

LeDeR Yearly Report

1 April 2023 to 31 March 2024



Introduction

This report is about Learning from the lives and deaths of people with a learning disability and autistic people in Bristol, North Somerset and South Gloucestershire, this is known as **LeDeR**.



LeDeR was started by NHS England to check on the care of people who have died and make sure we learn from the care they had and about why they died.

This is our 5th report.

We want to tell you what we found out when we did our checks which we call reviews.

We want to tell you what we have learnt and what we have been doing to make services better for people with learning disabilities and autistic people.

How we manage our LeDeR work.

We have someone called the Local Area Contact (LAC) who manages our LeDeR work.

They give review work to specially trained LeDeR reviewers.

Families, carers and loved ones are asked to take part in LeDeR reviews.

Once the review is finished, the review is sent to a group that check that all the reviews are done well.



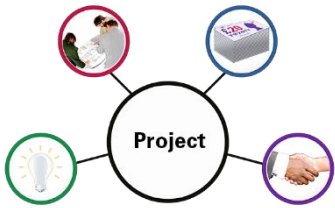


We have a group that meets every 2 months this is called the LeDeR Governance Group.

This group has people from all health providers in Bristol, North Somerset and South Gloucestershire and from social care.



The group check on the information we get from LeDeR reviews to plan how care can be better for people.



This group asks other groups to start projects that help people with a learning disability and autistic people.

The LeDeR Governance group work with another group called the Learning Disability and Autism Organisation Delivery Group to make sure that larger projects have everything in place to make them happen



We have a new group called the Learning Disability and Autism ICS Co-Improvement Group who work on small projects.

What we have been doing between April 2023 and March 2024.

We were told about 75 people who had died.

71 of those people had a learning disability and 4 were autistic people.



We completed 43 reviews.

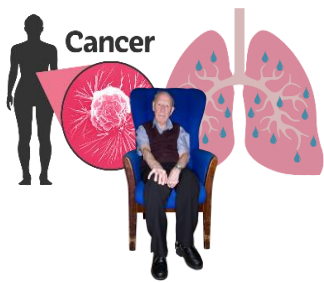
Some reviews were from last year, we finished these first.

3 of the people we were told about were from different ethnic groups.

3 is not very many people.

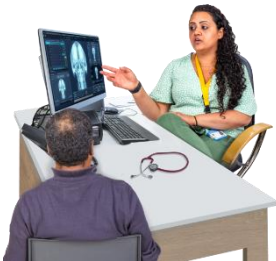
We want to find out why LeDeR is not told about more people from a different ethnic group.





This is part of our work to make sure everyone gets good help with their health,

Most of the people who died had either cancer, pneumonia or were older and frail.



Everyone who died had more than one problem with their health.

Some people had health problems that could have been treated or prevented. For example finding out about cancer earlier.



Our LeDeR team have looked at the way we manage our review work and have found some ways to make it better.

What we found out from the reviews:



- Health and social care teams are working well together.
- Good work has happened to support older people with learning disabilities and autistic people.
- There are GPs who have regular contact with people and care homes, this means GPs can help the person before they get too sick.



- People who have mild learning disabilities don't always get the help they need with their health.
- Cancer is not found quickly enough.
- Health and social care services are not using easy read enough to help people understand their health and care needs.



- People with learning disabilities or autistic people can go home from hospital without checking that they have the right support in the community.



- Sometimes people with a learning disability do not receive the support they need when in hospital.
- Health and social care staff need more training in how to support autistic people.

LeDeR will help health and social care services plan how to make services better.

What we have done:

Cancer

We have a new person to help people with learning disabilities understand about health screening. They are called a Screening Practitioner.



Health screening is for Breast, Bowel and Cervical cancer.

The Screening practitioner has been finding out what stops people with learning disabilities from having these checks.



The Screening practitioner has made new easy read training for people with learning disabilities.

The Screening practitioner trains health and social care staff in how to support people with learning disabilities to go to screening.

Annual Health Checks.

There is training for GP's about annual health checks.

A guide about how to complete an annual health check and health action plans is being made.



We have an information pack for carers to help them support people with learning disabilities to have their annual health checks.

Autism Independence help people from different ethnic groups know about annual health checks.

They have made easy read information in different languages for people with a learning disabilities. This information can be used in GP surgeries.



Autism Independence also help families and carers understand about health services and help people with learning disabilities have their annual health check.

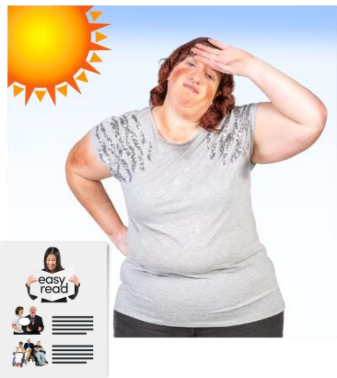
We are finding out why people with learning disabilities and autistic people don't always go to their healthcare appointments.

Heatwaves.

The national LeDeR report said more people die when it is very hot weather.

Sirona Care and Health made easy read information about keeping cool in hot weather.

Sirona Care and Health will also make a video.



Reasonable Adjustments Flag.

Reasonable Adjustments are changes that can be made to help someone access services. This could be things like having longer appointments or a quiet space to wait.

We are making a Flag on people's health records to show they need reasonable adjustments.

We are making an information pack to help health services know what reasonable adjustments are.



Catheter Passport.

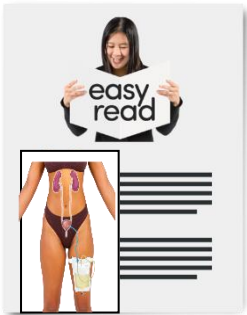
Some people can find weeing difficult and need a catheter.



A Catheter is a tube that drains wee from your bladder into a bag.

People with a catheter can get infections.

Caring for a catheter correctly will stop infections.



Sirona Care and Health made a Catheter Passport in easy read to help people with a learning disability to care for their catheter.

Constipation.

Constipation is when you find it difficult to poo or you cannot poo.

Constipation can be painful and dangerous to your health.

Not everyone with a learning disability or autism is able to say that they are constipated or have tummy pain.



People 1st



People First did some training for people with learning disabilities to help them learn about constipation.

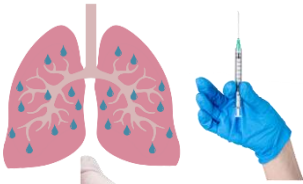
What we will do:

- We will get feedback from people with a learning disability and autistic people about what makes it difficult for them to access healthcare.
- Find out from different ethnic communities what makes it difficult for them to access healthcare.





- We will help people in health and social care understand about constipation so they can support people with a learning disability and autistic people.



- We will help people with a learning disability and autistic people to have vaccinations to prevent pneumonia.



- We are trying a new finger prick blood test. This will help take blood samples from people who are afraid of needles. This will help people to get the right health care quicker.



- We will plan how we can help people with learning disabilities and autistic people keep safe when the weather is very hot.
- We will help people with learning disabilities and autistic people have more say about what they want when they are at the end of their life.



We think our report shows how much we are learning about how we can support people with learning disabilities and people with autism.

We will carry on working together with Experts by Experience and other organisations to make our services better.



Thank you to everyone for their commitment and hard work.

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