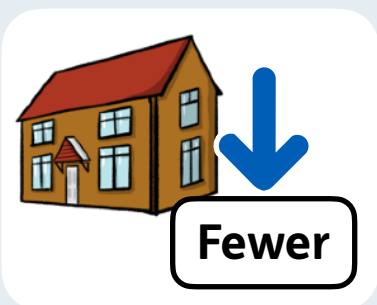


We were only told about the death of 1 person from an **ethnic minority**.

An **ethnic minority** is a group of people who live in a place where most other people are a different race.



Most people died in hospital.



Fewer people died at home or in a care home than last year.

Deaths of children

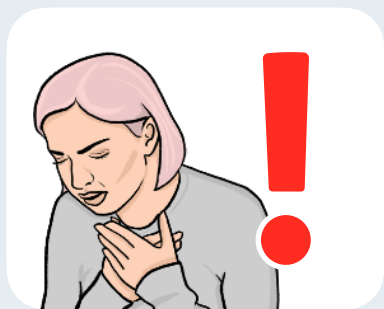


This year, we were told about the deaths of 6 children.



We also finished reviews about 3 other children who died before this year. All 3 were white British boys.

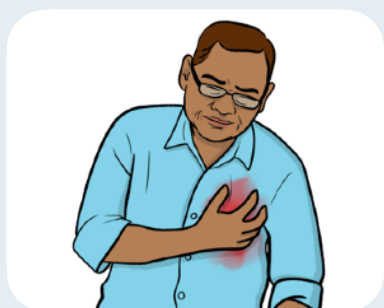
Causes of death



Problems with breathing were the biggest cause of death for people with a learning disability.



This is the same main cause as last year.



The second biggest cause of death this year was heart problems.

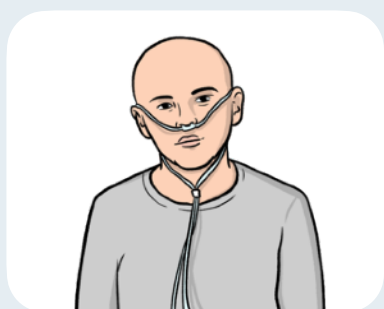
This year, there were fewer deaths caused by heart problems than last year.

The other causes of death included:



- **Sepsis**, which is when a body has a bad reaction to an infection.

The number of deaths caused by sepsis this year was the same as last year.



- **Cancer** - this year, there were fewer deaths caused by cancer than last year.

What we did well



Our reviews showed that we did lots of things well this year.

Here are some of the things we did well:



- We made **reasonable adjustments** for some people with a learning disability and autistic people, like having quieter appointment rooms.

Reasonable adjustments are changes that places and services can make so that disabled people can take part like everybody else.



- We made sure that people had the right vaccines.



- GP practices had given annual health checks to most people whose deaths we looked into.

Here are some more things we did well:



- GP practices did regular checks to see how patients were doing and make sure that they were getting the right medications.



- People were offered **screening** - tests that check for early signs of cancer. Some people agreed to have the screening.



- Some health and social care teams shared information and worked well with each other.

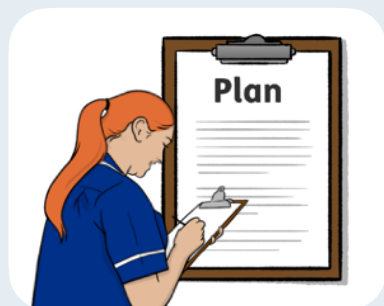


- Health and social care providers gave good end of life care to many people.



- Experts in long-term health conditions often saw people who needed help with those conditions.

Here are some more things we did well:



- Health and care staff followed plans and checks to help give patients the right care and understand what they need.



- Care providers and carers recorded lots of information about each patient and what they are used to in their daily lives.



- Care staff, hospital staff and nurses gave good or excellent care.



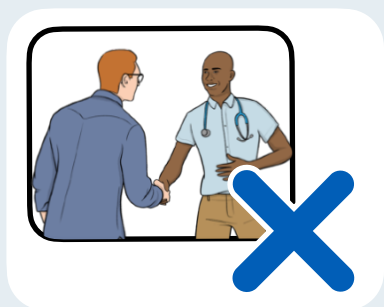
- Many people had help from an **advocate**.

An **advocate** is someone who helps you say what you need to, if you find this hard.

What we could do better



The reviews we did also showed that there are still some problems with services in our local area.



Lots of health and care staff and services did not work together well.



Some people did not have an annual health check, or their annual health check was not done properly.



This was sometimes because they were not on their GP's Learning Disabilities Register.

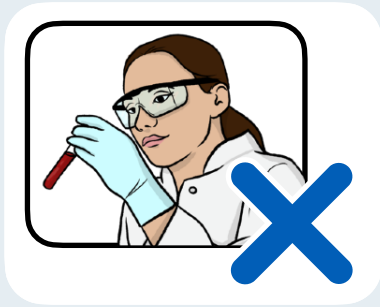


Some people who had an annual health check did not get a **health action plan**.

A **health action plan** is a document that says how you want health services to support you.



Some people did not get reasonable adjustments.



Some people were not given or offered screening, checks or vaccines when they were supposed to have them.



Some people did not have a **health passport**.

This is a document that explains what health and care support a person needs in hospital.



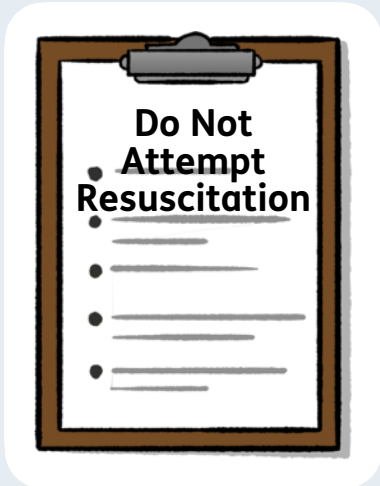
Some people with conditions like cancer and diabetes did not get sent to the right specialist services for care and treatment.



More people died in hospital than in the year before.



We need to do more to help people who are very ill get care at home or in care homes if they can.



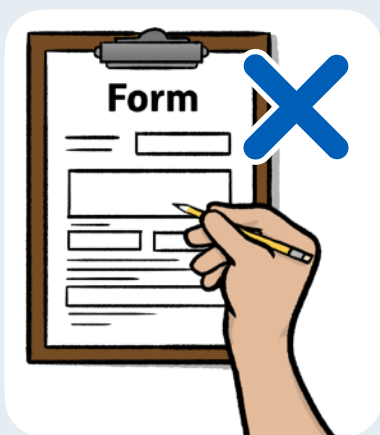
Some patients were given a **DNAR order** just because of their learning disability.

DNAR stands for Do Not Attempt Resuscitation.

A **DNAR order** is a plan that says doctors should not try to save you if your heart stops.



DNAR orders are only used after a lot of careful thought, when a person's quality of life is very poor and they are very ill.



Some important forms about the patient's care were not filled in properly, like **ReSPECT forms**.

A **ReSPECT form** is a plan for what should happen if a patient has an emergency and cannot make decisions for themselves.



Sometimes, health staff did not make end of life care plans for patients who were going to die from their condition.



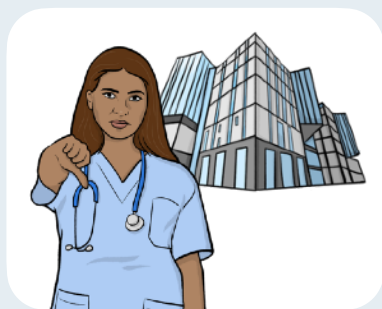
Sometimes, a person's death certificate said that their learning disability was 1 of the reasons why they died. This should not happen - having a learning disability is not a cause of death.



Health professionals and services did not always contact or share information with families enough.



Sometimes, care services could have been better at noticing that someone's health was getting worse.



There were not enough learning disability nurses working in hospitals.



Some people did not have a medication review, or the review was not done well enough.

What the LeDeR team did this year

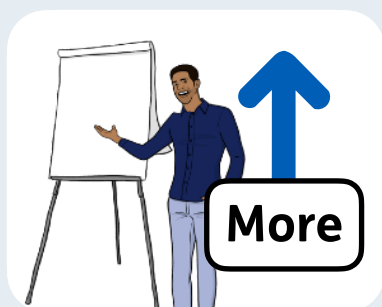
Here are some of the things we did to make services better this year:



- We now have more people taking part in the **LeDeR Steering Group**.



The **LeDeR Steering Group** is the group in charge of deciding the most important things the LeDeR team should work on.



- We gave more training on epilepsy and problems with swallowing (dysphagia).



- We worked with other LeDeR teams in the West Midlands to help us learn from LeDeR reviews.

Here are some more things the LeDeR team did to make services better this year:



- We had regular meetings with people with a learning disability and autistic people, and listened to their advice.



This advice has helped us make videos, projects and Easy Read booklets better.



- We made a newsletter about LeDeR for health and social care staff.



- We had meetings with health and social care staff to help them learn about the work LeDeR does.

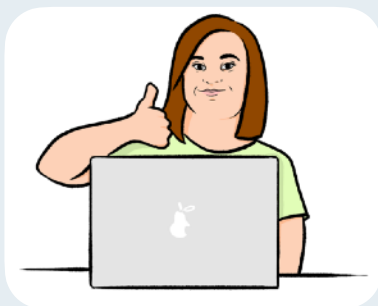


- We looked into how good annual health checks are and how to make them better.

Here are some more things the LeDeR team did to make services better this year:



- We made a new website for local GPs. This website has information about how GPs should care for people with a learning disability and autistic people.



- We worked to make the LeDeR website easier to use for people with a learning disability and autistic people.



- Our **LeDeR System Wide Action Plan** tells us what we need to do to make things better.

We have changed it to show extra things we need to improve.

What we will do next year

Next year, we will:



- Keep following the LeDeR System Wide Action Plan.



- Keep sharing information about how health and care staff and services can learn and give better care.



- Set up groups to work on different parts of the LeDeR Action Plan.



- Keep telling people about how it is important to have things like vaccines, screening, check-ups and health plans.



- Work with health and social care staff to make sure they help people get the vaccines, screening, check-ups and health plans that they need.

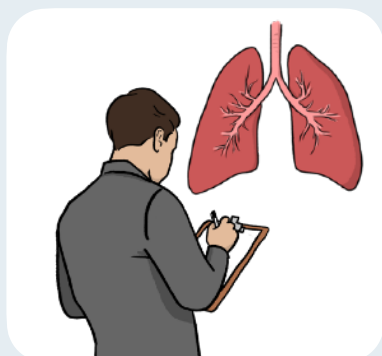
Next year, we will also:



- Keep working with Staffordshire County Council and Stoke-on-Trent City Council to make sure that social care staff have the help, information and training they need to do their work well.



- Keep offering face-to-face training about epilepsy and problems with swallowing.

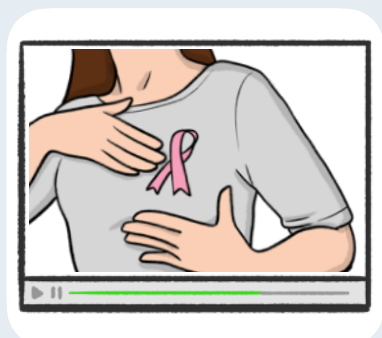


- Keep doing more detailed reviews about people who have died from lung problems, like pneumonia.

This will help health and social care staff learn how to keep improving treatment and care for these illnesses.



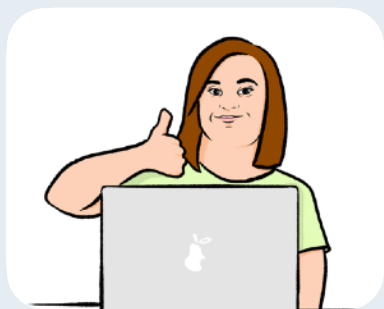
- Keep checking how good annual health checks are, and sharing what we learn with GP surgeries and learning disability nurses.



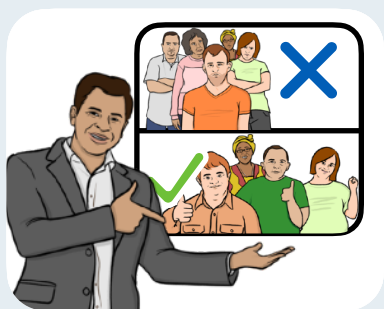
- Keep making videos to tell people about cancer checks.

We already have videos explaining what happens in a cancer check appointment on our website.

Next year, we will also:



- Keep working to make the LeDeR website easier for people with a learning disability to use.



- Keep sharing information about health inequalities.



- Keep talking to people from ethnic minority groups and autistic people about LeDeR's work.

This is because we want to hear from these groups when there is a death we should look into.



- Keep sharing what we are doing well, things we have learned and what we are doing to improve healthcare for people with a learning disability and autistic people.

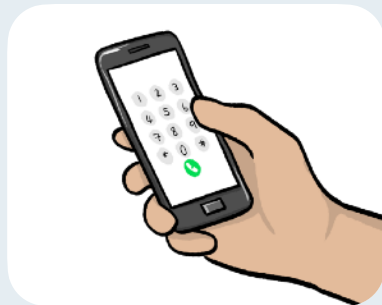
Find out more



You can look at our website here:

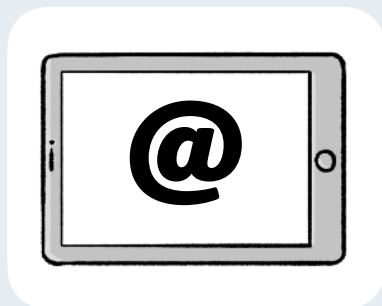
<https://staffsstokeics.org.uk/leder>

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- Phone: 0300 123 1461

If you phone this number, someone will talk to you and answer your questions.



- Email: enquiries@staffsstoke.icb.nhs.uk

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