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

Coventry & Warwickshire

Annual Report 2021-2022

1. Introduction

1.1 LeDeR is a national programme overseen by NHSE. Responsibility to deliver a LeDeR programme is devolved to local Clinical Commissioning Groups. In Coventry and Warwickshire, the programme is delivered in partnership with colleagues from across our local health and care system. In Spring 2021 a new national LeDeR policy was launched outlining a revised approach to the programme – these developments will be summarised later in this report, however, one of the key changes is that from 1st January 2022 the LeDeR programme has been extended to also include the review of Autistic adults who have died from this date onwards.

1.2 The primary aims of the Learning from Lives and Deaths of People with a Learning Disability and Autistic People (LeDeR) programme is to review the care and support that each person received preceding their death, make recommendations and instigate actions that could help improve care for other people and in turn, reduce health inequity and premature deaths. Recommendations from each review are intended to highlight best practice and thereby support health and social care professionals to implement positive change for people with learning disabilities and/or autism (LD/A) to have better access to, and experience, of care.

1.3 This is the fourth Coventry and Warwickshire LeDeR annual report, which presents data and review findings about the deaths of people notified to the programme from 1st April 2021 to 31st March 2022 and reviews that have concluded during this period that may have been notified but not concluded during the previous year.

1.4 National research suggests that 2 – 2.5% of the population in the UK are believed to have a learning disability (Mencap, 2019). We know that the population of people with a learning disability is growing and that people are living longer with more complex health and support needs. Population estimates suggest that in 2020, 14,400 adults with a learning disability were residing in Coventry and Warwickshire (PANSI, 2021).

1.5 Population estimates suggest that in Coventry and Warwickshire, in 2020, 5,950 Autistic adults were resident in the area (PANSI, 2021). A study on the lifespan of Autistic people concluded that people with autism, but no learning disability, have a lower average lifespan that the general population, on average dying 12 years sooner than the average age of mortality.

1.6 The issues and causes of death identified within this report reflect the challenges that people with learning disabilities continue to face and gives an indication of how we must do more to support them to live well within their local communities. The report also reflects on

progress that has been made in relation to actions identified in previous LeDeR reports as well as the local transition to the new LeDeR policy requirements.

2. The New LeDeR Policy and Approach

2.1 The New LeDeR Policy

Following a national review of the LeDeR programme, a revised approach and policy was launched by NHS England in Spring 2021. The policy set out the core aims and expectations of the health and social care system in delivering LeDeR programmes from June 2021 onwards. Some key requirements and developments include:

- A new process for reviewers to follow, including the launch of a new web-based platform;
- New training for the LeDeR workforce;
- A requirement to conduct initial reviews before making a decision whether to complete a more detailed focused review;
- An increased focus on the person's life before their death, not just the circumstances of their death;
- For the first time, deaths of adults who have a diagnosis of autism, but no learning disability are to be included in the programme – this change took place from January 2022;
- All reviews of people who are autistic without a learning disability will be focused reviews initially, to develop data and learning;
- All reviews of people who identified as belonging to an ethnic minority group will be focused, as evidence suggests these communities experience significant health inequalities which we need to further understand;
- A requirement to employ substantive Reviewers, including a Senior Reviewer, working as a dedicated Reviewer resource, rather than volunteers from local systems completing reviews.

2.2 The LeDeR Review Process

The LeDeR process is summarised below:

- When a person with a learning disability or an autistic person dies, the death should be reported to the national LeDeR programme. Anyone can make a notification;
- The national LeDeR team check the identity of the person who has died and ensure that they had not opted out of sharing their data before a review request is created and issued to the CCG;
- A local reviewer is allocated the review and will attempt to contact the following people to seek information to contribute towards the review:
    - Health care professional involved in the person's care
    - Their GP practice
    - A family member
    - Their care provider if care was commissioned for the person.

- Once we have the details of a person's death, the review process begins and we aim to complete this within six months. This is not always possible, for example whilst other processes such as coroner's inquest or investigations are ongoing. We also know that some family members may not be ready to talk to us straight away following the death of their loved one;
- A reviewer completes an initial review based on the information they have sourced and conversations with the people listed above. The reviewer uses their judgement to decide if a focused review needs to be completed – a focused review usually happens if:
    - The reviewer identifies areas of concerns or things they feel further learning could be gleaned from
    - A family member requests a focused review.
- A focused review looks in more detail at the person's life and involves a wider number of people;
- Focused reviews are presented to the local LeDeR Governance Group where areas of learning, good practice and concern are discussed. The group agree actions linked to the learning identified.

Learning in the form of areas for improvement, as well as identification of positive practice is recorded on the LeDeR Action Log. Where learning is very specific to an organisation, such as a hospital ward or social care team, this is fed back direct. LeDeR also identifies thematic and systemic learning which inform initiatives delivered within our wider portfolio of activity related to reducing health inequalities experienced by people with LD/A.

2.3 Involvement of Family Members

We recognise that families often know the most about the care that the person who died received and their input is valuable in identifying learning. Family members are informed when a review is being undertaken and are invited to contribute to the review. We respect that this is often a highly emotional time for families and reviewers are sensitive in their communication with family members.

2.4 Key Developments for the local LeDeR programme

The new policy required all systems to transition towards a new approach to LeDeR by April 2022. Within Coventry and Warwickshire, we have completed a range of actions to meet these requirements. The following key milestones have been achieved and position us well for the future of the local programme:

- Recruitment of a Senior LeDeR Reviewer and LeDeR Reviewer posts concluded – successful candidates joined the CCG based team in February 2022;
- Local charity, Grapevine, supporting experts by experience, has worked collaboratively with us to recruit local people with lived experience to join the LeDeR programme – during quarter 1 of 2022/23 a LeDeR Discussion Group will be established to explore learning from our reviews and to seek members' input into identifying action related to our thematic learning. We plan that a member of this

group will join our LeDeR Governance Group in due course to provide direct input into this stage of our local governance process;

- Our LeDeR Governance Group (LGG) is well established and meets monthly, with good attendance and representation from across the local system. The group are leading on systemic actions in response to learning, as well as monitoring organisation specific actions;
- We have sourced additional training for our LeDeR Reviewers to support them in completing the reviews of autistic people, as this is a new area of focus for the programme;
- Our first LeDeR newsletter was published in March 2022, sharing learning, topical information and resources. This newsletter will be produced quarterly.

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3. Data Analysis – Notifications Received 2021/22

The following section focuses upon analysis of notifications received by the LeDeR programme. Due to the changes outlined in section 2 of this report, reviewing activity was paused nationally during quarter 1 of the financial year and activity was slowly reinstated during quarter 2 as training and access to the new LeDeR electronic platform became available to the local team. Deaths of people with LD could still be reported to LeDeR whilst the platform was offline, so the system downtime did not impact upon the flow of information to the national LeDeR team, however, technical challenges associated with the new online system have meant that the flow of reviews from the national system to our local platform has been significantly compromised at times – we anticipate that some reviews submitted during quarter 4 of 2021/22 will be received onto the local platform during early 2022/23.

3.1 LeDeR Notifications 1st April 2021 – 31st April 2022

Since transferring to the new LeDeR platform in June 2021, Coventry and Warwickshire have received a total of 81 LeDeR notifications.

Table 1 – Summary of LeDeR Notifications 1st April 2021 to 31st March 2022

LeDeR Platform Notifications	Count
Total number of LeDeR Notifications Received (Total YTD) including those carried forward from old platform	81
LeDeR Reviews open at 31/3/2021, carried forward for completion during 2021/22 (of the 81)	19

Nineteen notifications open on the “old” platform as at 31st March 2021 were carried forward for completion during the 2021/22 financial year. Therefore, during 2021/22 we have received a total of 62 new LeDeR notifications. The cohort breakdown of the new LeDeR notifications is as follows:

Table 2 – New notification cohort data (2021/22)

LeDeR Platform Notifications	Count
New LeDeR Notifications Received (Adults) LD or dual diagnosis of LD/A	51
New LeDeR Notifications Received (Adults) Autism diagnosis only (from Jan 2022)	1
New LeDeR Notifications Received (Children with LD or LD/A diagnosis age 4 – 17)	3
New LeDeR Notifications Confirmed as Out of Scope	7

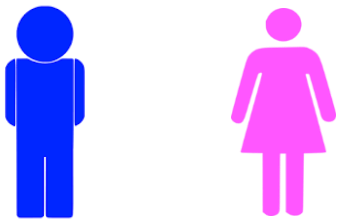
Of the new notifications, 7 were identified as being out of scope for LeDeR review and closed accordingly – those out of scope were either individuals who were identified as having a learning difficulty rather than a learning disability, or autistic people who died prior to the national LeDeR programme accepting reviews of autistic people without a learning disability. We also received one notification relating to a patient who lived in the Birmingham area, which was transferred across to the appropriate CCG. Therefore, a total of 55 new LeDeR reviews have been progressed during 2021/22 in addition to the 19 carried forward. Reviews have been allocated in chronological order.

The total number of new notifications received represents a slight decrease when compared to the 69 reported in the previous year. However, in contrast, we have also seen an increase in the number of notifications submitted per individual, suggesting an increased awareness of the LeDeR programme across organisations. As at 31st March 2022, we had received our first notification relating to a person with an autism only diagnosis.

The following analysis excludes any demographic data about the 19 notifications carried forward from 2020/21 (as these individuals were reflected in the previous annual report) and the seven notifications that were confirmed as out of scope for LeDeR review:

3.2 Gender

Of the 55 new notifications to LeDeR, 51% related to males and 49% to females – this is in line with previous years' data.

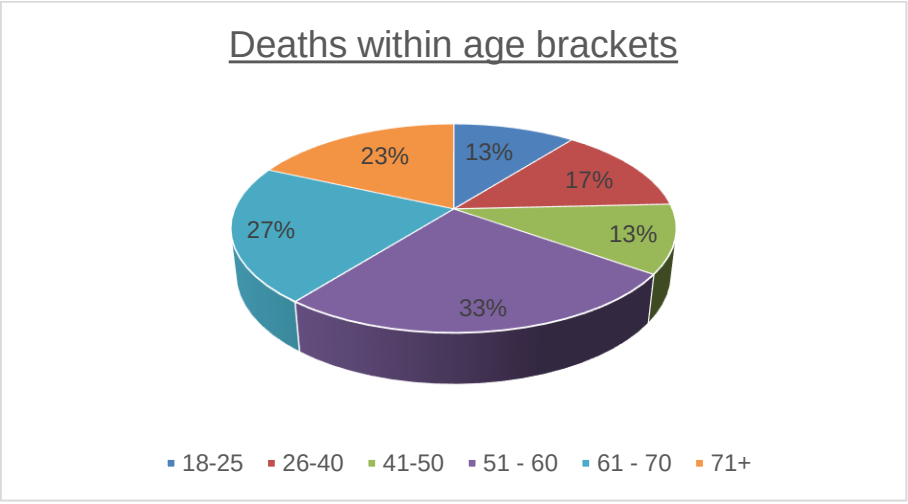


28 Male	27 Female
51%	49%

3.3 Age at death

The difference in life expectancy and age of death amongst people with learning disabilities and those without is significant. Across the UK, life expectancy in 2018 to 2020 was estimated to be 79.3 years for males and 83.1 years for females in England. The age range at death for the 52 adults notified to the LeDeR programme during 2021/22 was 18 to 93. Chart 1 provides an overview of this data within age brackets. Of the people for whom notifications were received, the median age of death was 60 years for men which is in line with the most recent national LeDeR data. The median age of death for women was 53 – this is much lower than in previous years, although it should be noted that the deaths of three young women aged 18-19 years has significantly impacted upon this figure.

Chart 1 – LeDeR Reviews completed by age brackets



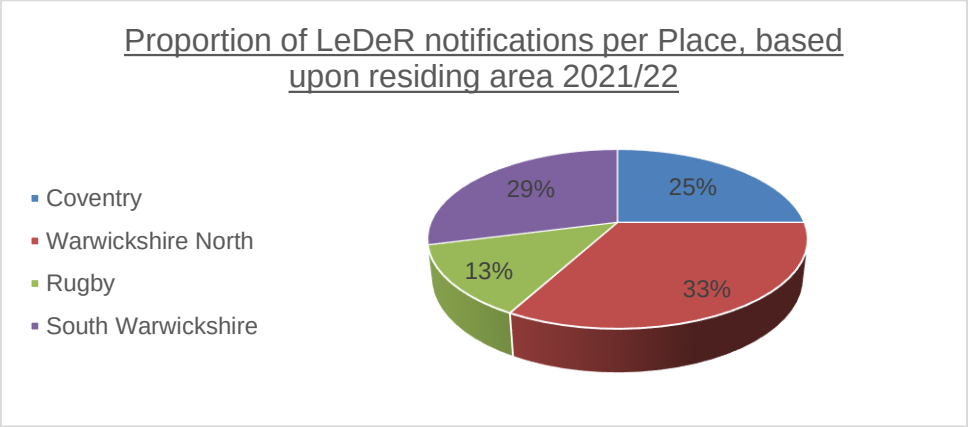
A third of the deaths notified (33%) were of individuals aged between 51 and 60, with 27% of deaths relating to people in the 61 - 70 years bracket. For comparison, last year the highest proportion of deaths occurred within the 61 - 70 year age group (31%). Notifications of

people aged 71+ accounted for 18% of this year's notifications, this is higher than the proportion of 13% reported in the previous year.

3.4 Area of residence

During 2021/22 there was an increase in notifications for residents living in the Warwickshire North and South Warwickshire areas and a decrease in the number reported for Coventry. This geographical variation should be monitored during 2022/23 to consider further trends as the sample size grows. We will also further promote LeDeR in the Coventry area to ensure that notifications are being made for all those who meet the criteria for the programme.

Chart 2 – LeDeR Notifications by Place (2021/22)

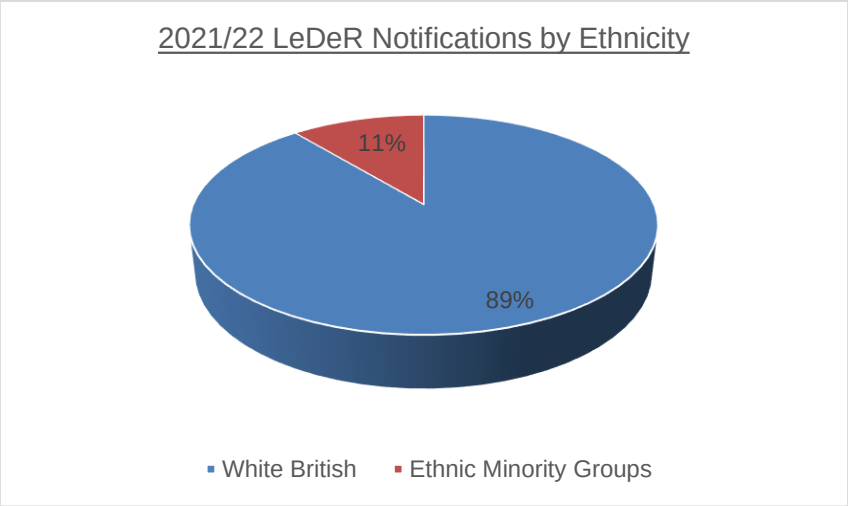


3.5 Ethnicity

As in previous years most people notified to the LeDeR programme during 2021/22 were reported to be of White British ethnicity (89%). This represents an increase in notifications relating to people from ethnic minority groups which has been noted as a challenge for LeDeR programmes nationally in previous years. This year across Coventry and Warwickshire, 11% (6 notifications) were for people from ethnic minorities, compared to 6% in 2020/21. Local population data suggests that across Coventry and Warwickshire, 22% of residents identify with a non-White British ethnic group.

Caution should be applied when making interpretations of the impact of ethnicity due to the small numbers reported for Coventry and Warwickshire. As a system we need to do more to ensure that we are receiving notifications from those with an ethnicity profile that matches our general population and understand more about the potential impact of ethnicity on the health equity and life chances of people with a learning disability.

Chart 3 – Ethnicity data for 2021/22 New LeDeR Notifications



4.0 Child Death Reviews (CDOP) Completed during 2021/22

Children with a learning disability, age 4+ are within scope for the LeDeR programme, however, reviews are progressed via the local Child Death Overview Panel (CDOP) process and findings are then shared with the LeDeR programme. Details of the LeDeR related CDOP cases have not been outlined in this report due to the very low numbers, however, it can be confirmed that the concluded reviews did not identify any modifiable factors specific to the learning disability related needs of the children concerned. A key action that has emerged from these reviews is identification of the need for increased hospice provision for children age 6+ and the LeDeR team have supported the CDOP recommendation for this commissioning gap to be addressed.

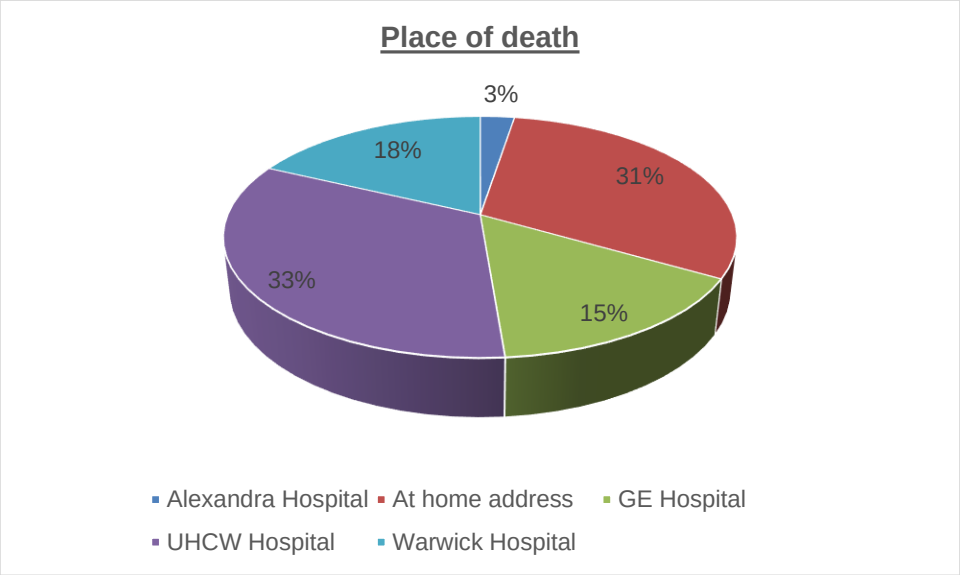
5.0 Adult LeDeR Reviews Completed during 2021/22

The following commentary and analysis is based upon the findings of the 39 adult LeDeR reviews completed during 2021/22. All of these reviews related to people with a Learning Disability or a dual diagnosis of Learning Disability and Autism – no reviews of Autistic people were concluded during 2021/22.

5.1 Place of death

Of the 39 deaths reviewed this year, 69% of people died in an acute hospital in the local area, compared to 60% of deaths reported in the most recent national LeDeR report. Amongst the general population it is estimated that 48% of the general population die in hospital. The high proportion of deaths occurring in hospital may highlight late presentation of illness and the complexities in arranging timely discharges to suitable placements after hospital stays. The remaining 31% of people died in their usual place of residence (including commissioned care settings). Chart 4 providers an overview of the place of death locations.

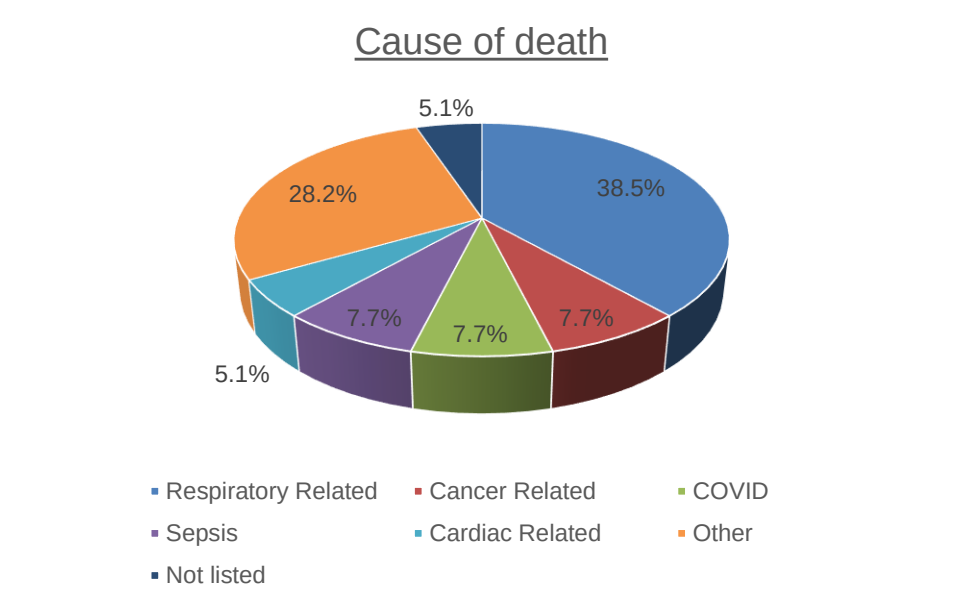
Chart 4 – Place of death as noted in completed LeDeR reviews (2021/22)



5.3 Cause of death

The cause of death is reported using, where available, a completed Medical Certificate of Cause of Death (MCCD), focusing on the Part 1a information. A summary of the causes of death descriptions are provided in Chart 5.

Chart 5 – Cause of death noted in completed LeDeR reviews 2021/22.



The most frequent causes of deaths within Coventry and Warwickshire as identified within the completed reviews were respiratory related. Aspiration and bacterial pneumonia

combined with COVID-19 represent over 45% of deaths this year - reviews noted these medical conditions were most frequently cited in Part I of the MCCD.

Locally, pneumonia (acquired and aspiration) was noted as the most frequent cause of death (38.5%) of the deaths reviewed this year, a further increase from 30% cited in the previous year. We continue to see a reduced number of cancer related deaths with this being the cause of death in 3 (7.7%) of the completed reviews this year – a significant reduction from 2019/20 when cancer was the cause of 21% of deaths reviewed. Sepsis is listed as the cause of death in three instances (7.7%), however, it should be noted that increased reference to Sepsis is being noticed within reviews and as a contributory cause. Where "other" has been cited, deaths were from causes including Alzheimer's, renal failure, bowel ischemia, necrotising fasciitis, intestinal failure, pulmonary embolism and epilepsy related.

5.4 Covid-19

The number of people with COVID-19 stated as their cause of death was 3 (7.7%), much lower than in 2020/21's report, within which it accounted for over 20% of deaths. It should be noted that the 3 deaths reviewed this year where COVID-19 was the cause were reported during 2020/21 and carried forward for completion during 2021/22.

5.5 LeDeR Adult reviews concluded during 2021/22 – 6 month timescales

Despite a number of technical issues related to the new national LeDeR platform and the workforce issues associated with the pandemic response and vaccination mandate, we have been able to complete the same volume of reviews as in 2020/21. A total of 39 adult reviews were concluded during 2021/22, 35 of which were initial reviews and 4 of which progressed to more detailed focused reviews.

NHS England expect that reviews should be completed within six months of notification, unless statutory processes prevent that being possible. Completion of reviews was suspended during March – June 2021 as a new platform was developed nationally during this time. Any reviews carried forward, or deaths notified during the period were not received by the CCG until at least 4 months had passed. There were multiple issues and delays with the roll out of the new platform and the useability of the system, with many reviews not appearing during the initial launch and delays in training availability for reviewers. We have continued to aim to complete reviews as promptly as possible. Of the 35 initial reviews completed during the year, 23 were completed by the end of the 6 month period following their original notification date. It should be noted that of those that exceeded this, they were either carried forward reviews from 2020/21 which lost time when the platform was decommissioned, or cases that had required time "on hold" due to ongoing wider investigations. This experience is not unique to the Coventry and Warwickshire LeDeR programme.

During 2021/22 we completed four focused reviews – these are more detailed and time intensive reviews which are presented to our LeDeR Governance Panel for consideration and agreement of SMART actions. The complexity of these reviews, delays with the national system as outlined above and other ongoing investigations linked to the cases meant they

took longer than 6 months to complete. This is a new process and we have fed back our learning about this new process to NHSE.

We have overcome many of the issues related to the system transfer and backlog that this created, as well as the resourcing pressures experienced during the Omicron and vaccination mandate response this year. With our substantive reviewers in post, we are in a strong position for ensuring that notifications which are not delayed by other statutory processes will conclude within 6 months as we progress in 2022/23.

6.0 Thematic Findings

When completing a LeDeR review, reviewers consider the care and support that a person received during their life and in the time prior to their death. As such, reviewers identify areas of common themes across reviews – this can be both in terms of areas for improvement and best practice. Learning from the reviews concluded during this year most frequently highlighted themes related to:

- Application of the Mental Capacity Act and the need for clear documentation on this in health records;
- Use of reasonable adjustments;
- Transition from paediatric to adult care;
- Continued need to promote access to high quality Annual Health Checks (AHC);
- Access to Cancer Screening;
- Supporting people who make unwise lifestyle decisions and those who may self-neglect.

6.1 Mental Capacity Act (MCA)

As in previous years, reviewers highlighted the need for better understanding and application of the MCA, identifying variable application of the Act and associated processes/documentation. There were some examples of cases where the MCA had been used appropriately to underpin delivery of care. However, there were a number of examples of cases where the use of the MCA and best interest decision making was not evident. This was most commonly a theme linked to care received in an acute setting. Reviewers have proactively identified specific hospital wards where this has been an issue, feeding back directly to local safeguarding leads to instigate action to address this.

It is also recognised that people with LD and their supporters are often not aware of their rights and how the Act should support decisions made about their care and support. We endeavour to work with experts by experience to address this gap and help to educate formal and informal carers, as well as people with LD about MCA and their rights in the coming year.

6.2 Use of Reasonable Adjustments

The reviews concluded this year frequently highlighted good examples of use of reasonable adjustments that had undoubtedly facilitated improved access to, and experience of, care. Where Hospital Passports were provided to Acute staff, there was evidence that content was considered and informed the care provided. Acute Liaison Nurses were frequently cited to have made a significant contribution to supporting patients, carers and those providing medical care to patients. However, in some reviews there was limited evidence of reasonable adjustments having been applied, accompanied by some examples which suggested a limited awareness of the needs of people with learning disabilities.

There were a small number of cases whereby the recognition that someone has a learning disability was delayed, which reduced the efficiency of the input of specialist provision – such as the support of Acute Liaison nurses in hospital. Where patients are known to Acute settings already, their learning disability is usually noted on their record – this helps to ensure that they receive appropriately adjusted care promptly. At least two care providers (non-LD specialist) who had been supporting people with learning disabilities prior to their death felt their staff required further training to be able to maximise understanding of the needs of people with LD and their rights – this was addressed during the review process. All of the individuals reviewed during the year were identified on their GP practice's LD register.

6.3 Transfer from paediatric to adult care

Some of the reviews of young adults have identified that there is scope for improvement in the transition between paediatric and adult services, particularly in relation to improving communication between professionals and families to ensure that handover is planned and navigated appropriately. These findings have been shared with the specific services concerned to inform their local review of transition processes.

6.4 Access to Annual Health Checks

As part of our review activity we also collect data as to whether the person received an annual health check (AHC) in the year before they died – this has been a priority area locally due to very low uptake/delivery of these checks in 2019/20 and we strive to achieve the NHS Long Term Plan ambition that by 2023/24, 75% of people on LD registers will routinely access their AHC. From the reviews undertaken in 1 April 2021 to 31 March 2022, there was evidence of AHCs having been offered/completed within the year preceding the person's death in 72% of reviews – this is in line with the local delivery level of AHCs reported during 2020/21 (73%). It should be noted that evidence to confirm whether an AHC had occurred could not be obtained for all of the 11 remaining people, however, in at least two cases the reviewer highlighted that although an AHC hadn't been completed, there had been extensive involvement of the GP in their care.

Evidence as to whether people had received a Health Action Plan as a personalised output of their AHC was variable – this plan should be promoted as a key part of the AHC process.

6.5 Cancer screening

Prior to 2020/21, Cancer was the most prevalent cause of death amongst LeDeR reviews, which led to focussed work on improving awareness and access to screening programmes for people with disabilities. Reviews completed during 2021/22 showed that three deaths were attributable to cancer – this is the same figure as noted in the 2020/21 report.

There are three national screening programmes in England: bowel cancer screening is offered to people aged 60-74, breast cancer screening is offered to women aged 50-71 and cervical screening is offered to women aged 25-64. Of the 39 completed LeDeR reviews, 25 (64%) of the people reviewed were eligible for a cancer screening based on age and gender (breast, bowel or cervical); 5 males (13%) and 20 females (51%). Of the 5 age eligible males, 3 (60%) had bowel cancer screening, however, there was no evidence within the records of the other two males to confirm whether they had or had not accessed this screening. The breakdown of cancer screening related findings from the completed reviews of women is outlined in Table 3; detail is only provided for those who were noted as age/gender eligible for the screening programmes:

Table 3 – Cancer Screening

Cancer Screening	Cervical		Breast		Bowel	
Eligible	13		11		9	
Yes	3	23%	5	45%	2	22%
No evidence to confirm	10	77%	6	55%	7	78%

Recording as to whether someone has accessed age appropriate screening is not a routine question within the revised LeDeR review system. Locally where this information was obtainable from records reviewed, data has been recorded. The above data represents a very small sample, however, when compared to last year's LeDeR report it suggests a higher level of uptake of breast cancer screening (15% in 2020/21). There is ongoing work being led by the Coventry and Warwickshire Cancer team to improve access and uptake of screening programmes – alternative options such as a specialist cervical screening service at UHCW are being promoted. Further analysis of screening access is underway and equity of access remains a key priority.

6.6 Supporting people who make unwise decisions and those who may self-neglect

Situations where people with mild learning disabilities have made lifestyle decisions that have had implications on their health and wellbeing have been noted this year. Often these individuals also declined or did not attend routine appointments. There is a need to recognise a person's rights to make such decisions but that an assessment of a person's mental capacity to make decisions in this respect should be considered. These findings have been shared with our local Safeguarding Boards who co-ordinate learning opportunities across the system. In addition to this our local learning disability awareness training for primary care has been reviewed and updated to cover this area in more detail and colleagues from across the local health and care system have worked with internal quality

and safeguarding leads to raise awareness of the importance of professional curiosity and the need to share safeguarding alerts across organisations.

7.0 Examples of Best Practice

It is important to recognise that in many cases LeDeR reviews highlight examples of best practice and personalised and high quality care. Within the majority of reviews reviewers identified examples of note, some of which are highlighted below:

- *The hospital learning disability nurse provided continuity throughout admissions and was a support to the family.*
- *Excellent relationship between this person and their Practice Nurse ensured positive interventions to maintain his health for longer than may have been expected otherwise.*
- *The patient's wishes were to remain at home provided it was in his best interest. The family and the care provider along with primary, secondary and specialist community services worked closely together to make this happen.*
- *The GP practice used the easy read preparation for Annual Health Checks tool that had been launched locally in 2020 – the Annual Health Check was thorough and identified a number of areas for action.*
- *The hospital staff did all that they could to ensure that the patients' religious wishes were followed during his hospital stay and in the days leading up to his death. This gave him and the family great comfort.*
- *This review highlighted a range of reasonable adjustments applied by the GP and by the breast screening service.*
- *The care provider worked hard to focus on healthy choices, foods and lifestyle to improve outcomes for this person.*

Where positive practice is identified, the LeDeR team highlight this to the team concerned. These instances are also shared within the LeDeR newsletter to promote positive practice and the impact of these actions and approaches.

8.0 Assessment of the quality of care

The new LeDeR policy requires local LeDeR programmes to grade the care the person received at the end of focused reviews only. We have decided that from April 2022 we will add these gradings to our initial reviews too, to enable us to further monitor and track outcomes of reviews.

Of the six focussed reviews completed during 2021/22, gradings were as follows:

1) Quality of the care the person received

Grading	Definition	No. Reviews Graded
6	Excellent care, exceeding expected good practice	
5	Good care, met expected good practice	
4	Satisfactory care, fell short of expected good practice in some areas but did not significantly impact person's well-being	3
3	Care fell short of expected good practice and did impact on well-being but did not contribute to the cause of death	1
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	1
1	Care fell far short of expected good practice and this contributed to the cause of death	1

2) Availability and effectiveness of services

Grading	Definition	% Graded
6	Availability and effectiveness of services was excellent and exceeded the expected standard	
5	Availability and effectiveness of services was good and met the expected standard	
4	Availability and effectiveness of services fell short of the expected standard but this did not significantly impact on the person's wellbeing	3
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	2
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	
1	Availability and effectiveness of services fell short of the expected standard and this contributed to the cause of death	1

9.0 Learning into Action

LeDeR Reviewers often identified actions to address small, quick-fix issues that via discussion with providers are promptly implemented as a result of the reviews (e.g. linking with training providers, providing information and blank copies of the Hospital Passport document). Informal discussions facilitate these smaller changes while other, more systemic actions are progressed via collaborative work with colleagues across the system. Appendix 1 provides an overview of a range of activity that has occurred during 2021/22 in response to LeDeR findings from this year, and previous years.

Learning from more recent reviews and feedback from experts by experience suggests that in addition to the ongoing activity in progress to reduce health inequalities (as outlined in Appendix 1), key priority areas for 2022/23 should include focus upon:

1. Achieving the best life chances for those at risk of dying from respiratory illness. A Priority Action Group should be initiated to focus on the modifiable factors that can contribute toward reducing the number of respiratory related deaths.

2. Ensuring carers, both formal and informal, and clinicians are skilled in enabling people to be supported to be part of decision making about their health and where this is not possible that Mental Capacity Act standards are followed, and Best Interest decisions are made and communicated.

3. Ensuring that people have accessible support to make informed choices about lifestyle factors that can improve their health.

4. Enabling our ICS workforce to be equipped to recognise the essential needs of people with a learning disability, autistic people and their carers, so that they can provide effective care that achieves positive outcomes.

5. Ensuring that we are sharing information about what we are learning and how we are working together to make improvements. We want to do more to give recognition and thanks where areas of good practice are identified within reviews and to share examples of good practice with others as another way of supporting improvement.

Over the coming year we will continue to collaborate with partners within the ICS, particularly Primary Care and Public Health, to understand the health needs and inequalities experienced by people with a learning disability in more detail. Health surveillance data can then inform population health management and empower each Place to address health equity for those who may be more vulnerable to experiencing barriers to happy and healthy lives, including access to programmes aimed to support prevention, diagnosis, earlier intervention or treatment.

10.0 Conclusion and next steps

This report presents the findings from reviews following the death of people with a learning disability across the Coventry and Warwickshire area, notified to the LeDeR programme and completed between 1 April 2021 and 31 March 2022.

The national and local approach to LeDeR has evolved significantly during the year with the transition to a new review system and approach, accompanied by the recent establishment of a dedicated workforce for the local programme. The local programme is in a strong position to deliver consistently high quality reviews and to initiate prompt action based on the learning identified. Our increased involvement of experts by experience in determining actions linked to learning will ensure that solutions are co-produced and meaningful to the people in receipt of health and care services.

As our LeDeR team progress reviews of autistic people who have died, we will develop further local intelligence to help understand factors influencing the health of autistic people, which will complement feedback shared by local experts by experience via our co-production groups. Actions will be identified to address and incorporate new learning themes as they emerge and we will review existing learning to action activity to consider how it reflects the needs of autistic people.

Progress towards translating learning to action has been made through collaboration of health and social care colleagues across the local system and we plan to do more to highlight and recognise the best practice that is evident in our local area, whilst striving to further improve provision for people with learning disabilities and autistic people, to reduce inequalities and enable people to live full and healthy lives.

11.0 References

Mencap (2019) How Common Is Learning Disability In The UK? How Many People Have A Learning Disability? | Mencap

PANSI (2021) Projecting Adult Needs and Service Information System (pansi.org.uk)

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12.0 Acknowledgements

With thanks to all those who have contributed to the Coventry and Warwickshire LeDeR programme, supported reviews and for their continued commitment to improving the lives and experience of people with a learning disability and/or autism.

We are particularly grateful to Grapevine and the Health Team of experts by experience for offering their insight and enthusiasm as we work collaboratively to progress service improvement and to action learning.

End of Report

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Chair - Clinical Quality and Governance Committee	Director of Nursing & Clinical Transformation/ Chair of LeDeR Governance Group
Coventry & Warwickshire CCG	Coventry & Warwickshire CCG

Appendix 1:

LeDeR Learning Theme	Actions Completed 2021/22	Ongoing Activity Planned for 2022/23
Uptake and quality of LD Annual Health Checks	• Ensured 2021/22 DES Sign Up for LD AHC delivery • Offered LD AHC training and support to all practices • Promoted importance of Health Action Plan and example easy read template • Promoted LD AHCs to people with LD and those who care for/support them, including specific sessions for parents of young people in transition • Co-produced LD Friendly kitemark including LD AHC quality measures • Accessed monthly delivery data to target support and monitor progress.	• Stratification of 2021/22 data to inform practice level support offer • Direct contact to practices where LeDeR reviews highlight gaps in LD AHC provision • Launch of evaluation questionnaire for feedback on AHC process • First trial of kitemark planned.
Low uptake of cancer screening	• Embedded cancer related content in LD AHC training • Cascaded Coventry/Warwickshire cancer screening guidance document to commissioned carers and others who support people with LD. • Ongoing delivery of cancer screening, signs and symptoms training provided to carers • Promoted specific screening services relevant to LD/A community, raising awareness of alternative cervical service hosted by UHCW • Developing data resources to understand screening uptake by people on LD registers at practice level, to target support offers.	• Analysis of local screening eligibility/non-responder data to target specific cohorts • Reviewing easy read information on two week wait process, with plan to co-produce an information leaflet.
Offer learning opportunities for formal and informal carers on common	• In collaboration with Warwickshire's Provider Partnership, virtual sessions have been delivered throughout the year on topics including: ○ Dysphagia;	• Planning for 22/23 programme of opportunities, including consideration of new areas of focus linked to findings of 2021/22 reviews. • Evaluation of impact of the programme.

conditions linked to LeDeR	○ Cancer Signs, Symptoms and Screening ○ Diabetes Awareness ○ Sepsis ○ Preparing for an Annual Health Check ○ Bowel Health Awareness *Since initiating this programme in November 2020, approximately 400 carers have engaged with the learning opportunities offered.*	
Improve hospital setting experience for patients with LD	• Promoted hospital passport use by people with LD within local Trusts and with people with lived experience • Increased access to LD awareness training, including sharing of e-learning tools and links with face-to-face training opportunities • Promoted the role of Acute Liaison Nurses in the Trusts • Supported the recruitment of an expert by experience to join PALS team as pilot within Warwick Hospital • Sought expert by experience feedback on proposed hospital passport revisions to create a single document for use across the area.	• Finalise and launch new hospital passport document for people with LD • Hospital experience to be focus topic for first LeDeR Discussion Group to expand input and development of actions to address thematic learning linked to this.
Reasonable Adjustments (RAs)	• Highlighted instances where RAs are applied well and have positive impact • Developed CareNotes RAs recording mechanism • Embed references to RAs within local training as opportunity to increase awareness or importance, rights and impact.	• Incorporate specific article on RAs in next edition of LeDeR newsletter • Continue build of RA recording form within EMIS primary care system for first trial during Q1 • Progress to business as usual approach for local recording of RAs for people with LD/A accessing CWPT services.
Learning Disability/Autism Awareness	• Delivered LD Awareness training across primary care, link to DES AHC requirement, including Reception/Administrative staff focused session • Identified training resources for use in secondary care	• Agree schedule for 2022/23 LD awareness training sessions for primary care

	• Numerous bespoke training sessions provided to primary care practices to address individual practice need • Acute trusts reviewed training and expanded internal offers on LD and Autism • Person with LD recruited into an LD Assistant role within SWFT.	• Review early impact of LD assistant role within SWFT and consider replicating role in other Trusts • Develop training/support offer for local ambulance service.
Mental Capacity Act Understanding	• Local hospital trusts reviewed MCA training and provided ward specific input in response to review findings • Area of focus for local conference hosted by safeguarding board with guest speaker expert on MCA. • Focused area of LD AHC training content • Explored opportunities to co-produce some resources for people with LD about MCA and rights – focus on educating people with LD and their carers/supporters. .	• Specific recording of MCA element of conference to be extracted and circulated across organisations via LGG reps. • Await feedback from experts by experience regarding existing MCA related materials before creating new resources or promoting existing ones within local LD/A community.
Pneumonia	• Included LD specific resources in local flu vaccination campaign communications • Highlighted opportunity to promote vaccines including COVID during LD AHCs • Aspiration pneumonia an area of focus for carer training sessions	• To consider further actions to reduce the number of pneumonia related deaths as this has emerged as the most frequent cause of deaths among the reviews concluded in 2021/22, including consideration of local uptake of pneumococcal vaccine, promoting oral care and further dysphagia related actions.
Self-neglect	• Shared learning with local Safeguarding leads • Disseminated materials to highlight importance of professional curiosity • Ensured non-attendance and what to do regarding repeat DNA/was not brought scenarios are included in primary care training	• Monitor instances of this in future reviews • Collaborate with safeguarding leads to share learning opportunities related to this.

	• Confirmed that all local organisations have responded to actions identified relating to organisational safeguarding policies.	
Services for carers	• Promoted the services available to support informal carers • Liaised with responsible commissioners and disseminate information via LGG members.	• Include carers service summary information in future LeDeR newsletter.
Children's Hospice Availability (CDOP Learning)	• Highlighted commissioning gap in relation to hospice provision for children aged 6+ within the area • Support CDOP approach to children's commissioner lead regarding the evidenced need for additional paediatric hospice access.	• To be determined as further CDOP reviews are concluded.