

# Learning from the lives and deaths of people with a learning disability (LeDeR) in Gloucestershire

April 2021 – March 2022



## Easy Read Annual Report



## Part 1 – The report

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This report is made up of five different parts to make it easier to read.

Each part is a different colour.

You can find what page each part is below.

| Report Section                                      | Page Number |
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## Part 2 – What these words mean.

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Tricky words are in **bold** in the report.

|   |   |
|---|---|
| <b>Advocate</b>                                     | An advocate is a person who helps another person to understand what is going on. They can help to tell people what someone thinks or wants.   |
| <b>Annual Health Check</b>                          | This is an appointment that happens once a year with your doctor. This is when you talk about your health and how to make it better. Annual Health Checks are for adults and young people aged 14 or over with a Learning Disability.   |
| <b>Best Interest (Decision)</b>                     | A best interest decision is made when someone cannot decide what to do for themselves. People who know the person will meet to talk about the decision and make a decision for the person that is best for them.  |
| <b>Community Learning Disability Teams (CLDT's)</b> | A group of healthcare workers from the NHS that support people with a Learning Disability in Gloucestershire to live a good life in the local community.  |
| <b>COVID-19</b>                                     | This is a virus that can make some people very poorly. It has spread around the world since the beginning of 2020.  |
| <b>COVID-19 Virtual Ward</b>                        | This is a way of looking after people in their own homes who may have COVID-19. Patients of the virtual ward are given a device for checking their own pulse and oxygen levels. The readings are sent to the COVID-19 Virtual ward. If this shows someone may be becoming unwell, they are assessed over the telephone. |

## Part 2: What these words mean.

|  |   |
|--|---|
| <b>CPR</b>   | <p>Stands for Cardiopulmonary Resuscitation and cover the stages that should be used if someone is unconscious and not breathing.</p> <p>When you are resuscitating someone, you are acting as a life support machine. When you push on their chest, you are being their heart – and when you breathe into them, you are being their lungs.</p> |
| <b>Dysphagia</b>   | This is the medical word for swallowing difficulties.   |
| <b>Fundamentals of Care (FoC) Learning Disability Pilot.</b> | Training all about the health and wellbeing of people with Learning Disabilities for healthcare workers.  |
| <b>General Practitioner (GP)</b>                             | This is a doctor who works in the community. They treat many common illnesses and make referrals to other community health services when people need more help.   |
| <b>Health Inequalities</b>                                   | Health Inequalities are unfair differences when someone has healthcare.   |
| <b>Integrated Care Board (ICB)</b>                           | An Integrated Care Board (ICB) manages the NHS in a local area.   |
| <b>Learning Disability Register</b>                          | This is a list that can help your doctor (GP) know what to do to make your appointment easier. This will also make sure you are invited for an Annual Health Check.   |
| <b>Local LeDeR Steering Group</b>                            | This is a group of people who help manage, support, and check on how the LeDeR programme is working in Gloucestershire.   |
| <b>Mental Capacity Act 2005 (MCA)</b>                        | This is a law which protects the rights of people who cannot make some decisions themselves.  |

## Part 2: What these words mean.

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|--|--|
| <b>My Health Passport</b>                | A health passport lists the things that a nurse or doctor must know about. It might have the medication someone is taking. It should say what is important to that person, and what they like and dislike. This can help improve communication with health care professionals.   |
| <b>Oliver McGowan Mandatory Training</b> | This is training that has been made and run by people with a Learning Disability, Autistic Adults, family carers and healthcare workers who work with people with a Learning Disability and/or Autistic Adults.<br><br>It is named after Oliver McGowan. Oliver's death showed there was a need for training like this.<br><br>It is now the law that health and social care workers do this training. |
| <b>Quality Assurance (QA)</b>            | This means checking to see if something has been done well, and what could be done better in the future.   |
| <b>Reasonable Adjustments</b>            | Reasonable Adjustments are changes to help a person with a disability to go to a place or use a service  |
| <b>ReSPECT Form</b>                      | ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. A ReSPECT form says what someone wants to happen at the end of their life. It helps healthcare workers to make decisions about a person's health when they cannot do so themselves.  |
| <b>ReSTORE2</b>                          | ReSTORE2 is a tool used by healthcare workers, to record things like a person's pulse. This can help to show if someone is becoming unwell. It can help a healthcare worker decide if a person needs different treatment.  |
| <b>RESUS Council</b>                     | The Resuscitation Council UK is a national organisation that is saving lives by developing guidance and delivering   |

## Part 2: What these words mean.

|                            |  |
|----------------------------|--|
|                            | training to ensure everyone has the skills they need to save a life using <b>CPR</b> .   |
| <b>Summary Care Record</b> | A Summary Care Record tells hospital staff the key points of a person's medical history. |

## Part 3 – Opening Words

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Trudi Pigott– Chair of the Gloucestershire LeDeR Steering Group and Deputy Director of Quality

Dr Marion Andrews-Evans – Director of Quality and Nursing



**Trudi**

This is the fourth LeDeR Annual Report for Gloucestershire

It looks at people with Learning Disabilities who died between 1<sup>st</sup> April 2021 – 31<sup>st</sup> March 2022.

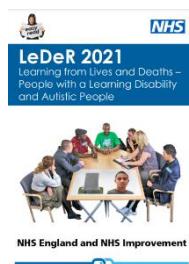


**Marion**

This report says what we have found out from our LeDeR reviews, what we can learn from them and how we can make changes to make services better in the future.

The reasons why people with a Learning Disability die too soon were written in a report by the National LeDeR programme in July 2020.

## Part 3: Opening Words.



This report was changed in March 2021 to add new information. We then made some changes to how LeDeR worked in Gloucestershire

Some changes have been hard, but the LeDeR team in Gloucestershire are doing well. We are meeting all our goals for LeDeR set by the NHS.



This report will talk about some of the changes to LeDeR. One big change was reviewing the deaths of autistic adults without a Learning Disability from January 2022.



Since 2019, we have been working with Inclusion Gloucestershire. This has been working well.



Experts by Experience are involved in every part of the Gloucestershire LeDeR programme. We make sure the voices of people with Learning Disabilities and Autistic Adults are heard.

### Part 3: Opening Words.



Learning from each LeDeR review is important to make healthcare services better.

We will continue to ask questions and try to stop **health inequalities**. We think it is important to stop people with a Learning Disability and Autistic Adults from dying too soon.

#### What our Experts by Experience Said

Sammy Roberts, Project Worker at Inclusion Gloucestershire and Expert by Experience member of the LeDeR Quality Assurance (QA) Panel



*This year we have continued to hear and build on the voice of people learning disabilities and autistic adults on the QA panel and also when coproducing accessible information. Experts by experience now have a role in the Steering and Learning into Action groups, making sure the valuable learning we get from LeDeR is put in to action.*

*We have also played a key role co-producing and co presenting the learning with professionals, carers and people with a learning disability and autistic people. The increasing focus on co production puts people with learning disabilities and autistic people at the centre of the LeDeR programme in Gloucestershire going into the future”*

Paul Tyrrell, LeDeR Project Co-ordinator for Inclusion Gloucestershire, and Expert by Experience member of the LeDeR Quality Assurance Panel says:



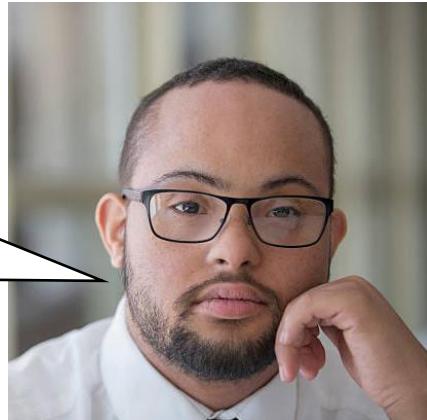
*Our voice as Experts by Experience on the LeDeR QA panel has continued to be prominent during 2021 – 2022. Our bi-monthly co-produced LeDeR newsletters are now well established, sharing the thoughts of the QA panel, examples of good practice and accessible health information resources based on the learning themes identified from the reviews.*

*Both myself and the rest of the LeDeR team at Inclusion Gloucestershire are proud to be involved in the programme and are pleased to have been able to play our part in raising awareness of LeDeR in Gloucestershire.*

*Recently, in partnership with our clinical colleagues, we have started to develop a suite of Easy Read resources focusing on specific health issues and things that can help make healthcare more accessible. I look forward to seeing this suite of resources grow during 2022 – 2023.*

The views of others at Inclusion Gloucestershire<sup>1</sup> about why LeDeR is so important and how the learning during COVID-19 has improved services.

I need to be listened to as the expert in my condition!



I'm not always aware of LeDeR.



I think it is sad and emotional when people die too young.



Attitudes need to change. Stop seeing us all as statistics and difficult people.  
Help us to help ourselves!



Reasonable adjustments should always be made if we want equality!



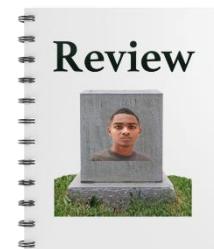
I think doctors and nurses need to be aware of LeDeR to stop it from happening again!



<sup>1</sup> Some of the images are from Stock photos available from [www.gettyimages.co.uk](http://www.gettyimages.co.uk)

## Part 4 – A summary of the report

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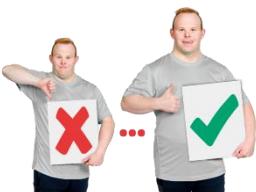
### Background

Deaths of people with a Learning Disability over the age of 4 years and autistic adults over 18 are reviewed by the LeDeR programme.



We know LeDeR may not be told about all deaths of people with a Learning Disability or an Autistic Adult.

We keep telling people about LeDeR, so more people know how to tell us if someone with a Learning Disability or an Autistic Adult has died.



LeDeR reviews try to make services better for people with a Learning Disability and Autistic Adults.



LeDeR wants to **reduce health inequalities** for people with a Learning Disability and Autistic Adults.

LeDeR wants to stop people with a Learning Disability and Autistic Adults from dying too soon.



LeDeR is a national programme in England. Every death is looked at in the same way.

## Part 4: A summary of the report



Some people will have their deaths looked at in more detail if the reviewer or the **Quality Assurance** (QA) panel thinks more can be learnt from looking at more information. We call this a focused review.



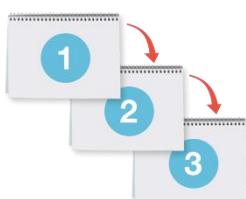
A reviewer tries to find out what happened in someone's life and death.

They will talk to someone who knows the person well, like their family, carers, and doctor.



The review gets checked by the QA panel. There are lots of people on the panel. There are doctors, pharmacists, nurses, and experts by experience.

We learn from each review and tell people what we learnt.



Over the next 3 years, we want to improve things and **reduce health inequalities** for people who have a Learning Disability and for autistic people.



We want things to get better for people with their social care, hospital care, physical healthcare, advanced care planning and in the way, people use the **Mental Capacity Act** law.

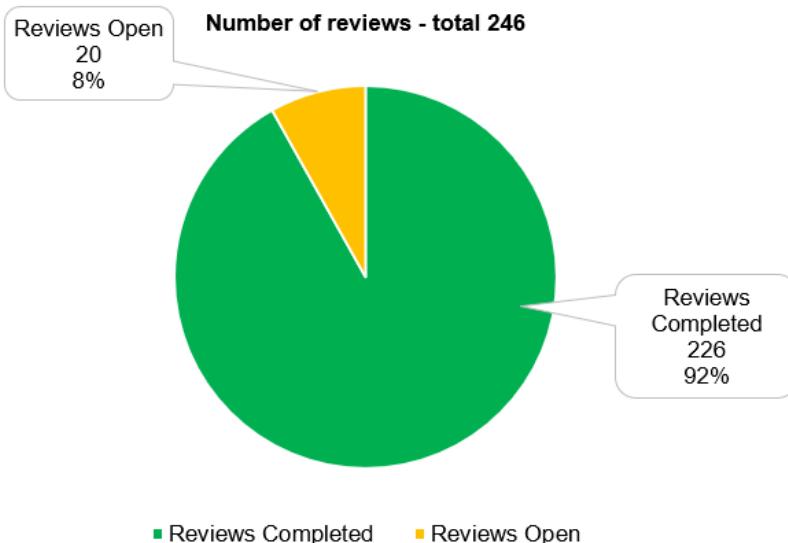
March

31

2022



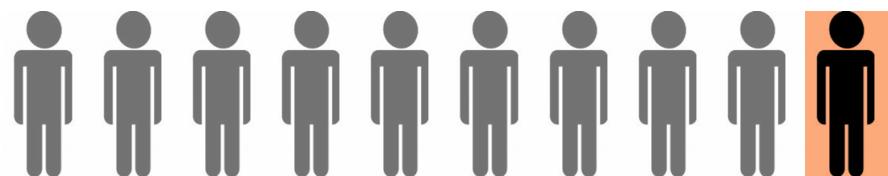
## How many reviews have been carried out in total (since 2017 up to 31 March 2022?)



## How was people's care?



About 9 out of 10 people's care was rated good enough or better than that.

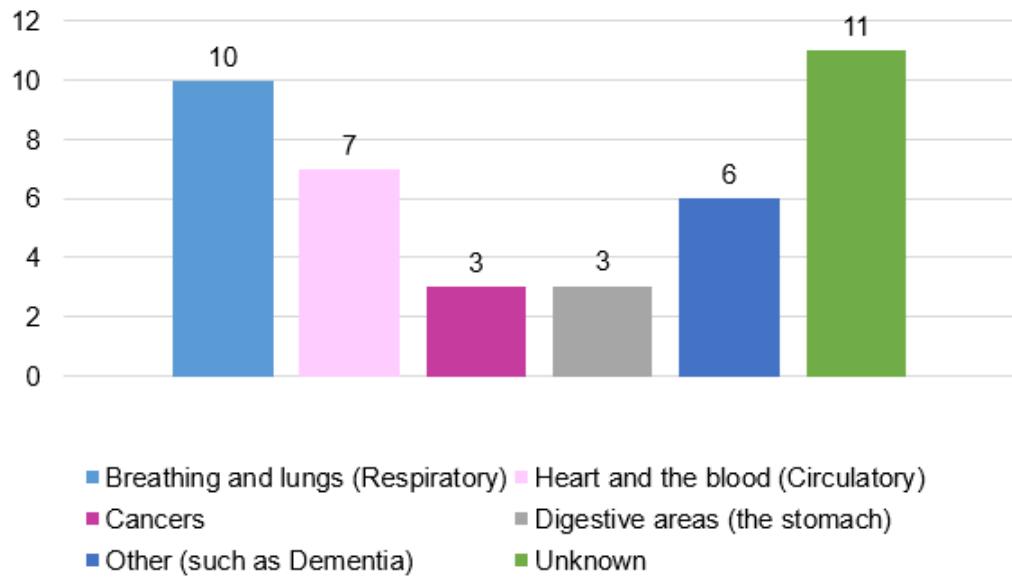


Most of the people died in hospital. This is more likely for people who have a Learning Disability in Gloucestershire than people who do not have a Learning Disability.

## Part 4: A summary of the report

40 people with a Learning Disability died during the year.

**Cause of Death 2021 -22**  
**Number of People**



There have been less than 5 deaths of people with a Learning Disability from **COVID-19**. The previous year there was 14 people who had died of COVID-19.

## End-of-Life Planning

More people had a **ReSPECT form** than last year.

ReSPECT Making a Recommended Summary Plan for Emergency Care & Treatment (ReSPECT)

What happens to you in an emergency?

Who is best suited to make decisions?

How does it work?

Why is this available?

What else can I do?

Find out more at [www.respectprocess.org.uk](http://www.respectprocess.org.uk)

We keep on telling more people about the **ReSPECT form** and are working with Inclusion Gloucestershire to co-produce some **ReSPECT** videos.

## Part 4: A summary of the report



What we have learnt, what we are doing and what we can improve - where people are living in a supported environment or a care home



The **ICB and Gloucestershire County Council** keeps in contact with care homes and care providers in Gloucestershire by sending a monthly newsletter and having regular meetings to talk about the big issues.

The **ICB** and Gloucestershire County Council ensures all care providers have the right skills and knowledge to do their jobs. Care providers can access training from a system called **Learnpro**.

Gloucestershire has made and run the **Oliver McGowan Mandatory Training**



Inclusion Gloucestershire have online easy-to-read **Coronavirus (COVID-19)** information, in different formats and languages.

To look at the information, visit this website:  
<https://www.inclusiongloucestershire.co.uk/covid-19/>

### Using technology to keep well.

People in Gloucestershire care homes tried using technology to help manage their health needs, without visiting the doctor. This is called **Telehealth**.



## Part 4: A summary of the report



Care Home staff keep being offered training on how to know when a person is becoming unwell, using the **RESTORE2** tools.

Gloucestershire's **Community Learning Disability Teams (CLDT's)** have been trained to teach other people about **RESTORE2** tools.



### End of Life

Easy read information about the **ReSPECT** process has been co-produced with the national organisation **RESUS Council**



Accessible videos about the **ReSPECT** process are being made to tell more people about ReSPECT



### Physical Health

We have carried on telling people about the why it is good to have an Annual Health Check. We have told people why it helps to be on their GP's **Learning Disability Register**.

## Part 4: A summary of the report



We shared information about how to manage some complex bowel conditions, including constipation. We have shared the “Dying for a Poo” campaign information developed by NHS England.



We carried on telling people about why **reasonable adjustments are important** and why people should use a **My Health Passport**.



If someone has Speech and Language Therapy Guidance in place the **Health Passport** can tell them how to help with **Dysphagia**, this should be followed in hospital too.



What people eat and how much they weigh should be watched carefully and written down.



We have given people information about mouth care; this includes how to look after your teeth.

### Using the law

Sometimes an **advocate** helps a person make a decision or helps them to understand why they have made a choice. People’s lives have been better when they have had an advocate to help with making decisions.



## Part 4: A summary of the report

1  
2  
3

A list of things to talk about at a **Best Interests** meeting is being made into a leaflet, so that everyone knows what the meeting is about.



### Hospitals

Referrals can be made by the disabilities commissioning team to the **COVID-19 Virtual Ward**.

This means that more people with a Learning Disability can be cared for where they normally live.

We carry on telling people why it is helpful to have a **My Health Passport** that people can fill in themselves when they are well.

The form can tell doctors and nurses about someone and is an important communication tool when going into hospital.



Someone's **reasonable adjustments** should be put on their **Summary Care Record**. Ask your **GP** if your reasonable adjustments are on your **Summary Care Record**.

A guide has been written to help staff know how to help people with a Learning Disability during **COVID-19**.



## Part 5 – Conclusions and What is Recommended

Gloucestershire LeDeR has a 3-year plan to help reduce **health inequalities** faced by people with a Learning Disability or Autistic Adults.



This report covers the first year of the plan.

The first part of this Chapter will look at what we plan to do next year.

### Training



Look at the results of training called the **Fundamentals of Care (FoC) Learning Disability Pilot**.

Make some resources about **RESTORE 2**.



Continue running the National **Oliver McGowan Training**.

Look at the training about Annual Health Checks and make it better. Ensure everyone has a Health Check Action Plan.

Run sessions to tell different health professionals about different things learnt from LeDeR.



Make sure training is the same for all healthcare workers.

## Part 5: Conclusions and what is recommended



Share learning from LeDeR across health, social care and charities that help people with a Learning Disability or autistic adults.



### End of Life

Show people the coproduced films about the **ReSPECT** process.



Keep on working with the **ICB** team that focuses on End of Life. This is to make sure people with a Learning Disability and Autistic Adults get personalised end of life care.

### Using the Law



Tell more people about the **Mental Capacity Act** and the **Best interest** decision making process.



Use guidance and leaflets for **best interest** meetings in Hospital.



Information should say how the law should be used, what needs to be written down and how **advocates** can help.

## Part 5: Conclusions and what is recommended

### Hospital Care



Keep on telling people about why it is good to have a **My Health Passport**

We want to improve mouthcare, **Dysphagia** and constipation care in care homes and hospitals.



We want to make sure people have the **reasonable adjustments** they need if they stay in hospital due to mental ill health.



### Physical Healthcare

We will meet our target for **Annual Health Checks** again. The target is for 75% of people on the Learning Disability Register to have their **Annual Health Check**.



We will look at what stops Children and Young People from having their **Annual Health Check** and being on the Learning Disability Register.



We will keep making sure people get the **reasonable adjustments** they need when having their vaccinations.

We will keep telling people about learning using national healthcare campaigns.

## Part 5: Conclusions and what is recommended



It is important a healthcare worker can spot someone is becoming unwell or is in pain. We will do this by promoting the **RESTORE2** and RESTORE2 mini documents and training

It is important a healthcare worker knows how a person tells people things, so they can understand if they are becoming unwell and need treatment.



We want to make sure carers in Gloucestershire understand people's health needs.



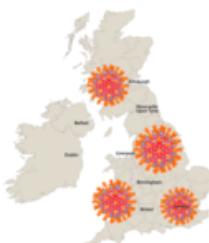
### Conclusion

This report says what has happened with the LeDeR programme from 1<sup>st</sup> April 2021 – 31<sup>st</sup> March 2022.



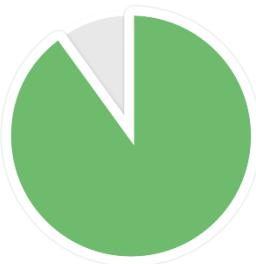
It shows we now have better ways we manage LeDeR.

The report shows that Gloucestershire has a good way of reviewing deaths of people with a Learning Disability and (from January 2022) autistic adults.



We have faced new challenges as we learn to live with **COVID-19**.

## Part 5: Conclusions and what is recommended



There are now fewer **COVID-19** outbreaks and the number of people with a Learning Disability in hospital has gone down to how it was before **COVID-19**

Just under 9 out of 10 people's care was rated good enough or better than that.



Over three quarters of the people (three in four people) on the GP Learning Disability register have had their Annual Health Check. But we know we have more work to do on ensuring everyone has a Health Check Action Plan.



Over 90% of people over the age of 18, on their doctors Learning Disability register, have had their **COVID-19** vaccinations.



Since 2019, we have been working with Inclusion Gloucestershire. This has been working very well.

Experts by Experience are involved in every part of the Gloucestershire LeDeR programme to make sure the voices of people with Learning Disabilities and Autistic Adults are heard.

All of the things that are recommended from the LeDeR reviews will be looked at by the **Quality Assurance** panel and put into a local action plan.



## Part 5: Conclusions and what is recommended



**The Local LeDeR Governance and Steering Group** will check that we are doing what we need to, to make the plan happen.

Gloucestershire want to keep making the LeDeR programme better!



We want to work more with family carers during the next year and carers who support people from black and minority ethnic communities.



Gloucestershire will keep listening and learning from the LeDeR reviews, to make our health and social care support better and **reduce health inequalities**.

This will make health and social care better and will help stop people with Learning Disabilities and Autistic Adults dying too soon.

