NHS
South East London

LeDeR

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

Annual Report 2022 to 2023

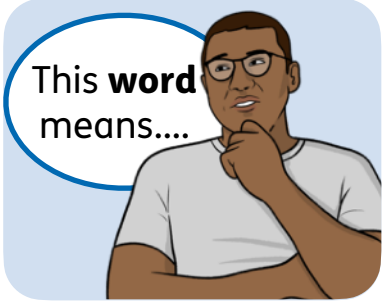
Easy Read

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. 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.

We write the report to follow the **LeDeR** programme - this 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 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 differently to stop them from happening.

This will help us to learn what we can 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.

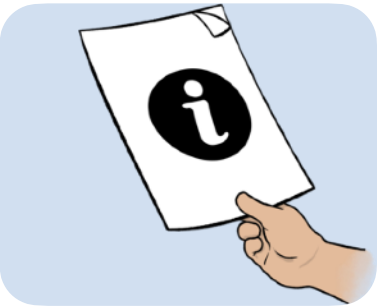
This could be a:

- Family member or friend.

- Doctor or nurse.

- Social worker.

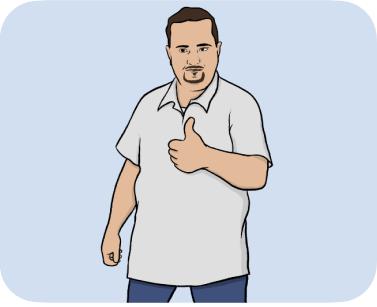
To tell us about the death, they need to fill in a form.



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 had 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 will try and look at their records within 6 months.

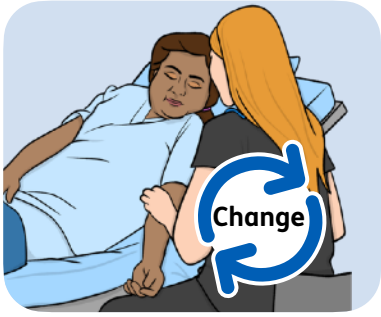
LeDeR in South East London

South East London NHS has put together a local team to work on LeDeR.

The team will make sure that we:

- Tell people how to report that a person with learning disabilities or an autistic person has died.

- Tell people what we learn from looking into the deaths of people with learning disabilities and autistic people.



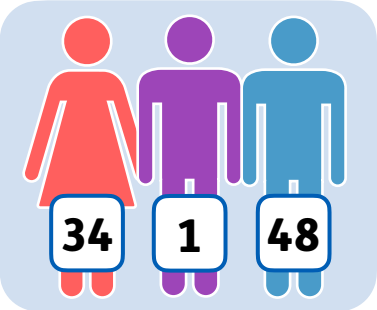
- Change the way we provide care based on what we have learnt.

Deaths in South East London

We were told about 82 deaths this year.

This might not include the death of every person with learning disabilities or autistic person because we are not always told when someone has died.

About the people who died



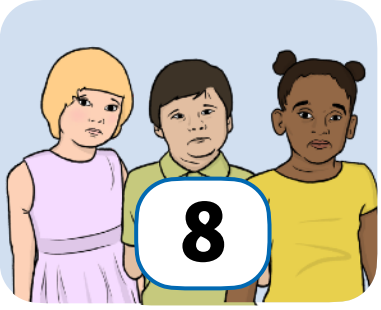
34 females, 48 males and 1 person who did not want to say their gender died.

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

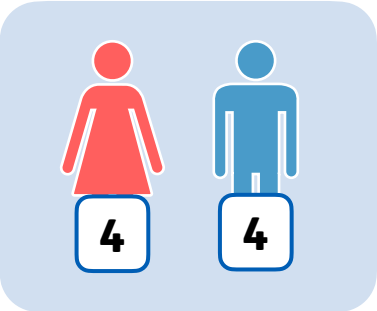
They were usually more than 20 years younger.

Most of the people who died were white.

Children who died



We were told about 8 children who died this year.



4 children who died were female and 4 were male.

4 of the children who died were white.

What we looked into

Of the 82 adults we know about, we looked into 40 of their deaths between April 2022 and March 2023.

We did not look into the deaths of any of the children.

We had problems looking into the deaths because:

- There were problems with the computer system people use to tell us about deaths.

- It took a long time to check the information about the people we were told about.

- We did not have enough staff.

We looked into the death of 1 autistic person.

We will not tell you about the death of this person in this report to keep their personal information private.

We contacted families of the people who died, and 20 families helped us look into the death of their loved one.

About the deaths

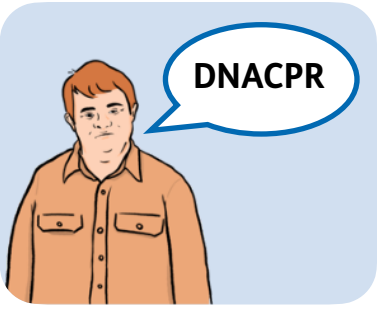
More people died in hospitals than in their homes.

6 of the people who died in hospital had also been in hospital in the 30 days before they died.

People did better when a learning disability nurse had helped them while they were in hospital.

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

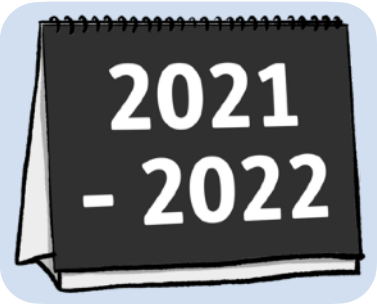
DNACPR means that someone does not want doctors to try and restart their heart if they die.



All except one of the people with a DNACPR had talked to their family about it.

Why people died

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



This is the same as last year.

Long term health conditions

Most of the people we looked into had long term health conditions, like:

- Difficulty getting around or falling a lot.

- Problems controlling their wee.

- **Epilepsy**.

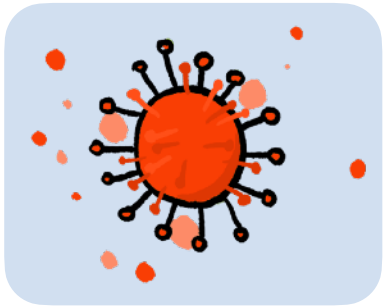
  Epilepsy is an illness in the brain that means people have fits or seizures.

People from an ethnic minority

An **ethnic minority** is a small group of people of the same race, in a place where most other people are a different race.

Of the 40 deaths we looked into, 11 were of people from an ethnic minority.

Most people from an ethnic minority who died were 25 years or more younger than other people.



2 people from an ethnic minority died from Covid-19.

Cancer

Not many of the deaths were because of cancer.

We know that some people who died had not been checked for cancer.

But we do not know why they had not been checked.

About the care

In 16 of the deaths we looked into, we looked into how good the care people got was.

Most people got care that was good or good enough.

Most people also got care when they needed it.

What went well this year

There were some good examples of staff working together.

There were some examples of staff and GPs working well with people with a learning disability and autistic people and their families.

One GP wrote in the notes that the person had a learning disability and needed more time to understand what people were saying.

What could have been better

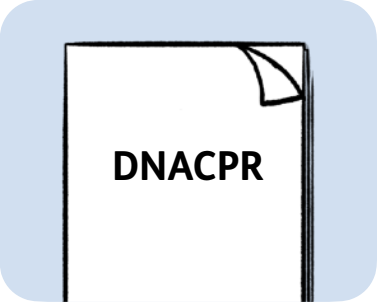
An **Annual Health Check** is for people with a learning disability. Your doctor checks your health and gives you some advice.

Annual Health Checks could be better so they:

- Find other health problems.

- Make sure r**easonable adjustments** are made if they are needed.

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



DNACPR should be in people's notes if they have asked for it.

Hospital passports should have the right information - these are documents that explain what health and care support a person needs in hospital.

We need to understand why cancer is not being found and treated sooner for some people.

We want to be told about more deaths of autistic people.

What has happened

We have heard about what people have done because of what we have learnt from LeDeR.

One team has been teaching healthcare professionals in South East London more about learning disability and autism.

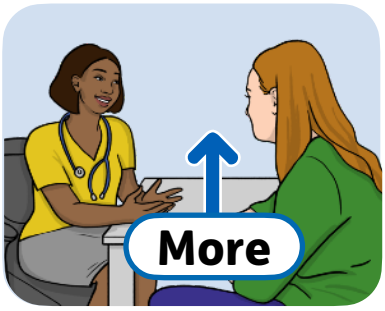
They have been talking about how to:

- Keep people safe.

- Stop people being given medicine they do not need.

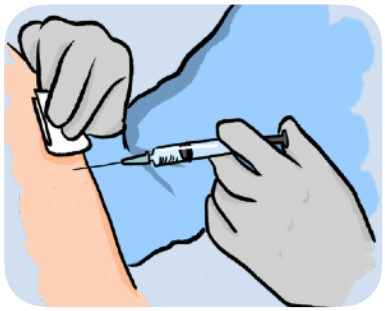
- Keep people safe when they take medicine.

The team are also working to make sure that:



- More people with a learning disability have an Annual Health Check.

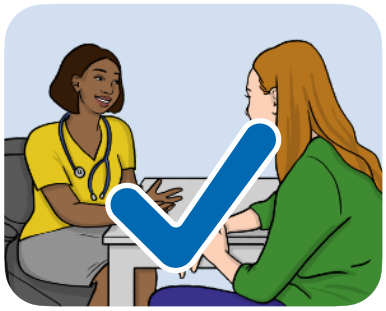
- The Annual Health Checks are done well.



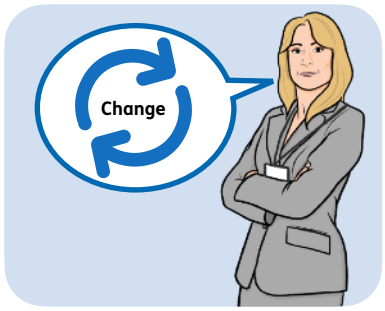
- People with a learning disability and autistic people have the vaccinations or jabs they need to keep them healthy.

- People in nursing homes get the right medicine.

There was a Learning Disability and Autism Week in November 2022, where:



- We talked about what a good Annual Health Check should be like.

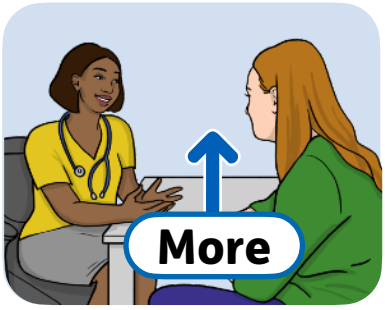


- We talked about what reasonable adjustments are in healthcare.

- Oxleas Community Learning Disability Team re-launched their Black Books, which contain all the healthcare information about someone.

We are having an online event every year to talk to doctors and nurses about Annual Health Checks.

In Bexley:

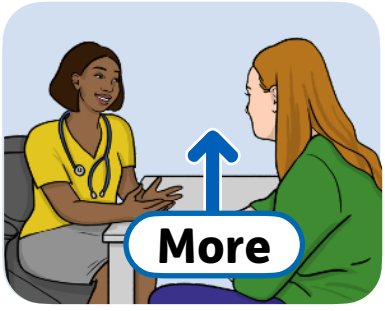


- We have helped GP surgeries get more people to come for an Annual Health Check.

- Teams are looking at how to make sure that a person's learning disability or autism is written in their notes, so they get the healthcare they need.

In Lewisham:

- We have talked to learning disability providers about what we have found out.



- There is an Annual Health Check coordinator in part of Lewisham. We are seeing if that helps more people go for an Annual Health Check.

In Lambeth:

- We have trained staff in care homes to know when someone is getting more ill.

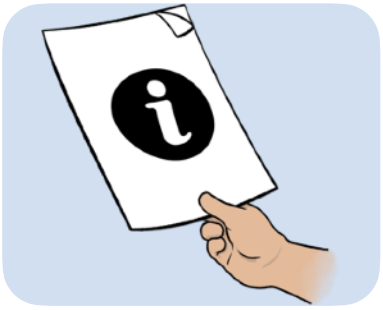
- We wrote an article for the GP newsletter about LeDeR and Annual Health Checks.

- We are looking at the best way to tell GPs about the things we have learnt.

In Bromley:

- We are talking to children's doctors, schools and the council about how to make sure we know about every person with learning disability or autistic person.

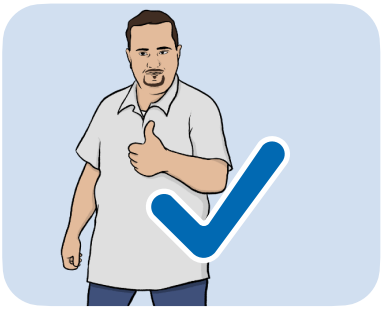
Next steps



Each year we get more information that we want to include in our reports.

This will help us:

- See what has changed.



- See if what we have done has made a difference for people with a learning disability and autistic people.

- Find out where we need to do more.

We also want to tell more people in South East London about LeDeR, so that:

- We are told about more deaths of people with a learning disability and autistic people.

- We can look into more deaths.

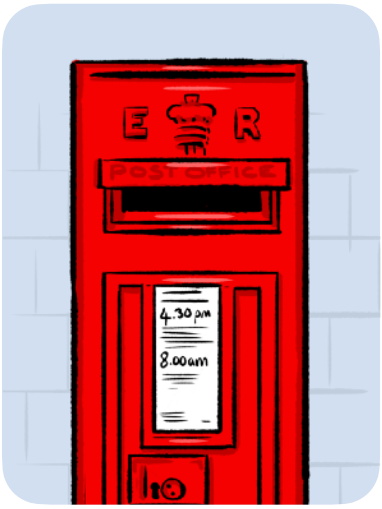
We want to keep working with all organisations to improve the lives of people with a learning disability and autistic people in South East London.

We will check that the things we are changing make their lives better.

We will keep checking how well services are doing.

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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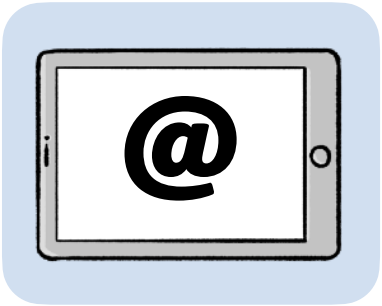

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