Learning from the Lives and Deaths of People with a Learning Disability and Autistic People (LeDeR)

Annual Report 2023/24

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Foreword

The Learning from Lives and Deaths of people with a Learning Disability and Autistic People, better known as the LeDeR programme, has continued to grow from strength to strength throughout 2023/24.

Coventry and Warwickshire have met all of the national performance measures and have regularly sat in the top 3 systems in the country for achieving set targets.

The oversight of the LeDeR Governance Group has ensured the programme continues to challenge itself and the outcomes of the reviews. Our team of reviewers, who combine sensitivity with a tenacious and enquiring approach, ensure reviews are of a high quality and that key elements of learning can be drawn upon. However, it is the work of the LeDeR Subgroup that I really wanted to highlight. As the group has matured over the last year, we have really seen the LeDeR programme accelerate the learning into action improvements. The work on constipation has been exemplary, both in its coproduction with experts by experience and its combination of fun and facts to get across a key message.

There remains a lot to do in the LeDeR space, not least in how we work to increase the notifications we receive for autistic people and those from ethnic minority groups. I am pleased to say that with our developing infrastructure, effective governance and the hard work and support of those involved in all elements of the programme, I am confident Coventry and Warwickshire is poised to meet the challenges and further improve outcomes for people with a learning disability and autistic people.

This report has been jointly developed with our LeDeR Governance Group which has ensured engagement from our experts by experience, voluntary sector, primary care, NHS acute trusts, social care and systemwide stakeholders.

Jamie Soden

Senior Responsible Officer LeDeR
Deputy Chief Nurse - Clinical Transformation, Quality and Nursing Team, Coventry and Warwickshire ICB

Background

Learning from the Lives and Deaths of people with a learning disability and autistic people (LeDeR) has been established since 2017 and is a national service improvement programme overseen by NHS England.

Responsibility to deliver a LeDeR programme is devolved to local Integrated Care Systems (ICSs).

In Coventry and Warwickshire, the programme is delivered with collaboration between partners across health, social care services, public health, the community and voluntary sector.

As of March 2024 there were 4,812 people aged over 14 on our GP practices' learning disability register equating to 0.51%.

National research suggests that 2 – 2.5% of the population in the UK are believed to have a learning disability. Currently the total population of Coventry & Warwickshire is approximately 942,073 (Census, 2021). This would mean an estimated 23,551 people with a learning disability live in Coventry & Warwickshire. The national autism prevalence rate of 1% would mean an estimated 9,420 autistic people living in Coventry & Warwickshire.

This percentage is a similar picture across England. There is no local or national register of people with autism, so the true number of autistic people in Coventry and Warwickshire is unknown currently.

The primary aims of the LeDeR programme are:

To improve care for people with a learning disability and autistic people

Reduce health inequalities for people with a learning disability and autistic people

Prevent people with a learning disability and autistic people from early death

Executive Summary

This is the sixth Coventry and Warwickshire LeDeR annual report.

The report encompasses data and review findings regarding the deaths of people notified to the programme from 1st April 2023 to 31st March 2024. It also includes data and findings from reviews which have been notified in 2022/23 but concluded in the above-mentioned period. Our previous reports can be found here.

As of July 2023 child death is no longer reported into the LeDeR programme and instead goes through the national mandated process of Child Death Overview Panel.

Reporting a death to the LeDeR platform is not a mandatory process, and a diagnosis of a learning disability or autism is not required to be registered on death certificates, therefore the data in this report does not accurately represent all the deaths of people with a learning disability and autistic people which have occurred in Coventry and Warwickshire during this time.

Anyone can report a death into the LeDeR programme and the online form can be found here.

The Coventry and Warwickshire LeDeR programme received 55 notifications of death between 1st April 2023 and 31st March 2024. There were 25 focused reviews and 24 initial reviews completed in this time.

There has been an **increase in reporting of death of people from an ethnic minority from 2%** in 2022/23 to **6%** in 2023/24.

Respiratory conditions were found to be the most common cause of death for people with a learning disability within the reporting period.

The median **age of death** for notifications received within the reporting period was **63 for men** and **61 for women.**

As of the end of this period we have 7 reviews that remain on hold due to ongoing external investigations, 5 from 2022/23 and 2 from 2023/24.

Of our focused reviews

76% were graded satisfactory or above for **quality of care** and

84% were graded satisfactory or above for **availability and effectiveness of services.**

One review was given the highest grade of 6 for both areas.

The 'Learning into Action' section of this report highlights the sustainable quality improvement projects that have happened in Coventry & Warwickshire over the last year. This work has been a direct result of the learning and themes taken from local LeDeR reviews, and aims to improve the access to, experience, and outcomes of care for people with a learning disability and autistic people.

The report highlights our priority areas for 2024/25 which can be found here.

Programme Update & Performance

The Coventry & Warwickshire LeDeR programme has a dedicated, sustainable workforce which includes:

- Administration Support Officer
- Senior Reviewer and reviewers that are all registered nurses
- Local Area Contact

Our LeDeR Governance Group (LGG) is well established and meets monthly, with good attendance and representation from across the local system. The group is leading on systemic actions in response to learning, as well as monitoring organisation specific actions. Since May 2023 there has been systemwide reporting from providers into governance group. This has increased sharing of learning, ideas and enabled actions stemming from LeDeR review learning to be embedded.

Launched in May 2023 our LeDeR Subgroup has enabled a dedicated space to explore the key themes highlighted in the 2022/23 report. This has led to fantastic collaborative pieces of work, including our constipation resource pack.

Coventry & Warwickshire is proud to consistently be one of the top performing ICBs across the Midlands and nationally in both these areas.

Our LeDeR newsletter is produced quarterly and shared across the system. This shares learning, topical information and resources, as well as continually promoting LeDeR to our wider health and social care teams.

The LeDeR programme in Coventry & Warwickshire is fully compliant with the national LeDeR policy and has this year produced a local Standard Operating Procedure (SOP) to ensure that there are clear governance arrangements and agreed processes in place for all reviews.

The national expectation is for all reviews to be completed within 6 months of notification, and for 35% of completed reviews to be focused. Monitoring and reporting of local performance against key performance indicators occurs quarterly to the NHS England Regional Team.

91%

of our 2023/24 reviews **were completed** within the **6-month timeframe.**

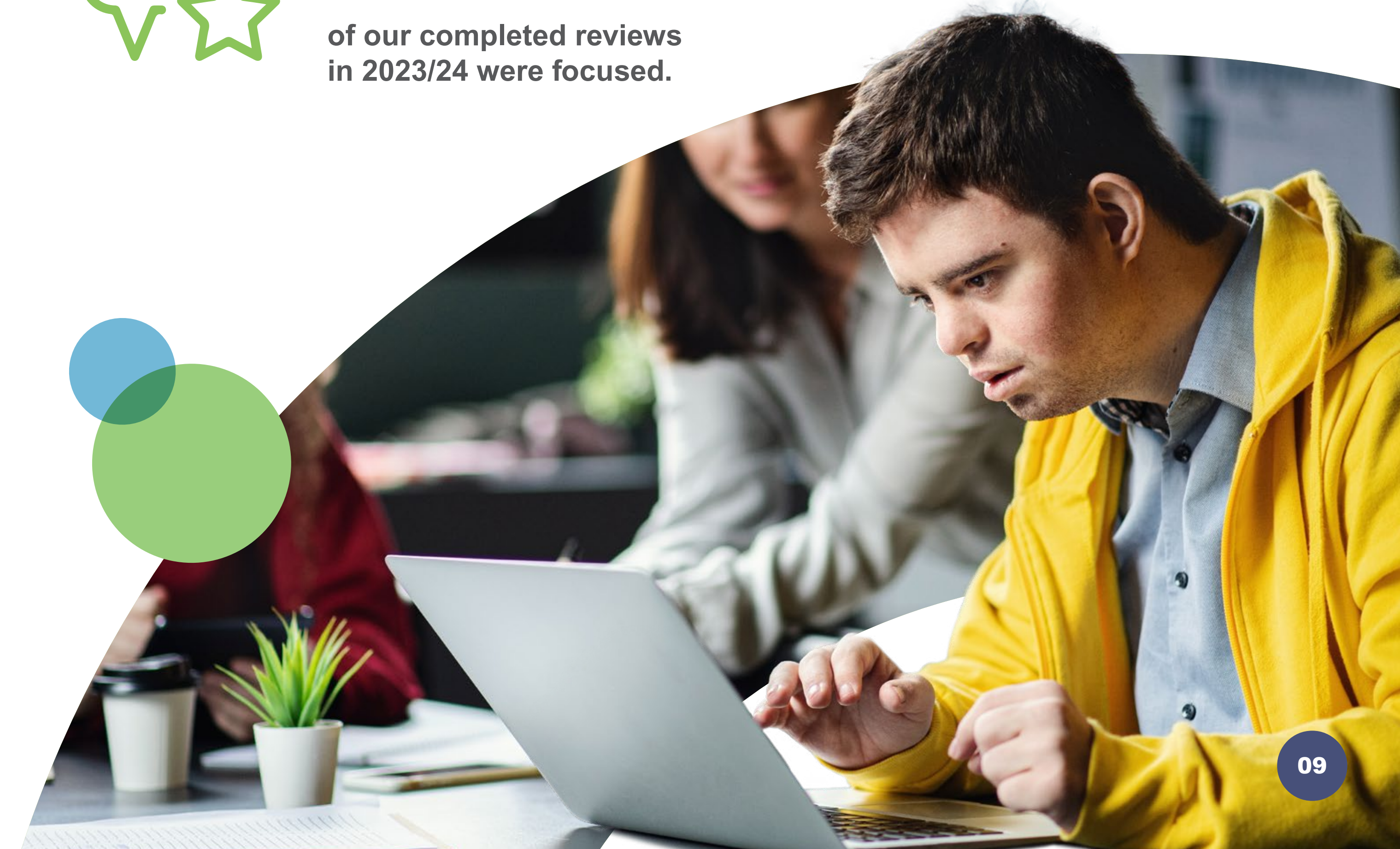
51%

of our completed reviews in 2023/24 were focused.

Four of our reviews were completed out of the 6-month timeframe:

- Two were due to the Data Services for Commissioners Regional Offices (DSCRO) process and delays in receiving the notification.
- Two were assessed by the LGG as requiring further information before a care grading could be agreed.

Where possible we aim to take focused reviews to LGG within four months of notification. This means if there is a delay following LGG to obtain more information, this does not impact the 6-month target.



Governance

Our LeDeR Governance Group has been established since April 2022, with senior representation from across the health and social care system who have the authority to influence change.

Support from Grapevine and attendance from an Expert by Experience at our LGG has strengthened the voice of the LD/A population.

Our Governance Group meets monthly, which allows for oversight and accountability of the LeDeR programme to fulfil its aims. Focused reviews are presented to the group where the grading of care is decided, SMART actions created, and learning actioned and logged.

Each systemwide partner provides bi-annual reports into the governance group. These allow for sharing of learning and best practice across the system. The report includes:

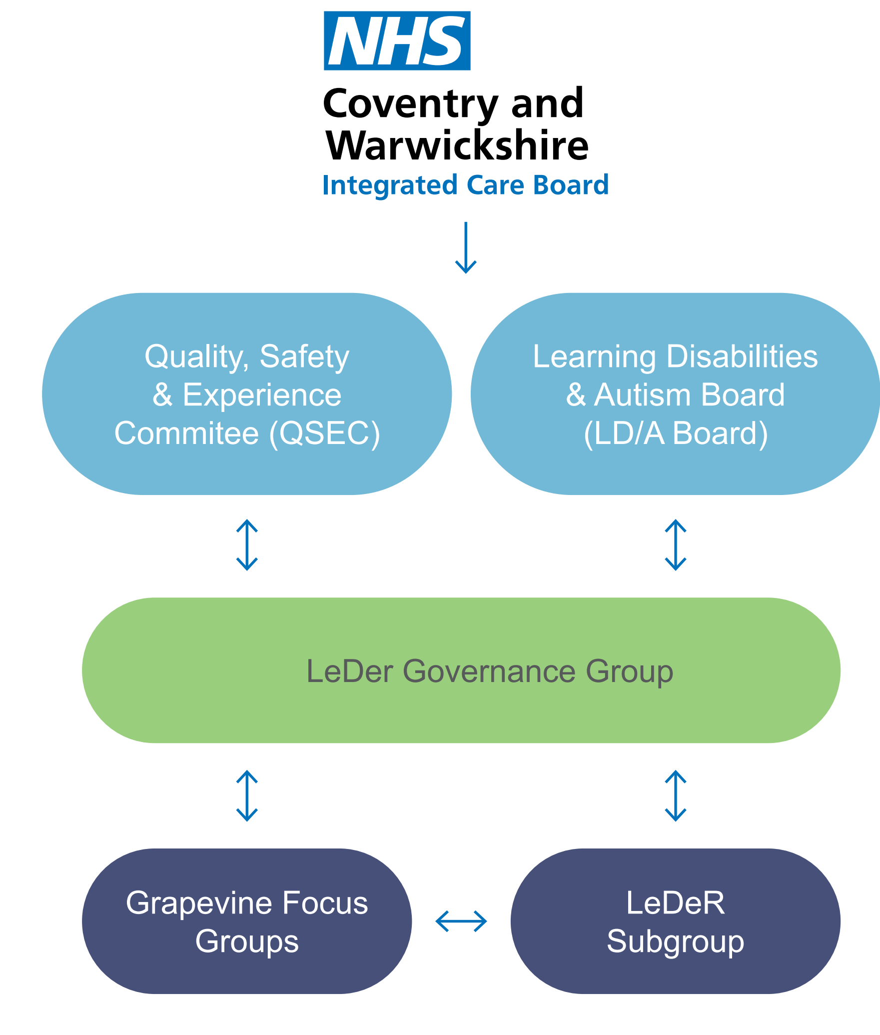
- Summary of work over the past 6 months
- Learning identified from reviews
- Actions completed
- Planned Activity and Workstreams
- Key issues and risks / Support required

Our LeDeR Subgroup launched in May 2023, with membership from key stakeholders from across the health and social care system, where broader themes have been able to be explored.

The LeDeR Subgroup has allowed for a dedicated space to work on the key themes identified in our LeDeR reviews and reports. The extent of this work has been detailed in our learning into action section.

The Focus Group held in collaboration with Grapevine meets quarterly. A key topic is taken for discussion, such as pneumonia, and then findings from the discussion are presented at the LeDeR Governance Group and fed into the work in the LeDeR Subgroup.

The chart describes the governance framework. The LeDeR Programme reports its performance monthly to the LD/A Board and bi-monthly to the Quality Safety and Experience Committee (QSEC).



Child Death

As of July 1st 2023, the national LeDeR policy relating to the death of children and young people under the age of 18 changed, and there is **no longer a requirement for deaths of children with a learning disability to be notified to LeDeR.**

The national mandated process of the Child Death Overview Panel (CDOP) will continue to review any death of a child, including those with a diagnosis of a learning disability or autism.

At the time of the change Coventry and Warwickshire had two open child LeDeR reviews on the platform. The decision was made to mark these reviews out of scope, as advised by the national team, and allow them to progress through CDOP.

There was one child death review completed by the LeDeR programme in April 2023 before this change took place. Due to the small number, and patient anonymisation, we are unable to include details around the death including demographics, however the outcome from CDOP was that there were no potential modifiable factors in relation to their death.

As a system we wanted to ensure a robust method for shared learning and best practice, therefore CDOP will now attend LeDeR Governance Group annually to present their findings from learning disability and autistic child deaths. The LeDeR team also offer support to the CDOP for any reviews for a child with a learning disability or diagnosis of autism. We have also ensured inter-programme working between CDOP and the Palliative and End of Life Care programme where themes and learning can be shared.

Notifications

During the period of 1st April 2023 – 31st March 2024 Coventry and Warwickshire have received a total of 55 LeDeR notifications.

Of the new notifications, four were identified as being out of scope for a LeDeR review and were closed accordingly. Those out of scope were either individuals who were identified as having a learning difficulty rather than a learning disability, or people without a confirmed diagnosis of autism.

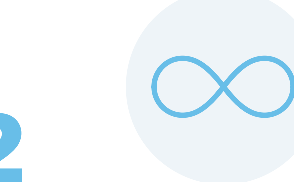
The total number of new notifications received represents a decrease when compared to the 64 reported in the previous year. There has also been a decrease of two autism only reviews compared to three in the previous year.

Therefore, a total of 51 new LeDeR reviews have been progressed during 2023/24, two of which were for the death of an autistic adult.

A decrease in notifications received has been reported both nationally and across the Midlands. This will be partly due to the fact child death is no longer reported into the programme. This year there has been an increased effort to promote the LeDeR programme across Coventry & Warwickshire which can be seen in our Learning into Action section. This promotion effort has been recognised as for the first time ever, we have seen two notifications for reviews received from family members, showing LeDeR is reaching wider than health and social care. We will continue to closely monitor trends in the numbers we are reporting in our quarterly reports.

49

LeDeR Notifications Received (Adults)
LD or dual diagnosis of LD/A



2

LeDeR Notifications Received (Adults)
Autism diagnosis only

4

New LeDeR Notifications
Confirmed as Out of Scope

The following analysis is of the 51 notifications that were in scope:

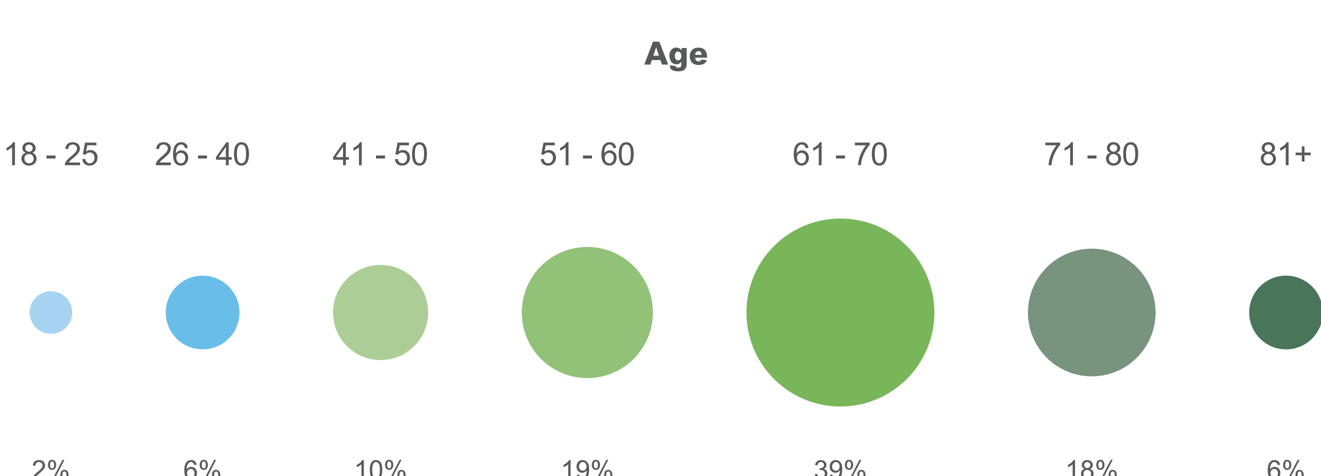
Age

The difference in life expectancy and age of death amongst people with a learning disability and those without is significant. Across the UK, life expectancy in 2020 was estimated to be 79.3 years for males and 83.1 years for females. On average, the life expectancy of women with a learning disability is 26 years shorter than the general population and for men 22 years shorter than the general population.

For Coventry & Warwickshire, the age range at death for the 51 adults notified to the LeDeR programme during 2023/24 was 18 to 84.

Of the people for whom notifications were received, **the median age of death was 63 years for men; an increase from 61.5 last year** and remains in line with the most recent national LeDeR data. The **median age of death for women was 62** which is the same as last year and remains in line with the most recent national LeDeR data.

National LeDeR data in 2021 found 85% of the general population died aged 65+, whereas only 39% of people with a learning disability died aged 65+. For 2023/24 **in Coventry and Warwickshire 43% of people died aged 65+; this is an increase from 42% last year.**

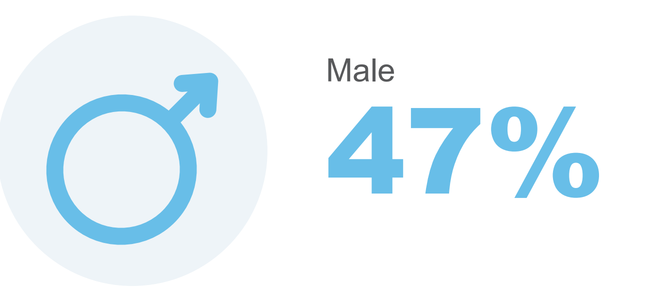


Gender

Most recent national estimates suggest that of those with a learning disability, 58% are male and 42% are female. In the 2022 National LeDeR Annual Report 55% of people who were reviewed were male.

Female

53%



When completing a LeDeR review we collect information about an individuals registered sex at birth and the gender an individual identifies as, along with their preferred pronouns. **Of the 51 new notifications to LeDeR in 2023/24, 24 (47%) related to males and 27 (53%) to females.**

In the reviews undertaken all individuals identified as their registered sex at birth. This is the first time that Coventry & Warwickshire has highlighted more female deaths, and therefore this will be an area to monitor moving forwards in our quarterly and annual reports.

The following analysis is of the 51 notifications that were in scope:

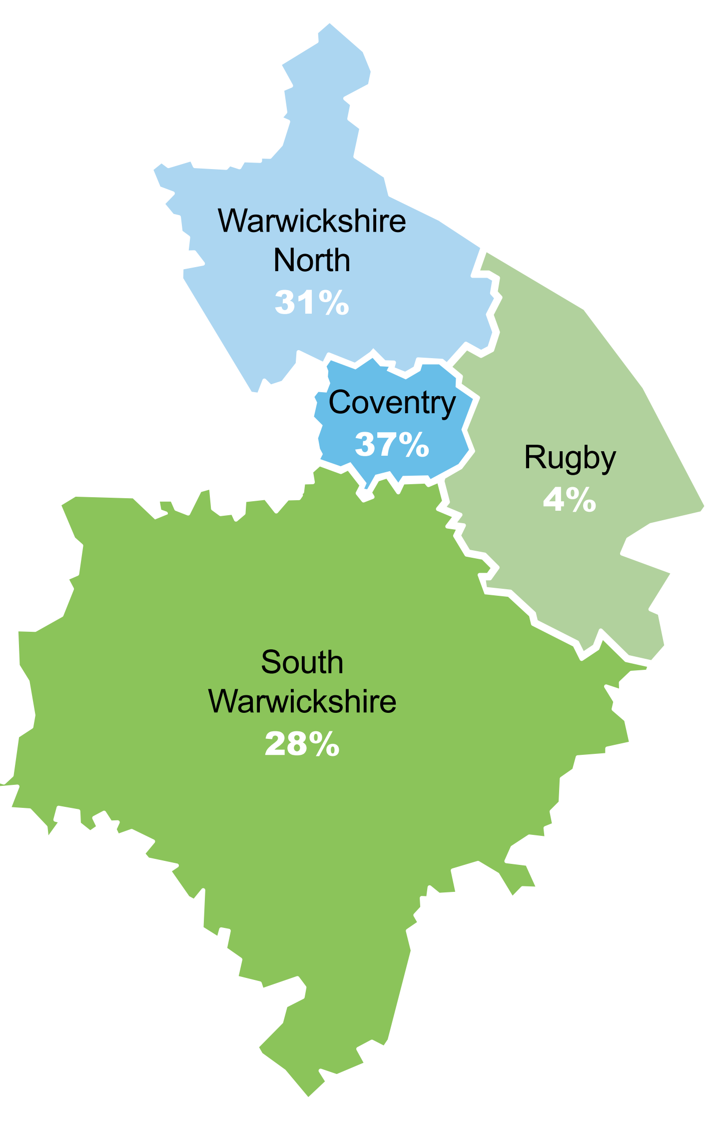
Place

The map shows a breakdown of the 2023/24 notifications based on each of the four places in Coventry & Warwickshire.

As of March 2024, there were 4,812 individuals on our 14+ LD GP registers. When broken down into place, **Coventry makes up 40.9%, Rugby 8.6%, South Warwickshire 25%, and Warwickshire North 25.5%**. There is no register of people with Autism recorded nationally or locally and so the true number of people with Autism in Coventry and Warwickshire is not known.

When compared to 2022/23, this year reporting has increased in Coventry by 11%. Reporting has decreased in Warwickshire North by 4%, Rugby by 6%, and South Warwickshire by 1%. These changes would mean reporting now more closely aligns with what would be expected when compared to the learning disability population of that place.

This year saw our biggest increase in the learning disability register of 402 people, when compared to 50 people in 2022/23. As a system it is recognised that even though there is a year on year increase for the learning disability primary care register size, this is not proportionate to the size increase of the population, or representative of the estimate that 2% of the population have a learning disability and 1% of the population have an autism diagnosis.

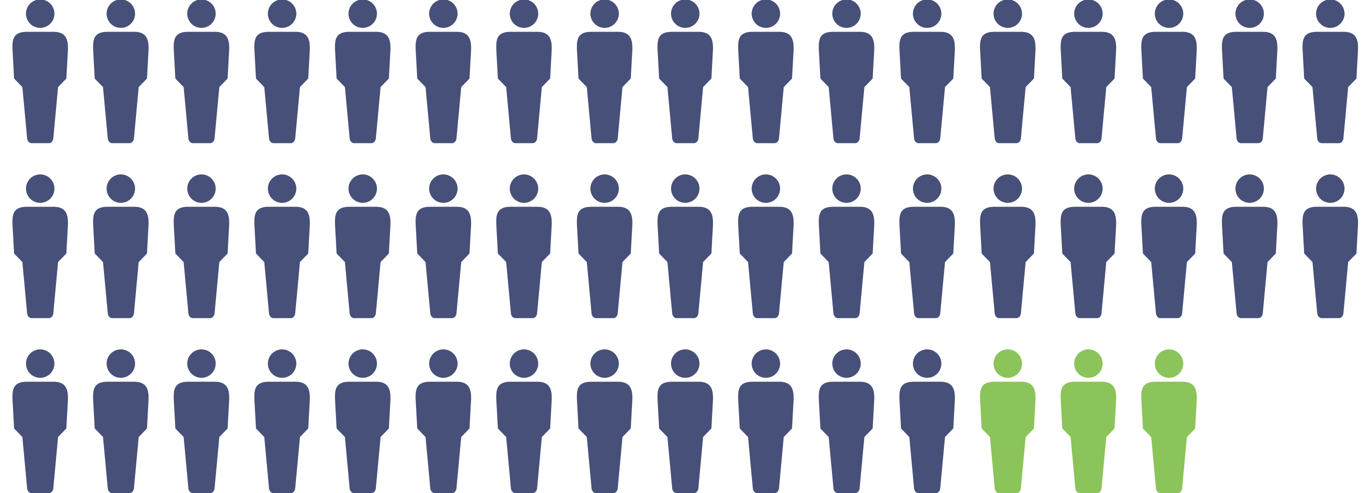


Ethnicity

Between April 1st, 2023 and March 31st, 2024, there were three people reported to the LeDeR programme from ethnic minority groups. Two were Asian and one person was Black British. Caution should be applied when making interpretations of the impact of ethnicity due to the small numbers reported for Coventry and Warwickshire.

As in previous years most people notified to the Coventry & Warwickshire LeDeR programme were reported to be White British (94%), however this is a decrease from the 98% reported in 2022/23, and in line with the national LeDeR report 2022 which found 94% of people who died with a learning disability were White British.

Work has continued throughout the year, both to understand more about the ethnicity of individuals on the learning disability register in Coventry and Warwickshire, and to promote LeDeR in this space. Details can be found in our learning into action section.



Completed Reviews

The following commentary and analysis is based upon the findings of the 49 adult LeDeR reviews completed during 2023/24.

This number is a slight decrease on the 57 reviews completed in 2022/23. The reduction in completed reviews is due to the fewer notifications received and the fact 7 reviews remain on hold due to awaiting outcomes of external investigations.

There have been 25 completed focused reviews during this period which is an increase compared to 21 completed during 2022/23. There have been 24 initial reviews completed. All reviews completed were of individuals with a diagnosis of a learning disability, or a diagnosis of a learning disability and autism. There were no autism only diagnosis death reviews during this time.

This year in Coventry & Warwickshire deaths attributed to constipation and deaths caused by pneumonia were conducted as focused reviews. This allowed for more in-depth information to be gathered and for the reviews to be scrutinised by LGG. Of the 25 focused reviews:

Reason for focused review to be completed	Number
Pneumonia as cause of death	17
Constipation attributed to the cause of death	2
Significant learning extracted	2
COVID-19 as cause of death	1
Admitted to a mental health institution in the last 5 years of their life	1
Ethnic minority review	1
Error in processing by national team	1

Level of Learning Disability

This is the first year where it has been mandated for the level of learning disability to be included in completed reviews.

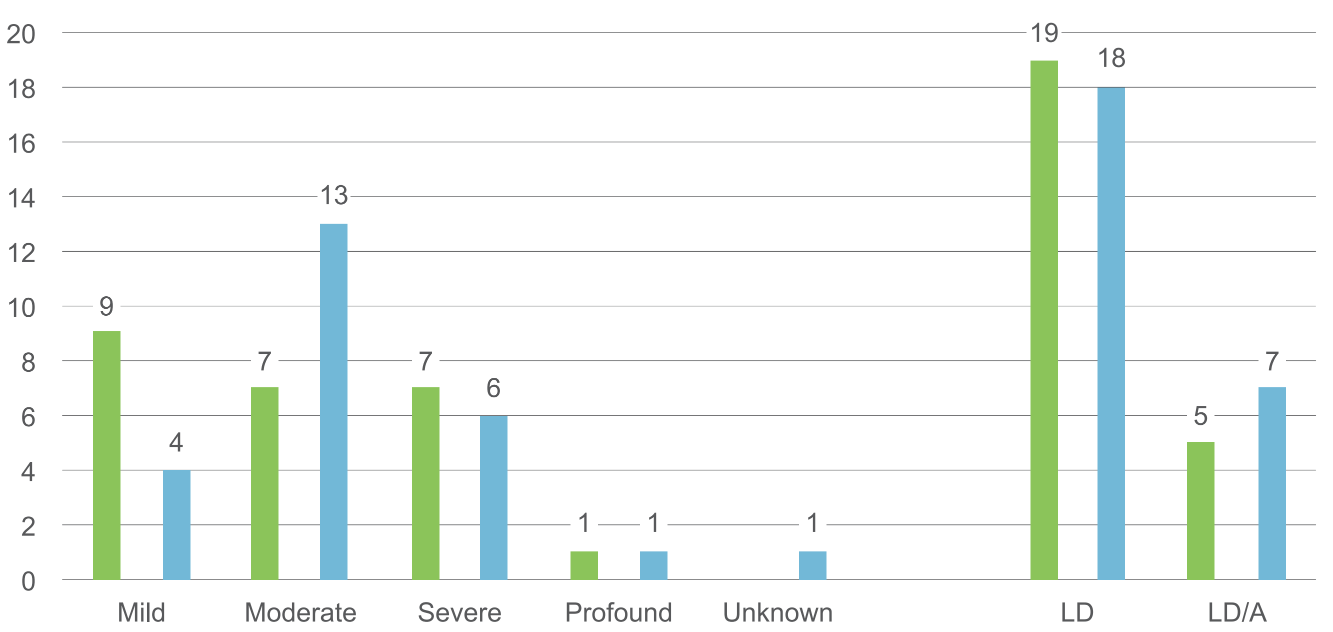
Key findings were:

- Most initial reviews completed were for people diagnosed with a mild learning disability
- Most focused reviews completed were for people with a diagnosis of a moderate learning disability

The LeDeR 2021 report found that people die younger as the severity of their learning disability increases. This could be due to many factors such as having multiple co-morbidities, as well as the challenges faced in being able to communicate their health care needs.

National research suggests 32% of people with a learning disability have a diagnosis of autism. Of the reviews we conducted this was the case for 24% of people.

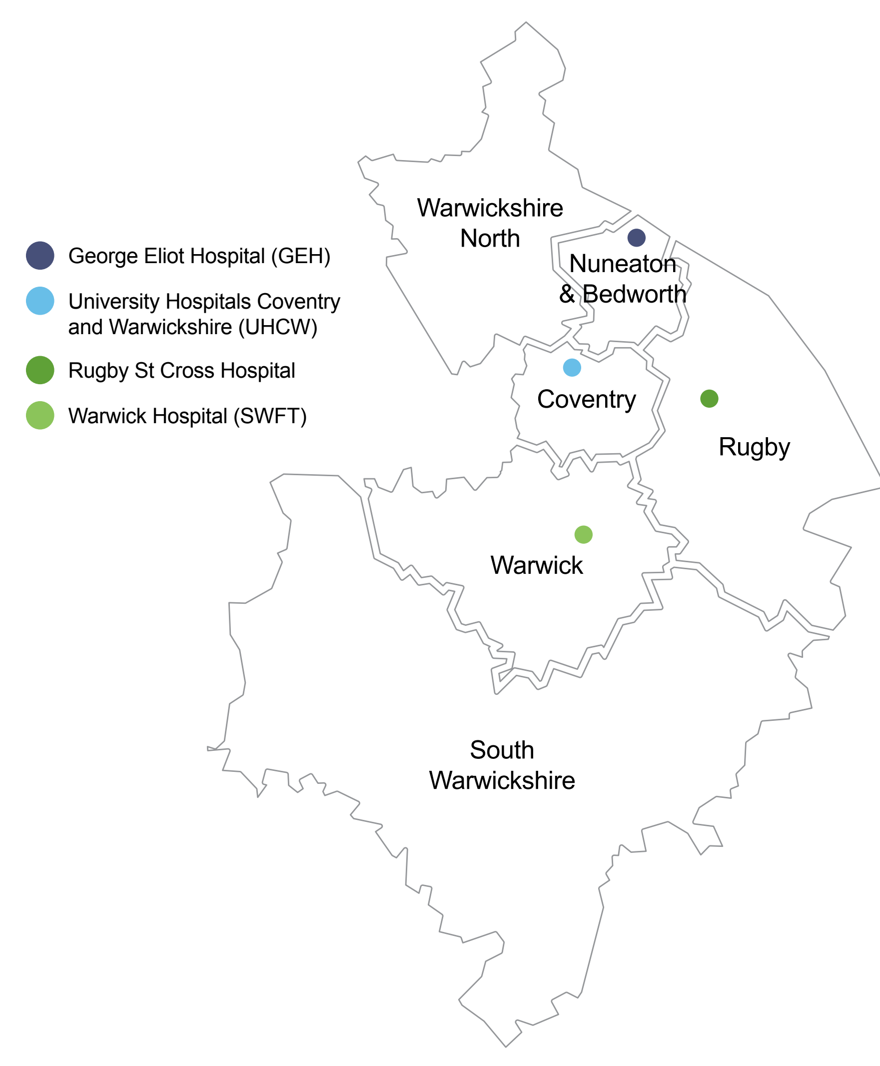
Level of Learning Disability and LD vs LD/A reviews
Initial vs Focused



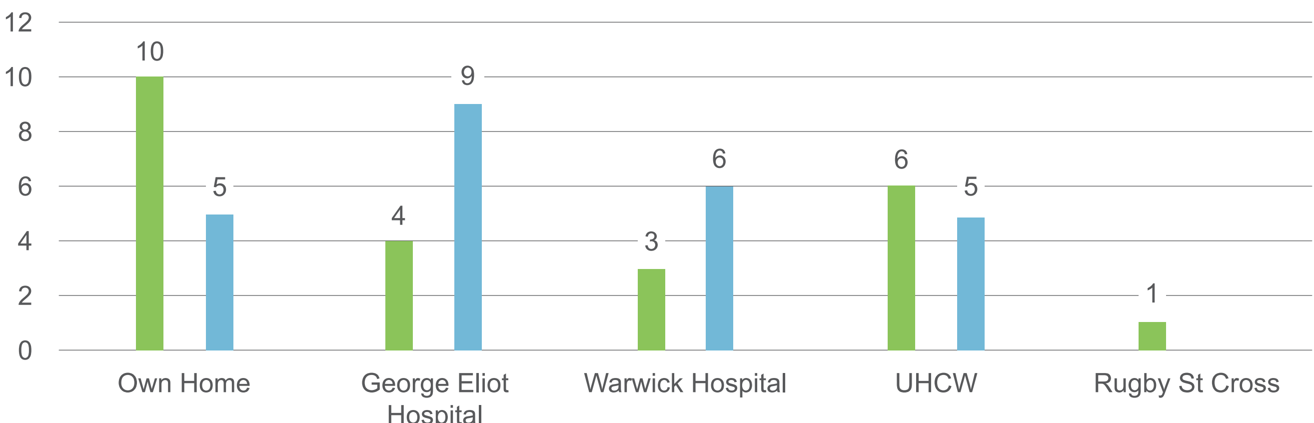
Place of death key findings:

- 50% more people died in their own home from initial reviews compared to focused reviews
- 69% of people died in a hospital setting which is an increase from 67% in 2022/23
- No-one died in a hospice setting, when compared to 5 people in 2022/23

When compared to our 2022/23 LeDeR report, the national LeDeR report, and the data for that of the general population, Coventry and Warwickshire have a higher incidence of people with a learning disability and autism dying in a hospital setting. This has been taken as a key theme for 2023/24.



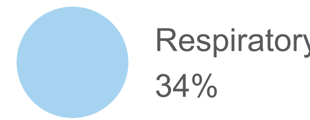
Place of Death
Initial vs Focused

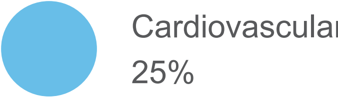


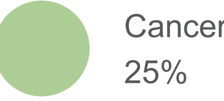
Cause of death key findings:

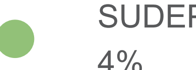
- In Coventry & Warwickshire the leading causes of death in 2023/24 were Respiratory, Cardiovascular and Cancer. This directly aligns with what is reported both nationally and across the Midlands and will be the focus of our work in 2024/25 as outlined in our priorities.
- The leading cause of death was respiratory, which was seen in 23 of the 49 reviews (47%). This is a slight decrease from 53% in 2022/23.
- Deaths due to cancer have increased from 12% in 2022/23 to 16% in 2023/24, despite an increase seen in all types of cancer screening.
- One death was due to SUDEP (sudden unexpected death in epilepsy). This is the first death noted of this nature. Epilepsy as a co-morbidity will now be closely monitored within our review process.
- Three deaths were due to Sepsis. Recognising the signs of deterioration was noticed as a theme at our LGG and explored in our local focus group.

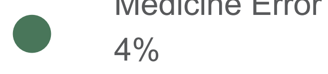
Cause of Death
Inital Reviews



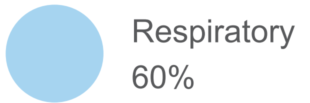


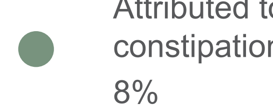


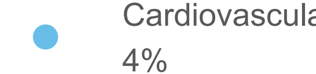


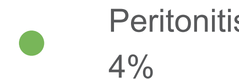


Cause of Death
Focused Reviews









Haemorragic Gastritis
4%

COVID vaccinations were given in **93%** of reviews

Flu vaccinations were given in **92%** of reviews

Pneumococcal vaccinations were given in **29%** of reviews

Cancer Screening

There were 69 opportunities for cancer screening to be carried out and on 29 occasions some form of screening was conducted (42%). This is a large increase from 22% in 2022/23.

- Cervical screening was completed for 6/23 people (26%)
- Breast screening was completed for 7/18 people (38%)
- Bowel screening was completed for 16/28 people (57%)

This year has seen an increase on all three types of screening conducted when compared to 2022/23. Information about the work that has happened across the local area in the past year to help increase screening can be found here.

Ethnicity

There was one focused review completed in 2023/24 where the person was Asian. Due to the low number we are unable to draw upon key themes.

Work has taken place over the past year to promote LeDeR for ethnic minority populations and gain a better understanding of the ethnic representation on our learning disability registers, as well as upskilling our reviewers; more information can be found here.

Down Syndrome

This year, following on from the Down Syndrome Act (2022), the national statutory guidance for Down Syndrome is due to be released. This is the first annual report to feature Down Syndrome deaths.

Of the 49 completed reviews in 2023/24, 6 people had a diagnosis of Down Syndrome. These reviews highlighted:

- The average age of death was 60 (59 for female and 62 for male)
- All 6 deaths were due to respiratory causes (5 due to aspiration pneumonia and 1 due to COVID-19)
- All 6 people had been fully vaccinated for flu and COVID, however only one had received the pneumococcal vaccination

The LeDeR team will continue to monitor trends from the deaths where a person was diagnosed with Down Syndrome to help inform future system work.

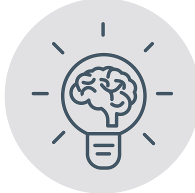
COVID-19

One focused review completed in 2023/24 had COVID-19 as the cause of death. This is a decrease from the two deaths reported in 2022/23.

Thematic Findings

When completing LeDeR reviews we often identify common themes – this can be both in terms of areas for learning and best practice. These key themes will dovetail into our high impact actions for 2023/24.

Best Practice	
Use of Learning Disability Acute Liaison Nurses (ALNs)	An increased use of the learning disability ALNs has been seen across the reviews. This has meant better support for individuals, their families and carers during hospitals stays. **“Good use of Learning Disability ALNs meant reasonable adjustments were made and there was a holistic approach to care and end of life planning”**
High quality Annual Health Checks (AHCs)	There were many incidents where good use of reasonable adjustments had been made for AHCs to be carried out, as well as high quality health action plans that were followed. **“Excellent thorough AHC that had considered reasonable adjustments to meet the individual's needs”** **“The AHC included evidence of STOMP as well as guidance and support to manage high BMI”**
Patient centred care	Lots of reviews demonstrated how when excellent personalised care is given to people, it allows them to live life to the full, enjoying their hobbies, exploring their interests and living rich meaningful lives. **“They received excellent advocacy support which allowed them to live a fulfilling and meaningful life. Also had help to build the care package he needed to stay at home and fulfil his wish of being independent”**
Delivery of end-of-life care	Whilst recognition for individuals in the last year of their life has been raised as a learning point, there have been multiple reviews where exemplary delivery of end-of-life care was given. **“They received excellent end of life care, with their wish to remain at home made possible. Care was respectful and delivered in a person-centred way with empathy”**



Learning	
Recognising signs of deterioration	Multiple reviews highlighted how a delay in recognising the signs of deterioration led to a delay in escalation of treatment. A focus group was held to explore this further with carers and experts by experience. This work will feed into the pneumonia LeDeR Subgroup work.
Capacity and best interest decisions around health screening	In a large percentage of the reviews where eligible health screening was not conducted, this decision was documented as 'made in the individual's best interests', however there was often no conversation documented around this decision. All individuals should be offered the health screening available to them and should have conversations that involve their family/carers to support in the decision making. We will continue to bring these findings into our local LD/A health screening projects, as well as give direct provider feedback.
End of life and advance care planning	There was minimal evidence of recognition for when individuals were in the last year of their life; this meant a lack of advance care planning and end of life discussions. The impact of this means individuals do not have access to the palliative care teams they require, as well as being able to express their wishes around treatment and death. This learning is being shared with the Palliative and End of Life Programme. **“No end of life care planning despite terminal diagnosis for almost two years. No ReSPECT/Advance care planning in place until day before death”**
Reasonable adjustments	Whilst some reviews highlighted excellent use of reasonable adjustments, others showed how an individual's experience of healthcare is severely impacted when reasonable adjustments are not made. These findings will feed into the RADF project and the Learning Disability Friendly Badge programme. **“The GP stated they had no means of getting a weight for the patient due to them being in a wheelchair, so this was never recorded during their AHC”**

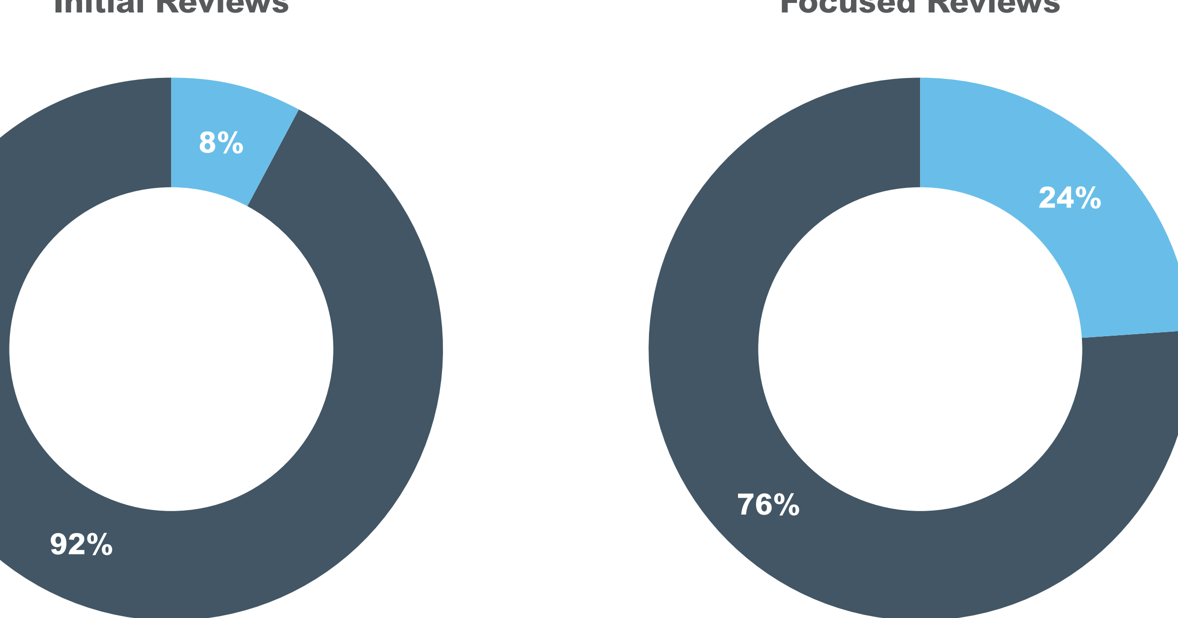
Grading of Care

The LeDeR policy requires local LeDeR programmes to grade the care the person received during a focused review. Locally we also grade the care quality of our initial reviews, to enable us to further monitor and track outcomes.

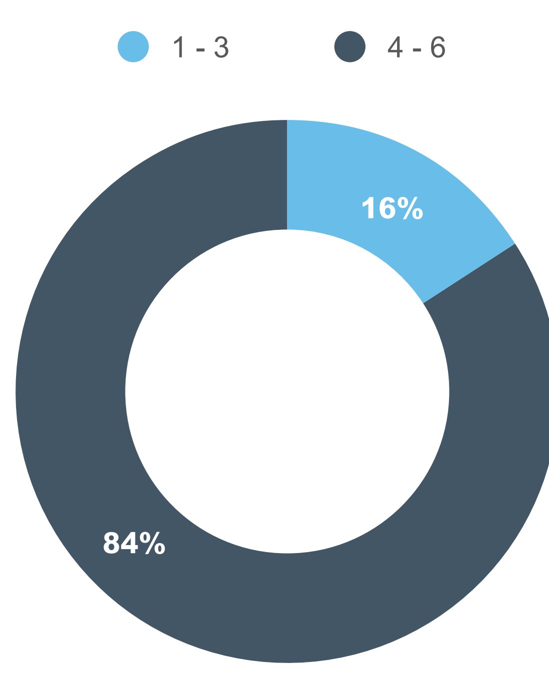
Grading for focused reviews is agreed by our LeDeR Governance Group whereas for the initial reviews this is decided by the reviewer and local area contact.

The pie charts below show what percentage of reviews were graded 4 and above, which indicates care was satisfactory and did not impact on the person's death or wellbeing. **Quality of care was graded a 4 or above in 92% of initial reviews and 76% of focused reviews. Availability and effectiveness of services was graded a 4 or above in 84% of focused reviews.**

Quality of Care



Availability and effectiveness of services



Grading of care for the 24 initial reviews and 25 focused reviews completed is shown below. Care gradings of 1 or 2, given by reviewers, are discussed and finalised at our LGG. Usually where care has fallen short of expected good practice, the provider organisation, local authority, or police have already conducted an investigation. If this is not the case, as part of action planning within our LGG, a review by the local authority or internally within the care provider, as appropriate, would normally be initiated.

One initial review received a care quality grading of 1. The cause of death was due to a medication error and a serious incident (SI) review was conducted by the acute trust. The learning from the SI was shared at LGG and no further learning was extracted. One focused review received a care grading of 1 for both quality and availability and effectiveness of services. The cause of death was attributed to severe constipation. Learning and SMART actions were taken to the care provider and the findings from this review fed into the LeDeR Subgroup constipation work.

One initial review and one focused review were given the highest possible grading of care. The providers involved in these reviews have been approached to give examples of the gold standard care they have delivered so this can be shared across the system.

Quality of the care the person received

Grading	Definition	Initial Reviews	Focused Reviews
6	Excellent care, exceeding expected good practice	1	1
5	Good care, met expected good practice	19	7
4	Satisfactory care, fell short of expected good practice in some areas but did not significantly impact person's well-being	2	11
3	Care fell short of expected good practice and did impact on well-being but did not contribute to the cause of death	1	5
2	Care fell short of expected good practice and did impact on well-being and/or had the potential to contribute to the cause of death	0	0
1	Care fell far short of expected good practice and this contributed to the cause of death	1	1

Availability and effectiveness of services

Grading	Definition	Focused Reviews
6	Availability and effectiveness of services was excellent and exceeded the expected standard	1
5	Availability and effectiveness of services was good and met the expected standard	14
4	Availability and effectiveness of services fell short of the expected standard, but this did not significantly impact on the person's wellbeing	6
3	Availability and effectiveness of services fell short of the expected standard and did impact on well-being but did not contribute to the cause of death	3
2	Availability and effectiveness of services fell short of the expected standard and did impact on well-being and/or had the potential to contribute to the cause of death	0
1	Availability and effectiveness of services fell short of the expected standard, and this contributed to the cause of death	1

Pen Portrait Jean

We thank the family of 'Jean' for consenting to her story being shared.
Names have been changed to maintain anonymity.

What we heard

Jean was a happy lady with an amazing personality, she liked to be made a fuss of and enjoyed the finer things in life.

Jean had attended college in her early years and later worked on a voluntary basis with children and in paid employment with a local grocery store.

Her family reported that there had been issues with historic care which they addressed at the time. Over the last 2 years of her life, with the current care provider, the care and communication had been good.

Her family felt that Jean was presenting with signs and symptoms of dementia. Unfortunately, they were informed by her general practitioner that it was not possible to diagnose dementia for a person who has a learning disability, and no further action was taken.

What we did

Working alongside CWPT and the wider ICS we looked at the services and care pathways for people with a learning disability requiring a dementia assessment.

Working collaboratively, we established a clear pathway for patients to follow and devised a new referral form to allow for the process to be streamlined.

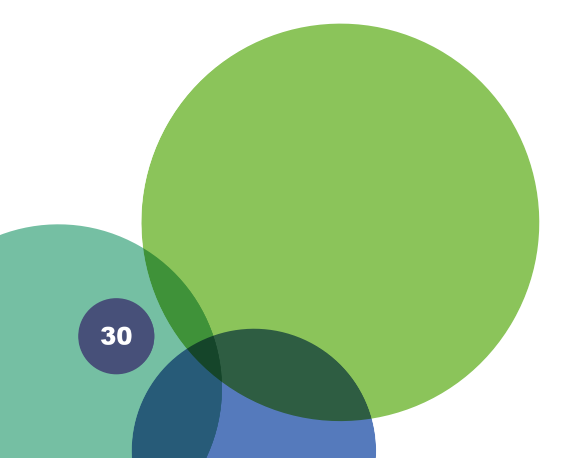
This work was then a spotlight feature in our LeDeR newsletter. This newsletter was published on our website and has been shared throughout the ICS, including primary care and the GP practice that Jean was registered with.

Next steps

We have established links with the learning disability dementia assessment team at CWPT to monitor referral rates and quality of the referrals they receive over the coming months.

It will also be important to monitor the level of learning disability of the individuals being referred to understand if there are challenges, specifically for people with a mild learning disability, to being diagnosed.

We will monitor future LeDeR reviews to assess the impact the newsletter and pathway has had on increasing the diagnosis of people with dementia and a learning disability.



Pen Portrait Fiona

We thank the family of 'Fiona' for consenting to her story being shared.
Names have been changed to maintain anonymity.

What we heard

Fiona grew up with her parents on a farm, she loved riding horses and looking after the family pets. Fiona liked spicy foods, chocolate buttons and cappuccinos. Fiona's other love was music – especially Tom Jones, Elvis and David Essex. She loved getting out and about, enjoying trips out in the car and going on holidays.

When Fiona's parents died, she moved from the family home to live in a residential home. Fiona had a moderate learning disability and latterly had a diagnosis of dementia. As this progressed, she became unable to communicate verbally. This meant that she was no longer able to express herself, requiring staff to anticipate her needs. Fiona did not have the capacity to make complex informed decisions and was no longer able to mobilise independently, requiring 24-hour care for all aspects of daily living.

Fiona had many comorbidities, however management of all aspects of her care was excellent, the attention to detail was exceptional. Her care provider anticipated her needs and constantly put Fiona's best interest and wishes at the forefront of her care. The advocacy that they provided for Fiona ensured that her needs were always addressed, and family were consulted about all decisions, in line with the mental capacity act.

Within primary care Fiona experienced holistic care that encompassed her needs. In secondary care, her needs continued to be met whilst in hospital enabling her to experience a pain free and dignified death.

Fiona's family reported that the aftercare that they received from the residential home following Fiona's death was extremely kind and empathetic and the practical support with the funeral and registering her death was above and beyond their expectations.

What we did

We recognised that her care provider had been the key to the continuity and consistently high standards of care. Their ability and drive to advocate for Fiona contributed to the high standards of care Fiona received across the board.

We met with the manager of the care provider to discuss their model of care and how they manage to attain such high standards across the staffing team.

Next steps

We are in the process of compiling a newsletter focused on good practice. Fiona's care alongside the conversation with the care provider will be featured to share positive practice to inspire initiative-taking change for other providers.

The LeDeR team are also collaborating with the local council's provider forums to share this example of good practice.

Annual Health Checks

- An Annual Health Check (AHC) is offered to everyone on the GP learning disability register aged 14 and above. The NHS Long Term Plan ambition is for 75% of people on learning disability registers to routinely access an AHC by 2024/25.
- Our Coventry & Warwickshire 2023/24 performance saw a total of **3,716 AHCs delivered, resulting in an uptake of 77.2%**, exceeding the 75% target. When including the 437 that declined, that means 86.3% of people on the learning disability register were offered an AHC.
- One of the key national aims is for local systems to increase the size of their learning disability registers. In 2022/23 the Coventry & Warwickshire learning disability register size grew by 50. In comparison, our data shows in 2023/24 the Coventry & Warwickshire learning disability register size has **grown by 402 people**. **In 2023/24 154 more people received an AHC**.
- Health Action Plans should be given to every individual who attends their AHC, as this details any actions that need to take place as a result. The **completion rate of Health Action Plans in 2023/24 was 97.1%**, an increase from 96.4% in 2022/23.

Our Coventry & Warwickshire 2023/24 performance saw a total of 3,716 AHCs delivered, resulting in an uptake of 77.2%, exceeding the 75% target.

- As part of our LeDeR review activity, we collect data as to whether the person received an AHC in the year before they died, as a good AHC is vital. From the reviews undertaken between April 1st 2023 - March 31st 2024, there was evidence of AHCs having been completed within the year preceding the person's death in **76% of reviews**, an increase when compared to 62% recorded in last year's report, and in line with our local delivery.
- Of those who did not receive an AHC, the average care quality grading was 5, meaning despite the lack of AHC, overall, the individual received good quality care that would be expected. This may be because all those who did not have an AHC did still have regular contact with their GP.

- Our AHC focus in 2023/24 was on two key workstreams:
  - To gain a better understanding of the quality of AHCs being delivered in Coventry & Warwickshire
  - To explore barriers to accessing AHCs in the underserved communities
- These two key workstreams formed the basis for our AHC Quality Project of which the published report will be available on our ICB webpages in the summer. This report will now be shared systemwide to ensure other workstreams and health and social care colleagues understand the barriers and enablers in people accessing AHCs, as well as the positive and negative factors that contribute to the quality of an AHC.

Learning Into Action

The Learning Into Action section of this report highlights all the amazing, collaborative systemwide work that has happened in the past 12 months.

Our 2022/23 LeDeR Annual Report highlighted nine key themes that fed into our work focus for the past year. The LeDeR Subgroup collaboratively decided constipation should be the initial key workstream, however all key themes have been prioritised during our local training, promotion and with our links into other workstreams.

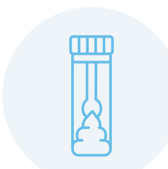
Key Themes 2023/24

Mental Capacity Act

Reasonable Adjustments

DNACPR /Respect

Best Interest Decisions



Cancer Screening

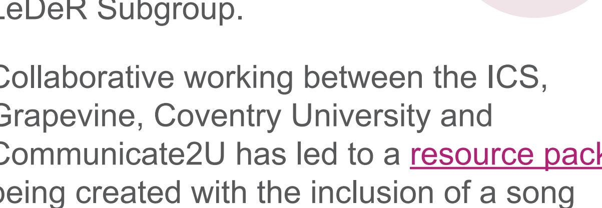
Vaccinations

Aspiration Pneumonia

Constipation

Minority Ethnic and Autism Only Diagnosis Reporting

Constipation



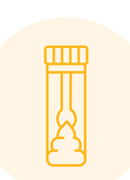
Constipation was the first focus topic of our LeDeR Subgroup.

Collaborative working between the ICS, Grapevine, Coventry University and Communicate2U has led to a resource pack being created with the inclusion of a song written and performed by a group of experts by experience.

This pack was launched in December, in line with constipation awareness month. It has been positively received and has been shared with all providers of health and social care across the local footprint.

This year we aim to conduct a survey to understand the impact the resource pack has had and whether this approach would be useful for other key topics in the future.

Cancer Screening



The LeDeR team strives to be linked into systemwide projects to ensure the voice and needs of the local LD/A population is understood.

UHCW are leading on a NHSE project, Cancer Experience of Care Improvement Collaborative 2023/24, which will focus on Information and Communication to improve cancer care for people with a learning disability. The LeDeR team are linked in with this work to ensure the voice and needs of the local LD/A population are heard.

Coventry and Warwickshire LeDeR team and National LeDeR team recently presented at Coventry and Warwickshire's cancer board to share learning from LeDeR reviews.

Our LeDeR team has connected with the new Cancer Screening Liaison Nurse for severe mental health (SMI), learning disability and autism within CWPT and aim to work collaboratively on future projects.

The LeDeR team are due to present at the primary care cancer network meeting in June 2024 to share key data around cancer and inequalities for the LD/A population.

Pneumonia

For the first this year time deaths from pneumonia were classed as a local priority within Coventry and Warwickshire and triggered a focused review.
This has meant more detailed information has been gathered from these reviews.

In February 2024, the LeDeR subgroup collectively decided that pneumonia should be the next focus of our work. This led to:

- A deep dive into the data we had available to us,
- A review of the guidelines from the British Thoracic Society and key learning extracted,
- A focus group with Grapevine and experts by experience with an emphasis on carers' views,
- Attendance from the LeDeR team at the Care Home provider forum.

Drawing upon the findings from the above, residential care home providers have been identified as an area of focus for the work. A survey for care home staff has now been produced and shared. Results will be compiled to map and gap knowledge and skills within this setting. The LeDeR Subgroup will then evaluate these results to allow the direction of this work to be decided.

Mental Capacity Act

We recognise this is a much broader theme that needs to be worked on across health and social care for the whole population. The LeDeR team continues to link in with wider system work.

MCA learning is shared by individual organisations via reporting at LeDeR Governance Group.

We conducted systemwide mapping across all providers for local MCA work, this learning and good practice was shared at LeDeR Subgroup.

Learning and best practice from reviews where MCA was conducted well is shared across the system at Governance Group.

All acute trusts within the ICS are conducting audits on their use of MCA and plan to report findings into LGG.

Our locally co-produced MCA document continues to be shared systemwide.

Vaccinations

Detailed data has been collected regarding the uptake of vaccinations from completed reviews. This has helped to inform the current LeDeR Subgroup pneumonia work.

Collaboration with a care provider and GP in an area of specific high vaccination uptake is underway. Understanding of their systems to ensure good concordance has been gained and work with these areas will continue as the LeDeR Subgroup work develops.

We have explored local available data on flu, COVID and pneumococcal vaccinations and reviewing this with a lens on wider determinants of health which has fed into wider LD/A intersectionality workstreams.

Reasonable Adjustments

The LeDeR team are working collaboratively in the planning of the acute hospital admission and discharge guidelines for patients with a learning disability to ensure reasonable adjustments are understood and considered.

The RADF continues to progress in Coventry & Warwickshire with provider leads identified from both digital and clinical perspectives. We have met with key members of CWPT to discuss the expectations of phase one (local flagging) and phase 2 (national flagging).

Best practice of reasonable adjustments from reviews and provider reports are continually shared across providers at LGG.

Equity in Reporting

An intersectionality working group, including LeDeR programme team members, is exploring all our local available data to get a better understanding of the learning disability population we serve, not just regarding ethnicity, but other protected characteristics. The key findings are being fed into all wider system work.

Collaboration with Coventry University has enabled identification of ethnic minority representation for our LeDeR Governance Group.

The LeDeR team presented at Coventry & Warwickshire cultural inclusion network and continues to explore ways to strengthen the voice of the ethnic minority population in our reviews.

The LeDeR team attended the Coventry Provider forum to raise awareness and in particular attention to the reporting of deaths of autistic people and those from an ethnic minority.

Training has now been delivered to the entire programme team on the intersectionality of race, being from a minority ethnic community, and having a learning disability and/or being an autistic person.

Training given by the LeDeR team was recorded by VoiceAbility to cascade to their new staff. This was presented to the Autism strategy working groups across the ICS along with raising the profile of the importance of increasing autism only death reporting.

We are working closely with our Medical Examiner Officers (MEOs) across the system to ensure this process is seen as an opportunity to increase receiving LeDeR referrals, specifically for autism only reviews.

DNACPR & Best Interest Decisions

Any reviews where best interests or DNACPR decisions have been raised as an action have been fed back specifically to providers.

The system continues to progress with the DNACPR project which the LeDeR team are linked in with to ensure the LD/A voice is heard.

DNACPR and ReSPECT documents were the spotlight feature of the Q4 LeDeR newsletter; this focused on completion and best practice when considering their use in relation to people with a learning disability and autistic people

As a team we will continue to seek examples of best practice and create SMART actions where practice has fallen below expected standards for the use of DNACPR and Best Interests application, to raise awareness and enhance practice.

All acute trust within the ICS are conducting audits on their use and completion of DNACPR /ReSPECT forms. Findings from this alongside any local work is presented via their reporting into LGG.

Training & Resources

Some of the work in the past year from the LeDeR team includes:

- Presented quarterly at systemwide mortality groups to share key learning and best practice.
- Provided training to each Palliative and End of Life Care (PEoLC) group and plans to present to the PEoLC Partnership Board annually to present updates on the programme and key themes.
- Provided a recorded training session with VoiceAbility to be rolled out when training new staff. This was also presented at the Autism Board.
- Provided training to GPs systemwide during protected learning time and created a one-page document of the role of a GP in LeDeR, which is available on the GP training platform.
- Created a document that streamlines the pathway for referring individuals with a learning disability for a dementia assessment.

Learning Disability Friendly Badge

September 2023 saw the launch of the Coventry and Warwickshire Learning Disability Friendly Badge accreditation scheme for GP practices.

The launch followed over two years of collaborative working in a project to set the scheme up, including GPs, members of the ICB and a local learning disability charity named Grapevine, including their Experts by Experience.

Practices can apply for this accreditation using an application form, which sets out four expected standards and criteria points within each standard, which the practice must evidence that they meet. More information on the badge and the application process can be found here.

A panel meets quarterly to assess the applications submitted by practices. The panel consists of members from primary care,

the ICB and Grapevine, including experts by experience.

The April panel awarded seven practices with the badge, with the next panel scheduled for July 2024. Case studies and best practice

examples will be gathered from the successful practices across the next year.

Quality & Governance

We have strengthened the quality of reviews and governance process by:

- Minority ethnic representation recruited
- Worked alongside the Chief Allied Health Professional to establish ways in which we can bring in AHP's to our LGG
- Recruited a clinical lead LD/A GP to sit on LGG and LeDeR Subgroup
- Partook in a peer review evaluation with three local ICBs and the national team to drive forward the national aims of improving review quality.
- Continued cross system working into other key programmes such as Palliative and End of Life Care and Enhanced Health in Care Homes

Priorities 2024/25

The national LeDeR team have set out several high-level impact actions for all local LeDeR teams to address in 2024/25 which will dovetail into our local priorities.

These are:

1. **Reduce avoidable mortality in the 3 clinical priority areas for Learning Disability and Autism**
2. **Focus on co-morbidities associated with premature death and Advanced Care Planning including DNACPR/ReSPECT**
3. **Assure and Sustain Performance**

   LeDeR review completion within 6-month KPI
4. **Improve the quality of LeDeR reviews and actions from learning**

   Facilitate peer review opportunities
5. **Improve access and understanding of importance of LeDeR review**

   Communicating with stakeholders to encourage referrals to LeDeR with the aim of better understanding the experience of LeDeR for families and relevant others, particularly minority ethnic groups and autistic people
6. **Improve accuracy of Learning Disability Registers**

   To support continued improvements in data accuracy for thematic analysis

Our 2024/25 Coventry & Warwickshire priorities, key actions and measurables:

National Aim	Coventry & Warwickshire Key Actions	Measurables
Reduce avoidable mortality in the 3 clinical priority areas for Learning Disability and Autism	• To explore trends and data for deaths where respiratory, cardiovascular & cancer are the main cause • To continue to support other work programmes to allow for the LD/A voice and their needs to be heard • LeDeR Subgroup to explore and action what work is needed in these areas	• Deaths recorded • Avoidable deaths
Focus on co-morbidities associated with premature death and DNACPR/ ReSPECT	• To explore local available data on the prevalence of co-morbidities for people with a learning disability and autistic people in Coventry & Warwickshire e.g. epilepsy, obesity, mental health • To collect data on co-morbidities within our LeDeR reviews to notice any local trends and themes • Continue to link in with systemwide Advance Care Planning including DNACPR/ReSPECT work programmes	• Review data • Local DNACPR/ ReSPECT audits
Assure and Sustain Performance	• All reviews to be completed within 6 months • At least 35% of completed reviews to be focused	• Reviews completed • Focused reviews completed
Improve the quality of LeDeR reviews and actions from learning	• Partake in peer review opportunities • Feedback learning from peer review into LeDeR programme team • Strengthen the quality of reviews by including allied health professionals and primary care in the review process and governance group	• Quality of reviews
Improve access and understanding of importance of LeDeR review	• Continue to promote LeDeR across all underserved communities • Continue to link in with other work programmes to help promote LeDeR	• Ethnicity reporting • Autism reporting
Improve accuracy of Learning Disability Registers	• Use gold standard GP practice to create tool kit for improving learning disability registers including list cleansing • Use those accredited with the Learning Disability Friendly Badge to pilot tool kit • Continue to explore local population data	• Number on learning disability register measured per practice

We will report on our progress on each of the above actions within our quarterly LeDeR reports.

Conclusion and next steps

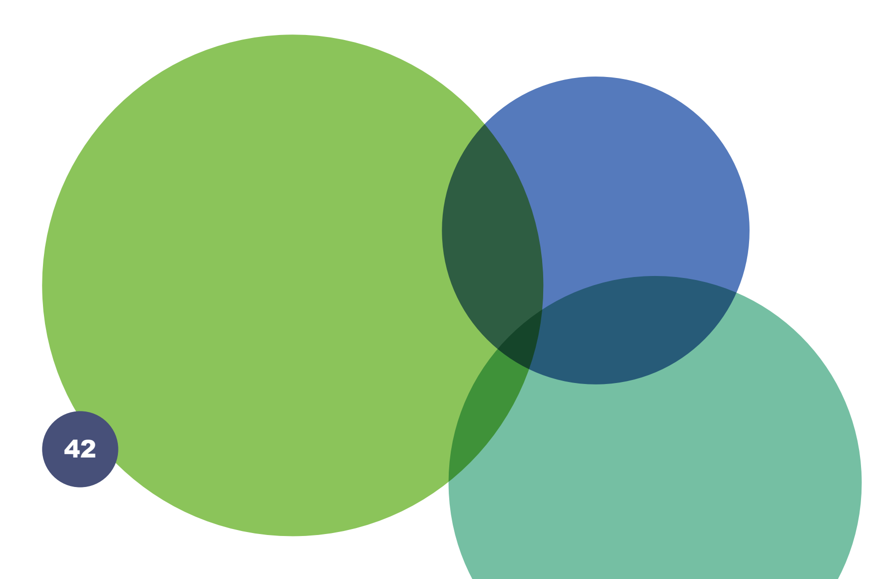
This report presents the findings from reviews following the deaths of people with a learning disability and/or autistic people across the Coventry and Warwickshire area, notified to the LeDeR programme and completed between 1st April 2023 and 31st March 2024.

We are proud to be achieving the national targets, being consistently ranked as one of the top performing ICBs nationally and believe this is down to the positive impact of a dedicated, sustainable workforce.

The new LeDeR Subgroup has allowed for a much-needed dedicated space to work on the key themes derived from the annual reports and has led to successful systemwide collaborative pieces of work.

Our continued collaborative working with Experts by Experience enables meaningful change, which impacts the people in receipt of health and care services. Their involvement and the coproduction of turning learning points to actions means that the voice of the learning disability and autistic population is at the heart of all we do.

Coventry and Warwickshire maintain a commitment to extracting learning from reviews, implementing actions and driving change. The purpose of this report is to promote and encourage active involvement and collaboration within the local system. It is essential to sustain efforts towards improving services for individuals with a learning disability and autistic people, with the ultimate goals of enhancing care, minimising inequalities, and preserving lives.



Acknowledgements

Coventry and Warwickshire Integrated Care Board would like to thank all who have contributed to the LeDeR programme since 2017.

We would like to thank all the professionals and organisations across the system who have contributed to the delivery of the LeDeR programme, as well as their continued dedication to drive learning into action to improve the lives of people with a learning disability and autistic people.

We are particularly grateful to Grapevine and the Experts by Experience for offering their insight and enthusiasm, as we work collaboratively to improve services, whilst ensuring we keep the voice of the people with a learning disability and autistic people at the heart of what we do.

A special thanks to the reviewers, whose continued dedication and passion results in meaningful, personalised and compassionate reviews that keep individuals at the heart of the process.

Most importantly we would like to acknowledge the people for whom this report is created; people with a learning disability, autistic people, and those who mean most to them. Their lives and stories continue to pave the way for a better future for the learning disability and autistic population and we will forever be indebted to these extraordinary people.

Glossary

AHC	Annual Health Check
CDOP	Child Death Overview Panel
CWPT	Coventry & Warwickshire Partnership Trust
DSCRO	Data Services for Commissioners Regional Office
DNA	Did Not Attend
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
EBE	Expert by Experience
GEH	George Eliot Hospital
ICB	Integrated Care Board
ICS	Integrated Care System
LD	Learning Disability
LD/A	Learning Disability and Autistic People
LGG	LeDeR Governance Group
MCA	Mental Capacity Act
PEoLC	Palliative and End of Life Care
RADF	Reasonable Adjustment Digital Flag project
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
SMART Actions	Creating actions that are Specific, Measurable, Achievable, Realistic, Timed
SOP	Standard Operating Procedure
SUDEP	Sudden Unexpected Death in Epilepsy
SWUFT	South Warwickshire University Foundation Trust
UHCW	University Hospitals Coventry & Warwickshire

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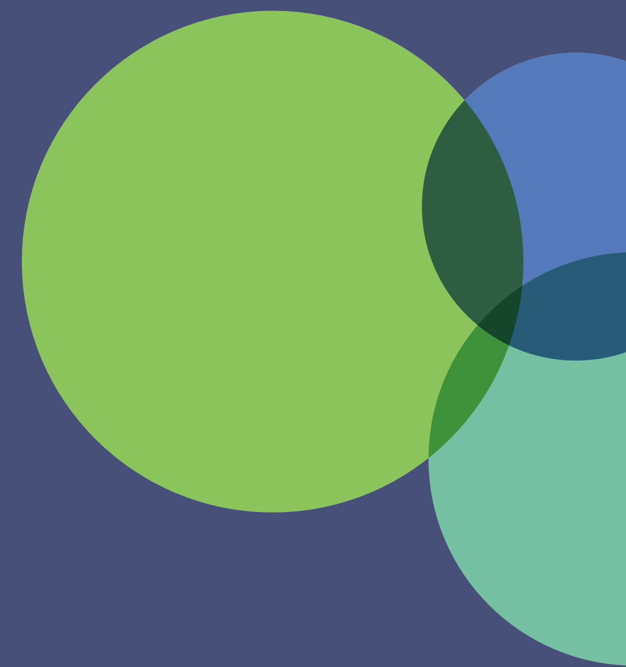

Learning from the Lives and Deaths of People with a Learning Disability and Autistic People (LeDeR)

Annual Report 2023/24