



**Integrated Care Board** 

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

2024 to 2025



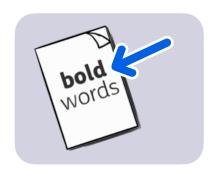
### **Easy Read**



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.

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

### **About this report**



We are the NHS in Bristol, North Somerset and South Gloucestershire.



Sadly, sometimes people with a learning disability and autistic people in our area die.



We always look into what happened when they died.

This helps us to learn and get better at caring for people.



Every year, we write a report about what we have learned.

We call this a LeDeR report.



This is an Easy Read version of our report for 2024 to 2025.

### What is LeDeR?



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

We try to learn from people's deaths. We do this to:



 Understand if we could have done anything to stop the deaths from happening.



• Learn what we can do better in the future.



 Make sure that people with a learning disability and autistic people can get the care they need.

### About the people who died



In this report, when we say 'people', we mean people with a learning disability and autistic people.



Between 1 April 2024 and 31 March 2025, we were told about the deaths of 86 people.



This is more than last year.

We think this is because more people know about LeDeR, so they make sure they tell us when someone has died.



83 people who died had a learning disability.



3 people who died were autistic people.



Most of the people we looked at were about 63 years old when they died.



A little less than half of the people were over 70 years old when they died.



Most of the people were White British.



More of the people who died were men than women.



Most people either died in hospital or in the place they usually live.



Many of people who died liked to listen to music.



Many of them had religions that were important to them.



They liked to go out and about in the local area.



Many of them liked to do things for themselves. This is called **being independent**.



Many people liked to go on holidays and trips.

### What we have learned



The biggest reason that people died was illnesses to do with breathing.

These illnesses have names like pneumonia and chest infection.



We think that about half of the people who died might have lived longer if they had got help for their illnesses earlier.



We found that there were some important things that we can learn from, so that people live longer.

## People did not always get the care they needed



Some people were scared of going into hospital or having operations.



Some people could not always look after themselves well enough.



Some people did not trust healthcare staff, like doctors and nurses.



This meant that they did not get the help they needed.



## The right support is very important

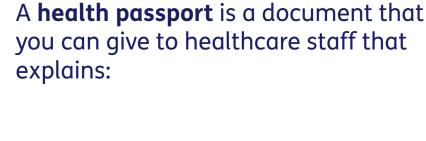
It is important that people get the right support.



It is important that people have family and friends who can speak up for them.



**Health passports** are a really good way of making sure people get the right support.





• Your learning disability or condition.



 How healthcare staff should support you.

## Health and care services should work together



When health and care services work together, it makes it easier for people to stay healthy.



Good care plans can help healthcare staff to check that people are getting what they need.



Healthcare staff should help people to make choices for themselves.

## People should get the right care at the right time



Some people had issues because of missing appointments.



Some people had to explain their illnesses to lots of different doctors and nurses.



This means that the doctors and nurses might not understand what the person needs.

### What we will do in the future



We have looked at what happened when people died.



This means that we understand more about how to help people in the future.



## Helping people who are hoarding

**Hoarding** means keeping a lot of things and not throwing them away.



We have learned more about people who hoard in their homes.



We may need to do more to help people who are hoarding.

### **Checking for cancer**



Checking for cancer is called screening.



We now have a special person who helps people with a learning disability get checked for cancer.



They will help more people to go to the doctor so the doctor can check their health.

#### **Annual health checks**



Everyone with a learning disability over the age of 14 should have a health check every year.

This is called an **annual health check**.



More people had their annual health check this year than last year.



We are training doctors on annual health checks, so that they are better at making sure people have them.



We have also written useful information for doctors to invite people to come for their annual health check.

### Missing appointments



We have a new way to see if people have missed appointments.

### Reasonable adjustments



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



All GPs now have to write down the reasonable adjustments that their patients need.



This will mean that people can easily go to appointments and get care.

### Things we have done well



Local care homes have projects that help to support people with a learning disability and autistic people.



One care home, called Brandon Trust, has a group that helps people to understand death and dying.



Another care home, called Milestones Trust, is helping people to make sure they eat safely.



Weston General Hospital has a new **Changing Places toilet** to help disabled patients.

**Changing Places toilets** have extra space and equipment to help disabled people.



The NHS in North Bristol is running a project called 'Poo Matters'.

This project is all about **constipation**. This is when you find it hard to go to the toilet.



They are also helping young people who are becoming adults to get the care and support they need.

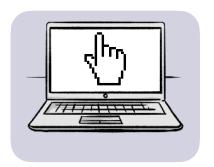


Sirona care & health has worked with People First to make a new health passport for local people to use.



Mental health services have got better at sharing when someone needs reasonable adjustments.

### Find out more



You can look at our website here: <a href="https://bnssghealthiertogether.org.uk/about-us/">https://bnssghealthiertogether.org.uk/about-us/</a>

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