South East London Integrated Care System

NHS South East London

LeDeR

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

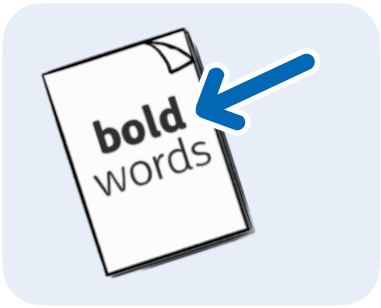
Yearly Report 2023 to 2024

Easy Read

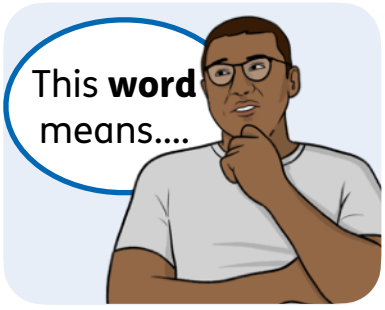
Easy Read

This Easy Read report will tell you about the important parts of what we have found out.

This Easy Read booklet uses easier words and pictures. Some people may still want help to 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.

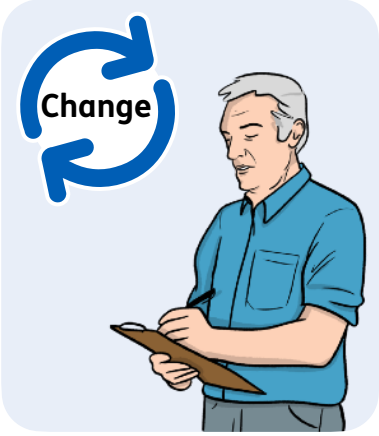
What is in this booklet

About this report

NHS South East London has to write a report every year looking into the deaths of people with learning disabilities and autistic people in our area.

The **LeDeR** programme is a government plan to improve the lives of people with learning disabilities and autistic people by providing better care.

LeDeR stands for learning from the lives and deaths of people with a learning disability and autistic people.



We look into people's deaths to understand if anything could have been done better or stop them from dying.

This will help us learn what we can change and do better in the future.

We want to thank everyone who helped us write this report, especially people whose loved ones died.

How LeDeR works

Anyone can tell us about the death of a person with a learning disability or an autistic person.

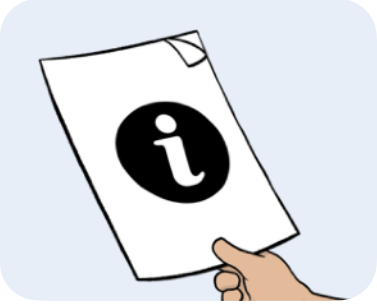
This could be a:

- Family member or friend.

- Doctor or nurse.

- Social worker.

To tell us about the death, they need to fill in a form.



The form will ask for information about the person who died and how they died.

We will then check that:

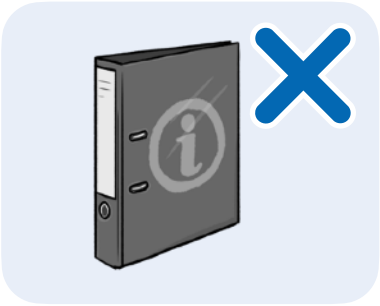
- The report is about a real person.

- The person gave permission for us to look into their death.

- A doctor has said that they were a person with a learning disability or an autistic person.

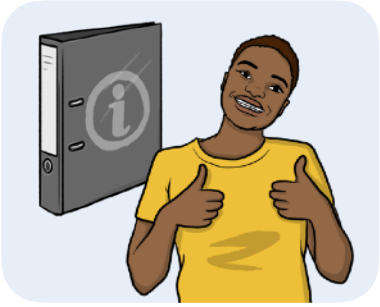
When we have done the checks, we will ask for the care records of the person who has died.

We try to complete the review within 6 months.



In the past, if someone said they did not want to share their information before they died, we did not use that information in our report.

But there were worries that some people with a learning disability and autistic people might be stopped from sharing their information by other people.



So next year, we will include everyone who we are told about.

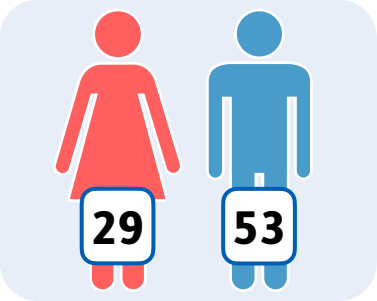
LeDeR in South East London

Deaths in South East London

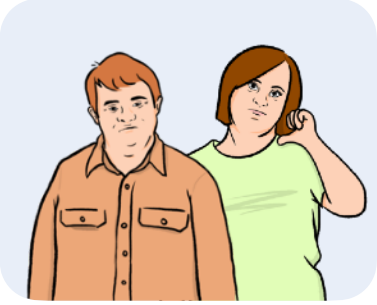
We were told about 82 deaths this year.

This is the same number as last year.

About the people who died



29 females and 53 males died.



Most of the people who died were white.

Most of the people with a learning disability and autistic people died younger than other people would have.

Women with a learning disability usually die 23 years younger than women who do not have a learning disability.

Men with a learning disability usually die 20 years younger than men who do not have a learning disability.

Most people were aged between 19 and 86 when they died.

1 person was older than 86.

What we looked into

Of the 82 deaths we knew about, we looked into 54 deaths.

We asked a group called Positive Support Group (PSG) to help us look into these deaths.

We helped make sure that Positive Support Group looked into these deaths in the best way possible.

We looked into the deaths of 2 autistic people.

We will not tell you about the deaths of these people in the report to keep their personal information private.

About the deaths

Half of the deaths that we looked into happened in hospitals.

Fewer people died in their homes than last year.

More people died in a **hospice** than last year.

A **hospice** is a place where people can get care if they are very sick and going to die soon.

23 of the people whose deaths we looked into had a **DNACPR** when they died.

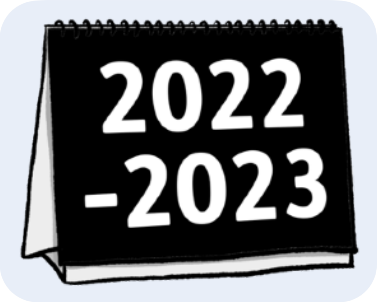
DNACPR means that someone does not want doctors to try and restart their heart if they die.

19 of the people who had a DNCPR talked to their families about having a DNACPR before they died.

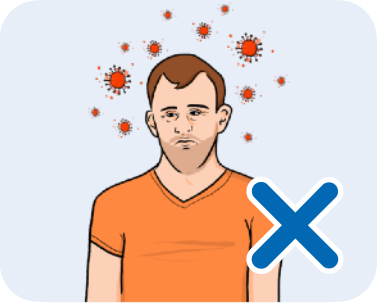
Why people died

The main reason that people died was an illness to do with breathing, like **pneumonia**.

Pneumonia is an illness where you cannot breathe properly.



This is the same main reason as last year.



No one died from Covid-19 this year.

Of the people we looked into, 9 people died from cancer.

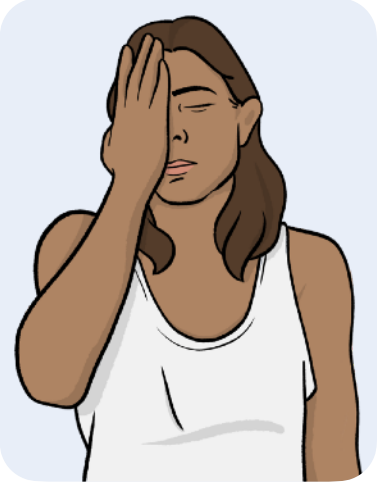
All of the people we looked into had 2 or more long term health conditions, like:

- **Epilepsy**.

  Epilepsy is an illness in the brain that means people have fits or seizures.

- Cancer.

- Problems with swallowing.



- Mental health conditions like **depression** and **anxiety**.

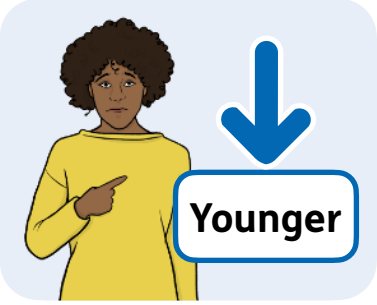
  Depression is when you feel very sad or feel bad about yourself for a long time.

  Anxiety is when you feel worried and stressed for a long time.

People from ethnic minorities

Ethnic minorities are Black people, Asian people, people from mixed backgrounds and other people who are not white.

Of the 54 deaths we looked into, 15 of the people were from ethnic minorities.



Most of these people were younger when they died than the other people we looked into

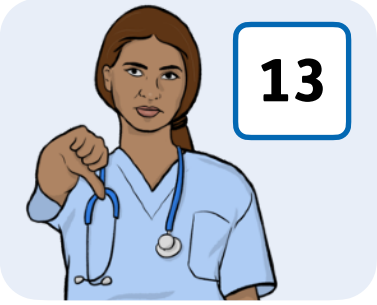
About the care people got

In 24 of the deaths that we looked into, we also looked into how good the care people got was.

This included all the care given to people who died from cancer between January and March 2024.

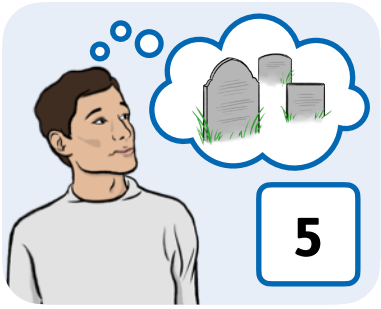
Out of the people we looked into, we found out that:

- 11 people got care that was good or good enough.



- 13 people did not get good enough care.

We also found out that:



- 5 people could have died because they did not get good enough care.

- 6 people did not get the right kind of care.

People did not get the right kind of care for lots of different reasons, like:

- There were not enough carers to help people with day to day activities like washing and dressing.

- It was difficult to find the right places for people to get care.

- Some families said they did not need extra support.

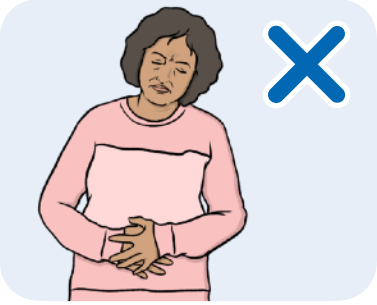
Some people were worried about the care that was given because:

- Health and care staff did not tell **social services** about problems with supporting people or changes to people's needs.

  Social services are services people can use when they need help and support.

- Some people got care in the wrong places, from staff who did not have the right training.

- Some care home staff made mistakes with medicines.



- Some people did not get help with their pain because staff did not understand their behaviour.

Some people were worried about the care because some family members said no to extra medical help without checking what the law says first.

What went well this year

Learning disability nurses helped make sure that people staying in hospital got the right care.

Some health and care staff followed plans about what to do at the end of a person's life.

Some people got support with going to appointments from care staff who knew them well.

Some staff worked together in a good way.

Some staff and GPs worked well with people with a learning disability and autistic people and their families.

Some people and their families were included in making choices about their care.

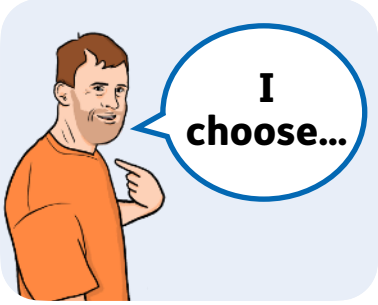
1 person who needed help with their mental health in hospital was visited by a mental health doctor often.

Many people got the **reasonable adjustments** they needed.

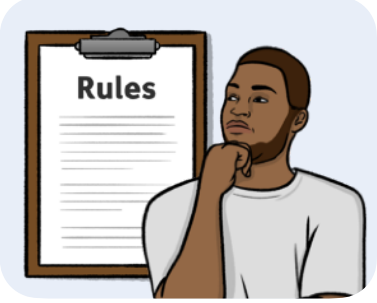
Reasonable adjustments are changes that services can make to make sure that disabled people get the care they need, like everyone else.

What could have been better

Families and staff did not always follow the **Mental Capacity Act** when they made decisions about someone else's care.



Mental capacity means whether you can make choices for yourself.



The **Mental Capacity Act** is a law that explains what rules people should follow if someone does not have mental capacity.

Staff find out whether someone has mental capacity by doing a **mental capacity assessment** with them.

Families and staff did not always do mental capacity assessments before making choices for someone.

Some people with a learning disability and autistic people did not get help from an **Independent Mental Capacity Advocate** when they needed it.

An **Independent Mental Capacity Advocate** is someone who speaks up for what you need if you cannot make choices for yourself.

Family members did not always know what the law said about making these choices.

This meant that some decisions were made without following the rules.

We have told the South East London Learning From Deaths Group about these problems.

We will use training and events to teach people how to fix these problems and stop them from happening again.

What has happened

The South East London Learning Disability and Autism programme has:

- Made a plan for how children and young people can get an **autism assessment**.

  An **autism assessment** is when a doctor tests if someone is autistic.

- Made a new team called the Learning Disability and Autism Pathway Fund.

  This team helps people get the care they need in their local area when they leave hospital.

- Helped provide **Oliver McGowan Training** across South East London.

  Oliver McGowan Training teaches health staff the skills they need to give good care to people with learning disabilities and autistic people.

The Learning Disability and Autism Team has:

- Worked hard to help more people get good **Annual Health Checks.**

  Annual Health Checks are yearly appointments for people with a learning disability. Your doctor checks your health and gives you some health advice.

- Trained health and care staff about how to support people with learning disabilities.

- Took part in events to teach people with learning disabilities, autistic people and their carers how to have more control over their health.

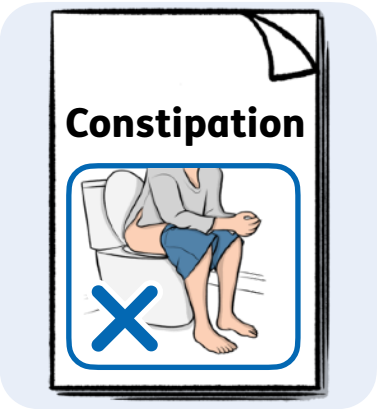
- Worked with local doctors in South East London to make sure the right people are on the learning disability register.

In Bexley, Bromley and Greenwich:

We have looked into how to help people with learning disabilities eat healthy food.

We have created a new way to test for problems with breathing.

In Bexley:



We have started making a training document about **constipation** for staff and people who use services.

Constipation is when you find it difficult to do a poo when you go to the toilet.

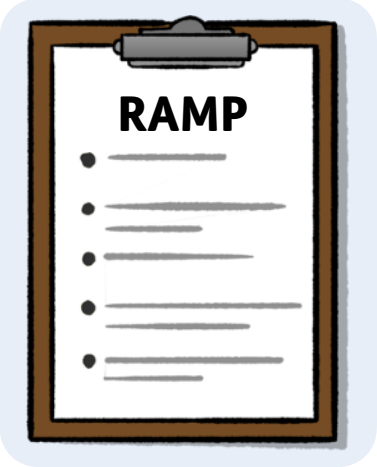
We will share this training document at the end of summer 2024.

In Bromley:

- The One Bromley Learning Disability Taskforce Team were given an award for looking after people with learning disabilities.

- We gave staff training about **epilepsy** in people with learning disabilities.

  Remember, **epilepsy** is an illness in the brain that means people have fits or seizures.

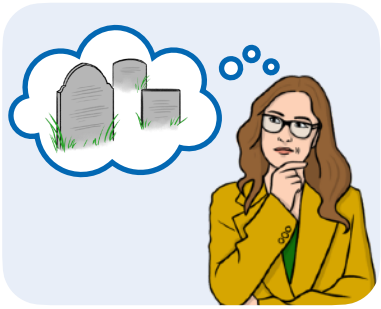


- We taught all adult learning disability nurses how to use the **RAMP (Risk Assessment Management Plan)**.

  The **RAMP** is used to make sure people with epilepsy are safe and get good care.

Lambeth, Lewisham and Southwark:

The local team for adults with learning disabilities has worked with local hospitals to set up a Living and Dying Well Group.



This group will help people work together to think and talk about life and death.

Lewisham:

Lewisham Speaking Up runs regular public meetings about issues that are important to people with learning disabilities.

In July 2023, they had a meeting about health.

In the meeting about health, Lewisham Speaking Up talked about:

- Why people with learning disabilities are dying too young.

- How to spot signs of cancer and get tested for cancer.

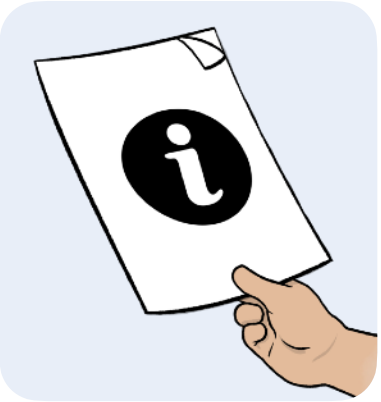
- How to eat healthy food when there is a **cost of living crisis**.

  A **cost of living crisis** is when the cost of things you need to live like food and housing has gone up a lot recently.

Lewisham Speaking Up is also working to help make sure that people with learning disabilities get medical help faster.

Next steps

We will use what we have learned from this report to:



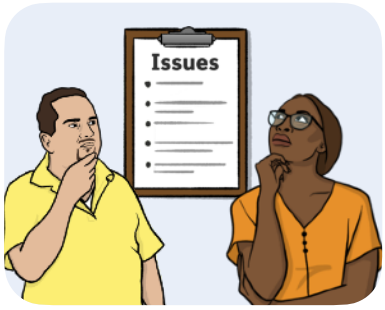
- Keep sharing information about the LeDeR Programme.

  This will help us make sure that we hear about all the deaths of people with a learning disability and autistic people in the area.

- Work hard to get more information about the deaths of autistic people.

- Work hard to get more information about the deaths of people from ethnic minority groups.

We will also:

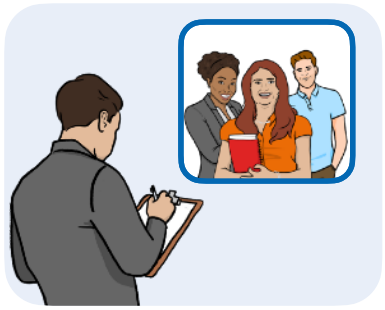


- Look into the issues that ethnic minority groups and autistic people often face to help us understand what we should change.

- Use what we have learned to make services better for people with learning disabilities and autistic people.

- Talk about the issues in this report at meetings and make plans to fix them.

- Keep working with local leaders to run activities that help with LeDeR.

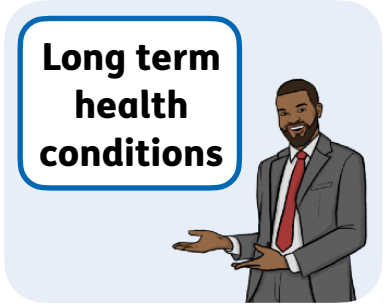


- Set up a group to check that the LeDeR groups are working well.

We will also:

- Help make sure that people with a learning disability aged 14 and over have their Annual Health Checks.

- Look into how to improve the way that LeDeR works.



- Share what we learned about long term health conditions in meetings.

- Look into the main issues that keep making it hard for our South East London services to work well.

Find out more

You can look at our website here:
www.selondonics.org/icb

If you need more information please contact us by:

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