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NHS

Gloucestershire's Learning Disability & Autism LeDeR Programme

Annual Report 2023 - 2024

Learning from lives and deaths of people with a learning disability and Autistic adults in Gloucestershire. A service improvement programme

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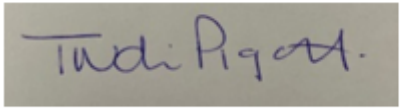
Joint Statement from Senior Responsible Officers



Trudi Pigott
Chair of the Gloucestershire LeDeR Steering Group and
Deputy Director of Quality
Gloucestershire Integrated Care Board

Marie Crofts
Chief Nursing Officer
Gloucestershire Integrated Care Board

The LeDeR Programme (Learning from Deaths Review of people with a learning disability) is led by NHS England and follows on from the work undertaken by the University of Bristol Confidential Enquiry into the premature deaths of people with Learning Disability (CIPOLD) 2013. The findings of that report demonstrated that on average someone with a learning disability lives 20 years less than the general population. On average people with learning disabilities in the Gloucestershire population live an average 61.9 years, compared to the general population national average of 82.6 years. We also know that people from Ethnic Minorites with a learning disability have an average age of 42 years nationally. There is important work we must do to improve quality of life and reduce health inequalities in order to narrow that gap.

This is the sixth annual report on the deaths of people with learning disabilities who lived in the Gloucestershire . The report aims to share findings from LeDeR reviews, on the learning identified and the action we have taken as a system to improve practice and service delivery, and address health inequalities for people with learning disabilities and autistic people.

Joint Statement from Senior Responsible Officers

The local programme has an established way of working in co-production with people with lived experience and this along with support from our dedicated group of Experts by Profession, continues to be a key contributor to the success of the programme locally. This co-production partnership approach ensures that we have the valuable knowledge, insights and co designed solutions in implementing and sharing action from learning across the health and social care system. Our Experts by experience have helped us get perspectives from the people who use health and care services locally.

We wish to acknowledge the valuable input of our experts by experience who act as both critical friend and supporter of this important area of work. We have been supported with this by Inclusion Gloucestershire

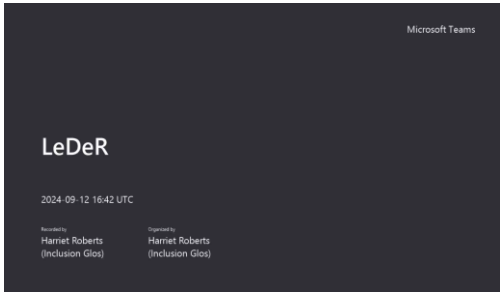
We have a strong commitment to learn from these reviews and a renewed dedication to turn this into real action, promoting learning throughout health and social care services and the wider system.

The success of the LeDer programme would not be possible without the support and commitment of the many people and organisations across Gloucestershire's health and care system who have worked to notify deaths, undertake and quality assure reviews, and implement service improvements arising from the learning from reviews.

The programme will continue to review, evaluate and adapt its approach in line with emerging good practice and policy in order to effectively challenge health inequality and advocate and lead on service and system developments to improve health outcomes for people with learning disabilities and autistic adults.

Welcome and Introduction Videos from our Experts By Experience

Sammy



Harriet

Nick

What is LeDeR

LeDeR is a service improvement programme for people with a learning disability and autistic people which aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care support people received. It does this by:

- Delivering local service improvement, learning from LeDeR reviews about good quality care and areas requiring improvement.
- Driving local service improvements based on themes emerging from LeDeR reviews at a regional and national level.
- Influencing national service improvements via actions that respond to themes commonly arising from analysis of LeDeR reviews.

LeDeR is short for a programme called Learning from Lives and Deaths of people with a Learning Disability and Autistic People.

Every death of someone with a learning disability (aged 4 and over) and every autistic adult (aged 18 and over with a clinical diagnosis of autism) that the LeDeR Programme is told about is reviewed by an independent reviewer.

Child deaths follow a separate statutory review process overseen by the Child Death Overview Panels (CDOP)

www.leder.nhs.uk

Background to LeDeR

Gloucestershire Integrated Care Board holds responsibility for delivering the local LeDeR programme.

How LeDeR fits with Existing local and National Reviews of Deaths

There are several different review processes for people who die. For example:

- child death overview process
- safeguarding adults' review
- review of deaths of people in hospitals – Serious Judgment Reviews
- System Mortality Group
- Mental Health Mortality Review Group
- Coronial Process
- Statutory processes take place before a LeDeR Review is undertaken

Local Area Contact (LAC)

LAC role sits in the ICB.

The LACs responsibilities:

acts as the contact person for the LeDeR regional coordinator

works with the review team

promotes LeDeR at a local level across health and social care

Contact Althia Lyn
althia.lyn@gloucestershire.gov.uk

Gloucestershire LeDeR Governance

LeDeR Reviewers include reviewers and senior reviewers. The review teams' responsibilities:

→ carry out LeDeR reviews in a professional, compassionate, and caring way

→ treat bereaved family members and loved ones with respect, compassion and courtesy

↓

share their findings with the local governance group or panel

→ LeDeR Quality Assurance Panel - sits at Integrated Care Board (ICB) level. The group quality assures , provides expertise and advice on premature mortality of people with a learning disability and completes sign off on reviews for that ICS area. The group determines the actions to take.

→ The LeDeR Governance and Steering Group – Recommends and provides the approach for implementing the actions from learning from reviews and monitors the ICB LeDeR local action plan.

Gloucestershire LD Profile

LeDeR is learning about people's lives and deaths so that we can make healthcare better for people with learning disabilities and autistic adults.

2% of Gloucestershire population has a Learning Disability. 11,746 this is expected to rise in 2035 to 11,820

41% % on GP LD QOF Register, 4863,

37% Male 63% Female

Approximately 4,918 adults in Gloucestershire are predicted to have Autistic Spectrum Conditions (ASC)

- Learning Disability Profiles PHE
- LeDeR Annual Reports

https://fingertips.phe.org.uk/profile/learning-disabilities

https://leder.nhs.uk/resources/annual-reports

Report Scope

This report is about reviewing deaths of people with a learning disability and Autistic adults, and the health inequalities faced by them. Clearly any service improvement to enable this group of vulnerable individuals to access health and social care services will ultimately reap benefits for the wider system in terms of accessibility, reasonable adjustments and consistent use of legislation such as the Mental Capacity Act.

Notifying a death to LeDeR is not mandatory and , therefore we would not expect LeDeR to have data on all people with a learning disability who have died, but the local programme has made some important links to try and improve reporting. From July 2024 all deaths reported to LeDeR will be reviewed regardless of whether the individual opted out of sharing their information prior to their death.

We continue to present this report in an interactive way, . bringing the learning to life. This presentation can serve as a resource for ongoing learning into action

This report focuses on activity 2023-2024 and is the 6th local annual report on the learning from deaths of those with learning disabilities and autistic people within Gloucestershire. The report covers from 1st January 2017 up until 31st March 2024.

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Preface

LeDeR

Annual Report

April 2023 – March 2024

Learning from lives and deaths of people with a learning disability and Autistic adults in Gloucestershire

This report includes the death of people with learning disabilities and autistic adults who died from 1st April 2023 to 31st March 2024.

It is the sixth annual report for LeDeR that Gloucestershire has published.

Previous reports are available on Inclusion Gloucestershire's LeDeR webpage.
Inclusion Gloucestershire LeDeR

The purpose of the report is to share our findings from LeDeR reviews and to share learning and changes for practice.

Links in presenters' notes will provide access to a broad range of additional information and learning resources.

Autism* only reviews – from January 2022

From January 2022 LeDeR reviews include people (aged 18+) with an autism diagnosis (but without a learning disability) from January 2022.

For an autistic individual to be eligible for a LeDeR review, they must have had a confirmed diagnosis of autism recorded (any of the terms as outlined in DSM or ICD) in their clinical records prior to their death.

LeDeR does not include those who self-identify as autistic but have not sought or not received a clinical diagnosis from a qualified health professional.

LeDeR does not include individuals who have been referred for a clinical assessment of autism, but who have died prior to the assessment having been carried out or completed.

* Autism is described in the diagnostic manuals used for clinical and research purposes. These manuals are the:

Diagnostic and Statistical Manual of Mental Disorders (DSM) https://www.psychiatry.org/psychiatrists/practice/dsm and International Classification of Mental and

Behavioural Disorders (ICD) https://www.who.int/standards/classifications/classification-of-diseases

Health Inequalities faced by people with a learning disability

(Source: Heslop et al. 2013; Tuffrey-Wijnes et al. 2013; Allerton and Emerson 2012)

Illness	Comparison of prevalence of certain conditions (person with a learning disability compared to someone in Gloucestershire without a learning disability (based on age/sex standardised prevalence ratio)
Epilepsy	More than 20 times higher
Mental health	9 times higher
Dementia	4 times higher
Hyperthyroidism	3 times higher
Heart failure	2 times higher
Stroke or Transient Ischaemic attack	2 times higher
Chronic Kidney Disease	2 times higher
Diabetes (Type 2)	2 times more likely
Cancer	Half as likely
Coronary Heart Disease	Half as likely

(Source: NHS Digital 2018 data for learning disability)

Some of the people who have died

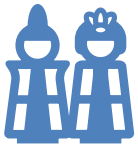
This report is about people with a learning disability and autistic adults who have died in Gloucestershire during 2023-2024. They were loved and cherished, and whose deaths have been heart breaking for their family and those who loved them.

Sometimes when we read reports such as this, we can forget that there are people at the heart of it. In the mass of data provided, there is a danger that people can become numbers, and numbers are impersonal.

We are therefore starting this report by sharing who some of the people whose deaths have been reviewed by the LeDeR programme were, what we learned from the reviews and the action we took as a result. All details have been anonymised, but the stories are those as told by families or paid carers, health staff to reviewers. We would like to thank the families who have given us permission to use their stories.

Please note that all names throughout this report have been changed to protect confidentiality. Unless we have had express permission to use their names and/or pictures from their family.

Case Study 1: Samantha's Story



Samantha had a close relationship with her mother and loved to spend time with people. She loved shopping for clothes and dancing. Samantha was of African Caribbean background. She had a severe Learning Disability and was an Autistic Person using vocal tones noises and Makaton to communicate

Samatha had multidisciplinary support from the CLDT a PohWER advocate and good reasonable adjustments to enable her access health care and improve her wellbeing.

Samantha was diagnosed with breast cancer and had surgery to remove a breast. Unfortunately, the cancer returned and because she would not understand and would have been distressed by the treatment options treatment stopped and she was provided with support from the Palliative Care Team.

Samantha’s health continued to deteriorate. A ReSPECT Plan was written which included a best interest DNACPR decision. She sadly passed away three months later.

Learning into Action

Good Practice

Use of a Care Act Advocate via POhWER

The Palliative Care Team gave training to care staff

The Disability Distress Assessment tool was used to ensure good pain Management

Help from SALT, CLDT, Palliative Care Nurse, District Nurses, GP, Stoma team, OT and Specialist Nurse.

Learning Points

Women from minoritised communities are more likely to be diagnosed with breast cancer at a later stage than their white counterparts and as a result will have worse outcomes.

It is not known the extent to which care staff are aware that this is the case.

Conversations about cancer and symptoms are not widely held in some minoritised communities.

Action

Work with LD Screening Nurse to raise awareness and communications to highlight the increased risk of aggressive and less treatable breast cancers in women from minoritised communities across the provider and carer community

Deliver small scale project to raise awareness and increase access to health care for individuals and carers of people with LD's and Autistic People from minority communities.

Accessible information leaflets about Breast Cancer Screening and video share in LeDeR Bulletin

Case Study 2: Marcel's Story

Marcel was described as a happy , resilient person. His close relationship with his mother was central to his well-being and they treasured time living together at home. Marcel received support from carers, but this ended at his mother's request. The family received regular welfare visits from the enablement team and district nurses to help manage his type 2 Diabetes.

Despite concerns about his mother's ability to provide adequate care due to her own needs, she was determined to care for Marcel at home. Safeguarding referrals were made and ongoing assessments including mental capacity focussing on Marcel's ability to make decisions about his care were undertaken.

Marcels health challenges were extensive and diverse. Refusal of certain medical interventions added complexity to his care. Hospital admissions became frequent. Complications of diabetes caused mobility issues for him. He experienced deteriorating renal function, persistent infections, blood pressure and heart issues.

Despite the best efforts of medical professionals, Marcel's condition worsened, and he started on Palliative Care pathway. Following episodes of unresponsiveness, seizures and episodes of pulse loss, multiple organ failure ensued, and Marcel passed away.

Learning into Action

Good Practice

- Extensive MDT involvement to ensure best pathways and decisions were explored for Marcel and his mother.
- Good use of reasonable adjustments.
- Input from a range of community health services – District Nurses, Rapid Response, Ot, SALT, Diabetic Community Nurse and Physio

Learning Points

- There May be instances when family/caregivers are acting with best intentions however Marcel's mother may have benefitted from access to an independent advocate as a least restrictive option and to support her t engage with support for both her and Marcel.
- A pathway for reviewing such cases with the advocacy service would be beneficial
- Clear communication around the benefits of advocacy to family carers, to encourage the use of the service and acceptance of support offers particularly where an older person is the sole carer for an adult with complex needs.

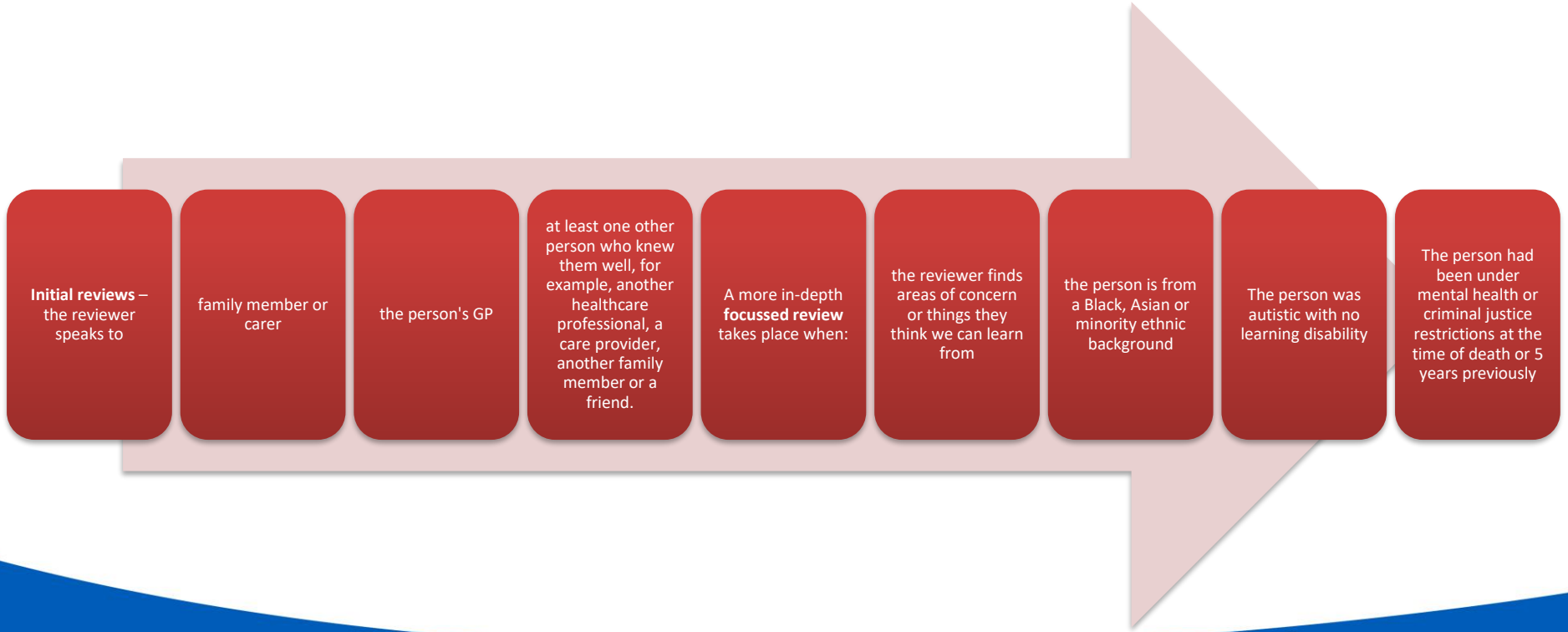
Action

Liaise with Advocacy Commissioner to identify and raise awareness of the need for a pathway to advocacy for family carers.

Ensure that the Council's commissioned advocacy videos reflect the needs of family carers.

Link with Carers commissioner to share learning and to encourage and promote the take up of MCA and Best Interests Decision making training by family carers .

Review Type


Initial reviews – the reviewer speaks to
family member or carer
the person's GP
at least one other person who knew them well, for example, another healthcare professional, a care provider, another family member or a friend.
A more in-depth **focussed review** takes place when:
the reviewer finds areas of concern or things they think we can learn from
the person is from a Black, Asian or minority ethnic background
The person was autistic with no learning disability
The person had been under mental health or criminal justice restrictions at the time of death or 5 years previously

Assessment of the Quality of Care

94% of the reviews completed were rated as delivering excellent or good care during 2023-2024 another 6% were rated as satisfactory care

Reviewers are asked to grade the quality, availability and effectiveness of services the person received the person at the end of a focussed review (cases which only receive an initial review will not be graded formally however the local QA panel will capture indicative grading as part of local processes).

Care is graded on 2 elements of the health and social care the person received:

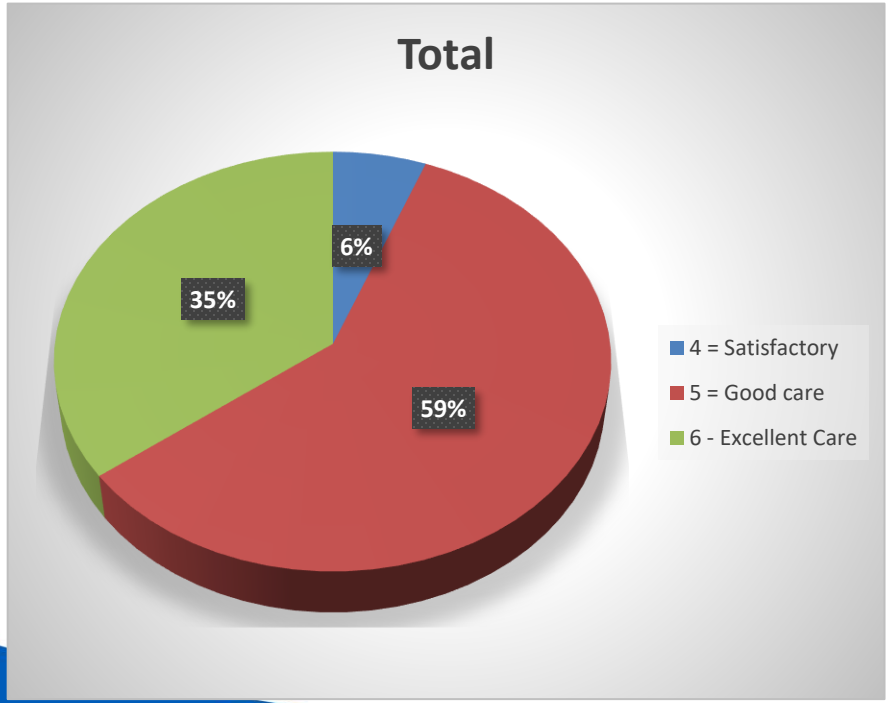
1. Quality of care the person received

2. Availability and effectiveness of the services.

Care is graded on a scale of 1-6. 1 represents poor care , 6 excellent care.

Grade	Quality of care	Availability and effectiveness of services
6	This was excellent care (it exceeded expected good practice). Please identify in learning and recommendations what features of care made it excellent and consider how current practice could learn from this.	Availability and effectiveness of services was excellent and exceeded the expected standard
5	This was good care (it met expected good practice). Please identify in the review learning and recommendations any features of care that current practice could learn from.	Availability and effectiveness of services was good and met the expected standard
4	This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing). Please address these issues in your recommendations for service improvement, and identify in learning and recommendations any features of care that current practice could learn from	Availability and effectiveness of services fell short of the expected standard in some areas but this did not significantly impact on the person's wellbeing.
3	Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death. Please address these issues in your recommendations for service improvement, and identify any features of care that current practice could learn from.	Availability and effectiveness of services fell short of the expected standard and this did impact on the person's wellbeing but did not contribute to the cause of death.
2	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	Availability and effectiveness of services fell short of the expected standard and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.
1	Care fell far short of expected good practice and this contributed to the cause of death.	Availability and effectiveness of services fell far short of the expected standard and this contributed to the cause of death.

Quality of Care and Services



94% of reviews completed were rated as delivering excellent or good care during 2023-2024 a further 6% was rated as satisfactory care.

Quality of care and support appears to be improving. 72 % of reviews completed were rated as delivering excellent or good care during 2022-2023 a further 20% was rated as satisfactory care

How we share what we are doing and learning from reviews?

LeDeR September 2022
Newsletter number: 7

Update on learning using a case study

LeDeR helps us learn about the lives and deaths of people with a Learning Disability or Autistic Adults. LeDeR wants to reduce the unfair differences in healthcare that can be prevented.

Ralf

Ralf liked steam trains and visits to the countryside. He had a great sense of humour, and his family were very important to him. Ralf had a Learning Disability, and he was autistic. Ralf used a communication book and was supported by Speech and Language Therapy. He had Cerebral Palsy and he was PEG (tube) fed, but enjoyed tasting some foods. Ralf was more likely to get chest infections because of his health conditions. He lived in a supported living setting and needed help from carers with lots of things. Ralf's family told the reviewer that he had led a long and happy life.

About his death

Ralf sadly died at Gloucester Hospital. An ambulance was called and the ambulance staff treated Ralf with oxygen for a chest infection. Ralf had a DNACPR, which means he did not want doctors to try and restart his heart if it stopped. At the hospital the hospital staff completed a ReSPECT form, and Ralf was put on end-of-life care. Ralf's family were with him when he died.

Learning

- Ralf's Speech and Language Therapist did not know about his chest infections. This meant there had been delays in looking at his eating and drinking. **People who are PEG fed, who are being given tasters and have regular chest infections, should be urgently seen by a Speech and Language Therapist.**
- When the Speech and Language Therapist visited, they could not find Ralf's communication book. **Communication books should always be with the person, so they can communicate.**

Good Practice

- Ralf's end of life wishes were written down and followed.
- The hospital staff communicated well with Ralf. They made reasonable adjustments for him.
- He had a specialist wheelchair and did not have any pressure sores.

We would like to thank the families who have kindly given us permission to share the stories of their loved ones to help improve services.

Resources and Action from Learning

From the case study of 'Ralf' above, the panel wanted to share information on training about when to refer for dysphagia assessment. Dysphagia is the medical word for when you have difficulties swallowing. The panel also wanted to tell care staff about some online Dysphagia training.

Access Dysphagia training via your LearnPro account, telephone 01452 324306 or email: Proudtolearn@gloucestershire.gov.uk

Link to a list of Dysphagia Videos on YouTube: https://bit.ly/3BzX7z4

- Annual report – Published September 2023
- Gloucestershire LeDeR Newsletters
- Easy read resources
- Presentations – GSAB, GHC, Carers PB, Health Action Group, Autism PB
- Conference (23rd March 2023)
- Care Providers
- NHS Trusts
- Clinical Programme Groups
- Commissioners
- Primary Care Bulletin

- Shared Lives Presentations March -July 2023
- LD Champions Conference June 2023
- Allied Health Professionals Away Day.
- Providers Forum
- Big Health Day June 2024

Access information on Gloucestershire LeDeR Webpage:
https://www.inclusiongloucestershire.co.uk/engagement/leder/

Gloucestershire LeDeR Quality Assurance & learning on a page

About the case

Age: Where died:

Cause of death: 1a 1b 2

Consent to share anonymised case further ☑☒

Level of learning disability Autism diagnosis ☑☒

Summary of the individual

About the person

About their death

QA Panel date

LeDeR Reference number

Good practice

Learning Points & themes

LeDeR Grading of care

Mazars grading

Actions?

Read & share this page | **Add to LeDeR Newsletter** | **Share with clinical programme/s for action *(detail which)*** | **Other communication (*detail what*)**

Specific organisational response | **Create new LeDeR learning resource** | **Wider system action (*detail what*)** | **Submit to national LeDeR Programme** | **Other action(*detail what*)**

QA Panel checklist

Detail of the person who died ☑☒

Detail of death (inc anyone else notified, ethnicity, NHS number, NoK, ☑☒

Did family/carer have concerns ☑☒

Structure of report (inc jargon free, 3 or more sources of information (list) ☑☒

The persons health
Treatment of conditions ☑☒
Reasonable adjustments ☑☒
Gaps in service provision/delays ☑☒
Timely appointments/screening ☑☒

The persons Care & Support
Suitable housing ☑☒
Evidence of use of MCA (inc use of advocates) ☑☒
End of life (inc ReSPECT form) ☑☒
Out of area placement ☑☒
Safeguarding concerns ☑☒

Concerns over medications (detail what) ☑☒

Concerns over STOMP (detail what) ☑☒

Concerns over supporting the needs of people from minority ethnic communities (detail what) ☑☒

QA Panel Members *(delete/amend)*

Cheryl Hampson (LAC), Althia Lyn (secondary LAC), Sammy Roberts (Expert by experience), Paul Tyrell (Expert by experience), Emily Luckham (VCS), Jeanette Welsh (Safeguarding Lead Nurse), Dr Mark Scheepers (Consultant Psychiatrist), Dr Tom Herbert (GP), Teresa Middleton (Pharmacist), Trudi Piggot (LeDeR Steering Group Chair and Nurse), Anna Holder (Social Care), Deborah Livingstone (LeDeR Reviewer), Paul Yeatman (LeDeR Reviewer)

Local Action from Learning 2023-24 Priorities

Dysphagia

Cancers

Diabetes, Weight Management and Obesity

Constipation

Management of Medical Conditions

LeDeR Policy in action – Sharing the learning

Use of legislation

Health Inequalities & People from Minority ethnic groups

End of life care & Advance care planning (RESPECT)

Reasonable adjustments

Support for carers

Changing how we work

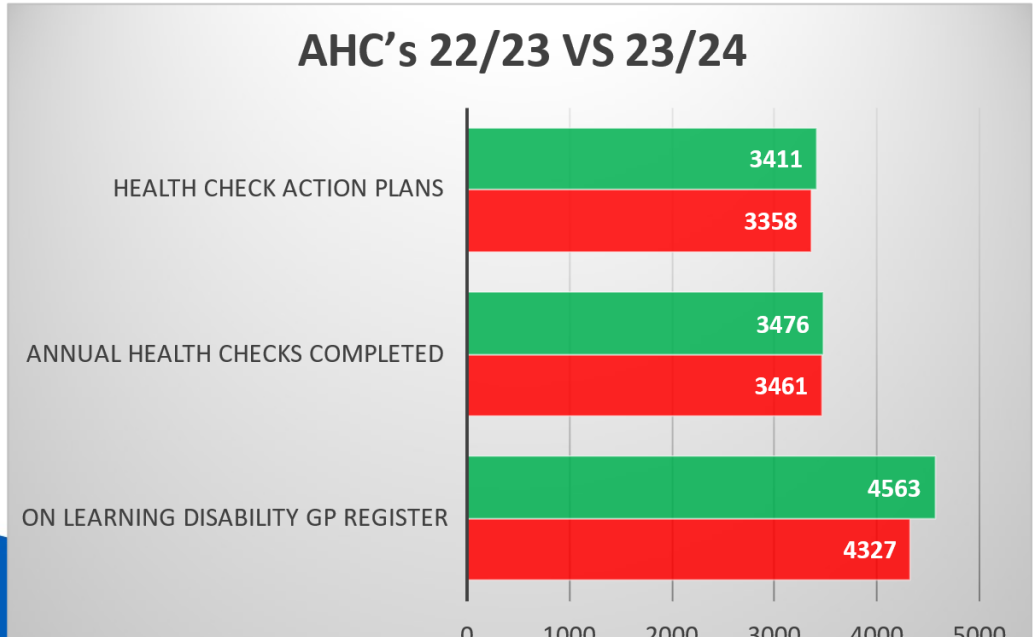
Transforming Care, Transforming Communities

Gloucestershire LeDeR Programme Achievements so far…

AHC's 23/24: How did we do in Gloucestershire

Key figures

- Age 14+ LD register size increased by 236 people.
- 76.2% of all people on the 14+ LD register received a health check
- 98.1% of all those people received a Health Check Action Plan following the check



How does this compare to the wider picture?

A drop in AHC percentage completio
was echoed regionally and nationally
compared to 22/23

At 76.2% Gloucestershire was th
highest performing ICB in the reg

National and regional figures show a
increase in declined AHC's, with Glo
seeing a **38.3%** in this area compare

Some key highlights from the past year

- The new Annual Health Check clinical toolkit
- The review and update of all easy-read Annual Health Check documents in collaboration with experts by experience
- Learning Disability Community and Hospital Champions Conference 2023
- Development of Annual Health Check Peer -Led training workshops with Inclusion Gloucestershire
- 16th Annual Big Health Day
- Learning Disability GP, Practice Nurse and Health Care Assistant Champions network

Annual Health Checks for People with a Learning Disability- Race Equality Foundation, Learning Disability England

Health Action Group Highlights

Checked and changed the Pre-Health Check Questionnaire, My Health Passport, Health Check Action Plan – https://www.nhsglos.nhs.uk/wp-content/uploads/2022/12/WHAT-TO-EXPECT-AHC-Ver1.pdf

Assisted in the planning of the **15th Big Health Day:**

Helped with a training programme for care homes. https://youtu.be/SOOJjF8bCmY

Worked alongside the Resuscitation Council and co-produced an easy read leaflet and two ReSPECT supporting films.

Jenny's Story:

Autism Only Reviews – Learning from National LeDeR Annual Report 2023

Nationally 36 autism only reviews undertaken in 2022. No autism only reviews were notified to the Gloucestershire LeDeR Programme in 2023-2024.

Limited conclusions can be drawn as a result. Increased reporting is needed.

As awareness grows around the need to collect data on autistic people's deaths, we will be better able to target services, identify areas for improvement and guide policy

National LeDeR Data 2022:	Median age at death of an autistic adult was 53 years	National median age of death for autistic adults with a learning Disability was 55 years	81% Male, 19% Female 91% denoted as White.	68% of autistic adults with a learning disability who died in 2022 were male, 30% were female	**Most Frequent cause of death:**	Suicide, misadventure* or accidental death**	Respiratory conditions	Cardiovascular and stroke related	Cancer

Mortality in Persons With Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder: A Systematic Review and Meta-analysis - PubMed (nih.gov)

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Autism Only Reviews – Learning from National LeDeR Annual Report 2023 Emerging Themes

Overall quality of care and support rated as poor:

A lack of high-quality training, awareness, or understanding of the specific needs of autistic people. A lack of adequate support services being provided, specifically tailored towards the needs of the person, or a lack of support to access services. Overlooking the potential impact of a relationship status change for autistic adults. A lack of crisis escalation plans, or a lack of an awareness of the increased risk of suicide in autistic adults. A lack of communication between different professionals and agencies providing support. Overshadowing of the impact of autism by other co-occurring g mental health conditions.

"[name]'s autism was rarely taken into account as to the reasons for non-attendance or self-discharging...little evidence of adjustments that may have positively enabled this person to access services, for example, only group therapy was offered, [name] could not cope with group sessions, but no one to one therapy was offered..."

"[name] was significantly failed by services in relation to assessment of [their] health needs in both community and hospital settings.... [name]'s mental health issues were not identified at an early stage and was viewed as largely behavioural..."

Autism Only Reviews – Learning from National LeDeR Annual Report 2023 Emerging Themes

Overall Quality of care rated as good or above:

An awareness of autism and efforts to make reasonable adjustments. Timely communication between agencies providing care. Plans in place for crisis and escalation supports where appropriate, including assessments of suicide risk. Supports are both offered and explained, tailored to the needs of the individual, and reasonable adjustments are made to help service users access these services and supports.

[name]'s wishes and preferences were listened to, and [their] care package was person centred."

"[name] had a thorough assessment of [their] risk of suicide and how to keep [them] safe at each appointment. [They] were also referred to talking therapies."

Learning into Action- Ethnicity

A small task and finish group within the LeDeR Learning into Action Group including experts by experience has started planning some targeted work around reducing health inequalities and raising awareness of LeDeR in BME communities. This work is aimed at:

- Increasing awareness of health inequalities and LeDeR amongst communities minoritised by race and health and with health and care services that support them.
- Increasing the uptake of Annual Health Checks amongst people with learning disabilities from communities minoritised by race.
- Continuing to embed the recommendations arising from Race and Health Observatory Report We deserve better: Ethnic minorities with a learning disability and access to healthcare - NHS - Race and Health ObservatoryNHS – Race and Health Observatory (nhsrho.org)

Learning into Action- Constipation

Constipation can be a life–threatening issue for people with a learning disability who are at heightened risk from complications if it is left untreated.

23% of people with a learning disability who died in 2019 had constipation as a long-term condition [LeDeR annual report 2019].

People with a learning disability may also be less likely to recognise the symptoms of constipation and be able to communicate their symptoms [LeDeR annual report 2019], increasing the risk of serious consequences.

Constipation has been a key feature in local LeDeR learning from reviews.

Local constipation resource has been developed with a plan to promote alongside national campaign. -NHS England » Constipation campaign toolkit

Learning into Action- ReSPECT and DNACPR

Action informed by:

ICB Audit DNACPR/ReSPECT Audit GHT completed Dec 2023

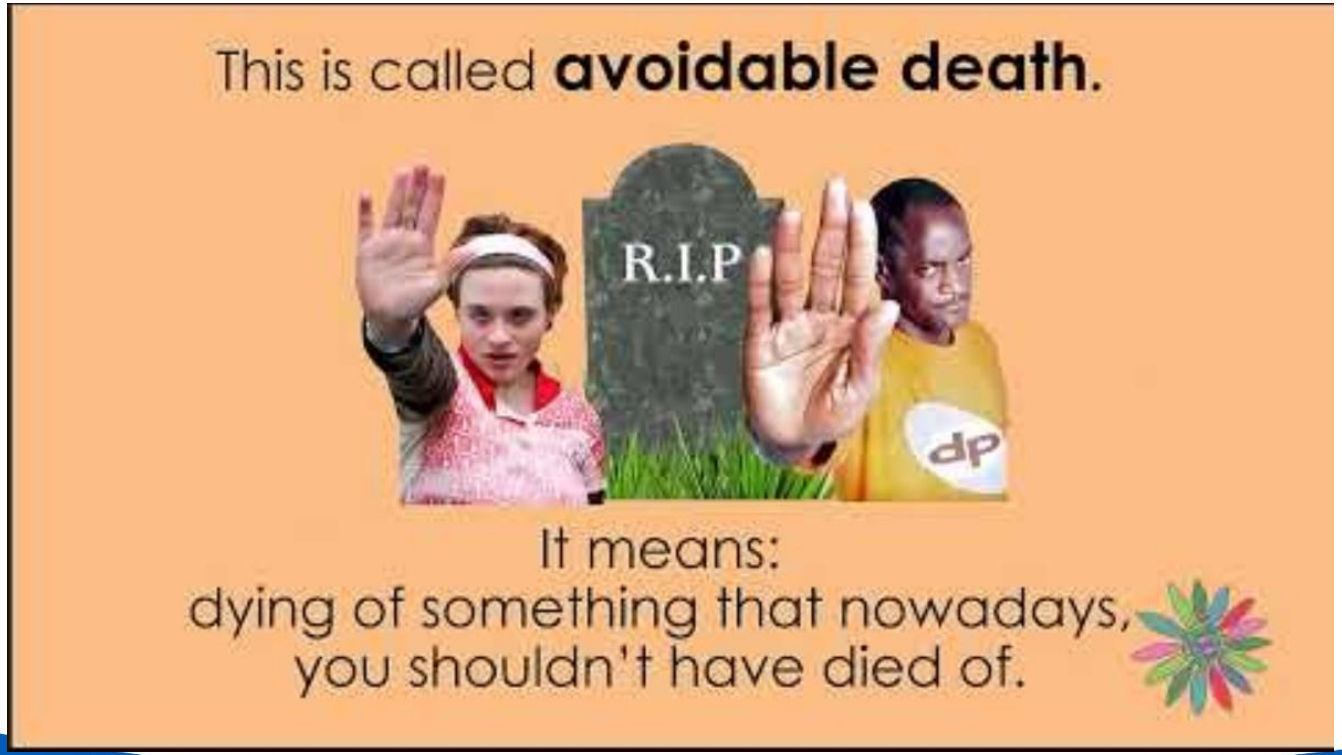
SW DNACPR ReSPECT Audit Report and Recommendations Parliamentary Ombudsman Report Easy Read

Parliamentary Ombudsman DNACPR and ReSPECT Conversations Report

Recommendations delivered through ICB LD Task and Finish Group, NHSE and SW Regional Operational Group.

Reasonable Adjustments- Accessing Healthcare

National LeDeR Annual Report 2022 Video



Notifications & limitations with the data

Unlike reviews of child deaths, which are required by law, reviews of the deaths of people with learning disabilities and autistic people are not mandatory so professionals attending deaths are not required to report them to LeDeR. There is no automatic communication to LeDeR of the deaths of people on GP Learning Disabilities Registers. This makes it likely that notifications of deaths to LeDeR will be incomplete.

Delays in reporting deaths to LeDeR may affect monthly notification figures as deaths can be reported to the LeDeR Programme at any time.

It is important to remember that comparisons with the general population are indicative but not directly comparable: deaths of people with learning disabilities are notified to LeDeR from the age of 4 years, while general population data also includes information about children aged 0-3 years.

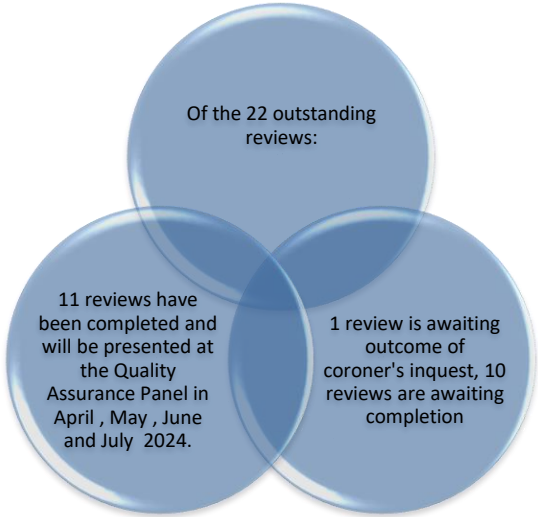
How to Report a Death

Status of Reviews by Year

Year	Closed	Open	Total	% Completed
2016-2017	7	0	7	100%
2017-2018	51	0	51	100%
2018-2019	47	0	47	100%
2019-2020	46	0	46	100%
2020-2021	54	1	55	98%
2021-2022	21	19	40	53%
2022-2023	26	22	48	52%
2023-2024	17	22	39	54%
TOTAL	269	64	333	81%

In the year 2023-2024 39 reviews were notified to the local programme compared to 48 in 2022-2023

17 reviews have been completed and submitted to the national programme.

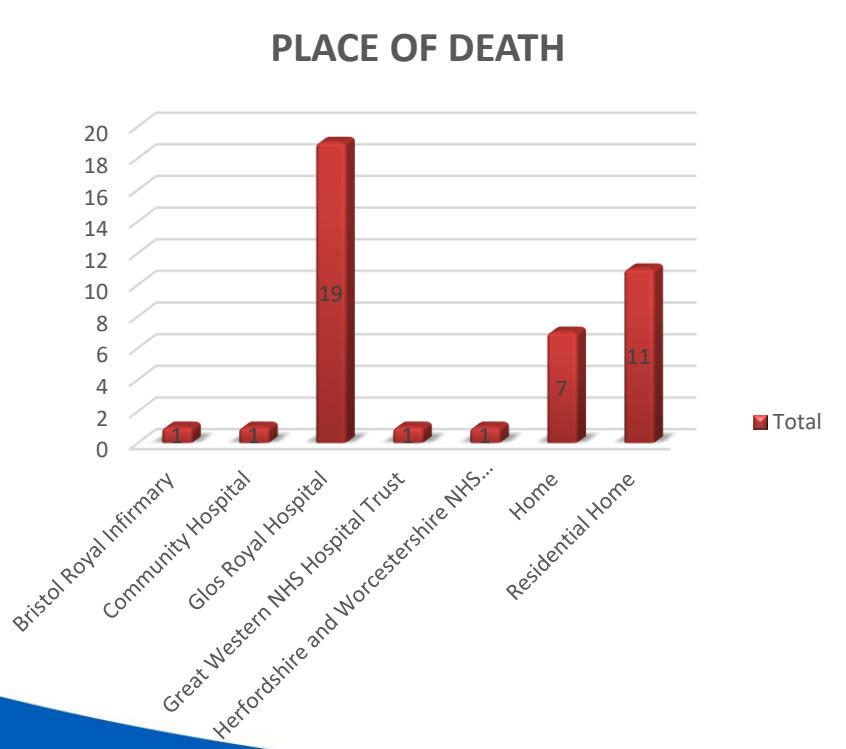


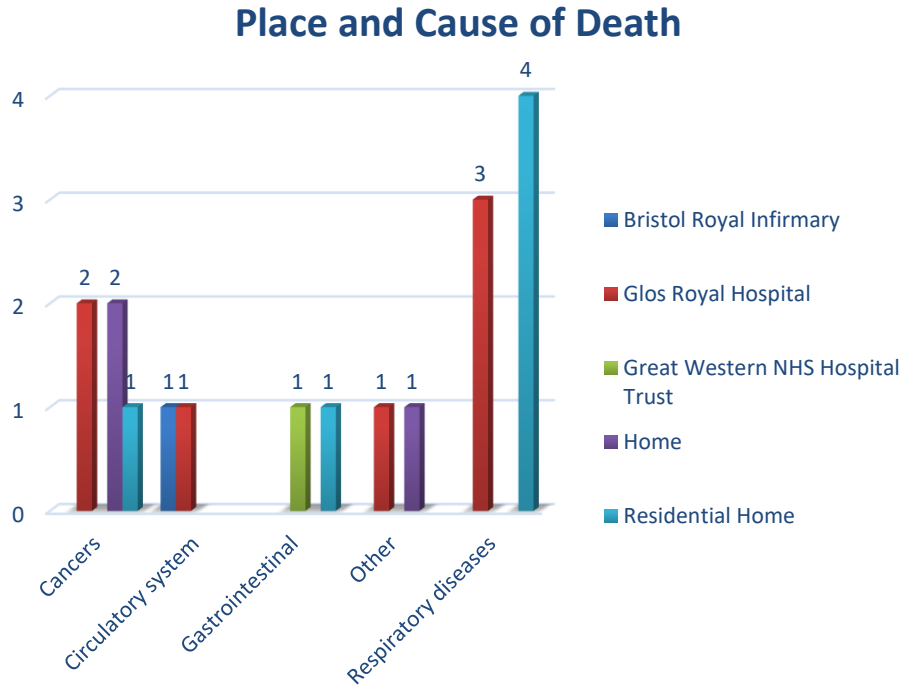
Reporters of Deaths

Gloucestershire Hospitals NHS Foundation Trust (Acute Care) were the biggest reporters of deaths since the programme began in 2017 (n= 113 deaths) 34%, with Gloucestershire Health and Care NHS Foundation Trust (the County's community NHS Provider) the second biggest reporters of deaths (n= 78 deaths) 23%.

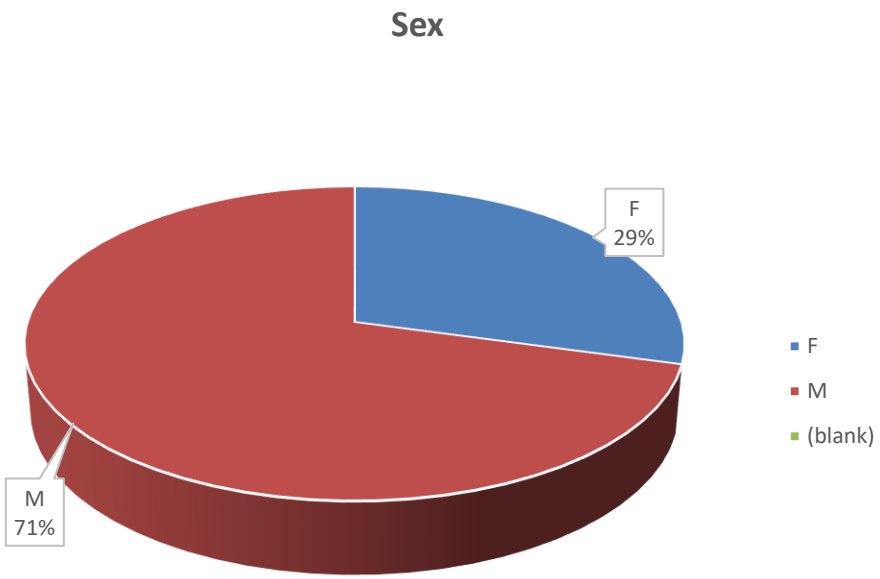
Year	GHC	2G[1]	GCC	GCS[2]	GHT	GP	Care Home/ Provider	Out of county	Other	TOTAL
2016-2017	0	0	2	0	5	0	0	0	0	7
2017-2018	0	17	9	1	16	2	4	0	2	51
2018-2019	6	9	12	2	12	4	0	2	0	47
2019-2020	8	1	10	0	12	2	1	5	7	46
2020-2021	17	0	9	0	17	5	2	0	5	55
2021-2022	16	0	0	0	16	0	4	0	4	40
2022-2023	18	0	0	0	18	1	8	0	3	48
2023-2024	13	0	0	0	17	0	6	3	0	41
TOTAL	78	27	42	3	113	14	25	10	21	335

Place and Cause of Death





Demographic Data - Sex

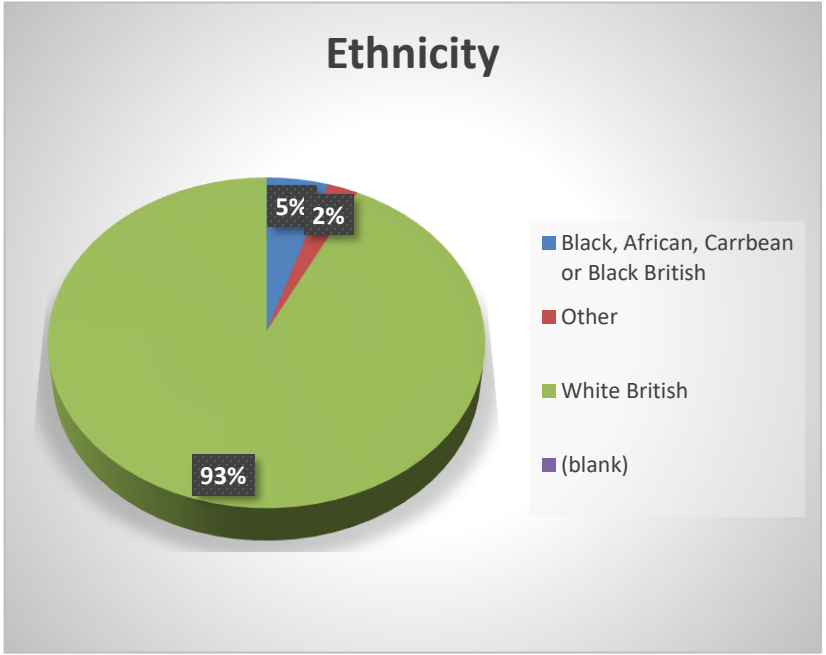


Gloucestershire LeDeR Deaths 2023-2024: 71% Male / 29% Female

This compares with 46% and 54% in 2022-2023.

Nationally 55% of people who died in 2022 were Male, 45% Female

Demographic Data - Ethnicity



There is an increased risk of dying earlier by ethnic minority group, in comparison with people from white ethnicity backgrounds, when adjusting for other demographic factors. People from all ethnic minority groups died at a younger age in comparison to people of white ethnicity LeDeR Annual Report 2022 (published 2023). In Gloucestershire <5 people died before the age of 20, <5 died before 62.9 years, the average age of death for people with LD's.

Ethnicity	% Increase risk
Mixed ethnicity	+81%
Asian , Asian British	+150%
Other ethnicity	168%
Black, black British, Caribbean, or African	+190%

Demographic Data Median Age of Death 2023-2024

General population average age of death - 82.6 years

2018–2020

Gloucestershire LeDeR Median age of death is 61.9 down from 63 years in 2022-23

2022–2023

National median age of death for Autistic adults with a learning Disability was 55 years in 2022

2022

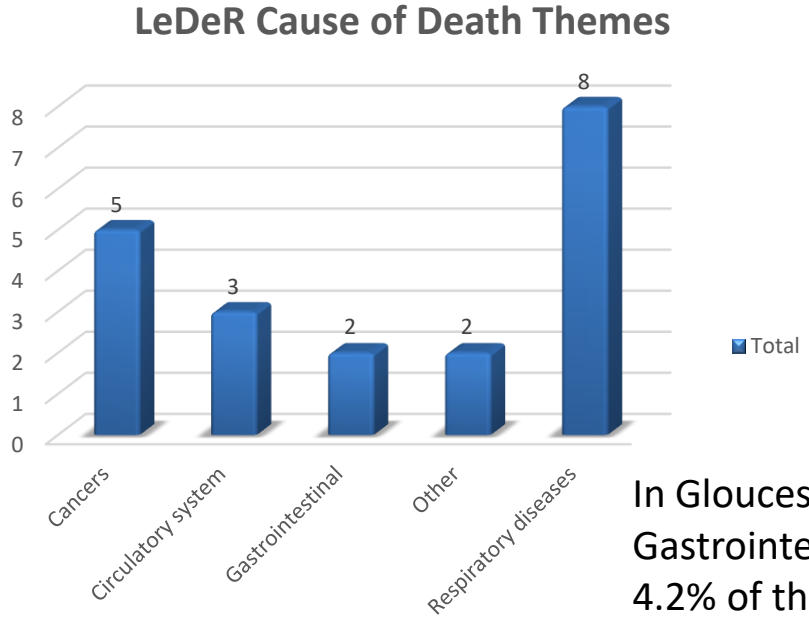
2022

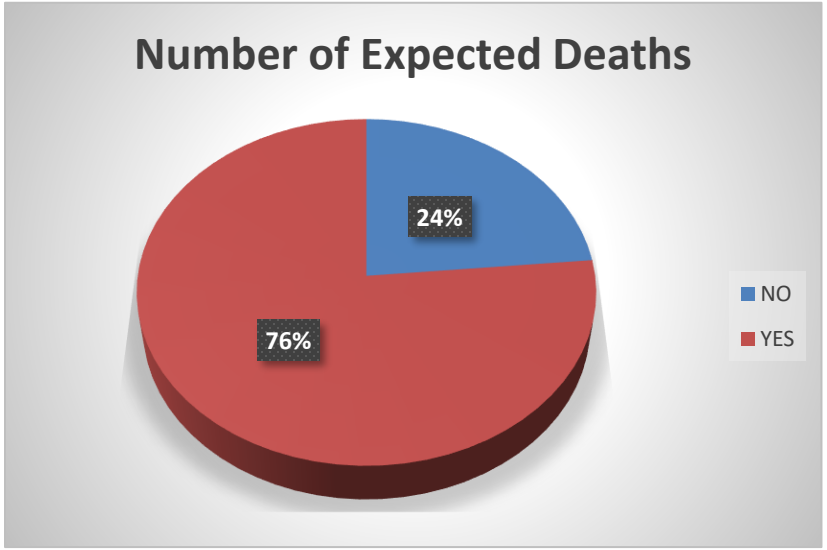
National LeDeR Median age of death – 62.9 years an increase from 61.8 years in 2022

2022

National Median age of death for someone with LD's from minoritised communities is 42 years in 2022.

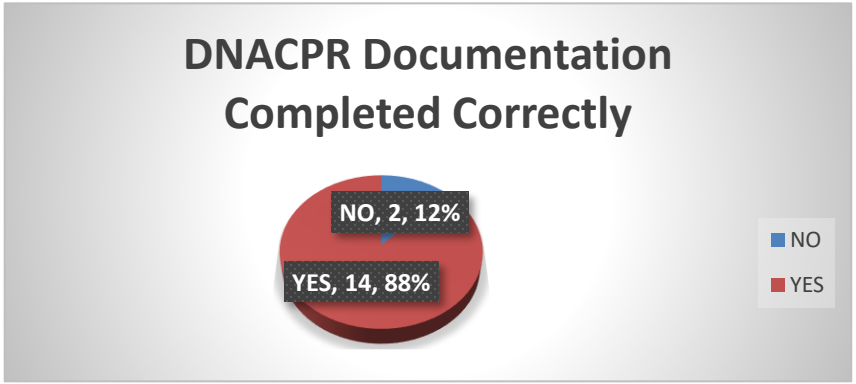
Top 4 LeDeR Causes of Death

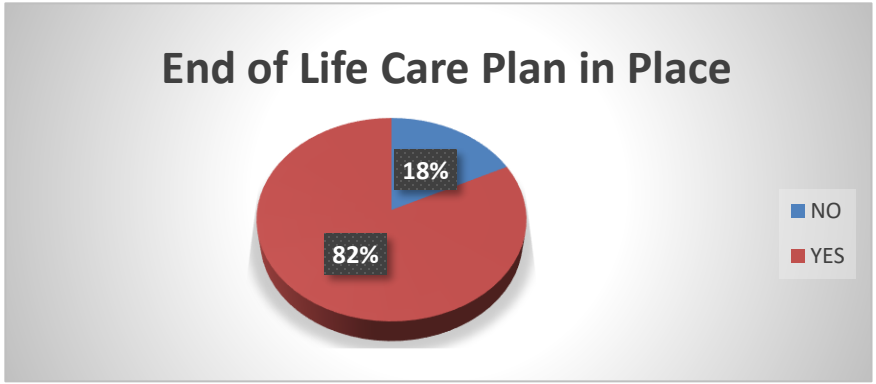




In Gloucestershire 50% of unexpected deaths were Gastrointestinal and 50% Respiratory.
4.2% of the population of Gloucestershire died from respiratory causes and 4.6% from GI related causes compared to 5.1% and 8.5% of the LD population in 2023/24

ReSPECT and DNACPR





RESPECT and DNACPR

Of the 17 reviews completed in 2023-2024 reviewers judged DNACPR documentation and processes to have been correctly followed in 14 of the deaths.

DNACPR was present in 82% of completed reviews.

Nationally 63% DNACPR's was followed at time of death, up from 61% in 2021.

Nationally in 2022 74% had a DNACPR.

In Gloucestershire only 2% of people didn't have a DNACPR compared to national and region

13 (82%), of the 17 reviews completed had an end-of-life care plan where the death was expected compared to 42% in 2022-23

13 (46%) of the reviews completed had an end-of-life care plan in place where the death was unexpected

Feedback about LeDeR and what is found out…

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

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

We have the right people involved who are just so motivated to make change happen

"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"

The QA Panel is a strong example of co-production in action. We work together as a multi-disciplinary team to discover the learning opportunities we can share

A Reviewer's Perspective

This has been a busy year for LeDeR in Gloucestershire and lots of information has been gathered regarding areas where improvements can be made and areas of good practice. After 7 years working on the LeDeR programme I am pleased to note that there have been certain improvements in health and social care for people with learning disabilities and autistic people, however inequalities are still evidenced, resulting in people dying sooner than they should.

There are several different review processes for people who die, child death reviews, safeguarding adults' reviews and reviews of people who die in hospital. We aim to work more closely with these processes to avoid duplication. I especially enjoy sharing findings from the reviews in order to make a real difference to people's lives. Aiming to Improve care, reduce health inequalities and prevent premature deaths for people with learning disabilities and autistic people, is what keeps me going!

Deborah Livingstone - Senior Reviewer LeDeR

A Reviewer's Perspective

"I have been a LeDeR Reviewer now for over three years and during that time I am pleased to say that I have seen some real positive changes within the health and social care system, as a result of the learning that we have all achieved locally, through the LeDeR and Learning into Action process.

Many local providers that I have visited have been very receptive to being involved in the process of conducting a review and are also equally keen to enhance the service they are able to provide within their own service, to the Learning Disability and Autism community.

There is still more to do to bring the good standards that we all want to see being delivered across the whole of the county, to ensure that individuals from the learning disability and autism community, can access health and social care services, and are therefore able to lead their best life possible."

Paul Yeatman – Senior LeDeR Reviewer

Useful Resources

Learning from Deaths Review Gloucestershire (LeDeR) : NHS Gloucestershire ICB (nhsglos.nhs.uk)

LeDeR - Inclusion Gloucestershire – Easy Read LeDeR Annual Report 2022-2023

Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR) | King's College London (kcl.ac.uk)

LeDeR - Action from learning report 2022/23

LeDeR - Resource Bank

LeDeR - LeDeR policy

Latest LeDeR Take Home Facts Infographic

LeDeR programme what works well and what needs to change?

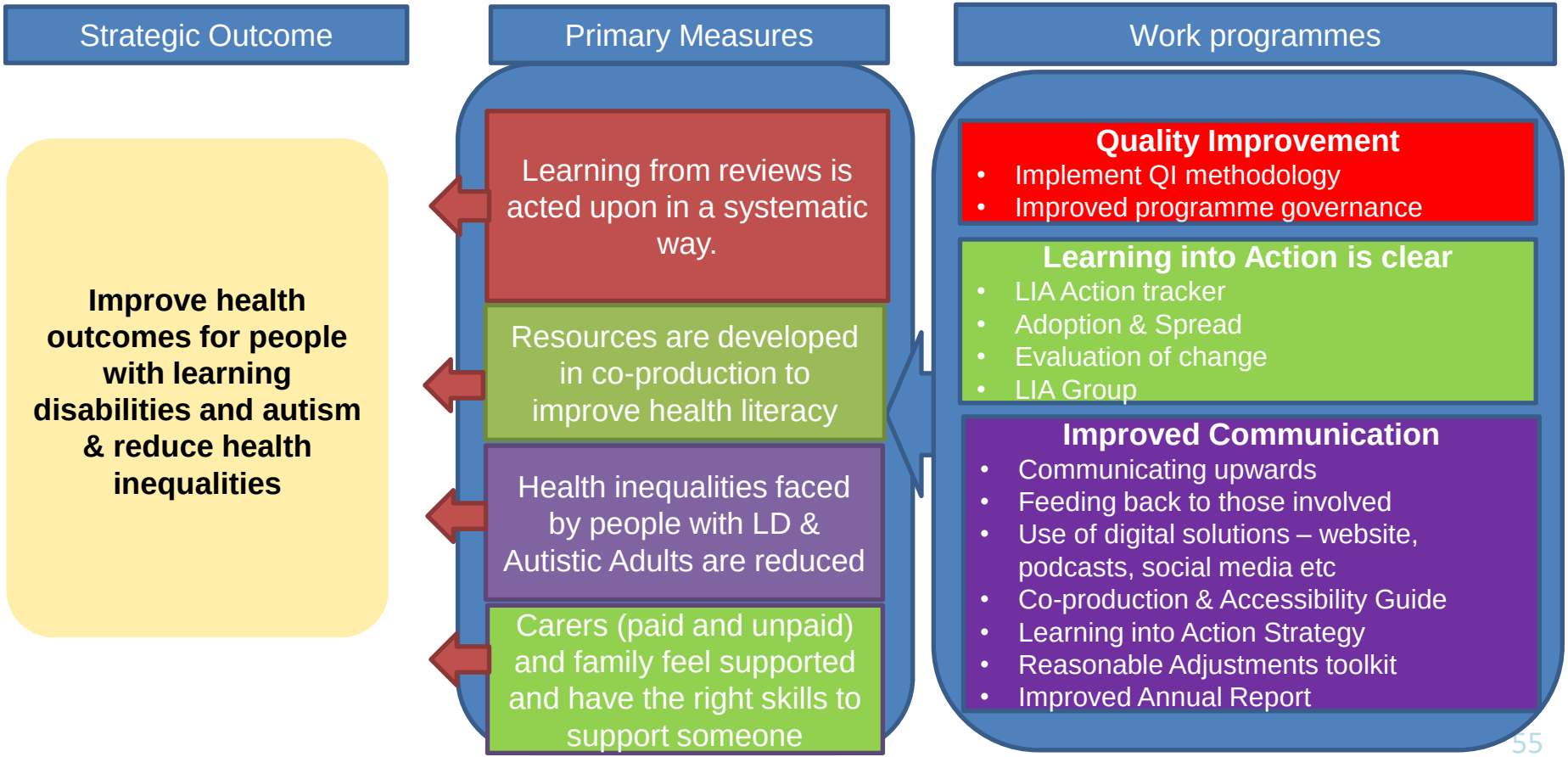
What does the programme do well

- Strong collaborative approach and quality assurance processes and governance
- Co-production
- How we communicate with those who are interested – respondents liked the communication that comes from the programme and found it useful.

Considering a reduction in capacity, the LeDeR Programme needs to adopt a smarter approach to sharing the learning more widely with system stakeholders.

- Investigate the benefits of using co-produced digital solutions to develop a suite of learning resources in various mediums.
- Raise awareness of the importance of the Reasonable Adjustment Digital Flag for people with Learning Disabilities and their carers.
- Using LeDeR Data Tool to prioritise conditions for focussed review and service improvement e.g. dysphagia, cancers , aspirational pneumonia.
- Review Membership of the QA panel to ensure triangulation of evidence between LeDeR, Safeguarding, Health Teams, Social Care Teams and Quality Assurance reviews to support discussion and agreement of learning into action SMART objectives.
- Develop a Learning into Action Strategy
- Work more closely with other CPG's to ensure learning into action is taken forward.
- Deep Dives and an increase in focussed reviews to identify and respond to gaps in leading cause of death.

LeDeR Programme Service Improvement Driver Diagram



Glossary

ASC	Adult Social Care
AHC	Annual Health Check
BME	Black and Ethnic Minority
CIDOP	Child Death Overview Process
CIPOLD	Confidential Inquiry into the Deaths of People with Learning Disabilities
CLDT	Community Learning Disability Team
CQC	Care Quality Commission
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
EOL	End of Life
GCC	Gloucestershire County Council
GHC	NHS Gloucestershire Health and Care Trust
GRH	Gloucester Royal Hospital
GSAB	Gloucestershire Safeguarding Adults Board
HAP	Health Action Plan
ICB	Integrated Care Board
ISCM	Integrated Social Care Manager
IHAL	Improving Health and Lives Learning Disabilities Observatory
KPI	Key Performance Indicator
LAC	Local Area Coordinator
LeDeR	Learning from Lives and Death People with a Learning disability and Autistic People
LD	Learning Disability
LIA	Learning into Action
MCA	Mental Capacity Act
MDT	Multidisciplinary Team
NHSE	National Health Service England
OT	Occupational Therapist
PEG	Percutaneous Endoscopic Gastrostomy
PHE	Public Health England
QA	Quality Assurance
ReSPECT	Recommended Summary Plan for Care and Treatment
RESTORE 2	Recognise Early Soft Signs, Take Observations, Respond and Escalate
SALT	Speech and Language Therapist
SATs	Oxygen Saturation
SMART	Specific, Measurable, Achievable, Relevant, Timebound
SWAST	Southwest Ambulance Trust
UTI	Urinary Tract Infection

Responsible committee:	Gloucestershire LeDeR Governance and Steering Group Learning Disability and Autism Clinical Programme Group Gloucestershire Clinical Commissioning Group Quality and Governance Committee
Target audience:	Report for those agencies involved in the programme. LeDeR Governance and Steering Group Members LeDeR Quality Assurance Panel LeDeR Learning into Action Group Learning Disability Partnership Board members Autism Partnership Board Members Gloucestershire Integrated Care Board - Quality and Governance Committee Learning Disabilities Lead Commissioner Autism Lead Commissioner Southwest Regional LeDeR Operational Group Southwest Regional Health Equalities Group National LeDeR Programme NHS England
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